

Poor Sophie's Dead, Lucky Us, Lucky Sophie

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It had been a strange week, very strange. While I wrote this, we were flying thousands of feet above the earth. I read the evening's local rag, trying to make up for opportunities missed the previous day. One is made to feel so guilty, so incomplete, if he doesn't read the daily newspaper daily.

My mind wandered, thinking about the last evening's meeting of our Advocacy Board. I could kick myself for getting angry, not really for getting angry but for showing my anger. Why can't these good people realize that case-by-case advocacy will consume us, will play into the hands of those who want to maintain the status quo, or regress? We "win" victory after victory on behalf of this family or that one. I am not knocking those accomplishments. However, while we win those skirmishes, the city again breaks ground for a new segregated facility. Case by case, we advocate for children and their families. Some we win, some we lose. The record is impressive. But, we are losing too many. Too many children are still denied educations; too many people sit in back rooms receiving little or nothing of society's interest or services; too many are in locked institutions, not because they must be locked up but, rather, because there is no other "place" to be, because others are presumed to need locked institutions. With most of those clients whom we cannot help, the problem is exacerbated because of a paucity of resources, and an absence of community interest in them. How could it be any different, when the major policy decisions have been, and continue to be, anchored to institutional development and support? So, I battle with my friends, decent people who are torn between what they want for their own children and what they want for society. And the debate wears me out, driving me eventually to leave the meeting, not because of my anger--but I am angry--but

because I am weary, and I want to go home, and remove those stale clothes and drive out of my head the morbid thoughts of practical people.

My eye catches an advertisement in the paper, by the State Comptroller. Hey, guys, we will sell from this office \$111,500,000 in Serial bonds. O.K., guys, now is your chance, \$14,000,000 of this offering will be assigned for construction of mental health facilities. Your investment is as good at the State. Standard and Poor rates our bonds as very low risk. And you get relatively good interest, and it's all tax free. Listen here fellows, we'll send you a descriptive circular, no obligation.

My thoughts have now fled from the events of the evening before. I ponder the idea of billion dollar mental hygiene funding programs, accruing for the banks and their investors two billion dollars in "earned" interest. What's that T.V. commercial about "we earn" our fees? I think about bankers and investors, architects and builders, and "tearers down". The thoughts are gloomy, leaving me to suspect that this will not be one of my better days. Still with the paper, I turn pages hoping to find more cheerful news. What do we have here? A lengthy study commissioned by the United States Senate concludes that poor nursing homes far outnumber good nursing homes in this country. Many elderly patients are abused and dehumanized. What else is new?

Indeed, it has been a strange week when I force myself to think about Sophie to cheer myself up. To cheer myself up? Last Monday was scheduled to be a routine day--a few appointments, the return of a few calls, some letters to write and, if I was lucky, a stolen hour or two to write for myself. Nobody knew very much earlier than Monday, therefore nobody told me that Sophie was to be buried on Monday. And even had they known it would happen that she needed to be buried on Monday, nobody would have suspected, then, that I would have been

asked to attend the funeral or that I would have accepted the invitation had the offer come. You see, the very first time I ever laid eyes on Sophie was at the funeral home. I saw her but she didn't see me.

Sophie was a resident at the State Developmental Center, nee the State School. She had been there for many years, leading what I was told was an uneventful, unhappy life. She became ill, very ill--so ill that she was removed to the hospital. There she died, approximately one week later. All of the aforementioned doesn't appear very interesting--even to me. But what was more than interesting concerned the allegation that Sophie did not die of natural causes. There were charges, confused and contradictory but strong charges, that--as they say--the plugs were pulled. Sophie was euthanasized. She was rewarded with a "good death". A big hurrah for Death With Dignity, Thanatos, and the Happy Angel that supervises it all. Rejoice, some told us, Sophie had left this vale of misery to an eternal peace and happiness that she did not find on earth. So we gathered together at the funeral home. The priest gave his blessings and read from the Scriptures. Some said their Hail Mary's or Hail whatevers. We signed the guests' book--Guests?--and went our own ways.

The local Death With Dignity Society, and there really is one here, should be pleased. The crazy thing about it all is that, in the Cosmos, there may be some explanation for all of this. And it would not surprise me if such an explanation agrees with the death wishers. Yet there is also something evil here, something that would tell a human being that it is time for her to die. But if we were in your shoes, sister, we would live! It's best that you die now, first because you're sick. But we hasten to tell you that, if you were not sick, we would not kill you. Yet, not only are you sick, you are old (Is 63 really that old?). And not only are you old, you are defective. Sickness we sometimes tolerate--if it's not too much sickness. The aged are revered, if

they are not sick. And even the defectives need not be marked early or, especially, with the Terrible Decree. But Sophie, even you must agree that you gave us no choice. Being sick, old, and defective necessarily must strip you of the rights other people have guaranteed to them. Don't blame us, Sophie. This is all your fault. Besides, you'll be happier up there than down here. You're really lucky. It's all over for you, but we have yet to face the terror that is now behind you. What we have done for you is the stuff that causes ordinary people to become humanitarians.

My thoughts continued to wander, focusing now on Tuesday evening. It is the day after Sophie's funeral. It is 8:00 p.m., then 9, then the hour approaches midnight. We are in Room 407 of the County Courthouse. The County Legislative Commission to Investigate Mental Health and Mental Retardation is holding its last formal hearing prior to the creation of its report to the citizens. I am a member of the Commission and, just before termination of the long evening's discussions, I asked the Superintendent of the State Developmental Center to reflect upon the future, "In the best of all possible worlds, what do you envision for the Developmental Center in ten years?"

"In ten years things will not be very much different than they are today. Can I speculate about the world in 50 years?"

"Will the people wait 50 years? Some deserve less than a 10-year delay. There are people who need help, not in 10 years but tomorrow."

"Don't misunderstand me. If I had my way, we would evacuate the Developmental Center in ten years, five years, or sooner if we could. We would give it to the State, or to your University, to use as a dormitory, or for some other educational purpose."

I don't respond. I am embarrassed for him. I think about those times not too many years ago, when it might not have been too late to stop the construction of this \$25,000,000 monstrosity. I attempt to avoid remembering the pleadings and

arguments, even the threats we made, anything to block construction of the new State School. I don't succeed. I remember too much, so with a cunning tactic, I ask my colleagues to conclude our hearing. Enough is enough. Quite early the next morning, I am back in my office returning calls again, answering mail, trying to see the people who want to see me before the next day's flight to Los Angeles. The phone rings. It's the Executive Director of the President's Committee on Mental Retardation. Not any president's committee, The President's! Would I do a study for them? Would I visit the institutions that continue to defy extinction? Would I expose the rottenness, the abuse, the mismanagement, the inhuman treatment?

"Sure," I reply, "what else do I have to do? As a matter of fact, I was just thinking about those problems today. Just coincidentally, the morning Times had an article by Murray Schumach summarizing the deliberations of the Select Legislative Committee Studying the Mentally and Physically Handicapped in our State. You probably wouldn't enjoy hearing this, but that Committee heard witness after witness berate the State Mental Health program for neglecting their clients, for the confusion it spawns, for its bureaucratic indifference and insensitivity. Sure, I'll study those state schools for you. But, hey, I hope you don't think my eagerness is a bit gauche. I hope you don't think I've been sitting by this phone all morning waiting for you to call. You just happened to catch me in, between assignments, so to speak, between life and death. You caught me just as I was beginning to believe that Sophie was the lucky one."

If you want me to examine those institutions, that will be O.K. with me. I won't mind. It's O.K.

This story I just told happened ten years ago. I write it now because I could write a fresh story today--one that occurred yesterday or this morning--which would be no different than Sophie's tale. So why bother. Better to go to

my diary and dredge up what I could have told when some of you were children, but will still be new when your children have children. That's the point.