

CENTER FOR MIND-BODY MEDICINE
COMPREHENSIVE CANCER CARE 2001: INTEGRATING COMPLEMENTARY &
ALTERNATIVE THERAPIES
PLENARY SESSION: Recovering A Sense of Service
Speaker: Rachel Naomi Remen, M.D

Arlington, Virginia
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P R O C E E D I N G S

DR. GORDON: -- Rachel Naomi Remen, who will speaking to us. Rachel said to me, when I saw her, I guess it was only yesterday, again, she said, "Why didn't you invite me sooner? I would have stayed for the whole conference?"

And I said, "Rachel, we invited you initially about 3 years ago and then a year and a half ago for this particular conference." And I think what her comment reflects, as well as her laughter now, is her eagerness to serve and be part of this community of healers. What the facts about the time required to invite her reflect is the enormous interest and passion that Rachel's work has evoked, particularly in the last few years, as she's begun to put on paper the wonderful stories of healing, and to convey to a large audience the spirit of the healing work that has animated her for many, many years, even longer ago than the 30 years' time that we've known each other.

Rachel's work, her work with people with chronic illness, her work with medical students and physicians, her work with a larger community of healers, her public work as a lecturer on television and the Bill Moyers series and as an author of kitchen table wisdom.

And "My Grandfather's Tales," is that what it is?

MS. REMEN: "Blessings."

DR. GORDON: "Blessings." I like "Tales," too. "My Grandfather's Blessings," her new book, conveys a kind of depth of experience that comes from her being. Even though she has all the right bookish credentials, the book that Rachel has learned in is the book of her own body and mind and her spirit, and from the way that book has opened out to touch so many of us.

So it's wonderful to have you here, Rachel, even if it took 3 years. (Applause)

MS. REMEN: I am so softspoken that I'm going to have to use this microphone and not the other one. Can you hear me in the back? Okay, good.

Well, first, let me say that I'm not going to talk about what it says on your program. I've changed my mind. I'm going to talk about the will to live, which I think is relevant to us

all as survivors and also as people who are professionals. And of course, as a storyteller, it's an enormous challenge to say something of importance in 40 minutes, but I will do my best. And so let me begin by saying that when we talk about integrative medicine or comprehensive medicine, what we really are doing is to invite life in its wholeness into our hospitals, our clinics, our workplaces, and be willing to meet it there. And this not always comfortable or easy. This is not the way we have been trained as health professionals.

You know, there's a lot of talk in the last 10 years about the care of the whole person. And the whole person is usually conceived in terms of needs. Wholism is conceived in how we meet the needs of the body, the needs of the feelings, the needs of the spirit, the needs of the mind. And you know, of course, there are many programs which are being developed nationwide to meet the needs of the whole person more fully.

But there's another way of thinking of this that goes beyond the meeting of needs and recognizes that the whole person brings a far greater power, capacity, and resource with them to encounter with pain and suffering than someone who is simply a body.

And this, of course, adds a whole new dimension to our work. It challenges our way of thinking about the work, about ourselves. And it can even change the way that we think about our own lives. When we're willing to see wholeness in situations and in people, what we see may transform us, and we may become far more than we were trained to be. And that, I think, is really the blessing in this work.

Wholeness includes dimensions that are not covered by our professional training. It raises questions that we have not asked ourselves before. For example, the whole person always includes the dimension of mystery. As a physician, I never heard this mentioned even once in all of my years of training, and yet I observe it every day in my practice.

And that's what I want to talk about: The dimension of the unknown, which is a part of wholeness. And I want to talk about it in terms of the will to live, the mysterious power that can move us past obstacles and losses and enable us to grow in spite of them. This is what we must be willing to engage with as people who practice whole medicine.

And I want to talk about the will to live not as an abstract or a theoretical construct, I want to speak from my own experience as a friend, a family member, a physician, a person who is a therapist to people with cancer for the past 30 years, and most importantly, a person who has a 48-year history of a severe chronic illness myself. I have Crohn's disease, which is a significant disease of the intestine, which I got when I was 15 years old.

So let me start by saying that the will to live isn't a preference. It's a powerful impulse towards life which is hidden in the heart of all living things. And, buried deep in the unconscious, it shapes our instinctive behaviors and influences our conscious choices, and even our physiology. The will to live is unconditional. The wish to live, on the other

hand, is highly particular. It has its reasons and even its terms. It's conscious and personal, rather than cellular and universal. The wish to live is shaped by the attachments of our individual lives, but the will to live is larger than ourselves. We may find ways to collaborate with it, to unblock it, even to strengthen it in ourselves and others. But it's a force of nature, an intimate experience of the life force itself.

Now, of course, the will to live cannot be measured, which puts it beyond the reach of science. But we may have allowed science to define life for us. Science will define life in its own ways, but life is actually larger than science. Many things happen that science cannot explain. These things are not replicable or quantifiable. They are observable, touching, moving, inspiring, powerful, and profoundly mysterious.

Life is full of mystery. There are many things that we cannot understand, but we can witness and even know in ourselves. In truth, we all know many things that we cannot measure. And over the years, I have found in a lot of circumstances, knowing something may be much more important than understanding it or being able to measure it.

I've been a physician for 38 years, and I've taught on the faculty of three major medical schools. I'm trained as a researcher. And for the last 30 years, I've cared for people with cancer and listened to their stories. And on the basis of all this experience in medicine, I would really want to say that it's possible to research and study and measure life for many years without knowing life at all. You know, some of the important things about life cannot be learned through analysis. It can be only learned by experiencing life whole. And so it may be important for us all to consider the possibility that science may have defined life too small, because when we define life too small, we define our work too small, and we define ourselves too small as well. And I have actually come to think that life might best be defined, not by science, but by mystery.

I want to start with a story here about the first time that I noticed the will to live. And it was something that changed my life, so I remember exactly where I was at the time. I was 14 years old, and I was walking up Fifth Avenue between 34th Street and 35th Street on a Saturday morning with two of my friends, and we were doing what young teenagers did on Saturday morning in the '50s: We were shopping.

And as we walked up the street, a little flash of green caught my eye. And there, growing right through the New York City sidewalk were two tiny green blades of grass. Now, they weren't growing through a crack in the sidewalk. They were growing right through the cement. And this, of course, stopped us all cold. Now we were very sophisticated young people. We were 14 years old, but of course, we were New Yorkers. So we knew quite a bit about power. But none of us had ever encountered this kind of power before.

And I remembered it for years, the image of the two little tender blades of grass coming right through the cement. I remembered -- even before I had a glimmer of its personal

significance and meaning for me, because at the time I saw it, it struck me as a kind of a miracle.

Now, about a year later, when I was 15 years old and I was diagnosed with Crohn's disease, the disease that I've lived with for all of my life, a group of experts in white coats gathered around me and my family, and they told us the facts. No one knew what caused this disease. No one had any idea how to cure it. I would have multiple surgeries and I would die by the time I was 40.

Now, at 15, this was not my dream of the future. I had something else in mind. So it was a time of great darkness and despair. And I come from a very medical family: In two generations of my family, there are nine physicians and three nurses. And so we never questioned what the experts had told us, and I made many life decisions based on this information, decisions about marriage and children. It didn't seem right to me to start something that I knew that I was not going to be able to finish. It would be years before I would make the connection between the two little blades of grass that I had seen the year before and myself.

Thinking back on this, if only one of the many physicians around me had suggested that it might be possible for me to find something in me that could break through this obstacle of this disease, something that medicine could not measure, even understand, that perhaps I could strengthen this in myself. It would have made a great difference to me. But no one did. And now that I've been a physician myself all these years, I think I understand why.

My doctors didn't tell me because they simply didn't know. You do not find will to live under W in Essentials of Internal Medicine. This is not something you learn from a medical textbook. This is something you learn only by being open to observing life itself.

You know, why allow mystery in life? In the presence of mystery, life becomes more filled with possibility, more inspiring actually, somehow larger. And in allowing a larger and more mysterious definition of life than science may offer us, we may discover one of mystery's greatest gifts, which happens to be hope. Now, you know, it's really sad, because the facts in my situation have never changed. There is still no known cause for Crohn's disease and still no definitive cure. I live with this problem daily. I've had eight major abdominal surgeries. I no longer have most of my intestine. But I have not been dead these past 23 years. (Laughter)

So I suppose I'm here to remind you that what was in those two little green blades of grass is in us all. You know, whenever there's a difference between the facts and the stories, you're in the presence of mystery. And life is often not limited by the facts. Life is filled with mystery. The world is not made up of facts. The world is made up of stories. And each of our stories is as unique as our fingerprints. Each of us is a story that has never happened in the history of the world before. You know, a diagnosis is a confrontation with the unknown, an encounter with mystery, and it would be good to acknowledge the mystery in things just a little bit more -- as friends, as family, as health

professionals, certainly as physicians. I think it's very important to be able to say that the diagnosis is cancer or Crohn's disease or whatever, but I think we also need to add that what that will mean remains to be seen, and then become a part of someone's story as they live it out.

You know, knowing life will require us to realize that all of our hard-won knowledge may only be provisional, and life may be far different than we believe it to be. This can be stressful or even frightening. But it's also deeply rewarding. Befriending the unknown can restore to us all a sense of wonder and awe and aliveness. You know, people who wonder don't burn out. We may need to know a lot less and wonder a lot more.

You know, sometimes the more we know, the harder it is to see something we can't understand. And we see this often in medicine. A medical culture is a clear mirror of the values of a larger culture, the values of the culture that it serves. And in fact, those values are generally intensified within the medical culture. Our whole culture is based on the pursuit of control and mastery, and so, of course, is our medicine. And we can get so deeply into mastery that we may not even see mystery when it happens right in front of us, even when it happens in its most dramatic form.

A number of years ago, I was sitting on a dissertation committee of a woman who wanted to study spontaneous remission from cancer. And the school, of course, did not want her to study this, because they believed that it never happened, and therefore her dissertation would fail. But she was a very, very stubborn woman. She lived in Moscow, Idaho, and she put an ad in the local newspaper saying if anyone felt they had recovered from cancer by means that could not be easily explained, would they call this phone number. And a surprisingly large number of people called.

Now, it was my job as the only physician on the committee to check the credibility of these people's stories and collect the medical evidence -- you know, the biopsy reports, the surgery reports and the like. And indeed, many of their stories fell into the gray zone. Someone had one course of a nine-course chemotherapy and then quit. Someone had one treatment of radiation and then stopped. And there were many people who had used extensive, unproven alternative methods alone. And who knew, but perhaps some of these things actually worked?

But there was one young man whose story was definitely outside of the box. He had been diagnosed with an osteogenic sarcoma, which is the bone cancer that Kennedy's boy had when he was a student in Boston. And he was offered the standard therapy, and this was many years before I met him. And the standard therapy was surgical removal of his leg at the hip. And despite pressure from his parents and his doctors, he resisted the surgery. And he went home to Idaho to die, except he didn't die. And the only intervention that was made in his behalf was the pastor in the little town asked people to pray for him at 7 o'clock every night, if they were so moved. And they prayed for him for 2 years. And gradually over time, the mass in his leg became smaller and ultimately disappeared, and it was now 20 years later. Definitely outside of the box.

And so in my role of needing to document the diagnosis, I tried to find his physician, which was a very easy thing to do, because his physician had been a young man himself at the time he had made this diagnosis; he was still in practice. And I located him and called him and introduced myself and said to him, "I'm calling for some very records and hopefully for a biopsy report. I doubt you remember the patient." And then I told him the man's name.

And he said immediately, "Of course, I remember him. Who could forget a thing like that? What a tragedy. Are you calling for the family?"

And I said, "No, no, I was calling for the man himself."

And this other doctor says to me, "Oh, thank God. Where did he have his surgery?"

And I said, "Well, he didn't have surgery."

And there was a silence. And then he said in a completely different tone of voice, "Well, what happened then?"

And so I told him the story exactly as it had been told me by this man. And there was another moment of silence. And then, without a single word, he simply hung up the phone. And I called him several times after this, but he never returned my calls.

(Laughter) It's very difficult when your basic assumptions about life are questioned, when our understanding of the way things are is challenged, but knowing life requires a willingness not to understand, an open-mindedness, a willingness to listen. Because if we're not willing to listen and we're not willing to wonder, we may have to hang up the phone on life.

And, you know, this is very difficult, very difficult on a number of different levels. When everyone is thinking inside of the box, it is very hard to think outside of the box. But often outside of the box is where life is.

You know, the will to live is a very common thing. In most instances, it's not as dramatic as this. Many people who are a living example of the will to live may not even notice it or recognize it in themselves or trust its power. Over the years, countless people have said to me in my practice that they have recovered from cancer because of chemotherapy, radiation, surgery or some alternative means. But perhaps this may not be the case. Perhaps such approaches have the same effect on us as pruning has on a rose bush: They create the conditions which gives the will to live the best chance to express itself, but chemotherapy or radiation or any other kind of treatment isn't why we recover.

You know, when we're challenged with a life-threatening illness, we need to mobilize the full power of our science and to draw on the wisdom of the world's healing traditions as well. But we cannot forget the will to live in us, the mystery which is at the heart of our own lives and all other lives.

Let me skip a bit here, because I realize I'm going to have to make this talk shorter.

So what does it look like when the will to live awakens in us, most commonly? Does it look like our cancers go away? Well, sometimes. You know, stories like the story of the man in Idaho, they do happen. But this isn't the most common thing that happens. You know, more often the will to live shows itself to us in ways that are much subtler than this. The will to live is the driving force behind the movement towards wholeness that's in us all. When it awakens in us, we may find we have become larger, freer to live more fully, richly, or passionately than before. We may find that despite of our illness, we have a greater depth and a capacity to live well. Because this power is in us all, it's possible even to die more fully whole than you have lived.

And I'd like to tell you the story of a patient of mine, a woman who very early in her life was diagnosed as an obsessive-compulsive. Cindy's husband described her to me as "crazy clean." Like her mother before her, her house was immaculate. Every drawer was perfectly organized. You know, every surface shone. And this was despite the fact that she lived with a big bear of a man and three little children. One of her young daughters told me that her mom could spot a Cheerio on the kitchen floor from the other room and would not be satisfied until the offender had confessed and actually picked it up. (Laughter)

But cancer changed all that. Her chemotherapy made her so weak, she couldn't get from her bed to the bathroom. She didn't have the strength to cook. And the whole neighborhood invaded her perfectly organized kitchen and fed her family. Kind hands, unfamiliar with the household rules, washed and folded and put away laundry in all the wrong places. Her perfect walls were covered with dozens of pictures made by the classmates of her children, each with a prayer for her recovery, each stuck on the wall with a big piece of Scotch tape. During the worst of it, her husband brought home a kitten -- a kitten! -- who shed everywhere and whose purring comforted her through the dark hours of the night, when she was so sick from her chemo that she couldn't sleep.

Now, 2 years later, she says with a laugh, she would never want to be the way she was before she had cancer. "I drove my family crazy. I resented them because they disturbed the order of things. I'd been that way for years, Rachel," she told me.

She also shared the story of a recent visit to her sister, a daughter of the same mother. They were sitting together in the kitchen, drinking tea, and she looked into her sister's living room, and her sister had one of those carpets that shows every footprint. It had been vacuumed so perfectly that every fiber was pointing in the same direction. She says to me, "At one time, this would have given me a deep sense of satisfaction," and she says, "Rachel, it just looked sad and lonely, untouched by life." And then she began to laugh. And she said, "You know, there is so much more to life than a perfectly clean kitchen floor, Rachel."

You know, there is such a greater wisdom to be found at the edges of life than in its middle, perhaps because the will to live is evoked by anything that wounds us. It's in a

lot of people today, of course. Life-threatening illness can shuffle our values like a deck of cards. Sometimes a card that we have been carrying at the bottom of the deck for most of our lives turns out to be our top card, the thing that really matters. Having watched people sort their cards and play their hands in the presence of death for many years, I would say that rarely is the top card perfection or possessions or even pride. Most often, the top card is love.

You know, crisis opens the heart. Crisis opens the heart. And it enables us to recognize what may be important in life.

You know, I'm going to skip over some more things here also. Let me simply say something important about the will to live, though. Strengthening the will to live is not the work of experts. It's the work of human beings. We've been strengthening the will to live in each other long before there were experts, long before there were surgeons, oncologists, what have you. You know, healing is a potential in all relationships. And sometimes we may have to step past our professionalism in order to reclaim our real power to strengthen the will to live in other people.

Let me tell you a story about myself. When I was 27 years old, most of my intestine was removed surgically and I was left with an ileostomy, an appliance which I wear on my abdomen and empty periodically. It collects my stomach juices.

Now, this surgery saved my life, but I felt maimed by it. I felt cut off from all other women my own age. I was a single, 27-year-old woman. I felt shut out of anything feminine or elegant, and I became very depressed. And in the week that I was in the hospital, I had thoughts of committing suicide.

And while I was there, hospitalized, professionals called on me everyday. They were called enterostomal therapists. And they came to change my appliance for me, because I couldn't do this yet for myself. And these experts were women my own age. They came into my room in their white coats. And then they would put on a gown, an apron, a mask and gloves, and change my appliance. And then they would take off the gloves, the mask, the apron and the gown, and very carefully wash their hands. This was not helping me reclaim a good feeling about my changed body. It actually humiliated me and made me feel deeply ashamed.

Now, one afternoon, a young woman I'd never met came in to do this task. She wasn't wearing a white coat. It was late in the afternoon. And she looked like she was going to go out on a date. She was dressed, you know, in stockings and heels and a twin set and a short skirt. And she introduced herself and went to the sink and washed her hands before she touched me. And as she was washing her hands, she asked my permission to change my appliance. And when I when I said, fine, she went to the bedside table, took an appliance from the upper drawer, and, chatting with me in the most natural way possible, she simply removed the old appliance and replaced it with a new one with her bare hands.

Now, I was a young physician, and the first thought that went through my mind was, "How unprofessional." Right? But as she continued to talk to me, I watched her hands, and they were soft and feminine, and her nails were painted pink, and she was wearing delicate gold jewelry. And suddenly, I experienced an expected rush of strength from somewhere deep inside me. And I knew that I was going to find a way to do this thing, that it was going to be all right.

You know, one of my medical students said to me -- I asked him what he had discovered in our course, the Healer's Art, which we taught for 10 years at UCSF. And he said, "Rachel, I found that I can heal with my presence and my love things I cannot cure with my science."

It's very unprofessional to do such things with your bare hands. But of course, this is the same way I've changed my own appliance every day for the past 37 years.

Sometimes what strengthens the will to live in others requires us to step beyond our professional image, to break our rules, our training, our professionalism. Professional behaviors can sometimes diminish the will to live in others. It's human beings that strengthen the will to live in other people.

Let me skip something here. So let me just say -- I'm going to close now because I'm actually over time. Yeah? Well.

Some of the ways in which we befriend life are very, very simple and very old. They have nothing to do with our expertise. They have everything to do with who we are. And these old ways have lost none of their power over all of these years.

Now, we do something in the last session of the Healer's Art every year which demonstrates this kind of thing. What we would do is to enable the young students -- they've been in medical school 4 months, they're first-year students -- we enabled them to rewrite the Hippocratic oath for themselves. Now, of course, the Hippocratic oath is part of the lineage of medicine. But I happen to think it's far more universal than that. I think each one of us carries within ourselves something very much like the Hippocratic oath, that in a very deep and private place in ourselves, it is our hope that we may be able to use ourselves to make a difference in this world.

And because I see the Hippocratic oath as more universal than medicine, it's an odd group that does this exercise together. There are 70 first-year medical students, usually, every year. There's also about a dozen physicians, and they are not holistic physicians: They are oncologists and psychologists -- or psychiatrists, rather. They are orthopedic surgeons and pediatricians and gynecologists and internists and cardiologists, all of whom are struggling to live the Hippocratic oath as a way of life.

So there's this dozen physicians, the 70 medical students. And then I invite the hospital chaplaincy program to join us. So we have a group of ministers, rabbis, and priests. And then, because the word has gotten out that this is an opportunity to strengthen

commitment, people drop in on us. So we have usually a number of nurses and psychologists from the hospital, social workers, all sorts of people.

And together in this group, we rewrite the Hippocratic oath in this simple way. We ask people to imagine that their work didn't tell them how to be; that your work didn't tell you what to say and what to wear and what to read, and, you know, what kind of an office you're supposed to have; that your work could be an opportunity for you to express your highest values into this world and make them real; to express what is important to you and make it real. And if so, what would your work look like? And then, people think about this dream of service that they have.

And then we asked them to ask for help: To write three sentences in the language of help, asking for help to bring this dream of service closer to them in their everyday work. Help me, give me, let me, may I, et cetera. And everybody writes. And then we spend an hour and a half reading these things out loud to each other. And it's quite a powerful experience, because someone will get up and read, and another person will get up and read. And it just goes on like that. And if you closed your eyes, you could not tell who was a first-year medical student, who was a surgeon or an oncologist, who was a rabbi or a minister or a nurse or a social worker. You know, we've gone past the divisiveness of our expertise to something very, very fundamental in us all, the meeting place of all the professions, which is the commitment to befriend life. And we each bring to that commitment our own expertise and training and background. But it is one work.

And it's a very powerful thing. And there are many other ways to do this work, than through the health professions. And I want to read to you what one young man wrote about 4 years ago now, his Hippocratic oath. He's a big fellow. He looks like a football player, which he was, until he went to medical school. And he did not appear to be a participant. He was leaning against the wall while everybody was reading with his eyes closed. And I was sure he was reviewing the cranial nerves in his mind, because you know, that's what he's going to be tested on; he is not going to be held accountable for his compassion. Not yet, not yet.

But I had him wrong, because at the end of the session, he opened his eyes and he said, "You know, I've been writing something in my head to my future patients. And I'd like to just say it out loud." And this is what he said. "May you find in me the mother of the world. May my heart be a mother's heart, my hands be a mother's hands. May my response to your suffering be a mother's response to your suffering. May I sit with you in the dark, like a mother sits in the dark. May you know through our relationship that there is something in this world that can be trusted."

The ways that we strengthen the will to live in other people are very old and very powerful indeed. And so let me close with a very simple, little story.

I was blessed with a grandfather, who was an orthodox rabbi, but he was also Kabbalist, which is of course the mystical arm of Judaism. So grandpa was a flaming mystic and a wonderful storyteller and a wonderful teacher. And his way of teaching

was to enable you to have the experience and discover for yourself the thing that he wanted you to know. And when you discovered it and ran to him to show it to him, all excited, he would say, "Why, Neshumala (phonetic), how wonderful!" And I have tried to teach in that way all these years, actually.

So once when he came to visit me, he brought me a present, a little paper cup. And I was thrilled. I was sure there was something magical and special in it, because grandpa was so magical and special. But when he gave it to me, I saw it was full of dirt, and I was really disappointed. And he didn't seem to notice that I was disappointed. He took me into the kitchen and he showed me how to put a little bit of water in the cup. And he said to me, "Look, Neshumala, you put a little water like this in the cup every day and something may happen."

Now I was, of course, a 4-year-old New Yorker. I lived on the sixth floor of an apartment building. This -- I had no context for this at all. I had no idea what might happen if you put water on dirt. You know, it didn't make any sense. But at 4, you know, adults were always telling me things that didn't make much sense to me, and I loved my grandfather and I trusted him, and so I gave him my promise that I would do this.

And for the first week, it was exciting. I was waiting for something to happen, but nothing did. And the second week, it got a little harder. And when I saw him again, I tried to give the cup back to him.

(Tape interruption)

MS. REMEN: -- every day, Neshumala." And the third week -- after all, I was 4 years old. The third week was very, very hard.

But halfway through the third week, one morning, there were two little green leaves in that cup that hadn't been there the night before. I was astounded. And I was certain my grandpa would be just as surprised as I was. But of course, he wasn't. What he said was, "Ah, Neshumala, life is everywhere, hidden in the most ordinary and unexpected places." And I was thrilled.

I said, "And all it needs is water, Grandpa?"

And he laughed and he said, "No, Neshumala, all life needs is your faithfulness."

And I think this is true. I think this is what we need to remember now. We can all bless the will to live in each other. This is something innate in all of us, and it goes far beyond our expertise.

May we bless one another. Thank you. (Applause)

DR. GORDON: Thank you, Rachel, for your blessing. It's time for us to take a break. Have a cup of tea. Have a cup of coffee. Have a glass of water. Rachel will be here for

a few minutes, if you'd like to talk with her. And we'll go to the concurrent sessions. And then after that, we'll have the reception.

(Whereupon, the PROCEEDINGS were adjourned.)

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