

## ON BEING A SUPPORT PERSON

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For almost five years now my wife Treya has been battling cancer and for five years I have been serving—sometimes well, sometimes not—as primary support person for her. She has chronicled her battle in a series of letters, and in an article in this *Journal* (Wilber, 1988).

For the most part, I have been somewhat reluctant to discuss the trials and tribulations of being a support person, which is one of my roles in this battle with cancer. There are several reasons for this. For one, my situation is not life-threatening, and so there isn't much urgency to communicate immediately. For another, I, like most men, tend to be quieter, or perhaps shier, about my emotions. For another reason, support people in general are the "silent ones," those who offer help but do not ask for it, perhaps because that would require yet another support person, and so on. Because the process involved in being a support person can be both painful and profoundly redeeming, I thought it might be helpful to others to share my perspective on this difficult and challenging human experience.

*those  
who  
offer help  
but  
do not  
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There are really two quite different types of support situations—short and long term. Neither is particularly fun, but in most ways a short-term support situation is much easier. It lasts from, say, a week or so to a month or so, or a few months at most. Such a support person faces many difficult and emotionally trying situations, but also may receive (depending on their attitude) a good deal of inner satisfaction and outer gratitude. In any event, the whole ordeal, from the beginning, is defined by a limited amount of time. The patients know that they are going to get better fairly soon, and the support people know it. Everybody, then, can more easily bracket off this

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period of illness; it will soon be over; things will be normal and one can go back to life as usual.

Not so with long-term, chronic, and possibly life-threatening illness. The patient knows that he or she might never get better, and the support person is thrown willy-nilly into a world for which the only exit may be, gruesomely enough, the death of the partner. But there is another exit, which is what I mostly want to talk about, and that involves a profound and far-reaching change in attitude on the part of the support person. The only way I can talk about this "metanoia" or change of heart and mind, is to describe what it was like for me to go through it.

*virtually  
everybody  
will need  
or be  
a support  
person*

As a preliminary, I want to describe, in the abstract, some of the difficulties of being a long-term or chronic support person, because I have noticed that these problems are not understood very well. Equally important is the inevitability that at some point virtually everybody will either need a support person or be one, and one might want to think about what that means before it happens, and possibly pick up a few pointers.

There are, of course, the obvious difficulties: the disruption of work; the demands on one's time; the necessity to, in varying degrees, wait on the patient; the enormous financial drain. (I don't like the term "patient" in this context, so I'll use "loved one." Doctors wait on patients; support people care for loved ones.) In one respect Treya and I were lucky, in that we didn't have to worry too much about finances. Not a day goes by that we don't thank our family and friends. I honestly don't know how we could have made it this far without them (and not only financially, as will be seen).

Aside from finances, however, we were spared none of the other difficulties of this cruel disease. As far as support people go, a particularly insidious problem begins to set in after about two or three months of care giving. It is, after all, comparatively easy to deal with the outer, physical and obvious aspects of care giving. You rearrange your work schedule; you get used to cooking, washing, housecleaning or whatever it is that you as support person have to do to physically take care of the loved one; you take them to the doctor's office; you help with medications, etc. This can be fairly difficult, but the solutions are also fairly obvious—you either do the extra work or arrange for someone else to do it.

What is more difficult for the support person, however, and more insidious, is the inner turmoil that starts to accumulate on the emotional and psychological levels. This turmoil has two

sides, one private and one public. On the private side, you start to realize that, no matter how many problems you personally might have, they all pale in comparison to the loved one who has cancer or some other life-threatening disease. So for weeks and months you simply stop talking about your problems. You sit on them. You don't want to upset the loved one; you don't want to make it worse for them; and besides, in your own mind you keep saying "Well, at least I don't have cancer; my own problems can't be so bad."

After a few months or so of this (I'm sure it varies from person to person), it slowly starts to dawn on the support person: the fact that your problems pale in comparison to, say, cancer, doesn't make other problems go away. In fact, they get worse, because now they are *two* problems: the original problem plus the fact that you can't voice the original problem and thus find a solution for it. The problems magnify; you clamp the lid down harder; they push back with renewed strength. You start getting slightly weird. If you're introverted, you start getting little twitches; shortness of breath; anxieties start creeping up; you laugh too loud; you have an extra drink. If you're extroverted, you start exploding at completely inappropriate moments; you throw temper tantrums; you storm out of the room; you throw things; you have an extra drink. If you're introverted, there are times you want to die; if extroverted, times you want the loved one to die. If you're introverted, there are times you want to kill yourself; if extroverted, times you want to kill *them*. In any event, death hangs in the air; and anger, resentment, and bitterness inexorably creep up, along with terrible guilt about having any of those dark feelings.

Those feelings, of course, are completely natural and normal given the circumstances. In fact, I would be concerned about a support person who didn't occasionally have such feelings. The best way to handle these feelings is to talk about them, and I can't emphasize this too strongly—the only solution is to talk.

*natural  
and  
normal  
feelings*

And here the support person runs into the second of the emotional-psychological difficulties that I mentioned: the public aspect. Once you decide you have to talk, the problem is: to whom? The loved one is probably not the best person to discuss some of your problems with, simply because they often *are* your problem—they are putting a heavy load on you, but nevertheless you don't want them to feel guilty about this, you don't want to burden them, no matter how angry you might be with them "for getting sick."

By far the best place to talk about all this is in a support group of people who are going through similar circumstances, i.e., a

*"nobody  
is  
interested  
in chronic"*

support group for support persons. Also, individual therapy might prove very valuable, as might couples therapy. But I'll talk about these "professional supports" in a moment. The average person, myself included, doesn't want to take advantage of these services until rather late in the game, and by that time much damage may have been done and much needless hurt suffered. Typically, the average person does the normal and understandable thing: he or she talks to family, to friends, and/or associates. And here the person runs smack into the public problem.

The public problem is this: as Vicky Wells (cofounder of Cancer Support Community of San Francisco) puts it, "Nobody is interested in chronic." The following example shows what this statement means: I may come to you with a problem; I want to talk, I want some advice, I want some consolation. We talk, you are very helpful, kind and understanding. I feel better; you feel useful. But the next day, my loved one still has cancer; the situation is not fundamentally better at all. In fact, it might be worse. I don't feel good at all. Later, I happen to meet you again, and you ask how I'm doing. If I tell the truth, I say I feel awful. So we talk. You are again very helpful, kind and understanding, and I feel better . . . until the next day, when she still has cancer and nothing is really better. Day in and day out, nothing really can be done about the situation itself (the doctors are doing everything possible, and she still might die).

So, day in and day out, if you are a support person you feel rotten; the situation just doesn't change. Sooner or later you find out that almost everybody not actually faced with this problem on a day-to-day basis starts to find it boring or annoying if you keep talking about it. All but your most committed friends start subtly avoiding you, because cancer *always* hangs over the horizon as a dark cloud, ready to rain on any parade. You may be perceived as a kind of chronic whine, and people get tired of hearing the same old problem. Hence the observation, "Nobody is interested in chronic."

This situation reflects what seems to me to be a fundamental feature of human nature: *people want to be helpful*, to be useful. When you and I talk, you want to feel that the talk has helped me, that you have been useful to some degree. But when the fundamental situation doesn't change, you start to feel helpless and useless, which is exactly what "chronic" makes one feel. The situation just goes on and on, day in and day out. Some people might be interested in it the first five or ten times it is brought up, but try bringing it up fifty or sixty times a year for several years. People get very tired of it all, myself included.

This is completely understandable, a reflection of the helplessness that virtually *everybody* involved in a chronic cancer situation tends to feel.

But, as I was saying, this situation can have a doubly jolting effect on the support person. The only way out of the private aspect of the problem is to go public and talk about it, even though "nobody's interested in chronic." At this point, unless the support person seeks professional help, things can get extremely difficult. It is not unusual for the support person to simply walk out of the situation. Treya and I have talked to women with cancer whose husbands lasted about six months, then walked, leaving them with the cancer, children, and no means of support.

So, support people eventually begin to find that their private problems are multiplying, and the public solution just doesn't work very well. They may begin to feel completely alone and isolated. At this point, one of several things tends to happen. They walk out; they break down; they get into substance abuse; or they seek professional help. A few "muddle through," although I have met only one chronic support person who managed to muddle through and still be a fairly decent support person—a late middle-aged man from New York City, a caregiver for his wife who had been constantly battling cancer for several years. Treya and I met him at the Janker Klinik in Germany, where his wife was being treated. He had put his life on the backburner for several years in order to care for his wife, and he seemed to have done a very good job of it. Each night he went out to various restaurants, called his wife at the hospital, read her the menu, ordered what she wanted and then brought it back to her. He had been doing things like this for years. But he had had nobody he could really talk to about his own difficulties, and he wanted terribly to talk to anybody about his troubles. He looked pathetically desperate; he talked in a constant whine; his eyes pleaded with you to listen to him. So intense was his need to talk about his travails that he would simply crash in on any conversation someone was having and start unloading. He would talk while we were walking; talk while we were eating; talk while he was eating. We listened to his woes on three or four occasions, up to an hour each time. But the fatigue set in eventually, so we spent the next two weeks doing anything to avoid this man. See what I mean? "Nobody is interested in chronic." In any case, I don't recommend "muddling through."

*"muddling  
through"  
not  
recommended*

As I said, by and far the best place to talk out your difficulties is in a support group for caregivers. When you listen to these groups, you find out that the main activity is basically bitching

receiving  
and  
giving  
love

about the loved ones. For example, "Who does he think he is to order me around like that?" "What makes her think she's so special, just because she's sick. I've got problems of my own, you know." "I feel like I've totally lost control of my life." "I hope the bastard hurries up and dies." Those are the kind of things nice people don't say in public, and certainly don't tell the loved one.

Yet, under all these dark feelings, under the anger and resentment is almost always a great deal of love, or else the support person would simply have walked out long ago. But this love can't really surface freely as long as anger, resentment and bitterness clog the route. As Gibran said "Hate is love starved." There is a lot of hatred expressed in support groups, but only because there is so much love under it, starved love. If not, you wouldn't hate the person, you just wouldn't care at all. My experience with most support people (myself included) is not that they aren't *receiving* enough love, but that they are finding it hard to remember how to *give* love, how to be loving under the difficult circumstances of being a caregiver. And since, in my experience, it is primarily giving love that is healing, support people really need to clear out the obstacles to love's presence—the anger, resentment, hatred, bitterness, even envy (I envy her having someone to take care of her all the time; namely me).

For this a support group is invaluable. Unfortunately, they are not common. The Cancer Support Community in San Francisco offers such an ongoing support group for caregivers, and if you need such a group they may be able to help locate support groups in other areas.

In addition to that, I recommend individual psychotherapy for the support person, and the loved one as well. You soon learn that there are some things that simply should not be discussed with the loved one. Conversely, there are some things the loved one ought not discuss with you. I think most of my generation believes that "honesty is the best policy" and that spouses should discuss every single thing that bothers them with the other spouse. In the situation I am describing it may not be the best plan. Openness is important and helpful, but only so far. At some point, openness can become a weapon, a spiteful way to hurt someone—with an apparently justifiable rationalization, e.g., "But I was only telling the truth." I have had much anger and resentment at the situation that Treya's cancer created for us, but beyond a certain point, it does no good for me to continue to dump my anger and resentment on Treya. She hates the situation as much as I; in any event it's not her fault. But still I am angry, hateful and resentful. So, sometimes

sharing all one's feelings with your loved one isn't best. Instead you can pay a therapist and dump it all over *them*.

This has the added advantage of giving partners room to be together without expressed resentment and anger on the caregiver's part and without guilt and shame on the loved one's part. You've already offloaded much of that in the support group or with the therapist. It also allows you to learn the gentle art of telling compassionate lies, instead of narcissistically blurting out what you "really feel" no matter how much it might hurt the other person. Not big lies, just little diplomatic ones that don't gloss over any really important difficulties, but at the same time don't stir up a hornet's nest of unresolved issues just for the sake of so-called honesty. On some days you might be feeling particularly tired of being a caregiver when your loved one asks, "How are you doing today?" You may feel like answering, "I feel like hell and my life isn't mine anymore and why don't you jump off a bridge." This is a "truthful" but damaging answer. Try instead, "I'm tired today, honey, but I'm hanging in there." Later, you can unload your deep frustrations onto the group or therapist. Let them have it.

One of the strangest things I have learned about being an adequate support person is that the primary job is being an emotional sponge. Most people might think that what is best is to give advice, to help the loved one solve problems, to be useful, to give help, to make dinner and drive them around, etc. But all of those tasks are secondary to the primary role of the caregiver, which means being an emotional sponge. The loved one facing a possibly lethal disease is going to experience an overwhelming number of extremely powerful emotions; on occasion they are going to be completely overwhelmed by those emotions, by fear, terror, anger, hysteria and pain. Your job is to hold the loved one, be with her/him, and simply absorb as many of those emotions as you can. You don't have to talk (there's not much to say that will help), or give advice (which won't help much anyway), or do any particular thing. You just have to be there, and breathe in their pain, fear or hurt—like a sponge.

*being  
an  
emotional  
sponge*

When Treya was first ill, I thought I could "make things better" by being in charge, by saying the right things, by helping choose medical treatments, and so on. Those actions were all helpful, yet beside the point. She would get some particularly bad news—say a new metastases—and she would begin crying, and I would immediately start in with things like, "Look, it's not certain yet; we need more tests; there's no evidence that this will change your treatments anyway," and so on. That was not what Treya needed. What she needed was simply for me to cry with

her, and so I did; to feel her feelings; and thus to help dissipate them, or soak them up. I believe this occurs on a bodily level; talk is not needed, though you can talk if you want to. It actually feels as if I have taken some of Treya's negativities into my own body, and helped to dissipate them there, though I think this may have worn down some of my strengths too.

Be that as it may, one's initial response, when a loved one is faced with terrible news, is to try to make that person feel better. This, I believe, may be the wrong response. Instead I recommend, first of all, empathizing. You just hold your partner and breathe in. You soak it up. There is much fear, anger and even terror in the loved one (not to mention in yourself), and no amount of "it'll be okay" talk does any good at all. In fact, it's just the opposite; the situation might *not* be okay, and your partner knows it. To say otherwise just shows that you are trying to make the situation go away, that you don't want to absorb this fear and anger, or relate to it in a simple and direct way.

Once when friends were visiting us in Bonn, and Treya got a particularly bad piece of news (this happened on a weekly basis and most were false alarms, but at the time we couldn't have known that), their response was usually the natural one: they would immediately try to cheer her up, or make her feel better, or point out that there was still much hope. I would pull them aside and say, "Save that for tomorrow, okay? Right now, if you're feeling sad about this new development, just be sad, okay? Today, just empathize; tomorrow we try to cheer her up."

*being  
present  
and  
not  
fearing  
fear,  
pain  
or anger*

The crucial point, as I began to see it, is simply to be present to the person, and not be afraid of their fear, pain, or anger. Just let whatever comes up come up. Most of all, don't try to get rid of these painful feelings by trying to make the person "feel better" or by "talking them out of" their worries. In my case, this "helping" attitude only happened when I didn't want to deal with Treya's feelings or with mine. Actually, I didn't want to relate to them in a simple, direct and uncomplicated way; I wanted them to go away. I did not want to be a sponge. I wanted to be an achiever, and make the situation better. I did not want to acknowledge my helplessness in the face of the unknown. I was as afraid as Treya.

Just being a sponge, after all, tends to make you feel helpless and useless, because it seems inactive just being there, doing nothing. This is exactly what so many people find difficult to learn. It took me almost a year to stop trying to "fix things" or



make them better, and just be with Treya when it hurt. I think this is another reason why "nobody is interested in chronic," because you can't do anything about chronic; you can only be there.

So I learned how to be there. Oddly, I found the same type of thing happened to me that had happened to Treya vis a vis "the sponge." Friends would often ask me, "What can I do to help? What do you need?" I never knew quite what to answer. The reason, I see now, is not as I had thought, that I have difficulty expressing my needs; rather the greatest help is not doing, but a simple being, a receptivity in which friends and family act like a sponge, absorbing for you the fear, anger and pain that you have absorbed from your loved one. Sometimes this can be very simple. One friend said to me, very simply, "Thanks for hanging in there;" at another time she and two other friends sent me a book with a card that said only, "To the world's greatest support person." Very simple, but enormously appreciated.

Of course, actually *doing* things—helping with chores, duties and tasks—can be a tremendous help both to the person with cancer and the support person. In the course of doing such chores a friend or relative can also serve in the important capacity of being a sponge.

There is one other important distinction that ought to be kept in mind for support people—namely, whether the support person is a man or a woman. In this society women are expected to be support people without complaining at all, and men are usually excused from being a support person because that's "women's work." To be a "male support person" in this society is about as highly valued socially as being a male nurse. Thus, men and women tend to run into somewhat different difficulties based on sex roles. Basically, what a support person has to learn to do is become very like the traditional and stereotypical housewife. When people ask me what I do, and I'm in no mood to chit-chat, I usually say, "I'm a Japanese wife," which totally confuses them. The point is that, as a support person, you are supposed to be understanding and simply do as your spouse wills.

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and  
the  
support  
person*

Men find this particularly tough; at least I did. It took me perhaps two years before I stopped resenting the fact that in any argument we had or decision we made, Treya had the trump card: "But I have cancer." Treya, in other words, would almost always get her way, and I was reduced to simply going along like the good little wife.

*making  
decisions  
and  
providing  
support*

I don't mind this so much any more, for two reasons. One, I don't just automatically "go along" with all Treya's decisions, particularly when I think they reflect questionable judgment. Previously, I would tend to go along with her because she seemed almost desperately to need me to support her decisions, even if it meant lying about how I really felt ("Do you want my opinion or do you want me to lie to you?" "Lie to me.").

The way we work this out now is that if Treya is making an important decision on, for example, whether to try a new treatment, I give her my opinion as strongly as I can state it, even if I disagree with her, right up to the point that she finally decides what to do. From that point on, I agree with her, get behind her, and support her in her choice as best I can. It's no longer my job to heckle her, or cast doubts on her choice. She has enough problems without having to constantly doubt her own course of action. If I don't think the treatment is going to work, I henceforth keep that to myself. She may ask, "Do you think I'm doing the right thing?" I can respond, "Kid, it can't hurt, and it just might help, so hang in there." This is no time for brute honesty. Besides, my opinion could definitely be wrong. On the other hand, on the rare occasions that she has considered doing something I think patently harmful, my foot goes down. In one instance, I thought Treya might be taken in by a fraud, and I suggested she could go alone. Learning to say no to a cancer patient is an interesting experience.

When it comes to day-to-day chores, I no longer particularly mind being the good little wife. I do the cooking, clean up, do dishes, laundry, and go to the supermarket. Treya writes really nifty letters, takes coffee enemas, and swallows handfuls of pills every two hours, so somebody's got to do all the chores, right?

My point is that men have a peculiarly tough time of it when they have to take the role of the chronic support person, the good wife. At the same time, I can imagine that today's modern woman, just gaining access to the employment market, just escaping being a good little wife, is also doubly burdened—she's asked to go back to being "a wifey," a 24-hour-a-day on-call support person. Not being a woman, I can't really speak for the traditional housewife who is asked to also become a support person, in effect becoming a "double wife." This is most likely not a particularly thrilling job in any event, whether it falls to a man or a woman.

I said that this task can have its profoundly redeeming moments, and it can. Unfortunately, my experience is that the greater the redemption, the greater the pain that preceeds it. Much grace seems to come only with much suffering.

During the first year and a half of fighting cancer both Treya and I handled the situation in an exemplary fashion. Treya had her first operation, then radiation; then a recurrence, more surgery, and then the decision to do chemotherapy. Those were extremely difficult times, but on balance we both deserved A+'s for the way we handled it. During that period, we also had to face a major move from San Francisco to Tahoe, Nevada and the added stress of building a house. How did we do it? We kept cheerful in the midst of these troubles, and we were pretty much admired for how we handled it all.

What Treya and I didn't know at the time was that, by the time she began chemotherapy, our energy levels were "on empty." The Zen Buddhists have a term "joriki," which roughly means "the power you get from meditation." The more you meditate, the more joriki your bodymind accumulates, until it explodes in a moment of insight called satori, or enlightenment. You can also get joriki from such introspective concerns as psychotherapy or contemplative prayer, and from yoga, tai chi, aiki, and so on; it's a type of personal power. Treya and I had both meditated quite a bit, and I believe it was our accumulated joriki, among other things, that got us through the first very difficult year and a half.

*meditation  
and  
energy  
levels*

But during that period we weren't doing anything to replenish our inner reservoirs, and this was a big mistake. Neither one of us was seriously meditating. Moreover, when we first found out about Treya's illness, Treya should have immediately begun some type of therapy or supportive counselling; so should I. Instead, we were so concerned with the cancer that we let everything else slide. So a lot of tensions and problems were building up, and they eventually came rather forcefully to the surface.

For Treya, the straw that broke the camel's back was doing chemotherapy. To her, it was "poisoning her soul." She felt that during that period, she just buckled. At the same time, almost the same month, I contracted a particularly mean form of Epstein-Barr syndrome—there was an epidemic of it in north Lake Tahoe the year we moved there. One of its main symptoms is debilitating exhaustion. The problem is, I had this disease and didn't know it. I couldn't understand why I couldn't move. I'd get up, brush my teeth, and consider it a day's work. It was a year before I was correctly diagnosed.

This was probably the darkest time for both of us. In my case, all the resentments, bitterness and anger I had toward Treya and what "her" illness was doing to us came to the surface. I really needed some support myself, a little care and compas-

sion, but she was understandably too concerned with her own pressing problems to hear me adequately. I felt that I had been supporting her for a year and a half, and yet the first time I need some support myself, it was as if she faded out, or so it seemed to my own self-preoccupied mind. I was very resentful and bitter.

What saved us was a dog named Ton and a therapist friend. I started seeing the therapist professionally—we had been friends for years—mostly because I couldn't stand the pain anymore. I felt I had totally lost control of my life; that Treya and her cancer were going to end up killing me, if not her, too. The therapist was perfect, and so good that Treya began seeing him. Then we both saw him in couples therapy as well, and it seemed that all we were doing was talking to him. As for Ton, he was just a big, elegant, huggable sponge, and his presence did wonders.

getting  
support  
resources  
as soon  
as  
possible

Anyway, the thing that struck me most about the work we did with the therapist, individually and collectively, is that we should have started it on day one, right at the beginning. The point I am emphasizing here is that in a chronic situation one should get support resources as soon as possible. The chronic situation doesn't go away—it gets worse and worse. You might think you can handle it, right up to the point where you go totally bonkers. Instead I would recommend you get yourself to a resource support, and get your loved one some outside resource as well—a support group, a therapist, a counsellor, a minister, whatever works. It should be some sort of *outside* and *ongoing* relationship.

Most of the first six months of therapy, for both of us, was spent digesting and re-experiencing all the hurts and resentments that we had built up over the past year and a half of fighting cancer, virtually none of which would have built up had we recourse to outside support of some kind, from the beginning. But we thought we could do it all ourselves—right?

After clearing up past resentments in our relationship, we went on to deal with our present. Then, individually, we explored our early childhood development and its effects.

The most difficult emotional problems I had to deal with as a support person were resentment and self-pity. For about a full year I had a great deal of hatred and bitterness about the situation I was in. I had greatly curtailed or given up editorships at four different publishing concerns, concerns that I was very proud to be associated with. Worse yet, I had given up writing, which I considered my life blood. You simply can't

be a full-time support person and carry on a full-time career at the same time. I can't, anyway. Ever since I was 23 years old, I had spent virtually every day of the week, fifty weeks a year, writing. Now, it would end up being almost three years before I would write again, during which time there were many days that I didn't particularly care if I lived or not. If I couldn't write, I saw no particular reason to carry on. Camus said the only really important philosophical question was whether or not to kill yourself. To be or not to be, that is the question. While contemplating this, I drank a lot of beer.

These difficulties were compounded by the fact that I had Epstein-Barr syndrome and didn't know it. Epstein-Barr is like having a bad case of flu, 24 hours a day, forever—constant fever, chills, aches, and exhaustion. There's a saying: with cancer you really want to live; with Epstein-Barr you really want to die.

Odd as it seems, it wasn't as much having this disease that bothered me as it was not knowing I had it. I was interpreting all the symptoms as if I were neurotically or psychotically depressed, and so did everybody else—friends and doctors alike. But the moment I was correctly diagnosed, most of the depression I had been suffering vanished. I was still exhausted, still tired, but I was no longer interpreting it as some sort of major neurosis. I was still very sad about the situation, but I wasn't morbidly psychologizing myself. I still have this stupid disease, and there's not much advice I can give on how to handle it. I find it best to just ignore it. Anyway, people don't particularly want to hear about it more than once or twice—after all, nobody's interested in chronic.

At that time I still had to work through my resentment, bitterness and self-pity. The therapist was a great help on that problem, but mostly he helped in regard to "blowing off steam." I'd sit on that couch for hours just bitching about Treya. Finally, large chunks of resentment began to break off and dissolve. Actually dealing with all of the resentment and anger would take another year, and I had to do it more or less alone, in what amounted to the solitary confinement of Germany, where I started to crack open my really deep wounds and let them begin to heal.

*working  
through  
resentment,  
bitterness  
and  
self-pity*

In the meantime, Treya and I began to get along again as beautifully as we had in the beginning. Therapy had helped us see how we can drive each other nuts, and how we can each halt that process; how it is better to just shut up if you can't say anything decent; and how a little forgiveness and compassion can go a very long way. These weren't new lessons for either of

us. It's just that in the heat of dealing with cancer, all sorts of tensions become magnified and amplified all out of proportion, and you have to start with basics—you have to go back and take Emotions 101 all over again. I think that Treya and I now have enough tools that, even though we haven't been in therapy for almost two years, we can carry on ourselves. But again, this is something we should have done at the very start, not just when it was almost too late. Nor are either of us against doing more therapy now, either individually or together. We're just keeping an eye out for the right person.

Three years after Treya was first diagnosed with cancer, we had one year almost free—one year where Treya passed her annual physical without any apparent signs of cancer. We both started to think she might actually beat this disease. Ironically, at that time she almost certainly had brain and lung tumors growing, but nobody caught them; they were discovered some months later. But during that year, and particularly those last few months, we were flying high. For the first time in three years, I sat down and wrote a book. A big book, 800 pages. A few months later, we found the spots on Treya's lungs and brain, and, after a month or so of more agonizing decisions, we were off to Germany for more treatment.

*the  
unfairness  
of  
cancer  
itself*

I think both Treya and I took this last recurrence with much more equanimity than we took any of the others, although objectively or medically this last one is much more serious. It was like asking, what else is new? Treya was more angry than frightened; I was angry but detached. But it drove home the unfairness of cancer itself. Treya had done everything right, and I mean everything. To give a small list: she did every major orthodox treatment available, including surgery, chemotherapy, and radiation; she did most alternative treatments, including Pritikin diet, visualization, mega-vitamin therapy, modified macrobiotics; she took her bodhisattva vows with Kalu Rinpoche, did tonglen (compassion) meditation, took salt that the Karmapa's body was buried in, took Karmapa pills, practiced vipassana; did acupuncture, went to a psychic healer and a Philippino surgeon; went to Christian mass and said her prayers. After three years of doing that regularly, we are looking at a CAT scan, and there is a new growth the size of a golf ball in her brain; another about the same size in her left lung; another half-dozen or so smaller ones scattered throughout her lungs; a month or so later, another growth appears on her abdomen. What's fair about all that? Fairness is a false god before whom you can torture yourself; what is, is—fair or not. I think Treya and I were slowly developing, the very hard way, a measure of equanimity and acceptance, an almost meditative

approach to the whole ordeal, a type of choiceless awareness that before we had cultivated only in the luxury of sitting meditation but now had to be learned in the midst of hospital wards, chemotherapy, and countless other tortures of civilized man's medicine. We both have a long way to go, but at the same time we have both come so very far.

As we were preparing to leave for Germany, I should have realized that I still had some "seeds to cook." The book I had just finished is a terrific book. But in places its tone would become very sarcastic and even mean-spirited. While I was writing it, I was rather enjoying slinging around some of this venom.

The tone of the book told me a lot about some of my own unfinished business. I was so enjoying slugging it out that I didn't realize that much of the sarcasm and biting humor was largely a residue of the bitterness I had felt toward this whole cancer situation. I still had not fundamentally made peace with my fate and with Treya's. So I guess I still had to fry a little bit more, get burnt a little bit more. Germany obliged.

*making  
peace  
with  
fate*

We landed in Germany full of hope and promise. The Janker Klinik had a significant rate of full remission for at least one month on the cases they treated, all the more remarkable considering that many people come to the Klinik when they have but weeks to live.

We had similar hopes for Treya, but from the beginning, things went rather poorly. First of all, Treya still had a cold, which prevented her from getting chemotherapy at the same time she received radiation and hyperthermia. The point was to combine all three therapies at once, thereby delivering a knock-out punch to the tumors. Treya couldn't do this, thus compromising from the start the effectiveness of her treatment. We had no real right to expect complete remission from that point on, but we were sort of denying this.

Second, this threw us both back into our own private worries and fears. Treya discussed hers in her letters. For me, it was the final realization that "this would go on forever." That is, I came to finally accept and acknowledge that as long as Treya is alive, we would be doing this, doing some sort of therapy, in some sort of hospital, with some sort of doctor, forever. This was almost unbearable. It was a combination of great sadness for Treya and much self-pity for myself. It was obvious that I really hadn't yet come to terms with this situation; I really hadn't accepted it in a simple, direct and profound way. I wanted out. I

wanted Treya to stop kidding around, tell me it was all a joke, and then we could go home. But this was no joke. I got drunk, and thought about it all.

The next day I had an even worse realization: "this is the easy part." In other words, as bad as the situation seemed, Treya still didn't have any really bad symptoms, no pain, no coughing, and so on. But sooner or later, unless a bit of a miracle came along, she would likely develop symptoms, and then it might be very difficult. It felt like I was being swallowed by these feelings, feelings of more sadness for Treya and more pity for myself. It seemed like we were forced to walk down a long tunnel, but there wasn't a light at the end of this tunnel, only a dirty brick wall. This was overwhelming for me and I got very drunk.

That was the first time I had ever been so intoxicated, and it is also the last. It was very painful but it was the beginning of a type of clearing out of all the leftover bitterness, resentment and anger. This process started in a little hotel room in Bonn, Germany, waiting for my wife to get over a cold, and has continued up to the present. It had nothing to do with getting drunk; it had everything to do with ceasing to blame cancer, Treya, or circumstances for my own fate.

*karma,  
chance  
and  
free will*

I personally do not believe that *everything* that happens to us is our own doing or our own karma. There is individual karma, it is true, but there is also collective karma, family karma, social karma, and instinctual karma. Further, there is chance, and there is free will—all of these are outside our own doing or our own karma. In other words, the notion that everything that happens to us is our own doing is silly, or at best, a very partial truth.

It seems to me the existentialists are right, however, in that within the realm of our own choices or our own doing (our own karma) we have to affirm the choices we have made. That is, we have to stand behind the choices we have made that contributed to molding our own fate; as the existentialists say, "We are our choices." Failing to affirm our own choices is called "bad faith" and is said to lead to "inauthentic being."

For me this came in the form of a very simple realization: at any time in this difficult process, I could have walked out. Nobody was chaining me to the hospital wards, no one threatened my life if I left, nobody had tied me down. Some place deep inside I had made a fundamental choice to stay with this woman through thick and thin, no matter what, forever; to see her through this process come what may. But somewhere during the second year of the ordeal, I forgot about this choice, even



though it was a choice I was still making, obviously, or I would have left. I was displaying bad faith; I was being inauthentic; I wasn't real. In my bad faith I had forgotten about my own choice, and therefore almost immediately fell into an attitude of blame, and consequently self-pity. Somehow, this all became very clear to me.

This, then, was the "metanoia" I mentioned earlier, a change of heart and mind. It is not always easy for me to affirm this choice, or my choices in general. It doesn't automatically make the situation any better. I think of it like volunteering to go into combat and then getting wounded. I might have freely chosen to go into combat, but I did not choose to get shot. I feel a little bit wounded, and I'm not happy about that; but I freely volunteered for the assignment—it was my choice—and I would freely volunteer again, knowing full well what it entails.

So each day I re-affirm my choice. Each day I choose once again. This stops blame from piling up, and slows the accumulation of pity or guilt. It's a simple point, but actually applying even the simplest points in real life is usually difficult.

*"I  
re-affirm  
my  
choice"*

In addition to slowly getting back into writing, I have also returned to meditation, particularly under the guidance of the Venerable Kalu Rinpoche. Kalu is an altogether amazing fellow. The Karmapa called him "a modern day Milarepa" (Milarepa was Tibet's greatest yogi). As a young man, he spent 13 years alone in a cave meditating, and would have probably stayed there to this day had not the Karmapa requested that he start teaching. Kalu is 84 years old now, and still going strong.

The whole point of meditation is really just to learn how to die (to die to the separate-self sense, or ego), and Treya's situation of facing a potentially lethal disease is an extraordinary spur to meditative awareness. She may die soon, she may not—the point is, you don't know which, and so death hovers over virtually every moment. But in a sense this is exactly the spur to maintain a meditative equanimity. Treya has written about how death "marvelously concentrates the mind," and it's quite true—*after* you somehow deal with the horror and terror of it all.

Kubler-Ross writes of the five stages people go through when confronted with death: denial, anger, bargaining, depression, and acceptance-peace-release. The first years for both of us were taken up with denial, anger, bargaining, and depression (bargaining, incidentally, is what happens when you finally realize you are facing death but you haven't totally accepted it; instead you bargain—you say things like, "I'll get on a

macrobiotic diet and I promise I'll follow it to the letter," and so on; many people plea bargain with God—"Honest, I'll never do it again, just let me live").

But recently I think both of us have moved closer to the acceptance-peace-release phase, and meditation has been a great help. No wonder don Juan told Castaneda: "Keep death on your left shoulder as a guide." As Zen says, "If you die before you die, then when you die you won't die." Zen even calls satori or enlightenment "the Great Death"—the death of the separate-self sense and the rediscovery of your True Nature, timeless and deathless and eternal.

The basic meditative path to this awareness is essentially the same in all the great contemplative traditions. It is, to use Krishnamurti's particular wording of it, "Cultivating choiceless awareness of *what is*, not what was or what should be; choiceless awareness of the present moment, without judgment, condemnation, or identification." "The Perfect Man," says Chuang Tzu, "employs his mind like a mirror; it grasps nothing, it refuses nothing, it receives, but does not keep."

*maintaining  
choiceless  
awareness*

In situations such as Treya's cancer, the implications almost force one into this type of awareness, moment to moment. The sages say that if you maintain this choiceless awareness, this bare witnessing, moment to moment, then death is just a simple moment like any other, and you relate to it in a very simple and direct way. You don't recoil from death or grasp at life, since fundamentally they are both just simple experiences that pass.

The Buddhist notion of "emptiness" has also helped me a great deal. Emptiness (*shunyata*) doesn't mean blank or void, it means unobstructed or unimpeded or spontaneous; it also is roughly synonymous with impermanence or fleetingness (*anicca*). The Buddhists say that reality is empty—there is nothing permanent or absolutely enduring that you can hold on to for security or support. As the *Diamond Sutra* says, "Life is like a bubble, a dream, a reflection, a mirage." The whole point is not to try to grasp the mirage, but rather to "let go," since there's really nothing to hang on to anyway. And again, Treya's cancer is a constant reminder that death is a great letting go, but you needn't wait for actual physical death to profoundly let go of your own grasping and clinging in this moment, and this moment, and this.

And finally, to bring this all back home, the mystics maintain that the type of action that one performs in this world, *if one lives by choiceless awareness*, is an action devoid of ego or devoid of self-centeredness. If you are going to die to (or

transcend) the separate-self sense, then you have to die to self-centered and self-serving actions. In other words, you have to perform what the mystics call *selfless service*. You have to serve others, without thought of self or hope for praise; you simply love and serve—as Mother Teresa says, “Love until it hurts.”

you  
become  
a  
good  
wife

In other words, you become a good wife.

In other words, here I am, cooking dinner and washing dishes. Don't get me wrong, I'm still far from “Mother Teresa status,” but I increasingly see my support-person activity as being a major part of selfless service and therefore of my own spiritual growth, a type of meditation in action, a type of compassion. Nor does this mean that I have perfected this art; I still bitch and moan, I still get angry, I still blame circumstances; and Treya and I still half-kid (half-not) about holding hands, jumping off the bridge, and putting an end to this whole joke (fortunately, we're both cowards).

And all in all, I'd rather be writing.

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