Colon Cancer Narratives: Voices of Experience

by

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Introduction:

This is a book of portraits of people with colon cancer. I call these portraits narratives, because they are not stories in the sense of being fictional nor in the sense of having a beginning, a middle and an end. They are not exactly biographies either, in that they do not attempt to capture the scope of a person's entire life. Sharon Kaufman has referred to the sort of narrative I've presented as an "interview speech," the narrative that someone chooses to present "in the special context of, and in response to, interview questions." (Kaufman 1988: 218)¹

At their best, however, these narratives contain within them all of the elements of stories and of biographies. As with stories, sometimes parts are made up, consciously and unconsciously. They contain a beginning, a middle and an end, usually all at once, for it is a constant beginning trying to tell the story of one's life, old experiences constantly evolving in light of new ones. Because the present moment is always the temporary last moment of one's life, these narratives are also spoken from the perspective of the end of the chronology. And because we are all aware that things change in the future, that life goes on, these are really just the middle part of everyone's narrative. Finally, an illness narrative may also contain elements of biography, as a life-threatening disease often demands to be placed into the context of the arc of one's life.

Part of the inspiration for the narrative format of this book lies in a distinction frequently made between illness and disease. Disease often refers to an "alteration in biological structure or functioning," whereas illness refers to the "lived experience" of disease, "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability," an experience which is

¹ The term "interview speech" she ascribes to G. Frank in "Finding the Common Denominator: A Phenomenological Critique of Life History Method." Ethos 1979. 7:68-94.
influenced by circumstance, personality and culture, among other things (Kleinman 1988: 3-6).

In my experience, there is little public discussion of colon cancer, as there has been in recent years for breast and prostate cancer. Yet, while colon cancer is less common for each individual sex than these two cancers, it is the second most common form of cancer overall and the second most common cause of cancer death. Because it is so common and also so little discussed, there is a great need for information about the illness experience of those with colon cancer. This book is a small attempt to stimulate discourse on colon cancer by presenting seven people talking about their illness experience.

These narratives are presented in the hope that one or all of them may help others who are confronting colon cancer, through recognition of familiar elements of another person’s experience, through learning practical information about the experience of colostomy, surgery, radiation, or chemotherapy, or simply through normalizing the diversity of possible reactions to a threatening disease. As such, it is meant as an orientation and companion for those diagnosed with colon cancer and those who love them.

It is also my hope that the interest and usefulness of this book need not be limited to those with colon cancer. For, as I have suggested, the unifying bond between these individuals may be greater than the specifics of the disease itself. This project is equally about people facing a threatening disease of any kind, how they respond to this threat, and how they construct their life story to find meaning in their disease. As such, these narratives may be useful or familiar to anybody who has suffered through disease or a crisis in life.

Finally, one needn't have suffered from illness at all in order to find these narratives fascinating. It has been a privilege on my part to be with these individuals as they talk about the essential values, regrets, and hopes for their lives. It has, once again demonstrated to me the eloquence of all people in describing their lives when given the time and attention to really stretch out and talk.
What this book is not: Biases

I have not attempted to present a singly optimistic picture of surviving colon cancer or the role of individual factors such as hope and empowerment in improving outcome. The narratives presented here have not been selected to present any particular viewpoint with respect to attitude and survival, nor have they been specially selected to present examples of colon cancer survivors. Most of the people speaking here are still struggling with uncertain outcomes. I do not mean to question to role of hope or empowerment; this project simply has a different focus, namely to present examples of the diverse range of experience associated with colon cancer and to leave interpretation of these experiences to the individual reader.

There are, however, personal interests which have colored the narratives presented here. Perhaps the main philosophical position which influences these narratives is my belief that while cancer is a terrifying, devastating disease, it need not be exclusively a negative experience. I have been curious about the transformative potential of cancer on an individual's life in a positive sense. Does a diagnosis of colon cancer causes people to re-evaluate their lives and conduct their lives in a more fulfilling or constructive manner? Are close relationships reaffirmed (or torn apart)? Do people become more spiritual? I have directly and indirectly asked people about these issues. I have also asked each person if anything positive came out of the experience of colon cancer. Clearly, then in presenting these narratives, I hope to provide more than a bleak picture of sorrow and death, but rather to explore the positive aspects of struggle and growth.

Methods:

The portraits presented here are highly edited and re-arranged segments of multiple interviews with each subject. I spoke with each participant two to four times (usually three) for a total of three to five hours each. For each person, this occurred over a period
of 3-6 weeks. After transcribing these taped interviews, I rearranged and edited the responses to present a more unified and coherent narrative than may actually have occurred. Therefore, a given section or even paragraph may intermingle statements made in several different interviews. I only indicate when comments occur at separate times when they contradict previous comments or when there has been a relevant development since an earlier interview.

The participants in this project were recruited in several different ways. Three were recruited through word-of-mouth, and the others were recruited through a colon cancer support group (one subject), a university medical center cancer clinic (three) and a community physician's office (one). One participant heard about this project through both the support group and the university clinic. They received no compensation for participating in this project. After each interview was transcribed, they were given the tape of the interview and a copy of the written transcript. They will also receive a copy of the final thesis.

All proper names have been changed.

Disclaimer:

While these are intended to be portraits of actual people with colon cancer, there are numerous ways in which these portraits have deviated from any sort of objective truth or authentic representation of each person's experience. Each narrative has now passed through several different filters and, thus, each is in some sense a creation more than an objective truth.

The first lens through which each narrative has been filtered is my guidance and questioning throughout the interview. While I have attempted, particularly in the later interviews with each person, to let their previous comments guide my questions, I have nonetheless influenced the content of these interviews according to my interests (as suggested above) and in numerous other ways. I may not have inquired about -- and the
person may not have volunteered -- information about some vital aspect of their experience. For example, with one person, impotence from the surgery proved to be a major aspect of their illness experience. If I had not asked explicitly about his sexual life following surgery, I may never have learned about this experience which so dominated his world. No doubt I missed numerous other such opportunities.

The second filter through which the narrative has been passed is the patient and/or spouse themselves. The narrative I heard may be influenced by a number of different agendas on the part of the interviewee: They may be trying to present a certain appearance for me or for their spouse; they may be trying to articulate the cancer so as to fit in with the rest of their lives; they may also be describing the rest of their lives so as to fit with the cancer. I do not mean to suggest that there is something sinister or manipulative in this filtering and narrative creation, rather that it is a dynamic process which is part of an ongoing sense making which may be influenced by the particular interviewer, interview situation, or passing mood.

Finally, there is the filter of my own editing. I have taken the narrative offered to me and constructed my own narrative to pass along to you, selecting the portions that I find interesting or that I imagine someone else might find interesting. In this sense, there is outright manipulation, through selection of quotes, thematic grouping, and juxtaposition of remarks for effect. While I am generally attempting to maintain or enhance the flavor of the narrative presented to me, I am also commenting, questioning and creating through selection and positioning of quotes. As such I may be exaggerating and even distorting the experience of that individual to create my own vision or their experience.
Andy Marino: Blessed by Cancer

Andy Marino, 47, was diagnosed with localized (Stage A) colon cancer in 1991. Five years, two reoccurrences, and four surgeries later, he was completing a course of adjuvant chemotherapy when these interviews were conducted.

Since the age of 22, Andy suffered from ulcerative colitis, an unpleasant disease of the colon marked by bleeding, pain and unpredictable diarrhea. It also carries an increased risk for colon cancer.

All of our interviews took place in the lush and comfortably appointed living room of Andy's suburban home. Both Andy and his wife Laurie participated in all three meetings. Although dressed casually in a sweat suit and slippers Andy has a commanding presence, and his enthusiastic account of his illness needed little guidance or interruption.

**Diagnosis:**

**ANDY:** To get to the horror between diagnosis and first surgery... First hearing the word "Cancer", and not at that time understanding... The only backdrop either of us had was our upbringing through the 40s, 50s, and 60s where cancer was a death sentence. The gastroenterologist tells me I've got colon cancer, and it's going to require a major surgery. He didn't tell us what the stage of cancer was. He just said it was cancer. He may have said it was "A" carcinoma. At that point we didn't understand or know anything about staging or any of that stuff. All I focused on was: Cancer, Major surgery, Need to get you in now. That was pretty horrifying, and I pretty much went into a hole, because it's just facing an unknown. And the unknown includes whether this is the end of the road.

Being at our age bracket and hearing you have cancer and you need major surgery now... It was awful. If it hadn't been for my surgeon, I had nobody to go to help me through the time frame between when I was told this and when the surgery actually occurred [one month].
I was convinced that I was going to die on the table, and that it was the result of me not being a good person, not being good to my wife, not being good to my daughter. All of that. My fear was to the point of breaking down. I'd break down crying in a moment. People would be calling to check on me, close acquaintances, and I couldn't talk to them because I'd just start choking up. They're trying to give me support, and it wasn't working. They weren't facing it. I was. And I probably was a little bit curt with some of them, because they're trying to tell me, "Everything's going to be all right." And I'm telling them, "That's easy to say. You're not in my shoes."

**Hospital 1: Colon surgery and complications.**

The original surgery [in 1991] I was terrified. I was terrified. Nobody can be more terrified than I was. They told me it was about a six hour procedure. You can expect to be in the hospital 7-10 days. Well, that didn't work for me, because about the fourth day following surgery I had developed infectious abscesses. The first one occurred around my spleen. And my white blood cell count was up to 40,000. I was running over a 104 fever. They couldn't bring it down. I can't remember if they did CAT scans or what, but I do remember that 10 days after the first surgery of 6 1/2 hours, I was back in surgery for another 6 hours to physically remove this abscess which equated to about 800 cc.

In other words, I should have been out of the hospital, but because of the complication, boy, I'm back under the knife.

**Laurie:** And they weren't exactly sure in the beginning where the infection was coming from. He had a slight fever and they were giving him all kinds of different antibiotics. He was really out of it. He was doing a lot of hallucinating. He was so drugged out. And they just couldn't break this fever. That's when they kept trying different antibiotics and things.
ANDY: They had brought in an infectious disease specialist. And this particular type of infection that occurred in me, [the surgeon] had not seen before, in all of the colon cancer surgeries he had done. We make fun of the fact that you can leave it to Andy to present him with a unique challenge.

I remember him preaching to me about: "Andy you've got to be thinking about the end state," and I know I got nasty. This was in the course of being in the hospital, multiple surgeries and complications, snapping at him and saying, "Easy for you to say. I'm the guy in the bed here."

They had me down for X-rays, because they were trying to zone in on this stuff and I won't forget it. It was the tenth day following the original surgery, and they were down in the X-ray area. My surgeon found this, and he had the X-ray results and he said, "Andy we're going to have to open you up again."

LAURIE: During this time period he was really really drugged out. They were definitely keeping him very comfortable. Morphine was his best friend, and he was just having a great time. It was scary for us, because he was doing a lot of hallucinating. And then sometimes he would go on rages and screaming at the nurses and stuff. It was sometimes embarrassing for the family.

ANDY: They performed the second surgery. I come out of that and now I'm in bad shape. Now I'm hurting. And three days following the second surgery, they determined that there is more abscess forming around my left lung, and they can't do anything surgically because I've been through thirteen, fourteen hours of major surgery in 10 days. Then they bring in a radiology hotshot from U.C. Med San Francisco.

An Elton John look alike. Just a great guy: "Call me Tom." None of this formality, you know? He shows up in a Polo shirt, baggy pants. That approach really puts people at ease. As a patient.
They ended up having to do an invasive radiology procedure on me where they took me into the CAT scan, and they put a catheter between my ribs and positioned it in this area around my lungs so they could suck it off. That wasn’t comfortable. And so I’m in the hospital following that procedure, and they’ve got the suction and they’re drawing it off. They’ve drawn off like 400 cc’s of it.

After the second surgery to get the abscess, they had tubes coming out of my crotch area here on my left side. Four huge tubes hooked up to me like plastic orange juice bottles. All this stuff is seeping. I’ve got all this baggage. That was awful that kind of stuff that they put you through. And then the catheter, and they’re taking me down for X-rays every day, tracking if there’s abscess going on other places. I’m getting blood tests six times a day. They’re X-raying everything. I think I had six CAT scans in the course of that whole process.

I guess finally the white cell count started coming down. The fever was going away. I was responding. So they left this thing in me.

After 27 days in the hospital, two major surgeries, loss of 36 pounds and invasive radiology procedure... I went in November first and they released me the day before Thanksgiving, the afternoon before Thanksgiving. I remember them rolling me out the entrance to John Muir and her mom and dad picked me up. I just broke down crying. The smell of fresh air. Because in a contained environment you forget about the smell of fresh air.

So, anyhow, that’s stage one. My first encounter with surgery. [laughs]

**Hospital II: Ileostomy “take down” and cancer reoccurrence.**

[My surgeon] determined early on that I was a candidate for reconstructive surgery, meaning, do away with the ileostomy. He [had taken] all of my colon and a third of my rectum, and I had an ileostomy. Under normal circumstances, since he had determined that I was a candidate for reconstructive surgery -- where they, in effect, take the small
intestine and create what they call a J-pouch, which simulates the ability to store like the colon does and then be able to expel like a normal person.

He would have done that two months following this surgery that removed the cancer and the colon and all that. Well, he had to argue like a Dutch uncle, because I didn't want anything to do with it. I said, "Hey, living with this bag ain't half bad." So, he agreed: We'll wait a year.

I didn't want to do it. I didn't want to be bothered with it in the summer time. We're into boating and water sports. So, he conceded, reluctantly. He knew that if he was going to get me back in to do the reconstruction, he was going to have to do it on my terms.

October of '92 we're back in there to do the reconstruction, which amounted to creating the J pouch, removing the ileostomy and creating a diverting ileostomy which was an ileostomy that allowed the discharge of waste and prevented that from flowing [through] what he had just constructed surgically. So that was a four month deal, while the J-pouch heals. So I went in October, Halloween of '92 and first week February of '93 they did the take down procedure, which removed the diverting ileostomy and connected me to the rectum, so the flow of discharge was as a normal person. Minus a colon.

When he went in to do the reconstruction, guess what? There's cancer. He wasn't happy. This was in October when he went in to do the reconstruction work. He had to make a decision at that point: Do I proceed with the surgery, not knowing the degree of cancer? Or do I close him up, get pathology and then go back in to do the reconstruction. Well, he made a take: I'll do the reconstruction, we'll get the margins, and we'll see what the pathology says.

He took out what he saw. The pathology came back. It was contained, and from what I understand in recurrent cancer, they don't stage it. They stage the initial. That's my understanding, because I've never been told anything other than the A carcinoma situation.
LAURIE: It was where the reconstruction was.

ANDY: I think it was in the rectal stub area. Again. Because that's where the original was. I really didn't get a clear explanation of why that happened.

... Then after this second surgery they had external, what he referred to as "tension sutures." And what it is, is a suture comes in one side, and it goes out the other, and then on the outside is this wrenching device, a plastic thing where they can tension it up. And I had seven of them going down. Huge things like this [holds fingers six inches apart]. They're going down here. It left scars along my belly for a period. I don't know if they're still there. He had to do that because he was concerned about me ripping apart.

**Hospital III: Cancer Reoccurrence and Complications.**

So, February of '93 I get reconnected, and life goes on. Every six months from the original surgery to this date, I've gone through CAT scans. And every three months, blood tests checking for cancer tracers, as well as the CAT scan to physically see.

I go through '93, '94. And then '95 hits and February rolls around, and it's time for my six month CAT scan. January I take the blood test. No traces. February I go through the CAT scan. Cancer.

So, he calls us in. By this time it's first name basis. The rapport. He proceeds to tell me that we need to operate. Where the cancer was appearing was in this reconstructive area, what he had reconstructed. It meant that I was going to lose the reconstruction and have to go back to the ileostomy for the rest of my life. My initial reaction was: "OK, so?" I wasn't really too concerned. Living with an ileostomy wasn't a bad experience for me. There wasn't any negative side. Yeah, I was kind of disappointed about having to lose the reconstruction, but if the surgery had to be done, it had to be done.
So April of this last year, '95: Surgery. It was supposed to be a three hour procedure and out in seven days. What I understood was at the back of the pelvic region where it was and to get the margins, they had to go into blood vessels or blood tissue in front of the spine to get the margin. As soon as they got in there, it was like an oil well. I just started hemorrhaging big time. Seven units of blood were transfused, and I was gushing like an oil well.

So, seven and a half hours of surgery, all the family is waiting, expecting three hours, and no feedback for them. Anyhow, they packed me. I don't know what the hell they use to pack you. Close me up. Off to intensive care I go. And I was pissed about that because I got all my girls on the surgical unit that have become family to me. The private suite is all taken care of. Special treatment for Andy, and here I am in intensive care.

And they got stuff coming out of me and stuff hanging from the rafters, man. I couldn't move. Any movement that they needed me to do in the bed, they had to. I was gone.

I pretty much don't remember much of anything about the intensive care thing. All I remember is my surgeon telling me, "We're going to have to go back in, Andy, to finish this up." And that's three days after this seven and a half hour thing.

Now, I don't know if its drugs or what. I don't remember going into surgery; I don't remember coming out of surgery. Nothing. In that second thing. And that was a four hour, five hour deal to get the packing out of there, do whatever they had to do. My guess is it was nine or ten units of blood they had to transfuse, which was an experience for me. That's taxing on the body.

Between the surgery and the blood, I was in intensive care for five days, and then they finally transferred me to the surgical unit where I was back with my family, the nurses that cared for me previously.
You don't remember a lot, because of medication and whatnot. It was touch and go there in a couple instances.

**Chemotherapy and radiation:** Andy's third hospitalization was followed by radiation and chemotherapy to prevent reoccurrence.

In this last go down they removed the rest of my rectum and sewed me up from the inside. I'm healing from the inside out. I still have an open wound there, all these months later. And the healing process has been delayed because of the chemo and radiation. And I probably will have a wound there until I'm done with the chemo.

I'm still on chemo. I started chemo and radiation treatment together, on the highest dosages that they could. I was getting 2000 cc of what they call 5-FU chemo. And then they turned the radiation, what they do in terms of rads... which all I understand is the amount of radiation which they blast me... and its over a cycle of days. So over the course of six weeks I'm getting chemo and radiation five days a week. High dosages. I mean, the radiation and medical oncologists, their philosophies are: Aggressively attack.

They started the process of chemotherapy. That was six weeks of hell. Lost your hair. It's hard to describe how you feel when you're under chemotherapy and radiation. A dullness. You just don't feel normal in any way, shape or form. Very tired. Your mouth has sores. Nausea. A lot of people have vomiting. I never experienced that. You just feel like shit.

The correlation of how you feel internally for me was like having the flu 24 hours a day for six weeks. The dull achy head, a nausea kind of feeling. Listless. Weak. You look sick. Your skin complexion changes. You just look sick, and you are sick.

I lost my hair. When they tell you about what to expect, that's the thing that affected me the most. It was just the vanity of not having hair. And it's funny, the other
things you can tolerate; it's just not pleasant. The best way for me to express it is that I'd rather go through surgery again.

But the experience about losing the hair... It's funny to watch people look at you when don't have hair. I mean a guy my age. Kids today shave their heads and that's the vogue thing to do. A guy in his mid to late 40s that isn't black, isn't that cool, they're looking at you like, "Who are you trying to be? A kid? What's the deal with you?"

What happened was the hair started falling out in chunks. I'd take a shower, and it was coming out, and I said, "Screw this, man, I'm getting this off." So I go to the barber, I said, "You cut and shave me." [Laurie] didn't know I was doing this. She came home from work that night and she just broke down crying. It was just such a shock.

LAURIE: Well, he was having a bad day. He was really under the weather. And I walk in, and he's in bed. He was freezing with the covers up to his neck and his bald head sticking out. I think that's when the realization really hit me. Up until that point, he had hair, he was functioning; he was doing things at a slower pace, but there was no visual signs.

ANDY: There were no physical signs of sickness.

LAURIE: Yeah. That part was devastating. It hurt. Because it was a real acknowledgment that he really is not well.

ANDY: Laurie protects me. My dad, all the family. Their grieving, their morning, their worry and concern throughout all of this time, they'd hidden. That was the only time she ever broke down crying in front of me.

...
I got off the daily routine of the combined treatment and had a month layoff with no
treatment. And then in August they started me on a protocol where I go once a week, and I
get a 900 cc infusion along with another chemical that enhances the effectiveness of the 5-
FU chemo medication.

The other thing they did was they installed a VAP - a venous access port - and what
it is a device about the size of a quarter, and it’s got what I would call an eraser type
diaphragm, and then has a tube that’s inserted into a vein or something and they do the
infusion through this thing. I have had tons of I.V.’s and I’ve never had anything that hurt
like the steel needles they use in the hand in chemotherapy.

So the protocol I’m on now is weekly infusion through the end of June of this year.
And then I’ll be off. And I hate going. I hate it. It’s a psychological thing. The people
are wonderful. I’ve got a little gal there who is like children to me. She’s like an adopted
daughter. She does my treatment and she makes it pleasant, but it’s just... I think it’s
mostly psychological. It’s just like an odd feeling inside. It’s nothing physical. No side
effects.

LAURIE: The side you haven’t seen of Andy is he’s a big kidder. He give’s people
nicknames, and he’s a joker and stuff.

ANDY: I lovingly abuse them.

LAURIE: Lovingly abuse. I think that’s how a lot of relationships start out, because
he starts kidding and joking around.

ANDY: It’s like when I go to my chemotherapy. In the treatment room there,
there’s probably ten chairs. I’ll come in today, and I’m like a relief for the nurses that are
providing the chemo treatment as well as the patients there. I’m boisterous and abusive,
and I can see the relief in them. It makes them forget about what they're dealing with. And I'm not doing it for that reason. Maybe subconsciously I am. But it's gratifying for me to see them respond to it, to hear people laugh, to see them respond to it, to also see the seriousness kind of dissipate for awhile.

There's this one lady, she came in and she wanted to sit next to me, because she knew I was going to be doling about the abuse. I mean silly things like I give them a bad time about, "We're the customer. You're the provider. Nordstrom service. Where are the truffles? Where's the margaritas? The customer is always right." That kind of stuff. And it just goes on. The more I know them, the more liberties I take. And the doctors seem to enjoy it too. Maybe my personality does have something to do with it. People tend to respond to it.

....

It's the worst part of my experience. The external physical effects, to me that's like: So what? It's temporary in most cases. From a human perspective, everything I've been through, the worst and hardest thing to deal with is going in for chemotherapy treatment, because I'm sitting there with other people that are far less fortunate than me, and to see their suffering and to put myself in the same pool with them.

Evidently, if I were to compare it to what women go through in their chemotherapy treatment and radiation treatment for breast cancer, I've had it easy. What they're given for treating breast cancer, I've watched them sitting next to me and throwing up right there in the chair. They lose their hair within a week. It's very hard. I hate it. I hate going. I guess that's why I go so much out of my way to make light of it.

When you're going every day, and all of a sudden you're not seeing the people you see every day, and you inquire, and they don't tell you, but you understand that they're no longer with us. Seeing the suffering and then the recognition that they're not with us anymore, that's the hardest part for me.
**Colostomy:**

I can't tell you how difficult that was to accept. Because I had known about the potential for a bag from the time I was diagnosed with ulcerative colitis, and I swore that I'd rather die than have to have a bag.

Then all of a sudden there it is. I didn't want to look at it. I didn't want to touch it. I didn't want to have anything to do with it.

And then when I came home, because all the complication, I had visiting nurse care. They did it for me for a month before... It was probably a three month transition before I was willing to even look at it. And then the other big thing was: I never wanted [Laurie] to see me. I never wanted her to see me without my clothes on. I didn't want her to see me with this thing hanging off of me. I finally got over that and never got over not wanting her to see this freak.

I like sleeping in the buff. After I came back this last go around [second ileostomy after recurrence], I was going through with wearing boxer shorts to bed. And now I don't care. I go to bed in the buff, because I'm comfortable. But I still consciously try to minimize any opportunity for her to see me like that. I know it doesn't bother her, when I see myself in the mirror, it's there. I know it's going to be there for the rest of my life.

**Laurie:** That was one of his concerns, too. How is this going to impair my life? And the doctor says, "Andy, you can do everything you've done before." And [Andy] says, "I water ski." He [the doctor] goes, "You can water ski."

**Spirituality / Religion**

**Andy:** We weren't regular church goers before. When I found out about the cancer, all of a sudden I wanted to have religion back in my life, and that's dissipated now.
The attendance in church is back the way it used to be. Today is Ash Wednesday, and we didn't go, haven't been to Mass.

It made me feel very good at the time, because I went through guilt in seeking help and forgiveness in facing it, and then afterwards it felt good just to be going and really giving thanks for my blessings and good fortune. We did do that on a regular basis.

Initially I felt guilt [at not going], because my dad wanted me to talk to a priest, and he arranged all of that, and we got close to one, and then I kind of dissipated. But I have this belief that I can be spiritual, and I don't have to be in a building going through a service to feel closeness to God. I'm not feeling guilt now, but it did feel good to be going after it, because I felt I owed that commitment to those that supported me, to the priests that were of support to me, which I guess is kind of warped.

When you go to church and you sit there and you're looking at everyone, I oftentimes wonder: Why are they here? We've encountered people in there with cell phones in the pew. Talking on the phone in church! It's like: Why are they there? What are they getting from this? Is it a thing where, "Geez, if I come to church then I'm going to be saved and I'm going to go to heaven and all this." What is all of that? What is all of that?

LAURIE: I think there's a lot of different reasons and different phases in our life that we need that. And we needed it then, and it was very supportive to us.

**Personal change:**

I was in the hospital the same time Magic Johnson was diagnosed HIV positive, and for the first time in my life I realized what a miracle and a blessing life is. I'd never thought about it before. And I've tried to share that with people, but when they haven't
been confronted with something that impairs their daily activity, its like talking to a wall. People just don't acknowledge or understand.

I came out of the initial thing saying, "What's important?" Life. Blessings of. Physical as well as spiritual as well as emotional. With each iteration of that, it's been a reminder to me about all those blessings, all of these things. This is most important and applicable to Laurie and my daughter, because they are the two most important people in my life, and I've taken the time to let them know that, in words, in actions, and just my general approach with them. They're the ones I neglected and abused the most prior to... and they're the ones that I'm the most cautious subconsciously about not doing again.

I'm not perfect by any stretch of the imagination in that regard. I'll get on Laurie and start nagging her about something and feel more guilt than I used to in what I do. And I always try to say, "I'm sorry" after having done it. Which is still wrong, because I should not allow these insignificant things to set me off. Probably I'm more willing to take time out from chores and just do play things, spend time with her. And I'm talking about little nit things like going to breakfast on Sunday, or going to brunch or going to dinner.

You get back into the trappings of the day to day rut that we all exist in, and I started losing sight of it. I keep having to remind myself of that. The gal I'm working for now, I've made it her job to, when she sees me veering off into the old behavior, to jolt me, to kick me.

I've had people that have known me for a number of years verbalize the change they're seeing in me. It's just kind of happening. I guess there's a certain element of me that's saying: "Be careful. Release." The other real important thing is: Work really isn't important. It's a means to an end. Keeping a roof over our heads.

The guy upstairs [points up] has sent pretty strong clues to me three times now, and I feel like anything beyond this and I'm tempting fate.
Support from family and friends:

I, Laurie:

ANDY: I think the whole process of colon cancer surgery, complications, all that... I think it's harder on the loved ones than it is on the patient. Because we're not necessarily really aware. I mean when complications set in, I was looking at myself like it wasn't happening to me. And that is depressing. I'm one that likes to be in control of things, and you're totally out of control. You're at their mercy and do whatever they tell you.

I think it was probably tougher for them [points toward Laurie], because I did a lot of hallucinating. They had me under morphine big time.

LAURIE: It was awful. It was awful. Because you feel so helpless. You just pray that they're going to do the best they can and that they're going to find it. I mean they're the experts but you do feel, as the outside person, so helpless because you don't want to see him suffer.

My family all was very healthy, physically and emotionally, so I guess I don't know how to interact with people that are sick, or I don't know exactly what to say, what to do. I don't have that compassion. That's difficult for me to communicate with someone. I didn't want to be there.

ANDY: Laurie doesn't know what to do. She feels helpless, I guess is the best description. She wants it to go away. She wanted it to go away, but she didn't know what to do or say to make it go away. And then the practical side of her said, "I can't make it go away, as much as I'd like it to go away. I can't change what's going to happen."

LAURIE: It's like, what do you say? What do you do? And the old cliché of "It'll be better." I'm not in his shoes. I can say those words to him and console him and just say,
"This isn't fair. It shouldn't be happening to you. You don't deserve it," and all those things. And that's my way of communicating.

As an outsider, you feel helpless. I can't do anything. I can be there for you. I can go the hospital. I can comfort you. I can feed you. I can do those kinds of things, but that's all I can do, is be there. And I was.

....

ANDY:  As far as our relationship, there was a lot of crying in that first month. A lot of crying. Because on a day by day basis, family's checking in to see: How's Andy? How's he doing? How's he feeling? Laurie masked her emotions a lot. She protected me throughout this by not showing emotion, but away from me she would let it out.

LAURIE:  [softly] Yeah.

ANDY:  Not on a frequent basis, but when it reached the point that she had to let it out. As far as our relationship in that month period... During the month, if I break down crying, the most she would do would be to hold me. Watching me cry would cause her to get emotional, so she'd cry. We pretty much didn't say anything in words. She'd say, "You're going to get through this. You're going to be all right." But not much more than that. There was not much more, in hindsight looking back, what much more can you say? She can't guarantee anything for me. She can't protect me or anything.

I do recall numerous times, saying that I don't want to leave them. [Softly, to Laurie] I said that a lot, huh?

LAURIE:  Yeah.
ANDY: Yeah. [to Laurie] I don't want to leave you. [pause]... Whew! The emotion comes back... [long pause]... Our relationship prior to that... I think we have a good relationship. Don't you?

LAURIE: Sure.

ANDY: We communicate. Our whole lives are pretty much one another. We don't have separate interests in what things we do. Our home's an interest to us; recreation is an interest to us. We do it together.

As far as intimacy, this is an item, that I've struggled with for a long time. Laurie and I don't need the intimacy, and we don't have it and haven't had it for a good number of years. Neither of us have that need anymore. After surgery, boy, the doctor wanted to know about impotency and our relationship's sexual... And I kind of was embarrassed by saying, "It's not an issue because we're not sexually active." But in colon cancer, at least my particular surgery, the risk for, in the surgical process, causing impotency is there. He counseled us about that. It didn't matter to either one of us. [To Laurie] I don't believe?

LAURIE: No.

ANDY: Our relationship, the biggest pleasure I get out of our relationship, before, during and since, is just having her close to me. At night when we come home, I'll watch news or sports or whatever I'm watching. I like the idiot box and she likes reading her paper. She sits right next to me, so we're next to one another. Or we'll go to bed and read for a little while, but we're next to one another. Just having the touch of one another gives me great satisfaction and pleasure. Going to bed at night, and she's there when I go to sleep, and she's there when I get up in the morning.
Sexual activity wasn't a need prior to, and hasn't been since. I just don't feel — now that I've had her validation about this, because we haven't discussed it — that there's anything missing in our lives. Because we're happy with one another. Each year that passes in our relationship, she means more to me than she... to look back 27 years and compare my feelings for her then as opposed to now... She is my life. If she weren't here, my life would be... it would be like living death, as far as I was concerned. I wouldn't know life without her.

II. Mother and Father:

My dad... when I first told him I had cancer, I remember him standing in the hall outside my doctor's office just bawling like a baby. And I can understand now, because we had an incident with my daughter, the pain of a parent watching their child suffer. I think it's different than a spouse. It hurts more.

As a kid I spent time with my dad doing the things he wanted to do. But he wasn't engaged in my life in terms of my activities. As a kid, I was pretty close [with my mom] and pretty protective of her, but she's not the person that was my mom when I was a kid. She's a different person. She isn't anybody that I can relate to. Whereas my dad has, since that time, made a conscious effort to spend more time with us.

At the recognition of the colon cancer, I think what hit my dad was the seriousness of it. He wanted to be there for me even though I wasn't asking for it. He went to all the exams with us, the consultations with the surgeon, all of the presurgical stuff that happened.

He'd hide his emotion from me. He would be very supportive and positive, but during the difficult times with the complications preceding that second surgery and the invasive radiology procedure that had to be done, he evidently had quite a bit of emotion about this, and his way of venting that was to go out in the parking lot. My dad used to
spend time just walking in the parking lot of John Muir crying. He says he knows every inch of the parking lot of John Muir Medical Center, which is quite a vast area.

He also acted as a filter. He was always questioning nurses about what was going on and very protective about if I showed any signs of pain or something that he thought was abnormal. He chased visitors away, coworkers, friends that he didn't know that were coming to see me. I mean he literally chased them out, because my surgeon didn't want me to have company. So my dad put a sign on the door, "Family members only." And he was downright rude to some people.

LAURIE: It's almost like his dad is trying to recapture all those years that he missed with Andy when he was a kid. It's almost like I think he was feeling that...

ANDY: Guilt.

[Eyes tearing] I'm getting choked up thinking about a couple of things. My dad... I mean, we hug and kiss and do that publicly. That's never been a problem. My dad's side of the family is Italian, and open affection and emotion is pretty common. But he did some things when I was in the hospital... I've been choking up thinking about it, because they weren't things that he... When I was a kid and got sick, my mother dealt with it. My dad didn't so much get involved. But when I was having the high fever and whatnot, I remember him putting cold compresses and doing that to me [dabs forehead] and taking ice on my lips and whatnot. And then when I was in discomfort after the second surgery, he'd just hold my hand. He rubbed my head, or he'd just stroke my brow. It was relaxing and very comforting. I didn't have to say anything, and he didn't say anything. I guess he looked at me and saw me suffering and made those gestures. That's something he'd never done.

I guess it's real tough for a parent to see their child suffer.
Now on the other hand, my mother throughout all of this showed no interest. No contact. Nothing.

As serious as this became, she never called. I mean coworkers called me daily checking on me. My mother, in the hospital and out of the hospital: Never heard from her. I can count on one hand the number of times she's seen me in five hospitalizations. But our relationship isn't good. I think she knows I don't have fond feelings for her. I don't say negative things to her, but I don't have much patience or tolerance with her. So I don't know if that's the reason why she didn't show more interest, or she just doesn't care.

The real kicker as far as my mom and my hospitalization and the first go around, to really put it in perspective to anybody that is trying to understand why I don't have fond feelings for my mother... Laurie's parents live within a mile of my mom. My mother doesn't drive. They would come up and visit me during the day and call my mother to offer to have her come with them, because they knew she didn't drive. In the height of my problems, after the second surgery, I'm in trouble and the white cell count is way up there, so things aren't improving. Her mother calls my mother to say, "We're going up to see Andy. Would you like to go with us?"

And my mother comes back with, "Well, today really isn't a good day for me. Today's my wash day." She does her laundry. So her laundry is more important than her son. That... that just really... That's fine. I don't care. It's just an example.

III. Friends:

It's interesting because there are different layers of friends, and the ones that I would have thought would have been there by our side throughout the whole thing weren't. And the other ones that were more friends as the result of working relationships, peers, were the ones that were closest to us.
Childhood friends, people we grew up with and maintained linkages with: They weren't there for us. They made a token effort. They didn't know what to do. What do you say? Afraid of calling and hearing something bad.

To put the shoe on the other foot, one of them who I worked with and had known for a number of years died last year of prostate cancer. They were dealing with that for three months before I found out about it. And I was very upset that they didn't let me know. The wife said to me, "Well Andy, what am I supposed to do, get on the phone and call you and say: 'Roger's got prostate cancer and he's in the hospital. They're only giving him six months to live."

And I said, "Yeah. Because we're going to be there for your support and for his support."

That told me: Most people don't want to hear that kind of bad news. Most people don't want to give back, don't want to help. And I told her. I said, "Sally, I've been there. I want to be there for him."

But the people that we spend more of our time with because of our work life... This one set of friends, the wife works with Laurie, and I used to work with the husband, they were there. Every minute of every day. For [Laurie] primarily.

In this last go-down, a different set of friends were added to that. And one to the extent that she actually has become my work sister and personal friend. When I went in for my surgery last April, she took time off work to be with me, with my family in the surgical waiting area. She wanted to be there lending support for them for me, as much as she wanted to be there for me. And I thought that was just way above and beyond.

Another key in my success and my attitude about it is I've just had a world of support. I've been with [my company] for 30 years. People are very caring, particularly when you're facing crisis or hardship. The support I've gotten from my boss, my coworkers has just been tremendous. Just tremendous.
IV. Confronting cancer in others:

ANDY: One of the patients that I got close with through chemotherapy treatment just died two weeks ago. A beautiful couple. The last we saw of him was in October of last year when he left the hospital. It wasn't a week or so after he left, I had my monthly visit with my oncologist and I asked, "What can I do. I don't know what to do. I understand the prognosis is not good for Larry."

So I visited him weekly for a couple of months. Then he went home, and I heard things were bad, so I asked my oncologist, "What can I do to support him?" My oncologist tells me point blank, "I don't want you seeing him. It would not be good for you."

I didn't call. I didn't go visit. I thought about him every single day. Not a day did not pass that I didn't come home or think without saying that Larry was on my mind.

He died two weeks ago. We go to the viewing, because the funeral was on a Monday and neither of us could take time off from work. His wife... We walked into the mortuary; there's a crowd of people; she leaves all of them -- I mean as soon as she saw us walk in the door -- and was there hugging us. I break down crying. She breaks down crying. I start spilling my guts about the guilt that I'm feeling because I didn't visit him, and she told us, "Larry knew you were thinking about him. And he knew why you were staying away. And it was OK."

I didn't feel good about it and I probably shouldn't have listened to Dr. Brown, but he kind of scared me when he told me not to visit Larry.

There's an example of me not knowing how to deal with this situation. And we had become close with these people, shared a bond of being cancer survivors and watching his hope going away and not knowing what to do or say.
V. Mike Spinelli: Both Andy and Mike Spinelli (also interviewed and presented in a separate chapter) are friends who met after their respective diagnosis. Since then they have become close friends. They both spoke at length about each other.

His wife, his parents and he think I walk on water, because I was there for him. He was being operated on in March of '92, and I had just come out of it in November of '91. What I represented to him was: One, somebody who's been through it. So what I had to say meant more than what anybody else had to say. Same kind of thing as my relationship with my surgeon.

And, two, I'm living proof that you survive it. I'm standing there in front of him: healthy, full of piss and vinegar, eating whatever I want, not concerned about the [colostomy].

But watching him, I could not communicate. I saw the fear in him that I knew was in me at the point of diagnosis and that period of time in-between. I felt helpless, because I wasn't putting him to the level of ease I wanted to. What I was communicating to him was, "You're anxiety and fears now, this is as bad as it gets. Because the surgery and after the surgery is nothing close to this. You will be in no pain. You will be in no suffering. They medicate you. They care for you. You may not like it, but it isn't going to be the agony that you're feeling now." And I could tell that it just wasn't sinking in.

I went to the extent of taking him into the bathroom and pulling my pants down so he could see this thing. I don't know if that was good or bad, because that really put him into a downward spiral. And he said, "There's no way man. I'd rather be dead."

Anyhow, his fears were pretty bad. The night before his surgery... At Kaiser they're admitted the afternoon before. There is he.

Laurie: All that time just laying there waiting.
ANDY: So I went up after work to visit him, and the next thing I knew, I'm the only one with him, and he's alone.

I stayed well past visiting hours. It was like 9:00, and I knew he was scared, so we were talking about things that we enjoy. We're car enthusiasts, so that really was getting him off the track as far as thinking about this. And then I said, "Well, Mike it's time for me to go." And two men... he breaks down crying like a baby in that room, and I was the only one there to hug him. I told him, I said, "I'll be back here in the morning before surgery, and I'll be here with you. I'll go down with you." Which I did.

Meaning of cancer:

Another thing that has gone on, happened coincidentally to this: I encountered major depression in June of '91. I was one stage away from severe clinical depression, lithium treatment, hospitalization. Major depressive disorder. I mean I lost all interest in life. All I wanted to do was sleep and go into a shell. Lost appetite, sexual interest, focus. Couldn't focus on a thing. The simplest of thought processes I was incapable of doing.

They put me on a disability. I broke down crying at work. I'd break down crying right and left. My emotions were shot. I had no control over them. That was horrible. Again, I'd take surgery over major depression.

....

[This was] before I even knew about cancer. I'm in the throes of them trying to determine which kind of antidepressant medication is working. I was on my fourth one and not getting any relief. I was also going through counseling. The counseling was beneficial to help me understand perfectionism, what it does to you.

I came to terms in terms of understanding all of that stuff, recognizing my traits and how it plays in negatively, and then how that can lead to you suffering a depressive state.

What ended up happening was our daughter is up at U.C. Davis. Her first year up there, because of being just like daddy -- perfectionistic tendencies, high expectations, no
self-fulfillment or acknowledgment of all the good things, only focusing on the negative, creating negative when there isn't negative -- she fell into a depression. Same as daddy.

She came home probably a month after we took her up there. She comes home on a Sunday. And all the things I experienced, wanting to be in a shell, withdrawal, "I can't do anything dad." She couldn't focus. She couldn't do anything. I knew right away what was wrong.

Anyhow, she wanted to go back to school and so we convinced her to stay home that Monday and miss classes, and we'd take her up [Monday] night if that's what she wanted to do. And she wanted to try.

We got up there and said, "OK honey let's go get something to eat." Because I could tell she didn't want us to leave. So we get something to eat, and by this time it's time for us to go. I've never experienced pain...[begins to cry]... leaving her. And her standing at the front steps of the dorm looking at us because I knew the terror. [crying]
But I had to let go to let her try. And as it turned out, it's all OK.

[Exhales loudly] Whew! My emotions. [Pause] I'm very open with emotions so it's not uncomfortable for me to cry or get emotional. I actually admire that, particularly in men. Anyhow. God, I'm just rambling all over the place.

And that's where I learned the pain of a parent watching a child suffer.

All of these things. Depression. Cancer. My daughter. All of it has happened over the same five year time period. And we've survived it. And it caused me to have recognition about: I hadn't been the father I wanted to be. I put it in my terms. I hadn't been the father my daughter deserved. I hadn't been the husband my wife deserved. And when all the cancer thing hit... That's why my belief that I was going to die and that I was being punished for being all the wrong things...

*Do you still think that?*
ANDY: No, because I think I'm a different person. I'm not where I want to be, but I think my relationship with my daughter is much better today.

LAURIE: If you had a choice, of course you wouldn't want to wish cancer on anybody, but what it does is it changes your whole perspective on things. He is a different person because of what he's gone through. The depression. The cancer. The surgery. The ups and downs. There are positives that come out of it. I think that's where I'm trying to get.

... ANDY: The notion of dying on the table was punishment for not being a good person. I told you about that before. I have regrets about my relationship with my wife and how I have treated her over the course of nearly 27 years, and my treatment and handling of my daughter in terms of expectations and affection and those kinds of things. Being a perfectionist and learning what I had learned about perfectionist thinking, it fit to a tee that naturally I vacillate to negatives, because a perfectionist never fulfills goals or isn't self-nurturing, doesn't feel ever any sense of accomplishment.

It was, looking back on it, a natural reaction for me to look back and see all the wrongs that I had done by the two people that mean the most to me in my life and feel guilt for that. And then the logical reprisal for that would be punishment, and the ultimate punishment would be death.

*It seemed that that matched up with some things that were going on in your life anyway. And it was a kind of catalyst...*

ANDY: Yeah. It was a fate that was bound to appear at some point in time.
I look -- and this again is against my manner of thinking previously -- I look at the depression and I look at the colon cancer as blessings. They happened for a reason. And I've always had a feeling -- Laurie and I, this is a shared feeling as a couple -- that things happen for a reason. And if it's meant to be, it will happen. So I don't view any of this experience with colon cancer as a negative. I believe that He chose to have it happen for a reason, and the reason is to make me realize the important things in life.

Coda:

ANDY: Yes. This guy [Larry] that we just lost affected me. I rage and anger over two wonderfully beautifully people that didn't deserve this in any way, shape or form. Cancer isn't selective about the people who it chooses to affect. My initial reaction to all his suffering and his ultimate death was anger. He didn't deserve it. And then, the other reaction was fear. I've lost two other co-workers to colon cancer. Another validation for me of my blessing. I have a tremendous fear of death. Right now if the cancer were to come back and be life threatening to me, I don't know whether I'd want to know anymore.

And I don't feel threatened now. But this guy's death, I can't ignore that. Even though the result of his death had little to do with the colon cancer. I mean his stage of colon cancer was worse than mine, and it metastasized to an area that couldn't really be treated. As my oncologist shares with me, just as a point of reference, there's no guarantees with cancer.
When he performed the colonoscopy the second time -- as I said there was nothing wrong with me as far as I could tell -- he found cancerous growth in the colon.

I arranged surgery a couple of months later. On the sixth of January 1994 I had the cancer removed from the colon at Mt. Zion hospital in San Francisco. After ten days I was released.

[One week later] I went to the physician to look at the fistula that I had here, which is a little attachment of the part of the intestine to the stomach, and he had one look at it, and he didn't even let me go home. Right into the hospital. Because I got infected. I'd gotten an infection in the space of that week.

I was 21 days in the hospital with that infection, and I think that was the worst experience I had of all my problems. Because I could hardly move. I was not permitted to get out of the bed, and they fought that infection for 21 days. That was unbelievable.

So, sometime later that year, September, August or September, I discovered that the cancer had metastasized to the liver. Then I heard about this man Dr. Williams, that he was an expert on the liver cancer. So in October 1994 he performed the following surgery: He removed cancer from the liver, at least then whatever he could see of it, and he sewed up the colon [removed the "fistula"]. This was in October of '94, five or six months later than when I had the colon operation.

That is a year and four months ago that I had the operation for the liver. Ever since that operation, I've been at times feeling very tired. However, a lot of that tiredness, I think, was due to another disease called ulcerative colitis. And that was why originally I went to this other doctor who performed the colonoscopy originally. The tiredness was almost entirely due to ulcerative colitis.

When I had the liver operation, there was a man beside me. I believe he was from the farming community in the valley. He was a Japanese gentleman. I was told there was
nothing they could do but sew him up again. I was really affected hearing that, seeing a human right beside you, and there's nothing you could do for him.

So that's it. Now every three weeks I've been going [since] last May. I had a pump installed, by the way, to deal with the liver cancer. And the idea behind this pump... What it does is it's a small pump about the size of the palm of your hand, and it's inserted under the skin, and they give you chemotherapy right through that pump into the liver so the chemotherapy doesn't go through your system. It's concentrated on the liver.

The only chemotherapy I had was subsequent to the liver operation in October of '94. Then I had the pump. They put the chemo in there. That went on for some very good while, until May of '95 when they stopped it, because I was getting jaundice.

That chemotherapy didn't bother me one bit. It's designed to do that. It's designed to go right into the liver and not into the bloodstream. It had no other effects on me whatsoever.

....

I have not been taking chemotherapy since last May, the reason being that I got jaundice, and they thought that maybe the chemotherapy was doing that. Since last May, which was nine months ago, all I've been getting in that pump is water, and the purpose of that is to keep it lubricated. In other words, if they ever wanted to go back to chemotherapy, they could do that.

I go every three weeks for this water in the pump. Then I go in every three months for a CAT scan of my abdomen and an X-ray afterward. That's every three or four months.

And then last November, when they put a stent in my liver to remove the bilirubin they call it, the material that causes this jaundice. You've heard of these stents haven't you? They put them in the liver, and it drains out this bilirubin the way it should go out. The reason you get the jaundice is, it comes out of the liver but goes into the bloodstream. And they diverted this into the... I guess it's into the intestines.
I got jaundice a number of times. Sometimes it went away again, but on the 14th of December, I had a second stent inserted.

This morning -- what's the date today, February 20th? -- I learned as a result of an interview with the cancer doctor, Dr. Varga -- I don't know whether you've heard of him or not -- but I have two small cancers, pieces back in my liver. I just learned that this morning. There's nothing they can do now, because it's so small. I think that's the reason, because it's so small.

This was suspected many months ago. My one physician told me I didn't have them there, and the other one thought I did, but they didn't know. So it's turned out I do. There's really nothing I can do now. It's just go along as I have been, and if the thing develops more, then the decision will be made what to do with me: Whether to give me radiation, give me chemotherapy or whatever. The one good thing about it is that it's my understanding that cancer can come on you very very quickly. Very extraordinarily quickly. But other times it's slow moving. Well, it appears in my case that it's slow moving.

*It seems like a surprise...*

It was a surprise. I didn't expect it because I feel extremely well, and I look well they tell me. And I feel well. So a surprise, but I haven't gone into a funk over it. Just surprised and a little upset. Not very much.

*Where did you think yesterday that your cancer was?*

I didn't think I had any cancer yesterday. I thought I was just going by to be reviewed. My condition was very satisfactory. That's what I thought. So it was a surprise then this morning.
What he said is: I do have two very small pieces of cancerous growth there. There's nothing they can do for me now. Meaning... I think what he means by that, there's nothing they can do. What can they do? They can operate on me or give me a radiation, but this is not the time. They have to see more development in this. That's what I understand.

The average time of death for some people like me can be anywhere up to four years from the time you get it. They generally say if you survive four to five years, you're going to be OK. Well, I've been two years on the colon, and a year and a half on the liver. And I don't believe I'm going to die of cancer. I think I'll survive it. And that's how I feel.

Either that's failing to look at reality or not looking reality in its face, I don't know. But I don't feel that. Part of the reason is that I feel so well.

*How long do you think you'll grow to live to?*

I think I'll probably live to the early eighties, somewhere around there. That's my own feeling. I had that feeling yesterday, and I have it today. I'll probably live to my early eighties. And I'll probably die of a heart attack or something like that. I hope it's quick. I don't want one of these long drawn out things.

"Cancer":

I was aware of "the big C" as it was called. And there was something in the society where I was brought up, it was something that was never mentioned. They wouldn't even mention the word "cancer," and that was probably true in the United States 50 years ago, too. It was something never discussed, like gonorrhea or something, just not discussed. So very often you didn't know what people died of. They died, but the word cancer was
never used. I guess I was aware just like your average person was that it was a killer, and I was aware that it could come on you very very quickly. I was aware of that. It was a killer. But I'd no personal experience with it.

*Do you have the same feeling about cancer now? That it's a killer?*

Oh yes. You look at the cancer society books and at the statistics, there's no reason to think that you're going to be different than anybody else. You can fall down the steps and die, you know, get killed. I'm well aware of how serious and deadly a disease it is. There is no cure for my disease. For some reason, somewhere, I survived. The mean is about four to five years. After that, if you're cancer free, you have a good chance of surviving.

**Emotional:**

Well, my reaction to the whole thing originally, of being informed that I had cancer of the colon, was possibly different to most people. I understand that many people go into a deep funk. Some say, "Why me?" I didn't have that reaction at all. I was very calm about it, and I'm no particularly calm person, but I wasn't. I didn't start blaming anybody or asking any question why it was me or anything. And the reason I think for that is, first of all, I was 69 in 1994. I'd just turned 69 when I was operated on. I'm 71 now.

And the second reason, I think, is that in my subconscious I had from the time I was a child, I was told and believed that this earth is a place where you're only passing through. We all have to die. We know that from our experience. Whether you were Napoleon or whether you were Stalin or Hitler, we've all got to die. And one of the best evidences of that is that I look at the New York Times death page every day. People who are prominent in every sphere of human activity: They're dying! You're not going to be
different. So, I recognize I'll die sometime. I had 69 years, and I recognize that this was only a passing through phase in life, and that's because of my religious beliefs.

I'm a Roman Catholic, and I've always followed the teachings of the church as best I can. I believe in the church, and I still do. I'm not a fundamentalist in that sense. I'm just a genuine bred and born Roman Catholic. This is a temporary phase. We've all got to die. We make the best we can of this life.

_Did you think about it when you were younger?_

Oh, I knew that from the very first. From six or seven years of age I believed that, because I was taught that. We were always taught that. Particularly where I was reared there's what they call a fatalism. You know that word? That was very much in the Irish character when I was growing up, and it's probably still there, that fatalism. It's not that it makes you sad or should have to make you sad. It really should make you face or understand what reality is.

....

It's not as miserable a thing to me, partly because I don't think I'm going to die of cancer. Why I got that idea... I guess I feel too well to die. And secondly, I'm 71 now, and I don't want to die, but given a choice it's a lot better to die at 71 than 21 if you love life, as I have most of my life. At least you've seen the ups and downs of life. You've seen people pass on. You've seen people do very well, then you see them collapse like a house of cards. You wonder at the fragility of life.

_Do you feel like you've lived a good life?_

Oh I have. By and large I have. I've lived a _contented_ life. I think so. I was pretty ambitious when I was young, and I guess in my late thirties I began to see so much
of the futility of it, and I found my enjoyment in playing golf and having a few beers and taking it easy. When I retired eight years ago I was earning $50,000 a year. If I'd put my nose down to it all along as my colleagues does, it'd probably be double or triple that. But I saw, I think, that the extra money that I could earn was not going to bring me any happiness. I was able to survive pretty well on what I had, and my wife was working. We were never in our entire lives in any financial trouble. We were always ahead of the game.

Support Group: (Mr. Galloway had been going off and on to a support group specifically for people with colorectal cancer.)

As regards the first time I got it and ever since, I've never been depressed. At least I'm not conscious of being depressed. Some people do. Sometimes it would depress me... It didn't depress me, but sometimes I would think when I go to these support groups, "Why doesn't it?"

I've wondered myself what kind of a person I really am. I wonder about that. And I think I've come to the conclusion that I'm not capable of deep emotions. When something strikes me, it kind of bounces off me. Maybe that's a good way to be. Maybe when I was a lot younger, I was different. I can't say that. I don't really know. But there isn't a deep emotional feeling in me about this cancer. There isn't.

I don't appear to have the depth of emotion in these things. Not that I'm not caring. I'm a very caring person. If people have problems, I go out of my way to help them. If I didn't have my kith and kin here, I'd show emotion and feeling. But in this case, it's like it's a ping pong or something going off my head and it doesn't penetrate me, the seriousness of it. And I think that's because I thought or think that I'm not going to die of cancer.

...
When I went to the support group, I didn't know what I was going to get into when I went. Support one another. Well, I'm more a task oriented person for support than for verbal support. If they want me to drive them somewhere, or if they want any information that I think would be helpful to them or anything I could do on the physical world to make their lives easier, I'll do it. But I don't have or don't express anyway... don't have the ability for small talk about support. It's not me.

You also said you went to the support group because you found it useful to hear other people's reactions. I was wondering what you meant by that.

What their reaction was; when they got cancer, how they were living. And what happens after a while is: It begins to pale. Because others are still living and they're still doing their own things. I'm not very good at giving them encouragement, and I know in so many of the cases encouragement is not going to do anything. It's kind of the will of God as I see it. There have been cases I know, they're miraculously cured for whatever reason. I don't know. But I'm not very good at expressing sympathy. Maybe in many of the cases they don't want sympathy, they want encouragement or help, and all I can do is tell them my story.

It may be some help to some of the cancer patients who come in to hear what the other people have, to know that they're not alone. When you listen to them, they're very often so much different, different types of people. Their outlook is different. Their cancer is different in many of the cases. Some of them get very upset. Some of them don't seem to show very much emotion. You don't know whether they're concerned, to use that word, or whether it hasn't dawned on them, or what it is. Or maybe it's their basic outlook, I don't know. After a while -- and I never said this to Dr. Farr [the group leader] -- it gets tiring, and there's no purpose in it as I see it.
He'd be five or six years older than you. And Bob was 39. But seeing these young fellows there going like that, that was a shock to me. They didn't die in front of me, I just was told by Dr. Farr or whoever. It just was a shock, a real shock. But again, I didn't dwell on it.

It doesn't stay with me very very long. I suppose the reason for that is: Inwardly I reason there's no purpose in thinking about it. I never reasoned it out, but I suspect that deep in me, that's my reasoning: That there's no purpose. It's a dead end.

It does provide value to me, some value, but it depends to a large degree on the cancer you have or have gotten rid of. It depends a lot on that. There is some value in listening how people dealt with things. The value in my case is offset a bit by the two things which I mentioned. To repeat them: You're well and the others have problems. And the second thing is dealing with someone who's there who's no longer there. They're either dead or on their way to death.

Wife / Family:

My family has been very supportive. Now what do I mean by these catch-phrases? What I mean is: my wife has been very helpful to me, making my meals, seeing that I did what I was supposed to do. And caring for me. I must say it: A lot better than before we ever had this thing. So that has been a good point about it. She was with me this morning.

....

My wife came [to the hospital] almost every day. My sister came a lot, and two or three of my friends came. I didn't lack for visitors, and small talk takes up a very short time. And then my wife says, "He's ordering me out now." I got tired of the small talk, and then I go back to listening to the radio or reading the newspaper. But of course I appreciated very much the fact that they came, and I think my wife was extremely
comforting to me during my illness and subsequent. She's back making my bed. It's not because I have any money. Whatever money I have she'd get it anyway. There's nothing I could do about it. [laughs]

....

I told my wife, my sister. I told my brothers and sisters in Ireland, and I told my friends across here [points across street]. I don't hide it. I don't think it's some terrible disease like gonorrhea or syphilis or something like that. I have no hesitancy. If someone asks me, I tell them. Not from as sense of bravado or anything, it's just the truth. I know it's not contagious like the other diseases I mentioned [chuckles].

I told them over in Europe. I told one, then the other would tell the others. Our phone prices are a lot less expensive than theirs, so I called. Then I wrote a series of three letters to them. To each of them I wrote the same letter, and I kept a copy of it. I brought them right up to date when I first caught it, what the story was, the second time and then the final time, as to what my situation was. I wrote everyone the same letter, so they knew exactly about it, because after a while when you tell a story, by the time you talk to somebody here, God help us! The guy next door mish-mashes a lot of it. By the time it goes down the ocean, there's just no relation between the story that's told and what really happened! So I thought I'd write them a letter.

And you said your wife and your son and your siblings, sisters responded...

They'd do anything for me. I knew they would. I expected them to be very concerned. I'd be amazed if they weren't. Not that I'd been particularly good to them or they to me, it's just that we're family, that's it. Because we all grew up together. A relatively small house. There were seven of us. A three bedroom home. Four girls and three boys.

....
They [brothers and sisters] didn't say very much. They're smart enough to know. They didn't offer their condolences. They weren't cheery. They had what I thought was a very right attitude: They listened to it, and they were sorry to hear it, and then they would ask me some questions about it. Then I'd talk to them over a period off and on on the phone, but they had the right attitude. They didn't say, "You're going to be all right," or something like that. They know who they're speaking to, and that doesn't make any sense. The medical condition is going to be determining how everything will work out.

The best questioner of the whole lot was my sister, because she's a bulldog. She would ask everything about the thing. And she's not asking just for information, she's trying to understand the thing in detail. And then she would come up with a suggestion, and surprisingly good ones. My sister's very thorough about that. She would have made a great FBI person or CIA or whatever. She's very good at questioning.

*Practical.*

Yes. Questions that are practical questions. She's a warm person again, but she doesn't give much outward show of that. Some, yes she does, a lot more than I do, but she is a very practical person. She'll come up with very practical suggestions about things that you wouldn't think she'd know about.

My wife never asks those... That is the way she is built. It's the way she is built. She doesn't ask any unnecessary questions, and nearly all questions are unnecessary. She carries her grief. She doesn't show it at all. She doesn't show any sign of religion whatever. She doesn't wear rosary beads around her neck or a prayer book or anything, but she is a religious person. She goes through sacrifices, whether it's raining or whatever, to go to church, to go to Mass, to be on time, to say the rosary. I know she does those things, but you hardly even notice her doing it. But I caught her up [laughs] shall we say.
And what about when you were sick? Did you find out if that was scary for her?

I'm sure it was, but she doesn't say very much about it. But I know it was. She's just that type of a person. She's not communicative. She doesn't believe in small talk. She's not a demonstrative person at all. I've never plumbed her depths, shall we say.

What was the reaction of your neighbors when you told them?

Well, they'd exhibit concern. But I told you what I feel about concern. But my family was different, my wife and my son and my brothers and sisters. They would call up continually to ask how I was and make suggestions and all that. I don't expect the man across the street to do that. They just feel: The poor guy got it, or whatever, and go about their business. So, you can't expect anything much beyond that in a society like ours. There's three-quarters of a million people in the city; you can't expect that. The only one you can expect it from is your family. Maybe with one very close friend or two close friends. I don't think anybody beyond two close friends.

Son:

He's very sorry to see me... He visited me a few times in the hospital, but he's not a very demonstrative person. I don't mean by that that he doesn't care. I know he does care, but my relationship is just the same as it was before I got sick. No change.

Doubt and Certainty:
Medical treatment:
You have to seek medical treatment first, because you don't know the parameters of medical treatment, what it can do for you, or what it cannot. After all, you're a lay person. You read these medical articles in the newspapers and you find out. "OK that's fine."

Come down right to the last part and you find that it's ten years from now it may come out. It's gone through the FDA and the Cancer Institute or the Heart Institute, or the Institute of Health, and it's got years of protocols and all the rest of it. So we don't know. We don't know. Sometimes the physician doesn't know whether it's going to do you any good or not. If it's a hopeless case, he's not going to give it to you. He's convinced himself that there's nothing that man can do for you. Why go through all that?

I think if the knowledge was that perfect, they'd cure the thing. Cancer by and large is not curable. Certain types of cancer, maybe. I think they do the best they can with the knowledge they have, because they still don't know what causes cancer. They can tell you it's the carcinogens in the air, it's food, but there's no certainty about it.

The thing about chemotherapy is this as I see it: I believe in empirical knowledge. I don't believe in recommendations for treatments by people who don't have to take the knowledge. Chemotherapy from everything I've read can hurt people very much. But what is the alternative to it? To let the cancer grow?

[Sometimes] God only can determine what's the right course of action. The physician, of course, is -- what do you call it, the Hippocratic oath that they take? -- is there to save life. There's always a chance. Man doesn't know the answers to some of these questions. You have to make the best judgments you can, based on your experience and your knowledge and taking the patient into account. If you have terrible pain day and night, particularly if you're over fifty or sixty years or age, if there's no hope for you, maybe you shouldn't get the chemo. You can't play God either. You see there's no simple answer. There's so many things that are imponderable.
Physician reputations:

Dr. Williams is UCSF. The reason I went to him was [because] a nurse that was looking after this bag mentioned to me about him. She didn't work for him, but she told me that he was the tops.

In the medical field, whether the surgeon is a great surgeon or not depends on his reputation. His reputation can be created by many ways, including nurses' word of mouth. And they've got a physician that if many only know as a specialist in that area, they say he's a great physician. I don't know what constitutes first in their field or whatever. I just don't know. Mostly it's rumor, references by people who, very often who know as much about medicine as I do, which is very little.

Kristoff [a surgeon], I'm told... I mentioned to this young physician last night: He has a terrible patient manner. He's absolutely terrible, and she told me, she laughed, and she said, "The interns or residents go in there, they're afraid of their lives of him." He an abrupt kind of person. He's superb, she says, in his field and he doesn't broach any small talk or anything like that. Abrupt kind of a person. Superb in his field.

I said, "How do you know that? He's superb in his field? You heard from others. How do they know? It's word of mouth. Somebody told you. Very often those people who say that are not competent to say that. They've heard it from somebody else." Now if his assistant, if he has an assistant there working with him all the time, and that assistant works with others performing the same type of work that he does, they generally can tell who's the better person. But the difference between them might be so small. Maybe Dr. Kristoff is marginally better than the other fellow. I don't know. So these are questions that it's easy answering, but you don't really know.

What was her answer?
She didn't give an answer. She didn't have an answer to that. His reputation had preceded him. And his manner, certainly; they all agreed on that. They had some evidence of that. His manner was abrupt, brusque kind of person. Poor with patients. I noticed that the two times I visited him. It was unbelievable ... bup bup and out the door. That was the kind of man he is. I can't go around looking for the best liver expert to put stents in your liver or whatever else he does. I go to the best man, whether he has a bad manner or a good manner. What I believe to be the best man, I go to him. And he's the guy, so I go to him.

Sincerity:

Part I:

I begin to doubt a lot of others that say, "I'm very concerned about you" or something like that. I wonder sometimes if these are just kind of buzzwords people have learned.

When you see the people who mouth these type of things, "We're very concerned about..." or "We're concerned." Would they walk to the park to the store to get a loaf of bread for you? Would that be their level of concern? Or what is? More and more people say these things and don't mean anything. It's like, "How are you." Everybody says, "Fine." Even if you're falling off your legs, they say, "Fine." That's part of the ethos. What's the reason for that I don't know, because I grew up in an agricultural country where you tell the person what you felt, how you felt. But in our society here, it's so enormous, so large, 275 million people. Everybody with their own problems. The best thing to avoid all the problems is to just say, "Fine."

I wonder about that.

Part II:
The thing is that in the old days when you see a private physician, say my internist, a lady down here. Very nice lady. You talk to her. You sit down there and quietly talk to her and go over it... what your story is, whatever disease or sore throat or whatever else you have. And you get the sense that she is listening, and by God, she is excellent. Both these two women doctors, the one that's my primary internist, and when she can't come there, some days I get the other, Dr. Andrews and Dr. Jones. They're here in the Mt. Zion thing down here at Ocean Avenue. I think I notice about them how well they listen. They impressed more than anything about any the doctors. They gave me a distinct impression that they were listening to what I was saying.

*What gave you that impression?*

Their concentration. They looked me straight in the eye, and they're never been fiddling around or anything, just listening carefully there, concentrating on what I was saying. That's important that you get that impression.

**Communication with and within medicine:** *(Mr. Galloway was being treated in a university affiliated clinic by a team consisting primarily of an oncologist (Dr. Varga), a surgeon (Dr. Williams) and a Pharmacist (Dr. Boil). The pharmacist, Dr. Boil, handled most of the routine visits, which involved filling the pump with chemotherapy or water, depending on the phase of treatment.)*

Then you wonder... The physicians these days are running around so much and when you're talking you're either thinking or something else...

And very often, with the pressure of work, maybe they don't think enough about it, you know? And that's why it's particularly so when I go into a physician, sit down and he talks to me, and he brings out his papers. And the first thing he's fiddling around with
all these pages to try to put the thing in order to see, "Now, now what was the case with this fellow." You know? It leaves the impression that "Geez, he hasn't thought about me at all." That's one man's opinion. It gives you a poor impression. He's harassed so much he doesn't have the time or whatever else it is.

I might see [the oncologist] go by and say, "Hello, Dr. Varga." And he'd say, "Hello Mr. Galloway." He remembered me. I saw him once before I needed to be operated on by Dr. Williams. Then I didn't see him for months.

I was primarily going to Dr. Boil, the Pharmacologist. They are part of a team. What does that mean? How often do they consult? Do they discuss cases individually? What's the role of the oncologist, the pharmacist and God knows whoever else? The biologist or whoever is there. I don't know that. But I was given to understand that there's a team and there's probably more than... I don't know who else is in it. Are there any other teams beside his team?

Then when you ask the pharmacist how the situation is, the question comes as to whether he knows or is competent to answer you. He's not a physician, but he knows more about medicines and drugs than any of the doctors does. So one of the questions I had to Dr. Varga when I spoke to him last week: Was he aware that I had not been getting chemotherapy for nine months? He's well aware of it. I didn't know that.

The question arose to me then: If I had been getting chemotherapy over the nine months, would this cancer have come up again?

I'll let you in on something. Who owns those medical records that the doctor has? You think about who owns it [walks into back of house and reappears with a binder containing copies of medical records].
It's my understanding that those records that the doctor has are the same records that a lawyer has. A lawyer's records are the property of his client. Did you know that? The doctor's records are... you're entitled to get them.

Rather than the doctor telling me something... He tells me, then I go down to the third floor of UCSF and I go down to the medical records, and I go in there and I get a copy of my CT scan. It's all written out here. You're entitled to that. Just identify yourself, or whatever. Now this fellow, Charles Kristoff, that's the man I mentioned to you. He put the stents in my liver. Well, this guy looks like a mad Russian. You see him for two minutes before you go in. The next thing, you're anesthetized and you come out, and you won't see him at all. Generally an assistant sees you. He's a mystery. He's supposed to be tops in his field. This is the thing he specializes in, putting stents in your liver. And he put two in me at two separate periods.

Now, I did not know, I would have not have known from him one single thing of what he found. There's no way of knowing. I didn't talk to him. And then I go and visit my other doctor, that would be Dr. Boil. Now I didn't know whether he had a copy of this or whether Dr. Varga had a copy of it. You see, there's Mt. Zion, number one -- that's out there on Divisadero -- the man there, that was where I had the colon operation. The doctor there or the specialist writes up a report on you. A copy of that does not appear on the screen in UCSF. It does not. It's like their own little fiefdom over there. So you have to tell them who you want to get copies. Now this one Kristoff, he's attached to both Mt. Zion and UCSF. I can tell you now, his assistant was Joseph James, and he sent copies of the report to John Varga, David Boil, Mary Jones -- that's my internist out here -- and the endoscopic suite, whatever that is. Now I didn't know a thing about any of the results of that. And, I didn't talk to Dr. Varga about it. Nobody asked me.

And you didn't know what Dr. Varga knew?
No. I didn't know. But I went down and I found these. Then I went down to Mt. Zion, and I got their copies of their files. Give them to you for nothing. As I said, you’re entitled in law to them. So now, here I see this one, this was done on December [reads]: "Tumor ingrowth with narrowing of the common bile duct. A new wall stent was placed inside the previously placed one in order to relieve the biliary obstruction."

Now here's his recommendation: "The patient should continue on his ciprofloxacin and should follow-up in the office in approximately one month."

I was never told I should go back in a month. Because I said when I came out from under this, I never even saw Charles Kristoff.

So that's a thing that patients need to be aware that they can get these.

**Explaining cancer:**

I suspect the reason I got cancer was it's part of my genes. My grandfather died at 47 of cancer. My great-grandfather died at 74 with cancer, both of stomach or duodenal cancer. My father only lived until 50 years, but he died of a heart attack. But there's cancer of other kinds in my father's side of the family. So I figured that's what happened. Although just a belief. I don't really know. I suspect there are many other children who have antecedents with cancer who never got cancer. They died in their bed or whatever. I just don't know.

**Personal Change:**

I suppose, you have to look at what kind of a person I was before I got ill. I generally looked at the silver lining before I got ill, and even since I got ill I kind of look at the silver lining. I suppose, I'm an optimistic person. It didn't depress me. It might have me down a little, but I was not conscious of being down, put it that way. People say
they're depressed. I don't know exactly, what do they feel when they're depressed? Do they feel life is not worth living? I never felt like that at any time of my life. Even when I was in the hospital, I didn't, no matter how sick I was. I never felt that way. I think part of the reason is, I mentioned to you earlier, none of these ideas penetrate very deep into that cranium of mine. It bumps off like a ping-pong.

The things I learned... More, fractionally more, about my mortality. I'm going to be alive, I think, for a good while until I get really old. And I'll just flop off, hopefully die a peaceful death in bed, without getting hurt or killed or go through any pain. I also recognized from visiting people in the hospital that I visited that last couple of years... I question some of the teachings of the church that I belong to about human life.

They are very much against anybody taking human life, even executions. I don't believe that at the moment. I believe if the person is in tremendous pain and there's no hope for them, there's no hope of being St. Theresa of Avila and being able to go on and offer this up to God. These people are in just tremendous pain. There's no putting them out of it. I think they should assist it. With proper supervision, with their family's approving it and the medical doctor, they should be permitted to die and life supports taken away. That's what I believe now. I believe that now more than I believed that before I got sick.

....

I think I have more empathy with others. I think so. Beneath my demanding nature or outward sign, I am very sympathetic to people. I don't express it very well. But I'm becoming more willing to go out and help people.

"Health:"

There is a time -- I'm not sure when it is -- you become more reflective. It comes with age. It doesn't come with youth. It comes with age. You think more about this
issue. You may not sit down, you probably will not sit down and go into a deep thought about it, but it'll hit you at various angles over the years about life, the value of life and how good it is to be in good health and be in cheer.

Actually that was a question I forgot: How would you define health?

I've thought about that. Health is really in the head. It's your mind. One man can walk down there with his one leg: It doesn't bother him. Another fellow walks down there with two perfect legs and he's concerned about something or other; he's not happy. It's your mental state. And your attitude, again: In part it's determined by your upbringing, by your experience. But in the long run it gets back to that thing behind your eyes, up in your cranium... How you look at things. One man can walk down the street, as I said, with one leg, and that doesn't bother him at all. Another fellow's running around with two perfect legs, running like hell, and he's not happy.

Coda:
[I] never felt bad. Not even from the treatments, just in the hospital. But I never felt really that... I was tired when I came out, tired for a good while. But it went away, and the only thing I think that they see is my tiredness over the past year or two was the ulcerative colitis.

This cancer may kill me, I don't know. But I certainly don't want to go through misery and pain and know that there's no end to it. If I'm not going to recover, I would want after a decent respectable interval to be taken off life support and die. These are tough decisions.

What was the name of the fellow in the old testament? Lazarus. There's a guy... You don't see anybody much with that name [laughs]. He's in the old Jewish Testament.
He had every possible disease, Lazarus, and still he didn't give up hope in God. I don't know much about Lazarus, but I know that about him. He had every possible disease.
Wendy Adams: Waging War

Wendy Adams was diagnosed with colon cancer with metastases to the liver at age 50. One year later, after two surgeries (one for the colon and one for the liver) and chemotherapy, she is currently cancer free.

A dynamic and social woman, Wendy Adams met with me three times, once each at my home, her home in Marin and her sailboat on the Bay. She was eager to include her husband Jack, a warm and soft-spoken man who was present at the second and third sessions.

**Diagnosis:**

During my forties I had been going into menopause. I have a very stressful job, which I kind of like. I'm one of these odd people that need a lot of things going on in their life to be real happy. You know, there's that little edge that you... Sometimes you fall over it, and that's not fun, but I like to be pushing right against it.

I was not feeling very good, not enough to ever say anything to anyone, but I thought, "Well, I'm going into menopause." I always gave blood, and I'd gotten where they said, "You can't give blood." That sort of was a strange thing to me, because I was anemic. But I was working really hard. I'd just gotten a promotion. I was spending a lot of hours working, so I thought, "Geez! I've run myself down here." But finally I decided I think I might need to go on estrogen. So I went down to see a gynecologist and had the blood test on that and had a mammogram. The mammogram showed something kind of strange. And at the same time, my estrogen showed up really low. So they put me on estrogen.

I did all this and then about that same time, articles started coming out that if you have breast cancer, some types of breast cancer are accelerated by estrogen. Even though I was really working these long hours and everything, it was just kind of nagging at me. So
I knew that I was turning fifty when the new year came up, and I made a New Year's resolution: I'm going to pull all my medical records together under one doctor and really pay attention to my health this year, see what the heck was going on.

_This was New Year's one year ago?_

Yeah. At the top was this mammogram that was kind of making me nervous. So I went to [a breast cancer specialist], and I explained the situation to her, and she said, "You can do three things. You can wait. They told you to come on six-month recall. You can wait and do that. We can give you another mammogram right now to see what's happening, or we can just go do a biopsy." And I said, "Let's do a biopsy. And then we'll know."

And it was from the blood test [from this] that went back to the internist that I went to, and she called me and said, "You know, this shows that you're really anemic. That means you're bleeding somewhere, and you don't have a uterus. So we need to pay attention to this. Do those stool samples and come in to see me right away, and let's talk about it."

So, I thought, "Oh my God, I've given myself an ulcer. A bleeding ulcer." I did the stool samples, and I went in. It was during her lunch hour when I brought them in, and she was training a new [technician]. She said, "Well, just come on back. I'll show this person how it goes. You just squirt this stuff on it," and I was standing there, "and if it turns blue..." And they all turn blue. She says, "Ummm... Well. You know..." Then she referred me to a gastroenterologist, Kramer is his last name.

So I went to him and gave him the history, and he gave me an upper and lower endoscopy. I was just so upbeat about the whole thing, because I just had no concept. I'm kind of a health nut anyway, so I had no concept that anything serious was wrong with me at that point.
(At that visit, Wendy learned that she had a tumor. A short while later, she was informed that it was cancerous.)

It was over the phone. I was so nervous about getting the news on whether it was cancerous or not, whether it was malignant, and I knew he had the news, and I kept calling. I wanted the news. I picked up the phone and called the secretary, and she said, "No. He's with a patient." And I said, "Well, I'll wait. I'll just sit on hold until you can get him to me."

And so finally he came on. He was not happy, but he said, "Yes. It is malignant." I said, "What's the bottom line. What are my chances." And he says, "It depends upon whether there are metastases or not. If there are, your chances are 20% chance that you'll make it five years. If there aren't, [they are] about 50%." My mind was starting to go a little whacko on that news, right then. And it just kept getting worse and worse mentally for me.

To tell you the truth, I hate his guts, and I know why: Because he gave me the bad news. And he's the one who said, "Lookit. This is serious." There was not a happy word from him. Consequently, I can't like the man.

I just kind of steeled myself. I thought, "My God. I've got to concentrate on getting, solving this problem here. No time to let down. You gotta stay going. Stay working on this."

.....

(Wendy called her son, Jim, who is finishing his training as an orthopedic surgeon.)

He said, "I'm going to try to come out and go with you." And just the fact that he said that felt really serious to me. He said, "Get all the reports that you can." In the meantime, he said, "I'm going to call around and see if I can get some names of some other people, and I'll bring those out with me. And you check out your insurance." He had a whole list of things for me to do.
That's when I started getting nervous, to tell you the truth. I thought I was invincible as a person. And from that moment on I just kept getting worse news. Every time I got worse news. One doctor or another doctor or another doctor. It just kept getting more and more grim.

So we got a CT scan. And again I went in. I laughed. I joked around.

Jim [was going to] be coming in, and we had an appointment. I'd pick him up at the airport, and we were going to see Williams [a surgeon]. So, I pick up the X-rays [from CT scan] and bring them home. And I can't not look at them.

Had you talked to anyone about them yet?

I had not talked to anyone. And I put them up on my dining room window, and I saw the circles and the little letters that were written out on my liver. I saw that there was more than one tumor on my liver. And it was right then -- we'll move into the emotion thing -- that I can remember I just stepped out. I stepped out of my mind. I said, "I can't take this emotionally. I'm not going to stay in. I'm going to observe this from afar." I know I'm back in and I'm back integrated, but I use that to cope. I just learned a whole new coping skill right there.

I was all by myself. But [my internist] did call me. And I said, "I know why you called me. I saw spots on this, but I want to talk to you about it." And so I did come in, and she sat down with me, and she cried. She cried. I still couldn't cry. Almost all last year, I couldn't cry. It was because it was that protective shield.

So then Jim came, and we went to see Doctor Williams, and they went through all of it. And he brought in Dr. Varga and Dr. Boil and said, "We work as a team." It was during a lunch hour and Jim just crammed us in there. They were just so grim. They said, "I don't know if we can do surgery. We want to do further testing."
I kept saying, "I want the facts. What's the worst thing that can happen to me?"
"If we do nothing, you have 18 months to live. If we can do surgery, but we can't resect
the liver, then we'll put you on chemo, and your prognosis is not so good as if we could
resect the liver," and all this other rigmarole.

One symptom I had was short term memory loss. I had noticed that in myself a lot.
I thought, "What's going on? Do I have brain tumors?" The first stand I took with the
doctors, I said, "Are you going to do a brain scan?" They said, "No. Because we'll do
your lungs and we'll do the ovaries, and we'll do the places where you usually have
metastases from colon cancer, but I'm sure there's nothing wrong with your brain." And I
said, "I want a brain scan." Because in my mind, I said, "If I have brain tumors and it's
malignant, then I'm going to go for quality of life, and I'm not going to have the surgery,
the chemo and all that stuff."

All that was clear. My lungs were clear. But they found three more tumors. So I
had a total of seven tumors on my liver.

**Surgery:**

Dr. Williams told me he would do this in two surgeries: One for the colon, and
then six-weeks later I'd have the liver resection, unless they found tumors in too much of
my liver. That would give him a chance to check the liver, to see how it was visually,
palpate it, and see if I was really in a condition to be able to handle it.

February 28th was my colon surgery. And April 15th was my liver resection. It
takes a lot out of you, but I did fine on it. And I am very hypersensitive to medications and
especially sedatives. So the morphine and the sedatives they use were awful. I had the
hardest time with that and basically did it on Tylenol. That's been my claim to fame
[laughs]. Not even Tylenol with codeine, Extra-strength Tylenol.

I feel safer. If I know the pain, I know the boundaries. If I'm masking the pain,
I'm thinking, "What is going on here?" I feel totally out of control.
I never did very well in the hospital, and as soon as I got home, I got better really fast. I started walking. I had all these goals. I knew that if I got up and moved, my body would heal itself.

It was that second surgery though that... I was very angry before I went in, and I was scared. First, that I would die in the surgery. And second, what they would find, because still, they don't know. They kept saying, "We don't know."

(The second surgery, Kay had 60% of her liver removed and all of the metastases.)

I was in the hospital eleven days with that, came home. It took me a little longer, but both times I was back to work before six weeks.

"Cancer:"

I felt normal. I felt fine. These people are telling me I'm sick, and I feel fine. And they're telling me I'm going to die. What is this? And the word "cancer," I can remember writing it down. I wrote myself this note and I put it up on the cabinet. "Cancer. Cancer. Cancer. Say that word over and over again so you're not terrified every time you hear the word." You know, so that you can get used to this word, because obviously you're going to be living with it here for awhile. But it's such a scary thing.

....

Everybody was wonderful and nice to me and everything like that, but after the pathologist first said that [it was malignant], I detected just a little bit of change. Almost like they were even nicer to me. There was a little bit of sadness. It's hard to say, but I thought, "I'll be God-damned. This is a Stage III."

....

[I was] very afraid. Today I'm very afraid that I'm going to die. It is the fear. I cannot explain to you the fear. I've never experienced terror before about anything like I have about the cancer.

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I think I keep it in a little bubble, because it came out again yesterday. I have this fear in this little ball that I keep in a bubble, and I let it out a little bit, but them I have to put the bubble back on it. So it's like controlling it; otherwise it's just totally consuming.

Dr. Hudson wanted to give me Valium. Of course I wouldn't do that. There's a couple of times when I totally broke down. One was right after I got home from Dr. Williams and Dr. Varga and Dr. Boil that first time. And the other time was right before the liver operation. That's when I let the fear take me over. And Maggie [psychiatrist friend] would talk to me. She lives in Portland. She called me on the phone. And she did come down and spend the day.

**Chemotherapy:**

So six weeks after the liver [operation], I started chemotherapy. And that was FUDR in the pump, and 5-FU and leucovorin in my system.

My side effects from the chemo were worse than they told me they would be. Now I continued working, all that kind of stuff, but I felt nauseas from the systemic leucovorin and 5-FU. I lost about half of my hair. Very very tired.

I can remember my goal was always if I could get up, get dressed and go to work, then I had a good day. And I can remember getting up and getting my hair half dry and laying down on the bed for awhile. We've got this plastic chair, one of those little deck chairs that I could sit down on in the bathroom. Those are the tangible things that show me that I was pretty tired.

....

When I got my chemo, I didn't like to lay down. I'd go out on the sun porch in the back, because I did not want to be like these people that were lying in this bed without any hair. They just didn't look like there was much of a future for them at that point. There
were people, I thought, "These people are a lot sicker than me. I'm not going to lay in that bed and pretend that I'm like them."

I wore my suit, my work clothes. I would go into work before and then go in, pull my blouse aside, say "Shoot me up!" And get my chemo and joke around with them and leave. And that helped me mentally to feel like I'm on the cure route. I'm not a sick person. This is what I'm doing to help myself stay cancer free.

*So not because you had anything left, but more just preventative?*

Again, Varga would say, "Well, there's no statistics that show this is any good." I'm thinking in my mind, "You're telling me that you're going to pump poison in my body and I'm supposed to feel better about it, but there's no reason. There you go again. You're not giving me any hope on this."

So I had to go home and make up what this chemo was going to do to my body. Meditate on it and try to change it, because I did not get that from Varga. I had a hard time bonding with him. I went in and saw him and said, "Look it. I'm fighting for my life here. Either we've got to bond, or I've got to get another doctor." And he said, "I'll do better." And, of course, he did.

**Explaining cancer:**

*Why do you think you got cancer?*

I think that it's a combination of: It's in my genes. That I've had a lot of stress in my life. That I happen to have the compulsive personality and thrill seeking personality that probably perpetuates that. And so there's that, and the fact that I eat a lot of meat. I grew up on a farm, and we had DDT, we had all this stuff that was OK to have then. And
I'm kind of a very kinesthetic person, so I like to get into the medium of what I'm doing. I don't shy away from getting dirty or painting my own halls or taking care of things where I am exposed to a lot. And I just think it's the combination of all that stuff.

I am a type of person that fits the cancer personality. Instead of blaming other people, you take things on yourself, that you could solve this if you really wanted to. I went through a divorce. I was married to a very possessive man, and so my image was never happy. A lot of mood swings. He was never happy with me, and I spent a lot of years, twenty years, saying, "I know that if I do everything right, I'll make you happy." That kind of stuff that I am way beyond that now. My second husband isn't... On purpose I shied away from any man that even looked like they had that kind of quality. And my second husband is very very complimentary to me.

**Support:**

**I. Doctors:**

They just never gave me any encouragement. I understand why medical science has to do that, because they're trying to keep themselves from being in a law suit, but they told me the worst. It's always grim, grim, grim.

Even if they would have said, "But you're really a young healthy person. I think you can do this." If I would have just heard that, it would have helped. I heard that from my kids and my son and my friends, my husband. But the people who are making these decisions and invading your body didn't give it to me.

*And what kind of information were you getting instead?*

Statistical and like chemotherapy. They don't know whether it's going to work.
For a long time I didn't have any hope. I was so scared I was going to die. I didn't want to reject that on the outside, but inside I just didn't have any hope, couldn't see any hope. I would try to read these statistics, and I'd read once it gets to the liver, you're in deep trouble. It's not what I want to hear.

Ideally it would have been to have been matched up with someone else who had had stage three colon cancer and survived. And they're out there. Six years. Ten years. You know?

JACK: I remember, it was like the second or third time that we were in visiting Williams, before, I think that we had even convinced him that the surgery was a positive direction to go. Each of these sessions were probably an hour of talking, just telling us bad news. At all three sessions. So at the third session, I said, "Tell us a success story. Tell us one of your success stories. Tell us about a survivor. I want to hear it." And, you know, he couldn't. He couldn't! He couldn't think of a success story! He stumbled and bumbled! And his eyes [rolls eyes around] were thinking, trying to come up with one. And he couldn't do it!

WENDY: That doesn't scare you?

JACK: I'm sure there's probably a thousand of them. But his mind-set didn't go in that direction at all.

WENDY: Boil asked if someone could talk to me.

JACK: They're using her as a success story. Which is positive reinforcement to us, but it's kind of like, "Gee. Is this the first one? Is she the first one?" [laughs].
II. Wendy's children:

WENDY: [Jim] said, "I'm going to get a leave of absence and I'm going to come out and I'm going to stay with you until we know what's going on. And I'll stay with you until we know what's going on. And I'll stay with you through the surgery, mom, however long that takes." Aren't I lucky?

JACK: And I truly believe that he was instrumental in the beginning of truly saving her life, because he really came in and took control. Managed it, really, when both Wendy and I were very fearful and frightened and confused and didn't know what direction to go. He pretty much came in and managed the doctors. [The doctors] saw him more as someone getting in the way of their normal routine. Unfortunately, their normal routine was -- as we saw it -- they paint a pretty bleak picture for Wendy's future and what they could do for her. They were not very enthusiastic about the resect of the liver, etc. until Jim really came in and forced the issue.

What were they going to do instead?

JACK: I'm not too sure. I'm not too sure of that. They kept telling us that essentially there was a formula that if you had more than three metastases on the liver then it probably was spread to other portions. So, in essence, that was the end of it. At that time, I think they were talking about nine or something.

WENDY: It's like my kids made a pact that until I got through both surgeries and down the line... There was one of them here with me all the time. My daughter stayed day and night with me at the hospital. I just felt so loved. I don't know for sure, but it's like -- I don't know for sure -- they talked and said, "Jim will do this, and then he's got to go
back to school. And she can take this..." You know, planned when they would be here. It was a very comforting feeling, the first time I felt that my children were taking care of me instead of me taking care of my children.

**Jack:**

**JACK:** It's turned our life upside down. Wendy was concerned that "I'm going to die." And a big underlying theme of life expectancy obviously haunts her, haunts me, and it's almost like she sees her destiny as death. And my destiny is loneliness. I don't know what the greater fear is: Her fear of not living or my fear of being alone. The fear of loneliness is very traumatic for me. It's almost makes me go back to a time after my divorce when I was alone and how sullen I became. I'm not good at being by myself.

Wendy came into my life, and my life changed. And when I thought of losing her, I just was blown away.

I think we've grown to really appreciate each other a lot more. Just recently Wendy has developed a greater lust for life. And that has sucked me into getting out of my level of complacency and a level of routine that had grown over our years of marriage. So she's turned my life around and made me aware of every day is a gift of God. So it's changed us. That's been the good part. The plusses.

Do you think your paths are diverging because of this?

**JACK:** I think that they were leading in different directions until, in essence, I felt Wendy get a wake up call. She was moving on in another direction, and it scared the hell out of me, which, obviously caused me to reassess my life and what was really important. And obviously the most important thing was her, our relationship.

Wendy's always been into hiking, and I've always been the one that said, "Go. I'm going to read a magazine." So now I go with her. And I've changed my diet. We're
kind of like doing the same thing, eating the same thing. I've lost a lot of weight. I feel a lot better. In many ways it's been a resurgence within ourselves. Enjoying life again.

In so many ways as Wendy was moving off to find new things to enjoy life to its fullest, I found myself struggling with wanting to spend more time with her and needing her and moving off in another direction. And so there was... it was kind of, "If I don't get on the train here, I'm going to be left behind."

Waging war:

WENDY: I started my own little program. I read everything I could get my hands on, all the alternative medicine things, asked people about things, started taking herbs, changed my diet.

I got manic instead of being depressed about it, saying, "Hey wait a minute. I'm not letting this thing get one step up on me." This is war. I want my life. I love my life. I want to live. I want to see my grandchildren grow up.

I called my one daughter who's been married for five years. She said, "What can I do mom?" I said, "Go off the pill today. I want a grandchild." And I would never have said that to one of my children, but I did become very selfish that way, saying "what do I need to make myself get well."

I went to a visual imagery, guided imagery counseling. I still use her, and that has been very helpful for me. The one son-in-law got me a Rocky tape, because I said, "These are the tapes I want. I want the things that reminded me of when I was young and vibrant. I want some rock-and-roll tapes, boogie stuff. Give me 'Proud Mary', 'Rocky tape'" and I took it and I taped all the war songs into that.

I made up my own imagery, meditation of how I got these "W" cells that go out after the "B" cells. When I first saw the picture of the tumor, I named it "Bufus." And the "B" cells are the bad cancer cells and the "W" cells would go after it. There were two kinds of "W" cells. There's the kind that eats them and holds them, and then the water would
wash them out of my system. And there's the kind that has a little thing on the end, and it would like dig out and chip them up, and the other ones would come and get them. It was very vivid.

I ended up, instead of having a God, I have five generals. And the generals are like the management team at the bank, their personalities, because I think the bank's well run. And there's the one that's really good in the systems and one that's really good in finance... I would make these generals in charge of different parts of my body, and I'd meet with them before, and I'd tell them to go out and build more white cells and go out and get those B cells.

The first song is where I'm talking to them, and I'm telling them that I want them to build more "W" cells. I don't know if you remember Rocky or not?

*Rocky the boxing movie?*

Yeah. "Eye of the Tiger." There's a thing where the music goes up, and I would visualize the white cells just multiplying like you wouldn't believe, the "W" cells just swooshing up my body and filling my whole body. I've mostly concentrated before the first surgery on getting rid of those tumors.

I did this probably an hour a day. Now by the time I went in, after they did the surgery, they said, "You only have four instead of seven." And, of course, there are all kind of medical reasons why that may be true, but I told myself, "I got rid of four those seven before the surgery ever came." One more power thing that I did for myself.

*Had you been working during this time?*
Uh-huh. I begged them to let me work, because you might have noted that I am anxiety prone. The work would make me think about something else. Otherwise, that's all you think about, is the cancer.

I would do the Rocky tape on my way to work. I just had a little routine, I would get in the car and do my little affirmations. Then I'd turn on the Rocky tape and play that on the way into work. During the middle of the day at work I had a rat that I would lay down on, and I'd do the breathing exercises.

....

[Now, after the surgery] I strive to keep a purified image. I use affirmations a lot to do that. I do organic foods, and I shy away from chemicals and all that kind of stuff, thinking that I want to keep my body as pure and healthy as much as I can. I'm anxiety prone, and it creeps in. The fear creeps in, and I use the imagery, I use the meditation, I use all this stuff to keep the fear at bay.

In my imagery we're working on trust. I've never been a person who's been able to trust very much. But I've always felt I knew I could count on myself. Now I can't even count on my own body. I can't trust my own body. And so that's one of the things that I'm going through, I'm working through. It helped me rid myself of some things that I've dealt with probably since I was a child.

**Personal change:**

*I'm curious if there's anything good that comes of having cancer?*

WENDY: A lot. That was what I was trying to make as the theme of the party, but I couldn't think of the word. It's like a paradox. People have reached out to me. The quality of my life is so much better. I don't drink at all now. Very selfishly of late, I just

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1 One year after her surgery, Wendy had a party to celebrate one year of being cancer free.
told my husband, "I don't want you to drink either." Because I want to change our lifestyle. Because I don't want to do things where I'm sitting around people that drink. And there's so many other fun things. We could be out sailing or doing something else that we like to do.

We're both committed to quality of life.

Were you before?

WENDY: We thought we were, but we've changed the criteria.

....

WENDY: I'm much more spiritual. I realize the importance of that side of your life. Mind, body spirit. It's very very crucial. I pray a lot more. I think that yoga and meditation are spiritual activities, and they get to the spiritual side of yourself.

And I've always appreciated nature and loved it, but I'm much more... I find God in nature. And much more focused on that when I'm in nature, and I find that you can find altars, and I kind of look for altars in the forest or at the beach. That just happened. And I find that very spiritual.

Did you change your behavior at work?

WENDY: It's been very hard to do. I really haven't. I have a very strong work ethic.

JACK: She's back to sixty hours a week.

WENDY: It's very hard to do. Very strong work ethic. I tie my self-worth into work. All those things you say you shouldn't do. I'm looking at maybe I need to change
that. If it would save my life, if I could believe it would keep me from ever having cancer again, maybe it's something...

**Limbo:**

**WENDY:** I don't feel cured. I have this sense that there's probably some lurking cells that I gotta be sure that they don't bond together and make another tumor somewhere. There are random "B" cells, and that's why you have to keep sending those "W" cells out to gobble them out. That's why I have to keep drinking a lot of water. I studied what kind of purification process to use, and I boil the water. I mean, I'm fanatical. And I accept the fact that I'm fanatical. I say, "Lookit. If I change my life dramatically enough, I'm not going to have cancer anymore." If I go back to my old ways, I might.

This is my, this year's New Year's resolution, to do what I need to do to stay cancer free. And that means everything else is secondary. Everybody is on alert. So it's a very very self-centered, very selfish thing.

*Where are you right now?*

**WENDY:** Mentally? Afraid. Very afraid. I'm feeling cheated since I've come out of the chemo. I started chemo in June, seven months of that. It's just like, after it was all over you feel abandoned by them. I still have this boomerang over my head, this doomsday over my head that my body could start building cancer cells and building tumors again. And yet, I'm not taking any chemo. I'm only seeing my doctors to find out if there's something wrong with me. You just go in and they take a picture. What does that tell you? How far along is cancer before you really know that it's coming back at you again?
JACK: We had this core of medical professionals that had been guiding your life for a year. You have this whole program and schedule that has been taking care of you, and you've been almost a robot under their control. And then all of a sudden, "Hey, see you around."

Obviously they're saying, "Hey, there's nothing we can do for you at this point, because there's no more cancer." The positive of that lasts for about maybe a half a day.

_The reason you stopped wasn't some ambiguous point. It was because you had no at least visible cancer. Have you internalized that?_

WENDY: Honestly, I think I'll get there, but it's still big on my mind. I don't forget about it for very long periods of time. [I think about it] probably twenty times an hour unless I'm really engrossed. And that's why I like to work.

JACK: It would be a little different if they could say... in essence, if they blessed you as cured, and you walked away and said, "Well, that's the end of that." But they say "There's no more cancer, but there's a chance of reoccurrence over the next year. Therefore, we want to see you quarterly." And so they may shoo you off with this last sentence stuck in your head. Now I've got this level of anxiety as to "Is it going to come back? And when? And how? And where?"

WENDY: Jim says, "You should act like you're only going to live two years anyway, mom, and do the things you want to do." There's got to be a balance between making long term plans, because that makes you mentally know that you're going to be there in a long time. Jack and I are making plans about two years out, not really ten years out.
As I come up to this test, I think about death a lot more. I'm probably more on the one day or short term, or something like that more. Maybe I'll calm down. I think I can get back in harmony as soon as I can get through this test and get good results.2

I guess I've bought into the statistics. If I can get out there five or six years... then I think I've passed it.

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2 Wendy had an upcoming quarterly CT scan and CEA test. Both were normal.
Alan Johnson: "I Just Got Hungry"

Alan Johnson, 64, experienced the most severe symptoms from his colon cancer of anyone that I interviewed for this project, symptoms that he tolerated for over a year before he sought medical attention. Curiously, he is also the person among the seven with the longest disease free period (12 years) since his initial diagnosis and treatment.

Mr. Johnson suggested we meet at the departmental offices of my program in the university, where he also passes through on business. In discussion he was warm with a ready laugh and was amiably vague in response to the more personal questions.

Onset:

The first indication I ever had was: I used to give blood at the blood bank, and I went once, and they sampled it, and it was breaking up. And they told me that I wouldn't be able to donate blood. That was the very first indication that I ever had. I think that was August 1981.

At that time, I had no illness. I was fit and had lots of energy, so I immediately decided that I would cure myself. My body probably needed lots of iron, so I started eating spinach salads for lunch and decided: This will take care of everything. I felt if I eat things that are good for me, my body will overcome it. I've always overcome any illness before. So, this is just another one of those things that maybe if I have an extra hour's sleep at night, take it a little more easy, then my body's going to take care of it.

And then the next indicator was: I was urinating at a hotel in southern California, and suddenly I felt something in my pants like diarrhea or something like that. And when I checked, it was bloody. When I had the blood was 15 months before I had the surgery.

I didn't have continual nausea at that point. I do remember once in a while I would throw up. After I saw the blood, it seemed to me that my stools became stringy. Wiping,
whether it was my imagination or not, I felt there was a little lump somewhere there. I suspected that I had a tumor of some kind.

And then probably almost a year later, I decided I have the flu. And this is what the indications seemed to be to me: I wasn't feeling well. I would throw up. Everything that I swallowed came right back up again.

It got to the point where I was vomiting my own feces. I was operating the cafeteria down in the basement here at the time. I would just keep on working, and I wouldn't eat anything before lunch time, and then I'd think, "OK, maybe this will stay down." And I'd go into the toilet and be sick all over again. Even though I wasn't discussing it, it's very difficult to conceal the fact that you have lunch and immediately go to the rest room, and someone else comes in and you're vomiting in the toilet. And I was still working. [chuckles]

I switched over to liquids, thinking, "If it's blocked, the liquid can trickle down past it." It got to the point where even that didn't work very well. That started to happen probably about September before my surgery. So that would be, I think, September 1983. [Five months before diagnosis and surgery].

I had not gone to a doctor in all of this time, because they tend to give you bad news. I thought, "Well, its probably time to go to the doctor." But I still kept delaying it, and my wife called our family doctor, and he said, "He'd better come in to see me." And she said, "I can't get him in."

My doctor said, "When he's weak enough, he'll get here." [laughs]

**Delay in seeking care:**

*I guess one of the things I was thinking about was...*

Why the hell didn't I go to see a doctor! [laughs]
What was going through my brain was: I don't really want to know, and maybe this would go away. I have always been fairly hesitant to go to doctors. And I think that this is a masculine thing. I told some other friends who saw that I wasn't all that well, and they encouraged me to go to the doctor, and I just didn't want to. Including some doctor friends. [laughs]

A doctor in Concord who was a friend of mine looked across at me and said, "John, there's something wrong. You really ought to go to see a doctor." And I thought, "Dave's specialty is a heart surgeon. What does he know about my stomach." [laughs]

Did the idea of cancer occur to you?

It probably did, and I probably didn't want to accept it. I think possibly that I suspected that I was very ill, but I did not want to know that I was very ill. I think somewhere along the way, I just did not want to accept it, that I could possibly be so weak as to have cancer.

I don't think that I wanted to believe that I had cancer, because I had a number of friends who died of cancer. And most of my life, I've been around people of the medical fraternity, and very often over dinner, and they'd be discussing surgeries where they opened someone up. This must have been the early 50s, late '49, where they opened people up and they just had to sew them up again because everything was too far gone. Or some of them theorized that sometimes when you open people up, whether it was when the air got in there, then the cancer would really start to spread.

And I had decided that if I find out that I have cancer, I won't let them operate on me. I would rather just die.

Diagnosis:
So I went to see [the doctor]. Initially, he said, "If there are some small polyps in there, we can actually do it right here in my surgery. We can do a colonoscopy and remove them." Then when they did all of the appropriate X-rays and etceteras, they came up with quite a large tumor in there. I said, "Well, I suppose we'll go for that colonoscopy." He said, "No no no. [laughs] That's fine for a little one. What you have requires surgery."

They said that I had this tumor of so many centimeters, which didn't mean much to me. It didn't sound enormous, you know? If anything, I would probably look at my thumb and say, "It's smaller than that. It can't be much." But it was sufficient that it was blocking the small intestine.¹

I'm from Northern Ireland originally. I had friends over there who were surgeons, and I said, "Call Willoughby Williams," who was a surgeon over there, "and I'll fly into Belfast airport and go directly to the hospital." And he looked at me, and he said, "I don't think you'll make it that far. You better go into a hospital here." And I said, "When?" He said, "This afternoon." [chuckles]

I was so weak that I could hardly hold my head up. They made arrangements for me to go into Veterans Hospital, and I was driven up there, and I couldn't walk to the door. They had to bring a wheelchair.

**Surgery:**

It happened pretty fast. He was right. I was so weak at the time, I could hardly hold my head up. They said, "OK, we'll prep you." -- This was on Friday -- "and next Tuesday we'll do the surgery." They started prepping me, but on the Sunday evening I started to shake. I hadn't had anything to eat, but I was retching, etc. So on that Sunday evening about 9:00 at night they took me into surgery.

When they came to take me down to the [operating] theater, there were two nurses, and they said, "We may have to help to get you on the gurney." And I said, "Don't worry

¹ Later, he expressed uncertainty as to whether it was the small intestine or large intestine.
Chemotherapy and radiation:

They decided that some radiation therapy on my kidney was what would be required, because they couldn't cut where the tumor had touched. They just had scraped it.

[I had radiation] on my kidney for three weeks, five days a week. Most people say that they feel ill after it. I was just hungry after it. I would drive up to Martinez. They had the little indelible pencil in X on me. I'd hop up... I was probably on the table for two minutes at most. And then I would go down to the cafeteria there and buy myself a hamburger to eat on the way back. I just got hungry after.

Other people that I know who say they have to have radiation therapy or something like that, I tell them about my experience and say, "It doesn't mean that you're going to be sick. It made me hungry." [chuckles]

I would just drive up there, arrive at approximately the appointed time. They take me right in, point the thing at me and say, "OK, we're ready." And just: Zzzzzzzzzz! OK. "See you tomorrow."

Colostomy: (For two years following his surgery, Alan had a colostomy, which has since been taken away and his colon reconnected.)

One of the things I didn't mention to you: For two years after my surgery, I did have a bag on my side. When I think back, having that reversed may also have been a contributing factor to snapping me out of [my depression], because I hated that. Primarily because if I had the bag on my side, and you and I were talking, I'd always be watching your face to see: Is there an odor going over there? That always bothered me when I was sitting in a meeting or anything like that. I kept thinking: "Am I used to an odor and other people are getting it?"
I was always watching that person's face to see if their nose wrinkled. It bothered me to stand close and talk to anyone for any great period of time. If I was going to have a conversation, I preferred something like we are. I'd be far enough away from you that if there were any unpleasant odors, you would not be able to detect them. That was one of the things that was uppermost in my mind.

*Did it actually smell?*

I don't really know. [laughs] But it bothered me with the idea that it could happen, because there was no control over it. When you're sitting and talking to someone and you start feeling the bag filling up. [laughs] You think, "How do I excuse myself here?"

I felt very embarrassed about it. A couple of times it came so violently that the top of the bag came off the sealing thing and stained my shirt and clothes, but I don't recall that that happened in this type of situation. It happened maybe when I was driving along in the car or something like that.

....

When people ask me about [the colostomy], I say, "You really don't understand what a great pleasure it is to take the newspaper into the toilet on a Sunday morning. Unless you haven't had that opportunity for two years!" [laughs]

**Limbo:**

When I was leaving the hospital, I was told, "If you survive for five years, you can consider we have it." And I think I was in a depression for about three of those years. And I hadn't realized until afterwards that I was in a depression until I started coming out of it. During that period of time I wasn't the same personality that I had had before.
For example, I would say, "OK. I've got to get to work. I'll go and visit some customers." I get in the car, and as I was driving down there, I'd look at my watch and say, "It's 10:00 in the morning. They'll be getting ready to go to lunch pretty soon. Maybe I'd better not call on them until after lunch time." So I'd just sort of drive around a little bit. And then, "Oh they're probably pretty busy." And I would spend my time just unprofitably, sort of mulling around and thinking, "Tomorrow I've got to snap out of this and do better."

[At the time] I didn't put it down to depression, because I could always give myself a perfectly valid reason for not doing a thing at that particular time. It was only afterwards that I realized that I could go for a whole day just driving and saying, "I have a reason for not doing this now." Where my normal routine is: There aren't enough hours in the day to get all of these things done.

I think that one thing that set it off... When I was leaving the hospital, there was one nurse who came to me, who obviously was mixed up, and she said, "Oh. You're going to the hospice, aren't you?" And I remember a feeling in my stomach: "Oh, they haven't told me what's really going on." It took three years to recover from [that comment].

*Did your wife or others around you make note of your depression?*

Yeah. I don't think that they understood what it was. I think that they thought I was just being lazy or something like that, which was uncharacteristic, because for 20-odd years I got up at 5:30 - 6:00 every morning and [I'd] go to work and work 12-14 hours. She would say, "Why don't you go and do something." And I'd probably be irritable with her if that came out. But I know that I had a completely different personality during that time.
I had sort of set a five year time limit on myself. During that first few years I was sure that there would be a reoccurrence or something like that, or they hadn't got it all. It was only when it started to come almost to the end of five years that I snapped out of this and then recognized that I'd been in a depression.

*How did you come out of it?*

I think that after a period of time, I found I was still alive. And a friend suggested I come to one of these lectures, motivational type lectures, didn't ask me, just said, "I got us tickets to go to this on Saturday night." In the past I'd been to motivational things, and yet I'm a skeptic as far as psychologists and psychiatrists are concerned, but I wasn't really doing very much anyhow that evening.

Whether there's coincidence there of not -- and I do not believe in psychologists or psychiatrists -- but I believe that starting with that lecture just gave me the little bump at the right time. There can be more factors in it than I actually remember, but it was somewhere around that point that I decided: "OK. I've been in a depression. Snap out of it." I said, "I've got to do something about this." I found myself OK. When I set out to see a customer, I saw the customer. [laughs] It wasn't until I snapped out of the depression that I realized I was depressed.

**Financial impact:**

Between [the cancer] and my depression, that just ruined my business and my ability to earn money. It wasn't the bills so much because the Veteran's Administration took care of me, but it was my inability to earn money. That ate through our savings entirely during that period. We had sold our house just a short time before this happened.
This was just the time that values had rocketed. We had sold the house. Whether that was a blessing or not, we had quite a bit of money from that.

*Mr. Johnson also had to borrow money from his children during his period of depression.*

I think I would ask them [for money] and they would willingly give. That's why I say my personality was completely different during that time, because that was completely alien to the way I'd been before. I was brought up that you don't discuss finances with anyone, and you'd sooner die than go on welfare or borrow money from someone. That was considered to be a sin, and yet here I was doing that. That was one of the things that after I snapped out of it, led me to believe I was in a pretty deep depression that I would do something like that.

**Life with / after cancer:**

That's been twelve years ago. I've had several polyps removed [since]. They started off doing it [colonoscopy] every six months. Then every year. And this time they said, "Well, maybe we should wait five years." And then they said, "Well, no, because I'd had that one thing two years ago. Do it again."

Almost every time there has been a polyp. And the one that was malignant was a flat polyp that was missed on the previous occasion. That was three years ago.

There was a surgeon in the system who called me, and he said, "Well, really we ought to open you up and go in there." So I talked to a friend of mine who's a doctor. He said, "He's probably a resident who needs the experience." [laughs]

So, it was one of those things and I thought, "I don't really want surgery, but if they've left some, then it would be too late." When I mulled it all over, and I talked to the
doctor who had done it, he said, "I'm pretty sure that we got it." We keep our fingers crossed about it.

**Explaining cancer:**

I decided that it was just something that happened. It's only afterward when I look on that diet we had as children. In Northern Ireland, we did have a very fatty diet. But, you see, I don't know if it's because some of the things that I've read that some of these things are in my mind. We did eat a lot of bacon and eggs, and the bread was fried in the bacon fat, and nothing was wasted. My mother and grandmother would cook a leg of pork and score the skin on it and then [we'd eat] the nice crispy skin with a big gob of fat on it. That was delicious going down.

I lived for years with a lot of stress. If anything, I would have tended to blame the stress on it. Being one of those people who tend to work all the time... That's why those three years or so of depression really stand out in my mind. I didn't really feel like doing very much in the way of work.

The only external problem that I can ever think of was: I was playing soccer once, and I still remember: There was snow on the ground, and someone just a matter of a couple of yards from me kicked the ball and it hit me right in the groin. And I went down. I still remember the pain of that, even though it was probably 45 years ago. At times, I've wondered if that could have had any kind of a connection with it. Because that's the only injury that I remember. I remember the pain when that snow covered soccer ball hit me right here. It stuck with me.

And there was one other incident. In Albany I was going towards my apartment. There were some PG&E or telephone workers working up a pole, and a cloud of white powder came down, and I breathed some of it in, and I know it was only a matter of 50 yards from home, but I lost control of my bowels before I got into the house. I did
remember later and wondered, "Did I breathe something in at that point." [That] was probably three years before I got my cancer.

These and the fatty diet are the things that I wonder about. Or the other thing is: Did it just happen?

**Personal Change:**

*Do you think you are a different person because of the cancer?*

I'm willing to talk about it, which is something. I would have been ashamed to admit that I'd had an illness. Just last week a lady who cleans house for my daughter, she just had a mastectomy, and she was really down. I sat down with her and said, "You know, 12 years ago, I had colon cancer, and it's all cleaned up fine." She was facing whether she was going to have radiation or chemotherapy, and I told her the story about my radiation. I said, "I wasn't sick. I just got hungry." And I've talked to a number of people like that.

*Are you back to 12 and 14 hour days?*

Yes, I started out at 4:30 this morning. I have every morning this week, actually, because we have a class... By 8:30 in the morning I will have set up maybe 5 continental breakfasts, or something like that.

**Support:**

*Did you tell anyone about the problems you were having?*
I don't think so. I probably kept it to myself pretty much. Even though people knew I was having some kind of a problem, I didn't discuss it in detail with anyone. I have the kind of a personality that my feeling is you tell people on the basis of a need-to-know. And I didn't feel that anybody else should know.

My son knew a little bit about it, but I didn't go into any discussions with him. I'm pretty sure I was fairly irritable during this time and probably discouraged anyone from discussing it.

....

[While in the hospital, I had] one cousin who... we're friendly, but I see him maybe once a year or something like that. I remember looking over at him and thinking, "Wasn't that nice for Tom to drag all this way." It was only after I got out of hospital, I realized that Tom came because he thought I was dying, and he had better come to say good-bye. [laughs]

**Interlude:** *(At one point we had an animated discussion of his service in an anti-terrorist regiment in Northern Ireland.)*

I was an officer in the [Ulster] Defense Regiment, which was the anti-terrorist regiment. I'll give you an idea of the level of stress. Each morning when I went out to the car, I didn't dare to open the door without having a look in to see if perhaps there were a couple of wires coming from the dome light, looking under the car to see if there wasn't a bomb there, raising the hood to make sure that no one had connected anything to the spark plugs. Even then, you thought: "Did I overlook anything." I remember coming out one night, and I had a flat tire, and while I was changing that tire -- it was at night in this dock-land -- thinking, "Did they puncture my tire, and are they going to get me while I'm changing my tire?" That was the type of stress that was involved.

*Did you enjoy that?*
[Smiling] I loved every minute of it. My wife and mother-in-law, any time the phone rang and it was a call-up, they said, "You'll be happy now." It was really a very exciting time. It was a dangerous time, but it was tremendously exciting, also.

*Was there a certain rush in dealing with the danger?*

Yeah. There was a high.

Even after I left, about three weeks after I came back here, at 3:00 in the morning there was a knock on the front door, and my sister-in-law came, and there were four men with drawn guns there who asked for me, and they were in civilian clothes. She said, "No. He's in America." They said, "His car was found with a bomb in it." They said they were from the police. Of course, I worked with the police at the time, so she phoned me, and I phoned them, and the police didn't know anything about it.

Another friend, John Taylor, he came out of work, got into his car and someone stepped up with a submachine gun and right across the face and shoulder, and strangely enough, he survived it. In fact, he's still around today. It was a continual thing. At any moment, someone could step out and put a bullet in you or other unpleasantness.

I don't think this has anything to do with my cancer, but I know that at one point, I thought, "I'm not afraid to die, but the method of dying is the thing that bothers me." I remember thinking, "I'd hate to have my throat cut. A bullet to the heart: OK." Whether that was bravado or not... I don't think I've had a fear of dying so much as a fear of the method of my death.

*How would cancer fit into that?*
I don’t think it came into the consideration. It wasn’t recognized as a palatable option.

**Coda:**

I’m quite sure that if this had happened to me 20 years earlier, I would be dead. I don’t think that the technology was around at that time to save me, even from myself.

I feel that I probably died on the operating table. I think it was very close. I don’t think I would have lasted more than another week or so if I hadn’t done the surgery, and there would have been a week of sheer misery. Talking with the doctors afterwards, when the tumor had ruptured, they said, “We figured you were just gone.” [laughs].

The whole thing was extremely foolish, but from the other hand, other than my months of misery with throwing up, something similar would have happened. There would have had to have been surgery.

*Is there anything positive that came from having colon cancer?*

I can’t immediately think of any positive results. If I could have gone through without having it, I would be perfectly happy. That would have been much more positive as far as I’m concerned.
Angela Frick: Not Ready to Leave the Party

Angela Frick, 65, was diagnosed one year previous to these interviews with colon cancer with metastases throughout her liver. After surgery on her colon and chemotherapy for the liver metastases, her cancer is currently in remission. Her husband, Clyde, has Alzheimer's disease and was put into residential care at the same time she went in for her surgery.

Mrs. Frick still practices as a therapist, a profession she began in her fifties, and we met in her living room / office decorated with books and art objects from around the world. Trim and lively, Angela sat curled in comfortable armchair picking her words carefully.

Diagnosis and treatment:

I was a perfectly healthy person, no physical complaints at all, and I went for a regular annual check-up last March. My doctor gave me some of those hemoccult packets. Last year she forgot to give me one, but I was doing it for twenty years every year. You have to go on little diet; you can't eat meat; you can't have vitamin C when you're doing the test. I put it off because I was traveling and doing stuff, and I didn't want to be bothered with that. So I didn't actually get it done and get it back to her probably until May. I was very casual about it, because I'd never had any problems before.

She called me up and said, "There's blood in the second panel. I want you to go see a gastroenterologist." So I said, "I know what I did." I was in a hurry, and I pushed, and I probably popped a hemorrhoid. Let's not worry about it." She said, "Well, that's probably true, but let's get to the gastroenterologist anyway." So I did, and she said the same thing. She said, "You know, you've never had a colonoscopy, and at your age" -- I'm 65 -- "you should have had one and we need to get one. If there's anything there, it's the easiest thing to get."
And so I did. I went and I had the colonoscopy, and I was fascinated watching the monitor, and then all of a sudden I felt the pain. And it wasn't interesting anymore. She said, "I think we've hit something, and I think it's malignant."

She said, "Go and see the surgeon on Monday." This was a Friday. And so I did, and he said he could feel it with his finger, and said, "I can feel it, and I know that it's malignant." They did the biopsy.

We made the appointment for the surgery, and all my friends said, "Oh don't worry. My father had this. It's just cut and paste. No big problem. You'll get rid of it and it'll be fine." So I was a little bit shaken up, but not too much. I thought it can't be very big.

Then I got a phone call from the pathologist saying, "I think we need to do something else here, because the CEA test has come back, and there's something else going on. We want you to have a CAT scan." So I went and had a CAT scan.

She called up and said, "It's metastasized to the liver. I want you to go see an oncologist." So I went with my son to see the oncologist, and she referred me to someone who was right downstairs from her office. I said to him, "I don't think I want to have chemotherapy." Because I've lost three friends to cancer who had had chemotherapy. Their last days were really miserable. I said, "I'm really not sure I want to do that."

I don't actually remember what he said, but I summed it up after he finished. I said, "Well, here's what I understand. You're saying that I have three to six months to live and that it doesn't really matter whether I have chemotherapy or not." And he said, "Yes. The bottom line." He said, "Of course, I'm an oncologist and I would recommend that you have chemotherapy, because there's some chance that we can abate this, but there's really no cure." He said I should just spend my last days in peace.

Well... [laughs] I was really shook up then. I was just in a lot of disbelief. I thought, "Here I am feeling terrific. How can this possibly be?" It just didn't compute.
So we sort of staggered up stairs to [the gastroenterologist's] office to see her and to
tell her what he'd said. I told her about the exam and she said, "You know we can get a
second opinion. We don't have to accept this." So she gave me the name of a man at
UCSF, Dr. Varga.

I began to feel a little better, and I went to see him. And David Boil, I believe.
They're really wonderful people and just a great team. Dr. Williams is the surgeon who's a
wonderful man. And so he said, "We do want to do surgery." I'd canceled, of course, the
previous appointment with the surgeon. And so, by this time we're into September. And I
had surgery on September 28th [seven months ago], and I was in the hospital for 10 days.

There were 12 lesions in my liver and they're all throughout. The pictures are kind
of alarming. It's all over. But they got it out of the colon, and they didn't seem to be any
place else.

Chemotherapy and radiation: (Only Mrs. Frick's colon was removed in surgery.
Her liver with metastases was currently being treated with chemotherapy.)

They put this pump in. I started right away with the chemotherapy. The 5-FU and
the FUDR, a five week course. I started while I was in the hospital, the first of October.
I've been doing it ever since.

I had a CAT scan after the first 15 weeks. The before and after pictures were just
amazing. The tumors had all shrunk. And the CEA... David Boil called me up and said, "I
just wanted to tell you about the blood test." I was so scared, because he called me at
home. He said, "It's six." I said, "What does that mean." He said, "In September it was
301." I said, "What's normal?" And he said, "Four."

....

I feel good. I'm tired. The third, fourth and fifth weeks of the chemo I really feel
it. I mean nothing compared to what a lot people feel, but I definitively feel tireder and odd
little things like the skin of this thumb breaks down. It can get to be cracked and
sometimes weep, but I figure if that's the worst symptom... I haven't lost any hair or anything like that. I still have intestinal discomfort.

....

(Two weeks later she was feeling more poorly)

This week I have not been feeling well. I feel so tired. Now I can sit here and talk and I don't feel tired, if I stand very long, I just can't do it. I have to lie down. And by 3:00 in the afternoon, if I don't go to sleep, I mean, five minutes down the road, I can't remember what I'm doing. And then I'll sleep for an hour, sometimes two, and I'll be fine, and then I'll go to bed and sleep for eight or nine hours a night. I just want to sleep a lot.

Mortality:

I've gone through a lot of different things. My husband has Alzheimer's, and that's really grim. The doctor at Cal Pacific told me that to die of this is really not an unpleasant death. You just get more and more tired and get thinner and thinner, and your appetite gets less and less, and you just take more and more naps, and one day you just don't wake up. And I thought, "Well. If that's the way I'm gonna end, it beats Alzheimer's."

It really isn't so terrible. I've had a wonderful life. I've got a great family. I don't have any terrible regrets. I'm not ready to leave the party, but it's not really all that terrible. It's like after my first wedding I was having a wonderful time dancing at the reception, and my mother said, "You've to go and get dressed upstairs. You're going to get on the airplane." We were going away on our honeymoon. And I didn't want to leave. I was having a wonderful time. And it's kind of that feeling. I don't want to leave.

....

Right before the surgery, I didn't think I was dying, but I considered it. I thought, "Well, maybe. Maybe this is what it's like." Who knows? I don't know. [laughs] I don't
have any fear about it. And I'm crazy about my grandchildren. Especially my granddaughter. I want to see her grow up.

....

I try to collect all the success stories and not think about Jackie Kennedy and Gilda Radner and all the people who didn't make it, who also seemed to be hale and hearty and then just sort of here one minute, gone the next, which was true of my friend.

If things aren't going well or something, I think, "Oh. Maybe I'm giving up." But it doesn't last very long. I'm very optimistic.

....

I lost a lot of friends, more than most people I know. I lost my current, at that time, closest friend in June of cancer. Well, actually not cancer, but she had cancer off and on. And so I've been through a lot with her, gone to cancer support groups with her. We went to a conference in Denver of cancer survivors.

Was this even before you were diagnosed?

Oh, long before! I wasn't diagnosed until after she died. So it was a very strange thing to have lived through all those years with Nina and then to have it myself after she died. I'm still mourning the loss of her, and the loss of my husband. I'm beginning to feel more lately -- just like today, yesterday, last night -- the effects. And as my therapist said... for a while I was saying, "I don't know what's the matter with me. I'm not really crying. I'm not feeling all this stuff that I know must be going on." [laughs]

The one time I cried is when I watched Forest Gump. And she said, "Well... you've got so much you have to take care of, that you have to be in your head right now. The time will come." And I think it's coming. I'm feeling depressed. Kind of like feeling the loss. My life is not what it was.
The loss in what sense?

The loss of my friend. And in the last nine years I've lost my sister-in-law and three other very close friends to cancer. And my husband, of course, which is just so sad. He's there but not there. It's just awful. So I'm feeling it more. I'm feeling the helplessness about it.

Then there's another part of me that imagines that all those people that have died are waiting for me, and that we're going to be together somehow. And I imagine them, of course, in their corporal form, which, of course, is ridiculous [laughing]. I'm going to meet Nina in her purple dress. But there are so many people now. There are more people close to me I think, who've died than there are alive.

*It sounds like you have grappled with issues of mortality and things long before...*

That's right. It was based on other people's, but every time you lose somebody close to you, your own mortality becomes important, let's just say.

Nobody ever thought of me as being somebody who would ever get sick. It was a big shock. My first husband said, "This is like the sinking of the Titanic." [laughs]

**Support:**

Both my oldest daughter and my son Paul live here. They're very helpful. And my daughter-in-law, Paul's wife Amy, is very helpful. And she's also a masseuse, massage therapist. And she gives me a massage. I was doing that once a week, but when I started the acupuncture that was just too much. [laughs]
Since my husband has been sick, Paul has really taken over more of his role. You know, the things that he did, certainly physically, coming over and doing the things that required more strength to lift or whatever. You know, fixing things around the house which Clyde's good at. Gradually over the last few years as Clyde's been unable to do those things, Paul does more and more of that, which is a source of great resentment for Clyde unfortunately. He really didn't like that, and he had adored Paul. But now Paul's kind of usurped his position.

So I do have that support. And my first husband is extremely supportive.

**Explaining cancer:**

The doctor says, "There's nothing you did. It's not stress or anything." But I don't believe that really in my heart. I believe it is the way you handle things that has something to do with it. I think my husband's having Alzheimer's, not his having it so much as my way of dealing with it... The big thing is: Don't think you can be the sole caretaker in the whole thing. I delegated as early as I could, because I wanted to keep on working. I don't know what I could have done different. I do know it was a tremendous strain. I know that I had really reached the end of my rope.

But cancer doesn't come that fast. I mean, I don't think that fast. I hadn't reached the end of my rope until the last year. My tendency to not put myself first might have something to do with it.

....

Last winter when I was taking care of my husband, and he was sort of a trial, I used to go and sit on the toilet and say, "I've got to get out of here." I would say it out loud. There is a book called *Your body hears everything you say*. When I heard that title, I said, "No. No. No. That's not what I meant." I didn't mean this is how I wanted to get out of here." I was feeling like I got to get out of here and saying it. I used to say it when I was sitting on the toilet.
The only other thing that I connect with it at all is that I've always had troubles... my response to stress has always been one of holding on, and I've had difficulty with my sphincter controlling the esophagus. Achalasia. And during the early years of my life I was constipated a lot. I wonder if maybe the constipation history might in a way contribute to it.

What is surprising to me is that I have always been so conscious of diet, a health food kind of nut. I've always eaten well. I always had bran, all those things. Avoid sugar. Avoid fats.

I used to drink a lot of coffee, and I cut down several years ago and started drinking two thirds decaf to one-third. I remember a friend of mine who's a doctor at Kaiser came over and I said, "Want a cup of coffee? It's mostly decaf." He said, "That's the worst." He said, "I'm avoiding that because I think it's connected to colon cancer." And that was years ago.

**Alternative therapies:**

There's a product called Essiac. Have you ever heard of it? It's very interesting. There's a book called *The Essiac Story*, which is a fascinating book. It's just a bunch of herbs, a potion that was developed by an Indian, a Native Canadian early in the century. And a doctor, a woman doctor up in Canada got it from him, and she started making it. It's a long story, but there were these people who had miracle cures, and she was interested, and the doctors started sending people to her. She was curing them. It's supposed to be good for a lot of things. My sister and brother in law are both taking it now. [laughs]. It makes you regular and your bowel habits and your sleep and everything else. So anyway, I started taking it. And I've been taking it ever since.
Have you found benefit?

I don't know. Who knows? Maybe it's not the pump. Maybe it's the Essiac that's doing the job [laughs].

I also have an acupuncturist who comes once a week. She started coming as soon as I got home from the hospital. And she has prescribed all these herbs and things that are supposed to boost your immune system and all that kind of thing.

And the other thing I did is another friend of mine said, "Oh, you have to get this book. It's called Cure for All Cancers." And it's five magic things that you're supposed to take. And you have to send to Denver for it. You can't even get them here. And I did that. You do it, and supposedly in five days you've cured everything. Cured the cancer. Well I did it for ten days, before the surgery. I stopped that. I didn't feel that great. I gave that a shot [laughs].

There's a limit to how much you want to do. I have another friend who keeps calling, "You mean you haven't started eating shark cartilage?" There are all these things. You could go nuts. Have all the fillings taken out of your teeth and replaced; the metal is what's doing it. Don't ever drink tap water; only drink spring water. But don't ever drink it out of cloudy plastic; you have to drink it if it's bottled in clear plastic. [laughs] You'd go crazy with all those things.

I just do what feels right and let the others go by. Something's working. [laughs]

(Mrs. Frick was also doing some visualizations)

When I think about it, I visualize a white light. All the visualizations have to do with light, imagining it coming into my body and purifying. That I can get into. I could imagine that the white light somehow is energizing the pump and the chemotherapy and augmenting it and helping to do it's work. Then I can imagine that somehow the energy that's in that light can attack the malignant cells. I think of it more as burning them out, or
zapping them. And then I imagine that my liver is healing. I visualize the tumor shrinking and the liver tissue becoming more and more healthy.

I've been visualizing for years, because I've had problems with my esophagus. So now I just visualize that the food goes on and goes into the stomach, and the enzymes work on it and goes into the liver and gets purified. The good stuff goes into my body and the bad stuff goes into my colon, and I imagine it going through this beautifully clean tube that the colon is. And I imagine that there are no polyps, and there are no tumors or anything on it. And it's just a beautiful clean thing. I do that kind of visualization, which is kind of as clear as I can imagine really what happens.

I don't have this idea of all those little men running around with guns shooting up cancer cells.

Changes at home:

I think that the lesson now is learning how to take care of myself and put myself first. And I'm doing that with a certain amount of difficulty, but also a certain amount of pleasure and joy and relief. Because I've got cancer, I had to put Clyde in residential care, which was an enormous relief. Which I wouldn't have done. Not that soon. Maybe by now I would have, because he has gone down hill so much, but he might not have gone down hill so much if he'd been home.

When I first came home and I told him the first diagnosis, he said, "Well, let's live it up." [laughs]. He's a very supportive man and always I could do no wrong, but he became really combative, last summer mostly.

He couldn't really remember. He still can't remember what's the matter with me. When he was first placed... He agreed to go to this place and then he just... "How could you do this to me. How could you put me here. Bring me home." I said, "I can't. I really can't take care of you." "Why can't you take of me. What's the matter?" The family
would all tell him I have cancer, and he was absolutely beside himself that he couldn't go to the hospital with me and that he couldn't come to the doctor.

He wanted to be there. He wants to be the caretaker. That was the hardest part of all. He was vicious to my sister and brother-in-law. They were taking care of me. He wanted to. And of course, he can't. He can't remember what he did five minutes ago. But he can be very much in the moment. It's really difficult to deal with.

I have never lived alone in my life until now. And I've always said that in spite of the fact that I have eight children and I've always had lots of people around me, there's a secret hermit inside. There's that role that I haven't been able to play. And I really enjoy that. It's like I can't be alone enough. And I love that.

*But* there is also a loneliness. At first there was a kind of a relief when my husband left and when all the caretakers, my sister left. It's kind of, "Oh good. Now I can just be." But I'm missing my life, the life that I had in some ways with my husband. I'm being kind of aware of that now. I'm not really lonely because I have *lots* of friends. I'm not in any way feeling bereft of companionship. It's just irreplaceable. Nothing can replace the relationship I had with my husband, and it's just gone. And yet he's still there.

We were a real partnership and did so much together. The loss of his participation in my life and the things I had to do to take up that slack, that can't quite be separated out. 

....

With the family dynamic thing, my first husband... I was married for about eight years. We had four children. He has always been a charming irresponsible fellow who never was around and would come for holidays or vacations or one thing or another and he goes and lives in Italy or France, New York or whatever.

A few years ago, the first thing that happened was his first grandson was born in Cambridge, and he is crazy about him and went there and was about to move to Boston, but he had a falling out with his daughter-in-law. So they had been totally estranged for almost nine years.
And a few years then when my grand-daughter was born [in San Francisco], he came back her, and he got very involved and interested in her. And then he got an apartment, bought a condo right across the street from here. And he started coming and taking Clyde out. And Clyde considers him his best friend.

When I got sick, he was just excellent. He said, "I would give anything for me. I've lived my life. I'm ready to go." And then he cried for the first time I've ever seen him cry. And we have the mostly lovely friendship now. I have absolutely no desire to be married to him. It's just fine that he lives across the street [laughs].

*In many ways, it's the loss of your husband. Who do you turn to?*

That's hard, because both my husband and friend Nina... There isn't anybody except my children. I'm concerned, especially about my son Paul. I talked to him this morning, and I said, "I just dump on you." He said, "No. No. That's all right." But he asks me, and I tell him. And then I feel bad, because he's carrying all this stuff, and I know he worries. And he's got a sore throat, and I think I'm contributing to Paul's being sick, and his feeling down.

We have a wonderful relationship. My daughter is too, is very helpful. And then my daughter in Los Angeles is extremely helpful, but she's in Los Angeles. When she comes up we talk. So the family. And my sister is extremely supportive.

*Now:* (Recently, Mrs. Frick has begun to notice thin stools, sometimes a sign of a tumor in the colon.)

I became aware of the pencil stools about two weeks ago. And I thought, "Hmm." I became aware of more of a feeling of constipation, which was very unusual, because mostly I just have to run all the time. It's just erratic, but the thing he was mostly
concerned about is that they're pencil thin. But they're not always. They come and go. Sometimes it's diarrhea. Maybe I should chart what I eat. I think the only thing they're really worried about is this pencil quality and the fact that sometimes there's a constipated quality.

That was the one symptom that I was having that I didn't realize was a symptom until somebody asked me, and I realized, Yeah, I did have what they call "pencil stools."

*Last time I talked to you, your CEA was down to an almost normal level.*

Six. Yeah. And that's why I said, "How could that possibly be?" Why would the CEA be so low if I had another tumor?" So it is unlikely, but we're going to have to look and rule it out.

*What do you think is the current state of your disease?*

I was pretty smug. I thought I was on the way to total remission. And now I'm thinking you can't take anything for granted and you don't know. I'm now in a state of not knowing. Because I thought, I really didn't even imagine that I could have more colon problems. I thought, "That's done. My problem is the liver." And that's what I've been mostly worried about. Not worried but, you know, focusing on. It just didn't occur to me I was going to have any more problems with the colon. And now to have that threat, it's just disconcerting. And I don't know what to make of it yet. I don't really know.

And now I'm paying so much attention to it, and I've been writing it down, so I can try to make some sense, because they'll ask me questions like that and I think, "I don't know." And then he says, "Is there blood?" Well, I eat a lot of beets. I don't know if it's blood or not. So then I quit eating the beets, and now it's still red, and I think, "How long
does it take beets to get out of your system?" [laughs]. You just torture yourself with all this worrying. I don't know.
Ulrike Green: All About Positive

Ulrike Green, was diagnosed with colon cancer four months before these interviews. On surgery to remove the tumor in her colon, it was found that the tumor had spread to regional lymph nodes. She is currently undergoing chemotherapy and radiation.

A 46-year-old divorced mother of two, Ulrike Green was born in Germany and moved to the United States with her American husband 22 years ago. She is an animated and jovial woman with copious henna hair. She spoke with me at her job as a shipping supervisor in a local warehouse, and her remarks were punctuated by the beeping of forklifts and the ringing of telephones.

Diagnosis:

In November I noticed blood in the stool. I thought maybe it was hemorrhoids, so I made an appointment with my primary physician. He said it wasn’t hemorrhoids, and he referred me to a specialist. It took almost a month and a half to get an appointment there. They did this test [colonoscopy] where they have the camera, where they have that two feet of... It was very uncomfortable. The doctor I seen, Dr. Lipa, was not a very friendly doctor. I felt very uncomfortable during the procedure. As a matter of fact, I cried. I was very emotional and very uncomfortable, going there for one reason or another.

I went there on December 31st. I started [this job] on January second. On January third I got a call from my primary physician, Dr. Martinez. And he told me that the test results were positive, that the biopsy they took was malignant. Dr. Lipa never called me to advise me what was going on. Dr. Martinez did.

My biggest fear has always been disease. Cancer or venereal disease. AIDS. Always had a huge fear. I’ve never been sick in my life. My dad passed away of lung cancer. He was only 64. Maybe that was one of my biggest fears, having cancer. First
thought came in my mind when I seen blood passing. I tried to do positive thinking. I said, "This can't be. I can't accept that."

*What did you think it might be?*

I thought maybe it was just a polyp. I talked to different people. They say, "Oh, they just can scrape that."

I was referred to a surgeon. The growth or the little tumor was six inches from the rectum up. He said, because of the way it was positioned, there was no other choice but surgical removal. He explained there could be a possibility that I have a colostomy afterwards. He said it was very small. It wasn't big. It seems like it was caught in the beginning stages, early. So kind of gave me a lot of hope, right? Like I said, until I seen Dr. Bruno, I did a lot of crying, praying, feeling that my life is over. I'm a single parent. I'm divorced. I have two children. I'm from Germany, I have no family here. So it was very difficult.

*Surgery and bad news:*

I made arrangements for surgery. I was very positive. My ex-husband was there. My boyfriend was there. My children were there. One of my practitioners were there. At the hospital when I went to surgery, they asked me, "You want something to relax you?" I said, "No." I was fine [laughs]. I am fine.

[Afterwards] I got up right away, started to walk, did whatever. And I thought everything was hunky-dory, right? He said he got it all, "Oh, we got it all. We cut so much and we got it all." But, he did put... "We have a colostomy, because we didn't want to put you back together just in case, if there's a little radiation needed."

*So you had a colostomy when you woke up?*
Yeah. And I really treated not to have one. I really treated hard. He said, "I could have put you back together." But he wanted to see if there was any radiation, anything needed.

The last day when I was in the hospital, the [radiation oncologist] came to greet me. He said to call and make an appointment, that my surgeon mentioned I should come and talk to him. So I still didn't think negative or anything. I'm very positive.

As much as I hated to be in the hospital, I really feared to go home, because of [my boyfriend] Daniel. He made me really very nervous. Constant questions. He's a pretty hyper person, and I can't stand it. I actually asked them for some Valium when I was there before he would come, to calm me down. I couldn't tell him, "Don't come." I couldn't be that cruel, saying "I really don't want you to come because you make me feel uncomfortable."

I go home and do what I always do, even though they say, "Don't do anything." [laughs] I was supposed to relax and not to work and recuperate. But I cook and clean and do what I always do. Taking out my children. I got out of the hospital on a Friday. I drove myself to Berkeley to the hospital on Tuesday. They have the morphine. You can give your own self medicine. The nurse kept on saying, "How come she's not using the pain medicine?" Don't need it. Don't need it!

So when I went to see the [radiation oncologist] I wasn't nervous or anything. He said, "I don't think you qualify for radiology because we don't give radiation if it's colon cancer. But in your case, you need to make an appointment with oncology for chemotherapy."
So I looked at him, "What?" He said, "Your cancer is not what we call a localized cancer. It protruded into the bowel walls, and then it went into the lymph nodes." Eight out of ten nodes were positive.

I sat there, just tears rolled down my face. As soon as you hear lymph nodes, it's like now you might as well hang up. Forget it, right? It felt like somebody just X-ing you out. Lymph nodes means it could travel through the blood. Now we're talking about it could go anywhere else in the body.

So he had me on the examining table. He examined me: the rectal and the vagina, and I'm just crying. Tears are rolling down my face. I didn't feel comfortable with him.

I have to be a true believer that no cells separated, no cells are in my blood stream, that I'm fine. I had to make a decision. He said I have to go for chemotherapy and radiation combined, for six months. I had to make a decision. I have faith in they got it all, even though the lymph nodes were positive.

And what was your decision?

The decision to go ahead through the chemo and the radiation, because again my only reasons are my kids. I had faith. I truly believe that things didn't go anywhere. But I can't take the chance, not when there are children involved. I just couldn't take that chance.

Chemotherapy and radiation

I'm currently doing chemo. I just got through Friday. Five days straight through. It's always the first of the month, that one week. So next month we're going to have five weeks of radiation on top of the chemo, and it's every day. Five weeks straight though every day radiation. Five weeks, plus the chemo.
They said the reason for the chemotherapy was to make absolutely sure that no cells... If there was any, which they don't think they did, they can kill it off right away. And the radiation is to make sure there's nothing growing. They said it grows so fast. You only have to miss one; that's all it takes. So this is really necessary, to go through the radiation on top of it. I have to accept it. Doctor knows best, right? Sometimes. [laughs]

When you go down to the treatment center, you feel so separated from the healthy normal world. I can't explain. I really can't explain how I felt. I was crying all the time. There was a Chinese man, he came over to me. He gave me hug. He said, "My wife is over here. The nurses are wonderful."

They put you in a room. You have TV, bathroom, what-have-you. They call the social worker down to talk to me. They try to make you very comfortable, but you feel like you're not a part of the society any more. You really do. You feel exiled.

I made up my mind that I was gonna be fine. And I was. I told them "You guys are so busy that one of these days you guys will have no business." [laughs.] That's what we're treating for. So I come with very good cheery attitude always. I don't talk about disease. I already know I'm healed. I already know. I don't accept this as part of me. So it doesn't exist actually.

God is all there is. There is a higher power and we cannot just rely on our earthly methods. And I share this. I don't go into no room. I don't lay down. I sit in the chair. I see people depressed, you know? I talk to them. And it's always going to be positive. It's not going to be about disease. It's going to be that you are whole, perfect and complete.

I went to the chemo last week. I had a little diarrhea. I didn't get no sores in my mouth because I already made up my mind I wouldn't. [laughs] I had the first time
because I was so afraid, and it was so new. I got a rash. I got all the sores in my mouth. Diarrhea. Fatigue, terrible fatigue! So I made up my mind for the second time around, right, I'm not going to be on no pity pot. I won't be fatigued; there will be no side effects.

(Ulrike was also treating stomach pains through meditation.)

I do breathing exercises. I have these sharp sharp pains right here on the side, which I never had before. I prayed on it, that the pain would go away, and it did. You have to really be quiet, really get within. Your hands can heal. You can put your hands on your own body and just say, "These are Gods hands," and you feel the energy. People who meditate, we always keep the palms open, and you feel the energy coming from them.

(At our final interview, Ulrike was four days into a new round of chemotherapy, this time combined with 5 weeks of radiation treatment. She was feeling extremely fatigued. Several days before the last interview, she had been hospitalized for severe stomach pain.)

Tuesday I got stomach cramps, and it would just go through the upper part of my chest, the airway. I couldn't even breathe. It was nonstop cramping, really severe.

They said radiation shouldn't take effect, the reaction, until about a week later. You will have diarrhea and stuff like that. [My boss] and his wife, they took me to the hospital, and they put me in a bed and took X-rays. They took some blood. My white count [was] up. They couldn't find anything on X-ray, so they started an IV with some Pepcid and gave me some Maalox and that made it worse. The cramping became real bad again, and they made me eat a couple of crackers, and that was Awww! I got into deep deep meditation and prayers and it stopped at 3:30.

I just know I'm really tired, much more tired. I come home, all I want to do is lay down. I have to force myself to cook. My son still complains, "Why can't things be the way they were." I used to do a lot of things in the evenings. We walk, we go to Lake
Chabot. We go fishing. We do things when it's so nice in the evening, and I just don't have the energy.

Reaction:

*Were you nervous that you were going to die?*

Yeah. That's the first thing that came in mind. And then I said, "Colon is one of the most common cancers which are curable. They operate and you're fine." That was what Dr. Lipa said, too. "Oh, people come here five ten, fifteen years later. They're fine." So that was the positive part. But I thought about, "What about my children? What about my children?" I'm not asking for me. I said, "All I want to do is see my children grow up. That's all. They don't have nobody but me."

We took walks. We did pray a lot together. And my kids say, "Oh mom stop whining. You're OK. You'll be fine. Stop." Because I look at them and I cry. I couldn't help it. Definitely when I look at my son -- he's only ten -- he was real real real close to me. And it was just like: Why? And then I said, "Well, why not me?" You know? Why should this be somebody else? Why not me?

*Not "Why me?" but "Why not me?"*

Right. Because you always expect other people to have things. Not us.

....

(Ulrike's father died of lung cancer, and she is haunted by a photograph sent to her of him in his final weeks.)

He wouldn't ask my mom to take him to the bathroom. He would be on his knees scooting to the bathroom. He'd be up all night long coughing, coughing, coughing. When I was home I just cried. I just cried. I did not know how to handle that.
It was such a shock. When I saw [the photograph], I screamed. I said, "This is not my father." And this is something I kept with me all of these years, that picture of him looking like death. To me this was the most shocking thing I'd ever seen in my life, and I could never let go. I'd dream of my father all the time.

I think this is my fear. When I got diagnosed, that fear immediately came, remembering the picture. And I told my ex-husband, "I don't want to go through this. Don't you guys let me suffer."

Church / Positive thinking:

Not having family, my biggest support group here is my church. About three years ago I joined East Bay Church of Religion Science. A girlfriend of mine, she said, "Why don't you come to choir rehearsal. We have this real cute choir director." I said, "I've got to come and check him out." [laughs] So I went, fell in love with him, and been there ever since. That's my best friend, Ben. [I've] been there ever since, but didn't stay because of him. We have a Reverend. Once I heard her speak, it was like you have to keep on coming back. She tells the truth. And there it's all about positive. All about positive.

We don't believe that the people are sinners. We believe that you make a mistake. God loves everyone. He loves the drug addict. He loves the prostitute. He loves everyone. He's not prejudice. I don't care how bad you are. God's not going to stop loving you.

There's lots of Religion Science Churches all over the world. They're wonderful. Positive. There are practitioners which are people who listen to you. They don't give you advice, tell you what to do or not to do. They listen. You do your prayer; you do treatments; you do meditations. It's a healing power. You can actually heal yourself.

I believe the body can heal itself. You can help the process of your healing with the doctor, with the right medication. I don't know if you heard about a little boy who had a
tumor, with cancer. They couldn't find it or couldn't operate. And he did visualization that he was shattering it, and it disappeared. It's gone. It actually happened. He really truly believed and made it go away. [chuckles]

... 

I don't look at it as a disease. I told [Daniel] from day one, even before surgery. I said, "Don't talk about it. I'm not sick. I don't accept that." If I think I'm sick, I'm going to be sick. But I don't believe I'm sick. I'm not. This is just something I'm going through right now, and it too will pass.

God is good. I always say that God is good, all of the time, regardless of what you're going through. We really have to look at the positive things in our life. And that's what I do. I look at the positive things in my life.

(Every day, Ulrike was writing an affirmation.)

God does recreate your cells according to his perfect pattern. And there is no room for anything else. Therefore, you do your affirmation. You make a statement. I even write them down. I write it down, what I believe. You read it again, and you read it again, and it manifests. My cells are in a pattern according to God's perfect light. There's nothing else. There is no room for anything else. There isn't! You really truly have to believe it.

**Explaining cancer:**

Eating cannot cause the cancer. I'm sorry. It cannot. It may aggravate it. That could be true, just like smoking and lung cancer, but I don't think cigarettes will cause you lung cancer. If it's in the DNA, if that cell is there, you're going to have lung cancer, even if you never touched a cigarette in your life.

...
No one is perfect. We all go through health problems. And just because you believe in God doesn't mean you never get sick. It's not that God didn't make you sick. I really believe God didn't make you sick. It's already in your genes or in your DNA, right? When things occur, we don't point, "God, why me?" You know? Why not you. You just take care of it and make sure you're being healed.

There is a reason why we get sick. Why things happen. There is a reason. And even if there was no reason, we'd have to take responsibilities for our own selves and deal with it. That's what I'm doing. I'm dealing with it.

**Home Life:**

I hated to go home, as much as I hated to be in the hospital, I hated to go home. None of them at home even think that I was sick. They say, "You don't look sick. You don't act sick. You do everything." So I don't get that kind of comfort at home. Nobody does anything. Moma works. Moma washes clothes. Moma washes dishes. I have a fifteen year old daughter who don't wash a dish. She's worried about her nails. And cooking, nobody cooks but me. Nobody cleans but me. I can't run around the malls like I used to, because I do get tired. Now they complain about that.

And then my boyfriend is a very jealous person, and I usually go out Wednesdays and Sunday. And I'm not changing my lifestyle. Just because of that, all of a sudden I should stop what I've done before? I don't think so!"

We were living together, my boyfriend and I. Up until yesterday. I told him he had to move. My husband comes by every day and he told the children and him: None of them are to upset me. Because my children don't like him [boyfriend]. They fight all the time. They burden me. Very abusive to each other. And I can't do no healing like that.

So I had to let him know. I said, "I think it's best that we have separate residencies." Maybe we get along a little better.
So it was really hard for him. He kept on rattling off about the relationship. I said, "I don't want to talk. I don't want to talk. I'm not changing my mind." I said, "Relationship can be fine. We don't have to live together to have a relationship." He was really upset. I told him, "If you get upset, OK. Don't call me. Don't see me." I'm fine. I'm fine. I'm whole, perfect, and complete.

He says, "You and your fake religion." This is the wrong thing to say to me, see? I need spiritual people in my life. You have to be spiritual, one way or another. You don't have to belong to my church. You have to belong somewhere, be somewhat spiritual. I told him, "You're not spiritual enough for me. I ought to be able to talk to you about anything. You don't want to hear about my church." He said they had brainwashed me. It's a cult. They had brainwashed me. I said, "You're crazy."

....

One day I felt like I just wanted to throw everything down and go on a plane and go home. There was a day. I really didn't care. I think it was after I heard the rest of that stuff. All I wanted to do, I said, "Just give me a plane ticket to go home." Leave all of this here.

Ex-husband:

Now we're best of friends. He has people come over [to] do the yard. He's a contractor, so he can do the repairs at the house. We never had problems, basically. He told me, it was a wake-up call for him. He said, "I haven't been there for you. I'll be there for you." And he means it. He said, "I'm one phone call away. Page me or call me." He got a car phone just for that reason.

When did he say that?
As soon as I came home from the hospital. He made it very clear, and he said, "I'll be there for you." And he's there for me. He is. I'm blessed all the way around. I have to count my blessings nonstop. I say, "God is good."

**Daughter and Son:**

I told them the truth from day one, and I'm still telling them the truth. But they're very positive thinking children. They'd tell me quickly, "You've no need to think negative. Everything's going to be fine." My daughter, she really cried one time. And it was, because she said, "You're all I have." Even though she's got a father, but she don't have no grandparents here. They're in Germany. So she say, "You're all I have." That was one time. And then from then on she really put herself together.

Sometimes I expect my children to be more understanding and they're not. My daughter, she don't do anything. She's sixteen. She don't wash dishes, she don't cook. She don't do nothing. They wait for me to serve them. They don't look at it as a change. They don't accept this, what's going on. They're blocking it out of their minds. Whenever I ask her, I said, "You're old enough to help me. Why don't you help me?" She said, "There's nothing wrong with you."

[My son] is spoiled. I spoiled him. I'm trying to pick up father and mother role. I tried to do the mother role and do everything and try and do the father role, do activities with him. And at this point it's just a little bit much, but he don't want to do nothing with nobody else.

I'm sure it's just as hard on him. He's ten and he's a big boy and you expect he should understand, but he really don't understand. He really don't.
They're so backed up at the chemo, sometimes you sit there, and you talk to other people. I talked to Tom yesterday. He was in his early 40s, he had brain cancer, and his wife was there. His wife looked more troubled than he did. And then his dad came with his daughter. He said the worst thing is now his wife has to pick up mother and father both, because he can't do it. Soccer, baseball practice, ballet, none of those things stop because I'm sick. Now my wife has to pick up more doing these activities. That's the worst thing.

I told him, "There's only one of me. I always had to do both." That's what he feels bad about the most, that he can't do these activities with his kids. But he said, "It's not us who suffer. It's our loved ones who suffer more." Because his wife really looked troubled. I could see the grief on his face. But his daughter, she was sweet about it.

....

I do get down. I do cry at times, not so much about the illness, because I know this is not me anyway, just about the things I used to be able to do for the kids. There is ups and downs at times. Definitely when you're a single parent and your family isn't here and what have you. It's sometimes hard, because I get lonely for my family.

**Coda:**

After you're all gone through with it, when it's in recession, that fear every time you go back stays. How you deal with that, right? That constant fear, not unless you're like me, where you say, "Well, I do not accept that anyway as part of me. There will be no fear because nothing is coming back anyway." Just really trying to focus on that, be very very positive. Now unfortunately, things do happen and you're positive, that's a little let down. You really have to soul search then, when things don't fall in place the way you wanted them to fall in place.
On the future, to be very honest, even though I accepted everything there is, there is still this scary feeling. Once you're finished with everything, you have to go back and always get checked. That unknowing feeling. No one can tell you you're cured from now on, and nothing will ever come back, and you'll be fine. You're going to have to live with this for the rest of your life.

That's what I'm kind of afraid of. If the time comes after six months and they put me back together, what then? I know you have to go on, but the feeling is, "What then?" Will anything ever come back? Do I have to go through this again with the chemo and all of this? The hardest part is the afterwards. Most people probably go through this, that unknowing feeling. They can never say, "You're totally cured." Never. Not with cancer. Maybe one of these days. Maybe they'll find something where they can say actually, "This is it. You're cured. You never have to worry about it." But we don't know. It's in my thoughts. I have to really really work on that.
Mike Spinelli: A Stronger Person

Mike Spinelli, 47, was asked to participate in this project by Andy Marino, who has become a close friend since they met after Mike's diagnosis. Like Mr. Marino, Mike Spinelli had suffered from ulcerative colitis for many years before his diagnosis with localized cancer. After surgery, radiation and chemotherapy, he is currently cancer free.

For both interviews he was dressed casually in sweat pants and T-shirt, and we spoke in the dining room of his spacious and tastefully decorated split-level home. Initially concerned that he was boring me, he soon became enthusiastic and voluble in describing his experience.

Before Diagnosis

It wasn't something that just happened overnight. I didn't go in there one time and say, "I don't feel good," and they say, "Oh, you have colon cancer." I've been fighting it since I was about sixteen years old. I'm 47 now, so you can imagine that's a long time to be battling this thing.

They always say eventually 99% of the people turn into cancer down the road, but I went a long time. What had happened is I started having problems, big problems. I was bleeding from the rectum. Usually I could correct it because I know what I can eat and what I can't eat diet-wise.

It just continually gets worse and worse and worse. I thought, "It will go away, and then I'll be OK," and it didn't. Luckily I went to the doctor, and that's when they diagnosed this.

They don't tell you right there. They just examined me, and I knew that that was the next step, and the doctor was very upset. He said, "We have to take a biopsy, and we'll send it to the lab, and we'll contact you." Just by looking and talking to him I was
99% certain of it, although he won't say that. They don't tell you that day, "Yeah, you
have cancer." It's pretty much a foregone conclusion that you do, and then they let you
know a couple days later.

The thing that they were most surprised about is the size of the tumor itself, because
I had gone for an examination, and everything was fine. And it couldn't have been a year
or less that I had problems. He said, "I wasn't surprised that it developed," but he said it
developed so fast and so big. It was a cauliflower.

And it's like anything else. I didn't want to accept it.

*What was your reaction when they...*

My wife was traveling at the time, so she wasn't home. I was supposed to meet
with my mom and dad over lunch after that day. Obviously you know you have it because
the doctor was very very upset, but you don't want to admit it. I went to lunch with them
and I was OK. I could deal with that. And then the rest of the day I was fine, and that
night I came home. She [indicates wife in other room] obviously wasn't here, so I was by
myself. Then it hit me probably 10 or 11 o'clock that night, and I called up mom and dad
and had them come out and stay with me [laughs], because I was afraid, you know? I hate
to put it that way, being like a baby, but I was. I was really really afraid.

*Afraid of what?*

Just the fact that knowing... when you hear the word "cancer" what do you
associate with it? People dying. Or something like that.

*Were you afraid that you were going to die?*
I didn't know. I just thought the worst could happen. It's possible it could happen. Yeah, I was... [laughs] Yeah, I guess you could say that. It crossed my mind. Just the word, I think, is more upsetting than anything. At this point I didn't really feel terribly bad. It's like, "Gee, I have some problems, but I don't feel *that* bad. How could I possibly have this?"

**Surgery and hospital:**

Up till the surgery, you don't know what you're in for, so you're not really afraid. You're afraid of the word and afraid of what might happen, but now if I ever had to go back, I have something to be afraid of. Where before I was afraid just because I was just afraid. If I'd known what I had to go through now [chuckles] a team of wild horses would have to take me back next time.

You have to meet with a surgeon. They explain it. I think a doctor is a bad patient. You know, the doctor can tell you all these things, but he doesn't have to go through it. You're the person to have to actually go through it. If I'm explaining something to you, I'm going to explain it the best that I can, step by step. They give you the, you know, this step, this step, and this step, and let's go, we have to move on.

Maybe they explained it and I was in a state of mind where I didn't understand all of it. I understood a lot of it, but *all* of it... She understood probably more than I did, because I think my mind was kind of drifting, thinking, "Let's just go in. Let's get this over with. I can get out and go back to work." It's not the case. You're dealing with your life here, not fixing a flat tire. You have to really take it step by step and slow down and really understand what they're telling you. But it's hard because they're talking in doctor's so-called terms. I'm obviously not a doctor.

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Maybe it was partly my fault. I just didn't understand what they were saying. Maybe they did what they were supposed to do, and I didn't pick up on all of it. And she had some times too when there were a lot of things she didn't understand. We'd come home and she says, "He said this." I go, "No. No. He didn't say this, he said..." There's a lot to it. This guy has got your life in his hands. You better pay attention and at least know pretty much what's going on.

The biggest education is when you go. Like I told you, you find out and you get a rude awakening. You find out in a hurry. You're there for them to open you up. It's no fun. There's different things that they have you do that you're gonna do. I said, "I can't do this" and "I can't do that." And that's too bad.

I even told them I didn't want to go through this. At one point I went to him, and he said, "Either you do exactly what I'm telling you or you're not going to live to have any options." So it's do exactly what I tell you, and let's get this started.

I went in the night before, and I was fine. I felt fine. What am I doing here? That type of thing. They flush your system out, and then once they do that to you, you're there the rest of the night. So you have all night, because there's really nothing wrong with you at that point. You're not cut open or anything. And when they flush you out, they give you an enema. I mean they really flush you. Then you gotta get off the table and run to the bathroom and then come back and then run to the bathroom and come back. It's really kind of embarrassing, really kind of a crummy.

Then at that point, you're left alone with your thoughts, because they don't do the surgery until the next morning. So that night you're in the room by yourself and with some friends with you or something, and you talk, and you really start to get scared after everybody leaves. And they turn the lights out and you think, "Boy. This is it!" It's like being drafted or something, you know? [laughs]. It's your last day. Kind of the same feeling. It was scary.
The next morning they get your full attention when they go over the whole program with you, what they're going to do. They shave you, and they come and get you, and they get you ready and all that. Then it really sets in. It's scary then. And once they wheel you down there then it starts to set in real fast. But at the same time you're scared.

I woke up in the room, and they gave me morphine, but they didn't give me enough. The dosage wasn't enough, and the incision where they cut... I was screaming. You're out of it, but you can still remember some things. All I remember was screaming. I can't remember opening my eyes. I can't remember anybody being there. I know I was in a room somewhere and just screaming. And they finally went and got the nurse and all that. And the morphine was not enough, so they increased the morphine and the pain went away within just an hour or two.

**After surgery:**

By the next day I didn't even feel anything. But then you have the side effects of hallucinations. So you don't feel any pain, but your mind is all twisted inside out. It's just like being on a bad trip, I guess. I've never done drugs, but I guess it's the same feeling. It's scary.

As much as I hurt, it was more of a mind thing. The mind you can't turn off. You don't just shut your mind off and say, "I'm not going to think anymore. I'm just going to stop thinking." The mind is doing ten-thousand miles an hour by that time.

I was in there eleven days, and towards the end, like the eighth or ninth day, I just wanted to get out of there in the worst way. I told them, I just want to go home. Even though you're still hurting.

They come in the night before and they say, "The next day you can go home." So stupid me, I'm up at 6:00. I was able to take a shower, clean up. I had my bags packed.
I'm sitting on the end of the bed at 6:00. They come in and wheel the breakfast in. She goes, "Where do you think you're going?" I said, "I'm out of here. I'm out of here. I'm going over that railing if you don't..." She says, "You can't get out of here until like 11:30 or after." Whew! "Just know that I'm really ready to go. If he doesn't discharge me, I'm going over that railing. I'm going bonkers in here."

When I came out of the hospital, I was on the morphine, and they had me really heavy with the morphine. I had dreams, just terrible. I would just close my eyes and instantly start dreaming. All bad things, like fires and falling off cliffs and being locked in a room or death and everything bad.

And I didn't want to sleep upstairs. I slept down there in a chair [points down stairs]. I just stayed down there. I don't know why. I didn't want to be confined. I slept. Believe it or not, I had to have the lights on. I don't know why this is, but I don't want you to think I'm some kind of a nut or something. I'm just telling you exactly what happened. I was afraid, just afraid to be there by myself, because I didn't want to fall back asleep and start screaming. But you're so tired. All you do is fall back asleep and start over again.

I couldn't really do anything. I could barely make it up here. You're totally helpless, but you can think. So your mind keeps going. Eventually she had to go back to work. I'm sitting down there by myself, so you think. I'm up at three in the morning down there by myself, so you start to think. It just keeps going and going and going. It wasn't like just two things that I'm stuck on, and I couldn't get them out of my mind. It was 100 things. It was very very bad.

And then you have pain, too. Lots and lots of pain.

And then after I did come home, I had to go back. I had a catheter in me. You know what a catheter is? They put the catheter in your penis. I had that. That was another
mind thing. They took it in and out of there five times. While I was awake. Over and above the time they do it when you're in surgery. That was a mind thing there. That bothered me more than a lot of things, to look at myself and having that in me. You already have stitches. You already have this bag [colostomy], your back hurts, you have hurts. Your mouth hurts, your teeth hurt, your mind is... on top of having that [points toward groin.]

So it's just a combination... It's not just going in for colon cancer and they make a cut on you and say, "OK, you're better." If that was the thing, but it's all the... starting, saying that you have cancer, admitting that you have cancer, going to the doctor, going through all this. I made probably more of it than it is. I probably let it bother me. That's just the way I am.

You get over it. I can't say that I just woke up one day and I got over it. Not being corny but that part of my life from the day they told me I had cancer to maybe the day after I went back to work and started to get in my routine, was like a black hole. Almost like somebody shutting your eyes and a bad dream you can't wake up from. It's behind me now, it really. I can discuss it with you and explain it, but it doesn't upset me, where before I didn't even want to talk about it.

**Chemotherapy and radiation:**

I go to the doctor and I say "I feel pretty good, pretty good." And he goes, "That's good because we're going to start you on your chemotherapy and your radiation treatment." Just when you start to feel good. I don't want anybody to touch me. I don't want to be bothered by anybody. I just want to go home and leave me alone. Well, then you have to go through all that.
Then they give you a pamphlet to read about your chemotherapy so you understand it. What they do is they list all the side effects. They list the things that possibly could happen. It doesn’t mean they will, but I read it as: This is going to happen. This is going to happen.

*It’s a big list probably.*

Yeah. I should have never have read it. That upset me again. I went through one year of chemotherapy and 25 treatments of radiation.

*Was it a surprise that you had to do chemo and radiation?*

Yeah. I thought that I could get by without it. He said that there’s a possibility of it after the surgery, but he didn’t say for certain, "You’re going to come in and you’re going to start on this date."

It was more a preventative thing, because they took just about everything out of me there is. I mean I don’t have anything left. The colon, the intestine, they took everything. It got pressed up against the lymph nodes, so they were thinking, "You don’t just say, ‘We’ll see what happens.’" They gave it to me probably for more precautionary than anything else.

That just wears you out, takes any energy you’ve got. I’d just come home and sleep. It’s bad, but you know it’s going to drain you, but you just work around it. I never took any time off as far as I know. I thought, "There’s no way I can work and do this." I’m talking about the chemotherapy. Going through the year of the chemotherapy it was only once a week for a year.
And how long was the radiation for?

It was 25 treatments, once a week. What happens is, you go and you lay on a table. It's like a laser, so to speak, and they zap you. You don't feel anything and the treatments are probably five minutes, seven minutes. I go and they do it, and she says, "You're done. You can go." I go, "That's it?" She goes, "Yeah, that's it." So I think, "Geez. Nothing to it."

But then you go again, and you go again. After about that fourth, fifth, sixth time, it starts to take a toll. I could just drive home and that was it. Sleep the rest of the day. It doesn't hurt you or do anything like that, it just wears on you physically. I got down to the last two or three, I told them, "I'm not coming here anymore." He goes, "You have to. You have to finish it." I go, "I'm not going to finish. I can't. I can't come. I can't even stand up enough to come here." So they give you time in-between. They give you a week or ten days to charge your batteries, then come back and finish your last three treatments.

You go there each time, and you see other people in there and think: "Gee, I'm just like all the rest of these patients." I don't want to be like the rest of these people, but I am.

Return to work:

And then you have the fear of going back to work, you know? I have a real physical job. I was afraid to go back to work, because I didn't think I could do the work. I was afraid even to drive down there. I hadn't done anything for five to six months.

Then you go back and you start working, physically, loading trucks and stuff. Instead of working eight hour days, I worked four hour days to start with. And then that first day I worked eight hours... I think I felt worse that day than any day I was in the hospital. I barely made it home! I don't know how I made it home. My back hurt. My
legs hurt. Everything. I was exhausted. Just exhausted. I came home and I got in that bed, and I stayed in bed all until the next day until I was ready to go to work.

But then you get into the routine, and right now I know I eat better, I look at things better. I think I'm stronger... stronger body, mind. Better physical worker, mental worker. I think I'm just a better person. I can keep up with the guys at work that are 22, 23 years old. The young guys come to me and they go, "How do you get done? How do you do it?" I go, "I just do it." Exercising, eating right, the right frame of mind. When the young guys say that, it makes you feel good. It gives you more of an incentive. Before, I was sleepy and just lazy and [did] just enough to get by and work slow, where now it's totally different. I just go in and go fast.

**Colostomy:**

It bothered me more than anything. Than anything. Than anything in the whole thing. My whole thing was: When we went to talk to the surgeon, he's talking cancer and saving my life. They have a reversal that you can go through, and I'm already on this next page thinking about this, and my wife and him are on the part with the cancer. All I'm talking about is getting in, getting this done, waiting six months, coming back.

He got real upset with me. He goes, "You're missing the whole point of the whole conversation." I go, "What do you mean." He goes, "We're talking about saving your life. We're not talking about whether you like this or whether you don't like it." So it kind of went over my head. I missed that part of it.

He said, "Down the line, we'll see if you're a candidate to have this reversed." So I had that in my mind. When I went in for this and I came home, I thought, "I have it, but I'm going to go and in a year from now I'm going to get it reversed."

Then [a year later] I went to my surgeon to talk about this, and here's another blow: He goes, "No. You're not a candidate to have this reversed. You can't have it done."
missed some of this conversation way back when, not listening or not understanding. He goes, "No. You can't have that done."

I said, "I was under the understanding that I could have it done." "No way," he said. "There's nothing there for you to have this done." That was like another setback. That really bothered me.

**Why do you hate it, or did you hate it so much?**

Because it's so abnormal. It's really abnormal. This is like something that you've done all your life and all of a sudden you don't do that anymore. There's something different. So it's just your routine of whatever your life is. Say you've done something for 25 years, and somebody some day comes to you and says, "OK, that thing that you've done for 25 years, you don't do it anymore. You do it this way."

I really didn't relate to this [indicates colostomy] until I came home, because everything else was gone and all of a sudden, "Oh. But this is not gone." So then you start to really focus on this, where I didn't focus on it in the hospital.

When I got home, I told her, "Will you help me with this thing?" So she helped me step by step. It's like five six, seven different steps that you follow. And it's like doing anything. It's like changing oil in your car for the first time or putting spark plugs in your car. You say, "Did I forget one of these steps?" I wanted her up there to remind me. "Don't do this. Make sure you do this. Make sure you do that."

So the first time I change it -- this is no lie, I mean I was pretty weak anyway -- but the first time I changed it, it took me probably about an hour, and I had to lay down after I changed it. It was like a trauma for me that I did it, and I just lay down for the rest of the day.
I have a little case like that I just put under my arm, make sure I have this extra set. I have this water bottle, too. You fill it up full of water, and you clean this thing out. I found that worked really easily. When I go on vacation, I keep it with me. It's like a hundred dollar bill, you know what I'm saying? Because say you put it in your travel bags and they lose your bag, and you're in Florida or something and what do you do?

What you do is you want to make it easy for yourself. If you go in [the bathroom] and this thing is a problem, and you're emptying it, and you're making a mess, then you get frustrated, then you get mad. If I go in there and I squeeze the water, I clean it out just like that [snaps fingers]. Put the water back in the case and no one knows you have it.

When I go on vacation, I'm walking in the middle of downtown Florida or something, people don't say, "Gee, he's got that thing." No one knows.

*Do you worry about people noticing?*

No. No. I used to. I used to. I used to walk like this [holds right hand over crotch]. It was a habit. But no, it doesn't bother me. Probably the worst thing is you're used to your routine and it isn't a routine, and it's different. It's extra hard because I'm a routine person, and all of a sudden you take me out of that routine and I'm lost.

*So you said it's the worst thing by far?*

It was when I came home. I wouldn't say it's the worst now. You have to get to that point where you can accept it. Until you get to that point, you'll fight it, and you'll look at yourself and you won't like it, and you'll walk like this [holds arm across groin.]. A lot of it's in your own mind. It's your own mind again playing tricks on you.

*Did it affect how you thought of yourself?*
Yeah it did. When you get around your wife and you take your clothes off. I wasn't happy with it at all. I'm still not. I'm still not. For the longest time, I apologized to [my wife]. But again, she's the type that... Some people can handle things, some people can't handle things. Some people can handle disappointment, some people can't. She's a very strong, very optimistic, strong willed, independent person. I see how she handles it, I think, "It doesn't really bother her, then maybe it's not that bad." You can tell when somebody's just telling you it doesn't bother, and it really does. We've been married for 22 years, so I think I know her pretty well.

And I talked to her, and she goes, "Look on the bright side of it. You're alive."

And that's the way you have to put it in your head: Would you rather have this and do everything normal, or would you rather be dead? Well, it's pretty obvious.

Probably my only option was to die or have this. And that kind of separates your feeling really quick. It's not like five options. I'm being honest with you. If I didn't have it done, then I'd be dead. So I think I'll take my chances with it, see what I can do with it. And it frustrates me even now sometimes.

**Sex life:** (It is common after colon surgery for men to be unable to get an erection.)

That is probably the second biggest if not the biggest thing. The first year anyway, I was so sore down there, I didn't want to even think about it. [laughs] But then after a point in time you feel good, and you want to do this thing, and everything else is back to normal and that's not.

And what happens is it's really frustrating, because you think, "Well, it will come back." Well, it doesn't, and it didn't. And that was really a frustration for me. I'll really be honest with you. As hard for me as any of it, that was right up in the top one or two.
What’s bad is the urge is there. All the tools kind of are there, as they say, but it’s like having a big power flashlight but you have no batteries.

And then your mind starts to play games with you because you wonder what your wife thinks. You got a guy here that can’t function. So she said, "You should go to a urologist." And luckily I did. I went to the urologist, and they're working on this all the time just like anything else. And he gave me some options, and the options are all kind of crummy. They’re all kind of crummy, but you have to pick one of them if you want to do this normal thing again.

So they gave me... [laughs]... this is really crazy. They gave me something that’s supposed to help you. It’s a whole suction that goes over you. It’s like a big cone. It looks like something from outer space. It’s got a handle on it and a gun and you’re... I’m telling you, that thing was the worst thing in the whole world. And we both were laughing. We’re up there and I’m going, "This is the most ridiculous." I must have tried this thing three or four times, and I thought, "There’s no way!"

It never worked for me. So I went back, and I told him. And he goes, "Some people have said that." I go, "Well, it’s a piece of garbage as far as I’m concerned." What other options is there, you know? We’re running out of options here.

They have the penile implant. And, I’m sorry, but I’ve got to draw the line someplace, and that’s where I do draw the line. Not for this boy. I’m not going to have somebody cut... No way.

I know this is going to sound terrible, but they have shots that you can give yourself. They get a solution and they give it to you you-know-where. And I thought, "No way. There’s no way." He goes, "It’s not as bad as it sounds." I go, "That’s you talking." He goes, "I’m telling you. Try it. What have you got to lose? If you try it and you don’t like it, then don’t do it." So he says, "Come back next week, and I’ll give you the shot." All week I’m thinking, "Oh my God!"

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So he gave me the shot, and it really wasn't that bad. It sounds ten times worse than it is.

Didn't hurt?

I go "Go ahead." And he goes, "That's it."

But then doing it to yourself is another thing. I'm all thumbs. Well, it's just like everything else that I had to do. You do what you have to do, even though I didn't think I could do it. Sure, if I had an option I certainly wouldn't do it. I have no options. That's my option right there. It's either that or nothing.

It's not that you just go in and they cut you and you don't have anything and you're done. Every day that I think of cancer, all I have to do is go like this [looks into pants] and it brings back memories. Then you have, like I said, the sex part of it. If the sex part of it was natural, then I'd be able to handle this more. But since you're fighting two things, you're fighting this [colostomy] and then that part too.

So it's just another step that you take. There's so many steps. They say you have cancer, the day you go in the hospital, the sexual thing, the bag, the chemotherapy, the radiation, the bag, your head. You take all that combination of a bunch of them and, boy, you can go nuts. If you don't have the right backing, and your head is somewhat screwed on straight, I think you can go bananas. Very easily.

Maybe I can just handle things better. Maybe that's it. I don't know that for sure. Maybe I can handle it a little better than I normally could before. It can't get any worse, so anything that they throw at me now, I can do it.

Support:

I. Friends:
The biggest thing is having friends helping you, at your side, phone calls and cards and people stopping in the hospital. I think that's what pulled me through. It's easy to just say, "Gee, I've got cancer. I'm gonna die." Then you have people that are on your side, so to speak, and it does, it pulls you through it.

You can always say, "I have enough friends." At that point, it just didn't seem like you could have enough friends. Just somebody calling you or coming by saying, "I hope you're doing good," or send you a card. You think there's somebody out there that they really care about you, rather than just say, "Well, I hope you get better."

I had some friends that lived across the street here, and they moved to Las Vegas, so we still keep in touch with them. And I love to go to Las Vegas. So they would call me every night in the hospital, which I thought was neat. I mean, they get to say, "Hey, we're in another state. We're busy. Hope you get better." But they called me every night and talked to me on the phone. And it really helps you.

There's people that I thought that would really be right there, really make a big thing. And there's other people that I thought, "I'll never hear from this person," that were at my side all the time. I couldn't understand it. I wanted everybody to be right there, but you can't have that. I have to say, I held a grudge... not a grudge, but I remembered. I remembered who came and who took the time to go out of their way and the ones that didn't. And I thought, "Well, I'm not mad at these people, but I'll remember that."

And only I know what I went through. It's like somebody hitting you in the mouth and saying, "Gee that hurts." But you didn't really get hit. Let me hit you and see, and you find out that if you just talk about it is one thing; you have an idea what it feels like, but when it actually did happen to you, boy! It's a big difference. People say, "I know what you're going through." And I go, "Well, I don't know."
II. Wife:

Your wife probably can tear you down and go that way, or she can build you up and you go the other way. And in my case, I'm just lucky. I went up rather than down. She's a very strong person. In the worst situation she can find some good in that, where most people say, "It's terrible." She can always find one little ounce of good that comes out of it. So you kind of think: "Well, maybe she's right." I'd get on something, and she'd give me the other shoe, "Look at it this way. Maybe this or maybe that." It gives you another way to look at it, rather than just a downcast one.

And she never did baby me, I mean, never. You don't want every body to walk you around, baby you, and she's not that way. But it makes you strong. If every time something went wrong, she held my hand and we started crying, then we'd both be down in the dumps.

What you want is to come home and say, "Gee, I don't feel good," and then they'll baby you. Where she does not like that. She doesn't let me get down. If I saw her go to pieces, then I would kind of go to pieces, but she's strong. I thought, "If she can be strong, then I can." I can be strong. Because she went through a lot too.

And she's not a outgoing, screaming and yelling and talking. She'll just say what she has to say, and I pretty much pick up on it. "Yeah. I think that'll work." She's a pretty level headed person. Catholic. Twelve years of Catholic school. Really strait-laced, really.

III. Andy Marino: (Mr. Spinelli and Mr. Marino were introduced to each shortly after Mr. Spinelli’s diagnosis. They were introduced to each other via their wives because Mr. Marino had been through ulcerative colitis as well as cancer surgery. They soon became friends.)
I'm friends with Andy because we have the same interests. We just happen to have the same disease, too. I can relate to him more. I have this kind of bond, I guess you could call it, knowing what he's gone through. I'm not friends with him just because he went through that, but it's more of a closer...

I would call Andy and say, "This [colostomy] is driving me nuts." He says, "That's because you haven't accepted it yet. Until you accept it, it's going to drive you nuts." But I had somebody I could call. I couldn't call the doctor and say, "Gee, this thing's driving me nuts." He doesn't have one, where I had a guy down the street that has one. So I could relate. I could say, "Gee, I'm having this kind of a problem." He says, "Let me come over. I'll show you what to do." That type of thing. He got me through a lot of rough spots.

We have our own times where he can help me with things, and I can help him with things. Somebody else can't come in and help me. A guy down the street can't say, "Try this. This worked." He's either done it or going to go through it or already has it, and he can tell me or vice-versa.

Like, I did the chemo before him. I explained to him. I got him set up for that. We help each other in that respect. We go to car shows and stuff and kid about it. In one way it's really not something to kid about, but on the other way it's more of a thing to keep you upbeat. Because he feels OK, and I feel OK. It's over. If it makes you feel better to kid around about it, then that's what you should do. Not constantly, saying, "Yeah, I'm a cancer survivor."

We kid around about it and say different things derogatory about ourselves and make more of a joke out of it than anything. We'll go to the car shows. They've got all these cars; you've got guys walking around. I said, "I'll tell you one thing. See all these people around here?" He says, "Yes." I said, "We're the only two guys that have got two bags hanging from them." He says, "You got that right." He says, "Who in their right
mind would have these things." I said, "Nobody does, It's just you and me." So we go
into the bathroom, I say, "We're the bag brothers."

I said, "We must be getting old if were talking about bags hanging. We're not
talking about cars or something. Or women. We're a couple of old men."

**Personal change:**

*Actually one of my things I'm wondering is: Is there anything good about the
whole experience?*

Yeah. I'm not going to get corny with you here, but I think it makes you, it makes
me... not a stronger... it just makes me a better person. I'm just a better person because I
appreciate things more. I mean, everybody takes life for granted. You do. I do.
Everybody does. You just get up in the morning and you complain about, "Gee, there's no
hot water."

It's funny because I see people that haven't gone through it, and I see the way they
act, and I say, "Gee, I know I acted like they did if not worse." I try to be upbeat and try
to help people at work. A lot of people are for themselves, not because they're selfish,
because I don't think they know any other way. That was my way too. It was like: Yeah,
I'll do everything for myself, and then when I'm done with that, if there's anything left,
then I'll help you.

Before, if you asked me a favor, I would say, "When I'm done doing such and
such, then I'll see if I can do it." Where now, like Andy, he needs a favor, I put what I
have to do aside and say, "Come on over and we'll take care of it." Where before I would
never do that. I would never do that.
I makes you a stronger person. Before, when things would go wrong for me, I would really be downcast. Part of the problem is, when you're real young, letting things bother you, upsetting you, and things like that. When I was younger, I had no way to deal with it. I just let it run me in the ground and make myself sick over it. I had no tools to say, "Well, that's that. I'll deal with it."

Now things still bother me, but I'm able to worry about it for an hour or two and say, "Well, shit, what the heck." I'm able to say, "Well, it's a bad situation, but I'll go to bed, maybe tomorrow it'll be better." You're just happy to be alive, I guess you could say. It sounds corny, kind of.

[I] don't take so many things for granted. And when I do take things for granted, I talk to myself and I say, "You dumbbell, what's the best? You could be dead, or you just have this little problem over here."

The future:

Are you worried that it might come back?

No. I don't think it will. I knew from day one I had the [ulcerative colitis], and I knew it would go into the cancer, and it obviously did. So I know that's how I got it. I didn't get it because I was sick from something else, or I did something else, or because my father had it or my mother had it or something like that. It wasn't anything to do with that. It was the ulcerative colitis.

To be honest with you, I probably won't live to be a old man. Life's too short to short-change yourself.

Why do you think you won't live to be...?
I just have that feeling. I just have that feeling. I've always had that feeling that I won't live that long. My dad's seventy-five, and he's in perfect health. His father lived to be eighty-eight, and he was in pretty good shape until right to the end. So we're pretty hard to kill off. [laughs] I don't walk around thinking, "I'm going to die next year," but I don't think I'm going to be an old man either.
Conclusion:

Clearly the experience of the disease colon cancer has been very different for these seven individuals. It is tempting to comment on each individual's narrative and what it reveals about their character, but I will avoid doing this, principally because this project has been a cooperative one between the participants/interviewees and myself. In addition to guiding me with respect to the issues which are important for them, several of the participants have also commented on drafts of my edited versions of their narrative. To analyze their individual narrative would enhance the "studier / studied" dichotomy which I have attempted to minimize and which goes against the intended flavor of this project: to have real individuals speaking for themselves.

However, I would like to comment across participants on some of the differences and similarities between their narratives and what these differences might reveal about the process of making sense of colon cancer and integrating it into one's life.

First, some of the participants described cancer as a transformative experience. Andy Marino described his colon cancer as teaching him to appreciate his wife and daughter and to understand "the miracle and blessing of life." Mike Spinelli described himself as stronger both emotionally and physically and more able to cope with the hardships that life might present. Wendy Adams described herself as having become more spiritual and more appreciative of each single day.

Others described minimal changes. James Galloway said he had learned "fractionally more" about his mortality. Alan Johnson described being more willing to talk about cancer, and Ulrike Green denied that she was any different at all.

Why did colon cancer seem to have this transformative effect on some people but not on others? The most obvious distinction is that those who described cancer as a transformative experience also described a greater level of fear concerning the cancer or its
treatment. Andy Marino and Mike Spinelli both described in detail their fear of surgery, and Wendy Adams continues to worry tremendously about cancer reoccurrence and death. On the other hand, James Galloway, Alan Johnson, Angela Frick and Ulrike Green talked comparatively little about fear, either that cancer would kill them or of their own death. Whether this has to do with a greater degree of emotional expressivity or whether the person’s transformation is a function of experienced fear is a difficult, possibly circular, question.

A slightly different group found meaning in their cancer, that is, some non-biological reason or justification for it’s occurrence which relates to prior or current events in their life. Andy Marino saw the cancer as a punishment for his previous behavior toward his wife and children. Ulrike Green’s cancer possibly acts as a reaffirmation of her religious beliefs and a demonstration of her belief in positive thinking. Angela Frick, who was feeling burdened and occasionally trapped by taking care of her husband with Alzheimer’s, continues to ruminate over the connection between her secret wish to be liberated from this situation and the subsequent cancer which brought about those changes. She cannot entirely ignore the possibility that cancer is a somatic expression of psychic processes. Furthermore, her personal experience of cancer is thoroughly intertwined with her husband’s Alzheimer’s and his institutionalization, that a question about her cancer is likely to yield an answer about her husband’s placement situation.

As I suggested in my introduction, these narratives are not just statements of facts, they are statements of events and feelings surrounding the illness as filtered through the moment of telling. The continuity in these accounts between concurrent life events and the illness experience is, therefore, not surprising. For each of these individuals for whom cancer had a particularly acute meaning, there was a concurrent life or psychological event which was integrated into the experience of the cancer. Ulrike Green enfolded the meaning of her cancer into her enthusiasm for her church as well as her desire to change her
relationship which is a source of negativity and stress in her life. For Angela Frick, her hospitalization for colon cancer prompted her husband's transfer to residential care. When she came home from the hospital, he was no longer there. At the time of his diagnosis, Andy Marino was already engaged in therapy and confronting issues about his own personality and perfectionism. Currently feeling good about the changes he made, the "punishment" caused him to transform his behavior and attitude, giving the cancer added meaning of being also a "blessing."

It was also interesting to notice the role of contradiction and thematic complexity in the narratives. For example, I found it more difficult to edit the transcripts of those still actively struggling with cancer than for those who are either cured or in remission. Although all of the narratives featured readily identifiable themes -- e.g. "positive thinking" in Ulrike Green's narrative and "radiation just made me hungry" in Alan Johnson's narrative -- the subjects with more active or recent cancer tended to have more contradictions and less easily flowing accounts of their illness. For example, in Ulrike Green's narrative, there was a tension between her willful denial of cancer, her contention that she was "whole, perfect, and complete" and her ongoing chemotherapy and radiation, daily affirmations, and admitted fear of reoccurrence. Her side effects from chemotherapy, despite meditation and positive thinking were also dissonant and troubling for her. Similarly, she seems conflicted about the burdensome pressures of the continued expectations of her children and her own desire to act as if nothing were the matter with her. No doubt once she knows the fate of her disease and with the distance of time, this colon cancer narrative will become more thematically uniform.

For these more recently diagnosed participants, their compelling personal narratives are heightened by their obvious struggle to find meaning in the illness and to make that meaning consistent with changes they would like to make in their lives or are in the process of making. The raw will of Wendy Adams to overcome her cancer, framing the illness in
terms of activity is to me the clearest example of a person gripped by disease, for whom the
interpretation is still in development. There are suggestions that she may have begun to
synthesize her story of disease and terror along issues of control and trust.

In contrast, the narratives of those who have had the disease for longer often
needed very little editorial assistance. Both Andy Marino and James Galloway told
moving, nearly seamless accounts of their illness from first diagnosis to the present,
weaving in observations on their own reactions and the behavior of others. These were
equally compelling for the ambition of their accounts, the eloquence of their words, and
their ongoing efforts to keep these meanings fresh. One of the most poignant moments for
me is when Andy Marino, in telling of the changed but continually intimate connection with
his wife, stops to check in with her that what he is saying is actually true, acknowledging
that he himself is still defining and learning about his experience.

I have been fortunate to explore so deeply different people's varied reactions to a
single biologic disease. A question which lingers for me is: Are these people really so
different from one another? Is Andy Marino, who says the disease has transformed his
outlook on life, really so different from James Galloway, who says he has no deep feeling
about the cancer? Obviously, I do not genuinely propose to answer this question, but the
basic hope and premise of this project -- that the stories of others may reach out to touch,
comfort or educate others -- assumes some fundamental similarities among people.
Although in describing their illnesses these participants have often tended to represent
themselves as different from others (for example, Mr. Galloway emphasizing how his
reaction was "possibly different from most people's." Ulrike Green's brash confidence,
Wendy Adams' consuming fear.) the subtext of concern, questioning (of others and self),
and occasional self-contradiction suggest a greater sense of their similarities, if not in
personality, then in struggle.
Most importantly, as suggested by the subtitle of this project, "Voices of experience," these narratives are instructional words of wisdom born out of experience. In this sense, I have been privileged to have these people let me into their lives and let me ask them about their bodily functions, their relationships, and their fears and hopes in life. I have found, as I suppose I was hoping to, that this project has been for me an acceleration of the broader inquiries into life that is life, that is, where to find meaning and how to live our lives day to day while also keeping in mind the possibility of an extended future. For this instruction and guidance, I am again grateful to those individuals who have let me into their lives and, despite their illnesses have lived more fully over the past six months than most healthy people do over many years.
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Appendix A: Colostomy Care

Changing the ileostomy: (Andy Marino):

ANDY: The patch itself that is affixed to your abdomen, they refer to as an ostomy appliance. I get in the shower in the morning... First of all, you lay out the new stuff. I do that the night before. You have to pre-cut the hole that goes over here, and there's powders you have to put on.

When you go in the shower in the morning, it's an out-of-course routine. I normally would shower and then get out and shave and dry my hair. The mornings I change my pouch. I shave first, I get in the shower, I take the pouch off, and I spend the time in the shower washing and cleaning myself, shaving around there. With an ileostomy, you don't control the discharge. When it decides it's ready to discharge, it's going to discharge. When that's going on -- it doesn't always happen -- if it is going on while I'm showering, it's just an added thing. When I get out of the shower, I have to use paper towels to catch here so I don't make a mess anywhere.

This is the bag, and they come in different sizes and different shapes. They come in see-through or opaque like this. This little thing here, this is a wax wafer. Under this piece of cardboard and these tabs here is like a cellophane kind of material, like you see when they install an i.v. and they put that-shrink-wrap thing over there... same principal.

There's so many different kinds of pouches and variations. This kind has been designed for active people. And my friend, Mike Spinelli, I got him started on this thing. It's great. You don't even know you have it on. But they aren't precut in size, because my ileostomy is the shape of a walnut. It's not perfectly round. You have a template so you can cut this out, and then you do little things like peel these corner pieces back. You do it this way and you do it this way, and I kind of put it from the bottom up. The important thing is that the hole isn't bigger than the stoma itself, because the discharge is very
caustic. It will eat away your skin surface like pouring acid on it. I mean raw skin. Skin care is the big deal with ostomy patients. Very important.

So there's powders to treat wounds that begin... and I've been very lucky, I've never had any wound problems. Right now, I'm suffering in one corner where it goes on my skin. I have a yeast infection that's the result of chemotherapy, and it oozes stuff; it can be very uncomfortable. Now I have Micatin powder that I put on there.

So anyhow, this is what hangs off my belly right about here [points toward lower right abdomen]. And then there's a clamp that goes on here, and this is how you drain the thing. Just imagine, all of a sudden, some day this thing is hanging off of you, and you've got this thing that comes off the surface of your belly.

LAURIE: Somebody called it a rose bud.

ANDY: And the small intestine is a moving organ. It takes a while to get used to.
In my first go around, my pouches were clear. They've got a two piece kind where you can unclip them and throw the bag away and put a new bag on. I wear these for four full days, and on the fifth day I change. The changing process is the washing and shaving. You shave around there so that it's easier when you peel this thing off. It doesn't pull any hair. You dry the skin with a hair dryer so you have a nice dry surface for adhesion purposes.

I wear it in Jockey shorts. It works under jockey shorts real comfortable, and you'd never know I had it, because it's below the waist line. The only time it shows a physical appearance is if I let the bag fill up and there's a kind of protrusion. It will fill up from gas as well as discharge. That was one of the odd things to get used to initially. When you're expelling gas, it sounds like somebody spit ting [does a raspberry with tongue between lips] doing that kind of thing. And you have no control over it.

[Laughs. Laurie laughs].
LAURIE: I don't mind at all [laughing].

ANDY: I might be sitting here with you, and depending on what I ate, it doesn't...

It's very rare. You start farting and it isn't like you can control it.
Appendix B: Penile Injection for Erectile Dysfunction

A common method for treating impotence (erectile dysfunction) in men with nerve or vascular dysfunction is through injection of, alprostadil, papaverine or papaverine plus phentolamine into the base of the penis. Together they increase arterial blood flow to the penis and produce an erection.

MIKE SPINELLI: It goes into the penis itself, but you're hitting the muscle once it gets inside. You're not hitting any fatty tissue. It's right into the muscle. So when it goes in, it just hits. It's like a little pricking sensation. And then once it goes all the way through, you inject the fluid in there. I know it sounds bad, but it doesn't hurt that much once you have it in there. And then you can become good at it, too.

Once you learn to do it properly, you hit it right in the right spot. Sometimes I'll do it and it hurts a little more. And other times I do it, and I go, "Geez. I must be getting good at this, because there's nothing to it." So it works.

Where you give yourself an injection, after that, it hurts a little bit. It's a different process. And then what happens is you have to measure your... It's got a little measuring... like 0.1, 0.2, 0.3. So they give you a thing that you...

[My doctor said] "Well what do you think?" I go, "I don't know." "OK, We'll start with 0.2 and then see." You give yourself the injection: "That didn't do anything." So I call up and he goes, "Try the 3.5" "It's a little better, but..." So my reading is like 5.5. Then I'd call him each time. I didn't just fill this thing up. Some people need to go up to ten. Some people need 2.0. Everybody falls a bit different. So I figure like 5.5 works for me, and it works for her too. Strong enough. It's not the best, but it's better than nothing at all.

There's a lot to it. You don't just wake up one day and say, "I'll go down there and get myself a shot." No. It's really a thing you got to go through. It's another set of whole things you have to face. But you do it. And now it's no problem. Like I said, it's only no
problem because I don't have any other way to go. If I had any other option, I certainly wouldn't do that. But I've accepted it just like anything else. Just like I said, when you first put the glasses on, it was probably awkward for you. But then once you do it, it's second nature, and you don't really think anything of it. And even though it sounds bad, it's not as bad as it sounds. It just sounds terrible. Because when he told me, I went "No way." But it's not that bad.
Appendix C: Pump

The pump is a device which is implanted under the skin and in the abdomen hooked into the blood supply to the liver. It delivers chemotherapy directly to the liver, thus minimizing side effects from chemotherapy going throughout the body. It is useful in people with colon cancer, because the liver is the most common site of metastases for colon cancer. The pump is a flat cylinder about 4 inches across with a spring-loaded chamber which pushes out the chemotherapy drugs at a slow, steady rate. The chamber is filled by injections through the skin.

For a description, see also the early pages of James Galloway's narrative.

Wendy and Jack Adams:

WENDY: They put the pump in. They wanted to try the pump. Boil's the one that handles that. I still have a pump in. I had a hard time making friends with it, and I used the guided imagery to do it. I felt like there was this foreign thing in my body. I had to work on saying: This is going to make me better. I had to stop it, because it gave me jaundice. It's ugly because it sticks out, but I've made friends with it. I'm fine with it. In fact, I'll probably go through this loss when they have to surgically remove it. And they say they'll do that when I'm cancer free for two years.

They've got this giant syringe. They poke in with a big needle. My husband can't stand to be in the room when I'm going through all of this stuff. But it's not that painful, the procedure itself. I don't feel that it's a problem.

....

Yeah, I notice it. But not anything near what I did when I first got out of the hospital. It was a while, but I convinced myself that it was my friend. Such an unsightly thing sticking out. But, you know... I'm aware of it. And I do feel it. The tissue is tender a little bit around it. And, of course they poke it all the time. It feels a little bit bruised. And he told me from the very beginning, "I have people wearing it who are weight-lifters
and gymnasts. There's all these people doing all these things. There's nothing you can't do. Don't worry."

**Angela Frick:**

[They said] you could do anything you wanted to. So, I don't let it bother me. I'm cautious with the little children when they...I like to roughhouse with them, but I don't let them get too rambunctious, kick, you know. I'm a little bit wary about that, but he says it wouldn't hurt.

I have one friend who says, "How's your new best friend?" That's what I keep telling: "It's my best friend." Instead of an unsightly... At first I hated it, but it's keeping me alive at this point.
Glossary:

Adjuvant: (Chemotherapy) In oncology usually used to refer to chemotherapy given as a precaution against any undetected or microscopic tumors.

Cancerous: Able to invade surrounding tissue and/or metastasize to a distant site.1

CAT scan: Abbreviation for "Computerized Axial Tomography," an imaging technique using X-rays from many different directions to produce a clear image of a plane or "slice" of the body.

CEA: Abbreviation for "carcinoembryonic antigen," a marker in the blood for certain tumors, usually colon cancer. Normal is <3 or <5 ng/mL in a smoker.

Colonoscopy: Examination of the intestine through the anus, using a several foot long scope, usually a fiberoptic cable connected to a monitor. A colonoscopy is usually able to visualize the entire large intestine.

Colostomy: An artificial opening of the colon (large intestine) through the skin, usually on the abdomen and the emptying into a bag. A permanent colostomy is common in people for whom surgery removed the portions of the rectum closest to the anus.

CT: Same as CAT

Endoscopy: Examination of the inside of the body using a scope, generally used to refer to entrance through the mouth or nose with a fiberoptic cable connected to a monitor.

Fistula: An abnormal passage from a hollow organ to the surface or from one organ to another.

Ileostomy: Establishment of a fistula through which the ileum (small intestine) discharges directly to the outside of the body.

Maalox: An antacid which neutralizes stomach acid.

Malignant: In cancer: Having the property of being locally invasive and/or able to metastasize.

Metastasis: (pl: metastases) The spread of a disease (such as a tumor) from one part of the body to another.

Pepcid: An antacid which blocks stomach acid secretion.

Pump: See Appendix C.

Stoma: Opening; mouth. An artificial opening between two cavities or canals, or between such and the surface of the body.


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Tumor: Neoplasm; An abnormal tissue that grows by cellular proliferation more rapidly than normal tissue and continues to grow after the stimuli that initiated the new growth cease. May be either benign or malignant.