

## ATTITUDES AND CANCER: WHAT KIND OF HELP REALLY HELPS?

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Five years ago I was sitting at my kitchen table having tea with an old friend who told me that some months earlier he learned he had thyroid cancer. I told him about my mother, who had surgery for colon cancer fifteen years ago and has been fine ever since. I then described the various theories my sisters and I came up with to explain why she had gotten cancer. We had a number of them; probably our favorite was that she had been too much my father's wife and not enough herself. We speculated that if she had not married a cattleman she might have become a vegetarian and avoided the fats implicated in causing colon cancer. Our other pet theory was that her side of the family's acknowledged difficulty expressing emotions may have contributed to her getting cancer; we may have been influenced by Woody Allen's line, "I don't get angry, I grow tumors instead." Over the years we had become quite comfortable with our theories and stories about this traumatic event. My friend, who obviously had thought deeply about cancer, then said something that shook me deeply.

"Do you see what you're doing?" he asked. "You're treating your mother like an object, spinning theories about her. Other people's theories about you can feel like a violation. I know, because in my case the ideas my friends have come up with about my having cancer have felt like an imposition and a burden. It doesn't feel like they're coming primarily from concern for me, and they certainly did not honor me at a difficult time. I felt their 'theories' as something done *to* me, not something done *to help* me. The thought of my having cancer must have frightened them so much they needed to find a reason, an explanation, a meaning for it. The theories were to help them, not to help me, and they caused me a lot of pain."

*"theories"  
as  
something  
done  
to me*

I was shocked. I had never looked at what was behind my theorizing, never speculated about what my theories might feel like to my mother. Even though none of us ever told her about our ideas, I'm quite certain she felt it in the air. That kind of climate wouldn't encourage trust or openness or asking for help, I realized. I suddenly saw that I had made myself largely unavailable to my mother during the greatest crisis of her life.

*judgment  
and  
unacknowledged  
fear*

*That incident with my friend* opened a door. It was the beginning of a shift toward my becoming more compassionate toward people who are sick, more respectful of their integrity, more kindly in my approach-and more humble about my own ideas. I began to see the judgment only partly hidden behind my theorizing and to recognize the unacknowledged fear that lay deeper still. The implicit message behind such theories began to emerge. Instead of saying, "I care about *you*; what can I do to help?," I was actually saying, "What did you do wrong? Where did you make your mistake? How did you fail?" And, not incidentally, "How can I protect myself?"

I saw fear-unacknowledged, hidden fear-as what motivated me, what compelled me to come up with stories that told me the universe made this kind of sense, that it was ordered in a way I could control. If people got sick for reasons they could, to some degree, control, I could feel a lot safer. In such an ordered universe, there were things I could do to avoid getting sick. I could avoid stress or change my personality or become a vegetarian. Indeed, some years after my mother's surgery I did become a vegetarian. Was I unconsciously trying to correct in myself something I thought my mother had done wrong?

Not even a year after this talk with my friend I was in the hospital awaiting surgery for breast cancer. I discovered I had cancer only ten days after my marriage to Ken Wilber; we now joke about spending our honeymoon in room 203 of Children's Hospital! A year later I had a local recurrence. Ken has been by my side the whole time, helping me with the research and decision making, driving me to the doctor, holding me when fear threatened to engulf me, helping me keep my head above water with his jokes and kindness, simply being there for me in every way possible.

During this period I've had two surgeries, six weeks of radiation, and six months of chemotherapy. I've seen a psychic healer, a Philippine healer, a hypnotist, and an acupuncturist, I practice meditation, I've been in therapy, I've practiced visualization and done imagery work, and I take mega vitamins under a doctor's supervision. I exercise daily and am very careful about my diet, which is basically vegetarian-Pritikin with some

fish. Recently I changed my first name, based on a series of insistent dreams that started after the most recent recurrence. I've been surprised by the emergence of a long buried artistic side and I now enjoy drawing, making stained glass and doing fused glasswork. I've learned a lot and changed a lot during the past three and a half years, both on the exterior and the interior. It's been an exciting, frightening, challenging and rewarding time, a time that has taught me a great deal about allowing myself to be helped and about helping others.

Because the kind of help and community that can be crucial during a time like this is often either missing or hard to find, a close friend who has also had cancer and I were inspired to start a non-profit group called The Cancer Support Community in San Francisco. After over a year of preparation, ESC now provides support groups, educational programs, and special events for people with cancer, their families and loved ones, all in the context of a community of people who have themselves directly experienced cancer-and all completely free of charge. The positive feedback from those who take part in our programs and have become part of this community has been overwhelming and most gratifying; I only wish ESC had been around for me when I desperately needed that kind of help! Places like ESC also help restore humor to a situation most people take terribly seriously. Other cancer patients and I can laugh together at things most healthy people find threatening; we can tell each other jokes that would make people without cancer turn pale, and our shared laughter in the face of adversity helps.

*a  
community  
of people  
who  
have  
experienced  
cancer*

Over the years I've talked to a lot of people who have cancer, many who have recently been diagnosed. At first I wasn't sure what to say. It was easiest to talk about my own experiences, but I soon saw that often that was not what a particular person needed to hear. The only way I could discover how to help someone was by listening. Only when I heard what they were trying to say could I get a sense of what they needed, of the issues they were confronting at that time, of the kind of help that would really help at that specific moment. Since people go through many different phases during the course of an illness that can be as persistent and unpredictable as cancer, learning to listen to what they need is especially important.

At times, especially when decisions about treatment options loom ahead of them, people want information. They may want me to tell them about alternatives or help them research conventional therapies. Once they've chosen their treatment plan, however, they usually don't need more information, even though it may be the easiest and least threatening thing for me

to give. Now they need support. They don't need to hear about the dangers of the radiation or chemotherapy or Mexican clinic they've chosen, a choice usually made with great difficulty after long deliberation. My coming to them at this point with new suggestions about healers or techniques or therapies might only throw them back into confusion, might make them feel I doubt the path they've chosen and thus fuel their own doubts.

to  
face  
the  
truth  
squarely

It didn't help when a friend warned me of the dangers of the radiation treatment I was currently having: I was already well aware of the dangers and struggled with my fears daily. It was not helpful when people warned me that worrying about a recurrence might make it happen, or when they pressed me to think positively. I needed to plunge into the depths of my fear, to face the truth squarely; only then could a genuinely positive attitude emerge. I remember my great relief at hearing from others that fears of recurrence and doubts about treatment are completely natural, and it helped to hear many others also felt the hardest part was the constant uncertainty, the *not-knowing* so characteristic of a sneaky disease like cancer.

My friends and family also supported me in many ways as I navigated the combination of traditional treatments and various non-toxic "alternatives" I chose. It helped when people supported me in following my new diet; it also helped if they didn't criticize me when I needed a break from the diet. It helped when people seemed genuinely interested in what I was doing, for example my visualization program. I wish I had thought to ask for help with my insurance forms—a huge headache for anyone with as many bills as cancer treatment generates. Sometimes I needed someone who would simply be there for me or hold me, someone who didn't push me to emote or bare my soul or be honest about my fears. And sometimes I needed someone to be with me as I struggled with these fears, someone who could listen to me talk about pain or euthanasia or suicide or death without retreating into their own fears or pressing me to think more positively.

I especially needed to be around people who loved me as I was, not people who were trying to motivate me or change me or convince me of their favorite idea or theory. And I needed friends whose definition of health didn't stop at the physical level, friends who recognized that success in healing myself included the quality of my life and of my personal and spiritual growth. Certainly I worked hard to achieve physical health, *but* true healing has to do with how each of us lives our lives on all levels, in *all* dimensions, and physical health is clearly not more important than emotional or spiritual health. We've all heard *stories* about people who have used a confrontation with

catastrophic illness to change themselves radically, to turn their lives more toward service, to learn to treat themselves and others with great kindness and compassion. That is the sign of true healing, and it may or may not manifest on the level of physical health.

The decisions I made were not easy; I know that the decisions everyone has to make in this kind of situation are some of the toughest they'll ever confront. I have learned that I can never know in advance what choice I would make when in someone else's place. This knowledge helps me feel genuinely supportive of the choices others make. A dear friend of mine, who was a great support to me during chemotherapy, who made me feel beautiful even when my hair fell out, recently said, "You didn't choose what I would have chosen, but that didn't matter." I appreciated her for not letting that come between us then, clearly the most difficult time of my life. Then I said, "But you can't know what you would have chosen; I didn't choose what you *think* you would have chosen. I didn't choose what *I* thought I would have chosen either."

I never thought I would agree to chemotherapy. I had tremendous fears about putting poisons into my body and fears about long term effects on my immune system. I resisted it until the very end but ultimately decided that, despite its many drawbacks, chemotherapy was my best chance for cure.

There were many times during my treatment when I envied people who have more faith in mainstream medicine, people who do not have to deal with the avalanche of doubts about traditional medicine or the flood of unproven nontraditional alternatives that I lived with daily. Part of me wanted to try everything that might help, but I simply did not have the time or energy or desire or money to pursue each new suggestion. I had barely enough time and energy to carry on with the treatments I had already chosen, and it was difficult when friends implied that they would have chosen differently, difficult when I felt I had to explain or defend my choices. Belief in one's treatment is important, and I try to support people's choices. What one person has faith in or is motivated to try is not necessarily appropriate for someone else. In addition, I am aware that efforts to help can too easily be derailed or distorted by unacknowledged fears. I am careful to not push chemotherapy as a way of bolstering my own faith in it. There are some who passionately advocate chemotherapy or an alternative like macrobiotics because a friend or relative who refused it died; others vehemently oppose the same treatments because their relative died in spite of it.

*to  
support  
people's  
choices*

*guilt  
and  
magical  
hopes*

Many of us like to theorize about why we get sick or why someone else gets sick. What motivates this, what fuels this kind of questioning? When my mother was sick, I was motivated by fear and a desire for self-protection. When I got cancer myself, my theorizing about myself was initially fueled by the "you create your own reality" philosophy, which generated guilt about my past and a feeling that others must think I had failed in some way by getting cancer. This philosophy also bred the magical hope that if I could find "the cause" I could correct it, root out the mistake, cleanse my past, change my future and, hopefully, thus cure myself. This philosophy also implied that the only proof of success at creating my own reality would be if I got well physically.

Probably everyone who becomes ill, especially when they are young (I was 37), will struggle with some form of the question, "Why did this happen? How was I responsible?" This can be a helpful issue to raise, especially when we deny responsibility for our lives or feel like victims of fate. But I have found it to be helpful only when done without judgment, only when the results of self-questioning are held lightly and recognized as tentative. For myself, the stories I came up with are probably only part-true. The fact that I can never know for sure which parts are true keeps me from using these stories to be unkind to myself.

*what  
I  
can  
do  
now*

I'm certain that I played a role in my becoming ill, a role that was mostly unconscious and unintentional, and I know that I play a large role, this one very conscious and very intentional, in getting well and staying well. I try to focus on what I can do now; unravelling the past too easily degenerates into a kind of self-blame which makes it harder, not easier, to make healthy, conscious choices in the present. I am also very aware of the many other factors which are largely beyond my conscious or unconscious control. We are all, thankfully, part of a much larger whole. I like being aware of this, even though it means I have less control. We are all too interconnected, both with each other and with our environment-life is too wonderfully complex-for a simple statement like "you create your own reality" to be simply true. A belief that I control or create my own reality actually attempts to rip me out of the rich, complex, mysterious, and supportive context of my life. It attempts, in the name of control, to deny the web of relationships which nurtures me and each of us daily.

As a correction to the belief that we are at the mercy of larger forces or that illness is due to external agents only, this idea that we create our own reality and therefore also our illness is important and necessary. But it goes too far. It is an over-

reaction, based on an oversimplification. I have come to feel that the extreme form of this belief negates what is helpful about it, that it is too often used in a narrow-minded, narcissistic, divisive and dangerous way. I think we are ready for a more mature approach to this idea. As Steven Levine says, this statement is a half truth dangerous in its incompleteness. It is more accurate to say we *affect* our reality. This is closer to the whole truth; it leaves room both for effective personal action and for the wondrous rich mysteriousness of life.

we  
affect  
*our*  
reality

I recently talked to a woman who had breast cancer five years ago, was in remission for a number of years, and now has metastases to the bone. She is a vivacious, giving, adorable woman in her sixties. Her sister, who is very interested in new age thought, recently took a workshop with a teacher who says that everything that happens to you-including disease-comes from within you, that you are therefore responsible for everything that happens to you. This idea motivated and empowered me when I was well, but when I became ill it revealed its hard, uncompassionate, even cruel face. I understood all too easily how it confused and upset the sister confronting the many implications, uncertainties and difficult choices of bone cancer. She told me that she simply didn't know what to do-should she try macrobiotics, should she find a psychic healer? She told me she worried all the time that it was her fault the cancer came back, that she was plagued with the thought she must have done something wrong or not done something she should have.

I know that her sister, also quite a remarkable woman, was motivated by love and trying to help. Because of my interests and my husband's writings in philosophy and transpersonal psychology, she assumed that I would agree with this workshop leader. When we talked, I explained my somewhat different perspective on this idea of responsibility for illness, a perspective Ken strongly agrees with. I tried to honor her beliefs-that's always important-while explaining that too many use this idea of self-responsibility not in a positive way but negatively, *against* themselves and others. Because it dangerously oversimplifies a complex situation, I have come to see it as only partly true. Although for many this idea has been empowering, for many others it causes suffering and confusion which do not promote health.

a  
dangerous  
over-  
simplification

As we talked I discovered that another sister had died of cancer some years earlier. I began to suspect that part of the reason she found these ideas so attractive was, understandably, her own fear of cancer. Because of my own experience I understood only too well the attraction of believing that if she changed her

lifestyle, if she meditated daily, if she used affirmations, if she cleared up aspects of her personality that might cause stress, she could gain some protection from cancer. The same kinds of fears and desire for self-protection were probably part of my reason for becoming a vegetarian many years earlier.

a  
"double-  
edged  
sword"

It can be very difficult for someone in this woman's position to realize that ideas helpful to her may not be helpful to her sister, that her sister is in a completely different phase of relationship to illness. In fact, talk about responsibility for illness at this point only made her sister *more* fearful, more confused, more caught up in the mind and its often punishing stories. I think of these ideas now as a "double-edged sword." A thought] use to motivate myself to make important changes can, if I get a disease like cancer or if cancer returns in spite of everything I've done, be used just as easily to beat myself up and undermine my innate drive toward health.

In trying to understand my own cancer and in working with others interested in this question. I emphasize that the causes of cancer are many and varied, that they are different for each person and each situation, and that cancer is a complex disease we are only beginning to understand. It helps me to visualize the causes as a kind of pie chart where a certain percentage or wedge could be due to genetics, another percentage to lifestyle, another to diet, another to environmental influences, another to past medical treatments, yet another to social factors such as strength of social connections. We don't know what the percentages might be for each factor; we don't even know what all the factors might be, and the chart will look different for each individual and for each type of cancer.

multiple  
causes

Research has shown us that one of these wedges—we don't know how large—is due to personality factors; ways of responding to stress is the favorite example. I have certainly found it helpful to be aware of this dimension, since it is one place my actions and my conscious choices can affect my health. What is not helpful, and is in fact actually harmful, is when I oversimplify a complex situation and believe the personality slice is the whole pie, ignoring the role other factors play in causation and in healing.

One way to steer away from the stagnancy of blame and move toward helpful action is to recognize that a chart for the *causes* of cancer will also look different from one depicting the factors that influence *healing*. The way we live our lives and the conscious efforts we make can play a large role in healing. With awareness, I can stop unconscious actions or thoughts that weaken me and learn to focus on actions and attitudes that help

me stay healthy. Sometimes this kind of effort is enough to shift the outcome, sometimes it is not. For example, in a hypothetical case I might guess that 5 or 10% of the reason someone became susceptible to a certain type of cancer was due to the way they handled stress. But up to 40% of their healing might be reasonably attributable to changes they make in the way they handle stress and in their attitude to life. In some cases that 40% might be enough to tip the balance toward physical healing. In other cases the same 40% might not be enough because the scales are already tipped too far by other factors that strongly influence the outcome such as the initial cause of cancer, the type of cancer, or the time of diagnosis.

During the late seventies I lived for three years at Findhorn, a spiritual community in northern Scotland. People there are particularly aware of the influence their attitudes and actions and beliefs have on their experience of life. The "create-your-own-reality" idea has been quite popular. I have three friends, all people who lived at Findhorn for many years, who have themselves experienced either a catastrophic illness or major bereavement during the last four years. The four of us were very close at Findhorn and have been drawn together even more by our recent experiences. We all agree that the question, "Why did this happen to you, why did you create this in your life, what did you do to bring this on?," is in most cases clearly not helpful. One of us said that when a healer asked her that question she wanted to throw the table at him. Each of us strongly agreed; we have all had the same experience at one time or another. Each of us has found that this question caused a great deal of pain and conflict and gnashing of mental teeth which only got in the way of truly feeling our fear and our grief and our pain, only got in the way of our coming to the point where we could begin to work constructively with the challenge before us.

*effect  
of  
the  
"create-  
your-  
Own-  
reality"  
idea*

If someone asks me a question like, "Why did you choose to give yourself cancer?," it often feels like they're coming from a righteous place, a place of separation where they are well and I am sick. This question does not invite constructive introspection. It used to make me feel defensive or apologetic about what I had done, whether I was acting consciously or unconsciously. I don't bring this question up with people who have cancer unless they do, unless it is something they worry about. I find that, more often than not, it is better to help people move on from "why" to look instead at the "what" and "how" of their disease. "Why" questions usually lead to feelings of guilt and self blame, to regrets about the past and wishes it could be changed, to fierce resolutions about the future that may be difficult to keep and only lead to guilt when broken. When I

look at what is happening now, how I feel about it, and what I want to do about it, and when I help others do the same, we move away from blame and judgment into the present, where we can consciously choose how we want to live our lives.

*"How  
are you  
choosing  
to use  
this  
cancer?"*

People sensitive to the complexity of the situation might ask a more helpful question, something like, "How are you choosing to use this cancer?" For me this question is exciting; it helps me look at what I can do now, helps me feel empowered and supported and challenged in a positive way. Someone who asks this kind of question conveys that they see my illness not as punishment for something I did wrong but as a difficult and challenging situation also potentially full of opportunities for growth, which naturally helps me approach it in the same way.

In our Judeo-Christian culture, with its pervasive emphasis on sin and guilt, illness is too easily seen as punishment for wrongdoing. I prefer a more Buddhist approach where everything that happens is taken as an opportunity for bodhisattvic activity, for serving others. I can look at "bad" things that happen to me not as punishment for past actions but as my chance to now work through the karma of the past, to cleanse the slate, to be done with it. This approach helps me focus on working with the situation in the present.

I find this very helpful. From a new age perspective I might be tempted to ask someone who's ill, "What did you do wrong?" But from a Buddhist perspective, I'm more likely to approach someone with a life-threatening illness, even someone working with it in a way I think I would not choose, and say something that conveys the thought: "Congratulations, you obviously have the courage to take this one on, the willingness to work this through. I admire you for that."

*to be  
emotionally  
accessible*

When I talk to someone who's been newly diagnosed with cancer or who had had a recurrence or who is growing tired after years of dealing with cancer, I remind myself that I don't have to give concrete ideas or advice to be of help. Listening is helping. Listening is giving. I try to be emotionally accessible to them, to reach through my own fears and touch them, to maintain human contact. I find there are many fearful things we can laugh at together once we've allowed ourselves to be truly afraid. I try to steer clear of the temptation to define imperatives for others, even imperatives such as fight for your life, change yourself, or die consciously. I try not to push people to move in directions I have chosen or think I might choose for myself. I try to stay in touch with my own fear that I might one day find myself in the same situation they are in. I must constantly relearn how to make friends with illness, to not see it

as failure. I try to use my own setbacks and weaknesses and illnesses to develop compassion for others and for myself, while remembering to not take serious things too seriously. I try to stay aware of the opportunities for psychological and spiritual healing all around me in the very real pain and suffering that ask for our compassion.