Dr. Sharon Bober and Ellen Matloff, Sexuality and Cancer April 27, 2008Welcome to Yale Cancer Center Answers with Drs. Ed Chu and 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 the 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 1-888-234-4YCC. This evening, Dr. Miller welcomes Dr. Sharon Bober and Ellen Matloff. Dr. Bober is the Director of the Sexual Health Program at Dana-Farber Cancer Institute through their Lance Armstrong Foundation Adult Survivorship Clinic, and Ellen Matloff is the Director of Cancer Genetic Counseling at Yale Cancer Center.Miller Sharon and Ellen, thank you so much for joining us.Bober/Matloff Thank you.Miller Sexuality is a very large topic. As you know, a lot of physicians and practitioners are not comfortable talking about it. Let's start by talking about that. Why are people uncomfortable, and what do you suggest for us as clinicians, and patients, to help us become more comfortable?Bober First of all, a lot of the time we do not have a lot of practice in talking with our patients about this. As clinicians, most of us do not get a lot of training in how to speak with patients about sexuality. It is a bit of a sensitive topic and for fear of either embarrassing the patient, or out of fear of not knowing how to talk about it ourselves, we often shy away from the topic rather than bring it up.Miller Asked a different way, from your experience, how often is it on people's minds when being treated for cancer?Bober Sexuality is one of the big issues that come up for many patients. It is often one of the issues that people are not prepared for, and it is a major part of quality of life for most of us. I would say it is on people's minds quite a bit.Matloff If I can jump in here Ken, I will tell you that as a genetic counselor, I had no idea that this was a big issue for our patients who test positive for mutations or learn that they are high risk for cancer. Many of them are already cancer survivors and have had prophylactic surgery of either their ovaries and/or their breasts. Who would think that the biggest problem after all of this is sexuality? Certainly, we did not anticipate this, but we have a discussion group for women who carry BRCA1 and 2 mutations. Part of the discussion group is online, and people E-mail unanimously, and share the intimate problems that they are experiencing. Much to our surprise, what came up as the number one issue was sexuality, and that is how we realized, "Wow! We are really missing the boat here, and not only are we missing it, but it is not being addressed by any of their clinicians." That is how we realized we needed to address this.3:04into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3Miller After or during treatment for cancer, who do people talk to, or do they just not talk about it at all?Bober That really depends on how connected people are to other patients. There are certainly peer support groups. This does come up, as Ellen mentioned, when there are opportunities, whether it is on a LISTSERV or in a support group, certainly for breast cancer patients. This comes up a lot when you talk with people who do these kinds of groups, but for

folks who do not have a community or a support group where the topic comes up, I think it is often very isolating, especially when clinicians are not bringing up the topic and patients feel that there is something terribly wrong with them and do not know that other people have the same problem. It in itself is a big issue just being isolated.Matloff One thing that we found is that people are so relieved to learn that they are not the only people having this problem. Let's face it, you go to your oncologist and you speak about everything, your hot flashes, lymphedema, all of these problems, and sexuality is not usually on the checklist. A lot of people do not even realize that the problems they are having could be related to their treatment or their surgery and they feel, as Dr. Bober said, very isolated.Bober I think people also do not realize that many of the problems are treatable. If folks are dealing with something that seems uncomfortable, painful or embarrassing and assume that they are the only one dealing with it, there is also a big misperception about what is treatable and what is manageable. If you feel like there is nothing you can do about it, then that's all the more reason why folks might be reluctant to even bring it up.Miller In a minute I want to talk about some of the special issues for men and some of the special issues for women, but let's cover a couple definitions that may be very basic, but I think we should put them out there. How do you define libido? What is the difference between intimacy and sex? What are your thoughts?Bober Certainly sexuality covers a very broad range. Sex is not just about an active penetration or about physical giving or getting pleasure. Sexuality really refers to how we are in the world in our bodies, how we experience ourselves as being able to be sensual, as being able to have physical intimacy that again may or may not involve sex in the traditional sense. I think it is also a matter of saying that physical intimacy and sexuality are a part of the human experience throughout our lifespan. It is a part of who we are when we are born until we die. Sexuality and sensuality are a part of the human experience in a very broad sense.Miller Your point is very well taken that it is a very broad experience in terms of the fact6:19into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp that being intimate does not necessarily mean being physical in a specific kind of way. I have heard in your talks that a lot of it is communication.Bober Certainly, a huge part of sex is about communication. Often sex therapists will say that the largest sex organ in our bodies is our brain, and that is not by accident that they would say that. So much of how we feel about ourselves, our bodies and our partners, really has to do with what we think, our perceptions, and again, the point around communication is that most of us are not comfortable talking about sex under the best of circumstances. Often we shy away from direct communication, frank conversation about sex, probably because of our culture, how we are socialized, what we learn from our parents and our communities, and that is the case before we get a cancer diagnosis. It is all the more difficult to broach this topic when we might feel ashamed or embarrassed after cancer treatment.Miller Ellen, if people are facing those issues, communication issues, what is your experience, after someone is diagnosed with cancer, what happens with some of those issues?Matloff It is interesting, and for people in a

partnership, the main goal is to survive this cancer. That becomes the goal and everything else is lost. How is your quality of life after this cancer, what is your body image like, and how is your sexuality? We are so glad that the person survives, that some of these other things fall to the wayside. Now that we are better at treating cancer, there is room to explore these other issues. Thinking particularly about women who are faced with a preventative or a prophylactic surgery, one woman comes to mind. She is in her mid-40s, absolutely gorgeous, very attractive, newly divorced, out on the dating scene, and her biggest concern about having a prophylactic oophorectomy was that somehow she would not be a sexual being anymore. She was not interested in having children, but she said, "I just picture myself like a dried up raisin." That was her expression, and she was very sad about losing her sexuality. Body image and self-perception as part of sexuality is such an important topic and we cannot just say to patients, "Listen, you have got to do this because it reduces your cancer risk, the rest you will get through." We need to talk through all of the issues so that we do not leave these patients alive, but with no support for quality of life.Miller Since we are talking about women, what are some of the changes in body image that women talk to you about?Bober As Ellen said, when you look at surgery as a major treatment for disease, whether it is preventive or whether it is after someone is diagnosed, we are looking at loss of ovarian functioning, loss of body parts, sensation, such as when you have a mastectomy, and that has a very direct and significant impact. I think that for9:36into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3 women in general, one of the common issues has to do with menopausal symptoms. There are a variety of menopausal symptoms, particularly dealing with sexuality. You are looking at vaginal dryness and vaginal atrophy that happens when you have an abrupt loss of estrogen. Many women are not prepared for the dramatic change. This is different than a natural menopause where it is slow and happens over time so your body has a chance to adjust. Lots of women in natural menopause still complain of very real issues, but there is much more drama when it is surgical or chemotherapy induced, again same abrupt loss of estrogen. Women who are dealing with pelvic surgery or any kind of pelvic radiation also suffer severe sexual dysfunction over time, partly from vaginal atrophy; tissue that one was elastic now is hard, fibrotic as we call it. There may also be vaginal narrowing. These are functional issues that can be treated but are very painful, are disruptive to sex lives, and quite honestly when women have pain during intercourse or their bodies have changed, they are not comfortable, it is not surprising then that there is also a lack of desire. Sometimes, there is lack of desire because of lack of estrogen, and there is partly a hormonal drive to that, but partly when you do not feel comfortable in your body when you have gone through abrupt surgery and hormonal chemotherapy intervention, you are also not feeling like yourself, and the issues of desire and low libido get tied in with all of that as well.Matloff Sharon, I have got a question for you. Listening to you speak, if I were facing a prophylactic surgery, or even a surgery for cancer, vaginal atrophy, vaginal dryness, is there a way to get to the other side for most women?Bober It is a great question. I

am glad you asked it. The answer is yes, emphatically yes. Many of these issues are absolutely treatable. Vaginal dryness is easily treatable with a variety of options from over-the-counter lubricants to bio-adhesive gels, vaginal moisturizer and non-hormonal treatments that are very effective. Lots of women do not know about them, but they work. There are also a number of treatments for other issues. If you are dealing with pelvic radiation there are a variety of treatments from pelvic PT, physical therapy, to a variety of other options that are functional and easy to use, but women need to learn about them. There needs to be some coaching and some education.Miller I am going to ask you the same question about a man who has prostate surgery and has erectile dysfunction, what can we do for him?Bober Unfortunately for many men who are dealing with prostate cancer, erectile dysfunction is a huge part of the picture and does not get talked about or addressed. What happens now, in the world of Viagra and Cialis, is that men will try a little blue pill, it does not work, and then they feel that they failed treatment. Unfortunately, what we know is that most erectile dysfunction after prostate cancer has to do with nerve damage. We also know that radiation therapy is12:47into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3 damaging to the nerves for men in terms of erectile dysfunction, and this is best dealt with using other options besides Viagra. There are options such as using medication, which can be injected, and a variety of other devices men can use such as a vacuum pump, which is easy to use. They are not painful and they work, but men do not know about them and unless they have had a conversation, typically with a urologist who can give them some coaching, this is not something that comes up.Miller It is wonderful talking about it on this show, and in a small way starts to promote some openness among clinicians who treat people with cancer. We would like to remind you to e-mail your questions to us at canceranswers@yale.edu. We are going to take a short break for a medical minute. Please stay tuned to learn about sexual health with Dr. Sharon Bober and Ellen Matloff.Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller, and I am here with Dr. Sharon Bober who is Director of the Sexual Health Program at the Dana-Farber Cancer institute, and Ellen Matloff, who is Co-Director of the Cancer Genetic Counseling Center at the Yale Cancer Center. We left the discussion talking about rehabilitation, about how people get back to normal functioning. I wanted to ask, when someone has gone through a major surgery or through cancer therapy, is there a period of grieving?Bober I think there absolutely is. It is critical to be able to acknowledge that there is loss. People's bodies are not the same. People's lives are not the same. This is certainly a different chapter, a new chapter, and I think it is critical to be able to acknowledge that loss and give people space to own that grief and then to be able to ultimately accept that within this new chapter. There is still plenty of room to rediscover pleasure, to rediscover sexual functioning.Matloff People go through a lot of changes in their sexuality, after a pregnancy a lot of15:48into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3 women say that their body does not look the same, it does not feel the same. A lot

of men have changes in erectile functioning as they age, and so, this is just another change in the pathway of life, when people have a prophylactic surgery, surgery or treatment for cancer. Our bodies do change, and we need to adjust to those changes over time.Miller We had an e-mail from Marsha who leaves in Longmeadow, MA. She said, "I have had a mastectomy and I feel different about my body. I have no libido." If Marsha were sitting here now, what kind of advice would you give?Bober Unfortunately, this is a common problem. Lots of women deal with it as well as men. Libido is complicated because there are a whole lot of ingredients that go into that recipe. Libido is influenced by everything from our energy level, to the medications we take. It is mainly influenced by how we feel, what we think and what is in our minds as well as our bodies. I would say to Marsha, as I would with anyone who is talking about libido, that I want to learn more about what it is that she is missing, the sense of loss again, what it is that she used to have, what things used to be like, and what she is hoping for. That would be a real starting point. I would also start the conversation with Marsha about pleasure. So much of the work that we do in cancer and sexuality rehabilitation has to do with shifting our focus from sex, maybe in the old sense or in the traditional sense, to regaining a sense of pleasure in our bodies. Trying to figure out what is pleasurable, using perhaps a set of simple exercises to rediscover pleasure, sensuality, thinking about massage, thinking about touch, thinking about therapeutic touch as a way to start re-igniting a sense of pleasure and a sense of desire. There are a number of ways to reinvigorate our senses that might also include exercise or stress management; those would be some of the starting points.Matloff I would add to that one thing that has surprised me when you have discussions with people about libido. Sometimes the answer about why they are not feeling sexual has nothing to do with them. I had a patient who said to me that she feels like her husband now views her as a cancer patient and that he was so loving and wonderful during her treatment, but now that she has had a mastectomy with reconstruction, he is almost afraid to touch her. It is a real sexual turnoff to her to feel like a cancer patient in the middle of this. We talked about lingerie and different ways she can broach this subject. I would also like to speak about some of our patients who are gay that are often left out of the picture. They have similar problems of, how do you talk to someone who still has breasts about the fact that you do not, and how do you bring these issues up? Often times, libido is driven by the fact that you do not think your partner is interested in you anymore or that your partner is afraid of your body or just does not know what to do. This goes back to communication.19:03into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3Bober Back to communication, and sort of a similar anecdote, this might be the case whether it is a male and a female partner or two female partners with breast cancer. We often hear the story that partners, as you said Ellen, do not want to touch a spouse or partner because they are afraid of hurting them. What happens is that this partner is not touching her for fear of hurting her, and the woman then feels, of course, they are not touching me because they are not interested. They are not touching me because they cannot stand my body

or they do not want to look at me, and nobody talks about it because each partner is in a sense trying to protect the other. But what happens is there is a lot of silence there, and there is not an opportunity to even straighten out what the miscommunication is about. Even just being able to figure out how to talk about it can open the door to a whole lot of conversation, which might end up igniting a very positive interaction. Suddenly somebody is willing to try and willing to experiment and touch each other, and people then find themselves feeling somewhat more aroused.Miller If you had a couple in the room that you were counseling now, and they were facing that very issue, how would you get that conversation going?Bober Certainly it is important to know a little bit about the history of the couple, as with any of us individually. We find out what they are comfortable with, what they were used to doing beforehand, their history and what really affects who they are currently. It is important for any of us who do this work to be sensitive to someone's history and values. These are all things that need to come into the room and into the conversation in order to get started. It is also important to be able to ask a couple what it is they are hoping for. To be able to speak with each partner to identify where they would like to go, where they are hoping to get to, and then start again, not with a focus on sex ironically, but starting with a focus on pleasure. Perhaps we would start with a simple set of exercises in terms of rediscovering what is pleasurable, how each partner can give and receive and start slowly.Miller I have heard you use the term desire diary. What is that all about?Bober A desire diary is a wonderful technique that we use and it has to do with cognition, another word for how we think about things. A desire diary is a way to tie people back into their thoughts, into their awareness of being in a world in a sexual way that they might not typically be aware of. For example, if you walk around saying, "I do not have any libido or desire. I just do not feel much anymore," you kind of have a sense of yourself as being deadened. And a desire diary, as we know in general when we ask people to do journaling, for example therapeutic writing after an illness, it is a really wonderful technique to help people connect to themselves. Sometimes, when we start to write about our experience, keep notes about our experience, we become aware of thoughts or feelings that we are not typically aware of, and this also extends to sensuality. If22:11into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3 someone starts to keep a diary, and literally you can use a piece of paper, it does not have to be anything fancy, but they can just make notes to themselves about something that they see, smell or hear, anything that might touch one of their senses and strikes them as being interesting, sexy or sensual. They write it down and try to become aware as they go through their day. It is really interesting what people might find at the end of the day, "I had not realized it, but I did notice I was in the park and I saw someone walk by and she looked kind of cute, or he looked kind of nice", and it does not mean you act on it. It does not mean that you are doing anything that is outside of the context of a partnership or monogamy, but it just gives you a chance to become aware of yourself in the world in a way that you have not really connected to in a while.Matloff When we think of sexuality, often times we think of sex

between two partners. I had a patient who was having a prophylactic bilateral mastectomy with reconstruction, and she said to me, "I do not know what to do because I have a young daughter, and we have an open door policy in my house. She sees me and talks to me when I am in the shower and she sees me naked, I do not know after this surgery how to suddenly shift gears so that she cannot see me anymore." And my answer was, "Oh well! She should see you after the surgery." And she said, "What are you talking about? I do not want her to see that I have had my breasts removed and reconstructed, I cannot believe you would suggest that." And I said, "Certainly with a fresh incision and with drains you are going to want some privacy, but when that reconstruction is complete you need to go back to the routine, the way it was, introduce her to your body so that she can see mommy is okay, and that this is part of sexuality and part of body image, let us face it. That daughter is at a 50% risk of carrying that mutation, and if she knows that when she was 6 years old her mom had a surgery and she looked so bad that she could never see her naked again, that is scarier than anything else she could imagine. Sexuality has not only to do with your partner, but with how you feel about yourself, how you feel about your naked body in front of family members. It really encompasses a great deal of issues.Miller As you know my wife is a cancer survivor, and I think about the survivorship journey and a lot of what we give to our children is role modeling of how we deal with these very difficult situations.Matloff That is right. It really is a gift to be a strong role model.Bober Sometimes when we try something that we are not totally sure that we are comfortable with, we give ourselves permission to try and then we see that it is not that bad; in itself, it is a therapeutic intervention. For example, Ellen, when you gave that woman permission to take her shirt off in front of her daughter, the first time she might see that her daughter walks right past and does not even notice, or notices for a minute and keeps going. The mom herself, then, has an25:15 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3 experience of realizing, "Oh my goodness! This is not as bad as I thought." And that in itself is a therapeutic intervention.Matloff I learned this lesson in a very interesting way because some of our patients have a type of colon cancer that causes so many polyps to form in their colon that they have to have their colon removed. These families and these children having testing at age 5, find out that they are somebody going to have to have their colon remove prophylactically, and they are going to have to have a permanent ostomy bag or colostomy, and I think, my gosh, how horrible. But then I watched the video tape of some young children talking about this, and I was shocked when one of the children said, "Yes, when I get to be 15 years old, I am going to have a bag like mommy," and they really did not think it was a big ideal. The reason children think it is a big deal is because we make it a big deal, and if that is how life is in their family, then that is how life is. Mommy is fine and she functions and deals with this issue, and they will deal with it too.Miller I want to take a minute and talk about men. We've talked a lot about breast cancer, but what have you observed in terms of men after major cancer surgery of any kind in terms of returning to feeling happy, healthy sexually and intimate?Bober

You know, I think that men have many of the same issues as female cancer survivors who are facing issues around libido and fatigue. Men, certainly after cancer like prostate cancer, are dealing with very significant high rates of erectile dysfunction. This is also the case with, for example, men dealing with bone marrow transplant; anything that stops testosterone production, similar to women with estrogen production who are dealing with many of the same issues. It is interesting because the breast cancer movement has been phenomenal in terms of advocacy and has raised a lot of issues, including some issues around sexual health for women, which for men have not gotten the same attention. I would say that to some degree men have not gotten as much attention around this issue, certainly issues such as testosterone replacement is something that is a very real option for a lot of men; not so much after prostate cancer which is a bit more controversial, but certainly bone marrow transplant survivors find that they get enormous benefit from testosterone replacement. It is available and needs to be talked about so they know that it is an option.Matloff It seems like when we are talking about male sexuality we really put a huge amount of pressure and importance on erections. We are having a very honest conversation here, if erections are no longer possible for a man, is his sex life gone?Bober That is a great question. Absolutely not, you do not need to have an erection in order to have sex; that is the first thing. This is not just about pleasure and sensuality, but in terms of penetration, you do not need to have a full erection in28:29 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Apr-27-08.mp3 order to have penetrative sex. This is also the case for men who are dealing with other kinds of libido issues. There is enormous variety in terms of sexuality. So, I appreciate you saying that because certainly erectile dysfunction, although it is often a number one issue, it is not the reason why you can or cannot have sex.Miller This has been an incredible conversation and leaves me and, I think, a lot of people out there, with a sense of positivity. You can talk about it and you can get help.Bober There are a number of really terrific books out there. There is a wonderful book called Sexuality and Fertility after Cancer, written by Dr. Leslie Schover who is a national expert on this topic. Also the American Cancer Society and the NCI has information on their website about sexuality written for patients.Miller Sharon and Ellen, I want to thank you so much for being with us tonight.Bober/Matloff It is a pleasure, thank you very much.Miller Until next week, this is Dr. Ken Miller from the Yale Cancer Center wishing you a safe and healthy week.If you have questions, comments, or would like to subscribe to our podcast, go to yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, we will examine the latest treatment options for patients with liver cancer.