

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 is an oncologist who 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 Dr. Chu sits down for a conversation with Dr. Marion Morra. Dr. Morra is the chair of the American Cancer Society's National Board of Directors and the author of "Choices", one of the first major self-help books for cancer patients.

Chu Marion, it's really a pleasure and an honor to have you on our show this evening.

Morra Good evening, I'm really happy to be here Ed.

Chu You are one of the "founding fathers" of the Yale Cancer Center, having been here for well over 25 years. Can you tell us a little about what the experience was like in those early days and what your role was?

Morra I'm happy to do that. I joined the cancer center in 1975, and as you know, Yale was named a Comprehensive Cancer Center in 1974, so I was here early in the fray when we were trying to put everything together and looking at what was happening in the state of Connecticut. My background is in communications and community organizations. I was working both on the communication pieces and also looking at the outreach. One of the things we did early on was have a major meeting with the five organizations in the state that were working in cancer at the time; the American Cancer Society, the State Health Department, the Hospital Association, the Medical Society and Yale and the University of Connecticut Health Center. We brought together organizations and people in the state who were working on cancer to try to decide what kind of a program we needed, and several things came out of that. There were a lot of professionals there. This was back in the 1970s, in the 1970s we were starting to have some successes with chemotherapy. We were having some good successes with radiation therapy, but cancer was still viewed as a death sentence by most people. There was a lot of information for doctors and nurses, but very little information for patients. At that time, an oncologist was a new specialty along with oncology nursing. I don't think we even called it oncology nursing at the time. We had some nurses who were trained to give chemotherapy under the aegis of the physicians. Most of those people were in the research setting, and Yale has been involved in research and cancer for a very long time. Today we have an explosion of information. We have a very active advocacy effort, and we have a growing number of survivors. There are more than 10 million people in the United States today who have survived cancer. Having that many survivors is due to several things. We are doing a lot of prevention and early diagnosis, so we were finding the cancers earlier. Cancer has now become more of a chronic disease than a death sentence.

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- Chu It is remarkable the advances that you have been part of during this 25-30 year period. The key role here at the cancer center back in the 70s was the formation of the Cancer Information Service. Can you tell the listeners out there what the mission of that service was at that time, and what the role of that service is today in 2008?
- Morra Back in the 1970s when the cancer act was passed, and the amendments of the cancer act passed in 1974, there was an aegis that we were to give up-to-date accurate information to patients, their families, health professionals, and the general public. When the National Cancer Institute got the mandate from congress that they were to do this communications piece, they started looking around and trying to decide what kind of information should be given. At the time, Ted Kennedy's son had sarcoma, and if you remember, at that time, sarcoma was in most places an incurable disease, most of the kids who got it died. The Kennedy's, however, had experience in knowing where the best medical centers were and they were able to find a medical center that was doing state of the art treatment in sarcoma. Their son was saved. His leg was amputated, but his life was saved. The people at NCI thought, wouldn't it be wonderful if the rest of the people in the United States who don't have access to this kind of care were able to get that access? What can we set up to make this access possible? They came up with the telephone service and decided that they would fund the Comprehensive Cancer Centers. At the time there were 17 of them, and they would give them communication contracts and part of it would be used to set up the Cancer Information Service, which is still in existence 30 years later. The aim of the cancer information service is to give accurate up-to-date information to anyone who calls.
- Chu Who provides the information, are they volunteers or are they trained specialists?
- Morra It is all paid staff, very highly trained because quality is a very big issue. In the very beginning there were a lot of discussions about what kind of program was needed and what role the cancer centers had in it. It was finally agreed that it would be nationally led, the information would be given regionally but the information would be nationally lead. It was not to be a PR program for the cancer centers, that is, you could not decide that since your cancer center is treating cancer one way, that is the information you are going to give. We would all give the same kind of information. Back in 1975 there was no Internet or fax machines, so when we started out it was a very big job to try to figure out how to get that information, give accurate information and how to train people to give it. The NCI very wisely set up a series of task forces and the people in the field spent a lot of energy and time setting up the systems, many of which are still in place. If the National Cancer Institute had a news release they wanted to give to the 17 centers, it would take them almost all day to call the centers and tell them what the news was. Now, of course, everybody is using the same computer program so that the information people are giving is more similar than it was in the past. It is a wonderful service. It is one of the most important things the National Cancer Institute has done because it has made a real difference. It has helped patients to become partners with their

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doctors and has made those really difficult decisions that cancer patient have to make everyday a little easier.

Chu Just to reemphasize the point, you played a key role in helping to launch the service that was based here at the Yale Cancer Center.

Morra We were one of the first centers to open our phones. We spent a lot of time pulling the information together and making sure that what we got was up-to-date and accurate. What is interesting is that it's a model that is now being used around the world. Germany was the first country that came to us and said they wanted to set up an information service. As a matter of fact, the German CIS people came to our offices at Yale to see how we were doing things. Now there are many countries around the world doing this. We have an International Cancer Information Service group where those of us who have been running services go out and help new countries who are trying to set up similar services.

Chu As I was getting ready for our show this evening I saw that you are the founding member of this International Cancer Information Service.

Morra Yes, and I am serving on their Board of Directors. It is very exciting because we have a lot of developing countries that are now doing cancer plans and setting up cancer information services. It is wonderful to see that this is a model that other countries can follow.

Chu It is terrific. Are those country specific cancer information services or are they linked with the NCI Cancer Information Service here in the United States?

Morra It depends on what they want to do. In some cases, they are using the same information, but in other cases, they are using the publications. Both the American Cancer Society and the National Cancer Institute are part of the international group, so it's really give and take trying to help others do what we have done very successfully here in the United States.

Chu The American Cancer Society also has their own cancer information services, is that correct?

Morra Yes, the American Cancer Society has an 800 number, 1-800-ACS-2345, where they give information. They give similar information to what the National Cancer Institute's CIS does. The National Cancer Institute was set up 10 or 15 years earlier than the American Cancer Society, but their services work very closely together. We find that some of the same people call us to make sure that each of the organizations is giving the right information, but they are both great organizations and we need to have this kind of service to serve the people. There are many people who need the information and phone lines are busy for both organizations.

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- Chu Over the past 30 years, what changes or advances have you seen in terms of the way that the cancer information is communicated to patients and their loved ones?
- Morra To me the biggest change is the sophistication of the people who call. People have much more information today than they had when we first started out. A lot of people who call have already been on the Internet and have looked up things, and are now trying to make their own decisions about what they are going to do. Now it is much more helping people to make decisions than it was in the early days. The explosion of information has made it more difficult for some people because they get a lot of different opinions as they are trying to figure out the right thing for them. People on the phone spend more time trying to help people sort out the issues that are bothering them than they did in the early days. Of course the technology is what's made the biggest difference. There is e-mail and text messaging now, and there is live help. There are a lot of ways of getting to the audiences that we didn't have in the early days.
- Chu We see this everyday in the clinic when we deal with our patients. They come in with printouts that they got off the Internet with new treatment approaches for their disease at centers all around the country and even in different countries around the world.
- Morra Do you think that makes it more difficult for the physicians?
- Chu I think knowledge is good, information is good, but sometimes too much information may not be so helpful.
- Morra Yeah.
- Chu It is harder for them to really understand the good from the bad. What is helpful is that it opens up lines of communication and dialogue, which is very important. The good thing is that it empowers patients and their family members.
- Morra What we have found is that when people see a cancer specialist, the physician does not know the patient. It isn't like going to your general practitioner who knows you and understands what you want. When you see a new patient, you do not know what the patient needs or what kind of attitude they have; whether they want extensive treatment or they don't want very much treatment. We try to help the patients by knowing the right questions to ask their physicians. That is another piece that the cancer information does, is try to help patients figure out what they really want to ask the doctor. Also, is the doctor the only person who can answer questions, because as you know, people don't have very much time with their doctors these days, which is another thing that's changed a lot.

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Chu We would like to remind you to E-mail your questions to canceranswers@yale.edu or call 1-888-234-4YCC. We are going to take a short break for medical minute. Please stay tuned to learn more information about cancer efficacy and the importance of Cancer Information Services with our special guest, Dr. Marion Morra.

Medical Minute

There are over 10 million cancer survivors in the US and the numbers keep growing. Completing treatment for cancer is a very exciting milestone but cancer and its treatment can be a life changing experience. After treatment, the return to normal activities and relationships can be difficult and cancer survivors may face other long-term side effects of cancer including heart problems, osteoporosis, fertility issues, and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancers such as the Yale Cancer Center to keep cancer survivors well and focused on healthy living. This has been a medical minute and you will find more information at www.yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Chu Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu, and I am here in the studio with my special guest, Dr. Marion Morra, talking about her work in cancer efficacy and patient support. Before the break, we were talking about the important role of the Cancer Information Services. I would like to give out two numbers that Marion has already given. There is the NCI Cancer Information Services number which is 1-800-422-6237, and the American Cancer Society also has a cancer information service number which is 1-800-ACS-2345. Marion, in addition to providing important information for patients and their loved ones, I understand that the cancer information service also has a research component to it that you played a critical role in.

Morra Yes, having the National Cancer Institute, which is an important research institute, funding a cancer information service, and Yale also being a research institute, we were looking early on to see what kind of research we might do in the communications field. In the beginning when a person called the information service, the person who answered the phone filled out what's called a call record form so we knew who was calling, what information they were looking for and what kind of cancer they had. In the beginning most of the research we did was looking at what kinds of people were calling us, what questions they asked and were they satisfied with the information we gave them. Then, Dr. Al Marcus, a research investigator in the cancer control area at the University of California and Los Angeles, was working with one of the cancer information service offices and was interested in behavioral research. His thought was, wouldn't it be interesting if we could do behavioral research across the country in all the cancer information service offices? It was a very ambitious thought and coming from Yale and its research interest, I was very interested

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in it and so he and I put together a grant that the National Cancer Institute funded. We looked at if we could change people's behavior by giving messages at the end of our usual service in the Cancer Information Service. The big question was, is it possible to do research and still give high quality service? That was the question that we had, whether or not we could actually put our research component into a service environment. It worked out very well, and we did three projects. We did randomized trials on three projects, looking at what people do with the information we gave them; do they actually change their behavior? One of the projects was, could we get people to eat more fruits and vegetables. We found that by giving a short message at the end of our usual service, we could get people to eat more fruits and vegetables during the day. Another project looked at how we can use the media to get underserved people to call the cancer information services. There were three projects and we were able to recruit 6000 people into the three projects in one-year. In doing research, you know that it is not easy to recruit people.

Chu Absolutely.

Morra And to have them then call back and answer all the questions, we did high quality research. The people on the phone followed the protocols, so the quality of the research was very good. Recently, we were again funded by the National Cancer Institute to do three more randomized trials that are about to get underway. They are going to be looking at how we can help people make decisions on both treatment and survivorship issues.

Chu Those are very relevant issues.

Morra I think it was a genius idea that Dr. Marcus had and they are very difficult research projects to do, but what he did was involve people at the Cancer Information Service offices. The people at the Cancer Information Service offices came up with a list of concepts that they were interested in and then he found senior investigators who were interested in those same projects. We married the researchers with the Cancer Information Service people and it has been a very successful collaboration.

Chu That's terrific. You have also been very actively involved, I am sure in large part due to your background in communications, in writing self-help books for cancer patients. You have a number of books, but your first one was called *Choices*, which was one of the first major self-help books for cancer patients. Tell us a little bit about that.

Morra I believe that from the very beginning patients should be partners with their physician in the cancer area, because cancer is still a devastating diagnosis. It is not the death sentence it was in 1975, but if you talk to any patient they will tell you that they remember the exact moment that they were told they have cancer. The treatment is not as difficult as it was back in the 1970s, but although we

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have tried and have done quite well with side effects, there are still long-term side effects that can occur. There are not benign treatments yet, and it is important for people to understand and be a part of making those decisions with their physicians. My book *Choices* came about in an interesting manner. My sister, Eve Potts, is a medical writer and we were reporting together the information at Yale to start the Cancer Information Service back in the 1970s. She had a friend who had lung cancer who would call her 2 or 3 times a week with questions about her treatment. She called her one day and said that she hadn't slept in 48 hours and had a terrible sore throat. She was positive that her lung cancer had grown and was in her throat. She didn't want to call the doctor because she was positive. She didn't want the bad news. Eve called me and I told her to ask her if she had radiation treatment recently. That maybe the radiation side effects are causing the sore throat, and sure enough she had. Maybe somebody had told her that she could have side effect from radiation, but she clearly didn't remember it when she needed to. My sister was raising 4 kids at the time and had a Dr. Spock book on her bedside table so that if something happened in the middle of the night, she could open her book and find the answer to whatever was going on. She said to me, "Marion, why isn't there a Dr. Spock book for cancer patients?" and I said, "I don't know." We had been starting to write some patient material at Yale; we did a book called *Chemotherapy and You* and one called *Radiation Therapy and You*, which are hallmarks in the field. We gave the rights to the NCI and they are still being published, but there was not one book that you could pick up and find the answers to your questions. We found a publisher who was interested in it and then we decided that we wanted it to be a book that was told from the cancer patients' point of view, and we would marry the medical information with what the cancer patients told us. We asked patients to please keep track of what questions they wished they had asked the doctor before they made their treatment decision and what kind of questions they had that nobody answered in the hospital. People said that no one would talk to us, but that was not true. The patients were very happy to give us their questions and so the book is a marriage of the everyday and the medical, and it turned out to be 1100 pages.

Chu I didn't realize it's that long.

Morra It is a big book and I'm always surprised when somebody asks me a question and I go in it and sure enough the answer is there; we don't even remember having written it. It has gone through four editions and is still one of the major self-help books in the field. Patients have told us that going into cancer is like going into a foreign country where you don't know the language. They don't even know the questions to ask their doctors, and we were the first people to put it in little boxes and say, here are the questions to ask your doctor. I thought all the doctors I know are going to kill me because their patients are going to come with lists of questions, but it was absolutely opposite. Doctors said it was very useful for them to have patients who actually knew the questions they wanted to ask.

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- Chu As we were talking about earlier, it is really important to have a close, careful, intimate dialogue between the physician, the patient and the loved ones, about really important issues.
- Morra It is very hard for the patients. I have another sister who has just gone through two cancer experiences in the past year. I went with her to a lot of her appointments and you are overwhelmed. You are overwhelmed even when you know a lot, but if you don't know anything, it can be really frightening and overwhelming to go to all those appointments and to hear all that foreign language that you do not understand. A lot of people are afraid to say to their doctor, "Hey stop, I don't know what you are talking about." They do not want to sound ignorant in front of a physician. So we try to make it simple and help people figure out what it was they really wanted to know, and needed to know, to make a decision.
- Chu I am just curious, given the fact that you are involved in the International Cancer Information Service and trying to bring this critical information to foreign lands, have you thought about Choices is already translating into the foreign languages.
- Morra It's been translated into several languages.
- Chu It has?
- Morra Yes. It is out there and when you write a book it is like having a child who goes out and does his own thing. It is interesting to see what happens with *Choices*.
- Chu It is amazing how fast the time has gone, but I did want to congratulate you on your recent appointment as chair of the American Cancer Society's National Board of Directors, which is really a tremendous honor that marks the great achievements you have had in the field of cancer advocacy and cancer care.
- Morra I was very honored to be installed in October as the chair of the National Board. I owe it to Yale and my work at the CIS because I got involved with the Cancer Society because of the Cancer Information Service. On my first day at work my boss said to me, "The first thing you need to do is talk to the people who worked with us and supported the grant that funded the Cancer Information Service." The first organization was the American Cancer Society. So, I went out and visited them at their offices and the chair of the Cancer Society said to me, "We need people on our communication's committee. I need to introduce you to the communications people here." Before I left I was chair of the communication's committee, and that's how I started volunteering for the Cancer Society and have been volunteering for them ever since.

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Chu Terrific. To remind our listeners out there of the two key numbers if they want any additional information relating to their cancer or loved ones with cancer, they are 1-800- 432-6237 and 1-800-ACS-2345. Marion, this has been really tremendous, and I thank you so much for joining us this evening on Yale Cancer Center Answers.

Morra Thank you very much Ed. It was my pleasure.

Chu Until next week, this is Dr. Ed Chu 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 www.yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, we will meet Dr. Tom Duffy, the interim section chief of Hematology at Yale School of medicine.