

CENTER FOR MIND-BODY MEDICINE
COMPREHENSIVE CANCER CARE 2001: INTEGRATING COMPLEMENTARY & ALTERNATIVE
THERAPIES

PLENARY PANEL DISCUSSION: What Cancer Patients Want and Need

SPEAKERS: D.G. Wilson Davis; William Fair, M.D.; Helen Moss, D.G.; Bill Manahan, M.D.

MODERATOR: Penny George, Psy.D., L.P.

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P R O C E E D I N G S

DR. GEORGE: Welcome to this panel on What Cancer Patients Want And Need. If you have come to this rather than staying home or doing something else, perhaps, like me, it's because you are aware that this about healing, and that we need that now more than ever. And this panel is perhaps the heart and soul of this conference and the place where all of what we've been discussing comes together.

My name is Penny George, and I am president of the George Family Foundation in Minneapolis. Our primary passion is furthering integrative medicine, and we are doing this in two ways. One of them is to take the role of convener, both in terms of bringing together integrative medicine leaders and philanthropists who fund in this area, and also bringing the philanthropists themselves together so that we can better collaborate and find synergies in the work that we do together.

The second way we're trying to do that, to further integrative medicine, is by funding paradigm-shifting programs that we find that have the potential to change the consciousness of medicine around the country. We are very committed to the work of the Center for Mind-Body Medicine. And in particular, we've supported the curriculum development for the cancer guides program that was offered for the first time this year in July in Aspen and received extremely high marks. And I would encourage you, if you can, to go to the meeting on cancer guides so that you can find out more about it. And I implore you to make sure that everyone that you have contact with, that is exposed to working with cancer patients, to come to that cancer conference. It is just a phenomenal training program.

There was a time in my life when I wouldn't have imagined that I'd be attending a cancer conference, let alone being involved in philanthropy, and that was before my own diagnosis with breast cancer 5-1/2 years ago. It was putting together my own healing program, which included conventional medicine, but really wasn't as focused on that as it was on all the other dimensions of my healing, that allowed me to move from a place of fear and devastation at the time of diagnosis, to a place where, more days than not, I have more joy and more freedom than I had before.

And it's for that reason that I think that this should be an opportunity that all cancer patients have, to receive the gift of the potential of transformation that's embedded in serious illness. But it doesn't happen just through conventional medicine as it stands now.

One of the surprises for me was the importance -- and I see this now in looking back -- of telling my own story. And interestingly, I never had the chance to tell it to any of the medical people who were involved in my care. But I'm on the board of a hospital in Minneapolis, and so I spoke to the board about my healing journey, and I also spoke to a task force at the University of Minnesota Medical School that was considering whether the Medical School ought to be teaching their students about complementary and alternative medicine. That's, in fact, where I met Bill Manahan, who was on that panel. But the process of reflecting on what I had been through allowed me to make meaning out of it.

And, interestingly, as I told the story three or four times, every time the story was different, until, at the end, it was clear to me that I could say that I really felt healed and that I had moved on.

And that's why, if integrative medicine does take seriously that the relationship with caregivers -- not necessarily just the physician, but with caregivers is a central part of the healing process, we simply have to make time to allow the patient story to be heard. I really don't believe that you can help someone deeply heal if you can't find time to listen to them.

I want to express my personal appreciation for the panelists who are here today offering their stories. To me, they're everyday heroes. They're the people who are living lives of meaning and purpose, while facing the challenges that cancer represents. Each of the panelists has been asked to speak for 7 to 10 minutes, and they'll speak one after another. And then there will be time for questions after that, questions and audience responses.

I'm going to introduce the panelists now. To my near right is Bill Manahan. Bill is assistant professor of family practice at the University of Minnesota Medical School and on the staff of the Center for Spirituality and Healing. He also runs a practice in Mankato, Minnesota. Bill created a highly regarded, experiential course to students of the academic health center to expose them to practitioners of complementary and alternative medicine. He's a former Peace Corps volunteer in Malaysia and Ghana. With his wife, Diane, he worked in the neighborhood health center in Boston, as well as in the squatters' camp in Kenya. He's the former president of the American Holistic Medical Association and author for the book, "Eat for Health: A Do-It Yourself Guide to Solving Common Medical Problems." He also is founding director of the Minnesota's First Rural Family Practice residency. He is going to speak about the journey that he and Diane took through cancer.

Next to Bill is D.G. Wilson Davis. A 10-year breast cancer survivor, D.G. is an advocate for patient empowerment and comprehensive cancer care. She was an early champion of breast cancer self-help awareness in Harlem and Washington Heights, New York. Among a long list of titles and achievements she has accrued, D.G. is currently community director for a program on cancer awareness and rehabilitation at the Harlem YWCA called Force. She's also a member of the National Black Leadership Initiative on Cancer. She designed and created a post-mastectomy center that offers high-quality, culturally sensitive services to breast cancer survivors called With You in Mind. She's the recipient of the 2001 United Hospital Funds Volunteer Achievement Award, and she wants you to know that she's a happy and healthy person.

Next to D.G. is Bill Fair, whom you've already heard introduced. But for those of you who weren't here for the award presentation, Bill is chairman of the advisory board for Health, H-e-a-l-t-h, a center for the integration of CAM therapies in New York. Previous to this, Bill was chair of Urologic Oncology at Memorial Sloan Kettering Cancer Center in New York, and before that, he was chair of the urologic surgery department there. He is a well-known and highly published scholar in prostate cancer epidemiology and of the role of diet and nutrition in the etiology of prostate cancer, as well as complementary medicine in the treatment of genital urinary malignancies. He is here today, however, to speak of his own journey with colon cancer.

And our cleanup batter at the end is Helen Moss. A pioneer and change agent for most of her life, Helen first raised four children on her own. Then she went to break the glass ceiling by becoming first a financial advisor and then a vice president at Merrill Lynch, her employer of 26 years. She founded the Helen Moss Breast Cancer Research Center, whose mission is to educate mainstream physicians about CAM. In fact, she's brought, I think, four physicians from Cleveland with her to this conference. Helen has been a champion of women's rights and a civic leader in Ohio -- is on the Ohio Arts Council. She is here with husband and her mother to share with us her story. Helen was diagnosed in July of 2000 with metastatic breast cancer and has had a whole new world open to her that she was totally unaware of before.

So I invite you to welcome our panelists and thank you for being with us. (Applause)

DR. MANAHAN: What Cancer Patients Want and Need. This talk was going to be a collaborative and partnership talk with my wife, Diane, but she died July 14, so I'm going to have to try carrying on as -- some of the things we had talked about, that we were going to say together here.

Diane had breast cancer 6 years ago and had radiation chemotherapy, and 2-1/2 years ago developed mediastinal mass, which was a metastatic cancer. But she remained quite healthy until a year and a half ago, when she developed metastases in the bone and in the liver and in the lung, besides the mediastinal mass getting bigger. And she remained quite healthy. And in early May, she developed what's called liver failure. The liver sort of had enough cancer in it that it shut down. And she remained quite healthy and continued teaching until the end of May, when school got out. And maybe in the last week, some people might have described her as not being as healthy as she usually was, but she died July 14. And so we had time to prepare the talk together, but it's a little harder to give it alone.

I'm going to talk today about patients who have cancer, the chronic disease of cancer, but whose life expectancy can by all probability be measured in months, rather than years. So often, we talk about the -- as a chronic disease, now, and that's good. And sometimes we don't pay enough attention to that last part when clearly life is measured in months, rather than years, with most probability.

Now, most patients say at that time, "I must do everything I can to beat this cancer." And most families say at this time, "You must do everything you can to beat this cancer." And most physicians and healers say at that time, "We must do everything at this time to beat the cancer."

The problem with this approach is that the patients are, I find, often limiting their fighting efforts of "doing everything" to primarily the material and the physical realms. Many of my patients who have had a significant cancer with extensive metastases receive chemotherapy. It is frequently difficult for me to find in the scientific literature enough to support the use of chemotherapy in many of those patients. I struggle with our medical system, using an aggressive treatment with multiple sometimes side effects, because I don't believe that the patients really are doing everything at that point they can to beat their cancer.

I think what I found with my own patients was often my favorite and most joyful patients that I had with metastatic -- or with cancer where it was measured in months rather than years of life -- were those who had been told by the medical system that there was nothing else to do for them. And I realized that these were the patients both that I enjoyed working the most with, and who seemed to do better, because once the system had given up on them, they started to empower themselves and sort of take charge and had what I would call in many ways a much nicer life. As Rachel Naomi Remen said yesterday, it may not be wise to allow science to define life. And I would add to that, it may not be wise to have science define what's doing everything.

I believe that doing everything's not just assessing the physical possibilities of treatment, but also the emotional, the social, the mental, and the spiritual aspects. Every day in our lives, we make choices about how much time we will spend at work, at play, with friends, at prayer, and many other ways. And Diane and I felt that dying is not something you do, suddenly decide to do, when you have a fatal disease with a bad prognosis; it's probably something we need to start making choices about right now at our life, at every time, because otherwise, there's probably -- it's hard to make those choices at a time of stress.

Many of my patients tell me continually, they're dissatisfied with the choices they have been making during their lives regarding how they allocate their time. One of the more common complaints I hear in my office is, they just don't have enough time for family, for friends, for fun, and I think all of us here can identify with that.

It seems to me that there's an excessive focus on attempting to do everything for the body and very little time spent doing it for the emotions, mind and spirit. After all, what really is healing? How connected are we to our soul to who we really are? What makes us fully alive? Diane and I thought the key to all of this

was choices, and as has been mentioned by other speakers, the empowerment that comes with making your choices.

So I'm going to just quickly say a few of the things that -- some of the choices Diane or Diane and I made in these last few years that I think allowed her to be fully alive until she died. I think the other thing we knew that she was fully alive is that one of the things after the memorial service, so many people in those next few days would say how devastating it must be. And as my four sons and three daughters-in-law and sister and her partner and Diane's sister sat around about 4 days after the funeral in talking about this, the most interesting thing was, we all had words like "beautiful" or "sacred" or "spiritual," and not "devastating" and "terrible" and "miserable." And it was sort of unanimous that we all thought it had been one of the neatest, most beautiful, most sacred experiences of our lives, through the whole dying process. So we suddenly looked at each other and said, "Maybe we should re-evaluate that," and the whole process.

Anyway, she did do some treatment, and she also did a number of alternative and complementary things, including acupuncture, Chinese teas, Qigong, high-dose micronutrients, energy readings, massage. And I think they played a big part all the time, from the initial 6 years ago to the time she died.

Socially, I think the main thing was, she really made sure she kept her friends and spent time with friends and family. But she kept staying on boards that she was on and kept running a cancer support group and doing a number of things that kept her involved socially.

Mentally, she continued to nursing at the local nursing school and did that up until the end of May of this year. And even when she was in liver failure and had a bilirubin of 14 and was all jaundiced, she said she felt okay and continued to go to work. She also continued to play bridge to stimulate her mind, and even continued to play Candyland with our grandkids.

Spiritually, we continued to pray, continued to walk in nature, continued to sing, continued to have friendships.

Emotionally, I think here was the key thing, that about after 5 or 10 years of marriage, she sat me down and told me that I didn't know how to listen very well. And that may surprise some of you women in here. And over the next 30 years, she sort of worked on me to teach me how to listen. And I think in the last 5 or 10 years of our life together, I think what Dr. Spiegel had mentioned, I'd finally learned how to lie down on the floor and cry with her. And that's hard to do for a male and for a physician, because we're taught to give answers. And so it is true; it's hard to do. But I'd had a lot of training. And I think when it came time for the performance, I was able to do that. And that was beautiful for me and for her. So -- and we did physical things like exercise and bike and a little golf and tennis, and all those things.

But anyway, what do people want, the title of the talk? I think they want the ability and the choices to be able to live as the person they really are, and to have the choice to be fully alive as they're dying -- in other words, the choice to have choices.

And what do they need for that? I think the key thing is what's already started by the Center for Mind-Body Medicine and by many other places. I think they need -- I think we all need guides or mentors or teachers, helpers.

And my suggestion and hope is that every cancer patient will eventually have access to a cancer guide, a mentor or a trained professional, who will assist that person with cancer in making appropriate choices for what is truly the ideal path for that individual. That path for some may be primarily therapies for the body. But our idea and our hope is that in a majority of patients, we suspect the mind, the emotions, and the spirit will be also a significant part of that treatment.

Thank you. (Applause)

MS. DAVIS: Good morning. I'm D.G. and I am a survivor of breast cancer.

I'm an advocate of life, living, and loving. I was drafted into this battle against cancer, and I'm one of the soldiers, I'm one of the footsoldiers. My mission is to organize, target, and unite the communities that I live in and that I work in to bring cancer survivors together. There's a myth in communities of color that we do not come out, we do not organize, we do not listen to new therapies. New therapies are not given to us quite often, because no one brings that information. My job is to get the information, share the information, and show that alternative therapies do work.

I am a 10-year breast cancer survivor. I was diagnosed at stage 3A. I was told that I only had 2 years to live. And he told me that in looking at my file after 10 minutes; I realized that he was not the one that I should really work with. That meant that he was only going to give me medicine for 2 years. (Applause)

Complementary/alternative therapies do work. I can say that over and over again, because our mission is to focus on life, living, and getting as much knowledge as we can.

The Force program stands for Focus On Rehabilitation and Cancer Education. It's just that simple. That's where our focus is: On rehabilitation through CAM practices, education, and nutritional counseling. It is a 16-week program that is a free program, and is being delivered through the YMCAs and the Encore (phonetic) program. It's based right now in Manhattan and in the Harlem community. It is 4 weeks of stress management, yoga, 4 weeks nutritional counseling, and 13 weeks exercise. And it's more than just doing aerobics. It's about exercising the mind and exercising our spirit in support group services.

We work together as a family. Each woman that comes in there is allowed to also bring her family, and if they have questions, fears or concerns, we are to address them. If we don't have that information, we find other information. It is a family affair.

Cancer will always be a family affair, but it must be a community responsibility. We must make our communities understand that we cannot do this alone. It is not fair for us to do this alone. We cannot heal alone. We must understand that at all times.

And the Force program, it's a proven way to fight cancer through physical activity and exercise, and to boost your overall health and well-being and maximize your body's ability to fight the disease.

As soldiers in this war, quite often, we lose body parts. We lose soldiers. But we cannot lose the spirit of survivorship. We have an award called SOS, which means Spirit of Survivorship. Within our first graduation, we had a group of women who wanted to do a special program, and their program was dancing. And they thought that dancing would bring laughter, happiness, to their friends and family, who could really understand that Mom was going to live, daughter was going to survive, girlfriends would be okay. And it works.

And our men in the community have really just risen to the occasion to bring us together, to let us understand that we are really not in this alone. And I understand very well what you were saying, Bill, and I can really appreciate it, because tears also is a healing process. We must understand the healing process is twofold. It's for you and then it's for me. And then our responsibility is that each one must teach one. Whatever I learn, it is my given responsibility to share that with the next person that I encounter. Doctors, I believe, are really beginning to stretch out in an area where they really didn't think that they were going to tread before, and that's with alternative therapies. They are really beginning to finally get it. It does work.

This group that I'm working with called Force, ----- magazine contacted us and they told us that they wanted us to pose for their fourth anniversary issue for October, National Breast Cancer Awareness month. So I called the women in the group and I said, "Look, ladies, I need you to come out and help me pose for a magazine." They came running in high heels, in lipstick, and head wraps, and they just wanted

to be cute for the program. Well, the magazine came out, and they are really cute. And they're signing autographed copies and sending it to their friends in the family. But what had really happened in doing that was that it became an empowering tool for everyone who saw the magazine. They said, "Well, who are these ladies?" Why are they on the cover? They don't look like they're sick. What are they doing here?"

And so we're not sick. We're healing. And that's the message, that there is life and love after a diagnosis of cancer. And it's not just for breast cancer. And in our support groups, unfortunately, they divide our illness among different cancers. We have a full circle at Norfolk General Hospital, and it's called the Circle of Support. It's open for all cancer survivors, men, women, and children. We come together once a week to let everybody know that there are special programs designed for the community. And we're trying to really focus directly to the media and try to get them to take some sensitive issues directly to friends and family, so they can really understand that we're out there, your family members do not have to go this alone. And it's working.

And I'm happy and I'm proud and I'm loving and I'm living. And everything is really a beautiful journey for me. This cancer experience has been very humbling for me in many different ways, but the best thing that I've received from it has been love, directly from my community, directly from my friends and my family. And I really do believe that the oncologist who gave me that very poor, poor prognosis is someone who's now smiling at me from wherever he's at, and it doesn't really matter, because I know where I'm at, and I'm right in the center of healing.

So, again, it's been my pleasure to be here. And if you need any information, it would be my pleasure to help you. Thank you. (Applause)

DR. FAIR: Well, again, it's a pleasure to be here. And looking at the title of this session, What Cancer Patients Want To Know, strikes a note in me that this can be the subject of a 3- or 4-day conference, just in and of itself.

But I will tell you what I think I've learned about of my last 7 years in dealing with this disease, and there are certain things that I think are extremely important -- at least for me, were extremely important.

First of all, it was a recognition, as was alluded to by previous speakers, that cancer is a chronic disease. And that seems like a simple statement, but it really is a mindshift in terms of training young physicians, because when we went to medical school, my generation, we were never taught that we were going to cure arthritis or diabetes or heart disease. Those were diseases that could be controlled. But cure was not an endpoint. It was only cancer that really came out as the endpoint. If you had to do everything possible to eradicate cancer, then control was not an issue.

Now we know that that's the wrong approach. Cancer is a chronic disease. And maybe the success of this approach is manifest most markedly in the treatment of AIDS, which looked like a real scourge and incurable, and now we know that with proper monitoring the disease, proper medication, it's possible for people which at least HIV-positive to go for many, many years before converting to AIDS. And we find this in other areas. I think David Spiegel's comments were very, very appropriate, how things like stress reduction can help manage the chronic aspect of cancer.

And when we think the study that's been pointed out numerous times, that 80 percent of all the healthcare costs that an individual accrues in his or her lifetime occurs within the last 6 months of life, you have to realize how much of that financial cost, as well as the emotional costs on the patient, is really more or less wasted on more and more aggressive therapies, more and more toxicity, without any real chance of curing the disease.

And so that's the first thing. I think that we need a mindset that cancer is a chronic disease; it should be treated as a chronic disease. And it may well be, at some point in the future as we look at cancer as a

chronic disease, that we're willing to accept the level of treatment that would keep cancer at a certain level, even though it doesn't cure the patient. So that's one of the first things I've learned.

The second thing is if you accept cancer as a chronic disease, you have to accept that, like any chronic disease, you need to consider chronic treatment. And I think this is one of the most misunderstood areas. And the idea that, oh, it's great to do stress reduction and nutrition and exercise and so forth and so on when you have cancer, but after it's over, you can forget that business -- that's about as rational as saying, well, we're treat diabetes and we'll get the blood sugar normal, and then we'll stop getting the treatment, because we're back to normal.

So I think that -- I tell patients that when they begin on this approach, regardless of how the cancer itself behaves, which hopefully will go into remission, that the things that they adopt -- stress reduction, nutrition, exercise, herbs perhaps, whatever it takes -- should be looked upon as basically indefinite treatment, and you don't stop them just when the things are looking good. Because I think in the long run, of course, what we'd all want to do is have an effective means of prevention. And as Jim mentioned, I've been involved for a long time with prostate cancer, and there are a lot of studies going on right now, prevention of prostate cancer, starting -- some of the studies starting in men age 55, which is probably at least 20 years too late to have impact on the prevention of the disease. So we have to carry these chronic approaches, hopefully in the form of prevention, but when the patient is treated with the disease, to recognize that where complementary integrative medicine fits in, it does fit in the area of a chronic, indefinite treatment.

So I think that we're beginning to get more and more scientific justification for this. In fact, I've got some of the vaccine therapies we recognize now, things like melanoma, probably some of the reason that the earlier approaches did not work is that we didn't recognize that the immune system required repeated stimulation, and that giving a vaccine for a year or two and getting a good response did not guarantee that that would be a response that would be carried over for the life of the patient.

The third thing, and one that was a bit of an eye-opener for me, was the necessity for the person with cancer to be proactive. And I had given lip service -- I think most physicians do -- to the fact that patients really need to be involved with their disease. And yet in my own case, where I believe I had the finest treatment in the world at my own institution, I would ask my physicians, "Well, what can I do myself?" The typical answer was, "Well, Bill, don't worry, we'll take care of it," which is not what I wanted to hear. What I wanted to hear was, "How can I help? What can I do?"

And I think that, again, there are many, many things that we can do. I was fortunate in having run into Sophie Chen, and Sophie sent me some herbs. And we had saved some of my tumor from one of my surgeries. We took that tumor and put it in nude mice, fed the nude mice the herbs that Dr. Chen sent me, and lo and behold, the tumor shrunk and the mice didn't die. That really wasn't rocket science, but at least it gave me some reassurance that maybe something good would come of it. And I think that, while not everybody has a chance to do that, certainly being proactive means finding out as much as you can about the usage and the effectiveness of whatever you're going to use and the potential toxicity -- and I keep mentioning again that I think treatment with complementary alternative medicine is a balance, as it is in allopathic medicine between what we might expect in terms of benefit and what we might expect in terms of downside.

One of the things that was most instrumental to me in deciding my course was the time I spent at Commonweal, and came across the concept -- which, for me, was a new one, although Jim and I had talked about this before, as did Dean Ornish -- and it was the idea, which was almost a mantra at Commonweal, the idea of healing versus curing. And again, a number of speakers have approached this, that it may not be necessary to cure a cancer, but we certainly can do these other approaches in, like, stress reduction and nutrition and so forth to give the patient the proactive feeling and accept the fact that death may be inevitable, but at least that the patient can be prepared for death with dignity and not dying suffering in some hospital with an IV plugged in for the last 2 or 3 months of their life.

What I found personally also was it was very, very difficult for me, even with my medical background, to coordinate this care, because doctors and physicians are often accused of not talking to one another. But I found among the CAM community, that was even worse. I was running all over New York City to find the best people, and then when I found them, the dietitian didn't speak to the yoga therapists or the acupuncturists.

So one of the things that I decided when we did this, "did this" being starting Health, was to have an integrated approach where we would have almost like a tumor board: That after the patient comes in, is initially evaluated by a nurse -- not a physician, because we didn't want to impose another bar between their referring physician and the CAM practitioners -- and the nurses, God love them, have been really this success story behind the growth of Health. And then we would sit around and have a so-called tumor board. And it's not only for cancer; it's for patients with any chronic disease, or even the worried well.

So what do you say to Mrs. Jones who comes in with diabetes or Mr. Jones who comes in with colon cancer? You say, this is the specific diet we recommend for you. And it's often not enough to say a 20 percent fat diet. You need to actually sometimes go shopping with these people, or at least read what they're eating and correlate that with what the diet is given -- make it very, very specific in each of these areas.

And one of the things that I think is a mark of the success is David Eisenberg's landmark study, as you know, showed that about 70 percent of patients will not tell the doctor they're using alternative or complementary medicine, predominantly because of fear of intimidation or embarrassment. Our communication with the physician is primarily, again, through our nurses. And we find out that when the nurses say to the patient, "After we finish this evaluation, would you like us to let your physician know," instead of 70 percent saying no, we have 90 percent saying yes. And when the physicians get an official report from our health center, we don't run into that intimidation and embarrassment that the patient is afraid of experiencing, because it's a professional-to-professional.

So I think it's important that we find some way to bridge this gap between what patients will generally tell doctors and what doctors need to know to help plan. And again, one of the things in Health is to keep the patients own physician intimately involved, because I don't think that there's anybody that knows more about cancer or heart disease or diabetes or whatever than the patient's own physician who's dealing with that patient. And you create a program where that patient is out of the loop, where that physician is out of the loop, I don't think it's a benefit for the patient.

And the last thing is, I take a little issue with David Spiegel's excellent talk in saying, it's hard to think there are good things coming from cancer. And I realize it sounds like an oxymoron. But at least in my case, it opened up doors that I never even knew existed. And what my approach was based solely on -- what I had to do. And I've people say to me hundreds of times, "Well, you're a real inspiration to us." And I honestly don't feel that way. One of my mottoes for many, many years had been a comment by Dag Hammarskjold, who was maybe the first Secretary General of the UN, who was killed in the '40s in a plane crash. But he had a saying, published in the book "Markings," "Only one thing is possible, not to have run away." And that's what I looked upon my treatment. The only thing was possible was to do what I could do and get the information I could do, whatever it involved, either the allopathic world in which I spent 30 years of my life or trying to be more open to these other areas that you're all familiar with.

So I think that in my life -- at least it does sound a bit unusual, but I have had good things from cancer. I wouldn't be standing here talking to this group today were it not for the approaches that I have learned, going beyond my allopathic treatment and finding out the benefits of some of the things that we talked about this conference in the management -- not necessarily the cure, but in the management of the cancer patients.

And I think that one of the things that I'm most proud of is what we have been able to do so far at Health, thanks to my son Bill and Pam Damsky (phonetic), and the three of us started this together. And I think

my personal philosophy is, all physicians ought to be CAM doctors. That doesn't mean you have to have a fellowship in CAM, as I said, but I think they have to be recognizing what CAM can provide, not only to the patient, but in the way of education of the physician.

And lastly, I believe that what cancer has given me is new definition of my role in life. I think, in all honesty, that my job on this planet is not yet over. And a part of it, a continuing part of it, is to try to spread this message that we have established at Health throughout the country, throughout the world, so that physicians and patients recognize that the treatment of cancer is not purely a technological thing, and as we go into the future and understand more and more about some of the things that are so poorly understood right now -- energy healing and psychosocial aspects -- and begin to realize that, as David mentioned, we can show physical changes as a result of mental changes, if you will -- the recent observation that women who work at night apparently have more breast cancer, a higher breast cancer risk than those who work day shifts, and it may be related to melatonin. I know when Mary Ann Richardson was at Texas, they were doing a lot of working in melatonin and breast cancer and finding out that meditation can raise melatonin levels to levels that are even higher than one can get by taking a pill. These are all the kinds of things that we need to look at in the future.

So anyhow, I'll sum up a rather rambling talk of what I felt is important for a cancer patient, where we would go in the future. And I salute all of you for attending a meeting like this, because I believe what we're seeing in this room, the spirit in this room and the type of people we have in this room, hopefully really marks the future of medicine, particularly as it relates to the treatment of cancer.

Thank you very much. (Applause)

MS. MOSS: I'm Helen Moss, and I do want to thank Dr. Gordon for having me. And I also want to thank my husband, Richard Fleischman (phonetic), and my mother, Frances Smith, for accompanying me to hear my speech. The head of Case Western Reserve Medical School also wished me well and said, Helen, I know you'll do well. I'm a little bit nervous, since I lost my glasses here.

The topic is "What Cancer Patients Want and Need." I think I'm going to talk about what I wanted and what I didn't get, and I think you have to fill in what I needed and what I should have gotten. So you can kind of work with me on this talk.

To give you a history of myself, I am a fortunate woman. I mean, God gave me a brain and drive and wonderful parents, and I raised children alone. I did so much with my life. And about a year ago last June --

(Tape interruption)

MS. MOSS: I had financial security. I had jobs. I had friends. And I can tell you what else I was so proud of: That I had tremendous health and that I had two grandmothers and two grandfathers who died in their nineties who had smallpox, diphtheria. I had four aunts and a mother who were between the ages of 80 and 90 in perfect health and no cancer. And I never read a thing about any kind of cancer, because I was busy doing other things, and I was immune to this.

So that when I went in to have my mammogram and they said, you've got a problem, we find two lumps here, I thought, no, you know, 85 percent of this at this stage is benign. Well, this is the one good thing that happened. The Cleveland Clinic did have a breast cancer center where you do your mammogram, you do your -- oh, and they can tell if a tumor is liquid or solid. And also if you need it, the biopsy within 3 hours. Within 3 hours. They didn't tell me I had cancer, but they said, well, your chances -- I said, "What are my chances now that you've done this?"

He said, "Well, at this point, 40 percent benign."

Well, I knew. I was shocked. I almost wrecked my car going to work. I tried to call everybody. And by the following Tuesday, I had the bad news that I had breast cancer, and I was going to meet with a doctor. I was so deflated. I mean, here I am looking the same, but inside, I melted. I was nothing. I had no strength. And I mean, I just saw death.

And my family came around me, I will say this. Three of my four children who live nearby came. Their husbands and wives, my husband, my mother. And they sat down with me, and they said, "Here's what we're going to do."

Now, this is not what the medical profession did. This is what they did. My son immediately bought a book called "Susan Love's Breast Book," which I used as my encyclopedia. And there are a lot of male doctors who don't like that, because she doesn't believe in Premarin. Well, forget about that; it's a great book. They said, "We will be with you at all times. We will be a part of the decisionmaking." You see how I'm doing everything all right? And of course, if I do everything all right in my life, things turn out, right? Nothing bad happens.

So we made our first trip to the doctor's office, and I walked in. Now, I had -- even though I was nothing inside -- I was, you know, mush -- I put on my uniform, which is a starched linen suit and a hat to match and my professional face and my husband. I put my jewelry on, which was all supposed to keep me together.

And the doctor immediately said, "Oh, I can just tell that you're just one of those kind I like to deal with. You know, you're rational. You're not emotional. And you're doing so well." And he said, "I can tell by looking at you that you have a 95 percent of survival. And this isn't -- you know, I don't want you to worry at all. By the way, I'm going to recommend a mastectomy." Well, I don't know if you know about the Cleveland Clinic. They were the founders of the ones that did lumpectomies.

Well, I knew darn right, I didn't have a 95 percent chance of survival with that kind of thing. A tear rolled down my face, my perfectly groomed self. A tear came down. And I thought, "This doctor is patronizing me and he's not telling me the truth." And he was not telling me the truth.

My husband leaves and says, "Oh, isn't this great."

The doctor did say one thing before we left. He said, "By the way, this is a very serious disease, and I want you to take it seriously." So there was my first disconnect in the medical profession.

Well, let's talk about the surgery, all right? I was in the room, waiting to be operated on. Now, I will tell you how I felt, this logical person that's always put together: I felt as if I was going to lose part of my body and it was going to be hacked off. Now, I am not attached to my breast. I have no sexual identity with my breast. But it is a part of me, and it betrayed me. And around my bed were all my family, and they were crying, and I loved it. I mean, that made me feel so good that somebody loved me.

But I was waiting -- before I cracked up and crashed, before this surgery, I was waiting for the Ativan or something like that to calm you down before they bring you into the operating room. So every surgery I've ever had, and I've had lots of little surgeries, they always give you this tranquilizer that's supposedly so good before surgery. So I was starting to think about this. And I felt, I mean, I hate to say this, but I felt as if I was going to be butchered. I mean, this awful image came to me that I was going to -- out to be butchered, but I was waiting for the Ativan so I would get rid of this image.

So they wheeled me out into the hallway, and I said, "Well, where's my relaxant? Where's this thing to help me face this as I go into this surgery?"

"Oh, we're sorry. We're using a different kind of anesthesia, and we won't give you any kind of a relaxant." And outside that operating room, I sobbed. And two other women were sobbing too. Three women were waiting outside that operating room, waiting to have their breasts cut off, thinking they may die. And they didn't think that it was very important to relieve that psychological fear or pain or lessen it at that point. And when I got in there, I said, "Just knock me out."

All right, that was a disconnect again, because they didn't understand. And I don't care how strong you are, you're not very strong at that time. And I just love this doctor that spoke earlier, because he really was right on.

Okay, I had my surgery, and I was very calm after the surgery. Now, the next step is waiting for the lymph node situation, because that's really what you want to know. Well, 3 days go by and I never saw my surgeon. Instead, he sent a little guy in in an Armani suit. His little assistant must have been about 30 years old, and he was so impressed with being a doctor. Now, I'm going to tell you it was very offensive to me, because remember what this previous speaker stated, that you want your doctor to be concerned? And the Armani suit represented to me that he was more concerned with his appearance with the nurses and everybody else, and he was so impressed with himself being a doctor, that I didn't matter. And every day, he'd come in and say, "Well, how are you today?"

I said, "Well, where's my surgeon?"

"Oh, well, you know, Dr. So and So has been practicing many, many, many years, and he just thinks that this is not a serious surgery, and therefore, he doesn't see his patients anymore." That's another disconnect, all right?

So I called my daughter-in-law, who's an attorney, on the third day. They wanted me to stay. (Laughter) Well, I mean, I wasn't going to sue them, but I was afraid that the fourth day, I wanted to know what my test results were, and I needed somebody very strong with me. And she's very much like me, and my son is a lucky man. So she came in. She has a law practice; she canceled her appointments. She came in at 7 a.m. At 8 a.m., the Armani doctor came in. And I said, "All right, we want to know what the test results are. Do you have them back?"

"No, we don't have them all back."

"Well, you don't?"

He says, "No, I want you to make an appointment 3 days hence to go see the doctor, because we don't like to give the test results unless we have them all back."

I said, "Well, do you have the lymph node back?"

"Yes."

"What is it?"

He said, "15 out of 16 positive." My blood pressure -- they've taken my blood pressure, and the nurse's aid screamed because, oh my God, the blood pressure machine is broken, it's 200. My blood pressure shot up. And my daughter-in-law immediately went out, demanded that the surgeon come in, the oncologist come in, and pull the team together.

The oncologist came in, and I was pretty upset. And she said, "I don't understand why you're upset."

The surgeon came in and he said, "Yes, when I saw those reports this morning, I said wow." You know, he did not come in. So there was another disconnect. Remember, I said that I was to be worked as a team. And I also wanted to know everything the doctors knew at the time the doctors knew it. And that was another rule broken. And this is at a first-class hospital.

Well, that's when I founded the foundation. And I said, no other woman has to go through this. I thought of women who were older. I thought of women who were alone. I thought of women who had young children. And I was lucky. I considered myself a lucky woman. And it's that point, I said, if I can just help one other woman. I mean, I didn't know how much, because I was -- you know, I was pretty upset.

All right, the chemo. So we got three opinions, three or four opinions, I don't know how many. My husband immediately got a hold of Larry Norton at Sloan Kettering, and of course, the doctor, my surgeon, said, "What do you want to get a hold of him for? He has a big ego, and as far as I'm concerned, all chemo is alike. Maybe you better not get too many opinions." I got one opinion that said all you need is tamoxifen. Another one said, oh, you do this.

And then I came to -- at that point, you know, I'd do anything. I mean, you will do anything. If they tell you to put your head in Lake Erie for 10 minutes, you would've done it.

So the oncologist that I went to said that there was a study out there that you could do high-dose chemo, four doses of it, and then bone marrow transplant. And that she said with ordinary treatment, with a regular protocol, it's a 50/50 chance, but the earlier studies -- now, this is a mistake, and I really think an awful lot of this doctor -- this doctor is in love with chemo. Chemo, chemo, chemo, who is a true believer of chemo, and obviously, the more chemo, the better. And as you well know, that's very controversial.

She said the early studies show 85 percent chance of survival. Well, of course. But you know, that was flawed. And so I made my decision to go with that protocol with flawed information.

And this is where -- I'll tell you why you're all here. There would be no need for CAM, no need for alternative and comprehensive, if chemo worked, if there wasn't the toxicity of chemo and the horrible side effects and the people who die of chemo. Now, maybe it's come a long way, but it hasn't come very far. (Applause)

All right, I went into this thinking -- and she said, "Oh, you're going to do just fine. I mean, some people don't do well, but oh, I can tell by looking at you that you're going to do just fine, because you have this great attitude and you're not depressed," and all that kind of thing.

Well, I woke up a couple weeks later. In the middle of the night, I pounded on my husband. I could not talk. My mouth had swollen up. The tongue had filled my mouth. I had thrush and I didn't know it, and I was in agonizing pain, and I felt like an animal. I couldn't even talk, because chemo is very degrading.

Now, I heard a talk yesterday that talked about, cancer can make you a better person. Well, first of all, facing death absolutely can change your life. But pain does not make you a better person. If it was pain, why would you be here? You're to lessen pain and suffering.

So I had the thrush. Then all of a sudden, one of my teeth went bad. And I had to have a tooth pulled. Then another tooth went bad and I had to have that pulled. Then all of a sudden, I had horrible bone pain in the middle of the night and I thought I was having a heart attack, and I was rushed to the hospital. It happened three times during treatment. I had mouth sores and mucositis, where from my mouth all the way down to every part of my GI tract was affected. I had emergency gall bladder surgery; my gall bladder went bad. But I will you, they did give me Ativan before I had the surgery. (Laughter)

I had cancer coaches, but not from the medical profession. My community -- I don't know, I didn't think I had any friends. I'm very controversial and very outspoken, and you don't always make a lot of friends doing that. However, I read every card three times. I must have gotten 200 or 300 cards. And I believed every word of those cards. They sustained me. They were like food. Flowers came to the house. And those flowers, I looked at them and I smelled them and I loved them till the moment they died. They sustained me. They gave me strength. People called my husband. I mean, I cannot tell you what got me through this that I did not go into a depression. I think I was so busy being sick that I didn't go into a depression. Cancer coaches. I had people who worked with me.

Now, I'll tell you what I did. I could not wear a wig. I put a wig one day and I felt like I was ashamed and I was hiding something, and this wasn't my fault. I thought I had done everything right in life. So I got rid of the wig. I put a hat on. And I would go into work, because I loved my -- I mean, I didn't work very hard. I mean, believe me, I was too sick. But I would go into the office, and I shared my illness with all the people in that office, and they thanked me for sharing my illness. And they came up and they gave me sympathy and patted me on the back and told me I was brave. My friends, the same way; my husband would let them know how I was doing. And the community came together.

So I'm saying, instead of -- you professionals there, encourage people to share. By sharing, there is not risk. You know, we saw so much evil September 11. There is wonderful good out there. So always remember that that balances that out.

My cancer coaches, they told me what to do through radiation. It did not come through the medical profession. They're very busy, very, very busy doctors, very good doctors. Radiation doctors know a lot about radiation, and yes, they know a lot about other -- as I was going through this, I said, "Isn't there something you can do? What about vitamins and minerals, what to eat?"

Well, I couldn't eat anyway, but I will tell you what happened, and this something that you all should take heart, let your patients know when something is going wrong.

After my second chemo treatment, just before my third one, my doctor went out of town. Another doctor took over and said, "I want you to have a CAT scan." I was too sick to ask why because I thought they would tell me. Three days later, they threw me in the third chemo. The chemo is 25 percent more adriamycin than a standard dosage and 100 percent more cytotoxin given simultaneously.

After the third one, my whole body collapsed. What happened is, I got a phone call from the bone marrow transplant people that said, "We can't do the bone marrow transplant because you have liver failure." And I had -- the enzymes in my liver were sky high. So a disconnect. I would not have gone into the third chemo treatment.

I was then hospitalized. I lost 25 pounds in 2 weeks, and I was very close to death because of the chemo. And because a doctor maybe, maybe thought that the study that I was on was more important than the patient. You doctors must take your patients off of a study if things are going bad. Do not err on the side of staying with the study. (Applause)

Well, after it was all over and my immune system was shot and I was a mess, I said, "What can you do for me, because if I do not increase my immune system, this cancer will grab me. And I have to become well and I have to stay well."

They said, "We're sorry. We're not trained in that. The body will just heal itself." That's a crock. That is not true. I had been doing a lot of reading, and I found an alternative medicine doctor in my community who had been practicing alternative medicine for 25 years. I went to him, and I will tell you that his -- you see how healthy I look and my energy level and everything? It is because of that.

Now, I have told -- through my connections, I have talked to the head of the medical school. And it's not money. My foundation raised about \$60,000. We could probably raise more. But it wasn't money; it was my experience and my influence to try to convince the Northeast Ohio -- which is a cancer center -- to take a look at other alternatives and absolutely train their doctors in this type of medicine. And that's what I've done.

And I am going to read to you the last paragraph of a paper. And if you're interested in some of the things I have to say, I made copies of it. My husband has it somewhere in the room.

"The Battle. Since the first diagnosis, I have been through a prolonged battle. Just as the discovery of penicillin led to its replacement of arsenic as a cure for syphilis" -- remember the movie "Out of Africa"? Karen Blixen's disease was syphilis, and she took arsenic, and we all thought, "Oh, wasn't that horrible". Another discovery must be made for the treatment of cancer. But until a cure is found, we must find ways of lessening the suffering of current cancer treatments and returning cancer patients to health as quickly as possible."

And with that, I thank you. (Applause)

DR. GEORGE: I'm aware that we're running over, but let's take a couple of questions, at least, because I promised you that we would.

MALE SPEAKER: Yeah, I would.

All right, I'm a physician, and I work at a cancer center. And I noticed that a lot of radiation oncologists, medical oncologists, and surgical oncologists are very focused on delivering the treatments that they are experts in. And oftentimes, the patients don't feel comfortable in expressing these fears to these other physicians, who are pretty much on the treadmill, and I hear a lot about their dissatisfaction. And I'm a rehabilitation doctor, so I focus in on a lot of the rehabilitation issues.

But one of the things that's amazing to me is that patients don't really advocate for themselves and speak exactly about what they're afraid of and what they want to their physicians, because they're intimidated. And I'm just wondering what anything thinks about encouraging and empowering physicians to speak exactly about what they're afraid of and what they want, and are not willing to tolerate to the doctors who promote and prescribe the conventional types of treatments?

FEMALE SPEAKER: My name is Serafina Cocerno (phonetic).

DR. GEORGE: Wait just a second. Who would like to take a stab at the first question? Bill?

DR. FAIR: Because of the acoustics, I may have misheard some of your question, but basically was it, how do you deal with the physicians that will not accept this approach of integrated medicine? Was that correct?

MALE SPEAKER: No, how do you encourage the patients to speak to their physicians openly, without intimidation, so that they can -- I mean, because it's clear to me that there's so many physicians who are just so locked into their thinking that it's going to take a lot to pull them toward CAM therapies, to openly welcome them, that it really may take their patient population to start to clamor for them, so --

DR. FAIR: Well, the way we have set it up in our center is through the help of an intermediary -- i.e., our nurses or nurse practitioners -- which has, as I said, greatly eliminated the problem of physicians being negative about this.

But we have to recognize one thing. There's some people, some physicians you're never going to convert. And I think that patients have to be aware that if you're not on the same track with that doctor about your goals, the patient's goals, that there are other radiation therapists and surgeons and chemotherapists. And I think it's important to find a fit. If the fit's not there, I would go to another doctor. We're not going to be able to convert 100 percent of people overnight.

FEMALE SPEAKER: Thank you. My name is Serafina Cocerno. I'm a physician in New York state. And like the doctor, this wonderful lady, I've been practicing complementary alternative medicine for a quarter of a century. I'm almost 69.

So I've been persecuted for 15 years for doing this. And a month ago, they lifted my license on ----- of a lawyer. The physicians never harm anybody, no lawsuits, no persons damaged.

What you people don't know is why we make -- I was one of the 25 physicians that sat at the Adult Committee of the Office of Alternative Medicine. And that, of course, exposed me. I speak for patients' rights, and that's a no, no, no for physician. At least it was.

So they started persecuting me and they're not stopping. A month ago, they stopped me from seeing my patients, and we're fighting in an appellate court. Of course, they're bankrupting me. And this is part of the war against alternative medicine. And my patients cannot see me; I cannot touch them, having done no harm, but actually propelling the cause of CAM medicine.

This country must know that while there are physicians like me that are persecuted -- we talk about progress in medicine. It can be made. Three young physicians came to my office and refused -- not refused, they were afraid to join me, having seen what I'd been going through for 15 years.

What do we plan to do about this war against alternative medicine? (Applause)

MS. MOSS: Until the general public gets the message, and they are getting the message, the pressure for mainstream doctors to change is not coming from within the profession. It's coming from the public. It's coming from patients. It's like a political thing.

And more and more people who can be heard -- unfortunately, I'm no different. I'm a person. I'm no different from anybody else. But if you can get people who have more power, and then they bring the people who -- it's like a democracy. Just go out there. Look at wild oats. Look at all the health food stores that are creeping up. Look at the articles in Life Magazine, Time Magazine, in the New York Times, even, about alternate medicine. The mainstream doctors are getting the message, and I believe the only reason that I've got some doctors coming from northeast Ohio to this conference is because not just me -- I'm just saying it now -- but because of the public. And that's what you have to get, is the public.

FEMALE SPEAKER: My strength are my patients. I intend to fight until I win. And I promise, if you watch me, I will win and I'll topple the evil power.

Thank you very much. (Applause)

(Whereupon, the PROCEEDINGS were adjourned.)

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