

**knows. We know what students get in the way of anatomy and physiology and that kind of thing but I think the medical ethics exposure is something of interest to the public.**

TS: What I did and have done ever since is when I returned from my sabbatical I then began to participate with the ethics committees of the hospitals. St. Mary's, developed under Sister Damien with my help and the VA developed an ethics committee, Washoe also developed an ethics committee. Parts of it came out of the Baby Doe conflict. When the big "Baby Doe" issue was in the national scene, Dr. Everett Koop was Surgeon General and Ronald Reagan was president. There was all this concern by the federal government that somehow babies were being killed in nurseries, which was not the case but that was the public perception. There was concern that babies were being abandoned, allowed to starve to death, etc. Well, at that time, as a part of a federal program, (actually as a law), hospitals that were getting federal dollars were expected to have ethics committees established. Particularly ethics committees for the newborn nursery. That is when I helped Sister Damien and John Brophy, (I guess he was there at the time or maybe Ken Maclean was still in that job), and a few others put together an ethics committee. This committee would help neonatologist, parents and others who were dealing with a newborn with severe disabilities or a newborn who had a lot of problems. They would act as an outside group "objective outside group" which could look at the ethical issues and decide if a particular infant should be treated or allowed to die. Frequently the physician might say continued treatment is futile and not only is it futile but it is imposing an enormous burden on this little infant. One of the parents or the grandparents would say, "I believe in miracles, let's keep treating". There would be all this kind of conflict, not unlike the conflict in adult ICU where one person would say keep grandpa on a ventilator and keep him going and maybe he will recover and others saying this is nonsense he is not going to recover. At any rate, the hospitals started to develop

ethics committees beginning with the newborn nursery because of the Baby Doe concern. I can get those dates for you later. It was around 1983 or 1984. It was after I returned from my sabbatical. Celia and I have often said that (just parenthetically) it was very fortuitous that I took an ethics sabbatical right at that time because there were very few in the country and it was the only place you could go and there were very few physicians with any kind of training. Then everything started to happen as you say, 1983,84, 85 was Baby Doe and the rest of these things. So I helped the three hospitals get started with their ethics committees and then I also began to give lectures. The VA was the first to begin a committee. It was mandated by their central office and they've had one for as long as the other two hospitals or longer. Paul Jensen was the one who started that one, Sister Peter Damien at St. Mary's and at Washoe, I've forgotten who was responsible but it might have been Whitey Engeseth, the minister. I think he was very influential in getting that started. Anyway, I helped them start that and I also began to make rounds with the medicine residents, mostly at the VA and sometimes at Washoe. Then rather than talk about paper cases, we would talk about actual patients right now in the hospital with one problem or another.

**EB: How did the ethics committee function? There was a chairman and so many physicians were on it? Did you review cases?**

TS: No, it wasn't a lot of physicians. There was a chairman usually appointed by the chief of staff or in the case of St. Mary's, appointed by Sister Peter Damien and at the VA appointed by the chief of the hospital. But at Washoe, I think it was the chief of staff. It was set up to be dominated by physicians. There were usually a couple of physicians, those who were involved with dying patients in coronary care units, the ICU, or the dialysis unit, so they were involved with that. Usually several nurses, often from the nursery and the ICU. A chaplain, a minister, at

St. Mary's a priest or a nun. Then often there would be a social worker, and then a couple of public members who had no particular involvement in the hospital per say. The idea was that if a physician or a nurse, (usually those were the two), or a family member had a severe problem with how a particular patient was being treated or not being treated they could call the chair of the ethics committee and say, "I would like a consultation from the ethics committee to help workout the problem. Often times the problems were not ethical or moral they really were communication problems. The patient, or the family, or the loved one, or the nurse, or physicians were all talking at cross-purposes and not really communicating well. I spent a number of ethics committee meetings and even afterwards when I was asked as a consultant to sit down with the family and the physician to workout the communications so that everyone understood what the problem was and what were some of the solutions. When that process took place usually the so-called ethical or moral issue evaporated. There may be no moral or ethical issue. It was essentially that these people are not talking with one another. Not understanding the words they were using. Physicians can use a lot of jargon, families can use a lot of emotional words, and nurses can also use a lot of jargon and people are talking past one another. Often times what the ethics committee did, was help with the communication process. I must say, for the record, I don't recall that an ethics committee ever made a decision. The ultimate decision in a hospital setting always rests with the physician and the patient. As I said earlier, the physician who can't resolve the issue with the patient can always withdraw from the case and the patient or guardian can always discharge a physician and say, "I want someone else put on the case." The committee was mostly there to help clarify what were the ethical issues, what were the communication issues what were the economic, social, other cultural issues and how could we help the physician and the patient or the family solves it.

**EB: So it wasn't a sanctioning committee?**

TS: No, it had no authority.

**EB: No review of records and saying this should have been done and wasn't?**

TS: There would be some of that but only if the physician asked. We did do a few retrospective evaluations after the patient died. The physician would come and say, "This is what happened, what can I learn from this?" So, yes there was some of that. The other role of the ethics committee was some public education but mostly professional education. So, we put on in all three hospitals, (and I participated as a faculty member in a number of those), conferences for nurses and physicians in the hospital, discussing these very ethical issues which were then being highly publicized. Long before society started publicly talking about assisted suicide and long before Kevorkian came along. So, this all began in 1984 and up to about 1997 when I retired. I did a lot of ethics consultations, ethics conferences state wide, I talked at all the hospitals and of course the big part of my ethics life, if you will, was the publication of our book *Playing God* in 1988.

**EB: That was almost a direct result of the Hastings year, wasn't it?**

TS: Yes, The book *Playing God* by Simon and Schuster was the direct effect of going to Hastings. The reason, I may be repeating myself but briefly for the record, Celia would often go to the Hastings Center to conferences. I was going there everyday to work but usually once every week or once every two weeks there would be a two day conference and Celia as well as other spouses were frequently invited to come sit in. We would rummage through the library and it became very apparent that all the books that we saw and most of those journals were written for the professional, by professionals, with a lot of professional, philosophical, ethical jargon. So, it was Celia's idea actually that maybe there was a time coming up, because it was hitting the

newspapers, it was on the Phil Donahue show about surrogate motherhood, Baby Doe was all over the New York Times, the Karen Quinlin case was in the newspapers. All of these different cases made Celia think that maybe there was room for a book that would discuss these issues in layman terms, in simple well-written journalistic style. So we talked to several people at the Hastings Center, Art Caplin was my mentor along with Dan Callahan. Art is now professor at the University of Pennsylvania. Anyway, he said, "That's a good idea, why don't you see what you can do." The last couple of months we were there we worked on an outline every night at home. Then we reviewed it with them and then finally, since Celia had already published a book on Health writing and had an agent, we had lunch with our agent in New York shortly before coming home in June of 1983. We gave him our proposal in 1984 and he went around over the next year and finally got a editor at Simon and Schuster who said, "I think this book is timely and if they will write a sample chapter and a fairly detailed outline and let us see it, we will consider letting a contract." Well, as it turned out our editor Bob Bender had just gone through this problem with his grandfather. He has just been through a very difficult period, a difficult ethical issue in the care of his grandfather. So he was attuned, as an editor at Simon Schuster, that this was becoming front-page stuff. Good timing. So in 1985 Simon and Schuster gave us a contract, with an advance, gave us a year to write the book and it was during that year (1985-1986) that I worked part-time at Special Children's Clinic and worked at home part-time writing the book. So Celia and I for that year wrote that book.

**EB: That's been rewarding for you?**

TS: Oh, wonderful, that was a great experience.

**EB: Not only just the writing but the end result of that has been well accepted hasn't it?**

TS: Oh, yes and it sold very well.

**EB: It's in what printing now?**

TS: Well, the paperback is in it's second printing. It was a good experience and a wonderful experience for Celia and I because what we had to sit down and discuss and argue these issues between ourselves before we could put on paper what we were going to say.

**EB: It was a good combination because you have a medical man and medical writer.**

TS: And she could write the stories, because we interviewed lots of people. We interviewed hundreds of people who have told their stories, many anonymously.

**EB: That's what makes it readable, by the way.**

TS: Yes, it is the human-interest stories. As we said in our forward, we tried to use one voice, so that the voice was one, but in order to get a single voice for the reader, Celia and I would have to discuss it. So we then, for the first time, began to discuss issues, which we had sort of unconsciously accepted. Unconsciously because of our similar up-bringing and our religious education had sort of assumed but had never actually written on paper why we believe one way verses another and what would be our attitude toward someone who disagreed with us. It became a very interesting experience in writing the book. I think I may have told you the story about Roslyn and Jimmy Carter.

**EB: I don't recall.**

TS: Okay, Roslyn and Jimmy Carter were in the process of writing or had just published one of their first books. It was stated on Phil Donahue or some show and written in one of the women's magazines, that it had almost lead to their divorce, because they made a classic error of collaboration. He'd write a chapter, she'd write a chapter, they'd give them to the other person and they'd criticize. Well, first of all they had two voices, hers and his. Secondly, one would be criticizing what the other had written. That becomes a very difficult thing. Once you put your

words on paper there is pride of authorship. So, their advice was if you were going to collaborate with anyone, truly collaborate. You should discuss all issues in advance and put it on a piece of paper so that it is your joint, agreed opinion on an issue before it ever sees print. So Celia and I would write and then the next day, when I was at the Children's Clinic seeing patients, she would type it up on her computer and print off the two or three pages she had done. Then that evening we would sit with a cocktail and I or she would read it out loud and we both would say, "Oh no, that's terrible, it sounds terrible, that's not what we wanted to say at all." So the next day we would edit it and make changes to it. But I wasn't criticizing what she wrote and she wasn't criticizing what I wrote. We simultaneously, I guess, were criticizing our joint work. We read the transcripts out loud, because when you read out loud you stumble over words that are too long or that don't work. Anyway, that's how we actually wrote that book.

**EB: Did you have any surprises between the two of you, you being a doctor having been in the field?**

TS: No, not really. We pretty much have similar views. I always acquiesced to her in the way she told a story. She usually acquiesces to me when it was a medical issue. But combined, the ethical issues are not only medical. They reflect the moral community dealing with a problem.

Physicians only have one piece of the ethical puzzle, as do nurses and the patient and everybody else. That's what makes it so fascinating. Traditionally of course, physicians always thought, paternalistically, they had the answers. Well, they don't, as we know. They know the scientific issues and they also have what may be the best scientific approach to an issue but it may not be the most ethical approach. So, we generally came to agreement on how we would express the ethical issues and that's the way we did it. Last part about *Playing God*, when I was in the hospital after my transplant operation we had already finished the book. We had sent the book



manuscript to the editor in early 1987 or late 1986 and we then spent the next three or four months sending things back and forth, Celia and he, because at that point it was editing because we were not going to change basically the substance of the book. So in the spring of 1987 we were sending back pieces of the manuscript after Celia had edited them on the computer. Finally, he knew that I was going down to San Francisco to get a kidney transplant. This was June of 1987. While I was recuperating, the editor sent us the galleys. They were all ready to go. In those couple of weeks sitting around the hospital, bored to tears, Celia and I got them to give us a small conference room and we would go in there and read the galleys. I'd read a couple of pages and she'd edit because we had two copies. Then she'd read and I'd edit. The reason we read out loud again was to be sure that we hadn't stumbled over words. Basically the galleys were pretty good. We didn't make many changes. Then we sent the galleys back in about August of 1987 but we didn't hear from Bob, the editor, for several months. So finally Celia called. I was home recuperating; I wasn't ready to go back to Special Children's Clinic. (I never went back there). Once I got the transplant I just simply stayed teaching full time and administering. Finally Bob called and said, "We've been holding up the release date because we couldn't get it out for the fall list." The fall list would help it sell at Christmas time, which was there original goal. "We wanted to be sure that Tom would survive and live so he could go on a book tour." Well, as it turned out it wasn't that bad because instead of putting a late...

**EB: Dead authors don't sell.**

TS: Right, dead authors don't sell. So instead of having the 1987 release for the fall book list for Christmas it came out in the spring book list so it has a 1988 date on it. They said fine it would be published in the spring. I was on about one hundred radio and TV shows (I have a list if you are interested in it), including Larry King and some others, talking about the book when it was



first released.

**EB: I would like to know who interviewed you and how the book was distributed.**

TS: Okay. It came out in January or February 1988, which was the publishing date. I went on a book tour. Celia and I went to Washington, New York, and Pittsburgh. We went all over the place and did a book tour. Mostly talk shows. I did a lot of talk shows from my office and from my home. Radio talk shows, because you can talk on radio any place. So I did a lot of radio talk shows from here and I did radio talk shows from my office. Someone would call in, some would be live, and some would be recorded. Some would say, "Dr. Scully I have your book here in front of me and my audience here in Des Moines, Iowa would like to ask you why you wrote this book and why did you call it *Playing God* and what do you think about...." Then they always ask some tough ethical issue trying to put me on the spot. "What do you think about Karen Quinlin?" Or what do you think about making babies in Petri dishes?" So you try to give a fairly non-committal ethically sound answer. That was in the spring of 1988. In the mean time, I'm putting together an ethic curriculum, I'm teaching ethics and all that sort of stuff.

**EB: Was your health good at this time?**

TS: Yes, once the transplant was over, I think I came back to work in about three months. The transplant was in June, I had to be operated on a second time because the first surgery went well but after a couple of weeks there was a kink in the artery that they used to hook-up the new kidney, the renal artery. So I actually was operated on twice. After the second surgery, which was in early August of 1987, I then stayed on sick leave three months. Remember that I'd been working at the medical school since 1971 so I had a lot of sick leave. I think I went back to work around the middle of October of 1987 but I didn't return to Special Children's and I did not go back to Sierra Developmental that was finished. All I did from that point on was to teach

pediatrics and ethics.

One day in late October, Bob Daugherty met Celia down at Raley's shopping and said how is Tom doing? Celia said, "He's fine, he's recuperating, planning to come back to work pretty soon." So, he said, "I'd like to come over and visit with him and see how he is doing." Celia said, "Sure, come on over." So, he come over the next day and said, "I've got a job for you." I said, "Sure, I'm looking for a job, I'm not going back to Special Children's, I would like to work part-time." So, he said, "I'd like you to be Dean of Students." I said, "You're kidding?" "No Dr. Grant Miller, (who I appointed in that job when I was the Dean in 1979), has decided to get out of that job". At that time Grant Miller was going to start working on the psychiatry residency program. He didn't want to put all the time in. The Dean of students was a lot of work. So I then took over as the Dean of Students in the late fall around Thanksgiving, of 1987, just after I recuperated from my transplant. I did that for about three years until 1991. I had a heart attack in the fall of 1989. Actually I was in St. Mary's for Thanksgiving because I remember Celia and Leslie and her husband, who at that time was a boyfriend, came over, with several of my other children, on Thanksgiving evening and brought me fresh hot Thanksgiving turkey dinner. I wasn't able to be at home.

EB: Now what was this heart attack? Or is this a personal thing? Was it a coronary occlusion?

TS: Yeah, I probably had an occlusion, probably because when I had my kidney transplant in 1987 the surgeon said my blood vessels are those of a young person. "You have very clean vessels; you don't have much Atherosclerosis at all" Well, I was fifty-five at the time when I had the kidney transplant. Later, Larry Noble, who did the coronary angiogram said, "No, the vessels look fine." I probably developed a clot, we'll never know for sure, but he thinks so and I do too, probably because of the medication I was on to prevent tissue rejection. Since the day I had the

kidney transplant I've taken Imuran and Prednisone and a number of drugs to both prevent rejection, which wasn't very likely because my sister and I have very good genetic match, but they think it probably was related to the Prednisone. Since then I've been on Coumadin and I see him regularly and I've done treadmills and all that as follow up.

**EB: Did you have surgery at the time of that heart attack?**

TS: No, they just went in and reamed out the vessel and the clot dissolved. As I said the vessel looked pretty good and the other vessels in my heart looked pretty good. So, as I said it was probably due to Prednisone rather than to some inherent vascular disease according to the cardiologist. That's been about nine years ago.

**EB: Did you change your diet after that? And Exercise?**

TS: Yes. So, that was that. I was hospitalized for the heart attack. Then that next year (which would be the spring of 1991), Bob and I had been talking and I said, "I don't need anymore stress of being Dean of Students, so I got out of that job and Bob appointed Jerry May. At that time he asked if I would take over and start an alumni office and be the Associate Dean of Alumni Affairs and start an alumni program. This I did.

**EB: I have some questions about the Special Children's Clinic from the early days until you stopped working there. A few more case stories. Do you remember Mr. Desibio's first name?**

TS: No, I'll have to look it up.

**EB: We'll end here.**