

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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Yale Cancer Center Answers

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Welcome 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 specializes in pain and palliative care. If you would like to join the discussion, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening Ed and Ken speak with Barbara Oliver, Executive Director of Y-ME, Connecticut.

- Chu Barbara, you are a breast cancer survivor, can you share a little bit of your personal story with us?
- Oliver I am a breast cancer survivor and it has been 20 years. 20 years ago the ACS, The American Cancer Society, was running an ad about doing breast self exams and I realized I had not done one. I had 4 kids, was healthy, exercising, all that good stuff, and I happened to see that ad and thought I should do one. The next day in the shower I found the lump. I talked to a group of women yesterday and told them that if they find something in their breast that does not feel like it belongs there, have it checked out. 80% of what they find is nothing, but I could not be sure of that so I had a mammogram. Nothing showed up, and in younger women sometimes they don't show up. I then had a surgeon look at it and he determined it needed to be biopsied. I had the lump removed and sure enough it was breast cancer. Thankfully I found it early, so I had some options. Through many opinions, through much searching around and decision making, I finally decided, as the youngest of 6 girls, that I was going to have the breast removed and have reconstructive surgery. It worked very well for me and I am still pleased with it. A year and a half later, I went back and had the other breast removed because I had a small chance of having a separate breast cancer in the other breast. I had it removed and had reconstruction and here I am, very fortunate to have found it early.
- Chu After your surgery, did you need to have any kind of follow-up therapy in the form of chemotherapy?
- Oliver I did. I spent 5 days in the hospital, and around the 5th day the doctor came in and said the pathology report came back and that there is one node and I needed chemo. He said that they urge and suggest I receive it, but they can't make you. I was really scared but thought about all the right reasons and did it. I had CMF, Cytoxan methotrexate, and 5 FU. After that I received tamoxifen and I was on it for 5 years.
- Chu For our listeners out there, 20 years ago Barbara had to be hospitalized for chemotherapy. We have come a long way in 20 years.
- Oliver Yes.
- Chu Today patients, who are in the same situation as you were Barbara, receive chemotherapy as an outpatient. They come in to the clinic and they go home that same day.

- Oliver Absolutely, we had a board member last year who passed away from cancer, but it was just an incredible journey and I was fortunate enough to accompany her to most of her treatments at the infusion centers. It was in and out one-day treatments, nothing like 20 years ago. I feel like a dinosaur sometimes, but my message is still the same.
- Miller It is a wonderful message for everyone listening out there. It has been 20 years which is wonderful. The name of your organization is Y-ME and I want to ask you, looking back 20 years ago, do you ask yourself "why me?" Is that a common question?
- Oliver I know some women that do, but most of the women we talk to say they don't, they ask "why not me." I never asked "why me?" I was just astonished that it was breast cancer and I dealt with that. It's an interesting point that I am the youngest of 6 girls. There is no history in the family, and that is the first thing most women say. Most women who have breast cancer have no family history. I am still the only one in my family. My sister's look at me thinking, same house, same parents, same foods, same whatever and no one knows what causes it. I never dwell on that. I did what I had to do and moved on.
- Chu That is another important point to emphasize, while we always think of breast cancer as a genetic disease that runs in families, the large majority of patients who are afflicted with breast cancer don't have a family history, as in your case.
- Oliver Absolutely. There is a sister study currently going on dealing with issues of connecting with the sisters of women who have breast cancer.
- Miller I don't think we have any definitive information from that yet. For the listening audience, there is also genetic testing available for women with a strong family history. If you find, as you were saying Barbara, a lump in your breast, regardless of your family history, obviously pursue it because early diagnosis makes such a difference.
- Oliver It is not only a lump in the breast. It is doing breast self exams, looking in the mirror and seeing what your breasts look like, is it leaning over, is there dimpling? Sometimes women say there is heat in the breast or particular soreness or a discharge from the nipple. Again, 80% note that it is nothing, but the only way to determine that and not be left worried and wondering, is to have it checked out by a doctor.
- Chu Absolutely.
- Miller Barbara, hearing your story, I got a sense that you made a lot of decisions, that you were faced with choices. Is that process of making choices, making decisions, helpful as you look back, was it empowering and sort of healing in its own way?
- Oliver I found it very empowering. I am out in the community a lot and we have support groups and I do a lot of speaking, and I tell women that it is really important to

realize that it is all about them. People mean well and they have all sorts of advice, but it is about you, so second opinions, third opinions if necessary, getting a notebook, writing down various suggestions from people and what the doctor is saying and maybe bringing a tape recorder to the meetings with the doctors, all that leads to empowerment in helping with your decisions.

Chu What is terrific is that now there is a support system like Y-ME.

Oliver Absolutely.

Chu It's important to offer advice on education and impart knowledge to women who have the disease. 20 years ago Barbara, when you were first diagnosed and going through the whole process, what was the support system like? Were there any such organizations to help you?

Oliver If there were, I could not find them. Y-Me is celebrating its 30th anniversary coming up, but back then it was not a national organization. They did have a nationwide hotline, but I was not informed of that. I really tread my own way on this journey of finding something. I have to give a plug for Bernie Siegel because my sister had been doing meditation, and was into that alternative lifestyle, and she thought that I'd need help facing chemo because I was so scared. Bernie Siegel was speaking in New Haven, and I joined one of his support groups. We were all women with various types of cancer. We met once a week and I found it so empowering. I went for the first 3 weeks and just cried, and then suddenly they would hug me and tell me not to cry. I could not even say my name until the third week, but out of it came such a wonderful support system. I knew I was not alone and that they were the only ones who understood. My husband and my kids all loved me and wanted to help, but they did not understand.

Miller Barbara, for the listening audience, can you tell us what Y-ME is. Obviously it has been around a long time, so tell us a bit about it.

Oliver Y-ME is a national breast cancer organization that provides support, information and education. It is an interesting story of how it started. Thirty years ago there were 2 women in Chicago who both had breast cancer, and at that point you could barely say cancer. Friends brought them together and decided that if they were dealing with breast cancer, others out there must be as well. They put an ad in the paper to have women come together in a support group, and all these women showed up and it grew so fast, so quickly, that they met at the Y. It became the Y and ME. It is a true story. Then it became Y-ME Breast Cancer Organization. The mission of Y-ME is to ensure, through information empowerment and peer support, that no one faces breast cancer alone; that is the big thing, that idea of no one facing breast cancer alone. That is why we have the hotline. Women in Connecticut can call our local number and we will talk to them and give them all sorts of local resources, packets of information and refer them to the national line which is answered by a trained breast cancer survivor 24 hours a day. I have tested it with that 3 o' clock call and it is answered, it's not an operator. You are actually speaking to a breast cancer survivor. We also have a translating line with

300 languages available. There is also a men's hotline for men whose significant others, wives, sisters, mothers, grandmothers, or he has breast cancer. You can not only speak to a survivor, but you can then be matched with someone depending on your issue. For example, if you are facing chemo and are going to be receiving Adriamycin and want to know something about it, you will be matched up with a woman who has had it, maybe even the same age, so it is a wonderful resource.

Chu Wow, that is terrific. How many women would you say you are involved in counseling and supporting here in the state of Connecticut?

Oliver We get about 900 calls a year just here and we are a small office with 2 people, but we track it. We also get women from Connecticut who know the national line and call there first to get information. They track that information back to us so we can make sure that they will follow up here. There is nothing like it. We are not the American Cancer Society, God bless them, that deal with all cancers, we are not the Susan G. Komen for the cure, which is fabulous, and they do research. We are the survivors on the breast cancer hotline nationwide and we are also women who want to empower others so that they, and their families and significant others as well, do not go through breast cancer alone.

Miller It is an interesting point you bring up that family wants to help and wants to be supportive, yet sometimes women may still feel alone.

Oliver Very much so. Well meaning people have a tendency to tell you what to do and having 5 older sisters, I love them all, but one of them in particular would say to me "you should." That phrase is not in the vocabulary of a breast cancer survivor or those that love her because it denotes you are doing something wrong by not doing what they want. My sister would say, "you should be going to Boston", "you should be going to New York," and would question me about what I was doing, so I pulled away from them until the sister that I am closest with talked to them and told them that it's my decision and they should support me. She told them that I have made my decision and now it is up to them to be behind me and that is what happened. I don't allow "you should" in my life.

Chu That is an important lesson not only for breast cancer survivors, but really for all of us in our every day lives.

Miller Barbara I want to ask you, Y-ME offers support groups throughout the state for women, can you tell us more about those support groups and what participating in a support group is like?

Oliver We have 6 support groups. The women that facilitate them are trained nationally by Y-ME. We just had a training up in Cromwell and national representatives came and we spent a very long day making sure that they know the principles of Y-ME; no two women are alike, we are not doctors or nurses, we are not there to tell them what to do, we respect their opinions and we want them to feel that they are in a safe environment and what is in the group stays in the group. The support groups started because wonderful volunteers called me and said things like, for

example, "I understand you do support groups but there is not one at Griffin." I told her it isn't that easy, you need a volunteer to step to the plate. Then she said, "I will volunteer." She had the administration call me and we met and then we started one there. There is a story for just about every one._We have one at Manchester Hospital, Griffin Hospital, Milford Hospital, St. Vincent Medical Center in Bridgeport, Old Saybrook at the congregational church and then our newest one is at the Yale Medical Center in the Shoreline in Guilford. We are really thrilled with that and several of them, like the one at the Shoreline, have an oncology nurse partnering with the survivor. But it is a breast cancer survivor that facilitates the group with an oncology nurse and we do have oncology nurses at the hospitals.

Miller We would like to remind you to email your questions for us, or Barbara Oliver, to canceranswers@yale.edu. We are going to take a short break for a medical minute. Please stay tuned to learn more information about Y-ME, Connecticut with Barbara Oliver.

Medical Minute

Over 170,000 Americans will be diagnosed with lung cancer this year, and more than 85% of these diagnoses are related to smoking. The important thing to understand is that quitting even after decades of use can significantly reduce your risk of developing lung cancer. Each day, patients with lung cancer are surviving thanks to increased access to advanced therapies, specialized care and new treatment options. This is giving lung cancer survivors new hope. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for lung cancer. Patients enrolled in these trials are given access to medicines not yet 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.

Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller. I am here with my co-host Dr. Ed Chu, and Barbara Oliver, Executive Director of Y-ME, Connecticut. Barbara, as we start this second portion of this show, I wanted to ask a little bit about family. I saw your wonderful brochure, "When the Women you Love has Breast Cancer." Let me start by asking what advice you would give to a husband, a partner, or a family member.

Oliver First of all, call the hotline because it is a tremendous resource. It is not just for women with breast cancer, there are family materials available as well. We can match calls for people. It is an interesting question because sometimes we see family members in the support groups. The mission of Y-ME is to make sure no one faces breast cancer alone and we are trying to incorporate that into everything we do. Most of the support groups, particularly the ones at hospitals, offer support lectures that include the family. They can call the office and get all sorts of material. We do not recommend doctors, and that is really important to understand, but we refer the patients and their families back to their doctors, back to the support system that they have medically for questions and answers. If they

are not sure about something, we tell them to go back and ask their doctor. The team begins to grow with the patient and the doctor.

Chu Relating back to your own experience, did any of the dynamics change between your husband, your children or your siblings, while you were going through the whole process of your treatment for breast cancer?

Oliver Interesting question.

Chu Not to get too personal, but I think it will be helpful for listeners out there.

Oliver My way of dealing with things is talking about them, it always has been. Other women choose to do it their own way, that is my way. I felt that if I was going to get through this, I would need my family around me, so I was pretty honest with the kids. I let their teachers know, I told everybody I knew, and said, "Do not leave me." I told them that if I am going in the hospital, if I am going to have chemo, take me to chemo, bring me flowers, I want it all. That is the way I dealt with it. I really needed that support system around me. My kids were great. My husband, it just was not in his vocabulary. He would hug me and do all that, but he just did not want to talk about it, which is so common. It took joining Y-ME to realize it. I thought I was alone on that and I am not. It is a very common thing for husbands, and other family members, not to want to talk about it, but that can hurt a woman terribly. They may think you are pulling away from them. Right before I went in to the hospital for surgery I called my husband's secretary and said, "I am going in the hospital, please let people know, and send flowers, candy the whole bit, don't let me be alone in there", and she said, "Mrs. Oliver, what are you going in for?" He was just not talking about it. So eventually I gave him permission. I told him it was okay and that I understood where he was coming from, but he needed to know that I was going to talk about it. That kind of cleared the air.

Chu That does seem to be a fairly common experience.

Oliver Very.

Chu What advice can you give our listeners out there?

Oliver This is why there are men's hotlines too. It is not just about the man whose wife has breast cancer. It's about the man that can't talk about it, who needs another man to say, "Hey, its okay. Deal with it the best you can and help your wife, or whoever it is in your life, and communicate with them on this topic."

Miller We look at the cancer experience as a difficult one for many people, and for some we see it as traumatic. As you look at your life, what kind of personal growth has there been from cancer? I get a feeling there has been a lot.

Oliver There has been a lot, and I think that every woman I see in the support group says she has grown in some aspect of her life, because it changes you. Life becomes

very precious. You have come through a horrendous experience, and on the other side of it looking back you see how far forward you have moved. So, I did not waste time. I got through the chemo and I had kids that were active. I am pretty active as well and joined the Leukemia Society and was there for seven years. I left the Leukemia Society in good graces, but had been doing more and more with breast cancer. The phone would ring, a patient would call regarding their patient fund and I'd take the call and talk to the patient. Eventually I was talking about my breast cancer experience to various groups privately so I wanted to move on. I was not sure it was going to be with breast cancer but then I saw an ad in the paper for a women's health agency in Branford for which I got the brochure, and it was Y-ME Breast Cancer Organization. They called me and asked for an interview, and I told them I get their brochure and that I am a survivor. I would presume that is not why I got it, but I think it helped the position. The experience is life changing absolutely, in small ways, and for others in big ways. Women in support groups say that they suddenly start hugging their kids more and sometimes there are problems, but it seems women get stronger having gone through it and do not revert back to something they were doing before that they did not like.

Chu Y-ME has a terrific hotline and you offer these wonderful support groups. You also organize terrific symposiums. In fact just last month you had a terrific symposium at the Yale Cancer Center.

Oliver Yes, and women really look forward to them. It is family event. Husbands, boyfriends, sisters and mothers come. Everyone is welcome.

Miller You are doing an educational program at high schools.

Oliver Yes.

Miller Tell us about that.

Oliver Y-ME has a team program. We go after seniors in high school. We do a program at Stamford High and other high schools as well, but we just got through doing it at Stamford high. We have Dr. Manasi who is a breast cancer surgeon. We have a representative of the hospital and we have Y-ME representing survivorship. We talk to the senior girls in high school and they are awesome. At Stamford High we had some 240 girls sitting in an audience, watching a short video on doing breast self-exams, hearing from me as a survivor and then having the breast cancer doctor talk to them. The talk is not about getting breast cancer; it is about being seniors in high school and going out into the community. They are going to be working next year, going to college, some will be in the armed forces, and now is the opportunity to learn what their breasts feel like and how to check them. As they grow older, if they find something they can have it checked out. We tell them to go out into the community, to their mothers, their grandmothers, and their aunts, and tell them to have a mammogram. We know that they do too because we get their calls. We get calls saying "My daughter had a recent discussion at her school, can you tell me where I can get a mammogram

in the Stamford area?" It does get back to them and they love it. We give them a bag of stuff and they ask wonderful questions. The doctor is the one that answers questions, such as, "If I were hit by a ball, can I get breast cancer?" No obviously, but no question is stupid and if they need to ask it, they do.

Miller I will pose a couple of questions to you that I think we should put out there. Is breast cancer contagious?

Oliver Absolutely not.

Miller I think it is important because these are some of the things people wonder about. Patients ask me, "I hit the steering wheel when I had a car accident, or someone hit me with a baseball, can I get breast cancer?" I will pose another one that I could answer, but I think it is better if it comes from you. Do you have to have a family history to develop breast cancer?

Oliver You don't have to have a family history. As I look out into the audience of girls in the high school, I ask how many of them know somebody who has had breast cancer or is undergoing treatment; 90%-95% of the audience raises their hand. They need to be educated. Their questions make it obvious that they do need to be more educated. They come and they listen to everything, but I think hearing a survivor is helpful. As I get a little older I am always a little reluctant and think that maybe they will not listen to me. But when I had my breast cancer I was the age of some of their mothers, so I can bring it home in many forms.

Chu That is a terrific program, because as you say, education is the key. Again for this disease, screening and early detection are the best ways to beat this disease.

Oliver They go home and spread the gospel of breast cancer awareness, so it is a wonderful program and we do not do it often enough. Stamford continues it every year, and we do it at Stratford High School, but we would like to expand that.

Chu Let me ask both Ken and you a question. Barbara, you have a terrific support group for breast cancer survivors, and Ken, we have heard on this show from you the important role of survivorship and you are the Director of our Connecticut Challenge Survivorship Program here at the Yale Cancer Center. Is there any possibility that we can bring the two worlds together, Y-ME and the Yale Cancer Center Survivorship program, to benefit women with breast cancer throughout Connecticut and the region?

Miller We actually had a program recently called "Dialogues" where we met with a group of women who were breast cancer survivors. We came up with two conclusions for our projects. The first one was a patient to patient program. I was sitting today with Barbara learning more about Y-ME which is a group that I know something about, but I learned more today. I told her that maybe Y-ME and our survivorship program can link together because they're doing this already, the patient to patient.

- Oliver Right, we are.
- Miller So what do you think?
- Oliver We should definitely get together and talk about it. If I can just add, the West Haven Breast Cancer Committee, a wonderful organization, has given us money these past couple of years and we created a program for the senior woman. Senior women are at highest risk for breast cancer so we wanted to get out into the senior centers, go to their gatherings, bring them material and talk to them about having mammograms and doing breast self-exams, making them aware of these things.
- Chu Barbara, for those listening out there that want to learn more about Y-ME, or want access to the hotline, can you give the phone number?
- Oliver Absolutely. I am going to give the hotline number because from there everything can start. It is 1-800-221-2141.
- Chu And do you have a website?
- Oliver We sure do. It is www.Y-ME.org. To list all the affiliates just click on to Connecticut.
- Miller Terrific. Barbara, I want to thank you for joining us on Yale Cancer Center Answers.
- Oliver Thank you for having me doctors, it was wonderful.
- Chu Barbara, it has been great having you and we look forward to having you on a future show to learn more about the great things Y-ME is doing.
- Oliver Thank you so much.
- Chu Until next week, this is Dr. Ed Chu
- Miller and 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, Ed and Ken speak with Dr. Ellen Sigal, the founder of Friends of Cancer Research.