Choices in Breast Cancer Treatment

Guest Expert:
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Author, Choices in Breast Cancer Treatment

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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 1-888-234-4YCC.

Barber

This evening we are going to turn the tables a little bit. Generally, someone is seated across from either Ed Chu or Ken Miller. Today, I am fortunate enough to be sitting across from Dr. Ken Miller, holding his new, since January, book Choices in Breast Cancer Treatment: Medical Specialists and Cancer Survivors Tell You What You Need to Know. Congratulations! I'll give you your book because I want you to read from it later. That’s got to be just such an amazing feeling to be holding that book in your hands.

Miller

You know what, actually it is, but I have to say it was actually fun seeing it in your hands; it gave me a nice feeling. This is a project that I actually thought of about 23 years ago, and it is nice to see it finished and on the bookshelves.

Barber

You are a busy physician and have always got a lot on your plate. What happened 23 years ago that made you decide to do this? How do you go about starting something like this?

Miller

23 years ago I was training in oncology. I was a fellow at Johns Hopkins and we found out that my oldest daughter was deaf. We were trying to figure out what to do; should we use sign language, should we use an oral approach? Then we read a very good book called Choices in Deafness.

Barber

Wow!

Miller

It was a combination of experts talking about deafness and communication and families telling their own stories. At this same time as a fellow, I was really involved in breast cancer research and treating women with the breast cancer, and I said, I would like to write a book like that for breast cancer called Choices in Breast Cancer. So the idea really started about 23 years ago.

Barber

And then what did you do? Were you actively cataloging the stories?

Miller

No, I was very, very involved with just caring for people for many, many years in a private community practice in Maryland and when you sit back people tell their stories. We talked about how they made their decisions and what the process was like for them from the moment of diagnosis on, as a cancer survivor. As I matured as a clinician I knew when it was time. About six years ago I started collecting the stories.

2:55 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Aug-24-08.mp3
Barber I would love to use, coming up, information in the book that may be of interest, but for you this is a very poignant odyssey because you have been going through a kind of parallel real world example of exactly what this book is about.

Miller People have to make choices. Now, if you have appendicitis, you go to the emergency room and the surgeon does not need to ask if you would like your appendix out. They say, this is what I am going to do. Same thing for a broken leg, but you know, with certain diseases such as breast cancer or prostate cancer, people are very involved in the decision-making. I will just share with you that 9 years ago my wife Joan had acute leukemia, and thank God, is doing well. This year, unfortunately, she did develop breast cancer. So we have had to make decisions ourselves.

Barber Let's start from the beginning. What goes through your mind when you hear those words and what are the first things you should do?

Miller As a family we have experienced this twice, and also with other relatives in the family, but there is this sinking feeling. Some of my patients describe it in the book as cold water going through your veins. There is a guttural, visceral feeling of, oh my God, I cannot believe I am hearing this. You sort of blank out for a couple of minutes and do not hear much else other than processing that you have cancer, or your loved one has cancer. There needs to be time for that processing and then there is a stage of almost regrouping and you say, this is how it is and I plan on getting better. That is gathering information, processing it and moving ahead with a good plan.

Barber Is there anything you can do for the ice water feeling? We have all felt it when we have gotten really, really bad news. Is that something that you just have to say, okay, I am going to experience this, it is going to pass and then I am going take action? Is that just the way it works?

Miller I think it is. I am not sure that we can take the ice water feeling away. It is real, but when I am sharing bad news with people, or news that they do not want to hear, I often will say to them, I wish I did not have to share this news, or personally I wish this was not the case. As a caregiver and as a physician I try to deliver it with a sense that I am in this with them. We are going to do this together, and that may help a little.

Barber Now lets talk about when you get to the point where you realize you have to get up and take action to get better and say okay, what am I going to do?

Miller In the case of a woman with breast cancer, most interactions up until a point are with one doctor. They go to their primary care doctor or their gynecologist and then all of a sudden there is a team, which is different. There is a surgeon, there is
a medical oncologist, a radiation oncologist, and these people have played
different roles at different times.

Barber Does this start generally with the general practitioner, is that where the diagnosis
is usually received, or are they referred to an oncologist?

Miller A woman may have gone to a primary care doctor, could be a gynecologist, and
they felt a lump, or they sent the woman for a mammogram, or a woman finds it
herself and then may have gone to a surgeon who does a biopsy, who then shares
information.

Barber Then you want to bring in what you are talking about, which is to start thinking
about this not as just going to one doctor and having them tell you what to do, but
start thinking about what your choices are.

Miller There are a lot of good practitioners in cancer care, both in the community and at
academic centers, but essentially, you want to create a team for yourself. You
want to feel that you have got good doctors that are communicating with each
other, and you want to feel like they are really focused on you. When you are with
those doctors, that is what is on their mind, how to get you better.

Barber In the book do you talk about the experience of the family members, because I
understand now that members of the family are referred to as survivors as well.

Miller Absolutely, the definition of a cancer survivor is the patient, family and
caregivers.

Barber From the moment of diagnosis, correct?

Miller Absolutely, for as long as they live, which we hope is for years. Along those lines,
there is a growing number of cancer survivors, it is 11 million now and what I
have heard is that 3% of the American population has had breast cancer. Now, it
sounds like, how could that be, but actually when you step back from it, there are
two to three hundred thousand women per year diagnosed, and over 90% are
doing well. So, that number continues to grow.

Barber Are you finding that the perception is changing, or is it slow to change about what
we can do for breast cancer now?

Miller I get a sense that people are feeling optimistic and positive about it. There is not a
sense that this is a death sentence, but rather most women, after they get over the
shock, have a sense of optimism that they have watched other women get through
it and they can do it also.
Barber: It is great that you are in this business right now; the survivorship business. The fact that this has become a growing field is because of what you just said, that there are so many survivors now, thank God. What are some things that are going on in the field?

Miller: This is a good chance to put in a plug for the following, which is, I hope and expect that women are going to live beyond breast cancer and this is what I impart to my patients. Good health is important afterwards, including eating well and exercising. Those things actually make a difference in reducing the risk of recurrence and the risk of new cancers.

Barber: And when you say that I feel like the first thing people are going to think is, okay, here is the doctor saying eat well and exercise again, but you know, having hosted this show and having heard the great things that you talk about with your guests, there is research going on right now looking into this exact question is there not? Research looking at exercise specifically and what benefit it has.

Miller: Right here at Yale, Melinda Irwin has done some wonderful research on exercise and the risk of recurrence and the risk of developing other cancers, and she has very good data. I used to think, oh! Come on, this is window-dressing, but it is not. It is real and we try to practice what we preach.

Barber: A little later I would like to have you read some of the stories that you said were part of the inspiration for it. By the way, we are talking with Ken Miller who wrote *Choices in Breast Cancer Treatment*, and he has his book proudly in front of him right now. Let's talk about the general treatment path you are going to find in breast cancer.

Miller: After a woman has found a lump in the breast she will see a surgeon and have a biopsy, often a needle biopsy. Once the diagnosis is established, there are three major issues. One is local control, how do we make sure that the cancer has not gone from the breast, and the second I would call regional treatment, which means some kind of assessment of the lymph nodes. The third is systemic, which means the whole body. Women will often say, well if I have chemotherapy does that mean I do not need to have the lump removed, or if I have the lymph nodes checked does that mean I do not need chemotherapy? I always try to stress to women, and the book does this also, that these are three separate issues. I even tried even on paper to lay them out as three separate issues because we want to make sure that each of those three have been addressed thoroughly to give each woman the best chance at long-term cure, survival, and care.

Barber: I would imagine, especially based on what you said before about that initial ice water shock, has not worn off, it is still there. But then you are moving on to,
okay what am I going to do; my first reaction would probably be that I have to
take action fast because I do not want the cancer to get any worse. But in doing so
this might deprive me of some valuable information. What should I be thinking
about once I have that ice water feeling, is it something I have to react too

Miller     It is a very good question and I know everybody thinks about it. I think there is
actually some value to not racing into treatment for breast cancer. I explain this to
patients, that it is literally not changing moment by moment, it is really not, and
there is time to make good decisions. I would not recommend that a woman wait
6 months to have surgery, that is not a good decision, but I think if they want to
get a second opinion or line up their team and decide to have surgery done in the
next 2 weeks, that is reasonable. It does not have to be 2 days.

Barber     This new idea of having everything in one place with respect to the team and
more collaboration is great. The other thing that impresses me is hearing what is
going on in terms of the psychosocial aspect which is coming into play a lot more,
with you especially, but cancer care is taking into account the greater effect on the
family.

Miller     Thank goodness. Because we are all not just bodies, we are people. A team, for
example, like the breast cancer team here at Yale, is a collaborative group
including social workers and nutritionists as well as surgeons and medical
doctors. For example, each patient is discussed and we look at the slides together
and we look at the x-rays together and talk about the patient. It allows a
collaborative effort to move forward.

Barber     His book is *Choices in Breast Cancer Treatment*, his name is Dr. Ken Miller, and
we will have him read from the book sitting right in front of him when we return.

Medical Minute

*The American cancer society estimates that in 2008, there will be over 62,000
new cases of melanoma in this country and about 2400 patients are diagnosed
annually here in Connecticut alone. While melanoma accounts for only about 4%
of skin cancer cases, it causes the most skin cancer deaths, but when detected
eyearly, melanoma is easily treated and highly curable. Clinical trials are currently
underway at federally designated comprehensive cancer centers such as the one
at Yale to test innovative new treatments for melanoma. The patients enrolled in
these trials are given access to newly available medicines which have not yet been
approved by the Food and Drug Administration. This has been a medical minute
and you will find more information at yalecancercenter.org. You are listening to
the WNPR Health Forum from Connecticut Public Radio.*

Barber     We are speaking with Dr. Ken Miller about his book, *Choices in Breast Cancer*

15:00 into mp3 file [http://www.yalecancercenter.org/podcast/Answers_Aug-24-08.mp3](http://www.yalecancercenter.org/podcast/Answers_Aug-24-08.mp3)
Treatment. It is so great to be with you today and so great to have you reading from this book which was an idea you had 23 years ago. So why don't we start with having you read some of the stories that are stories from patients, women, and from doctors.

Miller Yeah.

Barber Let's start with a doctor's story.

Miller We asked many of the doctors who treat women for breast cancer their own personal perspective on all this, what the process is and what being a doctor is like and helping women navigate this pass. I will read from Dr. Maurice Nahabedian, a plastic surgeon at Johns Hopkins. He writes, "Usually a woman has seen a number of other physicians before she sees me. So, by the time she sees me, she has generally processed the fact that she has breast cancer and that she might lose her breasts. She has dealt with these facts for a few weeks, or months, before she comes to see me. In some cases it has been a few years. He goes on to say that some women come to see him right away, but he says it is probably better to wait a couple of weeks or a month after the initial diagnosis before meeting with the reconstructive surgeon. In this passage that he writes he really talks about the process of seeing a woman who has been diagnosed and talking with her about a mastectomy and rebuilding and reconstruction.

Barber Because there are a lot of choices involved, correct?

Miller There are.

Miller The reconstructive surgeon can provide a tremendous sense of hope, despite the loss of her breast and the mastectomy, they are going to be able to create a new breast. But they also need to share the reality that it is not going to be identical; life will be different. If we look at plastic surgeons people think of them as somewhat glitzy because of some of the shows on television such as Nip Tuck, etc., but in fact, there is a lot of counseling and lot of psychology involved.

Barber It is good to have communication with the psychological side where you are able to walk the family and the patient through the process.

Miller Right.

Barber And also back to the team, I would imagine the plastic surgeon has to be having conversations with the radiologist and the oncologist as to where they are and when to do this treatment?

Miller Having all your doctors in one place, whether it is in a community or a cancer
center like Yale, it is nice that they see each other in the hallway. They are talking at conferences about you and other patients as well. Along those lines I want to share with you a story from a woman named Lilly Shockney who is Director of the Breast Program at the Johns Hopkins Cancer Center. She writes about her own reconstructive surgery. I will paraphrase it but she said her 12-year-old daughter and she were talking about her upcoming mastectomy and her daughter looked at her with a quizzical look and asked if they were going to move the remaining breast to the center, and Lilly thought to herself, that would create a new condition called uni-boob. It is an off-color story, but Lilly said that the two of them had a wonderful laugh and after that she made up her mind that they were going to find something to laugh about every day.

Barber: You have mentioned that using humor to try to work through something difficult is very important. Another dynamic that speaks to is, how do I talk to my 12-year-old daughter?

Miller: Well I think it is useful for clinicians like myself to help people with that because generally they have not had to do that before. A lot of the women we see are young women. They are in their 30s and 40s and have children that may be very young, or of different ages, and the way you talk to kids who are age 6 or 10 is different than if they are 14 or 15. We had to do that 9 years ago when my wife had leukemia.

Barber: I would imagine it is important to learn how to communicate with your partner about it and have your partner feel that you are there for them. We as men sometimes are just trying to solve the problem. We will go to doctor and will do this and that, but the woman may just want someone to listen.

Miller: There is a term that I like called dyssynchrony. Dyssynchrony means being at different places at different times, and it is almost invariable when there is a diagnosis of cancer, partners may be at different places at different times. One may be very much still grieving the loss of good health and the other one, like you said, may have the 'lets go get um' kind of approach. Identifying that and saying, you know, we are sort of at different places right now, can be useful in itself.

Barber: Do you want to stay talking about physicians who are in the hospital, or would you like to jump to a patient?

Miller: I will do another patient story because I really like this one and I have to say I get a smile on my face thinking of these women and their stories. As you read them you feel like you sort of get to know that person because they are personal.

Barber: That is nice to hear you say because sometimes when you have something that happens to your health it is very dramatic and you form this really intense bond.
with your doctor and then when you get better it is just done. You do not see this person anymore, so it is nice to hear that you are thinking of us.

Miller Oh! Absolutely.

Barber I'd love to hear this one

Miller I'll just share with you that some of the stories are about people’s past. One woman, Toby, talks about how she grew up. Her parents were Holocaust survivors and she talks about when it came time for radiation, her getting a tattoo, a tiny one for radiation, and it was very traumatic. That meant a lot. I read that and I said, Jeez, I never would have thought of that. But here is Luba and you've got to listen to this one very carefully, again humor is important. She said, "I was visited by a kind soul from the American Cancer Society who brought me a packet of information about postmastectomy exercises and a complimentary bra. She asked me for my age and my bra size over the phone and showed up at the door the next day bearing a size 44-B bra, having confused my age with my bra size. Since I am a 34-B person, we shared quite a laugh. Again, a little bit off color.

Barber But again it does sound important to use humor in whatever way possible. I imagine it is very important in the family setting.

Miller Women make different decisions sometimes and in the book there are these three women who had high risk of breast cancer; one of them chose careful surveillance, one of them chose to take tamoxifen, and one of them chose to have bilateral mastectomy. Three women, similar in many ways, but with three different decisions. Women make different decisions about whether to take chemotherapy or not, and also very different decisions about mastectomy, lumpectomy, and reconstructive surgery.

Barber We are speaking with Dr. Ken Miller about his book *Choices in Breast Cancer Treatment*. I would imagine pulling all of these stories together in this book got you thinking in new ways. How did it change the way you deal with your patients, or think about breast cancer?

Miller Medicine is a wonderful field. I feel very fortunate to do the work that I do, but it gave me a more mature understanding as a clinician in some ways, about the journey that people go through, and I am a little less afraid to ask questions now. For example, I have started to ask people about sexuality, such as, are they intimate with their partner? I used to be afraid to ask some of these things.

Barber I would imagine your patients are glad that you brought it up. It may be something that they felt uncomfortable bringing up as well.
Miller Absolutely, I have never had a bad reaction when asking questions like that. If I ask, how is your mood, how are you doing, and not just in a superficial way, people are pleased that I asked. So in a sense it has made my work more satisfying.

Barber In a family you are survivor because someone you love is dealing with breast cancer. What makes it easier when you have to tell people about it? You probably have to tell people from brief acquaintances, work acquaintances, all the way up to the family. We talked a little about how to talk with kids about it, but speak to that a little more.

Miller I think friends, family and your public, are looking for a way to frame this. When they hear the diagnosis of cancer and they see you have lost your hair, they could be thinking, oh my goodness, she is dying. So I think it is useful for women to put it right out there as much as they are comfortable with. Just say, you know what, I had breast cancer I have had surgery and now I am taking chemotherapy to prevent recurrence and I am free of cancer now. Most of the women we're treating are in that situation. They say, you know what I have breast cancer and these are the things I am doing to get well. I think it gives people a sense of what to expect and helps them understand the experience.

Barber You have said this before and it bears repeating, the fact that cancer while being that ice-water moment in our lives has also opened up things to a lot of people.

Miller There is something called posttraumatic growth, and people will talk about how a very tough experience, such as cancer, in a sense really led them to being broader people or wiser people, people that really take each moment of life in season and enjoys it. It has become clichéd to talk about taking time to smell the roses, but people actually do that and there are some good things that come out of the cancer experience.

Barber As we conclude, as a physician to have that book sitting in front of you, its got to be just wonderfully gratifying.

Miller It is a great feeling and it makes me very happy to think that people are reading it, and hopefully, walking away from it and saying, that woman Toby got through it and Luba got though it and so can I. I am also hoping they get a sense of personal feeling from the doctors, myself included, that there is a group of caring physicians who are going to help you through that.

Barber I always say, you can be in a restaurant and you would know if you are sitting next to a film star or someone from the media, but often times there are the celebrities of the mind sitting near you, and I think you are one of those. I feel lucky to be sitting here talking to you about your book Choices in Breast Cancer.

27:13 into mp3 file [http://www.yalecancercenter.org/podcast/Answers_Aug-24-08.mp3](http://www.yalecancercenter.org/podcast/Answers_Aug-24-08.mp3)
Treatment. I would imagine you can get it all over the place.

Miller Amazon, Barnes and Noble. If it is not at your bookstore, please ask them to order it. If there is someone that you know in your life that was just diagnosed, it is an easy book to read, and again, I think pretty inspiring and upbeat.

Barber To you and your family, you are inspiring and upbeat.

Miller Thank you.

Barber It has been wonderful being with you. Thank you so much for being with us on Yale Cancer Center Answers.

If you have questions, comments, or would like to subscribe to our podcast, go to www.yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, it is a conversation with Dr. Lyndsay Harris who talks about advances in the treatment of breast cancer. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.