

The Death of Hal Carlstad

by Marc Sapir

My friend Hal died a few years back. Hal was 82 which sounds like a ripe old age to die on. But Hal wasn't ripe, old or ready to die, though he'd been slowed considerably by a heart valve gone floppy. An avid walker and gardener he'd had his activity cut back too much to suit him. Even at 82, lean and tall—still about 6'2"—Hal cut a handsome figure. He'd a long angular Norwegian face and a friendly visage; still plenty of hair and bush grey eyebrow. He was so alive still that his death seems only an unfortunate incident in his life--as well as in the lives of others. Hal put his trust in his doctors and, to the end, he believed that they did the best they could for him. He told me that up front and assertively in the ICU at Kaiser Hospital Oakland 2 months before his death and two months after his surgery. Were he here right now he might even scold me for suggesting they/we failed him. He didn't want me to get too much involved with it. It's a bit of a contradiction, Hal such a trusting fellow. I say contradiction because he proudly told people that he'd been arrested about 180 times in civil disobedience actions for peace, civil rights, human rights and so forth throughout his adult life. Obviously he didn't trust everything or everyone to do a righteously good honest job. He was outspoken, if soft-spoken and had an infamous outgoing message--a two or three minute rant against U.S. imperialism's predations--on his telephone's voice mail. Hal was a retired secondary school teacher from Berkeley's Martin Luther King Jr. Junior High school where he taught science. He was an expert botanist and a dedicated gardener. And, well read and contemplative, he knew a lot about a lot of things. I'm sure he was a great teacher—kind, supportive, humorous.

Hal owned a home in Kensington where he lived with his partner, Cynthia Johnson. It's a nice old house—not real large, maybe three or four smallish bedrooms--here in the East Bay Area just a block below Kensington's small commercial area on the Arlington, overlooking the Bay. They took in a couple of borders. I'd been at a few meetings at the house. When Hal died the family sold it.

I felt that Hal and I were more than friends; I would say we were good friends. We had extended conversations and I had driven the two of us to some protests together. Along with my wife Sheila and another woman, Connie, we got arrested in 2003 at the headquarters of KQED, the Bay Area's largest PBS station (TV and radio) when there were big protests against the U.S. attacking and occupying Iraq. That arrest incident is an amusing story because we weren't part of the Iraq protests that day—we were demanding fair coverage of Palestine's plight under occupation--but we got our charges dismissed by being lumped together with hundreds who were. Perhaps I'll come back to that some other time. Cynthia, who is probably over 20 years younger and survives Hal, is a real sparkplug. She can't stop herself from being involved in about 15 activist causes and activities at the same time. She talks so fast and frenetically that she

sometimes loses herself in her words. Observing her is like watching a hummingbird buzz around the yard, praying it won't smack into something hard like a window. She and Hal centered their political and faith lives in the Social Justice Committee of the Unitarian Universalist Church at Cedar and Bonita in Berkeley, where they are both famous. Actually Cynthia is well enough known around to get herself elected to the station board of KPFA, the non-profit Left-wing station that founded the Pacifica Radio Network.

Hal had told me that he was going to have a heart valve replacement as an elective surgery. I was surprised. He was still getting around fairly well. I hadn't even noticed shortness of breath, but it had become troubling to him. He said that he was declining more than he could handle. Shortness of breath on even short walks was intolerable to him; and the Kaiser doctors thought, due to his otherwise excellent health status, that he was a good candidate for successful heart valve surgery even at his age. And that his heart would soon give out if he didn't. Unhappily, I didn't learn that his surgery had taken place, performed by Kaiser specialists at the Summit Hospital in Oakland, until about 6 weeks afterward, when Cynthia or someone else told me that Hal had just been transferred to the Kaiser Hospital ICU if I wanted to visit him.

From a technical "outcome" standpoint, the heart valve surgery itself had been a success. Not only did Hal survive the operation but the valve was working well afterward with his cardiac output much improved. But something else had gone wrong. Hal awoke after surgery and was lucid, but for some unknown reason his breathing was too weak to self-sustain and so they could not take him off the ventilator. He lay there in the bed wide awake, clear minded, able to communicate by writing messages with tubes coming out of his nose and mouth and penis. This had gone on and on and on and finally, unable to discharge him to home or rehabilitation, Kaiser had transferred Hal back to their own ICU team aiming for slow progressive progress.

Having cared for my own frail hospitalized patients from about 1993-2001, I realized immediately, even before I visited Hal at Kaiser Oakland and had more information, data, observations, that his chances of surviving this hospitalization were diminishing by the day. For most of us at that age, a lengthy hospitalization can become a death sentence regardless of the reason for the hospitalization, and regardless of how excellent the technical level of care may be. Hospitals are a dangerous place for the elderly. And the Intensive Care Unit or Cardiac Care Unit is even more dangerous. In his case Hal was in grave danger because of having all these tubes and machines attached to and penetrating him.

But Hal didn't die just yet. The process of his dying, being neither sudden, nor gradual, but protracted and convoluted, took a lot out of Cynthia. She had a bad time trying to deal with what happened, what was happening. But she wasn't alone. Hal's kids too; and to some extent the grandkids. And Hal's many friends, including me. I warrant that this essay is about my own role in life and my connections to Hal as much as it is about Hal's life apart, but I'm writing it as a tribute to Hal's humanity, his spunk, his wry sense

of humor and wit, and his determination to soldier on through life's thick and thin. That death was claiming him was not particularly of his own doing, but, then again, it kind of was. It was not like some act of God; I wouldn't exactly blame his doctors or the teams of nurses and other professionals that worked with him either. This story describes how human frailty in the guise of progress can get beyond our control; how Hal's medical care transgressed upon the human element in caring giving; and somehow got beyond the control of his Kaiser doctors. I'd love to find someone to blame in what happened, but it's just not like that.

Too, I won't second guess the judgment on either the doctors' part, nor Hal's about having the surgery. He knew there were risks, but he was willing to take them to achieve a better quality of life and some longevity. That's both brave and reasonable. However, there is plenty of data to show how and why the longer an elderly person is hospitalized the greater the chances that they will not survive. Among the reasons why are these: bedbound patients, like astronauts in space, lose muscle tone and mass quickly; they become weak, they have trouble standing and walking and become prone to falls and fractures. Within less than a week a person confined to a hospital begins to show deterioration in their mental state, loss of vital protein (albumen) in their blood, and anemia. The risk of blood clots forming in leg veins and lungs is measurable. Confusion, weakness, anemia, as well as care that focuses more on the technical side of tasks/things that must be regularly done for and to the patient rather than with them means that their psychological state—and the mental deterioration akin to sensory deprivation—cannot be well tended to, even with sweet quality nurses. The longer someone is in the hospital the fewer the visitors and hours of visitation they receive as the friends also grow weary. In the Intensive Care Units there is more isolation, less getting up to stretch or walk, less autonomy, more physical dependence and a more sterile, uniform, incomprehensible and monotonous environment. When you keep an elder in bed for just a few days their breathing effort declines. Their lungs are less expanded and they become prone to pneumonia. Hospitals are also the carriers of dangerous and deadly infectious organisms that can get into other parts of the body than the lungs. After 2 weeks, a growing proportion of people with catheters in their bladders begin to become infected. But I believe that the underlying factor that saps one's lifeblood is the loss of autonomy, the sense of who we are—who I am. All these factors are at play even in people who are not that sick to begin with. Within a week of hospitalization most elders are considerably frailer than when they first entered; and are at risk of nursing home placement when they are discharged.

In Hal's case the situation was worse than many aware patients because he was not only restricted to the ICU, but he was unable to eat for himself and had both a breathing tube and a feeding tube down his throat. Though he initiated most of his breathing, the machine continued to do much of the work, forcing air into him. Throughout his stay in the Kaiser ICU of more than a month, Hal remained fully alert, aware and able to converse through writing on a pad. He told people what he wanted. He asked us questions about the outside world. He commented on politics. And he assumed he would get better. I can't say for sure that his survival and return to normal life was in the

cards, but something then happened shortly after my second visit to Kaiser that wrecked his chances of that. The doctors decided, based upon his reasonable cardiac output and his ability to stay off the ventilator for a half hour here and an hour or so there that they would try letting him eat. I wasn't there when it happened but they put some food in front of Hal and, contrary to usual practice no one helped him or monitored him that first day. Typically an occupational or speech therapist will be the person working with stroke victims who have lost or weakened swallowing ability and cough/gag reflexes. After that a nurse takes over the responsibility. But Hal wasn't a stroke victim and the usual protocol was not strictly followed. Hal started gagging, may have aspirated some of the food and this led to a panicked response by the medical team. They decided that Hal did not have strong enough swallowing capability to be allowed to try again. They decided not to pull his feeding tube from his throat. Eventually they placed a stomach tube through the abdominal wall (a not uncommon procedure) in a sign that he might require long term tube feeding. They decided to keep Hal as dependent as he already had been-- now for the past 8 or 9 weeks. The error that the health care team made was not fully supporting and monitoring Hal's early attempts at swallowing. But instead of simply coming to terms with that relatively minor error and starting over again, they backed off (I say minor because Hal was still cognitively intact and thus he had some ability to protect himself in the situation; he was not like a stroke patient who had lost the ability cough, and so his swallowing weakness was not the result of central nerve damage but related to disuse). The Kaiser team, to my thinking, were more worried about what bad things "might" happen after that episode than thinking about what "was happening" to a depersonalized, dehumanized Hal.

The health care system in our country is technical, highly technical. Technique is great if you've benefited from a liver or kidney transplant or some electrophysiologic studies and such, but the problem is that the sicker we get the more technique and technology gets into the act; and then the focus of most experts is their technical ability. That doesn't always make sense. I've taken care of many people at the end of life; people whose deaths were usually not preventable. Helping people come to terms with death is a particular role that you learn in geriatric and hospice work (I've done the former, not the latter). But as Lonnie Chavelson wrote in "A Chosen Death" some people are also ready to live and soldier on even in the face of the worst of conditions and poorest odds of survival. Sometimes the people who are dying do most of the life teaching for us, I have to admit that. Some of the important lessons I learned about death and dying were taught me by humble people who were dying themselves.

While I was doing geriatrics with frail and disabled elders I had been a member of, organized and led OUR Ethics Committee and discussions with professionals, teams, families and patients. For some years I was also on a utilization review sub-committee at a local private hospital that was responsible for evaluation and prevention of medical errors and untoward incidents. In the case of my friend Hal, I believe that his death was preventable, and yet there were no gross medical errors so it would be hard to do an incident assessment that would change procedures to reduce the likelihood of it happening again. The problem is that subtle causes are too deeply embedded in the

culture of our contemporary medical care system—how we do the business of medicine. It's that culture that has to change. It's not that the system doesn't think outcomes matter. It does. But outcomes, though they happen to real people, are not actually the people at all. They are facts and figures, data and summary data, stripped of any humanity just as computers strip information of any qualitative identity.

As Hal's friend, I tried--without acting too authoritative, officious or self-important--to bring my understanding of geriatric care (and Hal) into the equation of how my friend was to be treated. For one thing, I realized from the moment I first visited him, that keeping a Foley catheter in the bladder of an aware adult without urinary tract obstruction was a convenience of typical ICU care that could not be justified. That was one tube that needed to be pulled out immediately so he could pee when he wanted and needed to. Then, once the episode of gagging and possible aspiration had occurred I needed to convince the Kaiser team that they had to try again soon with better supervision. I can't remember if the family conference with the ICU director was my idea, Hal's family's or that of the Kaiser staff. But in any case Kaiser staff was fully cooperative with having the conference. Hal didn't attend.

To me Hal again asserted his confidence in the Kaiser specialists, but I was not so sanguine about what was transpiring. Because I did have the backing of the family and Hal's permission, I participated in the conference as a sort of curbside medical consultant. I pointed out my concerns and pushed for first the removal of the bladder catheter, for more efforts to walk Hal more regularly, even outside of the ICU when he came off the vent for periods during the day and encouraged immediate and regular efforts to get him off the feeding tube.

Few of us can imagine how much of our autonomy, independence and life spirit is sapped by being unable to eat or taste food. Our body suffers also. I once had a stroke patient with mild-moderate dementia who had a gastric feeding tube and who lived with his mother. He would sneak downstairs after she went to bed and eat food from the refrigerator. In fact, although he had a few episodes of minor aspiration and even an aspiration pneumonia once, Fred's ability to break free of the terrible dependence of stomach tube feeding probably gave him more quality of life than anything a medical team could do to help him. Being mischievous also made him feel a more "real" and empowered person.

The problem in Hal's situation was that Hal didn't want to push the envelope. He was sure, had faith in, that the Kaiser doctors knew what they were doing, knew what was best; he didn't understand the importance of his own self advocacy with them. What I understood was that the difference in perspective (between myself and the Kaiser specialists) was not one of technical expertise—for he had some of the best intensive care specialty doctors. The difference was that my perspective was that of a geriatric understanding of the toll that was daily being taken upon his mind and body which would be unable to withstand these insults much longer without cracking.

As it happened the good Kaiser ICU head and his team did not resist my thoughts and suggestions. They promised to do their best to address these issues. But it soon became obvious to me that they did not feel (or understand) the same urgency that I felt. They did not grasp that Hal's very survival required treating the situation as a type of emergency though in fact there was no obvious emergency, technically speaking, other than the problem of him not yet getting off the ventilator. That, we could all agree, was a serious problem; but only that. And they were working on it.

Thus, the pace and intensity of efforts to resolve the intubations, to get Hal mobilized, to remove his Foley and his feeding tube and get him walking more and so forth increased only marginally. Part of the reason was that I was proposing that Kaiser take some risks with Hal's life. I wanted him to be sent home within some specified time that I called "soon", even if he had to go home on a ventilator and at considerable risk. I wanted them to return some quality of life to my friend, even were he going home to die. Quality of life parameters are--I believe—often inimical to how technical medicine views such situations. QoL parameters seem/are just too subjective. The specialists' parameters of outcome success are that the patient recovers and goes home, plain and simple. That Hal's chance of recovery was probably linked to his regaining some independence and autonomy, to his self-motivation, to their encouragement—even their insistence that Hal challenge the limits--did not fit the technical model of how to deal with a mid 80s man who was having trouble recovering from heart valve replacement. I thought, based upon my own medical experience with such patients, it perfectly obvious that there was no other course than that, besides a slow isolated death. I knew Hal. Faced with a demand that he had hard work to do or he might die, I believe he would have done the work.

Hal did not improve, but he did remain lucid despite all the weeks locked up in the ICU with the tubes and machines. Finally, under pressure to make a move, Kaiser made the wrong move. Instead of trying to send Hal home on a vent with heavy and costly home care nursing they sent him to another institution—a hybrid between a low level hospital and a nursing home. The place did have plenty of advanced equipment, but no doctors on site much of the time. Hal was there on his ventilator, getting adequate nursing care but farther from home by 20 minutes; the strategy did not change much. He became weaker and weaker. Eventually he became delusional. A week or so after that Hal fell into a sort of coma and died. A victim of what? I would say he was a victim of our health care system's disrespect of life, what it is, that intangible magic. For about 3 months Hal maintained his vitality, spirit, personality, verve, humor, humility, strength. And then almost suddenly it disappeared as he became aware that he was dying, all alone in a foreign place not of his choosing away from his home, his lover, his plants, his family. What a sadness, I think, though Hal's stoicism about his circumstance did not allow for much outward expression of that sadness. I speak only for myself here: I saw and felt a terrible sadness.

Almost two months after transfer out of Kaiser, when Hal died at that facility that was something between a rehab center and a real hospital, I did not go back and tell the

Kaiser specialists I told you so; why didn't you pay attention to me? Because the truth is that they know so much more about technique than I do that I would seem to them as an outsider, almost a non-physician, almost a common person who doesn't understand their world and its importance to the patients they serve and cure. But the sad truth is that Hal's chances of surviving depended upon Kaiser doing things differently. Working harder with him as a person rather than a collection of systems, taking the risk of him dying at home with less technical support than the place where he did die; spending the money that individualized care requires. They ought to have done what I had urged for Hal, but in some perverse way Hal understood me to be more a frustrated political comrade and friend than any kind of "expert" whose intervention might save his life. He did not fight back himself against this system of wrong rules, nor unleash me to challenge them more aggressively.

It's not that I know Hal would have lived had we forced this issue. Of course, I don't. What I do know is that the quality of the rest of his life—whether he got better or not, lived a week, a month or years—his ability to be himself was taken away and he needed it, even if only so he could die with dignity. And that is what technical medicine, like so much else in this modern capitalist market driven world, robs from us: our human dignity. And so I pined for Hal.

Some time after Hal's death a memorial was held in his honor at the St. Joseph the Worker Catholic Church in Berkeley. The former head priest, Father Bill Callahan had been a lifelong staunch activist for human rights and a friend of Hal's with many arrests. Bill led an activist parish. He was one of the great liberation theologians. He had died unexpectedly while sitting at his office desk during the previous year. The Church was packed with many hundreds of people who came to pay tribute to Hal and recount his exploits, his humor and his valuable life. Many of us spoke. It was a fitting event. Hal should have been there to see it.

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