

Comprehensive Cancer Care: Integrating Complementary & Alternative Therapies
Constructing Your Integrated Treatment Plan

Moderator: Martha Miller, PhD

Presenters: Pali Delevitt, MA, PhD; Diane Manahan, RN; William Manahan, MD; Carole O'Toole; Richard Steinberg, MD

Commentator: Henry Dreher

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Dr. Miller: Good morning. My name is Martha Miller. I'm happy to welcome you to this session on "Constructing Your Integrated Treatment Plan." I am a health psychologist and a passionate advocate for the use of alternative therapies. For the last ten years, I have been working to heal my own ovarian cancer condition through a variety of unconventional methods, following my initial surgery. During these years I've experienced depths of anxiety, been to the brink of death after a sudden recurrence of the disease, and received a dramatic healing when metastatic liver tumors were dissolved by a Chinese Qi Gong master. I know firsthand how challenging, wild, and rewarding it can be, in the midst of great fear and conflicting options, to develop and redevelop a complementary cancer treatment plan.

In the last year I've been doing case study research on individuals who chose to use alternative treatments for cancer. I wanted to use this case study method to look in greater depth and to record in detail some of the experiences of people who made these choices – what they went through, why, what they did, what seemed to work for them, and what didn't. Two of the people in my study are actually here in the audience today.

Gayle Cranford made her choices in 1984, which was an even more difficult medical environment. She lives in western Pennsylvania. In choosing alternative therapies at that time, she felt that she was out in the wilderness. Billy Best is also here today. In 1994, at age 16, he ran away from home because he knew he didn't want chemotherapy, but he didn't know there was anything else out there. I recorded these stories because I wanted to educate people, to

inspire, and to encourage the use of alternative treatments for cancer. It's with this background that I'm very excited to be able to moderate this panel today. I'm very interested and curious to hear the stories that are going to be shared with us.

We have five very different presenters, and we don't have a lot of time. They're all going to try to give very brief presentations of 10-15 minutes. They'll do the best they can. We want to leave more time for our questions and comments and to be able to have some discussion with you on this topic. We also have a wonderful moderator. Henry Dreher is a medical and health writer who is very knowledgeable in the field of complementary treatments for cancer and mind-body medicine.

I'm going to introduce our first speaker briefly and hope that you'll get to know her better through her presentation. The first speaker will be Pali Delevitt. She's a national speaker on the integration of holistic practice with conventional medicine and re-visioning medical education. She developed one of the first courses in integrative medicine for medical students at the University of Virginia in 1991. She's a two-time cancer survivor. Pali is going to tell us how she combined conventional and complementary therapies.

Dr. Delevitt: I feel privileged to be here with you all. I had cancer first back in 1987, quite a while before all of this was considered much more acceptable. I felt I was a voice crying in the wilderness. It was very difficult to even bring up the idea of alternative or integrative therapies to my doctors at that time. I got quite kidded, if not jeered at, for the concept of using things that might enhance my healing. I was diagnosed with squamous cell cancer of the tongue in 1987.

The most important thing I did was listen to my own inner guidance. If I could leave you all with one message, it's this: I believe that inside each of us there is an inner guide. There is something that knows what is right for us. When you start designing your own individualized program for cancer treatment, and when I work with patients as a consultant to help them design their own programs, I want to ask, "What feels right for you?" There are many ideas out there, as I'm sure some of you have experienced in just the last few days. There are some extraordinary treatments that are being offered or are on the horizon. You have to ask yourself, "What feels right for me? What feels right for me in this moment? What feels right for this body? What feels right for me at this stage?"

Things will continually change. What feels right when you're first going into chemotherapy or radiation treatment may be different a few months down the line. Be willing to be flexible. Be willing to change. Be willing to listen to your own inner wisdom as to what feels right for you.

For me, the first thing I wanted to know was what was the right nutritional program. I did go on a macrobiotic diet. I do not believe that for everyone a macrobiotic diet is the most important thing. I do believe that a vegan diet is extremely healthy and extremely healing for people who are in the midst of cancer therapy.

I also believe that the mind influencing the body was the other most significant factor for my own healing. I used a lot of meditation practice to help me step outside the emotional turmoil that my mind was leading me down the road of – "Oh my God, I've got cancer. I'm not going to survive." A very interesting point of reference for me was the witness outside the part of me that was having the cancer. There was a part of me that was in the middle of being a cancer patient. There was also a part of me that was outside, observing. "Oh, okay. This is the

drama that you're going through. This is who you think you're being at this moment." There is something beyond being a cancer patient. We think that cancer is our whole life, when we're having cancer. There is a portion of us that can say, "Okay, what part of me isn't in this? What part of me can step outside and say, 'All right, I have a life beyond being a cancer patient?' I am not just living with cancer, or I'm not just dying of cancer. I am this person in this moment in this time." That was really critical for me, partly because it was very easy to get lost in saying, "I've got so much pain. I've got my life on the line here, and I'm not going to survive." But there was a part of me that said, "Yes, you are. Look at this, or feel that."

The other significant factor was dreams. I don't know how many of you feel that you have dreams that give you access to your own inner wisdom. Anybody here? I have found it is very true, especially when I talk with cancer patients, that many people are able to access wisdom through their dreams. My ability to even know that I had cancer, when the doctors didn't, came through my dream state. I probably wouldn't have had my surgery if I hadn't listened to my dreams. The funny story is that my second opinion came through the M.A.S.H. characters, Charles Emerson Winchester and Hot Lips Houlihan. They told me, when my doctors denied that I had cancer, that I had a tumor in my tongue that needed to come out. That's a very strange second opinion, but it was indeed a fact. Even after a biopsy had come back negative, and doctors had examined me and said, "You don't have cancer," Charles Emerson Winchester said, "Yes, you do."

I had elective surgery that found the cancer. What was even more amazing was follow-up for the next four years. My dreams also told me the cancer would come back. I was prepared for the recurrence through my dreams. Maybe not all of us will know it in the dream state. But I believe that somehow, in our inner knowing, in our inner wisdom, we have phenomenal

guidance that tells us what really is going on with us. I don't think we have to be religious in a particular way, or even what we might term as spiritual. But I do believe in connecting with ourselves through whatever it takes. For some people it's going out in nature, for some people it's meditating. Whatever it takes to connect in here, with yourself, is your strongest foundation for choosing from that point what you do with your life.

Whatever amount of life we are given, we can choose to be spending it all the time fighting the cancer, or we can choose to be living our lives meanwhile, while we're making choices about how to heal our body. Do you understand the difference? When we're treating cancer, we spend a lot of energy about the cancer, instead of about the person, instead of about being ourselves. None of us knows, even those of us who are healthy, how long we're going to have on this planet in this body. If we don't live our lives completely and fully now, we're giving a message to our body and to ourselves that we are living cancer instead of living our lives. I think that's really, really important.

You're going to want to know what else I did besides meditation and nutrition. I found one thing very useful in radiation therapy. The doctors at the hospital had no idea that this was even a possibility. I had massive radiation to my jaw, my mouth, and my throat. I used aloe vera as a mouthwash and a gargle. Your mouth tissue gets badly burned from that treatment, and you want to restore the tissues. I also used a calendula and goldenseal mixture, also for restoring tissue. When my gums started to break down, there was also goldenseal in myrrh, for gum restoration. This was very significant, especially after the treatment. My gums had a tendency to start receding. I helped heal them with that.

You also have to be aware that radiation therapy to the mouth and to the tissue may create a yeast infection, or thrush in the mouth. It was very important to use a high dose of

acidophilus as a gargle and a rinse. You could even swallow it. That helped heal a massive thrush infection in my mouth following radiation.

I had to do a lot of research. Especially in '87, and then in '91 when I had the recurrence, the information was not out there. The other thing I want to say to you is educate, educate, educate. You have to self-educate. Unfortunately, a lot of the doctors do not know. Find yourself a physician who is willing to work hand in hand with you on learning what else is out there. Together, hopefully you can make the decision about what works for you.

What is the ideal combination of therapies? Some people may want to meditate. Some people may want to use guided visualization. I got a very important guided visualization at one time on an inner level of me lying on the operating table. All the doctors standing around me had their hands tied behind their back. They were blindfolded. There was only one physician standing at my head able to whisper to me, "It's time you stopped radiation therapy now." I pulled out of the radiation therapy before my entire mouth was totally destroyed and took a break for a week. My doctors did not like the idea at all. But I listened to the physician standing at my head, and looked at the image of all the doctors standing around me with their hands tied behind their back and their eyes blindfolded. Somebody knows something here. I'm going to listen to the one who doesn't have his hands tied and isn't blindfolded.

It takes a lot of faith in oneself. I learned a very important thing from my cancer. All the best experts in the world did not know I had cancer, and I did, both times. I'm not denying the wisdom of doctors. Please do not hear me denouncing physicians. The message for me was that I had an inner wisdom that I had to learn to trust, even in the face of authorities who told me something different. No matter what is out there that says, "This is the newest therapy. This is the greatest new trend in cancer healing," go inside. Begin to listen to yourself first. Educate

yourself. Listen to what feels right for you, what you know to be true for you, and go from there. I'll answer any questions.

I just thought of one more thing that was really important. The second time I had cancer was the worst. Emotionally, it was much more of a roller-coaster ride. I was angry. I was depressed. I was more negative than I had ever been in my life. There's a tendency to feel we have to be up all the time. We have to be positive and think positive. I think it's about a balance. It's about being able to express your anger, your grief, your negativity, your passionate intensity of fighting on that level. If you have the anger, you also have the fight inside you that says, "Damn it all, I want to beat this. I want to live."

Feel that you have a right to your feelings, whatever they may be, but also be able to balance them with finding reasons to have joy. Express the negativity to whatever degree it needs to be expressed. Don't push it away. Don't say, "This is going to drag me down." Feel the feelings. Move through them. The only way I got through the second time was going into the valley of the shadows. Somehow it was safe to go there, because only through going there – it's actually the path of the shamanic healer, to go into the underworld to come out the other side. I want to tell you it is safe to go there, because there always is that other part of you that can still express the joy. I didn't want to leave without telling you that.

Dr. Miller: Thank you so much. That was wonderful. We're going to save the questions until the end, and go on to our next speakers. They are going to speak as a team, which they are. Diane and Bill Manahan have been married for 33 years. They say they're best friends. They're the parents of four sons. Both have worked nationally and internationally in a number of roles. Diane is a professor of nursing with interests in mental health, transcultural and holistic nursing.

Bill is a physician, also a professor. He is primarily involved in the University's Center for Spirituality and Healing. Today they are going to talk about their integrated treatment approach following Diane's diagnosis of breast cancer in 1995.

Dr. Manahan: We were asked to do this separately. Since we went through this together as a team, we decided to present it as a team. We're going to go back and forth a little bit in talking. This is our journey through Diane's breast cancer.

Mrs. Manahan: Good morning. Thank you for coming. Thank you for attending the whole conference. It has been wonderful, hasn't it? As I was preparing for this today, I was recognizing how we all wear so many different hats. Both Bill and I are relatively used to talking to an audience as a physician or as a nurse, and as academicians. That's not that hard. But as I come to you talking as a patient, that's much less familiar to me. It's much harder. Speaking from my own experience with something which I never thought I would be doing is a new challenge. It's an opportunity to articulate some of the things that I have experienced, and Bill has experienced with me as my partner, in this journey.

The most important point that I want to convey to you is to have a partner in healing. I was lucky enough to be able to have a spouse who would do that and wanted to do that. He was helpful to me in many ways – informationally, emotionally, spiritually, physically, all of those. If you do not have that opportunity, then I hope that you can have a friend or an interested and willing colleague, or someone you can find who is willing to walk through the journey with you. It is of utmost importance to have that, not just as support, but also as a learning tool. I'm pretty savvy about the health and medical systems. I would go to appointments and walk out and say

something like, “Well, Bill, we never talked about this kind of thing.” He would look at me and say, “Yes, we did.” In my anxiety, or in my getting into, “What’s next? What’s next?,” I didn’t hear. It was very apparent early on that it was important for us to do this together.

What I like about talking at the end of the conference is that I’ve had the opportunity to be enriched these last 2 ½ days with what other people have said. I feel like I can change what we’re saying almost, based on the wonderful things we have heard in other workshops and from the plenary speakers. One thing that struck me early on was someone putting the saying from Einstein on the screen, “What you see depends on where you stand.” That was our first item of business in a way, to really look at where we stood. Being in mental health, I turned to some of the things from Jung. I realized right away that I needed a holistic approach, for me internally, and for my treatment and designing a treatment program.

Helping design a treatment program, especially using conventional and nonconventional things, is quite a task. We live in a fairly small city in southern Minnesota. This was new to a lot of the people that we encountered. Even though I had been a nurse, I didn’t work with cancer people. I wasn’t very savvy about that. The only experience that I had had personally was with my mother, who died of cancer 20 years ago. She took the stance that you do whatever the doctor says. She was lovely, but she thought that’s what you needed to do to get well and to promote your own health within an illness situation. She was quiet and passive. Even in the midst of her greatest pain, I never heard her complain. That was my picture of what you did when you had cancer. That’s not how I live my life, so I didn’t live my cancer that way either.

As both of us created the plan of care for me for breast cancer, we looked at these various things. We looked at the choices that were available to us through the resources I’ve already

talked about, the support person, and then collaborating with a health team. We did that from the basis of our own philosophical standing. I'll have Bill talk about that a little.

Dr. Manahan: The first choices that came up, before we got into any integration or complementary methods, were just the overwhelming choices regarding what Western medicine says should or shouldn't be done. Should there be any surgery at all on this positive biopsy? Should there be a lumpectomy? Should there be a mastectomy? Should there be a lymph node dissection of the axilla? Should there be radiation? Should there be chemotherapy? You can see why we all get overwhelmed by the choices. These were things I dealt with on a daily basis with my patients. Still, when it came to the personal experience of what do we do, it became more difficult.

You might be a little surprised at the problems and the differences we had. As a physician I tend to be a little bit on one end. I felt quite strongly she shouldn't have chemotherapy. I debated for a long time my own views on radiation therapy. I didn't think that lymph node dissection, from what I had studied, was a very good idea. Diane tended to have a little more belief in the system and that what the oncologists were telling us was the truth. Part of what we had to resolve was our own differences in going this path together. One by one, first it's even finding a surgeon who we feel we can really talk with. Second, it's a lumpectomy. We decided on that okay. Radiation therapy became more difficult. After some research and a wonderful radiation oncologist in our hometown, we decided to do that.

The real sticker was the chemotherapy. We got into statistics. I couldn't find many good ones. Two or three different oncologists were saying that the five-year survival if you did chemotherapy was 80%, and if you did without chemotherapy, at five years survival was 60%.

That's 20%. That's pretty good. I went through all the literature myself, and I could only find about 2-5% difference. I asked Diane if it is really worth months of chemo, putting this poison in your body, for a 2-5% difference, which means no difference. Why not use this energy to do something else? We were lucky in that we both have worked nationally with people like Jim Gordon and around the country for a number of years. We called some friends and asked about things. We asked, "What would be your suggestion on this?"

The most interesting one that really helped us was when we talked to a gynecologist friend, Chris Northrup from Maine. She said, "Well you know it's not as simple as you might think. My experience has been that a lot of women spend their life taking care of other people. If you're going to go outside the system and not get chemotherapy when they tell you to, you're not going to get the caretaking that you really get by staying with the system. You have to enter that in as a factor here."

It was true. I've done lots of counseling with cancer patients. Over half of them, when they leave my office, decide they are not going to have chemotherapy. Within the next week I get a call saying they decided to have chemotherapy. I say, "Why? When you left the office, we were pretty clear that there's statistically no reason to do that." Overwhelmingly, they say, "My family just feels I have to do it, and I don't want to go against my family." In a sense, that's what Chris was telling us when she asked if we wanted to go against the reigning paradigm, which is for this problem to get chemotherapy.

The second question Diane had to ask herself was, "If I get a recurrence in three years, would I blame myself for not having done this?" She asked me, "Wouldn't you?" I said "No, I would blame myself for having taken the chemotherapy and having one single side effect." It's so individual. We have to uniquely work with each person. I was very supportive that she

decided to get chemotherapy, but that's how we made some of those decisions. We would sit during this and wonder how our patients ever pull this stuff together. Of course they don't, hardly. We had incredible resources, expertise, and experience to do this, and it was a real struggle.

After making some decisions about the western methods, the next decisions were, what do we integrate? How do we complement this?

Mrs. Manahan: In planning my plan, it was my plan, so I had the last word. I decided what I decided. I also decided that whether it was an effective or a good decision or not, that's what I had decided. I was not going to look back on that, blame myself, or feel guilty for whatever happened, whether I did it or didn't do it. I had to feel grounded about that in order to proceed. I also wanted to look at my decisions to see if they fit for my truth, my wisdom, the love that I felt for myself and for others, and the beauty of life. I tried to sift things through those four elements as I made my decisions. Maybe Bill would like to talk about the nutritional aspects first.

Dr. Manahan: Nutrition was an area of interest of mine. The question was, what do we do nutritionally for this? The first thing that came up was IV high-dose vitamins for radiation and chemotherapy. That got into the problem of whether antioxidants hinder that. As we talked around, the thought was during radiation therapy it may, but not during chemotherapy. When she started the radiation therapy, I started giving her an IV at home twice a week of what's called a Meyer's cocktail. It's a gram of magnesium and a gram of calcium, usually high-dose vitamin C, which I left out, B complex, some extra B vitamins, things like that. That was very good.

Halfway through that I changed to once a week. I haven't started IVs for 20 years. IV nurses start IVs. I was so lousy at it that it started becoming a little bit difficult halfway through this with the veins. We decided once a week was enough. That worked. She was happy with that, too. That was something that we did nutritionally.

Second, I had a friend, Neil Nathan, out at Virginia Livingston Cancer Center in San Diego. He had been medical director there. He said one of the most important things he had found with radiation therapy, to avoid fatigue, was shark liver oil. I said, "You mean shark cartilage?" He said, "No, shark liver oil." His experience had been that shark liver oil was really good. We looked around Mankato, our town. They had none. We went to Minneapolis and found some shark liver oil.

We don't know if it helped at all, but Diane continued to teach 60% during her time. She had been on a 60% contract. She continued work on a second masters degree she was getting. She never took a day off work during the whole time of her radiation and chemotherapy. I think it was sort of stupid, but she wanted to do it that way. Again, it's your own plan of going ahead and doing what you want to do. We think the shark liver oil probably made a difference with that. With respect to the high dose Meyer's cocktail, I never have understood why, when we're giving toxins to people, we don't give back some nutrient support. I'm embarrassed to be part of the medical system and not doing it.

After the radiation therapy ended, I started with 10 grams of vitamin C in the IV and went up to 30 grams per IV, first twice a week, and then once a week. She didn't lose any hair. She had almost no side effects from her CMF. It's not as bad as adriamycin, but it's one of the more common types of treatment for breast cancer, with three different drugs. Just after we finished that, a headline in *Internal Medicine News*, which is a newspaper, stated,

“Megavitamins may boost efficacy of cancer therapies.” Dr. Simone, who has been at this conference, had this quote: “This thing about reducing tumor cell kill rates by interference with chemo or radiation therapy by giving high dose just is wrong. Right now there are roughly 130 references in the published literature stating vitamins and minerals do not interfere with radiation and chemotherapy.” I was happy to see that right after we had been doing this.

The other things we did I think a lot of you are doing. We ate a pretty good diet. We tried decreasing fat and increasing soy. The men in here may enjoy listening to this. The other main thing I did was make her cabbage juice every day for eight months. With half a glass of cabbage juice I would also mix carrot juice, because cabbage juice by itself is not so good. Cabbage is strong in antioxidants. From the literature and from our friends we knew that was probably a pretty good idea. That was something I did.

We also did Essiac tea. That’s one of those “why not” factors, meaning why not do it. The cost is very low. There aren’t any great studies that say it helped, but why not have a cup of Essiac tea every day? Every morning I would give her Essiac tea, and every evening I would give her cabbage juice.

I’m not sure either of those substances helped at all. But can you imagine having your husband serve you twice a day for eight months, a husband who probably hadn’t served her twice a month for 32 years? Let’s face it. The women in our society do the caretaking and do the serving, in general. We go outside the home and bring back some money. Most of us are not so good around the home. We started thinking that this is really something. It almost got to be a joke by the third and fourth month. Every day, twice a day, I was doing something very special for her, handing it to her to serve her. Can you imagine what that would do to her immune system?

At eight months I said, “Diane, I am not going to clean another juicer. Let’s quit.” It was two months past chemotherapy. She said, “Fine.” About ten days later she got sick for the first time, when I quit this. Not bad sick, but just sick. I think there’s much more to all of this. When we talk about trying to study it, I thought this would have been a terrible study. It may have nothing to do with Essiac tea and cabbage juice. It may have totally to do with the fact that I am really taking care of her. I’m probably paying more attention to her in those six months than I have for the last six years. That’s what we love. That’s what women are doing for us men, but we’re not so good. Those are my nutrition stories.

Mrs. Manahan: Any of you who do juicing know what that juicer looks like. Besides the fact of serving me, probably the real service was cleaning out that juicer every day. I never washed it or did anything like that, so that was a real service too. I’ll mention a couple of other things that I did for me spiritually and emotionally. That affects all of us, whether you’re a support person, or whether you are a person living with cancer or have had cancer in your medical history, your life history.

One thing that was and is important to me are relationships and making connections. Most of my self-interventions had to do with making connections. That meant making connections with me in a way that I hadn’t done before. I did that mostly through being in nature. Even though this was winter in Minnesota, I would go outside every day, usually for a walk, but sometimes just to be outside. I kept a journal. Making connections with people through correspondence, phone, letters and notes became very important. I used that in a meditative way. Each day I would make a little tea, sit in a little corner, and spend time thinking about the person from whom I had received a card.

I tried to do the following daily: 1) Give gratitude; 2) Do one life-affirming action; and 3) Lead a prayerful life. I did that before, but not as intentionally as I began doing. I had read about imagery for a long time. Immediately when I began to think about having radiation and chemotherapy, my picture was to do some imaging during those treatment times. I started with radiation. Halfway through my radiation treatments, I began chemotherapy as well. Radiation doesn't take very long, but there's time when you prepare. You're lying there while they're lining up all their laser beams. I tried it a couple of times, and I just couldn't get it. Rather than get down on myself for not being able to do that the way I thought I should, I just let go of it.

I have one son who is a Star Trek fan. I began to think of the beaming that happens there. Surrounded with the kind of equipment that I had never really been around before, I began to beam myself. For every treatment, I would choose who I was going to visit that day. I got excited on the way to the radiation place wondering, who was I going to visit today? I would beam myself, and I would be in their surroundings, if I had been there. We had one son living in Saipan at the time. I hadn't been there, so I had to visualize what it might look like from his descriptions in his letters. I would visualize myself with them, just for those few minutes that it took. I had great visits. If I got tired of visiting with someone, I would go to a place that I really wanted to be. I'd be there. That's how I did my imaging.

The first time I had chemotherapy I just sat there and cried. I didn't think that I would do that. It just came. It wasn't sobbing. It was like a cleansing of tears. After that I thought, I'm going to try to visualize. I didn't do that very well either. So I asked the people I loved who were close to me to give me some small token, or what I called a totem of themselves. I wanted something that held their energy and that would remind me of them. I had several of those in a little silk bag. I would take those to every chemotherapy treatment. Someone went with me to

those treatments, not because I was ill, but because I just wanted someone with me. I would take the totems out during the chemotherapy drip. I would tell the supportive person with me about the person represented in that totem. It became a wonderful way of including them, at least in my spirit and my emotions, in my treatment.

It was kind of funny. I would always be talking to the person who was with me. The nurse who was pushing in the medication was quiet. One time a male friend of ours from the Twin Cities had come down to be with me. I was telling him about it. Pretty soon the nurse was talking, telling him about all of my totems. I stopped and looked at her. She said, "This came from that person. They live in New Jersey. This is so and so. She likes this one really well because it's a little bear." I was amazed that she had taken this on and was telling about my totems. We all had a good laugh about that. She and I exchanged totems when I had finished my treatment time with her. Those are examples of connecting.

I want to say in closing that I know those of us who have survived a cancer time, or have gone through that with someone dear to us and have survived that as well, we think of ourselves as survivors. Indeed we are. I also think that we come out of this, through it and continue, because it stays with us, more compassionate, more intentionally tuned to ourselves and to others. This has been reinforced to me by listening to people at this conference. I had to coin the phrase that we're "cancer thrivers." I see myself as a thriver through this. I got some wisdom from Black Elk that it is a sacred time and a sacred experience, whether you're the patient or not, with anyone that you experience this with. When the good road crosses with the road of difficulties, which cancer certainly is, that place is holy. Thank you.

Dr. Miller: Thank you so much. These stories are very inspiring to me. I don't know how we're going to control for the healing power of love. Was it the love or the cabbage juice?

Our next presenter will be Carole O'Toole. She has a master's degree in medical anthropology and health policy. She says she's had several past lives in various professions. Then her experience with inflammatory breast cancer and her subsequent treatment led her to a new vocation as a writer, speaker, counselor and supporter of fellow cancer patients. She and the final presenter, Richard Steinberg, are also working on a book collecting resources for complementary treatment in the DC area. I present Carole O'Toole.

Ms. O'Toole: Thank you, Martha. Good morning. I'm always humbled when asked to speak to fellow survivors. Sharing each other's stories is one of the greatest treasures and comforts I've found in having this disease. I'm very grateful to be here with you today. I'm particularly grateful to my husband, who came down to support me this morning and is sitting in the back of the room. He was just as supportive as Bill described himself, and helped show me the way home.

We all have very important stories to share. Why am I up here and not someone else? The foremost reason is because I'm not supposed to be here. I was diagnosed with inflammatory breast cancer, which is a Stage III advanced cancer. That diagnosis was linked to a dire statistical prediction of eighteen months. That diagnosis, along with my planned treatment, which consisted of five months of very intense chemotherapy, a cocktail of five different agents given almost continuously, a mastectomy, radiation and a bone marrow transplant, led me to decide to try complementary therapy. I felt like I needed to do something for myself, rather than having all this done to me. I'm living proof. Not only am I the poster child for conventional

treatment, but I'm living proof that you can get hit by a train and stand up, and get hit by another train and stand up You know the story, I think. That was 4 ½ years ago.

The complementary choices I made include at last count about twenty-five different therapies. I'm not going to watch your eyes glaze over by listing all of them. More important than what I chose was what that gave me. It gave me a depth of healing that I don't think I could have ever attained using just the conventional treatment. It gave me a greater understanding of what healing is, and the incredible beauty that's within the pain that we all go through in dealing with this disease. My experience of developing an integrated treatment plan that, believe it or not, is still evolving, has sparked my passion to help others to create their own healing plans. That's my reason for working with Dr. Steinberg on our book.

Many cancer survivors are prevented from trying complementary therapy by the perceptions out there that aren't necessarily part of their own experience. They are voiced by other people, people around them who love them, their physicians, others. For me, developing an integrated treatment plan is not an act of self-destruction. It's an act of self-love. We're not delusional. We are extremely focused on doing whatever we can to help ourselves heal. It's a very heroic undertaking. I applaud any and all of you who are doing that, as well as the speakers up here.

I found the process to be highly intuitive, as others have mentioned. I found it an extremely individual process, very lonely, and also very chaotic. Blessedly, that's where the beauty of developing an integrated treatment plan lies. Out of that loneliness I found incredible empowerment. I found that I had to rely on my inner knowledge that my intuition was my best tool to guide me through this. That inner knowledge melded into a conviction that drove me to do anything I could to save my life. I found that following my intuition brought me to a new

depth of decision-making. I am a left-brained person to the core, so this was a whole new experience for me. It brought me to that depth of decision-making from the heart that permeated everything in my life. I didn't heal just from my cancer, I healed from so much more.

Out of that chaos came transformation and a reverence for the beauty and the mystery of the universe giving us exactly what we need to heal at exactly the right time. That transformation replaced many of my fears and gave me a strength that shines down to my soul. It has given me a trust that I know will never be shaken. While this path is not one that's well worn or clearly laid out for any of us, it's one that is well worth taking.

I believe there are some basic components to an integrated treatment plan. Diane and Bill and Pali have touched on a lot of those. I've laid these out along with some of my choices in a handout for you. Volunteers, go ahead and hand those out. They may generate some questions after we all finish speaking. I would like to focus the rest of my talk on four universal ingredients of an integrated treatment plan that might make it easier for you, no matter what you choose personally for yourself.

The first is confidence in your treatment plan. For many, complementary therapy is uncharted territory. Cancer feels like you're jumping off the cliff. It's an illusion sometimes, but conventional treatment can seem like a safety net. There's no 800 number for us. There's no integrated cancer treatment plan coordinator out there yet. There's just you and this vast ocean of information. How do you get comfortable with it? For me, trying to clarify my expectations and attitudes towards complementary therapy helped. Once I was able to decide what I wanted from complementary therapy, it helped determine what I felt was going to be most comfortable for me.

I asked myself questions like, how far out in left field was I willing to go with these treatments? Did I have to have recommendations from people I trusted before I would try a therapy? How far was I willing to travel? Could I rely only on anecdotal and very conflicting information? These types of questions helped narrow the universe for me and increase my comfort level.

The amount of information, as people have already mentioned and I'm sure a lot of you know, is staggering. It's wonderful to have options, but it can be overwhelming, especially when your time and energy are stretched to the limit. It's obvious where to start – your libraries. I was probably close to being arrested for loitering at many bookstores. I've spent a small fortune.

Support groups – I even advertised in newsletters, because inflammatory breast cancer survivors are hard to find. I ended up getting about 20-30 letters and phone calls from women all over the country. It was amazing support for me. I encourage you to do that if you're finding it pretty lonely. I cast as wide a net as possible with my eyes and ears. If you aren't confident in doing your own research, and you can find someone you trust to make that first cut, great. In my handout, I put down some suggestions on where to start your research and what books I found particularly useful in getting me started.

After doing your head research, you need to go back to your heart. Our instincts get easier to access when we're in survivor mode. I found that the veil was lifted between me and the universe. I could hear more clearly my guides and my angels and God when I prayed. The further I'm out from my disease, the more that veil gets thicker and thicker, so it was a wonderful time for me. I encourage you to get as much quiet time as you can for yourself, for reflection. Do whatever brings you a sense of peace, to go inward to get those answers.

Finding healers is a process similar to researching treatments. Local directories can help you get started, and survivors' recommendations and professional associations. I strongly recommend interviewing your healers, if you can, before you make a decision to try that treatment. I found that to be a wonderful experience. It increased my comfort level and established open working relationships from the start. Most were accessible and very happy to talk to me. I found if I came to them from a place of honesty and integrity and was open with them about my intentions and confusions and doubts, then they met me more than halfway. Those I chose to work with viewed me as a manager of my health care, versus a participant. They expressed great interest in working with me in partnership.

These are the types of healers that I looked for. When I asked healers specific questions (I put those down in the handout), I also felt my way through the interviews. I looked for individuals who would empathize and not condemn my cancer, who saw it as a manifestation of a deeper need to heal. I chose people who could explain the practice on a level that I could understand. After all the reading I did, often I was more confused than clarified. I searched for individuals who didn't claim to be able to fix me, but who were clear about what they could and couldn't provide me. I listened for healers who respected my decisions regarding conventional treatment. Not all of them were respectful. Those people I couldn't work with. I found that by choosing these types of individuals as part of my healing team, I felt confident they would help me find the message already inside me that I needed to heal. I was not an instant success. There were lots of trials and errors, but I learned, over time, to tune into the right people for me. It made the process a lot smoother.

Commitment is another attribute. You have to be committed to your treatment plan. That comes over time, but there are ways to make it easier. One of them which was already

mentioned was patience. For me it was one of the hardest lessons to learn. It's easier to remember that complementary therapy engages the whole individual on various levels, and employs different measures of success than what we're used to. The progress can seem elusive. I don't think the progress is ever linear. The effects are often very subtle and slow to appear.

Many times I was frustrated with my healers. They would cheer me on when I said, "I'm not feeling anything from this treatment," or, "I feel worse." They would be really excited for me. But hanging through that frustration, I found a whole new way to listen to my body. Commitment also means flexibility. Integrated treatment plans are dynamic. As far as I know, they have no closure. You'll be challenged to appreciate the process as much as, if not more than, the outcome. The changes take on different forms at different times. It can get discouraging when what seemed to be working no longer is.

Two things helped me during those times. Having faith in myself and faith in my healers. I learned that knowing when to stop a treatment was as important as knowing when to start it. I learned to be comfortable with my body's changing needs, viewing them not as a sign of a failure of a particular therapy, but as a message that I needed to move on, that I had gone to a different level of healing. It's all a learning process that takes place over time, and not as humans mark time, but in universal time. If you can learn to trust that, you'll be better able to go with the flow.

Another consideration in constructing your treatment plan is communication. One of the main benefits of coordinating complementary with conventional or a number of different complementary therapies is assembling a team. In order to make that team successful, you have to be able to communicate your needs. That probably sounds very basic and businesslike, but I wouldn't have gotten what I did from my healing without those open relationships on both sides.

I had to learn to share my misgivings and fears with my healers. I had to learn to doubt their particular practice, and ask questions, and express my feelings.

This experience went beyond my healers. It poured over into my medical team. I became much more up front with my doctors about my needs and my wants. I found that sharing my plan with them actually strengthened my relationship with them. Even though they didn't necessarily agree with everything that I did, just having that open dialogue showed a respect for me and my decisions. That helped our relationship. The knowledge of my plan helped my doctors to also pass along my progress to other survivors who were anxious to talk to people doing complementary therapies. Even if you have negative experiences with your doctors, I still encourage you to communicate with them. It hurts you in the long run if you go underground with this information. If nothing else, it helps to clarify your values on what's important to you and whether or not you have the support you need from all of your healers.

Finally, when developing an integrated treatment plan, you need to give some consideration to the roles that await you when you take on this responsibility. The current state of complementary therapy and cancer provides tremendous opportunities for growth, not just on an individual level but on a much more global level of consciousness. Those of us who are dealing with cancer and struggling to develop integrated treatment plans are at a crossroads. We're pioneers who are straddling two worlds and trying to build a bridge between the two. When we decide to construct an integrated treatment plan, we take on, sometimes unwittingly, many other roles besides that of the cancer patient. We become researchers, we're managers, we're advocates, we're educators, we're diplomats, we're cheerleaders, just to name a few.

I had no idea when I began this that I would create such a ripple effect among my doctors and healers and other survivors. We're the only ones that can make the allopathic and

complementary link work. It's by our example, our demand for quality therapies and better information, our sharing of our knowledge and our triumphs and concerns and our guidance and encouragement that this will happen. If you choose an alternative path in dealing with cancer, there's much to be done to make it better and easier for all of us. It's for you to decide which of those roles and how much of each of those roles you wish to take on. I guarantee you that as you heal yourself, you'll help to heal others. That makes all the difference in transforming this disease. I thank you.

Dr. Miller: Thank you, Carole.

Our final speaker is Richard Steinberg. He's a physician who combines both traditional and alternative medicine in his practice. Dr. Steinberg is board certified in emergency medicine. He's also a licensed medical acupuncturist. In 1996 he was diagnosed with non-Hodgkin's lymphoma and used many traditional and nontraditional forms of healing.

Dr. Steinberg: Constructing a treatment plan when I was diagnosed with cancer was probably the greatest challenge that I've ever faced. Even as a physician who is trained in both traditional and alternative medicine, it was incredibly difficult. As any of us who have been diagnosed with cancer knows, the initial diagnosis is shocking. It usually motivates some kind of action. In our culture, that means usually going to an oncologist. As an emergency physician, I think that is very important. That's a good starting point. It's important to go to learn as much as you can about your cancer from people who have been studying this, to understand what some of the treatment options are, and to learn especially what kind of emergencies need to be taken

care of. What do you need to do to stabilize your condition, so you can then have more time to evaluate alternative treatments?

My orientation is to take care of the life-threatening things first. Then you can slowly build from there. Even in this case, it's important to get second opinions. Especially in this country, physicians are very aggressive in trying to work toward a cure, and this is not common. It's important to look and see whether these aggressive treatments actually decrease mortality (such as the chemotherapy story you heard earlier), and to look at what the toxicities are. It's a balance that we need to look at.

After stabilization, and after you've worked through those initial life-saving measures, then it's important to look at how you can start to build health within your body. It's important to look at improving your diet, evaluating environmental toxicities, and what emotional and psychological issues need to be dealt with. The other thing is stopping to deal with the emotional impact of the diagnosis. That can be very profound. People can get paralyzed from that. Facing the cancer and looking at it was very helpful to me. Also look at what kind of life stresses and lifestyle stresses need to be addressed. What are significant relationship stresses that may be impacting your return to health?

I'm not suggesting to avoid conventional therapies. I want to make that point. They can be life-saving. But the cures are not common, and healing often involves a personal quest for health. Taking illness as a challenge was very empowering to me. It was overwhelming at times, but it was a time to really evaluate what my own life desires were. It sometimes means changing priorities and deciding what's truly important to you. There are many paths for healing. Most practitioners claim to help patients to heal, but it is really the patient who has to

do the healing. There are many choices to make. This process sometimes seems very overwhelming.

Sometimes healing centers can help. They help with integrating treatment plans. They can take you out of your environment and help to coordinate your effort in a time when things are overwhelming. There are many different approaches. It's important to evaluate success rates and whether the philosophies of these centers fit with yours. Also what are the potential toxicities in these centers? Most of them integrate diet, environmental toxins, detoxification, supplements, medical interventions and complementary therapy. They're also often very expensive. There are a lot of factors to be weighed.

Instead of going to a treatment center, I decided to build a plan of my own. It was amazing, in doing the process, that things just seemed to come to me when I knew I was on the right path. I would be in one place doing one thing. I knew I needed help with diet. I'd go to a garage sale, and there would be a book on diet. Or someone would call me when I was in some sort of crisis and say, "There's a program coming up I think you ought to take a look at." It's amazing when you're on the path how things seem to arise. It's just working toward that. It's an incredible journey.

As was said earlier, on June 21, 1996, I was diagnosed with non-Hodgkin's lymphoma. Within the first two weeks of my diagnosis, I saw six oncologists, three of whom strongly recommended intense chemotherapy and bone marrow transplants. The other three weren't so sure that that was necessary at that time. I read as much literature as I could. I decided to try to produce a remission on my own. I didn't want to subject my body to such highly toxic substances that might even kill me, if there was another way. I decided I had some time to try.

First, I wanted to learn to meditate. I had been interested in this for a long time, but now was definitely time to learn. It was primarily to provide a quiet, restful place to deal with the stress of my illness. It was also a place where I could, in a detached state, start to become more aware of thoughts and feelings, and tap into inner resources that might help me to achieve greater levels of health and awareness. I also used biofeedback and yoga to help facilitate this process.

I changed my diet to create more health and to reduce stress in my body. This was not an easy task. I evaluated many orientations to diet before I finally found one that made sense to me. I was tested for food allergies, and eliminated wheat and dairy in my diet to reduce stress on my immune system. This is a common problem that's often overlooked. I consulted physicians, nutritionists, and medical literature regarding diet and supplementation. I consulted acupuncturists for herbal healing. I even attempted detoxification energetically with a homeopath, and detoxification from heavy metals and pesticides, as this is a common relationship with non-Hodgkin's lymphoma.

I tried to address emotional and psychological issues. I spent a week at the Smith Farm Center for the Healing Arts, which was an incredible experience with Rachel Naomi Remen and Michael Lerner. Working with seven other people and sharing thoughts and feelings and fears in a nurturing and loving environment was probably one of the best things I did. It was an incredible experience. I encourage anybody to look into those type of experiences. I still meet with five of the participants in a support group once a week, faithfully.

I saw a therapist and discussed dreams to explore the unconscious. I thought that was also very helpful. It's a vehicle for looking at things that are going on that we're often not aware of. Friends and family were extremely important to me throughout all of this. I have to say that

through this I found much more peace in accepting who I am and appreciating what life has to offer, rather than being unhappy about things that I don't have. That had been a recurring theme in my life before. That's one valuable thing that has come out of this.

Lifestyle changes were important. I left my previous job to practice the kind of medicine that is more meaningful to me. Cancer has been a great motivator and accelerator for improving my life and striving to be the person I want to be. Cancer may be just a way that our body tells us that its needs are not being met. I believe that if we can create health and joy in our lives, then there's a good chance that we already have all the resources within our own body to overcome cancer. This is evidenced by many of the spontaneous remissions and some of the miracles that do happen.

Even if we don't recover, at least on this path we know that we're living the best health that we can, physically, spiritually and emotionally. There's really no loss in this. At least for the time we have, we're living the best we can. I do believe that actual physical changes can occur by finding the things that make us feel better. I also want to point out that I continue to stay very current on all the medical advances. If I do get into trouble, I know what directions I would go. I have teams assembled. I know what types of treatment I would choose, and what practitioners, what advisors I would go to to help me with those decisions. Thank you.

Dr. Miller: Thank you, Richard. Thanks to all the presenters. It's wonderful to hear everyone's stories. It's very generous to share them with such honesty and integrity.

I'm very pleased to introduce our commentator, Henry Dreher. He is a medical writer. He's very well respected in the field of complementary and mind-body medicine, and deservedly so. Mr. Dreher has authored *Your Defense Against Cancer* and *Immune Power Personality*. He

co-authored *The Type C Connection*, with Lydia Temoshok, a very important book, and *Healing Mind, Healthy Woman*, with Alice Domar, which has been very well received. A new book will be coming out next year also with Dr. Domar, *Self Nurture: The Healing Art*. Mr. Dreher has a cancer consultation service, in which he provides counseling and written reports on options in complementary therapy for cancer. He's very knowledgeable. I look forward to hearing what he has to say.

Mr. Dreher: Thanks a lot. I want to say what an honor it is to be with this panel. I'm going to try to honor my own intuition by being a little spontaneous in my reaction. It strikes me that the talk we heard this morning from Marilyn Schlitz was about trying to uncover or discover something about the mystery of survival, perhaps not finding final answers, but asking the right questions. It was about beginning to glean some sense of meaning and some sense of a pattern, without getting rigid about it, without saying this is the way to go, since clearly the best way to go is the best way to go for each individual. What we've learned here is that all of these individuals have done that to an extraordinary degree.

There are some patterns that have been observed and studied regarding a so-called survivor personality. Clearly there is no one answer. But what I detect in these stories, which astonishes me, quite frankly, is some healing of head and heart. What I've begun to feel is like a dance of the head and the heart, a *pas de deux* of head and heart, bringing the two together in such a way that this decision-making process and this path, this journey which people have to go on when faced with this extraordinarily difficult and confusing crisis, comes to some sense of resolution. Healing the head and the heart and bringing them together is one of the key

metaphors. It was one of the key things that seemed to come up again and again with this group. I don't think it's one or the other.

One story. I got into consulting with cancer patients with a woman who was my first girlfriend in high school, first love. We stayed in touch for 20 years, until she was diagnosed with chronic myelogenous leukemia. I had been doing some work in the field of cancer and healing and mind-body. I went on a search for her. I discovered in 1990, when she was diagnosed, that there was some research that suggested that interferon was an effective treatment for chronic myelogenous leukemia. It was very early. It wasn't clear whether it was really going to be effective. I felt, based on the research that I saw, that it was likely to be very effective.

Meanwhile her brother, who had studied a very arcane form of acupuncture in Japan, said, "I can save you." He came over from France where he had relocated, to Massachusetts. My friend Marcy said, "My brother is going to save me. I don't think I need any medicine." I bit my tongue, because I didn't want to put myself in the position, the hubris of saying, "I know what's best for you." This is something we all deal with, how to help those we love without taking that "take charge" role for people, and honoring their own individual choices. In trying to honor her own individual choices, I bit my tongue, not thinking that acupuncture wouldn't do any good, but having doubts in my own head and heart about whether that was enough medicine.

She did go ahead with it. She started to get a lot worse over the course of the year, at which point she finally did decide to try interferon, but only after I had a summit meeting with her brother. I felt like this was a summit of east and west, in which I was the head and he was the heart. I was west, and he was east. We got a dialogue going, in which I said, "Interferon is an immune booster. Let's get rid of all these labels. It's western. It's bad. Yours is eastern.

It's good. Let's bring down the walls. Let's redefine this." We began to talk. We began to have a conversation. In this dialogue it emerged that interferon bolsters the immune system. It enhances the white blood cells. It has some side effects, but they're flu-like symptoms. The fever may actually be a sign, or the fever and the flu like systems may be a sign of your body's immune system awakening itself to the cancer.

He began to understand my language. He began to hear me. I heard him. I began to understand and respect the value of what he did, even though it wasn't curing her, and not to dismiss his approach. He brought great wisdom to the table, with some arrogance, I might add, but nevertheless great wisdom. We got this dialogue going, and she decided to pursue interferon with his blessing. She really needed his support. I honored that, even though initially I thought, "Why do you have to listen to your brother? He doesn't know it all." He bothered me, irritated me. Nevertheless I had to honor that this relationship was important to her.

In this dialogue I began to see a change in her. She began to see that she didn't need just one source. She began to hear our dialogue. She began to look inside herself and began to connect with this new way of seeing her illness, and the new way of seeing her treatment plan. She did interferon, and she continued to work with her brother with his version of acupuncture. It is so arcane, the needles don't even go into the body. I watched him work. It was amazing. He would just flick his hand with the needle on the surface, but not ever penetrate. He was taught by some Japanese master who I never heard of, and who no one ever heard of. But it was remarkable. She really felt, and I feel, that this was important for her. How it works I don't know, but I think it worked.

She began with the interferon. Her white blood count had been over 200,000, which is the danger zone. You could have what's called the blast crisis. She was really in trouble. The

life span for chronic myelogenous leukemia with standard chemotherapy, which does virtually nothing for this disease, is almost the same as it is without chemotherapy. It's maybe six months better, but it's about a three or four year survival time. She was a year into this crisis, getting worse, now beginning a truly integrated plan.

It wasn't just interferon, and it wasn't just her brother's acupuncture. It was Tibetan herbs. She met with Yoshi Donden, the Dalai Lama's personal physician. She prayed. She rediscovered her Jewish roots. When I was in love with her in high school, she had no connection whatever to her Judaism. She began to become a practicing Jew, praying all the time. She did a whole lot of things, mirroring in many senses what we've heard here today.

She began to get better. Her blood counts fell precipitously within a month of beginning interferon treatment. I'm happy to say that it has been eight years, and she is in complete remission. She remains well and happy. Her 13-year-old daughter was bat mitzvahed yesterday. I was a little sorry I missed that. You can imagine how happy it made me to see this progress. It was a beautiful process. It was a process of healing way beyond cure, multiple level healing, healing of head and heart. It was in some sense healing her relationship with her brother, healing her relationship with western medicine, which she had been intensely skeptical of, healing her relationship to spirituality. This is what I think we've seen here. It has been a pleasure.

Pali said we all have to find our inner guide. We all have to trust our own intuition. Everyone here has done this in amazing ways. One of the things that Dr. Martin Rossman (a physician who practices complementary and holistic medicine) talks about is finding your inner guide, finding your inner wisdom. He has an imagery which might be very useful for people trying to construct their own integrated plan. During periods of confusion, and during periods in which the head and the heart are either at war with one another or not speaking to one another,

which happens all the time, go inside. Do an imagery in which you find your inner guide, summon an image of your inner guide that is meaningful to you. I've heard so many different ones – Jesus, the archangel Michael, St. Francis of Assisi. I have to say this is the first time I've ever heard Hot Lips Houlihan as an inner guide. Really honor individuality.

I'm going to wrap up in another minute, but I do want to talk about relationship. I've heard this again and again from all of you in different ways. Relationship is a way to help heal heart and head and to help bring them together. Go outside and talk to other people. Find a physician who will honor your choices. One study that I like to quote which no one ever talks about is a breast cancer study conducted by Elizabeth Maunsell in Canada. She followed several hundred breast cancer patients. She showed that those who had the same early stage cancer with no confidants, who reported no one that they could confide in, had a 56% survival rate after seven years. Those who reported two or more confidants, people they could confide in, had a 76% survival rate after seven years. That is a 20% difference. If this were chemotherapy, let me tell you, this would be the number one drug. We cannot underestimate the importance of social support.

There's a lot more I'd like to say, but I'm going to keep it short. We want to get a dialogue going. I'm thrilled to be part of this panel. I'm thrilled to be with this group of people who have so much to teach us about how to integrate treatment modalities. They set a great example and are a great inspiration to all of us. Thank you very much.

Ms. Miller: Thanks Henry. I encourage anybody here with questions, comments, or suggestions to come forward to the microphone so we can record it. I would appreciate it if

everyone could be fairly brief or succinct, also in their replies, so we can have as many people speak as possible.

Participant: Hi. I'm Gary Sandman. I'm here in the Washington area. I want to honor all those who have blazed the trail through innovating their own integrated approach to their health care, and also report that resources are starting to bound up around the country to help others be able to create integrated health plans. Here in the Washington area, we've formed an alternative medicine referral service for people to find help through credentialed, licensed holistic practitioners and match people up with appropriate credentialed practitioners who can treat those particular illnesses.

We have been approached by similar networks around the country that are starting to grow up. These are all grass-roots organizations. We're linking them together, so that individuals like those in the audience, as well as on the panel, don't have to go through this alone. There's a lot of support now available, both locally, and we're meeting with folks in New York, Boston, Texas, Florida, and California who have similar groups that can be provided for access. A phone number for those who want to get in touch is 888 560-HEAL. It's a toll-free service. We service Washington, Maryland and Virginia. If you're out of the area, we can connect you up with a similar resource group in your area.

Dr. Miller: Thank you so much. We also wanted to mention there are sign-up sheets over here for Dr. Steinberg's and Carole O'Toole's resource book they're working on.

Dr. Steinberg: Carole and I are putting together a resource guide to the Washington, DC, area. We're meeting every Tuesday afternoon at the Center for Mind-Body Medicine with volunteers who are willing to share their story of who they have worked with and what those experiences have been like. We're trying to put together a collaboration of those experiences into a resource guide for people in this area, and also to describe what some of these therapies and healers do by interviewing them. If anyone would like to participate, we have a sign-up sheet on the table here.

Dr. Miller: It's also on the bulletin board out in the lobby.

Participant: Good afternoon. My name is Laura Laroche. I am a holistic practitioner in the Washington area. I'm part of Gary's service. I'm a reflexologist. I want to thank all of you for sharing your stories today. I also want to especially thank Carole for her handout as well as what she spoke about, forming an integrated treatment plan, and how important it is to get to know the people you are working with, whether it is in conventional medicine or alternative medicine, and to have that symbiotic relationship. Many modalities have no licensing or any kind of credentialing, so it's very challenging to find out whether or not you're tapping into authentic modalities. It's very important the point that you raised about working with people who are credentialed, as well as somebody you connect with. That's very important, whether it's a conventional physician or somebody working in the alternative field. The service that Gary offers is extraordinary, because it gives you that quality of care that you need.

The second point I wanted to bring up was how important it is that when you go to a practitioner, that they be working with other practitioners, hopefully conventional and alternative. None of us can do it all. We need to all be working together as a team. Thank you.

Dr. Miller: Thank you.

Participant: I'm Joan Runfola. I'm an oncology social worker at Cancer Care, which is an organization in the New York metropolitan area. Having worked with patients for many years around decision-making about both conventional and complementary approaches and alternative treatments, I want to express my thanks and appreciation for how difficult a road it has been for all of you. I know trying to go this lonely road of making decisions and not having the support and not having the information readily available takes a lot of courage and strength. I want to praise you all for that.

Secondly, our organization has a toll-free counseling line. We provide free counseling by professional social workers to guide people through the decision-making process about complementary and alternative treatments along with conventional treatments, as well as regular counseling services. It's toll-free counseling, 1 800 813-HOPE. We refer to many organizations like Mr. Dreher's, where they can get more specific information. We provide that support and guidance in decision-making. Thank you.

Dr. Miller: Thank you. I'm sorry. We're going to have to limit people to standing in line, if that's all right.

Participant: My name is Gayle Cranford. I want to thank you all for expressing what I've been trying to express for 14 years. I'm a 14-year survivor of breast cancer. I did this on my own. It has been a long haul. You are affirming everything that I have believed and learned in the past 14 years. I want to say to trust your intuition, those of you who are trying to decide what to do. Trust your intuition. Find a good holistic doctor to monitor your progress, if you haven't done that. Learn all you can. Read, read, read. Also, as one nurse told me, and I thought it was appropriate, "Do your best, and bless the rest."

Dr. Miller: Does anyone on the panel want to make a comment?

Mr. Dreher: I want to make one little comment on that. One of the things I hear a lot is, "How am I going to find a doctor who is going to listen, who is going to understand what I'm saying, who is going to support my choices?" This is really difficult. The easy answer is, "Just keep going. You'll find somebody, and it will be okay." Probably not. There has to be a point at which people let go of that image. I wonder if the panel here agrees with this. The question is at what point. You fight for it. You try to find an oncologist who will support your choices. You are assertive beyond belief. You interview and interview and interview. You actually engage with these doctors. You try to get them to become something that most of them are not.

If it doesn't work out, or you get it to work out to the best of your ability and you find someone who is a compromise, or who is the best you can find, then you let go. You find other people to support your choices and other sources of information. If you find someone, that's a great blessing and will have been worth the effort. But even if you don't, it's worth the effort.

Dr. Delevitt: I wanted to say something very briefly. It is very important to take a break from the cancer battle. I may have mentioned that before. It's very important to do something besides obsess about what your next step is going to be or what your cancer treatment is. Cancer is a progressive illness. There will be valleys, and there will be peaks. Take the opportunity to go and do what you have denied yourself, what you haven't done in your life before. This is good for all of us, whether or not we are facing cancer. Take this opportunity to *carpe diem*. Ask yourself, "What have I denied myself in my life? What haven't I done that I really want to do? What have I said I'm not good enough to do or I don't have time to do or I don't have the money to do, or whatever?" Make an affirmation of your own life. That's one of the most important treatments or healings that we deny ourselves. We say, "I can't do this because I have cancer," or "I'm busy," or "I don't have the time." Just do it.

Dr. Miller: Thank you.

Participant: My name is Philip Nohr. I've been researching cancer for about ten years. It's not my profession. I still am learning, as I sense all of you are. I commend all of you for what you've accomplished. I would like to pose a question. I'm an economist. My first reaction from what I've learned would be to seek out the advice of those who have spent years doing what you have done. There are a number of consulting firms in the country. Several were just mentioned. I'm curious, if you had to do this over, if you would start your journey by seeking the advice of a number of leading consulting firms who have researched this for years, these alternatives as well as conventional therapy. I'm wondering if that would be a logical first step,

and then doing some of your own research as you've indicated all of you have done. Would that be a good first step?

Dr. Miller: That's a very good question. Would someone like to answer that?

Dr. Steinberg: All of us have tried to search out someone with a broader perspective, like a consulting firm. I don't know specifically the name of the firm, but there are many different cancer centers, there are many books and people that are willing to talk about what the research is and what some of the different ways of integrating treatment plans are. There are many different philosophies. It's a matter often of finding one that meshes with you. In relationship to the prior conversation we were having about finding an oncologist, and I think it fits with what you're talking about, there are a lot of skills to be drawn from each of these different specialists that we really have to integrate ourselves. It's a very intuitive process. It's not something that I think you can leave to somebody to plan for you. It's always an individual putting together of what's meaningful for you, and what makes sense to you.

Participant: The problem is most people don't have a lot of time to do a lot of research, so I'm thinking that maybe that's a good first step.

Dr. Miller: It really does depend on the individual. Are you right-brained or left-brained? Are you married to a research scientist? How do you deal with stress – by reading and reading and reading? Are you intuitive? Are you getting direct guidance from your dreams that you need to go on a certain diet or see a certain practitioner? It really is very individual. I know

when I was diagnosed, I was in shock. I didn't know what to think. There were places available, but they cost \$300 or so. I felt like I wanted to devote that money to one of the alternative approaches that I chose, so I did do that research on my own.

Ms. O'Toole: I felt initially that my cancer made me feel out of control. One of the things that I could do for myself was do as much research as I could. If I had to do it over again, maybe one of those consulting firms would be a place to start. But it's only a piece of the puzzle. You have to have your intuition lead the way. Initially, I didn't feel like I could access my intuition very well. You learn very quickly. I fired a lot of doctors along the way. My needs changed. As I grew and healed on one level, I moved on to another one. It's just a process that unfolds. As Rick said, one thing to remember, and it wasn't easy to remember it all the time, was that you have the time you need to find the information that's right for you. The whole medical approach to cancer is you need to start treatment yesterday. With alternative treatments, you need to feel into it and get comfortable with it.

Mr. Dreher: A brief point of information just on this question. There are consulting firms. In the issue of the Center for Mind-Body Medicine newsletter that came with our packets, there is an excellent overview of the consulting firms that are doing this. Mark Renneker is one; Pat McGrady is another; Ralph Moss is another. I have tried to do this to some extent. You actually have to shop with those too. Some have a bent a little bit more one way or the other, so you have to even shop for that. That is an excellent starting point. It is far from the answer, as Carole pointed out, but it is one place to begin to start to sort out these difficult questions.

Dr. Miller: Depending on who you are. Thank you very much. It was a good question.

Participant: I've been associated for the last several years with a place in Philadelphia, a nonprofit organization called the Center for Advancement in Cancer Education. We counsel people on the phone nationally. They have been counseling for 20 years. It's another resource for you. There are brochures on the resource desk. I appreciate your stories so much, but I haven't heard a lot of talk about detoxification and prevention. I myself was touched by my brother's cancer battle, with two bone marrow transplants. All of the technology in the world could not save him, because he did not heal. He did heal, but it wasn't the way I would have chosen, because he did not survive. He died, healed.

I have learned with my association with the Center for Advancement of Cancer Education that the organs of detoxification that we have, the skin, the lungs, the liver, the colon, the lymphatic system, are all being overburdened and overtaxed in our lifestyle choices by the toxic things we put into us. A lot of people are talking about what you can put into your mind and your body, but they don't remember the important aspect of what you can do to support the elimination of the toxins. Even chemotherapy and radiation produce many byproducts, including the dead tissue. I'm a holistic nurse, and I look forward to working in this field and helping people in that area in particular.

Dr. Miller: Thank you so much. Maybe one of our panelists would like to speak to that.

Dr. Manahan: It might be good for you to talk to Jim Gordon about having a half-day preconference on that next year. You're right. We've talked so much about the mind and the

spirit and the heart that we may forget that we need to work on the body at times too, with just a plain physical detoxification.

Dr. Miller: Maybe most of you did address that in some way in your treatment plans, but there wasn't enough time to go into detail. I think it is usually a part. Did you all detoxify in some way in your programs?

Participant: Hi. I would like to add one thing to what I thought were very heart-warming stories of recovery. I myself am in one. I have an anaplastic astrocytoma Grade III brain tumor. Upon getting that diagnosis, the key to me was not to panic. I know that it's easier said than done, but I'd like to throw that open, because you really don't have time. In my case I had two weeks to figure this out. I didn't have time to look for a consulting firm. Intuitively I knew what was right. For me it was exercise, and the two things that I can control, strength and attitude. Everything else is supplemental to my core values. Those core values have really helped me, much like everybody else has chosen their own path. But the first step, and the one I would like to endorse, is don't panic. Recognize what you have and deal with it. Deal with it immediately and with all the resources and strength that you can muster. Thank you.

Ms. Miler: Thank you. Does anyone want to respond?

Mr. Dreher: Yes. I want to say a brief thing about that. That is to reinforce some things you and others have said, that it has to do with feeling the negative emotions. Honoring your own process, that is to feel what you feel after the diagnosis, or indeed to not feel what you don't

want to feel. There's a place and a time for integrating emotionally the information that you're being deluged with. For some people it means to put aside the panic. For others it means to go into it.

I don't think there's one solution, although I tend to agree with Pali that there is a cyclical nature to the coping response, what Dr. Robert Chernin Cantor calls the resistance-surrender cycle. That is, you are inevitably going to go through this period of hopelessness and despair at times, of wanting to give up at times. If you allow yourself to move through that process emotionally, you will come out the other end, and there will be a sense of fight and a sense of hope. To allow that cycle to unfold naturally is often itself a healing process.

Participant: Hi. Just a real brief question. None of you have really addressed financial issues. What about the person who is not affluent? You can't go to six different physicians to find the one that's right, because your insurance company will only cover for a second opinion. Did this impact you at all in any of your treatment plans, and do you have any suggestions for people who don't have the resources available to really go out and look?

Dr. Miller: Excellent question.

Ms. O'Toole: Absolutely. I found that the financial constraints did force me to prioritize. I'm constantly having to weigh and measure which way I want to go with alternative treatments, because it is difficult to take it all out of your own pocket. One thing, in terms of a message of hope, there is some. Many healers were willing to do what I call creative financing with me. If I made a commitment for a particular length of time, they would give me a reduced

fee. Some would barter for services. If you had some particular talent or skill that they were interested in, they would swap talents. Some practitioners were willing to work with me on an extended treatment plan, where instead of coming on a weekly schedule, I would come every two weeks, or every three weeks, to stretch out the payment.

That was one of the reasons why I suggested strongly that you interview healers before you begin treatments. I was blatant about asking them up front. I figured I have nothing to lose. Cancer gave me so much courage. I started roller-blading. I started kayaking. Every time, my question was, “What the heck? I’ve got cancer. What have I got to lose?” You might as well be up front with these people from the get go and tell them where you stand. A lot of them were very open.

Dr. Delevitt: This is also a time for us to continue to pressure the insurance companies and other providers. This is our opportunity, as patients and activists being proactive in our own treatment, to say it is time that this type of health care is covered. It’s beginning to make headway. We need to pave the way for future patients behind us to say that doctors not only need to be educated about these types of materials and these types of treatments. They need to be able to provide it under the umbrella of the type of health care, HMOs, insurance companies, that are out there to cover things that we don’t want in our treatment. Thank you for bringing up the question. It’s a very important one.

Dr. Steinberg: I wanted to add too that it certainly was a factor in my choice of treatments. If I had all the money I wanted, I’d be going to lots of treatment centers, and doing great detoxes in San Diego at Deepak Chopra’s place, or the Upledger Institute in Florida. With

those constraints you often have to try to understand what they're doing, try to devise something of your own, and use what resources you can to improvise.

Dr. Miller: Thank you so much. We're going to have to close now. It was a wonderful presentation. I'm deeply moved, and I'm glad you were all here. Thank you.