

OREGON HEALTH & SCIENCE UNIVERSITY ORAL HISTORY PROGRAM

a project of OHSU's Historical Collections & Archives

an interview with:

Miles J. Edwards, M.D.

interview conducted on: November 3, 2005

by: Erik Fromme, M.D.



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Interview with Miles J. Edwards, M.D.
Interviewed by Erik Fromme, M.D.
November 3, 2005
Site: Dr. Edward's home, Portland, Oregon
Begin Tape 1, Side 1

EDWARDS: I went to medical school here between the years of 1951 and '56. I was really Hill-bound for ten years almost. I stayed on as an intern in the rotating internship at what's now OHSU, and then took an internal medicine residency in the late '57, '58. I got interested in pulmonary medicine and—it's a long story, because I'd worked in a TB hospital during medical school, which—and I got a master's in physiology, what happened to be respiratory physiology. So, there were a lot of things that kind of within the framework of medicine directed me toward pulmonary medicine.

So I—in 1961, I went into the military for two years and served at Fort Benning, Georgia, came back, took a year fellowship at the University of California San Francisco, and came on the faculty here in 1964. We were a very small division, just two of us at the time. I eventually became the only member of the division; the other person was let go, which left me alone, but he wasn't much help anyway. And we didn't—it was a very primitive time in medical history compared to today. I can remember—well, I won't go into that, but we didn't have ICUs, we didn't have the high tech stuff that we have today. And so I kind of grew up with the developing, increasing technology, eventually ended up as critical care—never having had any training in critical care, but I just did it, this grandfather stuff. And I was head of the Pulmonary Critical Care Division for sixteen years between 1967 and '83. And I stayed on in the Division but quit being the chairman of that division in '83. Still very active in both ICU and pulmonary medicine, and I did general ward attending at OHSU as well.

And in 1991 I was having some back problems and some health problems, not these problems I have now, and I decided to scale back out of ICU. And I was 62 years old, I—and so I moved into medical ethics. I took some training in it at the University of Washington, and found it kind of a way to use my background, clinical background—and correlate it with a different focus, in a way a challenging one. So by 1995 I had retired, quit my practice, my pulmonary practice, and am retired since and volunteering with the Ethics Center where I see patients with conditions which I variably am familiar with but in some, especially the ICU patients am very familiar with.

So I had a sense of deep meaning and purpose in doing that. So that, I think, sums it up. I continue to do quite a bit of teaching of medical students, which I thoroughly enjoy. And I even had a session with students a couple weeks ago where I talked about my illness, a little bit like I have here and I think there was, again, a sense of meaning. I figure you guys—guys and gals, the students—this is real; a person with this is sitting before you talking to you. I've got it. I've got to deal with difficult things. And it made a big impact on them, I think. [4:43]

FROMME: Miles, I think for the first question I'd like to take you back a little bit, and ask you how you learned that you had cancer.

EDWARDS: In the summer of—in June of 2003—that's two and a half years ago—I, one morning, just was having breakfast with a couple of friends, and came home, and about two hours later I had severe, couldn't quite tell if it was epigastric or lower substernal chest pain. It was alarming enough that I went up to Providence St. Vincent's near here, and work-up eventually revealed that I had a gallstone. The chemistries were—you know, ruled out heart attack, ruled in gallstone. So, I thought, well, maybe I'm going to have to have a gall bladder operation, and so the doctor's taking care of me. Well anyway, in the process of getting the magnetic resonance imaging over the gall bladder-pancreas area, instead of finding a gallstone, they found early cancer of the pancreas.

And this just absolutely came as a hammer blow. I was sitting in this room, visiting with my daughter and grandchildren and my wife, and the phone message came that their imaging had revealed this, and—I had known a number of people who died of cancer of the pancreas, and knew what a terrible cancer it is and what a death sentence, virtually, it is. And so, but then I thought the location of the tumor was between the body and the tail of the pancreas, which is a favorable location; it was an early pick-up, quite fortuitous, serendipitous or whatever; and I thought, gosh, if there ever was a chance to do something about it—I would not have gone for a Whipple or some of those bigger—not that a Whipple would have been appropriate in this—medically, in this case, because Whipple are designed for people with big central head of pancreas tumors. So they—I thought, well, let's go for it. And I was scared, you know, scared not to, scared to, more scared not to than to [laughs], to do that.

So I went in late July of 2003, I underwent surgery. The surgery was what I hoped, wanted it to be, and the surgeon, Brad Sheppard, totally agreed, was to be a subtotal pancreatectomy, leaving in enough head possibly if cancer—you know, if the margins allowed, to protect my insulin-producing cells at the head of the pancreas and whatever else they could of pancreatic function. [8:34] And then they took out the spleen and gall bladder—well, the gall bladder obviously because it's diseased, and the spleen because that's a likely place for metastases. Now, surgically there was an additional problem and that was that five years before that I had had an esophagectomy, with gastric pull-up into the mediastinum, so I had really altered anatomy and a lot of scar tissue down there when the surgery was done in 2003.

So this all combined to make the surgery more difficult, but I had a rough time post-operatively, and I've never had any kind of surgery they didn't have a rough time afterward for a while, and this time I was in the hospital ten or eleven days before I had GI function and before I was strong enough to go home. I was still very weak, and over about—this may be going a little deeper than you intend—over about two months time, I was starting to get a little energy back, and I had an appointment to see Dr. Sheppard again, the surgeon, and he said, "You know, Miles, we may have gotten it, we may not

have gotten it. We didn't knowingly leave in any tumors but"—I knew as well as he, that the chances were that there would be [...] tumors were notorious.

So I—and he said, “You really ought to see an oncologist.” Which meant, then, that I went to have an evaluation by Dr. Charles Blanke in the Hematology/Oncology Department. And Dr. Blanke indicated that, you know, there was some risk of cancer still being present—not known, but some risk, and that by going on a course of chemo and x-ray therapy, chemo being 5-FU, 5-fluorouracil, and radiation therapy that that—whatever that risk would be reduced by about fifty percent. I took his word for it—I trusted him and everything, and I think rightly so. And so I—but I knew that that would mean that my energy that I just was getting back would go down again [laughs]. And I wasn't having pain problems at all, it was strictly having just endurance issues.

I got the pick line put in, you know, where they delivered, by a constant pump injection, the 5-FU and I went daily for x-ray treatment. I got weaker and weaker, and lost some weight that I could ill afford to lose, and I got through that pretty much and then was kind of recuperating in December and then they started another course of 5-FU, and during that course I got the shingles, the herpes zoster, which was the first time I had really had severe pain, and then it was treated with that valacyclovir—whatever it is you take, and over time it got better. And I finished in March of 2004, I finished all chemo, all that course of chemo.

And I'd have to say that during the—during those periods, I did, in having this extreme fatigue, being—dogged me every step of the way—was a constant reminder of what cancer patients, or people who are inevitably dying of cancer feel similar to that. I think I gave a lot of thought to fatigue; fatigue really is—you know I think the anti-metabolite that I was receiving—after all, metabolism is what drives energy [laughs], you know, so that I, I did—you know, I kept thinking like a doctor while I was being a patient, and then yet in some ways beginning to think like a patient too. I was pretty hypochondriacal, armed with a lot of medical knowledge [laughs] lending substance to it. And I remember having, both after that surgery and the prior esophageal surgery, a lot of anxieties and things that being a pulmonologist, I was worried about aspiration, [?] and things like that. And with the declining energy, I—there was some sense to me of enormous vulnerability being that weak. I mean it was like—you know, in normal living you have a vigor to get up and walk fast and go places and keep an active day schedule. For me during that period, it was—I had to learn to budget energy, just like—I thought about this, you—we mostly all go through life budgeting time and money, but that this required budgeting energy. And it's become the dominant thing I budget when I consider doing something or not doing something, is do I have the—it's not that I don't have the time, and it's not, you know, money issues don't enter into it, but the energy. And I think it passes, crosses a lot of lines, that's why energy is hard to understand because chemo'll do it, surgery will do it, cancer itself without either will do it. So, you know, I was acutely aware of the impact of the drain of energy—which isn't necessarily the same as strength, by the way. I don't think. Maybe some more knowledgeable person than I would comment on that, but for example, I could pull myself up in the shower—probably was a dumb idea, but I had the strength to pull my body up and down and get in and out,

you know, but I had to budget: I had to rest a while before I took a shower. I remember going to church one time in my chemo. I found that was a big mistake because there's a fatigue that goes with just the visiting with people. [16:32]

Which brings me to another point: that the energy is not just physical energy, it's mental energy, and the brain-body's connected and—I almost had an auto accident when I was on chemo and if the accident had happened it would have been my fault and I knew that after the fact, and it was because I was not completely cognitive—I mean I was cognitive, I was conscious, I was trying to be very careful driving my car, but with the fast movement of traffic around you have to be extremely alert and have all your resources and I was—I mean, it wasn't like I was drunk or on drugs or on alcohol or anything, I just didn't have the mental agility; and that went with my chemo.

FROMME: Do you think that's what some cancer patients refer to as “chemo brain”?

EDWARDS: I do think so, yes, definitely. Now what that is in terms of physiology I don't know, but I think the chemo—the chemo part became clear to me, and I thought, an anti-metabolite, I'm taking an anti-metabolite, 5-FU, and it interferes my metabolic processes. And of course it affects my muscles and physical stamina, but it also affects my mental stamina. I realized I couldn't even read a full article in the newspaper 'cause I didn't—I mean I started out well, but then I began to have mental fatigue really early. And so I, yes I think that's the same as chemo brain. [18:37] And it's a real issue, and I think it isn't just chemo brain, I think that after the [dilatid?] I had last week, I noticed again that I—my brain, I kept saying several times, I said that my brain is mush. And you know, I knew it wasn't permanently mush, but it was—I didn't feel that—I don't think I could have done this interview then, in any kind of way that you'd find useful [laughs], I mean other than just observing somebody with chemo for an [hour?] or, that this chemo being a narcotics.

FROMME: Well, so you're describing, as you're talking about it, I'm thinking, you know, 5-FU is a chemotherapy agent that we usually think of as a relatively mild chemotherapy...

EDWARDS: And it probably is. You know, that's why I marvel at people who take more severe chemo. I was just marveling at Senator Arlen Specter, who'd been on chemo or, um, the Supreme Court justice who died recently, um, I'm blocking on his name for a minute—maybe a little bit of chemo brain here—Rehnquist—how they were able even to think of coming back and being actively participating in their activities. I—even though I was on something that was supposedly mild as chemo goes—I didn't lose any hair, I didn't have any mouth sores, I didn't have a lot of things I—not that hair was too big an issue with me [laughs], but I've had a history of mouth sores, but it didn't trigger those at all. So I just—profound fatigue, fatigue mental and physical.

FROMME: Well I wonder if part of the reason it's considered a mild chemotherapy is that it doesn't tend to cause a lot of nausea and vomiting or—

EDWARDS: And that's true—

FROMME: Or a lot of symptoms that an observer would see, but maybe it causes symptoms that are not necessarily apparent.

EDWARDS: I think fatigue is a symptom that has been spoken about too little. I don't know that we have quick answers for people to help them with it, but I think there's enormous psychological impact, at least for me on both the physical and the mental fatigue. I mean, I always prided myself as being pretty active physically and pretty active mentally both in my career—not because I was running marathons or anything, but you know I mean I was three- or four-mile walks before I was on any of this. You know, for a 76, 75-year-old man, I was pretty—doing fairly well. And then to have that clearly diminish made me feel extremely vulnerable and dependent, and I became more dependent, I had to have my wife do things for me that I would like to do for myself, but, I didn't have the energy to be able to do it. [22:18] And getting back to that going to the church for two hours, I—it took me two or three days to recuperate. You know, and that's not a big deal, I mean, normal, for a normal person, but—so there was a lot of these things. That's where I got the idea about budgeting energy as something that you have to do.

FROMME: I wanted to go back a little bit, when you were dealing with your illness sort of going back and forth between being a physician and being a patient.

EDWARDS: Yeah.

FROMME: And I wondered if you could talk a little bit more about how you—how that happened: was it an intentional going back and forth—

EDWARDS: No, I think it's just a natural event for a physician who gets a serious illness. There was nothing—I think that a physician will always deal with their own illnesses with a blend of being a patient and being a physician in their way of thinking. [23:32] I mean I—and some of it's good and some of it's not good I guess. I noticed that I would have—I'd be constantly analyzing my symptoms. And of course, plenty of time to do it, become obsessed about it, maybe have somewhat of an obsessive-compulsive disorder anyway. And I would fix on something like, after the esophageal surgery did I eat too much and gosh, I could feel it up here in my thing and I'd cough and I'd think oh my gosh I'm aspirating. And then I thought about—after having done maybe a thousand bronchoscopies in my life, I can imagine what the inner airways look like. That's not something average patients would do [24:31] of course. And my area of expertise, gastroenterology—and yet it has some benefits in that, some months after my pancreas operation, I noticed my stools were sort of bulky and I was losing weight, and I called it diarrhea and it was about eight or nine months after my surgery. It was the last shot of 5-FU and I realized I had dropped about fifteen pounds, and I thought, “I'm malabsorbing.” Of course! You know, I mean, my brain, my medical brain went to work, and said—and so I called my private physician who quickly agreed, said “Miles,

we don't even need to test you. We know, we know you've got malabsorption due to pancreatic endocrine insufficiency. So, I got on the pancreas pills and in a matter of two months I gained back most of my weight. Not to where I wanted it, but at least back to something close to what I had before the surgery.

FROMME: After all of your experiences, do you have any advice for physicians who find themselves in the role of patient?

EDWARDS: Well, one is to expect to be on an emotional rollercoaster. It should come as no surprise that—and for me, this happened—I would have my very good days and very bad days. And it wasn't necessarily a very good or bad day medically, it was a very good or bad day psychologically. I would go up and down, depending on how much hope I was holding for good outcome at the end. And one of the things that got me through the chemo and the x-ray therapy was that I always figured there was a light at the end of the tunnel, and there turned out to be light at the end of the tunnel. I eventually got my considerable vigor back, I went back to work in the Ethics Center, I—we even took a trip to Hawaii and took another trip to San Francisco and it wasn't like Russia or something, not overseas trips, not big-time overseas trips.

And so, first of all, my first statement would be for physicians: know that you'll analyze yourself; realize there's upside and downside to that. Sometimes that—for example my recognizing my exocrine insufficiency precipitated a needed action sooner than my doctor, who I didn't see for a while—and I'm not saying, it's no comment on my doctor, it was just that my doctor didn't know anything about my steatorrhea, I hadn't talked to her and so I—and I—so I think one's analytic ability is helpful in some cases, some circumstances, but at the same time I found myself obsessive and I know that there's a—I remember reading a paper some years ago about physicians being—having a high obsessive component and probably good physicians have more obsession because they're compulsive to cover the bases and thoroughly check out a patient and consider all the alternatives.

The other thing that one does, as one thinks like a doctor while being a patient, is that you consider the worst and best scenarios and blend them back and forth. And the worst scenario's going to put you into a tail spin sometimes. I found that if I just wrote them out, I could write them out in a day or two, and I'd be back in a better mindset. So there's this emotional liability that goes with the territory. [29:16] And I think it's a good thing in a way, and there's unavoidable—I mean I don't think you can be a physician and have—my wife accuses me of being pessimistic and I say I'm realistic, and I accuse her of being Pollyanna, and we go around and around about that, but I finally had to point out to her—and we were seeing a counselor for other reasons, but we talked about it this too, and I said, “There's no way I don't go into this with the mind of a doctor. There's no way; I can't possibly do that.” I mean I spent forty years analyzing symptoms in patients; why would I not when it's me? And so, I think I finally got her to understand that [laughs] and we went from there.

Other things are more general, not just physician-related, as far as being a patient, and that is confronting one's own death. I've had to confront mine, I still have to confront mine, I've thought about, you know, what would—how would I react if the—closer to the end than I am now, of course, when I'm still ambulatory but weakened, but ambulatory, but I know full well—again, this is my medical experience and having seen people with cancer, and especially this kind of cancer, waste away. And there's a psychological impact of looking in the mirror and seeing skin and bones, looking like an Auschwitz survivor or you know, Treblinka or whatever that was, or what was that place in Bosnia that was—showed these people who were just living skeletons and you look at yourself and see that happening. There's also appetite issues: you want to keep your weight, but eating sometimes is a struggle, the appetite center is somehow affected by this whole process both in chemo and with the cancer, I think. And that's something to live with.

I guess the positive side, I would just say [32:01] at least to me important is that life is a precious gift, and I consider my life a precious gift and I want to make the most of it as long as I can. And even under adverse conditions I want to teach—I love teaching, I've given ethics presentations; I'm actually doing this because—and I even finished writing a paper, you know, feeling like—it gives me a sense of meaning. Because if you don't have a sense of meaning, a sense of purpose, during life, and especially during this stage of life—the dying process is still a part of life. It's not the most—it's got its downsides, you know [coughs]—not feeling well during the process, but as long as I feel well enough and I store up the energy—there's that old budgeting thing again.

I've carried on at this church I attend a series on ethics, and one of them happened the day that I discovered I had a pleural effusion, a malignant pleural effusion of my carcinoma of the pancreas, and I was devastated but I thought, "I want to use that," to these twenty-two or -three people, lay people, who are in the room. And I had already scheduled a man who had taken care of his dying wife to talk about his perspective on it. And then I sat down and gave my story, and I thought, this is a teaching opportunity, and I enjoy teaching and it gives me a sense of meaning, and if I can leave something with people in this room, that is useful, and that's a part of my life, I use it that way. And I'm happy about it. It gave me some energy; it gave me some sort of psychic energy to do it. I was tired afterward, and, you know completely collapsed when I got home [laughs], you know, I mean in the bed [laughs], but...

So there's all those things, and there's always the Kübler-Ross progression, which is a back-and-forth thing, not a, as you know, a progression from denial, anger, bargaining, depression, acceptance. [35:00] And feeling challenged that, you know, I want to, when things are clearly pointing to my demise fairly soon, that I want to live that life the best way I can and reach this place that Kübler-Ross calls acceptance. Now that is its own story, because one of the things I—some of my friends have said—I mean, I remember—I'll just give you another little scenario. My—during the shock of finding out about the malignant effusion, I remember—I usually am very interested in the world news and stuff, I watch the *Lehrer News Hour*, I'm on OPB all Friday evening watching

the *Washington Week in Review*, and I love Fareed Zakaria's thing that he does, and Brancaccio and formerly Bill Moyers, I like those programs, and watching different channels and things—fascinating. But when I got hit with this malignant effusion, and I was stunned by that, suddenly, all I wanted to do was lie down in bed with my wife and hug [36:36] and listen to soothing music. And was I—did it mean that I wasn't interested in world affairs? No, it didn't mean that, it just meant I didn't have energy for it. But I had to devote all my energy to dealing with my situation, things that I could—the only thing I had control over was my attitude toward it. And so I've come to kind of roll with the punches: I let the downtimes come; I know they won't last too long—so far, [laughing] they might get longer in the future, but...

I hope that answers your question. [37:21]

FROMME: Absolutely. And I wanted to—because I heard sort of a theme there: you mentioned that, I think as you were going through chemotherapy, you mentioned that you—how you were feeling depended somewhat on how much hope you were holding—

EDWARDS: Uh-huh, yeah.

FROMME: ...were the words you used. And then later you talked about confronting, confronting death.

EDWARDS: Yeah.

FROMME: And then after that you talked about finding meaning and wanting to use your time as best you can.

EDWARDS: Umm-hmm.

FROMME: And it made me think about you know, as a physician working with patients, you were sort of told not to do anything that destroys hope.

EDWARDS: Umm-hmm.

FROMME: And I think a lot of people might think well, maybe confronting death or—might be something that could do that.

EDWARDS: Umm-hmm.

FROMME: And so doctors might, you know I think doctors are reluctant to bring up the issue of death and things like that. And I wondered if you could talk a little bit about your own process.

EDWARDS: Yeah. [38:50] I—I guess I believe strongly that—I like to go with the flow on this thing, and hope is always there, but it's in and out. I mean I even have hope that, you know, the next three or four months will be reasonably comfortable. I

know what will happen later will be difficult, but I have hope that I will handle it well. I've known patients who have, and I have known patients who haven't handled it well, psychologically, spiritually. And to me, that's a challenge. I think well, and maybe that helps others to see me struggle through this in a way that might help them when they have to struggle through it. And that's a part of the meaning thing.

So, you know, I don't think death is the worst thing that can happen to a person. Death may be—who knows, we don't know where we're—what really happens when we die. I mean, we die, physically, but I don't think we know, we don't—Kübler-Ross says that no one can really perceive of their own mortality; that their own death is something that is inconceivable mentally. And I'll have to say it is for me too. I mean, how—I mean, all I've ever known is being alive. And the thought of being dead conjures up all sorts of things: unpleasant, or even pleasant, or just a void, neutral. And I don't know that, and I won't know that until the time comes, and then there won't be any “me” to know that [laughs], I guess. [41:27] I have Christian friends who talk about heaven and I have a sort of a scientist's skepticism about that, but I can't say it isn't true either. And I see a lot of miracles in creation, in our existence, our very lives, which I realize are not explicable, so...

And somebody said that death is beyond the horizon, a place you cannot see. And so as I get closer to my own death, and I talk about that quite freely, I think well, I've got to—I really do, I've had a good life, in fact I was thinking about—I've been to the cancer clinic up at OHSU where they have people lined up getting their infusions. And I see a twenty-five-year-old kid or a teenager, looking dejected and sad, and I think, “What am I complaining about? I'm seventy-six, I've had a wonderful life. I mean something has to happen to me sometime, and look at this poor soul that got dealt a set of cards in which they're struggling with this at twenty-five or twenty or fifteen or ten years old.” And it puts me, puts things in perspective, it says—or even middle-aged people in their forties, you know, who are facing all the terrible trauma, psychic trauma of facing their own demise when they had a lot of life to live ahead. And you know, I'm seventy-six; I know if I even didn't have this cancer, I've got—it's only going to cost me, well, who knows how long, but not very many years of increasing frailty that's going to happen anyway.

And so I—for me, being an older person, I think you know that didn't get me something else would. It's not like the thinking of a thirty-year old. And so I have all the greatest compassion for those people who are younger, in the primes of their life, which I am well past my, the prime of my life, so... I don't know, that's another perspective, you know. [44:33]

FROMME: Do you, can you talk, have you had any thoughts or any insights about what role your physicians play in either giving you hope or sustaining your hope or taking it away?

EDWARDS: Umm-hmm. Mostly—I have my own imagination, which easily gets active—my encounters with physicians have increased my hope. Just the very simple thing of—I showed up in Dr. Blanke's office a week and a half ago, and he was

sad that all the treatment he'd administered had not succeeded in curing the cancer and—but he offered some chemo options that might be worth considering which I—and made an appointment to see me again in three weeks. Well, you know, just making the appointment for three weeks was hopeful because I was, in my worst scenario was thinking, “He must think I’m going to make it three weeks.” I know that’s real funny, but I mean that’s the way I reacted to it.

And then the chemo: well, he offered that the chemo wouldn’t cure my cancer, he was sure of that; but that it would offer some amelioration of symptoms and extend life somewhat, from what it would be otherwise. [46:29] And I thought, “Well, what have I got to lose?” This is—and that gave me hope. We all know the seriousness of this cancer, and we all know—I know it, they know it, you know. Again, the physician thinks differently than average non-physicians, so...

So, I think hope comes in a whole lot of sometimes rather subtle ways and otherwise pretty obvious ways. Taking away hope? That’s not been my experience yet, because—I mean, when I had this pleural effusion, and I diagnosed it myself [laughs], I got out my stethoscope and listened to my lung bases and heard breath sounds over here in the right and didn’t hear any on the left, did tactile fremitus and it was strong on the right, absent on the left, thumped, normal resonance here, impaired resonance here. Pleural effusion. Because I’m a pulmonologist, so, you know, I diagnosed myself. And then I got the x-ray, showed effusion, at the point I was tapped, I knew it was going to show cancer. So, by the time I got word that it was cancer, there was no emotional impact: I knew perfectly well it was going to be cancer—[laughing] what else could it be, you know?

So, I think that we as physicians are—what I’ll still say in my jousting with my wife, that we’re medical realists and can’t help but be. And that has its upside/downside, and we talked about that already.

FROMME: In all of your treatment and all the experiences you’ve had with healthcare, have you learned anything about how—well, have you learned things that you think other doctors should know, or that [48:54] you wish you had known before you became a patient?

EDWARDS: Well, I think yes, the answer is an emphatic yes. I’ve learned what it feels like to be a patient; I’ve learned that it isn’t just something I read in a textbook or a medical article, or from personal experience as a doctor; that it’s a different mindset and a different place of being. To be sick and—I think doctors need to know that their patients are suffering something they have to suffer, they have to deal with, in however they’re equipped to deal. And I think it adds to the physician compassion for their patient. And there are things that are not fixable in a medical way, but human understanding and connection is important. And that—I am very much a believer that physicians should not abandon patients who are dying; and sometimes physicians are spooked out by having a patient who’s dying, and I’m not saying they shouldn’t do that, exactly, but, I’m saying that it’s hard on the patient. And I think physicians should be

honest and say if it's the way they feel. You know, "I don't know how to help you now, but I'll stay with you, I'll be with you, we'll get to palliative care or something or help from others who know how to do that better than I do." I, meaning that physician, as the best way you can handle it—"and I'll just continue to keep an eye on you." In other words: not walk away. I mean, at the end of it. Because that leads to a psychic trauma that's not necessary and is actually very damaging.

FROMME: I think we have about fifteen or twenty minutes, [51:35] and I wondered if there was a topic that you would like to speak on, as, you know, putting on your educator's cap.

EDWARDS: Well, the one is, in the last days, what would I consider doing? And, of course, we're in Oregon and we have assisted suicide, physician-assisted suicide, or death with dignity, however you want to label it, law. And in years past, I took a public position against assisted suicide because I felt it was not an ethical role of the medical profession. I wasn't so bothered by it—whatever the act was by the patient, but there was one dragged the medical profession in to what I think violated its own ethic of do not kill. Do not administer poison, that goes back to Hippocrates.

Having said that, and having taken that position, I then became sick; and now, sick, when I was going through chemo and feeling pretty raunchy through a lot of that time, I had to rethink this in the role of patient. And somehow the ethics thing kind of disappeared from my consideration and my reasons for opposing it. But it was replaced by a rather visceral dislike of the idea that I would take a medication to willingly shorten my life, and in fact take it and know it happens in minutes or hours or so. That is just was, to *me*—and I'm not saying other people have to agree with this, I'm not being political here or anything, I just say that for me, that was not an option [54:15] and that I wouldn't elect that option. Now, down the road, I don't think I'll change my mind, but—because I haven't gone down the road that far yet.

What I did consider was, if I got to the place—I mean, I want to live out my natural life span, okay, whatever that is; I don't necessarily want to lengthen it much, like putting in a feeding tube and IVs and narcing me out with something that would make me unresponsive to my environment. At the same time, I don't want to foreshorten it. And so, I thought about—and it's an area I know something about—is the voluntary abstinence from eating and drinking. And I know that's effective and relatively painless. Just to get into a little physiology, the cessation of nutrition—well, the cessation of hydration results in hypernatremia which has a sort of numbing effect on the central nervous system. And the absence of caloric intake leads to ketosis which also does that. Both of them lead to a rather quiet state. Now there's—obviously, there may need to be administered pain medication for the underlying condition concurrently, but that could be done with minimal fluid administration.

And that I would consider—but I'll tell you the conditions I'd consider [56:20], would be that I reached a place where my appetite—I mean, I would, you know—is severely curtailed or maybe I'm nauseated and vomiting; my GI tract isn't working; and

my—I don't—I'm not thirsty, don't want to take fluids; I don't want to take food. And I think that's my body telling me that my time is up. And at that time, I would consider voluntarily abstaining from eating and drinking, not just because I'm trying to end my life prematurely, because I don't think that's premature, but rather let nature take its course and cooperate with the way people have died over the centuries—in other words, without medical intervention. The thing I like about it also is it doesn't involve the medical profession, doesn't involve other people; there aren't the psychological impacts on doctors and patient and family that I think PAS does cause, or can cause.

So, I'm not—this is not to say how others should think; it's only how I sort of put it together, that if I got to that place, and my time was up, and I could feel it in my appetite, thirst, all that, I'd just stop, and want to be made comfortable.

[Pause.]

FROMME: Are there other things?

EDWARDS: There have been certain joys in this period of time which are important. I have four adult children, all married, and nine grandchildren; they all came as their schedules allowed, but rather quickly to Portland. [58:45] They live in scattered places: Denver, Sacramento, Seattle, and the only one who's close is my daughter in McMinnville. They've come by; they've played in this room; adults have sat around and talked in this room, my adult children and their spouses, interacted with each other as well as with me. I had great satisfaction in just seeing family, seeing what's following me. I had enormous satisfaction. The only downside was fatigue; I would get tired, and I learned to say, you know, "Give me a thirty minute break, I want to go lie down, and somewhere in there I'll come back and we'll visit again, and please have fun with each other." And they did. And that was nice.

And so the side—that side is important. I got a paper published; it's about to be, and I know you know about that. And I have satisfaction that it dealt with some things about end-of-life care that, I thought, there's a sense of meaning again, a sense of meaning in that the lot of work I did on that paper is reaching fruition. And by all appearances I should live long enough to get to see it. And so—I mean, those are the little satisfactions that come.

I got some wonderful cards and phone calls; the phone calls kind of wore me out, but the cards—but at the same time I like getting them because they were sincere expressions of affection from friends of mine. The cards, some of them were absolutely publishable; they were beautiful, beautifully written, and I'm sure sincere. And so, knowing that people are praying for you, or some of my nonbeliever friends are thinking of putting positive energy my way—[laughing] I'll take all of it, you know, and appreciate that, so...

There's meaning in relationships, there's meaning in work output, there's meaning in family—well, relationships, both social and family. All those things are

important. And I think in this time of life, which is a difficult time, it's still good to have a balance and realize this is—I'm still alive. I tell my wife that, sometimes when we lay there hugging in bed or just wake up in the morning and I say, "Well, I'm still here. There's another day." And there'll be some more. And I can't count them on—you know, it's not like years or maybe months, maybe it is months—but, there's something about just living each day for itself and making the most of it.

[End of interview]