

-I'll fly away-

I'll Fly Away

Sketches from the Center for Elders' Independence--
a near-decade living with amazing disabled elders

By Marc Sapir

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Dedicated:

to the memory of Oliver Sacks,
one of the great humanist physicians of our time.

Appreciation and Attributions

My thanks and deep appreciation to everyone who lived, participated in and inspired these tales; to all the staff, families and participants of CEI who gave me their support and trusted me; and to those who read and commented on earlier drafts—especially Ann Moghaddas, Lilian Stoval and Theresa Drinka—and later drafts—Evan and Anne Stark and Sheila Thorne. Apologies too to anyone whose contributions I've forgotten to remember or mention due to my own aging; and for any errors in fact or misrepresentations that may appear, inadvertently, in the text. As described, a few of the writings are the work of others-- staff and participants of CEI. I have included entries by staff members Robin Bon Fredericks, K.C. Chapek, Nettie Stoval, and Thomas Irungu, and participants Odille Ricks and William Usher. I am indebted to them and the rest of the staff at CEI for their dedication and their love and care for disabled elders and the communities in which they work and live. In most cases I have used only first names (some of them pseudonymic) of the elders. Where I have included true full names I received permission to do so from the families. The title of the book is explained in an endnote.

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Introduction

I –What it is

My friend, Evan Stark, challenged me to describe the theme of this book. Evan recognized 3 potentially distinct themes about which 3 different books might be written. How do they fit together, he asked, and why did I decide to limit details about the PACE model and the CEI program I worked in.

Well, I settled on stressing the tales of, about (and a little bit by) the elders and staff, concerning identity, aging and dying in place, in a supportive community, as the thread that unites the book. Though the book is a memoir, the intersection of the lives of these elders with my own life is but a part of the story because these essays are not mine and theirs alone; they do occur in a well defined certain context of community that will become clear in the unfolding. Moreover, the stories—following no real-time chronology--fill out, as it were, a rainbow's arc (the Spanish term arcoiris seems appropriate) of how individual elders and their families as well as myself face and deal with death—at least to the extent that I am able to represent this.

This book, like the world around us, is also a tale of bipoles--opposites that are inexorably and inseparably bound together and married forever in a constant tussle (the opening of Salmon Rushdie's *Satanic Verses* with two fighting brothers tumbling to earth from over Lockerbie after that terrible plane explosion comes to mind). Revealing the mystery of how and why these opposites can not break apart without annihilating our identity—whether as individuals, as cultures or as a species--is a tough nut, but it's a large part of my effort.

What are some of these bipoles? They include the relationships between living and dying, decline and reanimation and recovery, blooming and withering, wellness and serious disability, despair and hope, the individual and the group or the community, the whole and the parts, culture and individual separateness and alienation, dependence and autonomy, spirituality and nihilism, collaboration and isolation, rights and responsibilities, power and loss (or powerlessness).

Because the stories herein take place in the very particular context of CEI/PACE, inevitably the book ebbs and flows--like the ocean tides--between the particular stories and personalities of the elders out into the cultural realm, the context in which the stories are embedded; but it can never move far from the realm of these individual stories, which are at the heart of the book, as our own tales are often at the heart of our story telling.

II-Genesis

In 1992 a former classmate and friend from the UC Berkeley School of Public Health asked me to become the first Medical Director of Oakland, California's new entry into the PACE Model Replication (see www.npaonline.org if not familiar with PACE) for frail and disabled elders. I was not, at the time, interested in practicing geriatric medicine. That idea did not appeal to me. But out of respect for her and our friendship, I agreed to have lunch that day with Barbara Gregory, the executive director of the soon to begin operating Center for Elders' Independence (CEI), and her Associate Director, Bobbie Rockoff. At lunch, Barbara insisted I was a "perfect fit" for this comprehensive care and interdisciplinary team-based project even if I had no geriatric training. She knew that I did have over 20 years experience in community-based and public health primary care clinic medicine (and administration) had a holistic approach to health, and that I was a social justice activist.

After Barbara and Bobbie explained the model for preserving the quality of life of disabled elders that On Lok had developed in San Francisco's Chinatown beginning in 1979 (under the direction of a brilliant and forceful Swiss-born Social Worker—Marie Louise Ansak) I was intrigued enough to agree to visit that San Francisco program. To my own surprise, one day of observation was enough to convince me of the importance and power of this integrated and integrating model of team based care. This was obviously something more than a "medical program." The community based multi-dimensional, well resourced approach to well-being and quality of life reminded me of how community medicine is practiced in Scandanavian countries and in Cuba. And so I surprised myself and accepted their offer.

Although my intention then was to spend no more than a few years assuring that CEI became a stable and successful project before I moved on to other interests, I stayed with CEI almost a decade until my 60th birthday in early July of 2001, leaving to embark on other paths.

Barbara and Bobbie were, by 2001, many years long gone. But after I retired, CEI's executive director since about 1994, Peter Szutu, asked if I would write a history of the early years of the project. "You're really the only one who has been here the whole time in Admin and has the ability to write it," I recall Peter saying. Truth is I was intent upon doing a lot of writing in retirement and had already drafted several of the essays found in this book (such as those about Ara Belle, Leroy and Cornelio) beginning less than a year after being appointed Medical Director. I had envisioned a book entitled "In Concert," which I outlined in 1995-6.

In September, 1995 I sent Oliver Sacks, who always seemed to find time to enage with everyone who wrote him, a note about this effort and he responded with

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encouragement..."I resonate to what you say about Losing Identity and Gaining 'Rights', and the other paradoxes of our time – I hope you will be able to get your observations and thoughts together for 'In Concert' –it should be a valuable book." However, although I continued to write essays during my time at CEI I did not find the energy or time then to create a complete work.

But in 2002 when Peter asked me to write CEI's history, I was retired and had just written a full length play--my first play, Zara's Faith--in which I tried to capture the personality and strengths of Zara R., a Jamaican-American woman who was one of the CEI participants. The play, a fiction, concerns the police shooting of two young Black men and their grandmother's tireless struggle to rally the community and save her surviving grandson from a prosecutorial conspiracy.

Although I was not much interested in writing Peter an organizational history of CEI, I did have these essays based upon so many enriching, surprising, meaningful relationships and even confounding experiences during my 9+ years at CEI; so I offered to write a history based upon stories about how we (and myself in particular) lived in concert with the lives of participants, their families, and staff. I agreed to include various challenges, successes and failures we (the administration) encountered along the way, but my focus would be on the participants. Peter agreed and quipped, "just don't be too hard on me." This was how the first full draft of *I'll Fly Away* came together in 2002-3.

The 2015-16 revision brings to the fore and interweaves a number of related elements. These include 1) a bird's eye view of death and dying within a supportive community for disabled elders (thus the book's title) 2) Memoir—narrative and reflective autobiographical elements pertaining to how these elders impacted my life, added mystery and meaning to its thread 3) Medical case histories often contextualized within the social being and surprising life stories of these courageous elders and 4) reflective comments on the importance of community, collaboration and family within our alienating culture. I think you will see the contribution that a collaborative environment makes to the health and wellbeing of its members. Sometimes these various elements appear uniquely in a story; elsewhere they are joined into a tapestry or take battle with each other, each fading away only to resurface again elsewhere.

I decided to remove the narrower material about the institution's growth and transitions, as well as my role in those events. I found that necessary if I was to bring the character, personalities, and complexities of these sometimes charming, sometimes humorous, sometimes difficult people to the foreground. I hope that the reader will also find these stories, events and experiences with the aging process engaging. The memoir element is unavoidable, but including my own reality was the only way to convey that I was not/ am not a dispassionate observer looking at these events with the distancing lens known as "professionalism."

III-Memory

When I ran into Barbara Gregory in early 1992, I had just finished setting up the Berkeley High School Health Center. I was working in the clinics of the Alameda County Medical Center and also doing intake exams in the psych ward in an 80 year old squat many fingered building behind the Highland Hospital. The Community Adult Day Health Center, an independent program, occupied an adjacent wing of the same squat 1906 SF Earthquake-era building as psychiatry and it was apparently by chance that Barbara and I were walking up the driveway at the same time. Perhaps her telling me I was a perfect fit for the new PACE program was an act of desperation. They were about to open just a month later. But it wasn't the flattery that moved me to accept her offer. It was the obvious power of a team-based and community based model that I experienced when visiting On Lok in San Francisco.

When I decided to work for Center for Elders' independence, the thought of dealing with death on a regular basis had little appeal for me; not what I wanted to do with the rest of my own professional life. Twenty one years before, in 1971, I had begun a residency in Obstetrics and Gynecology which I quit while going through a divorce. Both then, and later while working with the United Farm Workers' Union clinics I had delivered almost a hundred babies. And for the next 2 decades I found nothing more fulfilling than being involved in new life, in healthy care, disease prevention, attending to and playing with young children, and providing health education.

Moreover the idea of making tough medical decisions in very frail elders in complex medical situations where sudden crises require quick judgment and errors might contribute to death or suffering worried me. I had already spent 2 decades doing down-home basic family medicine, mostly in outpatient settings. I was pretty good at the kind of medicine I did and I thought that I had helped a lot of people, yet I had done very little hospital care in that period. After 20 years the daily routine of primary care medicine was getting old. Not the people, mind you. I loved interactions with people, but the medicine became tedious and routine—thousands of cases of high blood pressure, diabetes, heart failure etc. I had seen so many patients in my various jobs that even though I had a very keen memory for faces and names I began to not remember my patients when I saw them again the second or even third time—as if a harbinger of dementia.

When I thought about working at Center for Elders' Independence, especially the idea of caring for dementia patients struck me as particularly unfriendly. Seven years earlier in 1985 I had noticed that "Alzheimer's" disease was beginning to get a lot of attention in medical media and public media too. "How come?", I thought to myself. I didn't really know anything much about this disease process that everyone was saying had become a major public health problem that would grow along with the aging of the general population.

I looked at a few journal articles and began to familiarize myself with dementia. But after I had read these articles I was surprised to conclude that I still didn't know what the heck this animal really was. Shortly, in 1986, in search of a life change, I was accepted to the Masters Degree program in Public Health (in Epidemiology) at UC Berkeley's School of Public Health. When I entered that program and chose Alzheimer's dementia (then called Dementia, Alzheimer type or DAT in the literature) as the subject of my major literature research review paper in Epidemiology for the year, that decision was based solely on inquisitiveness. While at Berkeley I also wrote another paper on the classification of dementias for a second course, "the epidemiology of aging" a largely guest lecture series led by George Kaplan, then Director of the Alameda County Study. Looking back it seems as though I had unconsciously steered myself toward eldercare, but that was actually the farthest thing from my mind.

By the time that I went to work for CEI in 1992 I knew quite a lot of what was then known about dementia. I was unconvinced that most dementias fit neatly into two simple categories as popular and professional pedagogy portrayed it (Alzheimer's and Multi Infarct Dementia). I won't digress here into an academic discourse on my views on dementia classification. I present this background only to say that knowing more about dementia did not make me more interested in working with people who suffer from it. To the contrary, except for a need to master some of the cognitive testing necessary for mental status assessment in patients, I believed, without good evidence, that working with dementia patients would be burdensome, tedious and boring.

For me, personally, establishing a social interaction with my patients about their lives had been my joy and my forte. Many a diagnosis had been made and or helped along by my exploration of aspects of people's lives that lay beyond the usual basic cut and dried medical history and "review of systems". Whenever I see a puzzling diagnostic case before me I shift into a different gear. Rather than being only a medic I turn to my more inquisitive, even nosy, side—an interlocutor interested in every life detail of the person before me. I am no voyeur, but I suppose that, as in so many realms of human behavior the border between appropriate and inappropriate behavior is socially and culturally defined. Doctors need to be inquisitive. My own inquisitiveness about peoples' lives often serves an important role for the patient and is also how I accumulate fascinating life vignettes and tales.

So, the demented? They can't tell you anything about themselves because they often don't remember. And they can't get to know you because they won't remember you. And when they are ill they usually can't give you a useful history. And often they may notice only that you are someone they have seen before. "What is it you do around here?" I have been often asked by demented. "You look familiar by I can't quite place who you are."

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One can only imagine how that kind of response feels to the loving daughter or son who one day finds their parent's dementia has reached the threshold of loss of personal recognition. Though my own mother died with late stage dementia two months before her 98th birthday in 2014, the one mental faculty she somehow managed to retain was recognition of my sister and myself up to the last day of her life. We were thankful because often that is lost by the end of life.

No, I thought, that kind of medicine and care relationship is not my cup of tea; it doesn't fit my personality and abilities. Yet, a high percentage (almost half) of participants in the CEI program (when I was involved) had some degree (though severe dements were only about 15-25% of the population) of cognitive impairment and short term memory loss. The Reading and Reminiscences group which I founded and led, inspired by Ms. Kingsby as related in the first story to follow, was how I tried to cope with these feelings and concerns. A discussion of the profound experience of the R & R group will be found in the middle of this book.

Initiation: The Rites of Spring

Ara Belle Kingsby¹

In the early afternoon of Easter Sunday, April, 1994, a deeply religious and dearly loved 87 year old African American woman I knew and cared for died of pneumonia and dehydration. Beyond her children and grandchildren, the silky voiced poet Ara Belle Kingsby left 35 great grandchildren, and 5 great great grandchildren to celebrate her "homegoing".

Editing down the epitaph written by her family:

Born Ara Belle Dalphinia George, the eldest of 5 children, in Mornings Port Louisiana, Mother Belle as she was to be later called, graduated a valedictorian from the first high school for African Americans in Shreveport, Louisiana. She devoted her life to family and community, married twice, and had herself 5 wonderful children. She served as an elementary grade teacher, a local church and community missionary, a community activist, and a health nutritionist. In the 1940's she moved to Oakland, California. In later years she dedicated herself to her church and community work.

I first met Ara Belle Kingsby when I became the medical director and first physician at the Center for Elders' Independence (CEI), Oakland, Ca, in April 1992. She had a quiet wispy voice, a gentleness and a peacefulness about her demeanor and although I was her physician I did not take particular note of her, nor her past life, until

¹ It is customary, in presenting medical cases, to conceal the names of patients to protect their privacy rights. This essay was submitted to Mother Kingsby's family for approval because I felt that her particular historical individuality was a part of this story. As I suspected they would, the family photo-copied the essay and distributed it to all of her children, who approved its contents and agreed that names not be changed. That was in July 1995.

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a Center picnic outing to Crab Cove, late the same year. Crab cove is an idyllic small park on the San Francisco Bay, with green grass, groves of trees and picnic tables set back from a sandy semicircular beach facing Southwest on the Bay's eastern island city, Alameda. I had brought my guitar at the request of our young white South African-born activities director and was just preparing to sing and lead the elders in a few songs including Negro Spirituals and folk songs. I began with Huddie Ledbetter's Goodnight Irene. Lead Belly became world renowned as practically the grandfather of American folk music for his songs after he was discovered in a Texas prison serving time for murder by Alan Lomax and Pete Seeger. Due in part to their intervention he was released and joined the growing number of travelling folk singers in the 1930's and 40s.

Climbing up on a picnic table so I could be seen by all the elders, I introduced the song by asking how many had heard of Lead Belly. Most of the 35 or so folks there raised a hand or cried out in affirmation. Then I heard that wispy voice of Ara Belle from one of the farther out tables call out, "I knew Ledbetter".

Despite her ethereal voice Ara Belle Kingsby was a strongly framed and far from frail appearing woman. She was hefty, though not obese--still attractive in her mid-80s. She had a lilting southern accent. Tell us about that, I asked of her and she continued. "His sister married my brother. After he got out of prison he would come by our house in Shreveport and talk and sit out on the front porch and play guitar and sing of an evening. All the people from around would come over when he started to sing and play. I remember him real well." It was as if a living history from over 50 years before had blossomed totally unexpected.

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Listening to the stories of other patients' lives, I realized that these folks in our Program of All-inclusive Care for the Elderly (PACE model²)—most of whom, though living in Oakland, were Blacks raised in the South—held within themselves a treasure of living history. And so from that realization I decided to organize a reading and reminiscences group for mentally high functioning members. The group, which I'll return to later, met in the day center almost weekly for several years.

But at Crab Cove, hearing Ara Belle's brief talk had taken me by surprise. I had sung and listened to Lead Belly's songs then for over 35 years. Goodnight Irene, a sorrowful prison lament, had a particular significance to me because I too had been married to a young woman named Irene. We divorced after only 2 and half years of marriage and I later learned from her mother that Irene had died of liver cancer at the age of 50. In any case, this introduction to Ara Belle Kingsby as relation to Lead Belly began for me a new and different type of relationship between us and for me a greater

² A rudimentary description of the PACE model may serve the reader of these essays. 70—80 PACE programs across the country effect a very specific model of care for frail and disabled elders. To gain entrance elders must be certified as disabled and at risk of nursing home placement, then join the program and get all their medical care from that program although they live wherever they choose out in the community—often with family and support in the home. Program goals include keeping people out of Nursing Homes and other institutions through the end of life and maximizing quality of life. Although PACE may use hospice methods sometimes, PACE differs from hospice care because many participants are not terminally ill and some members have survived 10-15 years in the program. Each PACE site has several adult day health centers with daily programs providing social activities, a medical clinic with doctors and nurse practitioners and physical therapy. The care and care planning of members (participants) is coordinated through broad interdisciplinary teams. Teams of a dozen or more professionals and semi-professional staff (including drivers, social workers, therapists, day center staff and medical staff) meet daily to discuss care plans and problems—chronic or new—of participants in that program--including non-medical, social, family, housing and other problems as well as medical issues. Participants may be seen in the clinic or the therapy center daily (as needed) and care plans can be changed according to changing conditions, at any time. The social activities of the Day Center are central to the program. Other details are suffused within these essays and more info about PACE can be found at www.npaonline.org

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insight into how fortunate I was to be so engaged with this community of elders at CEI (the Center for Elders' Independence).

PACE program members live out their lives in their own homes. At entrance to any PACE program participants are asked how they want to be treated or not treated in crises and end of life situations. Ara Belle Kingsby had, from the time she entered the program, stated that she did not want to be hospitalized or placed on machine ventilation in the event that her heart stopped. She based this on religious convictions. She had lived, she said, a long, satisfying, and prosperous life—had a large extended family. She was prepared to pass on when called by her God. She believed she would be going home to a better world. Doctors were only going to add unnecessary burdens.

A few short months after I arrived at CEI, Ara Belle had an abnormal PAP smear (a test no longer recommended for women this old). She acceded to a biopsy by a Gynecologist and this showed moderate cervical dysplasia--possible early signs of cancer. As a result our nurse practitioner then scheduled her for a recommended more extensive curative biopsy procedure called a LEEP. On October 14th, 1992, a day before the procedure, Mrs. Kingsby declared that she would not go. She spoke carefully and calmly, without any touch of hostility in asserting that it would be best if she were left alone. About this same time she also refused to go for a recommended eye exam to check for glaucoma. She clearly said she did not want to be bothered with all of these doctors. I had been medical director of CEI for only 5 months.

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Just two months later Ara Belle developed a rapid irregular heart rhythm and was briefly admitted to the hospital. A short time later in January of 1993 she developed a blood clot in a leg vein and again required a brief admission to start on anti-coagulation. In the tension of these episodes of acute illness, she did not resist the care strenuously but when her general condition was more stable she again asserted during her regular complete exam (this time to a woman physician on our staff) that she wanted no treatment for her cervical dysplasia.

Nevertheless, on June 30, at her next quarterly examination, at my persistent urging, she again acceded to see the gynecologist anyway. Ominously, I also noted she had an enlarged liver and an easily felt abdominal mass as well. A C/T scan was done with her agreement and revealed two different masses in her colon, one probably expanding into the gallbladder.

Meanwhile, Ara Belle had been again scheduled for the cervix (LEEP) procedure. A tug of war was going on, and in retrospect, Ara Belle was wiser than we--our medical staff-- given that her abdominal mass was menacing her, not her cervical dysplasia. On August 9, after being taken to the Gynecologist's office by our transportation staff, Ara Belle emphatically refused to transfer onto the table and then insisted that no further evaluation be done.

Once back at our Day Center's clinic she again patiently told me that her life was in God's hands and she would like me to let her live and die as God wished it. Apparently, I then realized, I (and others as well) had been refusing to listen to her wishes. I had simply not wanted to "just let her die." Somehow it had seemed to me

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too early in her medical evaluation-- despite her age. In consultation with Ara Belle and her daughter Ruth, however, I agreed to better carry out her wishes. A gastrointestinal procedure to diagnose the abdominal masses was canceled. Ara Belle well understood all the time that she might have an abdominal cancer and that she was risking its spread without treatment.

At the same time, though understanding that I should carry out her wishes, I was becoming frustrated, failing to see that I had to give up the typical medical role for Ara Belle. I felt that, as a doctor, I now had very little to offer her. And, moreover, that the clash between our two value systems and personal judgments about her situation lent itself to personal failure for me. I liked this proud woman, but unlike others of the feisty (sometimes obnoxious) people I had to deal with, who I could easily laugh with, she was unnerving me. In her priestly gentle way she had an untiring resolve; she was unbelievably forceful in her gentility. She challenged my self-defined role as physician. Though the situation was complicated, I was new to geriatrics, to dying and palliative care.

I have had patients to whom I could minister mostly emotional support, companionship, guidance, and a soothing influence even when I had little to offer as a curing physician. I have always felt that the doctor role was as much caring as curing. But what if Ara Belle had a curable cancer, I thought to myself? And besides that, what could I offer someone so accepting of death in her righteousness? Thus, when a second doctor joined our team and I had to divide the patients between us, Ara Belle was one of those who I passed on to him, with her permission. She expressed no

concern. We saw and spoke to each other frequently and she greeted me cheerily each time nonetheless. -I'll fly away-

In September, 1993 Ara Belle Kingsby suffered another deep vein clot in her leg and was hospitalized for 5 days. Two weeks later at a family conference with her new doctor, her daughter and her social worker, she again made herself clear, declaring that she wanted "no further work-ups" of her medical problems. Three weeks later she came to the center with visible blood in her stool.

By December 21, she had developed right sided abdominal pain in the area of the mass; she did not want any evaluation. She was treated with pain medications and her condition stabilized for a while; then, on March 7, of 1994, she was hospitalized for two days with a urine infection. A day after leaving the hospital she came into the center seeking to be seen in clinic. I examined her for complaints of vaginal and anal pain and found she had become incontinent of both urine and stool. Her stool was brick red and tested heavy for blood. Her blood level had fallen progressively over a one month period; she was anemic, anxious and in pain, and under these circumstances she agreed to my insistence that we do colonoscopy to finally identify what was happening and whether we could do anything to help. I wanted this done because even if her cancer was incurable, surgically preventing a bowel obstruction—a terribly painful way to die—or stopping the internal bleeding might still be possible and a useful palliative measure to make her end less difficult. We treated her for abdominal pain.

At colonoscopy the Gastroenterologist found that the higher up mass was, as expected, bleeding and an invasive cancer, and too advanced to be removed via

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colonoscopy. With these findings, her answer, firm as it had been so many times before and now communicated through her daughter, was "she doesn't want any surgery" not even to prevent an obstruction of the bowel. Nevertheless, the following week Ara Belle came in to CEI in even worse pain and now she was jaundiced. Under these stresses she acceded temporarily to seeing the surgeon. Two days later, before evaluation by the surgeon, her jaundice was worse; she was bright yellow and the mass was very tender. Our usual surgeon was in surgery all day, so I scheduled her to see him the next morning but that wasn't to be.

At 5 a.m. that morning I was awakened by a phone call from Ruth that Ara Belle was unable to breathe and Ruth had called 911. I met them, and many other family members at the hospital emergency room. Ara Belle's blood pressure had fallen to 60/40; with a pulse of 130 and her hemoglobin was 6 reflecting now potentially life threatening blood loss; but she was conscious, alert, breathing well and, as usual, calm and reflective. We had talked about palliative care. I had discussed with Ruth the issue of Ara Belle dying at home in her own environment. But now they both preferred that if she were dying she spend her last days or hours in the hospital with nursing attention and family by her side and so she was admitted.

At that moment,--knowing that Ara Belle Kingsby would die from this malignant condition (later if not tonight)--I found myself ready to think and act as if I were Ara Belle Kingsby herself rather than as her doctor. We worked on the palliative principle that Ara Belle, who reiterated again very clearly and even blissfully that she

was now ready to leave, was in the hospital only to make her dying easier, with less pain and suffering. -I'll fly away-

Although this palliative approach is followed every day by practitioners in hospices and hospital settings for terminal cancer patients, my relationship with Ara Belle had unfolded in a most unusual way. As I have mentioned, when I was appointed Medical Director of CEI I had already been practicing family medicine for 20 years, but I had little geriatric experience and no end of life care expertise. I was now the student of Ara Belle as well as her guide.

Ara Belle was admitted to the Oncology ward for cancer patients who were under palliative care. The first day I did nothing but prescribe small morphine injections for pain; her condition did not change; she was alert; she ate dinner, shared time with dozens of family and friends, spoke about her passing as a blessing. At night, she began to have more pain. With the advice of staff nurses, her treatment now passed on to an intravenous morphine drip which would, I hoped, control her pain, but also the desire to eat or drink; Ara Belle became more lethargic, but also pain free. But on the third day she showed no signs of weakening. Her body was strong. We did not give transfusions for her severe anemia. Then I realized that the IV, which had been placed only to allow access for medications, was providing her some sustenance. The IV fluid rate was decreased to almost nothing, though she was provided any oral liquids she desired.

At the hospital I visited with her daughters and other family daily and I told them she would likely die within 2 or 3 days from dehydration, a painless, almost dream

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like death. But Ara Belle was not yet ready to die. In making such a prediction I learned an important lesson about the unpredictability of the trajectory of life and death even under such conditions. Ara Belle wandered in and out of consciousness and mental clarity and did not die.

As the days went by, I now recall, I had some misgivings about my decision to not do anything besides pain medication. I doubted myself, worried that somehow I had failed her. The family, on the other hand, remained close by and calm. Each daughter and her son fondly provided me, as well as Ara Belle, their support; told me I was such a wonderful person to be there daily going through this with them. I re-examined my ambivalence, accepting that, even if "brought back to life," Ara Belle would only live to suffer a more tortured death from metastatic cancer—soon, very soon; or worse. To force her in this, the gravest moment of her life's vulnerability and hypersensitivity to noxious stimuli, to have the palliative (not curative) surgery she never would have wanted, to suffer that pain and indignity as she was dying, would have been a terrible decision.

As firmly as the family stood by Ara Belle, they stood by me standing by Ara Belle. That helped me develop confidence in my own almost shamanic role, which was as much a symbol of caring as it was anything else. As her state worsened we progressively raised the level of the morphine drip to treat her restlessness and any apparent pain. She became semi-comatose and more relaxed. The hospital nurses on this ward had been through this dying process with cancer patients hundreds of times before and they offered suggestions and parameters for the morphine drip. I was using

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morphine levels that were common for terminal cancer pain they assured me; we were not doing anything unusual under the circumstances.

Two nights before Easter, Ara Belle had an increase in muscular spasms and tension. With my doctor mind I could imagine: uremia from her kidneys shutting down; electrolyte abnormalities; hypocalcemia, hypercalcemia or other causes of nerve-muscle membrane instability; hypoxia and acidosis, the pneumonia she had now acquired. I could guess but not know; I must not become the "distant" investigator, I thought. Clinical diagnosis and treatment was not my role. I ordered the morphine to be upped to the "usual" maximum dose and I imagined inside Ara Belle's mind: Ara Belle wondering if she might have the privilege of dying, of being resurrected--for she surely believed she was going home on Easter Sunday.

On Easter Sunday morning I visited Ara Belle and three of her daughters, and found her comatose and relaxed. The neuromuscular instability had been broken by the morphine. Her breathing had now become agonal. She was dying. I suctioned her briefly myself, talked with three of her daughters--Georgia, Ann and Pam and stayed around a while believing she would die then. It was now the 10th day since her admission. But I had also given up thinking that I could predict the procession of this process. The family was calm and resigned to her death. I went on home. 90 minutes later around noon on Easter Sunday, 1994 the nurse called to tell me that Ara Belle Kingsby had died.

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Two days later, 4 of Ara Belle's 5 children attended a prayer circle for her at CEI and presented me with a scrapbook of photos of dozens of family members taken during the prior 10 days in and around Ara Belle's hospital room. Seeing them taking flash photos I had--on the second day--asked if I might have some family pictures. And despite their family crisis they had gone a step beyond and assembled this scrapbook. At the prayer circle they spoke of poems that Ara Belle had composed for each of them when they were children and they read some of her religious poetry.

I also spoke—though not of Ara Belle's enduring faith--but of the wonderful support that she and her family had given me as we had moved through her dying process together. "I can not imagine", I said "a family (including my own) giving me better or more deeply felt support than I have received from this family. It is an honor to have served and known them".

From Ara Belle Kingsby I learned more about myself than I would have thought could happen. Because I am Jewish I have never believed in euthanasia. I identify assisting death with eugenics; with the reality that Governments do try to decide who is to live and who to die, who is too old, too frail, too dangerous, inferior, and expendable. I am also uncomfortable with the idea of someone assisting the death or suicide of a person with whom they are not deeply familiar, because what a person says they believe or want at any particular crisis moment may or may not reflect the totality of their lives, their values, their being, themselves. But I learned from Ara Belle Kingsby and her family that, if only we try, people can allow each other to get close enough to understand and do the right thing.

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What I also learned from Ara Belle is that some of the gifts of life can come to us in the most unimaginable ways and from the most unexpected others, such as in the form of death and dying friends and patients who simply reach out and ask to be understood and accepted, still, as equals.

First draft written 1994.

How Death Saved Barbara's Life

Barbara was looking for a real home. She came to us almost lacking an identity, almost a non-person. She did have an apartment, unkempt, reflective of her disorganized, withdrawn and depressed self. It was in an unsafe neighborhood in Oakland. It was all she had; that and a distant dismal past, and no sense of a future. Her married name sounded Italian; but her own background never came into focus.

Barbara had been long estranged from her two living daughters (children by different alcoholic husbands). One daughter refused to ever visit or talk with her. Barbara herself had a lifelong history as an alcoholic and as a mother who had neglected her children and had had them taken from her. She carried a diagnosis of chronic schizophrenia and was being maintained in the community by the Public Mental Health clinic on a dose of Haldol (25 milligrams) that would probably put you or me to sleep for days. Despite the diagnosis she carried, however, Barbara had for many years manifested only social isolation and withdrawal with no psychotic behaviors, hallucinations or delusions. But she did almost nothing, except chain smoke. And she was just a sad sack.

5 feet 3, with an indifferent look, coarse reddish brown greying hair, an average build, a wardrobe neither striking nor particularly shabby and a weight of 122 pounds, Barbara didn't stand out in a crowd, except for a tendency to protrude her lower jaw in an underbite, and her anxious pacing which suggested a restlessness that lived just beneath her stoical surface (perhaps a side effect of her medications).

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Everything about Barbara suggested an inner world of resignation. She rarely initiated conversations with anyone. Her moderately lined face, though not unpleasant, had the appearance of a hardened mask. She sometime seemed to float above the ground like a spectre; at other times she paced like a zombie. She responded only when probed, though she was intelligent and observant. Her memory and her thoughts were often clear, even sharp and perceptive, yet fleeting; and she seemed so indifferent. Like many elders with schizophrenia, the disease--and perhaps the years of medication--seemed to have burned out her life force.

When Barbara was referred to the Center for Elders' Independence (CEI) she was, at 67, nine years younger than the average participant. She had been recently hospitalized for shortness of breath the cause of which was not determined. No pelvic exam had been performed, but she was referred to a community gynecologist for a vaginal exam due to an odor. The gynecologist had found that she probably had a cancer with many symptoms that she had been ignoring and not telling anyone about, but the doctor was unable to perform the exam adequately for diagnosis.

The day of her initial visit to CEI, I consulted a different gynecologist and then referred Barbara to a radiation implant specialist for full diagnosis and treatment recommendations. Not only did we hope to help her get rapid treatment, but our multidisciplinary team needed to know if she was likely to survive long enough to benefit from our day center and comprehensive support program; we needed to decide if she was a candidate for team evaluation and admission.

The specialist's answer came back in a matter of days: it was an invading

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cervical cancer that had expanded into the bladder and out to the walls of the pelvis, forming a tract between bladder and vagina that drained urine. But the tumor had not yet spread to lymph nodes or distant organs. Once radiation treatment had shrunk down the size of the tumor there might be a small possibility of cure of the cancer. She would also need to have tubes put in her kidneys through her back to drain her urine because either the tumor or the radiation would probably block the ureters. And since she was also having a lot of local infection and irritation, these could get more serious if we allowed urine and debris to drain constantly.

But Dr. Demanes thought that even without cure Barbara could maintain a stable quality of life for a year or so with treatment. He offered to stay closely involved in her care for the duration, not just during her treatment phase. As Barbara then agreed to be treated, we decided that she could benefit from CEI and enrolled her.

* * * *

Stoic and depressed as she was, Barbara went through the heavy radiation treatments as though it were like getting dressed and brushing her teeth in the morning. She had her kidney tubes placed; they blocked or fell out periodically and she would have to return to the hospital to have them replaced. The radiation procedures involved repeatedly placing a large insert with many radiation probes inside the vagina and pushing it high into the pelvis. There must have been pain, but she never complained or admitted to much. "It was kind of uncomfortable", Barbara said. And then, "it did hurt a little when it was in there", she would casually monotone. We had sent her to live in a nursing home for supportive care during, between and after

treatment as a temporary measure. Barbara lived at that convalescent hospital for 3 1/2 months.

Meanwhile she became a regular attendee at the day care center, finding places to lie down, rest, or sleep frequently, but nevertheless getting to know staff and participants and slowly making a new home. She still had the attention span of a hyperactive child. She would come into an activity sit for 3-5 minutes then get up and wander restlessly about the center or find somewhere to lie down; or rush outdoors to chain smoke compulsively.

So our team tried to develop an interactive strategy to engage her, calm her, and slow down her restlessness. This included bingo on Wednesdays, small tasks, a try at the reading and discussion group, symptom management with her social worker, Rachel, Drama Therapy on Thursdays, art and mural work and talking with Rachel on Mondays, working with children when they visited, and so on. I steadily reduced her Haldol dose and decided to treat her depression if it didn't respond to the social stimulation. We waited to see if she would become more agitated on less Haldol.

Often now I came upon Barbara sitting in the hall, smiled at her, took her hand, and talked with her briefly. As time passed staff members, especially Rachel, were also developing a more interactive relationship with her. But Barbara's responsiveness was marginal. She seemed disinterested in life's nuances. Still, she offered that she liked the Center, and felt supported.

* * * *

When she started at CEI Barbara was told, and she acknowledged, that

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she had a serious cervical cancer that had spread, but amidst the talk of treatment, and "possible" cure, and the support she received--as she later expressed herself--"I thought I was getting better". In a sense she was right. On the other hand, denial ran--had been running--rampant through Barbara's conscious life for a very long time before this. It wasn't just death or the cancer. I hoped that, if perhaps briefly, denial might serve her positively. Besides that, one kind August day with treatment completed, the team returned Barbara to the community to live in a small residential home.

Improved independence, improved health. Barbara heard her doctors say that the tumor was shrinking. And in the first 6 months or so her weight had returned from 100 back to 120 pounds and her strength improved even during radiation treatment.

* * *

Despite new stable surroundings, however, Barbara soon became progressively weaker, with recurrent weight loss, and increasingly difficult ambulation. She began to faint frequently after compulsively smoking cigarettes, finishing each one in about 30 seconds; she fell and had several minor injuries, once requiring 5 or 6 stitches to her scalp. She was obviously anxious and worried. Asked if she thought her cancer was getting worse or the fear of that possibility was bothering her she flatly denied it. I started her on an anti-depressant.

The CEI team noticed the changes and intensified the effort to involve Barbara with a painting project, for she had wanted to paint again. She got part way through, putting in 5 to 10 minutes each day at the center during 2 different weeks; she

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sat in a reading and discussion group for only a few minutes. Though she anxiously sought cigarettes and, if not provided, smoked butts she scrounged or scavenged in the street and ashtrays, on some intangible level she seemed to be feeling more secure. I wondered how, paradoxically, Barbara could be feeling better and worse at the same time; I could not understand this contradiction then.

* * *

Throughout those months, Rachel and I maintained close contact with the daughter who had become, the past year, very involved in her mother's support. Sheila, 40ish, a woman who seemed to share Barbara's serious and unreadable facial expression, worked successfully in a professional capacity with a local county health department. She had helped Barbara to accept us and the various housing changes we pressed on her. Barbara had initially resisted leaving her own apartment; And though Barbara had successfully moved in August, a while after returning to the community she initiated--through slovenly fecal incontinence--a confrontation with the residential home owner and was expelled. But now, by early 1994, despite the fainting, the weight loss, and weakness, things had calmed on the home front. She was happy with her second new home of 3 months--as she was with CEI--and these were important areas of calmness and achievement.

* * * *

In early February, at her new Board and Care home (the Nest) which she shared with 4 or 5 other residents, Barbara became increasingly withdrawn; she started to stay in bed all the time at home and to resist coming to the Day Center; she began to

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have more frequent stool incontinence. Her Haldol was increased from 5 to 10 milligrams. Now she became dramatically weaker, confused and increasingly more withdrawn.

This apparently was not a psychiatric flare-up. Blood tests showed that Barbara had hypercalcemia (known as the para-neoplastic syndrome--due to regrowth and spread of her cancer) and had become dehydrated, explaining her increased weakness, confusion, and withdrawn behavior. She was hospitalized, treated with intravenous fluids and pamidronate to lower her calcium and this rapidly--though only temporarily-- rejuvenated her. Just 2 days after admission she was lucid and alert; and so, with Barbara's agreement, I called Sheila and asked her to come to the hospital for a much needed conference.

* * * *

Barbara was able to walk from her room to a big well decorated lounge at the end of the corridor with comfy sofas and chairs spread about. She came without support, wheeling her own IV stand. She sat down; she sat quietly, peacefully smiling at times. "I'm sorry to tell you that you are dying of the cancer", I said. Whether weeks or months remained to her life, I could not know, but the process was inevitable and the calcium problem would probably keep returning until then. "Did you know that this was coming", I asked Barbara. "No, not really", she responded. "It seemed I was getting better."

Then Barbara and Sheila calmly and warmly shared their feelings and fears with each other for an hour on that Saturday morning in the empty hospital ward

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lounge that was way too big for three people seated alone in a tight group. I sat witness to a sadness and a harmony blended into a common acknowledgment of each other and of themselves. For Sheila, particularly, it was an epiphany, because she and her mother had never, to her recollection, shared so much.

But what did Barbara feel; Barbara, who was dying? Finally I asked her if she was frightened, for she had often said that she was afraid of dying and wanted to live. "I'm not afraid anymore," she replied directly. I heard a lightness and relief in her voice. Did I imagine this? Was I projecting? Well, no.

* * * * *

Barbara stayed in the hospital a few more days and then went home to her Nest. We agreed upon a plan of support and palliation. Her Center days were cut back to 3 a week and I told her she could be in control of whether or not she came in and whether to continue her medicines. On any particular day she could stay home if she wanted to.

Immediately, she showed a new outward assertiveness. At the Center she began openly discussing her impending death with people she related well to. She no longer was interested in smoking. She did decide to stay home more often, but she was not withdrawing. On March 17, with her wanting to stay home more, I negotiated 2 days a week at the Center with her, telling her I needed two days to monitor her medical state. She agreed.

Later in the day, back home, she refused all medications, including her Haldol. By phone I could not convince her to reverse the decision. My goal had always

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been to get her off psychiatric drugs and she knew it. Barbara was not hostile; to the contrary she was friendly, peaceful and determined. Now she spoke more frequently, and still more forcefully and assertively. She smiled more spontaneously. She was relaxed and she initiated topics and conversations. At one point, out of character and somewhat out of context, she said to me, "Dr. Sapir, I just want to tell you how thankful I am for your kindness."

* *

On March 18, now two weeks after Barbara's hospital discharge, the staff at the Nest went into rebellion over their fears of someone dying at the home. They had been instructed that Barbara was terminal and that both she and CEI hoped to keep her calm and happy until death at home (residential care staffs are not licensed nurses). Placing Barbara, who was not demented, in a Nursing Home at this time would be taking away her home and security for no reason. She was finally achieving some sense of self, some real autonomy, and with this an ability to direct her own life positively, with dignity.

Our Program's Home Nursing Director visited the Nest Home staff and gave them an in-service on terminal care and dying patients and assured them that we would manage any medical issues 24 hours a day. She helped the staff express their personal fears. Though no permanent agreement was reached, peace was restored. At least for the moment, Barbara could stay, and the team assigned a Health Worker to spend several hours a day supporting her at home to supplement the staff of the Nest.

Now over the next week Barbara's hypercalcemia began to return, and she

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became weaker and unable to come to the Center. She stayed in bed much of the time. Nevertheless she responded to encouragement and continued to keep up her intake of liquid and calories by mouth so that she did not suffer the disorientation that had caused her earlier hospitalization. In the midst of an overwhelming cancer burden, she remained in focus, in harmony and intact. And she was not becoming depressed. She received intensive support from Denise, her home health worker who had strongly bonded with her.

*

On March 23, with Barbara no longer able to attend the Center, I also began home visits. The next day, she was calm and resting. I sat beside her. We conversed about her contentment with the room and bed location that she had. From her room, sometimes even from her bed, she could watch the squirrels in the back yard playing in the trees. "I love to watch the squirrels", she said, smiling. "I'm not afraid of dying", she told me, now at her own initiation. "And I'm ready to die".

Four days later, Barbara did die, peacefully, in bed at home. That very same day she had still been able to get up with a little assistance and walk to the bathroom. Her incontinence had improved dramatically and there was no indication that her life was at its ending. A few minutes before death she had actually been up talking. I thought: Barbara's death had become one of the most vital and developed works of her difficult life; it was a work of art as well as of her humanity. For her death was serene. Or it at least appeared so. What evidence?

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Time passed after Barbara's passing, after her wishes to be cremated had been carried out, after a remembrance and prayer ceremony had been held with the participants at CEI's Day Center. One day Sheila stopped in briefly. Thanking me for helping her regain a meaningful relationship with her mother, Sheila agreed that Barbara had found both inner peace and some kind of meaning in the last weeks of her life.

Then she hands me a sealed envelope that Barbara has asked her to deliver to me. The envelope is simply addressed, "Dr. Sapir". I have no idea what to expect. I hesitate briefly then open it. Inside is a card. On its front two cherubim gaze upward toward heaven from a famous painting, faces posed in idyllic wonderment. I open the card. Inside is written "Dr. Marc Sapir" then the imprinted words, "Seasons Greetings". It is signed simply "Barbara".

Though briefly stunned I began to chuckle and could almost feel Barbara's presence. This card hung on my bulletin board beside my desk at CEI. As I looked up or still think of it I could never, can never, help from smiling, warmed by the black and wry humor of Barbara's post hoc greeting--and remembering the harmonies of her passing. My glimpse of Barbara's humanity, poignantly revealed--as well as the wonders of PACE--evoked this essay.

The card front reproduced here

Families and Kin Folks

Doctors save lives, cure diseases, comfort people; but we also make mistakes that can cause pain, suffering and death

Christine

Christine was already a member of the free standing Community Adult Day Health Center (CADHS) in Oakland, CA when it was transitioned into a PACE (Program of All-inclusive Care for the Elderly) project as the Center for Elders' Independence (CEI) and I was appointed Medical Director of CEI . She was a friendly and pleasant “young woman” of 58 (average age of our elders was close to 80) who had suffered a stroke and had a hemiparesis (paralysis of one side of her body). She had a mild dementia (perhaps stroke related) with some loss of short term memory but no significant progression and her speech was not affected. She was obese—though not rotund--wheelchair bound, and had little motivation to regain any physical independence. Christine always complained that she wanted to walk but then she resisted the work in physical/occupational therapy necessary to achieve that. The staff thought she had the potential to walk independently. But, she remained immobile and sedentary. And so she developed a gigantic pressure ulcer on the outer surface of the dependent leg which lay heavy and useless against her wheelchair's leg support and against her bed at home. The ulcer was open for most of a year and a half, breaking down again even after skin grafting because the pressure that caused it was still

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present due to Chris' inattentiveness. Ultimately, however, Christine did heal her leg wound. Additionally, she also had that most common of heart arrhythmias in the elderly (atrial fibrillation) and, for several years, she received Coumadin (warfarin) to prevent future strokes which atrial fibrillation too often causes. Then she got fed up with blood being drawn to regulate the blood thinning by the Coumadin, refused to be tested and said she preferred to be taken off Coumadin. We told Christine several times of the increased risk of another stroke before stopping the medicine; but she was stubborn and she took that risk, either not believing us or not caring. All the staff and other participants were fond of Christine despite her stubbornness, irrespective of her failure to take any actions to improve her condition. She was direct, very friendly and personable and in other respects she had positive life energy—a seemingly strange contradiction. But as I said, she wasn't an "old" 58, but a young "58".

After Christine was a member of CEI for a few years, we enrolled her mother, Helen, in the program. The mother and daughter lived apart. The younger was cared for by her own adult daughter (Eu), and Helen was cared for by another daughter (a sister of Christine's). An African American, Christine was unsurprisingly protestant by religious upbringing, but her mother had later converted to Catholicism. The two were quite close emotionally; they had no friction over religion.

Both women separately declared their end of life health care wishes to be DNR (do not attempt resuscitation when the heart stops). Christine in particular was adamant from the day she entered CEI. "Don't put me on those machines, no matter what", was her mantra. Her mother was a bit more vague than Chris. She often seemed to be in

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denial about her own situation as a disabled elder. Upon first meeting her, one might easily imagine that Helen had memory loss from the vague way she interacted. Yet despite this, she did not show any dementia on testing with the mini mental status exam, scoring near perfect. Her vagueness was sometimes like this example: after successful surgery for colon cancer, Helen flat out denied knowledge that she had had cancer in the first place. Nevertheless, when it came to end of life discussion, Helen was very consistent over time, if not as demonstrative as Chris. The discussion was repeated as part of quarterly examinations and as part of hospital care and she always asked for no resuscitation.

When Christine first declared her DNR status at intake, CEI was a new PACE program and I was a new PACE physician. Though I'd practiced primary care medicine in California for 20 years, I had no specific geriatric training up to then. Our CEI procedures and protocols, which I was to write myself, were not yet fully codified. Though I obtained Chris' wishes, I did not suggest to her, as one always should, that we discuss her advance directive with her own daughter who was her main caregiver. Nor was it brought up at the sign-in family conference when her daughter was present. These omissions were not without major consequence. Some months later we realized that we did not have a filled out DNR form on the chart or in the home, as required by the Emergency Medical Services in order to prevent resuscitation efforts in an emergency. And so I had Chris sign one, made a copy and sent it home with Chris to be kept by her bed in case of emergency. Unfortunately, this simple (and necessary) act initiated all manner of disasters which continued until Chris' death in August of 1995

over a year later.

In large part because I (and the social worker assigned to Chris) had failed to discuss end of life care wishes at the family conference with Chris' daughter present, Eu viewed the appearance of the DNR form as reflective of a desire by CEI to euthanize her mother, rather than our failure to engage her in a conversation and dialogue about her mother's wishes. In response to her phone call of protest and anger we scheduled a meeting to help clarify our processes and goals and the rights of our participants. But we had put ourselves, as they say, behind the 8 ball by then. Despite our desire to start over and reestablish a trusting relationship, Eu could not be calmed and would not accept the idea that her mother could make such a decision for herself. General medical ethics and principles of autonomy be damned. She insisted that we had manipulated her mother who "just doesn't want to offend you." She also insisted that her mother was not competent to make such a decision; and that since she was the primary care giver she had as much right to determine these matters as her mother did. (During my future years with CEI I had similar experiences with several other family caregiver who felt their opinion on such serious matters was more important than the patient's. As a result, I eventually understood that even though the law and medical ethics are clear that it's the rights and autonomy of the individual patient that are protected in this situation, that doesn't necessarily hold sway with someone who is sacrificing their own life and autonomy—whether out of love or obligation or both-- to care for a disabled parent or other family member.) There was no consoling Eu. Discussing death was for her as if to bring her mother's demise nearer. And then, of

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course, the similar wishes of her grandmother came to light which only made matters worse. Eu saw the Center as conspiring against her mother's and grandmother's welfare. The discussion took on racial overtones.

She then enlisted the support of Christine's two sisters in decrying the conspiracy we had visited upon them. She thought the entire program was designed to euthanize the African American population (since most participants of CEI were then African American). Attempts to apologize for not having involved them at the earliest (and more appropriate time) were rejected as were explanations of individual rights under the Patient Protection Act and customary medical ethical cannon. So we asked that they all come to a CEI Ethics Committee meeting where they would meet community as well as staff members willing to hear them out and help mediate this crisis. This began a crash course for me. Moreover, many "crashes" of a different type were yet to come.

Ethical dilemmas generally arise from mismatches in perception, understanding, philosophy, values or perceived need. Thus an ethical crisis or dilemma at the end of life is not usually a new problem but the culmination of an unresolved cultural divide made acute by an impending death. Back in the early 1990s doctors and other health care providers in the U.S. were rarely involved in values assessment discussions with the people whose lives they were entrusted with. Often a medical crisis resulted in a social crisis; sometimes in legal actions against doctors and hospitals. As a result of such conflicts and inappropriate end of life care, there are now laws requiring that

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hospitals and doctors carry out end of life discussions to ascertain patients' views and wishes, to document them, and to follow the patients' wishes. The design of PACE integrated these discussions and methods into the care of disabled elders way back in 1979 when the model was first designed by On Lok Senior Health Services in San Francisco. I learned "on the job" how sensible the design of the PACE model was in assuring that our health care teams be actively involved with the families and participants views, values and desires long before medical crises are apparent. We needed to understand and to try to resolve any potential mismatches, and to develop mutual trust and understanding over time and not wait for a life threatening crisis.

The word mismatch implies a social and cultural context: two or more people, two or more sets of values etc. Chris and Helen's story is far from over, but even to this point it illustrates how the PACE model, though dealing with disabled elders near the end of life, looks at peoples' lives through a fundamentally preventive, cultural and socially integrating lens. As I unfold what happened to Chris and Helen I think you'll see how their story reveals the dangers and poor quality of care that result when a health care system doesn't honor that effort. In this case the complicated ethical crisis I am describing was not resolved until one participant had died and the second stood on death's doorstep.

Eventually CEI required that any participant and their family who is to be discussed by our Ethics Committee be invited to those ethics discussions of their case. However, this was the first time that we had asked a participant or family members to

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attend an Ethics Committee meeting. I had high hopes that, because we had some very good community representatives on the Committee--including African American members--there would be a congenial atmosphere, a meeting of the minds, and a good outcome. My hopes were dashed when the family, led by Eu the youngest member present, did not come willing to listen or to discuss, but only to accuse. Indeed, the three women—2 of Christine's sisters and her daughter--focused their accusations on the African American social worker on the case and the other African American community members on the Committee who had, to their thinking, betrayed their people and Christine and Helen. The family stormed out of the meeting in mid discussion and threatened to take Helen and Christine out of the program although neither participant was willing to leave or to change their health wishes. Our attempts at an open, safe, and fair ethics discussion had failed and we were at loggerheads. Not only that, after the meeting some personal threats were made against staff members and that worried us and added to the challenge.

On my own initiative, I notified Eu that we would transfer Christine's care to our other physician, an African American, and he and I agreed that he would not press the health wishes issue with the family, yet try to carry out the participants' wishes in any crisis, if at all possible. We knew full well that this dilemma could not now be easily resolved, and this plan was but an attempt to temporarily defuse the tensions. Further negotiations would have to wait. Our hope was that when death came, like most deaths, it would not be under circumstances that required consideration of resuscitation or other life prolonging actions.

However, six months later the other physician left CEI and I was back on both cases as the primary physician. Then, a few months later, Christine suffered an unusual slowly evolving stroke. We tried to monitor her out of hospital hoping that the damage was small and would stabilize, but on the third day her eyes deviated to the side of the stroke and she became almost totally unresponsive while sitting upright in the Center. Hospitalized, she continued to deteriorate, falling into a coma. Eu demanded that I get off the case. We weighed the options of disenrolling Chris from the program because of an irresolvable dispute with the primary physician, but decided that our obligation to both Chris and Helen precluded such action. Violating Chris' wishes and acceding to Eu's demands seemed better than leaving her and her mother without our comprehensive care and support under these circumstances. Christine had entrusted herself to us. Our consulting neurologist agreed to temporarily become the primary physician in the hospital.

After about 10 days in the hospital, with Christine showing no improvement, the neurologist felt the prognosis for recovery was terrible. Despite her assessment, however, Eu insisted that Chris receive a long term stomach feeding tube placed through the abdominal wall in a simple surgical procedure, something Chris had said we should not do to her. Chris also developed a pneumonia and other complications, but, despite staying in a coma, she did not require ventilation and was breathing on her own. The neurologist felt uneasy about the primary care management at this point and asked to retire from that responsibility. She knew that Chris' right to refuse the G-tube had been ignored. With nothing more that we could do, Christine was placed in a

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nursing home to live out the rest of her unconscious life. Because of Eu's hostility, after discussion with CEI's Executive Director, I searched for and found a physician who had many patients at that Nursing Home and was willing to take responsibility for her care, to coordinate with us and communicate regularly with me. Chris' mother Helen remained in the program.

Christine remained in a vegetative state for two months and died at the Nursing Home. No efforts at resuscitation were made. She was found dead by nursing staff. Her wish to not have a feeding tube if she was unable to swallow or eat—had not been honored, but at least she had not been put on a ventilator. (Originally I wrote "ignored", but of course her wishes weren't exactly ignored. They were just incompatible with the circumstances we found ourselves in). The case was sent to our Professional Medical Advisory Committee for review and discussion. I recognized how the omission I made early on contributed to this outcome, although we have no way of knowing if there might have been a better outcome and relationship had we told Eu of Chris' wishes at the initial family meeting. At the least, had we done so, we would have had some years for Eu to get to know myself, our staff and our program better on a personal level; Eu would have had more time to discuss this situation repeatedly with Christine and possibly she would have accommodated to her mother's wishes. Or perhaps not. But if not, we would have at least been in a better position to honor those wishes in the care we provided.

Helen

Death usually signals the end of direct relationships with participants and

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families, but in this case it would not because Helen was still a member of the program.

Two months after Christine died, Helen fell at home and suffered a hip fracture. Despite her age (79), she was in good enough physical condition that surgery could be considered. She and her family wanted her to have surgery and our orthopedic surgery consultant agreed. He thought he could perform it successfully. Surgery was scheduled and performed. However, Helen developed cardiac complications under anesthesia though the cause remained undetermined. I never received any proof of an intra-operative error, but the anesthesiologist was later censured by a Hospital Committee for negligent behavior, which I should explain.

On the day of surgery, I was leading a meeting at the Center when I was called away to answer an important call from a physician. The anesthesiologist on Helen's case, who I did not know, told me that Helen was in recovery but had not yet awoken. She asked me if she could go to a Dentist appointment that she had scheduled for that afternoon. I was confused. I didn't understand why I was being asked this. "How long has she been in recovery?" I asked her. "About 15 minutes", she responded. "Is that within a range of normal? Might she still wake up? What can you do for her?" She responded that there was nothing else she could do and I told her that she should do what ever she thought right. Only later did I fully understand that this anesthesiologist was actually seeking my permission to leave an unstable patient who needed her attention. Caught unawares of what was going on, with neither adequate knowledge nor a good understanding of what had transpired to respond, I did not act assertively enough to tell the anesthesiologist she had a responsibility to her patient. And I had,

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without understanding this, unintentionally collaborated with her desire to leave an unconscious patient in the recovery room to go to an appointment. Shortly after the anesthesiologist left her, Helen suffered a cardiac arrest in recovery and was resuscitated by the orthopedic surgeon who then notified me of what had occurred. She never regained consciousness, ended up in a coma on full life support in the ICU³. Helen had been in good general health and had survived that colon cancer resection (mentioned above) only a year earlier. She was only 79, average age for our program. No one had anticipated a bad surgical outcome, although the family was, of course, briefed by the surgeon and anesthesiologist in the usual way about risks of surgery and anesthesia, particularly in the elderly.

The orthopedist later explained to me that there had been a short period of time when he applied the glue to the bone when fastening the new hip ball, that Helen's blood pressure had fallen dramatically. He said he was aware of a few reports of isolated cases of this glue causing a sudden drop in blood pressure. He had no way of determining if it was the glue that caused Helen's blood pressure to drop, if the drop in her blood pressure was so severe that it caused her brain to become oxygen starved for too long, if the anesthesiologist made some other mistake or was negligent during the surgery. That remained—and remains a mystery still. But my own feeling of collaboration with the post-operative irresponsible behavior of the anesthesiologist leaving her patient in trouble to go to the dentist, remains with me to this day. Because

³ Typically, DNR orders are suspended during and just after surgery on the grounds that ventilation is required under anesthesia and even a cardiac arrest during or just after surgery would not be a "natural" event, but could easily be related to the surgical and anesthesia intervention.

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specialists are higher in the power pecking order than primary care physicians few primary care physicians would be assertive with a consultant specialist. But even though they have important expertise, even though they earn as much as 10 times the earning of primary care docs, it's the primary care physician who has to play the role as the patient's chief advocate within our too impersonal health care system. Although I do believe that I was then being manipulated by the anesthesiologist, I nevertheless know that I failed to carry out my full responsibility to Helen, my patient. Maybe the outcome would have been no different, but regardless I should have called out the anesthesiologist.

We would all like to live in a just world, but life often dashes those hopes. Sometimes bad behavior is rewarded and good behavior punished—that's hardly fair. The peri-surgical brain damage to Helen was terrifying. There was a thorough case investigation at the hospital. The anesthesiologist was censured, which I believe was a just outcome. If there was negligence during surgery she should have suffered a worse fate. But I can only surmise that there was no evidence, only her word.

In the end I was patted on the back by the committee that reviewed the case and told that I had done nothing wrong at all. Perhaps my behavior was not egregious, but I did do something wrong. I failed to advocate sufficiently.

However, despite all earlier tensions around Christine and Helen's health care wishes, the family, to my amazement, responded very differently, supportively and positively in this disaster. The sister of Chris who was the care giver of Helen took me aside in the ICU and said that the family understood how emotionally involved Eu was

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with these crises (of both her mother and now her grandmother), and that they would manage her grieving and help her work through the need to allow her grandma to die. She asked me to discuss changes in Helen's status with her or the third sister first and that they would then include Eu in family discussions after they had prepared and calmed her. I breathed a sigh of relief and thanked her.

Based upon the earlier events around Chris, they had learned how to respond to Eu's fragility and support her differently. And despite much emotion and some commotion, Eu was, indeed, able to allow the process of withdrawing Helen from life support to proceed as the daughters (her aunts) wished.

Helen died in the hospital, in an irreversible coma probably resulting from hypotension during surgery for a hip fracture. She never awoke. After she was resuscitated and sent to the ICU on a ventilator, her EEG the next day was consistent with much brain damage, but was not a flat line. On the fourth hospital day with no change in condition, the family agreed to stop support of her blood pressure and then to remove ventilation and to not attempt to feed her through tubes. Off the ventilator she was transferred to the ward and lived several hours and died peacefully. In the aftermath the family was remarkably supportive of CEI and the care provided, wrote us letters and thanked myself and other staff for all that we had done for Chris and Helen. I had tried so hard to get things right for Christine and failed, with much resulting tension and hostility; I did little for Helen in her crisis and the one thing that stands out in my mind was that I made an error in my own judgement when that anesthesiologist tried to use me to cover her unethical behavior. This surprising turn of events ended one of the

most complex and difficult ethical crises I experienced.

So we learn. And I learned. First, to always include major players in decisions and let them know your expectations unless the participant forbids it. If a family member cannot allow the participant any autonomy at the outset, be prepared, if that patient is admitted to a hospital later, for ethical dilemmas. And we shouldn't assume that some written rules of medical ethics supercede real life. In real life family members have more than just some rights. They are who they are and that's important in a crisis with an unconscious participant; their collaboration is inevitably necessary. Thus, when one assumes responsibility for the full healthcare of a frail patient, understanding the family and support system dynamics needs to start at the very beginning of the relationship, in part to learn who you can rely on to support your work over time and in part to begin to build the relationships that will endure through these travails. Signing people into PACE or any other comprehensive program without their families' presence is not a good idea, as many cases and problems have repeatedly demonstrated.

Families learn from experience just as we professional staff do. I spent the next 6 years explaining to new staff what happens when families are not involved with the team process and the care planning process and health wishes from the beginning. I won't say that we achieved 100% performance and no similar problems ever again occurred, but we learned to highlight these issues. This family saw the disaster that resulted from a younger generation member (Eu) whose emotions complicated their relationship to the health care team they depended upon. They were not willing to confront their niece at the early stages when it was her own mother who lived in her

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home, and who was at the center stage. At that point their familial loyalty forced them to do things they might not have wanted to do or say. However, by the second instance they did realize the need to surround Eu with support and love and to be able to blunt her initially inconsolable emotions.

I, myself, spent the best years of my medical career learning about life and death and about the lives, families and histories of disabled elders in our communities. Even if I should get dementia before I pass out of this world myself I'll probably never forget Christine and Helen. Nor will I forget the phone call from the anesthesiologist asking me if she can leave her unconscious patient (and mine) to go to a dental appointment. And the non assertive answer I gave in which, without understanding it, I compromised my own values.

Weighing Fred Lee affirmed the quality of his life

Thomas Irungu is, as of this writing, a practicing physician on the East Coast. He was originally trained in his native Kenya. He emigrated to the United States with the intention of gaining licensure here. This required him to complete (once again) a medical residency and take the FLEX and other exams required of foreign graduates. When I met Thomas he was a quiet, friendly and mature man, working as a day center worker at the Center for Elders' Independence. He had no medical responsibilities then and it's only because I got to talking with him that his medical background came out. I don't know if other staff were aware that he was already a practicing physician in Kenya. But he was very conscientious in his work with elders. When I learned about his background directly from Thomas, I had him moved--with his enthusiastic agreement--to work as a medical assistant in the clinic. There he not only functioned as an assistant but regularly performed medical evaluations of our patients which we reviewed together. Some years later Thomas applied and was accepted to a medical residency in a teaching hospital in New York City. He married and stole off to NYC with one of our valuable lead nurses. Although he later came to dinner at my mother's home in Yonkers once when I was visiting, I've lost touch with Thomas and so never met his children. He rose to chief resident during his residency and then upon completion moved to Minnesota to work at the Mayo Clinic. He spent some time practicing in Oregon then moved his family South to Virginia, where he worked in Public Health.

During the 1990s, Center for Elders' Independence produced a small book

(about 80 pages) of writings—essays, poetry, reminiscences—by staff and elders themselves at our program. It was entitled: Keeping PACE. Thomas submitted the following brief piece about, Fred Lee, which was included in the collection. Thomas' description of Fred Lee perfectly captures the spirit of Fred Lee. It was originally formatted as a poem in blank verse, but I reproduce here in prose style.

“You can make it if you try.” Simple but profound axiom. Mr. Lee not only verbalized it...and quite frequently, but he lived it every day. Mr Fred Lee tried, Mr Lee made it. “It is hard to try” he later added. And how true! It wasn’t an easy road, but “you can make it if you try.” One of the few clients who lived with his mother. The only client in the Center with a G-tube, yet he walked tall and made his presence felt. Hey! Hey! Hey! HI DOC! As if saying: “Don’t pass me by!” “I am here”, “I exist.” In other words, I am here because I am here. And even the blind and deaf among us, saw and heard Fred. “How are you doing? How do you feel?” Always interested in others, warm and outgoing, always reaching out for all of us. He touched our hands, and he touched our lives!⁴

Insert picture of Fred Lee and day center worker here.

Fred was a member of the pre-existing Community Adult Day Health Center in Oakland, California and joined CEI's PACE program at the time we became funded by our Medicaid waiver on July 1, 1992. He died there in the Center, by his own choice, on February 3, 1995, at the age of only 70. His experience is representative of the level of autonomy and quality of life people can achieve in a sympathetic and supportive model like PACE.

Throughout his membership at CEI, Fred lived with his mother in a two story

⁴ by Thomas Irungu, MD (from Keeping PACE)

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house not far from the Highland Hospital. He had had a stroke around 1980, a dozen years prior to entering CEI. He was cared for, sometimes by one sometimes the other, by two nephews who then became uncertified paid CEI Health Care Workers. Fred was ambulatory with a walker on entry to the program and remained ambulatory until the last weeks of his life despite progressive slowing. On entry Fred Lee's Mental State (MMSE) score of 19 reflected a moderate dementia, but he was remarkably stable, intact, friendly, positive and interactive. His geriatric depression score was 2 (5 or higher suggests depression). His medical history included weakness on one side as well as difficulty forming his words and poor swallowing--all this the result of his stroke. He also had a seizure disorder related to either the stroke or possibly his history of alcoholism. And additionally he had a large uncomfortable scrotal hernia, urinary incontinence, a history of aspiration pneumonias due to his swallowing problem, anemia of chronic disease, high blood pressure, a past history of bilateral hip pins, and an aortic aneurysm.

Fred was divorced, had 2 adult sons and 2 adult daughters and a large extended family. (Incidentally, having attended many of the funerals of our participants I was surprised by the huge throng of family and friends attending Fred's--well over a hundred people; retrospectively it fit the personality of a man who, though severely debilitated, always greeted staff and participants daily with his friendly "how are you doin today?").

Fred's weight on entry to CEI was only 102 pounds. His weight at his final quarterly evaluation on November 19, 1994 was a remarkable 133 pounds (a thirty percent increase). As an objective indicator of the level of continuity of care and

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intensity that we were able to provide participants, Fred's weight was recorded 117 times at CEI in the interval between those two measurements—an interval of under two and half years; this incredible watchfulness regarding Fred's weight reflected a unique part of Fred's ongoing care plan. Obviously our team was very concerned with his swallowing dysfunction and progressive debilitation.

On July 6, 1992 just 5 days after CEI began Medicaid capitation, Fred was 911d to the County Hospital in "status epilepticus" (continuous seizures that do not abate). His mother had called our number for help but when she did not get a rapid response from staff she called 911 and so he ended up at Highland Hospital under good care, but not under our care. Being a teaching hospital, Highland had not figured out how to allow outside physicians to follow their own in-patients. The nurse practitioner and I visited Fred in the hospital; he was stuporous ("post-ictal) for a prolonged period. We explained our program to the medical residents to expedite his release and he was discharged, alert three days later, on July 9 to our care. A home visit by our nurses led to a special mattress and bedside commode. Our Physical Therapist provided an upgraded walker and a program to increase stamina lost in hospitalization. Fred's first health care wishes were obtained a month later in August and were Do Not Resuscitate me when my heart stops. A feeding tube was not yet discussed.

By his third quarterly evaluation 6 months later in December, 1992, Fred had lost more weight--7 pounds, down to 96 pounds; he also had increasing fatigue and worsening pain in hips and knees. He verbalized despair, and had fairly frequent, though isolated, seizures. OT (occupational therapy) at CEI put him in a swallowing

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group, home health added Ensure supplements and we consulted our team nutritionist. The nurses consulted closely with family regarding home nutrition and medications-- there had been concerns by some staff regarding caregiver medication non-compliance with fluctuating blood Dilantin⁵ levels that had contributed to earlier admissions for seizures. Fred had a medical evaluation of a positive TB (tuberculosis) skin test and some changes on his chest x-ray, but he did not have TB. The changes were due to recurring small aspiration pneumonias from his swallowing problem with some residual scars in his lungs.

Fred continued to decline and had lost weight down to 85 pounds when--on January 21, 1993-- the clinic received a call from his mother that he could not eat or swallow at all and was too weak to get out of bed unassisted. The social worker and I went to the home and held a family conference with Fred, his mother and others. Given the option of a feeding tube or dehydration and death, Fred was very specific: "I want to live" he said. "Give me the stomach tube". During a one week admission to a different hospital where we, by that time, cared for our own patients, Fred's tube was placed but his hospital course was complicated by a yeast infection in his esophagus, pneumonia, Dilantin toxicity, and worsening anemia. After that week he was stable, so Fred was transferred to the Hospital's acute rehab unit for reconditioning. With CEI less than a year old and still not capitated by Medicare for some of our services, we did not yet have the staffing level to provide full acute rehab services, but, lacking that capitation, standard Medicare would still pay for these services at the hospital. Fred was

⁵ His seizure medicine.

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discharged from acute rehab with his gastrostomy stomach tube on February 17, 1993 with the recommendation by hospital rehab staff that he not be allowed anything by mouth except during swallowing therapy by our OT/PT staff.

At this point a debate ensued in our interdisciplinary team, consisting of over 15 staff people at morning meeting, as to whether or not to permit Fred, who wanted to, to eat. Because of his mental slowing and poor swallowing function, OT was interested in working with Fred regularly for training, but keeping him otherwise NPO (“nothing by mouth”). His nephews were trained by OT in swallowing assistance for small amounts, yet they were advised that he not be allowed to eat independently.

But Fred became increasingly more depressed and resistant to help from caregivers; he had insomnia and sat around the Day Center lethargic, looking very sad. Then we learned from his family that he was sneaking downstairs at home late at night to eat from the refrigerator when everyone was asleep. We tried him on medicine for his depression. A couple of weeks later, on March 23, Fred complained to his social worker that one care-giver nephew in particular would not let him eat anything and just bossed him around in general. He was clearly feeling a loss of autonomy as a cause of his depression. Perhaps he was also wondering why he had to work so hard and be babied by our occupational therapist for just a few spoons of apple sauce.

You could understand Fred's feelings of loss of control just by the smile and the glint in his eye when you mentioned his sneaking food at home. Fred's social worker continued to document and bring to team confrontations between Fred and the nephew over control of many aspects of Fred's life, such as diapering and incontinence, not just

food.

We decided to present Fred's situation to our Ethics Committee and after that a family meeting was convened with social work, medicine, nursing and OT to focus on the importance of Fred's autonomy and the team recommendation that care givers allow him to choose some relatively safe food to eat each day and not be locked out of the kitchen, or otherwise harassed in other areas of life. The home situation improved somewhat, and so did Fred's affect. But, despite the team recommendation, he was nonetheless kept NPO in the Center and at home until May 11 when the team--after repeated discussion---now decided to accept the risk of providing a complete pureed lunch once a week under occupational therapy supervision. This was achieved, and Fred's attitude, affect, and food intake improved dramatically with time.

Over the next year and a half Fred had intermittent medical problems including several further episodes of minor aspiration pneumonia treated with outpatient intravenous and oral antibiotics, dehydration secondary to poor home health worker compliance with his tube feeding, and a urinary tract infection. But Fred remained out of hospital and his quality of life and affect improved progressively, reflected in the impressive weight gain mentioned earlier.

Fred had successfully adapted to a more dependent life precisely because people were allowing him more autonomy, more choices, and a level of aspiration risk-taking that would probably not be acceptable to many non-PACE professionals in other medical settings. The hospital rehab department had advised against it. As he gained progressively more weight, Fred gained progressively more authority and self-

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monitoring over his oral intake. Having achieved some control over his eating, Fred's oral intake then declined voluntarily, but his weight did not decline. We continued to monitor and counsel repeated confrontations in the home between Fred Lee and his over controlling nephew. His family even tried to prevent him from going out and sitting on the front porch fearing he might fall down the steps. But we defended Fred's right to sit on the porch. They could help him.

In June, 1994 Fred's quarterly evaluation reflected 3 team problems: 1) limited communication skills (due to his mild expressive aphasia) impacting his socialization as his dementia worsened, 2) incontinence and the need to respect and be sensitive to his autonomy in this area, and 3) medication non-compliance, a caregiver issue. Fred was added to a communications group at the Center; the family, and health workers were again counseled to not be so controlling.

In December, 1994 Fred did fall on his front steps and was having trouble with weight bearing bilaterally. X-rays showed a break in his old left hip plate but most pain was on the right, with degenerative changes. He resumed ambulation, though not without difficulty. On January 17, 1995 he simultaneously developed dehydration, aspiration pneumonia and some GI (intestinal) bleeding with distention and tenderness and was hospitalized, very ill. Fred received antibiotics, blood transfusion. Endoscopy showed a recurrence of severe erosive esophagitis and an ulcer. Coincidentally, while hospitalized a small nick between two toes developed into a localized abscess that was drained. After a 6 day hospitalization Fred was discharged to the Center on January 23rd on high doses of oral antibiotics, but appearing stable.

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Nevertheless, 3 days later he developed GI symptoms with vomiting and diarrhea, worsening anemia and his white blood count was again elevated. The possibility of sepsis (blood poisoning) from his toe was entertained but rehospitalization was against his wishes and so seemed inappropriate. He then received an outpatient blood transfusion and was evaluated by the vascular surgeon as he had now developed an extensive blood clot in a leg vein and he had no blood pressure at the toes indicating a threatening arterial occlusion. The entire leg was tender. Fred's pain worsened over night and then his leg became cold with decreased sensation, a menacing sign indicating complete loss of blood circulation in the leg. He was unable to move the foot or ankle. Amputation was presented to him as potentially life-saving. Fred was clear minded at this time, but he adamantly refused even if he would die. He also refused further hospitalization, asked to live at home and to keep coming into the center daily until he died.

The next morning after arriving at the Center he appeared near death. I called his mother and explained he was in critical condition and asked the family to come in quickly. When the family arrived we explained his stated wishes to die without further interventions. Shortly, Fred had a cardiac arrest in the next room and the nurses called us to allow his family to be with him. Fred died according to his own wishes. By asserting himself under very difficult conditions and situations throughout the last year or so of his life Fred Lee had maintained his social relationships to his comrades in the day center and to staff. He had achieved a good quality of life and physical well-being in his last years that restored his happiness and contentment.

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Fred so well embodied the principle that autonomy, enhanced by good guidance and some risk taking, is achievable even in unforgiving circumstances, and is the hallmark of quality of life, particularly for the disabled, whether living or dying. Fred taught us a lot about that.

The indomitable spirit of Merion R.

Before 1992 when she joined the Center for Elders' Independence, Merion had survived several strokes impacting both sides of her body, but not her speech. She had recovered a lot of function, including walking. She walked with a cane and had a limp, but Merion was a gamer. Predating her strokes she had glasses so thick that you might feel you were peering into a fish bowl when you explored her face and her ever present smile. Merion worked out in physical therapy with Nettie, the PT aid and Susan Musicant, the therapist, every day she attended the Center. She got OT help also. Merion was a friendly, smiling and solicitous woman, about 80 years old. She was African American with a rounded face and light complexion. Like Fred Lee, she thanked people sincerely for their assistance or, sometime, just for being there and interacting. She was also keen on sharing stories of her life.

As late as 2001, her x-husband, despite many years of separation, would still occasionally drive to Oakland from out of state to visit her. They'd sit in the center talking about old times and how things had been going.

In 1994, Merion suffered a new stroke that did her a lot of damage to her brain. Not only was one side of her body paralyzed again but her mind and her already poor vision were affected. She suffered a terrible feeling of dislocation, confusion and loss that made her extremely anxious. She could still speak, but wasn't seeing clearly

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because she had a visual field loss, called a hemianopsia⁶, which blinded her vision to one side. That is she could see out of both eyes, but she could not see anything to the right with either of them. On top of her severe myopia this caused her severe mental confusion. Confused, Merion couldn't stand to be left alone.

For the first few weeks after the stroke Merion would scream or yell almost continuously when she attended the Day Center while belted in a wheelchair or geri chair for safety. The screaming might be best described as shrieking. Other times she was calling out for Nettie or nurses to come and help her; "Nurse, Nurse, Nurse, Nettie, Nettie". The shrieking was particularly disconcerting for it seemed she was in great distress. She could usually be calmed with soothing voices and touch but only for a minute or so. We could not leave her alone.

Merion could not be brought into group settings either. The impact on other participants and staff at CEI was dramatic and disruptive. Some participants in particular became very aversive and upset. They demanded that something be done. So Merion had to be put in a room to scream where she would not disrupt the activities program and upset other participants. And during this period of time—a time that she was staying at a nursing home and coming to the day center from there--a few participants even threatened that they might hurt her.

Of course, the team was deeply concerned and trying to figure out how to deal with this problem. We tried drugs like Ativan and other benzodiazepines (the Valium

⁶ A homonymous hemianopsia is a loss of vision to one side or quadrant of the visual field that affects both eyes. People can adapt to this loss but there is a tendency to walk into things and ignore potential dangers because one sees nothing in that direction unless the eyes are turned far to that side allowing the good side to received input.

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family of anti-anxiety medications). They helped very little. We gave strong pain medications, narcotics; these seemed to worsen her confusion.

At that particular time I was reading a marvelous book by the self cured autistic writer and expert on autism and animal behavior, Temple Grandon. Temple had realized from her own crises that she needed to be held--cocooned; that tactile surround warmth, touch, and control were soothing to her when her world was fearful and inchoate. She had designed equipment for herself that had effectively calmed her, by physically surrounding and "hugging" her. Later, in her study of animal behavior she had also noted how distraught cattle going to slaughter became. She designed similar apparatus for cattle that would gently squeeze, pressure and touch all around and control an animal, prevent movement, without any pain or distress.

Reading Temple's work I wondered if this had ever been tried on someone with emotional confusion like Merion's, which had apparently resulted from a stroke disrupting her brain function. And so I called Temple Grandon at Colorado State University in Colorado Springs where she taught and did research. To my surprise, she herself answered the phone directly. In response to my question she told me how costly and how much time it would take to buy, build or otherwise obtain such an apparatus. She didn't think it was the thing to try first. Instead she recommended that we try valproic acid, an anti-convulsant that came into wider use as a "mood stabilizer" in the 80s and 90s, impressing me with her knowledge of medicine and pharmacology. Our consulting psychiatrist, Bob Dolgoff, agreed with her suggestion and so we added valproate to her medications while Staff continued to have to stay with her.

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Within a day or two Merion's calm and friendly former self reappeared, as if magically. It was a dramatic and joyful event for all involved, especially for Merion. I am reminded of Oliver Sacks' book *Awakenings* and the sudden impact of levodopa/carbidopa (Sinemet) on the elderly nursing home patients who had been in a state of suspended animation from the 1919 post influenza encephalitis lethargica epidemic. Merion's change seemed that dramatic.

In subsequent years Merion suffered still more strokes, yet her emotional stability and her friendliness and positive outlook remained intact. Despite difficulty using her hands and arms and no return of her walking, she still was able to learn to feed herself with specially designed implements.

Besides my fond memories of Merion's beaming eyes through her thick lenses and her voice which I can conjure even decades later, I think that her's is a story that describes the difference between a health care system designed to invest time and resources in finding creative responses to solve unique problems and one that relies more on efficiency and algorithms. The U.S. health care system was consciously dragged down into the stock market economy beginning in the Nixon years leading to the imposition of cost-based efficiency algorithms. What the changes did was create an environment where good doctors often have trouble practicing good medicine. The data provides evidence that the PACE model in which an interdisciplinary team of health workers look at problems globally and integrates quality of life and non-medical support with medical care, actually costs no more than standard care of the disabled elderly. Nevertheless, no insurers—other than government based Medicare and Medicaid—

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have been willing to include it as a benefit these past 37 years since its inception. Most “private” doctors are now practicing in groups “owned” by insurers, hospital chains or other corporate forces. Now doctors divide their limited time and attention between their patients and billing problems, fighting insurers to overturn denials of care and payment, complex computer programs, and assuring standardized algorithms for diagnosis and treatment that tend to downplay the inevitable differences between the needs of two people with the same symptoms or the same disease.

The “better” record keeping that was promised by computerization remains in great measure an unfulfilled promise since many of the proprietary computer programs are designed to prevent cross communication with each other. As well, computerized output reports, though containing valuable information, make people look more similar than unique. We are actually both, of course. But teasing out the details of how we are different is a major part of good care. And so reading someone’s computer chart often hides the particular unique qualities of individual patients.

Today, most patient care involves a 10 minute visit and nothing close to an interdisciplinary team approach in which the goal is to understand or respond to the complex social and environmental forces impinging upon the function and health of the individual recipient of care. There is very little room in today’s US health care “system” to assure the quality of life of someone like Merion—or most of the others I write about in these essays. Merion thrived at CEI through her travails because she had been integrated into a larger community of concerned staff, family and other participants--a community and a health care team with its own well codified culture of caring.

Live Theatre and a Heavenly Choir

inspired disabled elders win State Award--Under the direction of Jackie, Dino, and Lillian

Peter Szutu , executive director of the Center for Elders' Independence (1993-2014), told the story of Morris, one of the members of CEI. Morris was a depressed man, a diabetic, a friendly man, but seeming to us a loner—withdrawn and quiet, a fellow who could not overcome his sadness. Morris, who died many years ago, had an elder brother in the program who outlived him. Indeed, his brother lived past 100 years of age. For reasons they wouldn't talk about with us there was such bitter anger between the brothers that they explicitly chose not to attend the Day Center on the same days. They hadn't been talking to each other in years. According to Morris, this ongoing enmity wasn't his choice. Peter was interested and got to know Morris. He discovered that Morris was a jazz aficionado and a disco jockey as well. He learned that, underneath the outward sadness, Morris was not quite the introvert we thought him.

Peter coaxed Morris, who was not reluctant, into disc jockeying jazz shows and telling tales. Morris did a strong job at both for CEI participants; and then he started appearing at other senior centers in the community. Morris was such a good disc jockey and story teller that his dramatic transformation lit up CEI's young activities directors, Jackie and Dino. They decided to form a theater group—CEI Live. And that theater group gave Lillian, a lead day center worker and activities staffer the inspiration

to form the Heavenly Choir—all to be made up of disabled elder members of CEI.⁷ -I'll fly away-

Jackie is South African. I don't know where she and Dino met up or how they became a couple, but they were a great team as the activities staff leadership for the first CEI center and obviously much in love—and soon to marry. They sought challenges and their enthusiasm for working with the elders was boundless. Both of them were studying to become licensed psychotherapists. They exuded fun, joy, warmth. In their late 20s to early thirties both handsome, quick minded, and agile, they were like the squirrels that Barbara F. loved to watch playing out her window. They often made fun of themselves too but they were exceedingly competent and good at running the activities program. At one point Jackie, without telling the team or Peter, organized an awards festival for clients, family and staff. (I still have a little gold statuette and a Goofy doll, the awards they gave each staff member). Before Peter found out about this event, Jackie had already invited the entire staff of the County Hospital to join in. She turned it into a happening—a major event in the Hospital's main auditorium. Her successes and leadership abilities led Peter to appoint her as the coordinator for the complex opening of a new center in downtown Oakland, dividing client populations and staff in half. Unsurprisingly she did a fine professional job. The second center opened with only minor hitches.

Dino's concern for the people he worked with (both participants and staff) was obvious. Moreover, he was not afraid to argue his points in team meetings. (Like his

⁷ Lillian Stoval is one of the “Stoval Sisters” who sang back up behind Ike and Tina Turner and other Motown fames. Their lives were like those of the back up singers portrayed in the film “20 Feet from Stardom.” The three sisters all worked for CEI over the years. Nettie and Lillian were among the long time CEI staff still there when I left.

-I'll fly away-

Medical Director) Dino had strong opinions about many things he thought belonged in his realm of understanding. After all, he was a budding therapist and great student of life and human behavior, though occasionally others did not fully agree with that assessment.

One day, I walked into early morning briefing to find Dino holding a quart bottle of a green slime with a fancy label he was trying to sell staff members. He represented the slime as having almost uncountable health benefits. He swore this algae was bottled in Siberia and would cure most anything and everything that ails. There he was, actually selling the slime to fellow team members, though there was no way to know what was in the bottles. I can't say how many staff people he got to buy and drink the green slime, but he was seriously hoping to turn it into a commercial venture. At that moment I wanted to run him out of town, but, really, the scene was comical. I'm sure we banned his snake oil cure-all effort just as we had done with the pharmaceutical drug reps that invade clinics and doctors offices like yellow jackets, passing out their endless promotions, gifts, freebees, and article reprints that "prove" how invaluable their company's products are. Later, when Dino and Jackie were to move to Hawaii I sang a satirical green slime song (that I composed) at their farewell party.

Jackie and Dino (eventually with the help of Shefa and AJ, newly added activities staff) organized the CEI Live theater project into a functioning theater group among the elders. CEI Live created and performed vignettes from the life histories of the program participants. By the time CEI Live was up and running CEI had two centers, and theater group members (including some of the very disabled) were

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shuttling back and forth by CEI's pastel shaded transportation buses to make rehearsals—quite an added challenge for the transportation team. In tandem with the theater group, Lilian and the Highland (first site) activities staff had formed a gospel choir with some of the most beautiful and practiced voices of elders, even including participants with Alzheimer's dementia (who often retain their memory of songs—see the story of Almost in this book). The choir's music was integrated into the theater group's performances--Lilian reliving her Motown heyday in a sense. As noted, she and the two of her sisters had performed as background singers for Ike and Tina Turner when they were young under their true maiden name--the Stoval Sisters. Many years later, watching the film 20 Feet from Stardom I realized what a hard life with little public recognition and inadequate compensation that must have been for the three then-young women.

* * *

The impact that working in real theater had upon elders who had become accustomed to the feel of total dependency was obvious to any observer. For most, the effect was dramatic, livening—certainly more livening than any green slime might have been. But satisfaction wasn't the outcome for everyone. One of CEI's participants, who I will call Stevie (not his real name), was a talker and a tale teller. Invited into the theater group he became enthusiastic and successful. The effort fit his garrulousness. But he didn't stay high on his personal successes in this endeavor as long as others did.

Stevie was a street cat, a hustler type guy, who had never taken good care of

himself. I don't recall if he'd done or sold any drugs (probably not), but alcohol was his problem. At CEI he replaced his sadness about his serious disabilities with macho talk. Not mean tough macho, but just a pretense to being both cool and able to handle his affairs. Stevie was pleasant enough, a real nice guy, but his façade of being in control of himself was just that—a façade to hide his sense of loss and his extreme dependency.

In the real world Stevie was a screw up. He had serious and poorly controlled diabetes which he did not manage well because of his drinking—which continued; the combination of alcohol and diabetes had led to bilateral lower extremity amputations and he had terrible extreme tremors from his alcoholic brain damage; and he had contractures of his fingers and hands so between contractures and tremors he could barely use them. If you met Stevie you wouldn't know how bad off he was unless you hung around him a while, but he could do almost nothing for himself beyond eating and even that was very difficult. He could only feed himself with specially designed utensils because of his severe tremors and hand contractures. He had difficulty both grasping and then keeping a grip on a fork or spoon.

On the one hand Stevie sort of pulled off his macho cover quite well. And people accepted him. His friends on the street, at the bar and where he almost lived, took him in stride. They inevitably learned that he was extremely dependent but most people gave him the space and support he needed to help him feel accepted. The trouble was that Stevie knew the truth and he didn't believe in himself, so he always over inflated himself. He wanted comfort; was desperate for companionship; And there was no

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doubt that he hated his dependency. He didn't want to be who he had become because of his physically compromised life on the one hand, but perhaps more importantly he was, inside, particularly unhappy because he was unable to change the life behaviors that caused and worsened his dependency. Which is to say he was addicted to hopelessness and his own impotence.

Still Stevie did make some small efforts to challenge his dependence and his life with us was more than interesting enough for me to write another essay devoted to him later in the book.

Despite the reality that Stevie could do almost nothing for himself, Jackie and Dino did successfully enlist him into the CEI Live theater group. He did have his unique voice and dramatic tales after all. They made him the star of his own story and, as well, an actor in the dramatization of the lives of others too. Stevie did well on stage and before audiences—he was persuasive, somewhat charismatic and had that good voice. Audiences were enthusiastic. He played his parts with feeling. For a moment in time it seemed like a real study in achieving autonomy. On stage, Stevie got to brag about his days as a pool hall hustler; he claimed that he had once beaten Minnesota Fats. And then he faltered.

It was not enough. Stevie lost interest and quit the group without explanation. He circled his wagons again, spent his time with his small group of friends at the bar down the street. That's where Stevie felt most secure, independent, and supported. To us outsiders Stevie seemed to have achieved something really tangible with his acting, yet to him the rewards couldn't overcome the rest of his life's baggage despite the

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staff's encouragement. Life at CEI, a disabled community, inevitably vivified his actual dependency.

However, Stevie didn't quit CEI live before the Theater group and the Choir had achieved great acclaim. Stevie didn't quit before they got to travel all over the Bay Area to other programs, churches, schools, senior centers to perform and answer questions about their lives and their theater work for awed audiences. Nor before they filmed their performance, submitted the film and won the State of California's best practices award for an activities program in long term care. An awards ceremony took place in San Diego and the award plaque sat in Peter Szutu's office for many years. When I first drafted this essay in 2002, Stevie was still alive hanging at the bar and complaining to all listeners that the home care workers and home nurses who, in the real world, did have to do everything for him to keep him alive and functioning, didn't respect him enough.

At the time of my retirement, Stevie was still grumbling and grouching about why should he have to be back to his apartment by a certain hour, like 9 or 10 p.m. for them to do their jobs cleaning him up and getting him into bed. He seemed to blame them for his lack of autonomy. But at the same time you could sense his gratitude somewhere beneath this. He knew that he needed CEI and he knew that there were people, at the bar, at the Center and in his life who cared enough to assure he could keep going on without judging him for the things he did or had done or had failed to do that got him into his totally compromised state of affairs. He knew and felt these things well enough to

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not hurt himself intentionally at a time when despair might cause many elders to seek the comfort of death.

Unfortunately, by the time that CEI live toured the Bay Area and won that award, Morris, the inspiration for the theater group, was not alive to witness what his awakening had brought forth from the minds and the hands of Shefa and Dino and his fellow participants.

Cornelio's chosen death

Just let me die, Cornelio told me. He didn't mean if/when his heart stopped. He meant that he wanted to die now, period! In my mind's eye I can see Cornelio sitting on the bank of a slough northwest of Tracy and west of Stockton in the Sacramento River delta. The wind was howling, cold. We've gone out on a fishing trip. There are 4 other CEI participants. The only fishing trip (out of many I'd led for CEI participants) that ventured out beyond the Bay Area's eastern mountain barrier, over the two passes and into the vast central San Joaquin-Sacramento valley. Mattie, who used to fish every weekend with her husband before he died and loves the delta, is there. And my stepson Shep and his son Jon are there, rolling down from Winters to join us with their companionship. But the wind is nasty in gusts to 35 or 40 mph, winter cold, though it's still autumn, blowing sand and dust in our eyes and making the event less than idyllic. Not only that, we catch nary a single catfish, nor a bass nor anything else either. But still it was fishing and that's more than just something to do for the elders—and for me as well.

And I can see Cornelio, a chunky good looking Mexican-American man, not at all withered and wrinkled, sitting there by the slough in a portable aluminum chair enjoying the end of his life and knowing that he is dying for refusing to do anything about it; except welcoming death, wanting death. For he knows there is something he could do to stay alive. Despite his disabilities, Cornelio does not have a terminal illness. He can just say yes and we will put him back on kidney (renal) dialysis a few days a week and

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he will regain strength, come back to life and live and live, maybe 10 or 20 years or 30 years or more. But Cornelio says no. Emphatically, no! Nonetheless, he is content to ride out with me into the delta (if only he hadn't gotten nauseated) and sit on the bank quietly, speak a few words, in Spanish, and feel the cool breeze and act like it's all ok and this is the way it should be.

Cornelio wants to be with his wife. And he cannot listen to his two grown children, a daughter 22 with her infant, nor the son in his mid-20s who need him, who love him, who, desperate, can't bear the thought of him following their mother to the grave. But Cornelio is determined and obstinate. He cannot hear them though his ears hear their words; he cannot listen to anyone about this dialysis; not to his kids, not to me, not to the social worker, the therapists, the home care nurse, the other doctor, not to anyone. Maybe we didn't talk to him right.

They say that suicide is quite prevalent among the elderly. But elders, I found, are usually very discreet, probably more determined and successful about their suicides than younger folks. To my knowledge we never ever found a single person's death at Center for Elders' Independence to have been the result of suicide. How is that possible given the national statistics of suicide in the elderly? It seems that out of close to 200 deaths in our program during my tenure there, we would have noticed an occasional suicide. Were we doing such a great job that the idea was banished from the minds of the elders? I think maybe we just tried to not notice; or didn't want to notice because of how hard we worked to help maintain quality of life for our participants. Maybe the positive environment engaged the disabled elders enough that

they felt less alone. But still, it seems unlikely there were no suicides.

Regardless, this question arises: did Cornelio commit suicide in his slow death enactment? The concept of suicide doesn't seem to fit this picture. Who ever heard of suicide by degrees, an act lasting 6 months. That can't be called suicide, can it? Suicide seems the wrong word, the wrong language to describe this.

And indeed the problem with Cornelio wasn't so simple. Sure he was depressed for having lost his wife, but his single mindedness and determination were somehow beyond the lassitude of depression--impregnable and related in part to how the loss of his wife was married to his own becoming very ill. We took the case to our Ethics Committee for discussion and recommendation. I'm reproducing some of the case write-up which I think reveals Cornelio to be a most interesting man.

March 95: Ethics Committee Case

"C. is a 71 year old Mexican born participant. He had recently suffered the sudden death of his wife due to a stroke. He found her dead himself. Subsequently, in a matter of days or weeks, he himself suffered a brain hemorrhage requiring extended rehabilitation and leaving him with severe chronic dizziness and instability of gait and a risk of falling. He then joined CEI and we found he also had chronic renal failure from Diabetes. He had been told while in rehab from his stroke that he might well need dialysis in the near future.

"C. lives in his own home with his 22 year old daughter and infant grandchild. An older son also lives at his home. Due to his disability and grieving there has been a dramatic role reversal between him and the daughter who tries with much difficulty to play the role of responsible caregiver. She works outside the home and has a taxing schedule. C. –still the father in his own mind--resists being the care-receiver, viewing the daughter's role as compromising his autonomy and parental authority. He does not state this overtly, but often refuses her assistance and does not cooperate with her guidance, though she is very attentive, helpful and in no way resentful of her role.

“C. entered CEI with some enthusiasm for the project but also with acute depression. He is somewhat handicapped by limitation of his English and he feels embarrassed by his compromised language skills as he has lived in California most of his life. These pre-existing feelings, increase his tendency to withdraw. However, he has many hobbies in the areas of arts and crafts, sketching, drawing and painting caricatures at the Center. He is a remarkably adept portrait artist. He is a practiced handyman having all his own power tools and building his own home addition. He also repairs things like TVs, radios and other electrical equipment. He worked many years for PG&E (Pacific Gas and Electric). He also appears to have good social skills.

“With increasing nausea, vomiting, weight loss and some mild dehydration a dialysis shunt was surgically placed late in February. He required initiation of dialysis soon thereafter. Although initially receptive of the need for dialysis he became resistant to dialysis one week after it was started, telling various professional staff that he would allow no more than once a week dialysis, and later telling the physician once a month. It has been repeatedly explained to C. that the dialysis is required to maintain his life. In response to pressure from physicians he has resorted to the position that the dialysis is making him worse and is the cause of nausea and also that dialysis may be putting poisons (like bleach used to clean the lines) into his body, although he smiles when he says this. Objectively, even with just one week of dialysis he became stronger with better appetite and less vomiting and weight loss.

“The consulting psychiatrist agreed that the client is very depressed and should be treated. But despite anti-depressants he continued to demonstrate a laconic melancholia. He denies any suicidal plans or ideations, but expresses the view that life is just not worth it when one has to suffer these things--mainly the sudden death of his wife. He says he is prepared to go to join her, that God will take him when it is appropriate and that the dialysis seems superfluous.

“A few days ago in a discussion with his physician, Cornelio responded positively to an invitation to go fishing although he has not been fishing since childhood. He also invited the physician to join him and his family when he cooks carne asada next year on the anniversary of his wife's passing. This kindly gesture seems a paradox--at odds with his determination to refuse treatment for kidney failure and planning to die.

“The ethical dilemma facing the CEI team is what to do if the client digs his heels in and continues to refuse dialysis. “Some team members believe that the man has a right to refuse any and all treatment. But when people are motivated by a depressed state they are considered to be a potential danger to themselves and not free to make such choices. Also Cornelio seems inured to the feelings of his children who live with him. Should the team and physician support the man's right to refuse treatment even in the face of his depression and grief?”

Actually our choices in the real world were seriously limited. We were not going to imprison or otherwise institutionalize Cornelio and force dialysis on him. We were just looking for a way to help him identify life as a more meaningful choice than death by intention.

Cornelio died within a couple of months. For me, the most difficult part of his demise was witnessing the despair that Cornelio inflicted upon his children, they being unable to convince him to want to live. He had become incapable of seeing the torture to which he submitted his own children. Despite being a fairly “traditional” Mexican man Cornelio had lost the ability to appreciate what he was putting them, his only remaining family, through in the face of his personal losses—of his wife, his balance, and the debilitating effects of kidney failure and dialysis. Cornelio died a chosen death, but he left his despair quite alive in others in his wake.⁸ Only later did I realize that we did have a choice and had failed to recognize it. Our main responsibility to Cornelio, given his intransigence, was to help his daughter and son understand that they had to honor his choice and allow him that degree of freedom and autonomy. Had we done so perhaps his death would have been less traumatic for them both. But that is an unsolvable mystery.

⁸ Like Cornelio, an old family friend of my parents, William (Bill) Silversman, a neonatologist who created the first premature neo-natal ICU at Columbia Presbyterian Hospital in New York, was a Pediatrics Professor and later became an ethicist who wrote a regular column on medical ethics in a major pediatric journal, also rejected renal dialysis (thus allowing his own preventable death). Bill, however, was well up into his mid-late 80s. His sudden kidney failure was a burden on him and his family that he, like Cornelio, did not find bearable. The difference, in Bill's case, was that he discussed his feelings and his wishes fully with his children and wife and gained their acceptance of his choice. I should have helped Cornelio to do the same. Bill continued to write his regular Pediatric Journal ethics column up until his death. He died peacefully at home with family in attendance. I now believe that, in the face of Cornelio's intransigence, my focus—our team focus--ought to have been convincing the children to let him decide.

-I'll fly away-

Probably put in a picture from fishing trip at Chabot with caption that this is a different fishing trip from the one described. But include the author—the white guy—and the transportation director—Paul Johnson.

End Stage Dementia and the apparent Miracle of Stability

These days, what adult American isn't worried about Alzheimer's Dementia? The thought of losing one's mind, one's orientation and grip on life terrifies some folks as much as fears of terrorism. People search for pills, diets, exercise regimens, other behaviors, herbs, anything that will lessen the odds of becoming mentally compromised by dementia. The anxiety over dementia approaches hysteria in some settings. The Pharmaceutical giants smack their lips, for they have come up with a class of drugs (a type of cholinesterase inhibitors) that forestalls the cognitive decline in primary dementia.....but only for a short while—about 6 months. These drugs cost thousands upon thousands per year, but many doctors are willing to hand them out to worried adult children whose parents have begun to slide down the cognitive slope.

However, amidst the fear of mental decline certain important details get lost. First, as many as 45% of people who test + for some degree of cognitive loss have a form of dementia that results from multiple small strokes (Multi-infarct dementia--MID). MID plateaus; it may not progress. Yet, these patients may not show other stroke signs like paralysis or weakness in which case they are hard to distinguish. Unless the patient

suffers repeated new strokes, the MID dementia can remain stable rather than progressive. When stable, these patients are usually not at risk for severe agitation and ever worsening confusion and dependency. They are easier to manage and they suffer less mental anguish.

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Secondly, all Alzheimer type dementia patients do not go through the same trajectory. At an early point in dementia when people still retain substantial cognitive ability and awareness many demented become painfully aware that they are losing their mind. Two factors determine the way people react to this awareness--their underlying personalities and the extent to which the frontal lobe is isolated from the rest of the brain probably determine how agitated and for how long a period of time a dementing person will become/be agitated before they pass into a stage of relative unawareness of their actual state.

Certainly, stopping, reversing and preventing dementia are worthy research goals, but in the short term doctors and families greatest need is for an effective drug to help the frightened, anxious and disoriented dementia sufferer who is aware enough to be terrified by their losses, as if living in a perpetual horror movie. Some Alzheimer type dementia patients go through such an extended period of agitation that they become unmanageable and die from the terror in their lives. They stop eating, can't sleep, cry out, and sometimes become aggressive, as in the story of Tom. Any drug that might lessen the anxiety and terror for this group of dementia patients is of tremendous value. For a while it seemed that several of the cholinesterase inhibitors accomplished this, but the studies no longer seem credible and in the last 5-10 years the conclusions have been challenged by new research studies. The same thing had happened with the Selective Serotonin Re-uptake Inhibitor anti-depressants (SSRIs), which were touted for a while as also useful in dementia agitation. In at least one study, demented on SSRIs died sooner.

But even in the event that some of the current drugs help a few dementia patients the problem of selecting which patients will benefit and which will not, remains. And the proposition that all, or most, dementia patients develop similar symptoms and coping problems is not so clearly established nor supported by evidence as people may think. Some people who become demented do not need anything more than supportive care; in those cases the patient doesn't really suffer. In some cases people become agitated for only a brief while—a month or so—and then become a burden only for all the direct care they need, as if they were infants. That care can be overwhelming even without agitation. Then it's their loved ones who take on most of the stress, do most of the suffering, not the patients themselves. But it is the agitated patient who presents the greatest problem, just as is the case in other mental illnesses.

Nevertheless, given a good team with adequate human resources families can support dementia patients who are not severely agitated to maintain a reasonable quality of life. Here are 3 narrative examples from CEI about participants with late stage dementia for whom the serious cognitive losses caused little suffering and their management required only a supportive and collaborative environment to keep them happy and healthy. The first story is miraculous.

Aunt Lottie's coma

Everyone at CEI knew her as Aunt Lottie because she was enrolled by her niece Nicki. And Nicki always referred to her, Catherine Paglia, as "Aunt Lottie". Lottie didn't enroll herself into CEI because she couldn't. She had late stage Alzheimer's dementia

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and knew only her own name. At first she did recognize Nicki and Nicki's partner Janice-- barely. And could say only a few sentences. Lottie was wheelchair bound, progressively incontinent and couldn't do much for herself.

Nicki and Janice had more than a sentimental attachment to Aunt Lottie because, as Nicki told us, Lottie was the only one in a traditional Italian family who did not belittle and attack her for being a lesbian. To the contrary, Lottie had loved and defended her.

When Lottie began to lose her mind and could not care for herself it was natural for Nicki to step in and tell the rest of the family that Lottie was not going to a Nursing home. Lottie, she told them, was moving out from the East to the Bay Area and would live with Nicki and Janice who would honor and support her. They had a modest but well-kept house in a relatively safe area of East Oakland. The home, on a quiet street of simple single family dwellings, had traditional contours, with a garage that had been converted into a 3rd bedroom, down one step from the living room.

Lottie was getting her medical care at the Over 60s geriatric clinic in Berkeley until Nicki decided that they needed more support than just a doctor and social worker and they found CEI. It wasn't that Nicki and Janice were looking for hospice care. They knew that Lottie was nearing the end of life and they wanted her somewhere that the transition between supporting her medically and supporting her in the dying process would be easier for them to be part of. CEI looked to them like that place. They had recently had some confusion about levels of medical intervention because Lottie had repeated urinary tract problems and urinary bleeding and had earlier had a stent (a rigid mesh tube) placed in one of her ureters to keep that kidney draining and not blocking

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off. Nicki and Janice were clear between them that given Lottie's major decline in awareness and mental abilities they did not ever again want to put her through hospitalization, or even minor surgeries or procedures. Neither did they want her to end up in a nursing home. "We realize she is near the end of life", Nicki told me "and we want basic care and treatment such as antibiotics and IV fluids if needed but nothing aggressive at all."

Because Aunt Lottie was this far advanced in her dementia and seemed to be near the end of life, her entrance was passed to me for approval before going through the team intake process. I was to determine if she might live long enough to gain benefit from the program. Nicki's approach seemed so genuinely rational and appropriate that I had no qualms about our accepting Lottie (we would not accept someone who would shortly be placed in a nursing home for the rest of their life since the goal of the program—as well as its financial structure—is to keep people out of such institutions).

At the time of her entrance Lottie could still feed herself a little bit and could follow some commands. But over the next several months her condition deteriorated even further and she needed to be fed and progressively lost her ability to interact with people and her environment. Then, without a medical explanation, one day Lottie lapsed into a coma, unresponsive. CEI received a call from Nicki that she was not responding. I drove to the home. Arriving at Nicki's I found Lottie as she had said. I tested her urine and she did not have a urine infection, nor a fever or other signs of infection. My initial thoughts were that Lottie was dying from her end stage dementia

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whether due to dehydration, chemical imbalance or general involution of her mind. I presented Nicki and Janice with some option. We could simply withdraw all support and allow her to die peacefully, making sure that she had medication in case of pain or other distress. This seemed a reasonable course. We could force nutrition upon the comatose Lottie with a stomach tube of one kind or another. This seemed to me inappropriate, a form of intrusive life prolongation that did not fit what Lottie's conditions and cognitive state were telling us. Or we could provide some IV fluids to maintain hydration for a while and see if Lottie's condition changed one way or another. I did not favor this latter alternative because it would likely only artificially prolong the process of death and dying that Lottie seemed to have entered. However, Nicki and Janice were not ready to give up on Lottie. Nicki said, "I know that Aunt Lottie isn't ready to go yet."

So I placed an IV access, provided sufficient supplies for several days in their home and warned Nicki that without nutritional input Lottie would become protein deficient and then would start to breakdown her skin and possibly suffer unnecessarily as she edged toward death. After I reported back to the team, we arranged for home care nursing support, but Nicki didn't want much help and insisted upon managing Lottie herself with Janice. So we just provided regular nurse and medical visits at the house to check on Lottie. A week went by and nothing changed, then two weeks and three. I checked her skin but they had been guarding her and turning her so effectively there were no signs of breakdown. Lottie remained in her coma, totally unresponsive to any stimulation, but with normal pulse and blood pressure. More time passed; the weeks meandered into a month then 5 weeks and then 6. Lottie lay, sat, or however they

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arranged and propped her and was unresponsive, hooked up to the IV drip that assured she would stay hydrated. Then one day, 6 weeks after this unexplained state of suspended animation, Nicki called me at the CEI center. "You'll never believe this, Marc," she said, still in disbelief herself. "Aunt Lottie woke up about 20 minutes ago and looked at me and said my name. Then she said, "I'm hungry".

"You can't be serious," I recall saying. "I'm serious," she responded. Why don't you come out and see her." I had to see this to believe it. "Sure I will. I'll be there in just a few minutes."

I grabbed my stethoscope and rushed out to my car. The house was only about 10 minutes down the freeway. I knocked and entered without waiting and rushed right to Lottie's side. There she was in a soft cushioned chair, semi upright. She saw me coming, focused her eyes on my face and smiled. "I'm hungry," she repeated.

Lottie ate. She had to be fed but she ate; and she ate and she ate. Earlier she had weighed around 130 pounds, with a slender figure. But now that Lottie began to eat and was being fed by Nickie and Janice there was no stopping her. At the same time her cognitive state continued to wane. Over the next year she became less verbally responsive. She maintained a dreamy smile on her face but soon stopped interacting at all with people or anything in the environment around her. But she never again became comatose. Eventually I wondered why we even brought her in to the Day Center, but Nicki was adamant that Lottie was benefiting from the "social interaction", even though she had no social interaction.

By all accounts Lottie had reached the end in her cognitive deterioration and

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would undoubtedly die within a matter of months. But she didn't die. In fact Lottie stayed in this awake but not aware dream world for years---about 5 more years. With each passing year, with her weight increasing not decreasing, her care became more difficult and Nicki became fanatical in her demands upon homecare staff who were never meeting up to her own personal standards of care. Nicki fired one after another of the CEI staff that were sent to work with her and Lottie. Finally an episode of illness led to Lottie's short hospitalization and the team used the opportunity to place Lottie in a nursing home, something no one had ever intended to happen. At first Nicki fought this and tried to manage her at home again, but without CEI staff --and she had already rejected CEI home support--she allowed Lottie to live in a nursing home. From that moment on Nicki and Janice began to live a lot of their lives in the Nursing Home and to try and force the Nursing Home staff to conform to their own definitions of good and attentive care. Even after Lottie had been almost 2 years in the Nursing Home, Nicki and Janice were not yet sure that they were ready to let Lottie die. In the intervening period I no longer had any role in Lottie's care which had been supervised by Maria Magat, the CEI physician who had become the main provider at the third Center at the Eastmont Mall. But toward the end when Nicki was still fighting to keep Lottie alive I did talk a bit with Nicki about it being time to let Lottie go. Finally, eventually, Nicki was ready to say goodbye to Lottie. And then it was time for Lottie to let go also. Who knows if Lottie had some unconscious subcortical intuitive understanding that she had permission from Nicki to die?

From the case of Lottie and those below I learned that the love of attentive care givers with their boundless support can create an almost metaphysical bubble around an elder, can magically prevent degenerative processes such as skin breakdown and nutritional risk and the falls that customarily can be expected to end the life of the late stage Alzheimer's patient. It's possible that Alzheimer's patients' lives are only shortened because of how difficult it is to provide total 24 hour care and nurturing for them; I've seen that dementia patients, given the best care, may live on for an exceedingly long period, and in a state of total unawareness making their disease process of no concern to them whatever. In such circumstances it's the caregivers who suffer, and whose lives are most in danger, not the person who has lost their mind.

Barbara B.

Barbara was, as I recall, the favorite participant/patient of CEI's first Nurse Practitioner Ann Walker. Every time that Ann saw Barbara's round face she (Ann) would break into a huge grin; she knew immediately that Barbara would do something either entertaining or silly. Every time that Barbara saw Ann in the clinic (and sometimes if she saw other nurses) she would walk right in, sit right down, and start talking a blue streak.

She talked in sentences in perfect English, yet she often spoke as if in riddles, or deadpanned comic remarks. Her language was coherent yet she made very sharp turns in the middle of a sentence or thought. That is, coherent but not linear. Barbara had been a member of the Community Adult Day Health Center for a good while before

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it became the first CEI center. The artistry of her language had me thinking she had been a librarian, until Lillian refreshed my memory.

Long time CEI staff member Lillian (Stovall) Jackson remembered Barbara fondly as her talking buddy. “She used to tell me all about herself”, Lillian related. “She acted as if she was ‘out of it’ but she had moments of clarity and that’s when she talked a lot to me about her earlier jobs. At first she had been a secretary at Macy’s; then she had worked her way up to being a bookkeeper. And by the end she was some kind of system auditor or bookkeeping supervisor”, Lillian told me. “She just loved to tell me about those days and her work. You know, she got to travel all over to different Macy’s as part of her job and she really enjoyed traveling.”

Barbara B. had never married and didn’t have much family. A brother showed up at CEI toward the end of her life. He had been involved with her and handled her bills, but somehow hadn’t been around the Center or the team. Medically, Barbara had a seizure disorder, perhaps from an old stroke or head injury. She also had a balance problem, sometimes falling over without warning. As her falling became more pronounced and common, Barbara was given a wheeled walker, hip pads and a helmet. The helmet looked like one of those old leather football helmets from the 1920s or 30s. Of course that all added to her comic aura. She looked a bit like a character from Doonsbury.

Barbara’s most famous act was her snow angel. Usually after lunch she would go casually over to the physical therapy room and there plop down on the floor mat, face up, with arms and legs spread to the four winds. In no time she would be sound

-I'll fly away-

asleep snoring in the configuration of the perfect snow angel. It was Ann W. who named her act the snow angel. By the time that Barbara awoke she would be wanting to go home. It wasn't her time though, as she was generally on the late run. So instead of returning to the activities room she wandered up from therapy to the clinic, sat right down again and started her daily discourse with the nurses or Ann.

That's how I remember Barbara B., sitting in the blood drawing chair gabbing away with the nursing staff. Of course she became more frail over time, was eventually wheelchair bound and her dementia became so dense that she no longer bemused people. Until she stopped communicating toward the end of her life, Barbara's act was an exotic entertainment for her and her many fans. We surmised that this was probably a side of Barbara rarely seen within the walls of Macy's finance departments. But who knows?

Lovely Jolene

“I’m gonna sock you!” It was, of course, a joke even when she put up her dukes. There was the sly endearing grin; the knowing wink; the good mouthful of teeth, at 90--even if one front one was chipped. “If you do that again I’m gonna sock you” she said with gusto, but without anger. Jolene wasn’t serious, but she disguised it well; a born actress. Yet, when she did sock an occasional peer in the program up side the head, it was no joke at all. And then you couldn’t tell why it happened, because she didn’t shout out or argue much and couldn’t explain it herself. Maybe a small warning of irritation or a misunderstanding of intent....or maybe not. Then, she just went ahead and did it. Pow.

Jolene’s story belongs in a book about mothers and daughters, because of her dedicated daughter, Frankie, the psychologist. The story is as much Frankie’s as Jolene’s. For Frankie was unrelentingly committed to her elderly demented mom with an indefatigable sense of love and obligation.

Frankie worked across the Bay in San Francisco, in a County health program, had a husband and three kids, yet hardly a day went by that her full sized Mercedes wasn’t seen curbside because she was visiting with Jolene who lived in her studio apartment alone in the Senior Housing above the San Pablo Center. And hardly a week went by that Frankie did not express to the CEI health care team a concern or her own need that something be done differently with her mom. Back later to Frankie.

For our staff, Jolene was an amusing character for a presumed Alzheimer's patient. She ambulated well, was in great physical shape for a nonagenarian (her body I would liken to a healthy woman of 55-65 and she was an attractive woman). She was fully continent, ate well. She had a somewhat flattened affect; at least until she got energized. Intermittently she might be sitting content and silent and then, as if falling back into this world, her voice would, of a sudden, come out of nowhere with expression and meaning. Sometimes her communications were not of a purposeful significance, but she usually kept up a coherent if not fully oriented line. After 5 or 6 years at CEI she showed no slowing of her speech or verbal ability.

Jolene came into CEI with dense short term memory loss, unable to care for herself, and with her wry sense, and a bit of coyness. She was obviously comfortable with her surroundings at CEI and with her dementia, but she never really knew much about anyone around her. It didn't matter to her. She participated without reticence; she even did Tai Chi when we introduced it.

In general, Jolene was able to learn enough to become accustomed to her surroundings; to find her way here and there. She did not wander. She probably recognized Frankie much of the time. This could be because Frankie visited so often and spent even more time on weekends. But that recognition of daughterhood could have been partly an act too. There was a lot of "put on" going on when Jolene rose to the occasion.

Jolene surely did not know who all these people were around her that kept her life in order. She did not know or believe I was a doctor or that others were nurses or

-I'll fly away-

day center health care workers etc. In fact, it didn't matter to her a whit; she enjoyed playing and talking with us. She might occasionally ask "who are you?" when told to do something like open her mouth for an exam or if someone tried to get her to move. But that was about the extent of her interest in such meaningless trivia. Sometimes she required a little playful cajoling, but she was generally cooperative while, in short, she was very demented.

It wasn't too hard to get to know this residual Jolene well because of the lack of depth left in her personality. But receiving uncountable calls of concern from her daughter, the professional health provider, who seemed overly attentive in the care of her generally healthy though demented mother, aroused my interest in their relationship. On a professional level alone I needed to know more so that I could form a bond with Frankie. I needed to survive the frustration I felt when, for example, Frankie rushed Jolene off to the hospital and had her admitted for a low grade fever and what turned out to be a tooth ache one weekend because the on-call doctor took too long, in her opinion, to return her call. Frankie knew that in our program you only did such things as calling 911 in a true emergency—because CEI was paying the bill. Why did Frankie repeatedly manifest this kind of behavior and over-concern for Jolene, one of our healthiest participants?

Late in the first year after Jolene's entrance, after a few of these incidents and Frankie feeling that her mom was not getting as much support as she needed I sat down with Frankie and asked her what this was all about. She seemed to welcome the

-I'll fly away-

opportunity to talk about the backdrop. As a child Frankie had been physically abused by Jolene. There were beatings and there was also neglect. I can not say if this was the result of mental illness, an abusive personality, an alcohol problem or a combination, but it had taken a hard toll on Frankie. When I commented to her that her fierce concern for her mother appeared to be a form of victim guilt she agreed without resistance. As a psychologist she had looked into her feelings in that realm.

“But I have to do this,” she also responded. “She’s my mom and I want to make sure that she gets the best care.” It was as if Frankie’s early abuse would not let her rest. If she did not overcompensate with intractable concern for her mom there remained the dim possibility that she would later hate herself for something she didn’t do, even if it wasn’t her responsibility. Thus her Mom was getting, sometimes under duress, excessive attention and resources, undoubtedly at the expense of other participants.

On a rational level Frankie was in tune with these feelings, but she could not extricate herself. We continued over the years to have numerous minor tussles. Occasionally she was right that something had been neglected, but most of the time her requests (such as to cut the dose of this or that medication by a tiny amount or to do things that I, or other team members, felt were not called for) remained over-involved in unimportant details. Often this would end with loving cards of appreciation to me or other staff, which were heartfelt and accepted as such. I kept a collection of such appreciative cards from families. They are important to me as a physician and Frankie’s meant as much as any since they were an affirmation that she understood that I did

-I'll fly away-

care about her mom, and being stern with her (Frankie) was not a sign of arrogance or dismissiveness.

But were Frankie's "over-concern" and "over-involvement" not of benefit to Jolene? In the end, Jolene lived on; and on; and on. Unlike Lottie who looked like she might live forever despite becoming ever more functionally debilitated until she was as if vegetating, Jolene never changed, did not deteriorate mentally nor physically, though she was well into her 90s. I do believe that the cross Frankie bared made a difference. It probably did prolong Joleen's life. She protected and nurtured her mom in a wonderful, if somewhat sad, cocooned assertion of love, that seemed to say, I forgive you for what you did, mom, because you are still my mother.

So close and yet so far--Henry and the United Farm Workers

There was no question that Henry was 100% paranoid. But frankly, no one really knew if he was a schizophrenic. And because diagnostic labels were of less concern to us than social integration in this program that focuses on functionality and quality of life, I doubt that anyone cared as much as I did about Henry's state of mind. As far as "we" could tell (and WE included a large family of brothers and sisters) he didn't hear voices or see things that weren't there and his paranoia was, in a sense, a practical convenience that helped him explain why people were often very unhappy with many things he did that were bizarre, if not definitely crazy. The most obvious reason that no one else cared about a label for Henry's mental condition was that he was never interviewed by CEI's consulting psychiatrist because he was not a candidate, a member, a patient. Henry was not a participant in our program. He was instead the son of a very elderly bed ridden woman who became a program participant in a particularly unusual way.

I, myself, very much wanted to enroll Henry in the program, though. I talked to him about it from time to time when he would come to the downtown San Pablo Avenue CEI center on the van, on those rare days he allowed his mom to come out to the program. He'd hang around a while to be sure we weren't going to steal Blanca from him--which, ironically, he eventually forced us to do. Had Blanca lived, rather than suddenly died, I think I would have eventually convinced Henry to join. And that could have changed things both in his life and his mom's (as well as mine, the CEI staff's and

-I'll fly away-

his brothers and sisters) for the better. Henry was so paranoid that it was contagious.

When Blanca died less than a year after joining CEI my first thoughts were whether he had something to do with it, though that was highly unlikely. But let me explain.

The way that I met Henry was as unusual as our program's relationship to him. A phone inquiry about a prospective new participant was referred to me. Usually such inquiries are effectively handled by the Intake staff. Now, however, on the other end of the line was Robert, Henry's brother who explained that he was calling about his mom and representing his 4 sisters and a brother who were at their wits end about what to do for her, and with her. His mom owned the house they had grown up in, in Oakland, but for years, since his father had died, she had become reclusive, progressively worsening. Eventually she had taken to her bed and was now totally bed ridden and so thin, frail and twisted that she could do little more than lie in the semi-dark and not interact with her surroundings. She had been diagnosed with a severe anemia and was presumed to be very ill, though no comprehensive work up had been performed. Robert and his sisters felt that their mother was dying, but with her age being in the mid 90s that was not their main concern.

They wanted her to die peacefully and to have as good a quality of life as possible for the remainder of her time, given these circumstances. However, residing in Blanca's house were her eldest son and one of her daughters. The daughter worked and was not an assertive person but the son, Henry, who had taken on the role of main care giver of Blanca did not work outside the home and intimidated people who tried to get near her or to check up on why she seemed in distress and so withdrawn. He'd let

-I'll fly away-

a doctor who specialized in home care visiting come in only a few times but would harass any one else who came around. Henry almost seemed to treat his mom like a property, according to Robert-- like his doll, or possession. He did seem attentive, but he wouldn't let anyone move her or take her out of the room or get her dressed, claiming that anything other than lying in bed in a dark room distressed her. He became agitated when his sisters or brother came around and then he created unpleasant scenes. They all knew that Henry had been unemployed and dysfunctional for a long time, which is why they had acceded to his living there.

The siblings suspected, and had some evidence, that he was not caring for Blanca well. About 8 months before this call, the family, excluding Henry, had decided to hire a home health aide to assure that Blanca's basic needs were being cared for—to make sure she was being adequately fed, changed, bathed, dressed, moved---because her frailty and weight loss were frightening. Robert reported that she had suffered some skin breakdown also and was in diapers for incontinence of both bowel and bladder. This new arrangement with a home health aide seemed to go well for a short while but then Henry became agitated at the intrusion of a helping figure into his controlling role in the home and with his mother. He had made accusations against the woman and verbally intimidated her into quitting, although he was not the one who had hired her.

When Robert called me, the family had already decided that they would seek legal Guardianship of Blanca with Robert as the Conservator. Henry was loudly proclaiming that he was both the de facto and de jure Conservator and controller of all

-I'll fly away-

her property as well. And that he was getting a lawyer to defend himself and his mother. Henry's argument was a big stretch, but it was true that the family had let him live at the house and do the care because he was unemployed and probably unemployable and they didn't want to be unreasonable to their own brother even though he had always been difficult. Had they put him out of the house he might have become homeless, destitute and deteriorated psychologically. For a while his remaining in the home as caregiver had served as a workable relationship. But no longer.

Now they had not yet decided if they would try and put Henry out of the house altogether or to use the power of conservatorship to loosen his control of Blanca. Regardless, they needed to find a way to improve her care and monitor her medical status, assure she wasn't being neglected, and they had heard that CEI had a home care program. Would we consider her for CEI given that she was bed bound?

It happened that CEI was, at that moment, experimenting with enrolling a new type of participant—one that could not come to the day center and would receive all their care at home. This was a big change because the heart of the program and all of the services it provides is the Adult Day Health Center with its activities program, socialization, clinic, and rehabilitation center. In agreeing to come out and visit the home and see what I thought about accepting Blanca and trying to determine if she was, as they thought, a hospice level patient, I was planning that Blanca would be under the care of a Physician's Assistant (PA) who could assure regular home visits and monitor Blanca in concert with the social worker and home care staff.

-I'll fly away-

Arriving at the home, I saw a Victorian style two story house, probably a 3 bedroom; a nice home for the area, but in somewhat poor repair. The long wide outside wooden staircase was precarious, a potential danger to anyone climbing it, especially if they were to try and carry a 70 pound withered woman in their arms. Some steps were loose and bowed. Others had some dry rot. The interior however had been well maintained and had the feel of a typical older California Mexican American home---neat, decorated tastefully with quality antique type wooden furniture, a glass door bookshelf, with the little brick brackets—presumably decades of life's quaint collectables--here and there.

I recall that Robert had arrived with his wife before me, having driven in from the suburbs, and that two sisters arrived after me. We talked a while--both getting to know one another, and I learned more about Blanca. Henry was present. Then, I went in to visit Blanca in her bed in the bedroom.

I saw immediately that they were certainly not wrong about her frailty. She was little more than skin and bones and had one knee flexed tightly as if in a permanent contracture from disuse. But as soon as I approached and began to speak to her in Spanish, those appearances fell away to create a new impression. Blanca did not ignore me at all. She was not staring blankly ahead. She looked at me with inquisitive eyes. As I began to speak she looked anxiously, but directly, at me and responded : "I can't hear anything. I'm deaf and I don't speak English." With me shouting in her ear and once she understood I could speak Spanish, we had a small conversation. If Blanca did not have a deadly incurable physical illness—which remained to be

determined—I already knew she was neither as reclusive as they thought, nor necessarily near death. -I'll fly away-

Henry was watching all this probably worried that I represented a new threat. After a time with Blanca I sat down in the kitchen, apart, with Henry. Trying to allay his fears and get to know him I asked about his own life and learned that he was a strong supporter of the United Farm Workers Union (the UFW-founded by Cesar Chavez). He had been involved in the boycott of the grapes in the early 70s—a touch point, for so had I. When Henry found out that I had actually worked for the UFW as a doctor for several years, he began to see me in a different light, one which calmed his fears...for a while.

The family agreed that we would try and periodically bring Blanca out of her home to the Adult Day Center and clinic, though Henry was not happy with this. CEI agreed to enroll Blanca over the concerns and objections of Henry, who began focusing his anger on his family. The family's effort at conservatorship was begun about the same time that CEI home care was initiated. Henry vowed to resist.

On the medical front, we found only that Blanca had a non-threatening iron deficiency anemia. The cause appeared to be nutritional rather than a disease process. With homecare and other visits Blanca began to show more interest in life, and it was clear that as stiff as she was, she was not permanently contracted, but simply needed activity and range of motion work.

But in the meantime Henry began to push the new CEI home care worker out of the picture and to dictate that Blanca be left in bed and in the bedroom. As the

-I'll fly away-

conservatorship proceeded Henry became more resistant, obstinate, paranoid and confrontational; so Blanca was back to bed. He thought the family was trying to kick him out of the house and to take his mom away from him. At Robert's request I agreed to testify if they needed me and I wrote up my observations of all that I saw. Henry decided I was a traitor.

When it became clear—unrelated to this case--that the Physicians' Assistant was unable to respond to the need for regular home visits, we decided to bring Blanca in to the Center once a week even over the objections of Henry. Henry responded by riding with her on the CEI van to assure that we did not capture her or turn her against him. He imagined we would not send her home at the end of the day. He insisted that she hated coming to the center and was suffering. But our experience was the opposite. At times she was gay and talkative with staff and others. She never cried out in anger, fear or sadness.

This day center strategy and the hearings over conservatorship forced the issue with Henry. He became more frightened and thus more resistant and hostile, particularly toward his brother and sisters. It got to a point where Robert called one day and said they were going to move Blanca to a residential home for a while because she was being neglected again and Henry's behavior was too unpredictable.

We worked with the family to assure the move. Blanca would come in to the center, but be taken out to her new residence afterward. If Henry came along with her that day, we would separate them and he would be told what was happening. Ironically, the plan confirmed Henry's earlier fears. He had created the need for that

-I'll fly away-

which he had feared most to happen. After much planning the day came and Blanca was successfully transferred. I was looking forward to a rapid trajectory of improvement in her physical and mental state once she was out of Henry's strange-loving clutches. We planned to allow Henry to visit her under supervision when she was at the Center and the family was also allowing him to visit her at the residential home. Despite her age, I had proposed a colonoscopy to be sure that she did not have an underlying cancer as the cause of her frailty and anemia. But her ability to gain weight while getting much needed attention suggested she might prove cancer free.

But in her 90s Blanca was, indeed, near the end of life. Within a couple of weeks of her housing transfer, we got a call from the family and the residential home that Blanca had collapsed and suddenly and unexpectedly died. It wasn't supposed to end this way, I thought. This was supposed to be a great success story—bringing a frail elder so far back from the darkness. My hopes for a spectacular Hollywood ending were dashed. My hopes to help Henry find a suitable and engaging social environment with us were also dashed. We had all gone through a lot to create a possible bright and calm future for Blanca and to help her children resolve their family crisis. But at the same time we had pushed Henry to the edge. In the end the family was very content with the outcome, with our care, attention, and the support that CEI had give to Blanca and themselves. They had never hoped for more than what they got. They all thought that the end of Blanca's life had been perfect. That is, of course, except for Henry—whose sadness I can only imagine for his disappointment and my own were bonded together like Siamese twins unable to escape each other.

Curtis—a tough way to quit smoking

Actually there were two Curtises at one of the Day centers. Both were African American men but they had little in common. One Curtis was very shy and quiet. The other Curtis, whose story this is, was an outgoing friendly sort. He was a heavy smoker and he had a good degree of dementia. His short term memory was shot. Yet during the years I knew him, Curtis' mental state remained remarkably stable, leading me to consider that maybe his dementia came from a history of alcohol abuse since he had no history of strokes.

When I say that Curtis had a good degree of dementia, interactions would go something like this: Curtis is sitting by the front entrance of the senior apartment building where the Day Center he attends occupies the ground floor. He lives upstairs in this building. He's sitting by the full floor to ceiling glass windows just looking out at the boulevard. It's a large lounge area for building residents and he is not inside the CEI area or the Day Center. It's 8:30 a.m. in the morning and I'm rushing in on my way to morning briefing.

"How's it going doc?" says Curtis brightly with his friendly smile. "Just fine, Curtis, how be yourself?" I rejoin. "Oh I'm fine, and it's a nice day, ain't it?"

An hour later when I'm heading out to the hospital. Curtis is sitting in the same location by the main building entrance. I don't know if he's even moved. "Say doc, how are you today." "I'm just great. And yourself?" "Oh, I'm just fine, but I haven't seen you

in quite while. Where you been hiding yourself?” Same interaction almost every day. -I'll fly away-

Curtis knows me, but he doesn't remember he just saw me an hour or a day ago.

Curtis is about 5'8", rather portly, maybe 250 pounds and he has a really bad knee and tends to fall because of it. I'm not his regular physician, but I cover this Center's clinic on days when Lyn Stromberg, the regular doc, is off. I'm in and out of the Center on other days too. One day, when Lyn is away, Curtis has a pretty bad fall. It's mentioned in the morning team meeting so we bring him to the clinic to check him out. When I examine Curtis I find the cause of his falls is, indeed, his knee, as others had said in team. He has a totally disrupted ligament on the medial (inner) side. It's rather obvious that he lacks the supportive structure when he walks because he drags the leg through an arc as he walks and the lower leg deviates out away from his body. Then when he goes to put his weight down on it the leg is unstable, angled out in a way that shows something is askew. Without the stability of the ligament he's bound to fall if he puts his weight down on that leg. This is an old injury, so it would be hard to repair surgically, but there are lots of splinting gadgets available to improve stability for such a knee. At my request, Susan, the Physical Therapist, orders Curtis a hinged knee brace that will keep the upper and lower leg aligned while still allowing some knee movement. Curtis doesn't understand the explanation of his condition well at all. Moreover, he can't remember anything more than what happened 15 seconds ago. But being the congenial guy he is, Curtis, a few days later, lets us put on the splint and he leaves the clinic, walking pretty nicely, with his leg well stabilized. A success story.

-I'll fly away-

Curtis kept the brace on his knee about 30 minutes as the rehab staff worked to train him with it in the Physical Therapy area. That may have been the last and only time he wore it. "It don't feel good doc," is about all I got out of him. "But Curtis, you're going to hurt yourself with a bad fall or tear up other parts of that knee too. Give it some time." "I know doc, but it don't fit right." Efforts to improve his comfort fail. On my mental scoreboard I give one star to Curtis for autonomy and take away one star for worsening disability and functionality--and note the absurdity of it all.

Well it wasn't long after I had accepted the fact of personal failure in this medical situation that Curtis became terribly ill with shortness of breath. He had pneumonia, a disease we often treated out of the hospital. But in this case Curtis' blood oxygen (the saturation level) was so low that he had to be hospitalized.

I again happened to be the physician that cared for him most of this hospital stay. His breathing and oxygen capacity were so precarious that I consulted one of the pulmonary specialists. Within a day, pneumonia was not Curtis' main diagnosis but only a side bar. He had pulmonary interstitial fibrosis, a terrifying disease that progressively scars the lungs and destroys their ability to adequately exchange gases—oxygen and carbon dioxide. Scarring lung diseases are terrifying because the patients find their breathing can not keep up with their oxygen needs. Fibrosis falls into a different class of lung diseases than emphysema because of the pattern of scarring. But from the standpoint of someone with these different diseases, being oxygen starved is being oxygen starved.

-I'll fly away-

From the medical side of the picture, fibrosis (a restrictive lung disease) is treated with high flow oxygen to push oxygen into the blood vessels mainly during times of higher demand. Although oxygen is also a mainstay in the treatment of emphysema, using oxygen mainly in high demand situations doesn't work as well with obstructive lung disease (emphysema) because of the different type of disruption of the lung architecture. With emphysema the shortness of breath may be almost as noticeable without exercise induced oxygen demand. And high flow rates of oxygen won't do much because the "dead space" created within the lungs in emphysema puts tighter limits on the improvement in oxygenation possible by increasing the oxygen flow.

Curtis was tested on the hospital ward by a standard empirical method of walking him vigorously while on an oxygenation monitor and seeing how rapidly and how far his blood oxygen declined; then increasing the oxygen flow through his nose until as much of that decline could be eliminated as possible. The test provides an estimation of the best oxygen flow rate for treatment. We were told that Curtis would need a very high flow rate during exertion, 12 liters of oxygen per minute, or he might black out, fall and be injured.

The team knew Curtis' life style, his leg problem and his dementia. He spent plenty of time outdoors, on the streets, especially going to the store for cigarettes. If he fell crossing a major Oakland street he might get hit by a car. And Curtis now had not one, but two good reasons to fall: his knee and his lung disease.

On the other hand, 12 liters of oxygen a minute would require that Curtis carry or wheel two portable oxygen carriers linked together at the same time because the

maximum delivery rate for one portable machine is 6 liters a minute. In Curtis' case ^{-I'll fly away-} imagining him dragging two oxygen canisters around seemed far fetched.

In the hospital, Curtis had improved enough to be discharged home. While trying to decide how to deal with the oxygen portability issue we set Curtis up in his apartment and in the Day Center with large, five foot tall, high capacity oxygen tanks as a stopgap. And initially we restricted him from going out to the store and the streets. Of course in our discussions with Curtis we stressed over and over and over again that he had to quit smoking once and for all; that he had no choice both because it would make his disease worse and because of the danger of oxygen catching on fire.

But Curtis couldn't remember. Within just a day or so of hospital discharge Curtis was outdoors on the patio in the interior courtyard of the apartment building, a pleasant V shaped area with a garden which sat between the CEI adult day health center and the clinic. This patio is part of the CEI territory. He was tethered by a long length of tubing to one of those large, 5 foot tall, generally stationary, oxygen tanks. Before anyone could even take note of it (though there were Day Center staff near him), Curtis suddenly pulled a cigarette from somewhere, put the cigarette up to his mouth under the mask, lit a match and tried to light the cigarette. At that time he still had his oxygen mask in place on his face with the oxygen flowing and he briefly ignited the oxygen with a flame up like a rocket ignition. Staff immediately shut off the valve. It was over in an instant. It was all over so fast that the flare may have actually extinguished itself. Curtis was terrified and trembling. He had singed off his eyebrows and some of his hair.

-I'll fly away-

Luckily most of his skin was intact with only first degree burns. He did well with local burn treatment.

But immediately Curtis quit smoking, and for good. Whenever anyone asked him about this he said he didn't want to catch on fire again. Despite his dementia Curtis vividly remembered this experience, overcoming his short term memory loss. Even years later his memory of it never faded. The strong emotional experience was powerful enough to bypass his short term memory loss and send a message directly into his long term memory bank.⁹

After this episode, and because of his shortness of breath, Curtis tried to just stay put in a wheelchair. Keeping Curtis under close watch and trying to avoid his falling were aided by his becoming sedentary. But lack of exercise presented many deleterious possibilities also. He needed to keep his lungs going both for the health of his scarred lungs and to maintain some level of cardiovascular fitness. There was also concern about the general conditioning of his body musculature and bones. Without weight bearing he would lose bone calcium and strength. We didn't want Curtis to sit around like a lump, just waiting to fracture a hip; but we also hoped he would not go out and fall either.

While we were fretting about this problem, the physical therapy staff was working with Curtis on activity and conditioning, even without that brace. Nevertheless, he now

⁹ We had another participant, David H, a demented smoker who lit himself on fire briefly without the help of oxygen. David lit up a cigarette and then, without extinguishing the match, dropped it into his shirt pocket. The shirt caught on fire and David received second degree burns to his face, but he also healed his burns. Since I don't have a photo of Curtis, I've placed a photo of David showing the results of his burns at the end of this chapter.

-I'll fly away-

took to just sitting out in his wheelchair in the lobby (where he would greet me in the mornings). Sometimes he'd play some games in the lobby with other senior apartment residents, those who were CEI members and those who weren't. He didn't appear daunted by the loss of mobility. Sedentary, Curtis' oxygen demand stayed quite low so he didn't need to wear or carry two different oxygen carriers. One oxygen carrier was much more practical for someone who wouldn't even wear a knee brace that dramatically increased his stability and function.

Then, on his own, Curtis stopped wearing oxygen altogether and he was ok. Then he started going out on the streets on his own again. The team was very concerned about him going out without oxygen. He was crossing streets again. People tried to get him to either use the oxygen or not push his limits in travel. A tug of war ensued. But Curtis was demented and on another planet; the team could not win that argument.

Eventually Curtis did settle back into a sedentary lifestyle. He didn't seem to notice shortness of breath in this lifestyle. And he often went without oxygen. The pulmonologist had said that his fibrotic scarring was inevitably progressive and that, given the oxygen requirements they had seen upon the testing in hospital, he was at a late stage of the disease. They predicted not only that he would need 12 liters for exercise but that soon he would be needing high flow oxygen even at rest and would then go into respiratory failure. Instead Curtis and his friendly dementia defied these predictions and kept death at bay. Over 3 years later when I wrote the first draft of this essay, Curtis was still the same Curtis—friendly, outgoing, implacable.

A photo of David Hogan to go here.

-I'll fly away-

Jamie—The Sex Life of a Bachelor

He was a squat man, about 5 foot 3 inches tall, but pleasant looking with a rounded face and smooth skin. African American. Rotund, he weighed close to 260 pounds and could barely waddle. When he first joined CEI--the Center for Elders' Independence--he did waddle better, though he had had a stroke or two and had a bad heart. He had diabetes. He was a quiet person. As they say "a man of few words". But he wasn't sullen. He just didn't have much to say. When Jamie spoke it was usually in short slow sentences. Still, you could get a rise out of him if you tried and he would chuckle if you said something amusing. He'd get a flash in his eye at times.

We couldn't tell if Jamie's lackadaisical nature was the result of a little post stroke dementia or if he might be mentally challenged. But Jamie was pretty inert unless you engaged him directly. The main way one could tell if Jamie was ill was by a pained or frightened expression on his face. Occasionally he would complain of pain or discomfort, but most of the time he seemed content and sedentary, wheeling himself around in a wheelchair. Like Curtis, he hung around the lobby of his senior apartment building and could also be found in the CEI Day Center as well. He had his friends and sat in at activities that didn't require too much energy. Challenged about his weight or his staying in the wheelchair--his unfortunate self-collaboration in losing his strength and ability to walk—Jamie would listen and agree, maybe smile timidly. He didn't seem to feel intimidated, nor willing to change. Rarely he'd go into physical therapy and get up on the stationary bicycle. That took much encouragement.

Then quiet Jamie started having absence spells. We couldn't tell if he was having seizures or not, but he would just become totally unresponsive, in a stupor. All his vital signs were normal. He wouldn't fall over because his rounded body was packed into the wheelchair. He wouldn't slouch either. But he couldn't be roused. His eyes were often open, staring blankly. There were no movements apparent. His blood sugar was normal. His chemistries were normal. His heart was normal. So, maybe these were absence seizures, though the time span seemed troublingly long for absence seizures. The first several times we were quite worried. He would be out for 20 minute or more. Then he would just start responding again in his single words, short sentences, and slow drawl. "Jamie?" "Yeaaaahhhh". "Are you ok". "Yeaaaahhhhhh." "What happened to you:?" "I dunno."

Before Jamie reached this sedentary wheelchair life and his absence states he was far from active. However, one morning at briefing we learned that Jamie was more active than we would have thought. A home health worker had been searching for Jolene and another demented woman who were living in the same residence building as Jamie. The two had managed to slip away from a group area unsupervised. They were in the building somewhere, but had to be found before possibly hurting themselves. The health worker knocked, then entered Jamie's room. Jolene's underpants were on the floor in the center of the room; and she was in bed with Jamie. In further discussion it turned out that Jamie had previously been found with another female dementia patient in his room, perhaps with similar intent. There was no evidence of coercion in either case.

The team decided to notify Jolene's daughter of the incident and to give a stern talking to Jamie about the fact that dementia patients aren't able to make informed decisions. I was the team's agent for this lecture. I talked with him that day, doctor to patient. We do know that dementia patients might consent to sex, I told Jamie, but we can't allow you to take advantage of them in that way. They don't remember things, or people, and can't understand. I was quite direct with him and suggested we might call the police if it happened again.

Poor Jamie. The next day he was brought to the clinic after vomiting blood. He had developed a bleeding ulcer. He had to be briefly hospitalized. I don't know that my talking to Jamie caused him a stress ulcer, but the temporal relationship certainly suggested it. I warned myself to treat him more gently in the future. Beneath his quiet stoicism and mysterious absence spells, I now saw a particularly sensitive fellow who probably had never understood the vulnerability of our dementia patients. After that, Jamie was almost never to be seen out of his wheelchair.

Odalia Cricket and her four daughters

According to Odalia she grew up in an idyllic family with lots of kids, in New Orleans. She loved her parents dearly and especially admired her father. He died at a fairly early age which was a big loss to her. I can't ask Odalia to repeat her description of their home because she's long gone now. But she told me about family life as a child, taking a bath in one of those big corrugated metal tubs with the two handles on the kitchen floor. You'd heat up the hot water on the stove—a wood burner—and then mix it with cold water to get the right temperature and then someone, maybe your mother or older sister, would pour it over you with a pitcher, lather you up and rinse you off.

Odalia was a hard luck woman, and pretty sullen about it. She had had a major hemorrhagic stroke over ten years before joining CEI. That's the kind where internal bleeding in the head can do extensive damage to any or all parts of the brain from the internal pressure--as it did in her case; but not at first. When she woke up from that stroke—she was in her mid 40s—she learned her husband had died. So that when she awoke she had lost not just her own physical identity and mental clarity but her husband as well.

This was enough sadness to send anyone into the tailspin of severe depression. In Odalia's case she had been an extremely powerful matriarchal woman and role model to her four daughters and no sons. From what I heard from them she was very

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loving and deeply loved, but at times could be tyrannical. From the Odalia that I knew, who was very smart, sharp witted, and could be demanding, I could believe it. At first, after her stroke, Odalia didn't have a complete paralysis; in fact she seemed to recover most of her strength, but then over a year or a few years she became weaker and weaker and lost control of her extremities and her trunk; eventually she was left spastic and her legs and arms were nearly uncontrollable. When the doctors at Stanford saw her deterioration developing they had found that it was due to increasing pressure in her brain, a late after-effect of her stroke. She then had to have at least two operations to put shunts into the brain to drain the excess spinal fluid and prevent pressure buildup. Odalia's belief was, like Leroy's, (see Leroy) that her losses came from doctors' errors causing a bad result with the shunt(s). I found no evidence in review of her records to support that. It seemed little more than relentless bad luck because, besides the stroke--which could of itself cause such a pressure problem--she also had a minor, undetected, congenital malformation of her skull and brain (known as an Arnold Chiari malformation) which probably made her more prone to this effect. In fact, just about 2 years before she died, she had had to eventually be referred back to Stanford when her shunt (which was a complex mechanism unlike any our East Bay neurosurgeons had worked with) failed and she became confused and showed signs of pressure building up on her brain again.

Odalia wretched her depression by intermittently exuding bitterness, and self pity toward her situation. You couldn't blame her of course, but I wished there was a way to help her out of this particular loneliness. So we invited Odalia to become one of

the participants in the Reading and Reminiscences group that I organized and led.¹⁰ -I'll fly away-

She had plenty of keen insights into the readings, though sometimes she, like some others, would overpersonalize the meaning and intent within a story to make it more relevant than the author intended, to her own life. That was fine in my book for it was why we did the readings in the first place. I thought it an effective way to get into the reminiscing that the group was really about, even if I could not tell if the participant was just anxious to share her or his life or had actually misunderstood what the writer's intent was.

In the early days of the reading group many of the participants would collaborate in the reading itself—each reading a page or two aloud--from the selected short story before we had the discussion. Odalía, however, could not see without her glasses. And so if she forgot them she couldn't even try to read. Early on I was surprised that Odalía seemed nervous and anxious about reading, for she was a good reader, and as I said, she had a sharp mind. After a while, she usually forgot to bring her glasses. And once when she did bring them, she did not read very well, clearly below her own facility with language. I surmised that she had lost confidence, in part through the passivity imposed upon her by disability and age, which she had come to see as her new self.

Back before that time Odalía had told a story that allowed her to deeply amuse the entire group. It was in the telling of this story that Odalía became fully relaxed and her inner self, her glow, showed through like the sun breaking through on a cloudy day. Here she forgot about the extreme disability which was always the first thing on her

¹⁰ See chapter on Reading and Reminiscences

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mind and her tongue (especially around doctors and nurses). She fully enjoyed herself in the telling, smiling and chuckling.

The events took place when she was in her early teens in New Orleans. It happened that their home was located directly across the street from one of the main Black Churches in New Orleans. Odalia's family belonged to this Church. She and her sisters and brothers liked to watch, peeking from their window at the comings and goings on across the street. A prominent citizen and member of their Church was cheating on his wife. Apparently everyone in the Church knew about his goings on. But Mr. D. wasn't just having an affair. He was a lady's man. He was hanging around with a number of the unattached women who liked a good time man, including some of the women of the night.

Of a sudden, one day Mr. D. just upped and died. He croaked without a word of contrition or advance warning to anyone. He wasn't even that old. Of course, word got around that his funeral would be a few days hence at the Church. The day arrived and the Church was packed with family and friends. It must have been a weekend day, for Odalia was home and watched from her home turf, her porch or window. The funeral service ended and, as usual, people poured out onto the street. The streetside was lined by the hearse and the obligate procession of rented "limos" (though there were not really big limousines as we know them back in those days), lights on, flags waving, ready to take the parishioners off to the burial. The cars were now filled with the people and getting ready to take off. Just then, Mr. D's wife came out of the Church being consoled by family and friends. After a bit she took a good long look around, with an

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eagle's eye, and did a double take. Then she rushed down the row of limousines carefully looking into each. Each time she spotted one of the hussies who had been betraying her marriage behind her back, she reached in and grabbed that woman with all her strength, pulled her out of the vehicle, gave her a swift kick in the behind and sent her packing. Odalia told us how the rest of that family and friends laughed and applauded. When Odalia finished her story she leaned back and chuckled, a full belly laugh. I had never seen her so serene and content.

As she aged Odalia complained more and more in the clinic to nurses and doctor about every small thing which we were unable to do anything about. The trigger, it appeared at first, was that she was becoming less able to do even the few things that she had been able to do—eat and drink by herself, get around in her electric wheelchair. Increasing anti-spasticity medicine did not help calm her restless muscles. And she demanded more help, at home and at the Center. Meanwhile her slow decline, her loss of muscle control and her irascibility became a form of road rage—making her a menace on the “highway”. Driving the corridors and rooms of the Center erratically she was putting both herself and other disabled participants at risk of injury, knocking into things and rolling over feet.

At home, Odalia was cared for by one of her daughters, Carol. Carol had become a CEI home care worker because the other three daughters were all professional women with advanced degrees, and they had, for all intents and purposes, assigned Carol to care of their mother. If I recall one was a teacher, one a lawyer and

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the third was a social worker. Carol on the other hand had neither a husband nor sufficient education to earn the kind of money necessary to live alone in the Bay Area these days. She stayed at Odalia's house in East Oakland, near a lonely warehouse district not far from the Oakland Coliseum, where they had all grown up—perhaps before the warehouses--and her sisters expected Carol to earn her keep by taking full responsibility for their mother's care. Oh, not to say they never visited or checked in. They did that, but basically all the work and all of the expectations were on Carol's shoulders. Her sisters were Odalia's "advocates". As if Odalia, strong willed, strong voiced, needed advocacy.

In truth, Odalia's irascibility did not begin with any new physical or mental decline after she joined CEI but with her years of frustration with her post stroke losses. I find it hard to imagine the emotional impact of surviving a stroke, then regaining much function, only to see it whither away before one's own eyes. At the time that process first unfolded, Odalia was still a fairly young vibrant woman, in her 50s. Now there was constant tension between her, CEI and Carol. She had a habit of complaining bitterly about one to the other and finally to the uninvolved daughters about both.

For example, she made it very difficult for the transportation drivers and dispatcher. Customarily Bridget, the dispatcher, calls every morning to be sure people know it is one of their Center days and to give them the time they should be ready to go out the door when the van arrives. The exact time of pick up cannot be given because with severely disabled people, often with dysfunctional families as well, anything can go wrong in the morning and any participant can delay the van arrival time. But people

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have to be ready to roll when the van arrives. And anyway the drivers are usually on time.

Odalia sat out on her porch waiting for the van 10 minutes one day. Then she became angered and had her daughter take her inside. The weather was clement. The van arrived but Odalia refused to come out, saying she had been mistreated. There followed a period of refusal to be ready on time as reported to team by the dispatcher. In part, Odalia began to complain of intractable back pain upon awakening and resisted Carol's efforts to get her out of bed. Carol then hurt her own back lifting Odalia. Odalia made her driver and other participants late on many occasions with this passive aggressive one woman "strike" activity. She then agitated her three professional daughters to complain to CEI about CEI's laxity, and to demand more homecare. Finger pointing got around to Carol who was responsible for having Odalia ready. Carol didn't want to complain about her mother's behavior, but team could see that the problems were not Carol's. Meanwhile her sisters, who were prepared to rage against CEI (or Carol) were doing very little that was supportive or helpful and so both CEI staff and Carol were feeling animosity toward them on that score.

We could see what was happening. Feeling dis-empowered and fairly hopeless about life, Odalia was trying to recover some lost control. Her constant carping about the smallest things had driven her professional daughters and CEI staff to distraction, though her daughters loved her and CEI staff too were concerned for her pain and well being. Moreover, the daughters had no way of knowing whether her complaints, her pain, her multiplying anxieties reflected real physical problems or were part of her

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syndrome of loss. Enrolling Odalia in CEI and having their sister take care of her had been about the best (and last) thing they could do before totally burning out themselves. They just had exhausted their emotional energy with Odalia's negativity, and so they were sort of dumping her onto others, even though they were available to hear her complaints and to be her dutiful advocates; they were surviving by behaving like her social workers or ombudswomen.

The team realized that, as in the case of Luan (see Luan later), Odalia was successfully splitting her care givers, family, and team members against each other as an unconscious tactic to get more love and attention. In the face of the transportation crisis and family accusations, I, along with our Executive Director Peter Szutu, had gone out and visited the 4 sisters at Odalia's home to try and reduce some of the stress and acrimony. That conversation had been fairly successful for quite a long time. Then--a couple of years later--after her shunt revision seemed to stabilize her medical issues, but as a new crisis in complaining and family loss of confidence in CEI overcame us, we had them all in for a team-family conference at the Center one evening. Our hope was to create a common front of unity among the four sisters and the staff that would assure maximum communication of concerns and maximum responsiveness. We also needed the family to accept, agree, understand, that much of the hostile complaining from Odalia was a reaction to her generally dis-empowered state, not to acute medical changes.

We planned to talk first with the four sisters and then include Odalia. But Odalia, was too keen; she caught on to what we were up to—that we would ally with her

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daughters with her out of the room--before we had the meeting and refused to come in to CEI with them that evening. She realized that we were “teaming and scheming against” her. Of course we were not scheming “against” her, but the truth is that we were trying to take away her power to disrupt CEI and to cause CEI staff and family members to blame each other for not doing enough.

With Odalia absent, there was a meeting of the minds. We acknowledged that the family was very stressed for good reason; it was natural to be so, both by Odalia’s terrible life situation and by the incessant complaints and bitterness that Odalia brought forth. We praised Carol for continuing to provide care and work under such difficult circumstances. We acknowledged that we were also susceptible to finding Odalia’s negativity difficult to deal with. That seemed to help them understand. For a while after that, the love of all the daughters was manifested by a greater involvement with Odalia and in efforts to discipline her in relationship to her provocative behaviors and her responsibilities as a CEI participant. She was less able to blame CEI to her family and her family to CEI staff. But these were long standing patterns of dominance and family relationships that even went back before Odalia’s terrible losses. The power of Odalia, as matriarch of the family, could never be fully ignored.

Odalia lived another 2 years after these episodes and died suddenly. I had seen her again only a few times in reading group in that intervening period and was no longer her physician. In the group, she still tried to participate in discussions with some vigor and autonomy, and within the discussions I was able to keep her focus on the joys she had had and the good feelings that attend telling a spellbinding story for other. I turned

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aside physical complaints she brought up to me within the reading group setting, asking her to talk instead directly with Maria Magat, her physician.

A magical Readings and Reminiscences group helps me survive

Having accepted the Medical Director position at CEI because the team based interdisciplinary model (PACE teams meet daily for 60-90 minutes to discuss all aspects of participants care and lives—acute, chronic, social situations) seemed so powerful and humanistic, I hunted for a strategy for my own survival, given my reluctance to work with dementia especially. It didn't take long to find an answer as revealed in the very first essay about Ara Belle Kingsby. I love teaching, talking with people, and especially getting to know all about them. I realized that I could combat my concerns about the lack of dimensionality in working with the cognitively impaired by allocating some (of my own) quality time to working with a group of the mentally high functioning program participants in the Day Center in a non-medical context.

Fond of literature and culture I understood the importance in later years of life of remembering and “re-living” some highlights of our earlier life and loves, joys, achievements, trials and tribulations. In fact, there is an entire field of work examining and prescribing the therapeutic value and methods of reminiscing and of autobiographical writing for elders: memoir writing for the elderly. This book is, in fact, a memoir, and I am an elder.

After pondering Ara Belle Kingsby's relationship to Lead Belly, I enlisted the support of staff in the activities program (Jackie, Lilian, Shefa, Mary Watson and others) to help establish a “Reading and Reminiscences” Group. Mary served as my co-leader until her retirement. The group was open, but by invitation only, to those elders who

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expressed interest and who demonstrated an ability to speak out in groups and to talk about themselves with other participants. Usually attendance ranged from 8-12. Over the years the group existed, we accumulated a fantastic dedicated core that included William Usher, James Williams, Rosie Goodman, Odile Ricks, Gladys Hill, Vera Culpepper, Sylvester Hawkins, Albert Lute, Josephine Herring, Leonetta Roberts, Ernestine Ware, Helen Bell, Bobby Gay, Ara Belle Kingsby, Sofronio Zambrano, William Allan, Florene Thornton, Verdell Cartwright, Carlina Benehan, Georgia Wishups, and several others.

The format of the group was straightforward and was left untouched during the many years that I coordinated these sessions. The sessions lasted about one hour during which two or three 5-10 minute readings of short stories, sections of autobiographies or poems were read aloud. These readings were usually selected by me. I found brief stories and essays focused on people's lives which might evoke thoughts about the participants' lives. After each selected reading I would ask people if specific things that occurred in the story or autobiographical sketch brought back any memories to them and then a spontaneous discussion would occur for about 15 or 20 minute. Sometimes I asked more specific and challenging questions of the group. I found one of the stories told by William Usher so moving and engaging that I transcribed it and, with his permission, included it in the Keeping PACE book we later put together. Here's Mr. Usher's story:

HAMP

From the Life of William Usher--Age 93

[Transcribed from the Center for Elders' Independence Reading and Discussion Group 12/27/95: Reflections after a brief oral reading from Nelson Peery's "Black Fire" where Nels and Six become blood brothers: (page 33)]

I have a statement similar to that. Only I have a working situation, not the schooling. I grew up on the farm which I've talked to you all about from time to time. The farm where sharecroppers farmed. This man here is wealthy owned a hundred, a thousand acres of the land and little houses scattered about in terse spots (that mean's good land). Every so many acres, here's a house. We lived on that man's farm. They had white attendants lived on that man's farm. And I myself, no brags or complaints, I still think of that boy today.

I was a Black boy that'd make friends everywhere I went. And I had three white boys on that farm that were lonesome seemingly. And I had seven Negroes to play with. We had a little ballgame to play on the pasture land. Well these white boys would come up and set and watch us so eventually one of them ventured out to me. And I had been playing around my house and his house for quite a while.

And he told them he wanted to join the team. The other two set back and said, "what do ya mean?" And he said "I'm gonna ask William, could I join the team." Well I was the middle age among em, but I was the biggest guy there. I weighed 200 pounds. (How old were you then someone asks Mr. Usher) I was 18 years old. (And you were 200? a woman's laughter). Yeah.

That boy he said, "I'm gonna talk to him". And he did. And one of em said, "supposen he turn ya down". He said, "No he ain't gonna turn me down." "And he (one of the white boys) said well if he takes you on, some of the rest of em ain't gonna like it. Then whatcha gonna do?"

"Well as long as I got William on my side I'm not gonna worry about anything." So he all up and come up among em and asked em out like we talking now. And I reached out and got him and shoved him up beside and he locked his arm around my shoulder. He said, "we're all dust farmers. We plow just like ye do, use the garden hoein and scrapin just like ye do. Why we can't play like ye do?"

So I said, "Come on over here Walter". The other two they wouldn't join. But they wanted to watch us. They set out under the shade tree. We had lemonade in the jars and jugs setting in a #2 washtub with ice, cold. And made em welcome to that. My parents and others around there, bout 3 or 4, cut a ham. And we had it all spread out there--corn bread, whole cake, biscuits. We cut it up, slug as big as this hand (Mr. Usher raises a gnarled, but very large and impressive hand). Everybody had a good fill when they get a piece. But let's leave that alone and let me come back to tell ya what really happened:

I took Hamp in and we joined; we had a good team. (Someone asks Mr. Usher: What's his name? Hamp. Hamp Washington). Well he tied on to me; when we broke up that game he went on home. He used to come to the house. Up there on the porch. We played jacks stone with rocks. Catch em up here. We had a lot of fun.

Photo of William Usher and Ella Barfield to be inserted

-I'll fly away-

Well it got to where the saw mill moved into town. And now we lived in the country but I called it a town. Well He (Hamp) had a father that was shift man; that man was the engineer for these standard engines that buckled down on the ground, all goin around this way with wheel and a band. Well he take care all of that and he was a fireman. He fired to keep steam going. He taught me how to fire.

Well to goin in here we did and that mill come and it was a saw mill and they put that boy to work in that sawmill. And they didn't have no blacks up there; they had all whites. And I'm telling ya the truth; ain't got to lie to ya, I'm gonna tell ya the truth. That company that owned that mill wasn't used to no black people. Where they come from they had brought most them boys with em. But this boy Hamp they gave him a job in there through his father. Workin on the roller bed with a overhead saw we called a cut off saw, cut bad ends off a lumber and roll it out there to a foot marker on that wall and when they cut it it'd be an even cut, 14 feet, 16 feet, 18 feet, and then the other boys u'd runnit off down the road and off it'd go to a pile up on the side there.

Well this boy he'd worked there about 4 weeks and he somehow, he didn't like the boy that was workin, we call off-bare. When he cut this lumber the other boy kick it and roll it on out. Well, Hamp wanted me there. He told his daddy, "I want William to be my off-bare for this saw". He said well we can't do it that way. All's they got in this here mill is white. He said, "Well, who stacks that lumber out there? They ain't white."

"No, those are Negroes. They do the hard work" And he said, "well this ain't no easy job. William'd be just fine. Say, look ya got two over there runnin from this saw. And William take that lumber and run it on out yonder and take it up on the ramp and tell

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all the people kick it up on the ramp where it go. So his father, Mr. Luke, his father's name Luke, he looked into it and said well we'd save some money. Well he talked to the boss and he didn't know nothin about it. The boss, JJ White was the boss' name, he became governor too of that state ("he did?"; "he sure did"); he give me a job through talking to Mr. Luke. He told me come along boy and I always would go up there and sat around watchin them work, but I never could get..look I would go up and go to Mr. Luke and tell him..I said I would like to get a job here. And he'd said I'd like to see you get a job here. We'll have to work around to it. But I'm gonna tell yer daddy to don't let you keep comin over here and standin around like this. They wonder why you keep doin it.

"Cause I want a job". He says, "well I knows that too, but they don't, and I don't want them to jump on ya." So I just carry a bucket; that little lunch bucket used to carry to school. ...with a little tin top on it. I carry that little buck with corn bread, slug a hard meat, a sweet potato and some black molasses ("oh yeah"). I'd hang that bucket up on the side of a tree, on a nail, anything. I just stand right around until that whistle blow. When they go to dinner I go and take my bucket. Yeah, set right down, aw a little further than from here to that wall (though now blind from glaucoma, Mr. Usher gestures toward the wall). They'd look at me and I'd look at them. And I'd just keep on and eat. When I'd get through I hang my bucket back up. When I go home I'd just tell my mother that I didn't get no job today.

She'd say, "well ya keep tryin." She was innocent about it, ya know. I said well, I'll go keep tryin. So when Mr. Luke told me they were goin to try to get me job I told him what he (the boss) said. He said well that's gonna be fine. I think ya probably might get

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it before the weeks out. I be glad if ya do. 15 cents a hour that's what they were payin.

Alright, I got that job and went to work. And they put me beside that white boy.

Him and I run that saw and that, that roller bed ran all the way out, out 35 feet. I run that thing out to where they had two other boys out there, I run it out there by myself. ("by yerself") Yeah, I take that board and I go with it. And the rollers had little roller bearings in there they call it. they oiled them up every morning. Hamp, was his place to oil them up. They rolled grreeeeeeouwwwww....You could cry with the board if ya didn't get up on the work, ya know.

Had to walk along; that roller bed is up about two foot high. Ya wasn't bent down and ya wasn't strainin. Just put yer hand down on that board and away ya go("way ya go"---Ella Barfield). And I carried that lumber like that for 6 weeks. So one day out of that 6 weeks we was laughin and talking. Hamp said to me, he said, "we got to get brand new overall suits." I said yeah? Well I ain't got no money, I can't get none. He said aw yeah you gonna get one.

So I went on up to work. That Monday morning I come out. Hamp come up to me and said, we called it piscetony. It was wrapped up in a big brown we called it sugar paper--brown sheet a sugar paper. I caught it this way. He said go down behind the road there where just the top of yer head'll be seen and pull off them clothes. I said, "what's that for?" "Open it up fool, and look and see." (laughter all around the audience). I ripped the paper back and its a brand new overall suit. Yeah it had a jumper with a blanket liner in it. These overalls, the insignia on the buckle here that said Carhart. There were some good overalls in those days: Carhart, Dixie, and another

one--I forget the other one's name. But anyway, I had the best suit ("you had the best suit" echoes Mrs. Barfield). Yeah. Well I went down and put that suit on, look liked my leg fit me just right, wasn't too low to fold up, none a that fold and I had on a good pair of old hobnailed shoes and that made me dressed up when I had good shoes on. And I come up out a there and them white folks looked at me --the company servant to them-- they looked at me and they all had a big laugh.

"Come here boy." Turned around me and looked at me. They wouldn't hit ya know; they'd take a hand and catch ya here on yer shoulder and push it back. "Get on out there and go to it." (gruffly). "Well you earned that suit. Now go on out there and earn yer days pay." "Thank you, sir".

Went out there,...we worked there about 10:30. Well ya know we wasn't working any over 10:30 when that boy, my best friend, pullin that saw and cuttin that lumber and he started singin one a them little cookoo songs. Ahooaaahahooaa. You could hear him hollerin out there for miles. That boy could sing. He called out some kind a way. And he cut that stuff and turned himself around, and swung around playing. And he caught that saw and it went yeeeoowww, and went back. And when he turned around he turned it loose with power. Let it go ya know. The weight 'll snap it back. And that thing snapped back. And that doggone saw come right on back out when he turned, it caught that arm. Cut that hand off. ("Cut that hand off?"). Cut it off.

And went in his jumper. (He had his new suit on) went up it like that. tellin ya all what happened. It split that man's arm--bone--all open; fillet on just like that. He hit the floor and screamed one time. And I was right up under him. I grabbed him--I tell ya all

-I'll fly away-

the truth--I got this judge it. ("You picked him up?") I didn't pick him up. I got him on my knees. I put my hand under his head and I had it to my chest screamin all the while. Well they heard that screamin but they didn't pay no attention.

When they turned around to look and see. Then everybody come. Had 15 men working that mill. All of em come. Said pull him off of ya, pull him off. He gonna bleed to death. And he gonna bleed like that with him. So they tied him off up here (gestures to just below his shoulder). Still didn't do no good. ("Cut that hand off?", Mrs. Barfield)(Yeah, cut that hand off,--Mr. Usher). And cut that arm up just like you split a watermelon. I was right down there hanging on to him. When Hamp come to hisself and stopped cryin he threw that other arm around this back a mine and he said, "You're with me, huh?" And I said, "yeah, I'm with ya."

"Thank God. I'm hurtin, but thank God. Tell them to get me out a here." They all standin on over us now.

Boss man come and he said put him in a car. And they took, and run him on out a there and check into, named Brookhaven. ("that a hospital?" Yeah). They took him to Brookhaven and they took that bone on out, right out of his shoulder. They didn't lose no time they took in out. It was split open and they took it out at the joint. And Hamp stayed in the hospital 7 weeks.

And when he come out he come out askin for me. Well they put me on that saw. Hamp came by and he said, "let me pull it one more time?" I said, "no Hamp. I don't want ya to do that."

-I'll fly away-

Well they all saw him standing around me. They saw me talking to him. And after a little time they come on down. Said, "what's the matter William?" I said take Hamp away from here. He wants to pull that saw again. I said, I don't want him to pull this saw no more.

He said, "well if you say he not pullin, he don't pull it." And he (Hamp) cried. Got on that shoulder right there, he cried. God, I wish I could see him right now, here with us. And he says as long as he lived and the mills runnin anywhere, to give him a job.

Yes, I stayed with that man 4 years, with that mill. And when it cut out, they moved away. And when they moved away they moved out here to Eugene, Oregon-- some big timber. And my partner told me not to come cause I was not experienced to work in big timber. I said, well we can learn.

As long as we're getting all that other equipment anyway. This carriage and stuff is too small. We'll try and get stuff to handle that job. So he did. He got a 22 inch shotgun beam. 22 inches is a pipe that big around. With a piston in it works just like the piston in an automobile. Well that thing had a shaft, 30 feet long shaft, right down this track. Hooked that to the carriage. When they turned that steam on and moved that lever, that thing run on just about like that. Could hear that thing singin like..yeeaaoooooowwww. It done cut on 20 foot long.

You run right back; and they had a seat made just like you got here; with a cushion in it. Strap around it and you buckled that man in. And the bloss is up the center right up in front of you just like the typewriter. You had two little levers you matched with the air. You hit that little button. You watched and you watched your

-I'll fly away-

sawyer there. When it go this way you look back there; when you turn your head he was there ready to go again. This man here, I had to tie him up all up like that; but that man's story there. And this thing hit me just like it was done yesterday. (end)

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For several years these Reading and Reminiscence sessions kept to a monthly schedule. In my last year or two when we had 3 centers operating I continued the sessions but held them more occasionally and only back at the founding CEI center. Twice I tried to run a group at the downtown San Pablo center but could not arouse sufficient participant commitment for the idea to get good attendance. Some favorite authors in the series included Toshio Mori, Langston Hughes, Alice Walker, David Hilliard, Nelson Peery as well as a host of other poets. Each of these sessions was audio-taped and several were videotaped as well. In the early years the readings were often performed by the participants—the book being passed around among them--as well as the leaders. Later, because some people attending had dysarthria (with poorly decipherable word articulation), poor vision, or weak reading skills, making it difficult for the group to understand, they (the group) elected to have Mary and myself and other group leaders do most of the readings, but participation in the discussions was always lively and engaging.

The participants loved this group and, of course, so did I. On the one hand I came to know intimate aspects of people's lives that I would never have had contact with as their doctor. Besides that I was honored to be hearing oral histories that reached back almost to slavery in the South and all of the trials and tribulations of

-I'll fly away-

sharecropping and farming and moving to the cities and living under very unusual and often difficult conditions. Our participants were from several countries but many were from the U.S. South and some from the Midwest and West. This group provided me a rich experience that did far more than fill the personal need that I had perceived. I was so excited by what we were doing that I made a composite video tape and gave a workshop about the group at one of the National PACE Conferences hoping to see other PACE programs adopt it too. If I recall only 3 people attended. I was saddened by that but the quality of my video editing (done then on my home VCR with no editing software) was so poor that not having a good audience was probably a blessing. I don't know if anyone in other PACE programs replicated this particular project, but I think it is a wonderful tool for enhancing the quality and meaning of life for elders. I still have all the tapes, though whether they have become demagnetized I have no idea.

Post Script: As the insightful reader will have surmised by now from previous essays, the concern that first motivated my organizing the Reading and Reminiscences group—that working with dementia patients would be tedious and boring—was not born out in my real-life CEI world. We, who work(ed) with this population, quickly learn(ed) strategies—often from the patients themselves--for sustained humanistic and often humor-filled interactions with them. Except in the case of the occasional bane of unremitting agitation (many dementia patients pass through an agitated phase but its time length is quite variable and many leave it behind over time), working with the demented can actually be a hilarious, joyful and a personally and socially meaningful experience. However, that is only so long as you are not the lonely single caregiver—

husband, wife, child or other relative or friend--stuck with the entire burden on your
back).
-I'll fly away-

---The Longevity Project: the Impact of the PACE model on the Lives of its Participants

When CEI finally hired Amy Hephner as its first Quality Improvement Coordinator in 1998 I breathed a sigh of relief. Amy was skilled and intelligent and she had some organizational and project leadership experience with the Georgia State Health Department. Although I had given up the role of Quality Coordinator to Occupational Therapist Peggy Elms some years before, it was an obvious holding action. CEI was becoming too big and complicated for all concerns about quality to be the province of on-line staff like myself or Peggy who had full time obligations in direct care, staff management and department administration. Amy coming on provided not only an opportunity for the quality of the program to be better monitored and improved but a chance to look at what we were achieving more broadly. Foremost for me was the poverty of proof in the literature that PACE really was as vibrant an environment for enhancing quality of life of the frail elderly as we claimed it was. Yes, there had been several dozens of descriptive papers on the model by leaders at On Lok and other PACE program and these were both excellent descriptions of how PACE worked and why it succeeded—complete with many anecdotes--but some “experts” were writing much of this off as self serving.

Then about 1996-7 ABT Associates which had been contracted to provide an overall evaluation of PACE came forth with 4 volumes that began to substantiate with outcome data what had been obvious to anyone engaged in implementing this model of care. ABT showed that PACE was doing remarkable positive things for this population

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in terms of reduced hospitalizations, early diagnosis and treatment and quality of life.

Meanwhile, there was informal talk around the meetings of the PACE Primary Care Committee (made up of the Medical Directors and other key care providers of the PACE programs) suggesting that on average participants were living about 2.5 years after enrollment in PACE. Looking at our experience this didn't make sense. It had to be an underestimation. A simple thought experiment showed the error. If the length of stay in the program was calculated based on those participants who had already died (and it was) the average would sharply underestimate the true average length of life in CEI or PACE nationally by ignoring all those who were still alive in the program for longer periods at the time of the study.

The idea of estimating how long people live in the program interested me. It might also be a way to estimate the quality of life that PACE was providing (as well as the quality of the medical care). In general, people in great distress, depressed, severely ill, suffering a poor quality of life are not likely to stay alive very long, no matter how good their medical care, as some of these essays demonstrate. If people are staying alive longer in PACE, that would imply a better quality of life in general. If we were extending life, we were simultaneously enriching the lives of participants in ways that participants and families could appreciate and be satisfied with.

Amy and I decided to perform a study with CEI data to look at how long people really do live in the program and then later to also look at which types of disabled people (demented, heart disease, stroke victims, diabetics, etc) seemed to do best—live longest-- in the program. For the data to ultimately stand up to rigorous scrutiny we

-I'll fly away-

wanted to merge data from all the PACE programs and find a comparison group with similar medical problems and level of disability to see if we could show significant differences from Nursing Home patients. With statistical advice from Steve Selvin at University of California, Berkeley we elected to use the Kaplan Meier extension of the SPSS statistical package in order to be able to include estimates of the length of life of participants entered in the program who had not yet died.

When we ran our analysis on the several hundred total participants (with 108 actual deaths) we found that the estimated length of stay to death was almost 4 and a half years. We thought this was quite good, given that a requirement to enter a PACE program is that the participants must be at a level of disability which might otherwise require placement in a nursing home or 24 hour supervision or nursing support. And the average age of our program's participants was about the same as the average expected life span of Americans (at that time) of about 78-80 years.

A search of the literature revealed a few studies on nursing home populations that showed high percentages of deaths even in the first year after nursing home placement, as high as 50% whereas only 12% of CEI participants died in the first year. In one study of all people in Virginia who had been in nursing homes for several months and then were able to go home with support due to improved status, 26% still died in the first year after discharge to home compared with our 12%.

We wrote up our findings including graphs and graphics and presented them as a poster at the annual meeting of the American Geriatric Society in Nashville. Although we never were able to run the Kaplan-Meier estimates on a merged data set from all the

-I'll fly away-

PACE programs in the U.S., I surmise that the results would have been similar. Amy and I posted our findings at each of CEI's (then three) centers for a month so that staff and community members could appreciate that our community was providing relatively long life to its members. And although the estimated average was 4 years and 5 months I note that when I left CEI in 2001, several participants were still alive who had entered the program at its initiation in 1992, some of these folks were, by then, in their late 90s and others over 100, despite living with severe chronic disabilities.

The Keeping PACE Collection

In 1996 I formed a small volunteer committee of staff from 4 PACE programs (ours, Milwaukee's, South Carolina's, and East Boston's) interested in publishing a collection of writings of staff and participants. We called it Keeping PACE. As I mentioned we included William Usher's story, Hamp in that collection. Here are a few more excerpts that we found remarkable:

Paul Dudock Finds His Family

by (Detective) Robin Bon Fredericks RN

I work at the Center For Elders Independence in Oakland as a registered nurse. I have come to know most of the clients, some more than others. Paul Dudock is in his 70's and has a history of a stroke. The stroke left him with a right side weakness and aphasia (the inability to talk). Paul is a pleasant man who always greets me with a smile and a tip of his hat. While reading his chart I discovered he grew up in Saginaw, a city in Michigan next to Midland, the city where I grew up. When I mentioned this to him he was pleased and I felt, because of this mutual beginning, our relationship was a little closer.

Some months later, as I was standing in the hall saying "Hi" to Paul, his social worker Ann Moghaddas walked by. Paul stopped her and pointed to her. He then pointed to me and again to Ann. After the third round of this I felt compelled to get a conversation going. So, I told Ann the only non-medical thing I knew about Paul, which

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was that we had grown up in neighboring towns. I swear a light went on in Ann's face as she said, "I know what Paul wants you to know. Paul has a brother, John Dudock, whom he has not seen for years and we have not been able to locate. Perhaps you still have some connections that could help find his brother." Tears came to Paul's eyes as he nodded his head. I assured Paul that part of me has always wanted to be a detective, and I was happy to have my first case.

Ann filled me in. She had called the phone company who knew of a John Dudock but, because his number and address were unlisted, would not give them to her. The Red Cross was also not helpful stating that unless it was a matter of life and death they could not contact John Dudock.

I began immediately by calling my mother who now lives in Concord CA, to get phone numbers of the people I thought could help. My godmother, Margie Loessel, who was the former director of nursing at Midland Hospital, was someone who would understand the situation, be willing to help, and know a few strings where a tug or two might get past the red tape that had stopped Ann. My other hope was my "Uncle" Bill, a retired minister who is very good at getting results, though not always through traditional channels. Mom gave me both numbers but told me Bill would be at his cabin till the end of the month 2 weeks away, and Margie may be at her cabin too. I tried both. Both were indeed at their cabins but Margie had a phone in hers. Margie did understand the situation and agree to help. She planned to pick up the trail at the Red Cross and see where she could get it to lead.

A week and a half passed and I didn't hear from Margie. When I called her she

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told me she had not been able to contact John Dudock but had gotten the address of a Crystal Dudock. She wrote her a letter explaining the situation and enclosed her phone number and self address stamped envelope. She was still waiting to hear from her.

I gave Uncle Bill a call; he told me he'd be happy to help and planned to start with the phone company. He thought that although they could not release the information, they may be willing to call John Dudock, explain the situation, and give him the option of contacting us.

About a week later on a Friday as I was cooking dinner, the phone rang. The voice on the other end said "You don't know me but I'm calling from Michigan and my name is John Dudock." I was ecstatic. He went on to explain that he was John Dudock Jr. John Sr., Paul's brother, had died 2 years ago. John and his mother Helen (Paul's sister in law) had been wondering where Paul was but had not been able to find him. Helen was living in Riverside Ca. with her daughter.

When I asked John who found him, he told me a woman in Midland gave him my phone number. The phone company had called his house earlier that week, but his daughter had answered the phone and she had never heard of Paul Dudock and did not know she had an uncle by that name. It was the contact through Margie that proved successful.

John said he had a video tape of his father at his 80th birthday party that he would make a copy of and send to Paul. He would also call his mother and give her Paul's address and the phone number of the board and care where Paul lives. Explaining Paul's aphasia I assured him someone there would interpret for Paul on the

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phone.

Since that weekend, Paul has received a letter and family photo album from Helen. We have taken pictures of Paul and sent them to Helen with an invitation to visit. For the first time in over 20 years, Paul Dudock has a family.

Case 1: Solved.

Willie and Me

By K.C. Chapek, R.N.

*"We are each of us angels with only one wing
and we can fly only by embracing each other."*

Lucian de Crescenzo

His dark wrinkled face lay cradled in my arms. "Just like a baby," I thought. "Once a man, twice a child" - a phrase repeated often here. Deep furrows in sunken cheeks and sharp gray stubble on a chin moist with drool hinted at a life full of stories I probably would never hear.

Six months ago, this same weary face met me at the door of my new - my first - RN position at CEI. A shrunken old man in a wheelchair - crisp clean blue jeans, pant legs tucked up because there were no legs, head slumped forward over a filthy moist

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plaid flannel shirt, a long string of drool running from a protruding lower lip to the curve of a white feeding tube poking through the opening in his shirt. His pants were always so clean, and his shirt was always so dirty.

Willie came to the center every day for several months because he “wasn’t doing so well.” My job was to push two cans of Ensure through the white rubber feeding tube and on into Willie’s belly with a 60 cc syringe, helping to keep him alive a while longer.. He rarely said anything. What he did say was usually inaudible. So, day after day I sat and pushed the chalky fluid, Willie slumped and drooled and slept, and I think both of us wondered, “What is this all about?”

What did Willie think of me? Did he like me? Did he wish I would shut up and stop asking him how he felt? Did he wish I would just go away? What’s the difference anyway? He completely ignored me. I was sure he hated me, or at best, resented me. I was young. I could walk and talk. I had legs.

One day was unusually quiet, but I felt restless at my feeding job. Willie was snoring. I was fidgeting. The room was absolutely still. Without thinking, I blurted out, “Hey, Willie, I invite you out to lunch and all you do is fall asleep on me - and drool!” Both eyes shot open. I didn’t know they could open that wide. “Now I’ve done it,” I thought. “A real professional approach to conversation with your patient!” His eyes narrowed to a slit and drilled straight into me. “Could I disappear now?” He slowly closed his mouth, wiped the long string of saliva on the back of his arm, and turned his head to glare at me sideways. The corners of his mouth twitched, as I braced myself for impending rage. Like a huge explosion, laughter came bursting out, filling the room with

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life and merriment. Two other nurses sitting silently at their desks started to giggle, then laugh outright. I reached for Willie's hands, and we clung to each other, laughing until the tears rolled down our cheeks. We laughed for a long time and held our hands together even longer.

We became fast friends after that. The feeding tube was soon removed, and I helped Willie eat normally again. He seemed to enjoy looking at our hands side-by-side - his, so dark they were almost black, dry, scarred, misshapen; mine, so white the blue veins glowed and also scarred. We would point at different scars and speak of the hazards of working in the fields. We both grew up on farms and still missed that life - free in the outdoors, free of pain, free of wheelchairs, free of blue jeans with the legs folded under.

Willie and Jimmy, another client, often sat side by side in their chairs in the hall, silent and content in each other's company. They both loved the blues, so whenever I could, I would crouch down between their chairs and we'd sing, "The Sun's Gonna Shine in My Back Door Someday." Two shriveled up Black men who couldn't remember the words and a white girl who couldn't sing to save her soul. But we looked straight into each others' eyes and held strong to each others' hands and opened our hearts with no shame. And it felt true and good and very real.

I hold Willie's head in my arms. I don't call the health worker to change his soiled diapers, his wet blue jeans, his drool soaked shirt. Something is different. It smells different. Nine years ago, I smelled this same smell on my mother. Slowly and carefully, I remove all of Willie's clothing and wash him with warm water. I rub his

cracked skin with lotion. I massage his misshapen hands and his stumps of legs. I
comb his hair and put clean clothes back on his painfully thin body. I hold him close
and sing, "The Sun's Gonna Shine in Your Back Door Someday." . . . And the next day
it did. "Oh, Willie! Dear Willie! Thank you for coming into my life, for coming close into
my life and embracing me. For a little while, we flew together, side by side, arms
around each other.

Sometimes I look into the mirror and see the wrinkles starting to form, eyes a
little more tired and droopy, hair a little grayer, and I try to imagine what I will look like
when I'm 80. . . 85. . . 90. Will someone smile and sing to me? Will someone hold my
hands? Will someone not care if I drool and mess my diapers and smell badly? Will
someone care enough and get close enough to wrap an arm around me and fly?

Emma¹¹--by Nettie Stoval, Physical & Occupational Therapy Assistant

Emma is a daily guest at the soup kitchen.

She's small and stocky and slightly stooped-a sign of her advanced years.

She climbs the long flight of stairs with difficulty to join the hundred others for the midday meal. All of the street people know Emma. Some call her "Bird Lady" because

of the hours she spends each day sitting

on the bench outside the railroad station,

feeding the pigeons she

calls her babies.

"Do you have some bread today for my babies?" she asks. The kitchen volunteers save stale bread for her and send her off with a supply.

They put in some pieces of fresh bread, too,

in case she needs it

for her dinner.

I think about my own aging and wonder if I will cope as well as Emma does. With meager resources, and dependent on charity to meet her own needs, she is cheerful

and shows concern, even asking for help

to care for some of

God's small creatures.

¹¹ Emma was not a CEI participant.

Playing House

by Odile Ricks, Participant, Center for Elders Independence

**When I was a child,
We used to dress up like grown-ups
And make a funhouse,
Then we would make imaginary food,
We would also make grass dolls,**

**Now all of my children are gone,
A lot of time has passed since I was little,
They are busy making families of their own,
The children they have different lifestyles
They don't make funhouses,
Or make-believe food
Or grass dolls
I don't even think that kind of grass grows here
TV and fast food places took the funhouse away.**

10/19-94

Investing in Loss—Tai Chi's lesson

We brought the ancient Chinese art of self defense and spirituality known as Tai Chi to the disabled elder community. Tai Chi contains a central theme and five basic principles. The principles are Relax, Turn the waist, Keep the back strait, Separate the weight, and the Beautiful lady's wrists. Conscious relaxation is fundamental while a theme of Tai Chi is "invest in loss". When I wrote these words in 2002, Sheila (my wife) and I had been studying Tai Chi with a fine teacher at Berkeley Tai Chi, Lenzie Williams, for about 8-9 years. That is, I began Tai Chi a year or so after I started working at CEI. Tai Chi had an important place in my understanding of my role at CEI--more than I realized in 1995-6 when I decided to ask Lenzie if he would be interested in leading a class at the San Pablo Avenue center for some of the participants, and he agreed.

About the time I became immersed in Tai Chi, studies and reports began to appear in the medical literature showing that Tai Chi was beneficial to the health of seniors. Of course it makes sense in that exercise, in general, is well known for its role in cardiovascular fitness and lowering of blood pressure. But Tai Chi has other beneficial effects too. It improves posture and balance and, as a result, it's associated with a reduction in falls and fractures. When we brought Tai Chi into CEI in our 5th year we had already instituted another Chinese art, acupuncture (almost from the beginning of the Project) and it had been well received by participants. Ironically, the parent PACE program--On Lok in Chinatown, San Francisco--had not gotten on either

-I'll fly away-

bandwagon and CEI became the first PACE replication site to institute both of these modalities born in China.

Where acupuncture is a passive modality applied “to” the patient, Tai Chi is an activity that requires intense conscious participation by the student/performer. They are both connected however by the Chinese theory of chi (energy flow) in the body. Acupuncture graphs out meridians along which chi flows and can be enhanced by treatments. Whether there is any objective science (other than the history of Chinese culture) of “chi flow” to explain why both of these activities are useful in health and fitness, I have no idea. I am skeptical of metaphysical theories, but some ancient health practices were adopted by peoples because they empirically appeared to sustain health. I have also learned from Tai Chi that there are powerful forces in the human mind and spirit that can tune the body just as a mechanic fine tunes a precision engine. This tuning approach is apparent to us all in the amazing achievements of professional athletes, and Tai Chi is a form of mind-body tuning.

When Lenzie, who is African American, 6 feet tall, 220 pounds, a calm, supportive and gentle man, a storyteller, a Vietnam war vet, came to teach and lead a Tai Chi class at CEI he had already done work with some senior groups, but now, in working with demented and the severely physically disabled, he faced new challenges. He reduced his teaching module to a few movements and patterns he thought would be most beneficial and which could be done either sitting (in a wheelchair or regular chair) or standing. Staff were intrigued by the Tai Chi and for most of the time that Lenzie taught (about 7-9 months I believe) they assisted in getting the appropriate participants into the

day center and ready for practice on the appointed day of the class. A few staff also participated in the class and Susan Musicant, the physical therapist, joined Lenzie's Berkeley Tai Chi school for a while as well. Participants learned, among other things, to hold the ball, shift the weight, turn the waist and coordinate this with the hand movements of the 4 corners.

About the time that Lenzie decided to discontinue his role, one of his senior students, Ruth Minka—a chiropractor who was already working with us in that capacity--began to teach Tai Chi class at CEI's Highland site. A couple of months after Lenzie left, Don Gillespie, an RN from Marin who had studied Tai Chi with Ben Lo--the same master as Lenzie-- for many many years, took up the San Pablo class.

Although—at this writing in 2002--acupuncture was in its tenth year at CEI, sad to say that Tai Chi was discontinued after about 3 years. While Ruth simply had done as much of this work as she felt she could contribute, Don thought that someone on staff needed to lead a practice class once or twice a week besides his teaching day for the Tai Chi to have any lasting effect. (Usually students of Tai Chi are urged to practice daily, but achieving this was beyond the resources of the activities program). He also thought that staff were no longer interested and were not giving the support in terms of assembling and motivating the participants in the group sufficiently. Although Tai Chi remains a proven positive modality for strength, balance, improving affect, and preventing falls and fractures that asset is gone from CEI.

In terms of Tai Chi's impact on CEI through its direct impact on me, however, it remained boyant and could not be so easily banished. Before Tai Chi at CEI I knew

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intuitively how important it would be to find a way to successfully integrate losing a participant to death into our team culture in some systematic way(s). We could not just announce a death at morning team briefing and go about our routine business. Of course I was not alone in this feeling. The social workers, the day center staff, the activities people, the nurses—everyone--wanted to take time to remember the person, to revisit their life with us, to reminisce and to consider whether there was anything we should have done differently for that participant.

In the early days of CEI the first team at the first Center began to take the time, upon a death, to have a few minutes of remembrance and sharing about people who passed. Understanding the importance of religion and religiosity in the African American and Latino communities, and finding that I wanted even more closure than a morning circle in the Day Center, I began to attend funerals whenever my patient care could be scheduled around them. I not only found this experience personally calming and edifying but the families were obviously proud and appreciative that the doctor would take time out to honor their loved one thus. I think that the social workers, led by Ann Moghaddas, were already carrying out this role when I joined in. But bringing the doctors along was something that I thought important and began to encourage of our new physicians. By the time I left CEI in 2001 it was not uncommon for a whole van load of staff and clients to attend the funerals--and memorials in some cases--and for some one or more of us from CEI to get up and say our piece/peace to the family and congregation about our love for and life with that departed soul.

So what does this have to do with Tai Chi? As I wrote before, a central theme of

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Tai Chi is “invest in loss”. I think it so important to consider the idea that loss is as much a part of life as gain, defeat as much as victory, sadness as much as joy, death as much as continuity in life, decline and decay and dependence as much as growth, rejuvenation, fortification and independence. We all know these things but **to invest in** the idea of loss is more profound. What does Tai Chi mean by this phrase?

We accept unpleasant things that happen to us with resignation, with indignation, with passivity, with dignity or with anger or resistance. Yet in none of these ways of acceptance are we investing in our loss as if it had some important meaning, some value to give us. Tai Chi teaches that loss is a way to explore our own personal limits and learn more about ourselves, both physically and emotionally. Tai Chi students are taught to not resist too hard the advances of their adversaries in games or combat, but to allow—to make room for--the adversary and let the adversity in. In exploring the limits of our acceptance of confrontation, by creating distance, we slow time down and can appreciate the “other”-- how they are engaging--while developing and understanding our own reserves, our capacity for growth and response. As we practice and study our ability to accept loss, consciously, our limits expand, our ability to absorb loss and shocks and attacks, and our engagement with the outside world actually deepens; and as a result our responsiveness is fine tuned. We are strengthened by our losses if we pay close attention to expanding our limits, our engagement deepens. That process advances our understanding and our ability to respond successfully to adversity. I believe, as many traditional cultures claim, that we grow with our losses and if they do not topple us, we accumulate wisdom from our experiences. Through their

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experiences—and losses--our elders express that wisdom as a form of history that may be absent from academic discourse and history books. As history is a profound teacher, our elders are a repository of history and meaning.

Investing in Loss: Leroy, Sadie and Rosa

(Thanks to CH (“Rosa”) for sharing her reminiscences of Leroy).

Fact was that Leroy was staying alive because he loved and was loved. He didn't dare die on them. For most of his life Leroy had given much to others—to family, friends and anyone who needed help—emotionally, physically, materially. Now his wife, Sadie, and his grandniece, Rosa, were reciprocating for his life's gifts to them. Sure, at home he was gruff, but they knew it was “an act.” He'd act like they were intruding into his peace of mind. When they asked him to confirm something he'd said he'd come back with: “I didn't say that.” The way Rosa explained it to me this grumpiness was a coy game. He'd make you work; give you a hard time. Engage you so as you would appreciate him. He worked hard at it and he had fun doing that. He loved it. He loved for you to care; and he liked to act like you were just pestering him.

Leroy's mom had died in childbirth. He was raised by his grandmother who must have given him much love and support, given who he became. Beyond his gruff exterior at home Leroy was a social, good hearted and outgoing fellow. As a teen he became a chauffer, then moved to construction work in Phoenix. Arriving in the Bay Area of California he worked before and after World War II at Mare Island Naval

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Shipyard. Besides putting in 4 years in the Army in the hell of the Pacific theater, Leroy put in about 25 years or so in unionized construction until his retirement.

Leroy loved card games and dominoes and Sadie and he would go out to Tracy fishing regularly in the Sacramento River delta. They'd stay overnight in their camper out there. Leroy and Sadie were together almost 60 years but they had no children of their own, but they did have Rosa.

Back home after he retired Leroy would hang out in front of the house just standing out there on the porch smoking (a lot) and watching the neighborhood goings on. He didn't like to sit down on the porch; he'd just stand there watching. Sometimes Ricky from across the street--25 or 30 years his junior-- would come over and they'd sit in Leroy's camper and talk like folks do, and have a nip. Leroy was slowing down, yet Ricky was his steadfast companion.

Many years earlier the 14 year old Rosa had been unceremoniously thrown out of her Fresno home by her aunt (she'd been farmed to her aunt because her mom was in the mental hospital) for rebelliousness beyond their capabilities. She was taken in willingly by great uncle and great aunt, Leroy and Sadie. They gave her their boundless support and attention. She was as if their own only child—the child they never had. She arrived in the late 60s and they'd put her through a private high school in Berkeley, where she'd done well; well enough to enter at a UC campus after graduation. She never forgot their generosity, nor their loving support. They were her surrogate parents.

I learned details of Rosa's life after Leroy died because she wanted to tell her story. She had now bought her own home a half mile from Sadie's and checked in with

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her from time to time, sometimes daily. She was helping Sadie who was now 93--still clear minded and determined--to stay living at home.

But back in 1991, living with Leroy and Sadie, teaching in Oakland, newly married to a Marine based at Camp Pendleton, with her own beautiful children--a 12 year old daughter and 9 year old son--Rosa moved back in with Leroy and Sadie after many years on her own. She and her husband had bought a home out in Stockton where they planned to move together when he retired (he said he'd retire in 4 years; they'd live apart until then). Sadie who worked in Real Estate had helped Rosa with the details of that house buying, but Uncle Leroy had said, "that ain't no marriage". Rosa ignored him. After all, that was just Uncle Leroy. The problems attendant to living at Leroy and Sadie's in a single bedroom with one bed with a pre-teen daughter and a 9 year old son (from before her marriage), in their 2 bedroom house seemed to her surmountable. She'd wait.

But after a year and a half, things started to fall apart nonetheless. The kids complained mightily. The boy didn't fit in that room without a bed, with his sister and mom always there, and so was moved into the basement. The kids continued to complain. Sadie too complained that this arrangement was too much for her. Only Leroy never complained. But the complaining was unsettling Rosa and for all these problems she decided to move out.

It was then 1993 when, without forewarning, Uncle Leroy suffered a stroke. Rosa could see that Sadie would need her help. Sadie would not be able to handle all of Leroy's needs. So Rosa and the kids stayed. At first, despite some weakness, Leroy

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was able to help himself. He seemed to be recovering from the stroke, regaining strength, until he developed severe headaches and worsening weakness that troubled his doctor. These concerns led to a neurosurgical consultation and tests showed he had “normal” pressure hydrocephalus. (Though they call it “normal pressure” there is evidence of fluid pressure within the brain). The neurologist and the neurosurgeon recommended that in order to avoid more permanent brain damage Leroy should have a shunt placed running from his brain into his abdomen that would drain off excess fluid continuously. At the time of this procedure---usually not a risky one---there was a rare complication in the brain. Leroy was left paralyzed with little control of his arms or legs.

Rosa had to dress him, put him in bed, bathe him on days when there was no home health care. He could move his fingers and hands just a little, but they wouldn't do the work of hands and fingers. His legs were near useless. Leroy was left wheelchair bound and fully dependent. The doctors were talking about putting him in a nursing home. Sadie was adamant. Never, never would she give up Leroy. That's when they found us at CEI.

When he entered CEI in July 1994 Leroy was not only permanently in a wheelchair, but his legs had contracted, tightened into a 90 degree flexed and fixed position. He spoke (though he preferred not to speak) in short pressured staccato phrases and became hostile when touched unless he was peremptorily prepared for physical contact by some anticipatory soothing and a verbal explanation of what was to come. What was Leroy's quality of life like then—to Leroy himself. I surmised that the hypersensitive Leroy was probably the result of his tragic stroke and later complications,

brain damage. Leroy's quality of life seemed quite tentative, marginal. I didn't know
Leroy's underlying personality, nor his in-family gamesmanship. But Leroy, even with
some measurable memory loss and confusion, retained his underlying personality
according to Sadie and Rosa. They saw him as the same man they had known. His
irascibility was always part of him, even if now somewhat accentuated, they told us.
And by dint of their collective will, they were determined to prevent a break in the
continuity of his relationships to family and his more extended social relations.

To Sadie and Rosa, Leroy's losses were perceived of as their own and they were
going to invest in those losses just as Tai Chi masters advise their students, and keep
him whole. Leroy accepted and participated in this continuity in his community; coming
to terms with the tight bonds of his family I revised my earlier conclusion that Leroy's
disabilities, his almost total dependency, reflected a poor quality of life. I decided that
his quality of life was not nearly so insufferable as we doctors, nurses, psychologists or
ethicists might have imagined.

Some months went by. Despite some initial withdrawal from the new Day Center
social environment, Leroy eventually adapted to coming to the Center 3 days a week.
He seemed to like coming and to be fitting in. But his physical losses continued to
worsen. Though Sadie and Rosa agreed that he was less depressed and was
beginning to enjoy the program, his nutrition and hydration began to falter. Progressive
neurologic problems continued and eventually damaged his swallowing ability; he lost
weight, he got sicker and weaker and with the beginning signs of skin breakdown we
decided to have the GI doctor place a feeding tube in his stomach. By that time Leroy

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had been in the program only about 9 months, yet from a medical standpoint his outlook was bleak. As his management became more complex, requiring daily regular skilled nursing care, coming to the center could no longer serve as a valuable social support for Leroy. He became more and more “medicalized” (the focus turning to almost daily medical care in the clinic, and trying to prevent his further deterioration).

After team discussions, and with Sadie’s input, we then decided to keep Leroy at home, essentially as a hospice home care case. Sadie wanted this so that Leroy wouldn’t have the stress of going back and forth in the CEI vans all the time to the Center just for nursing attention and medical checks. Simply getting up and out of the house had become too difficult. Nevertheless, neither she nor Rosa viewed this as the end of Leroy’s life. They were still invested in the hope that he would improve and be restored to a stable condition. They pleaded with Leroy to fight to get better, though their pleas were, in my medical opinion, unrealistic at this point given the messages his body was sending out. Unlike Fred Lee in an earlier story, he was not regaining weight. His ulcers were not healing. His pain was persistent. They moved Leroy’s bed into the living room. He was visited daily by nurses to change dressings, maintain his tube feedings, and assure treatments with pain medications and antibiotics when needed. The social worker came by to visit regularly. I made visits at least twice a week, and daily toward the end of his life.

I could see Leroy losing his grip and being pressed deeper and deeper into a hollow. And so I talked to him and asked him if he wanted to continue with all these

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treatments. And he was coherent enough to understand me and said “yes”, to continue. He wanted to still fight to stay alive.

Seeing how difficult, painful and depressing life had become for Leroy, accepting his latest expressed desires was a struggle for me, though I was certainly going to honor them. But Leroy had been through the Pacific theater in the War, and he had clocked 25 years of construction work. He refused to give in, while I had trouble understanding how deeply his feelings were entwined with Sadie, and also Rosa; that he viewed his life as through their eyes—and that provided him significant autonomy in his life still. Until near death, Leroy would hold on to that connection for dear life. The three of them together viewed Leroy’s illness, failing health, impending death in a family context. The two women saw the dependent, wasted, contracted Leroy as only the mere surface of a larger continuous Leroy. So long as he had any identity that was “Leroy-like” his losses were simply a necessary part of life.

I only came to fully understand the depth of the attachment and collaboration in life between Leroy and Sadie in the last month of Leroy’s life—that they were as a single person. Then, when it got to the point where Leroy was certainly going to die within a matter of days or a week or so, I decided to bring this reality out in the open with Sadie. Not that we hadn’t discussed Leroy’s decline and impending death before this; just that it had always been in the “future” rather than staring at us in the present. I needed to say more. I knew she would be heartbroken, but I also could hear from Leroy for the first time that he needed her permission to die—would not let go without it. We had a family conference in their living room with Sadie and Rosa and Leroy present. I

again explained how bad Leroy's prognosis was, but for the first time pointed out that death was no longer off in some vague indeterminate future. I noted that--against my expectations--Leroy had continued to ask that we do everything possible to keep him going anyway. I told Sadie that I thought Leroy didn't want her to suffer his dying and so he was holding on by a thread, despite his own suffering, because she wanted him to stay with her so much. I turned to Leroy. "Is what I am saying fair and true, Leroy?" I asked him as gently as I could. Leroy looked directly at Sadie and he said "yes" without any hesitation. That was when Sadie agreed to let her Leroy die. And with that affirmation we stopped aggressive efforts to keep him hydrated with intravenous fluids and bother him with aggressive wound care, with pushing hard to maximize his nutrition, and instead changed the focus to pain control and comfort.

Rosa, who had never worked in support of a dying person-- let alone the one man she'd ever known as a father figure--had been an amazing asset for Leroy. She'd been the mainstay of the family care system for her beloved uncle and she felt crushed by the end of life conversation. Leroy died shortly after this. In an effort to continue the role she had played for Leroy, Rosa went on to play a particularly important voluntary role at CEI, helping CEI staff work with complex ethical problems of other participants and families over the next several years while serving on our Ethics Committee.

Tom W.

Today is March 24, 2003 and such a long time since I knew Tom Williams and his wife. Tom died, a CEI participant, over 10 years ago. He came to us after a repeating series of 911 emergency calls, Emergency room visits and a couple of admission to the hospital. His wife's calls to the Emergency Medical Services had been more on the basis of his behavior and her own coping fatigue and desperation more than due to any emergent medical need, though she never would say this up front to the paramedics. Tom was the first agitated male dementia patient we admitted to CEI. And he was a terror when agitated. Tom was the first hint to our team that, like full blown psychotics, the agitated dementia patient can become physically dangerous.

From time to time over the ensuing years when things went poorly or a dementia participant "escaped" from our watchfulness at the Day Center and was then found wandering the County Hospital (which could be accessed through an indoor bridge to the Highland Hospital from the building where our first center was located) one or more of our team members threw up their hands and claimed that CEI was not a good place for dementia patients; some claimed that staff training wasn't adequate and that these participants should all go to Alzheimer's centers.¹² Thank goodness many of those

¹² PACE sites all over the U.S. have had to cope with this debate and some have come up with creative solutions such as separate Alzheimer's day centers or special dementia program rooms nested within general day centers. CEI's third center was designed for a mixed general population but with special rooms and staffing for dementia patients who need it. Bienvivir of El Paso has some fully designed and executed separate dementia programs, but still nested within the site of the general Adult Day Centers.

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agitated staff members were not yet working at CEI when Tom arrived or they might have been even more adamant later on. Tom really stressed our limits.

On his first screening visit to the Center, Tom became agitated and belligerent. Staff could see he would be difficult to control. The team debated whether or not to accept him into CEI and decided he—and his wife-- needed us badly and so we should try to accommodate him. Almost immediately Tom showed the potential for serious hostility and physical confrontation.

He was a tall man, a bit over 6 feet, about 185 pounds and although in his late 70s, Tom was strong and had the physique of a younger man. Compounding matters Tom's wife, I'll call her Etta, presented her own problems. She was obviously enrolling Tom in the program because, unsurprisingly, she was having difficulty managing him at home. She needed lots of support as do most caregivers of dementia patients. That's the case even without serious agitation so this was no surprise. But imagine trying to deal with a child who has attention deficit disorder with agitation but is twice as big and many times stronger than yourself. That was Etta's task, and she was a small woman. But her commitment to her own marriage vows and love for Tom prevented her from admitting to these management problems Tom presented. She was not even willing to say to us that Tom was "difficult." In fact when Tom would resist getting on the CEI van at pick up time in the morning or even resist getting dressed, Etta would decide that she should respect his wishes and keep him home, in pajamas, even sedentary in bed. She then complained that he was resisting because he was not being treated right at the Center. However, keeping Tom home only compounded her own stress and

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defeated the purpose for which she had enrolled him and hampered his social integration.

Because of his frequent failure to attend on his regular scheduled days from the get go, Tom never really adapted to CEI. Dementia patients need routinization to adapt. Once they are in a new environment repetitively they perceive the new environment as a “safe place” for them. But that may take quite a while for a person with no short term memory. Arguments between Etta and transportation drivers and supervisor, the social worker and other staff ensued, but the situation wasn't solved. We could not get Tom in regularly at all. Then one day when Tom did attend he shortly picked up a chair and threw it at someone. Though not his first outburst, throwing a chair was a qualitatively new level of violence, and was perceived as a threat by staff and participants. Tom was immediately isolated and then sent home.

The team re-evaluated Tom's care plan including the problems we were having in communicating with and supporting his wife. By this time Tom already had some open wounds and wasn't eating well. His quality of life—we could only guess at how he might be perceiving this himself –seemed to us quite poor. We decided to approach Etta with the idea of keeping Tom at home (which seemed to be her preferred approach already) putting in home health support such as meal preparation, feeding, and hygiene, having nurse visits regularly for wound care, and regular doctor and social worker visits as well. Because Tom's wounds were worsening and he was also now in danger of dehydration, malnutrition and infection we included the idea of hospice status with avoidance of major medical interventions like forced tube feeding and hospitalizations in

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our recommendation to her as well. It was only a few months since Etta had been regularly calling 911 in desperation asking that they fix Tom, hoping for a medical miracle cure.

But Etta was very happy that CEI's plan addressed her own perception of Tom's needs. Surprisingly she now admitted for the first time that Tom was making her life impossible and also she readily agreed that we would have to let his procession take its own course and not try to force him to stay alive against whatever will he still had. The plan provided the support that she needed. The team went to work. In no time an excellent supportive and cooperative relationship between Etta and the team developed. I, myself, and Ramonda, the social worker, made regular home visits and she received us endearingly.

As Tom deteriorated he was nevertheless given intra-venous antibiotics to treat his infected wounds at Etta's request and he received intravenous hydration for a week or so—so long as he did not resist it strenuously and pull out the lines—which sometimes he did. We provided as much supportive care as he could allow.

Tom died peacefully at home. Etta noted, and was comforted by, the quality of his last weeks and his death. The hardest part was not the hospice care, but deciding that Tom needed hospice and then working with Etta to change the medical paradigm she had been holding on to.

Katy and Almost

Learning to work with families and participants around death and dying was part of my job but became part of my own mid-life crisis also. I was 50 when I started at CEI, and I was not in “denial” about death. The very idea, the very existence of DEATH always seemed to shout at me especially through a persistent childhood nightmare. My dream mind argued a kind of hopelessness to me: “what’s the use of doing anything with one’s life, if nothing one does can slow the inevitable fate of people, of all living things: to die, to suffer and also to inflict pain, make war, then disappear?” Was my dream channeling Hamlet’s soliloquoy? Little did I imagine that working on the cusp of living with dying, would provide greater meaning to both death and life. I suppose it shouldn’t have been a surprise for we often hear of people who, after a near death experience or some terrible loss, suddenly find great meaning and purpose in their lives.

In any case, in working with participants and families like Leroy and Tom above—and Almost and her daughter below-- it became very clear to me that death was not the enemy at all. The enemy was the fear and lack of support and trust and the feeling of helplessness that death and dying instill in and represent to all of us. Death is real, of course, but it is also a simulacrum for all our other fears and insecurities. If we can help people to titrate life and death successfully in a way that they feel they have had the best possible life and some control of the dying process, fear and helplessness, as I’ve often seen, gives way to relief and acceptance. If we can help people to do some things with their remaining life that are exploratory, creative, eye opening, extraordinary,

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challenging and self asserting—no matter their disabilities or prognosis-- then we create meaning in life at one of its most important and fragile junctures. These are the kinds of experiences that religious people hope for in their search for God. Surely belief in such a God—as the case of Ara Belle-- can be a great solace for some, but I think that there can never be a more powerful God than human kindness, understanding and support as people lose their functional independence.

Almost was a beautiful woman in her old age. She had a face delicately lined with sadness and warmth and a softness in her eyes whose warmth drew you in. She spoke endearingly to everyone she came in contact with despite the fact that she hadn't any idea who we were. Like Lovie who is mentioned elsewhere, she thought us all old familiar friends and family, even when she couldn't place the name or role or job each of us had in her life. She would call us things like "chile". She spoke as if in a far off paradise which we were privileged to populate with her. And her absence of present memory did not stop her from singing. When she sang church or gospel music I had to drop everything and go and listen. She had been a member of her Church choir all her life, and at CEI she sang in the heavenly choir, but that didn't say half about her voice. It wasn't a blues or jazz type voice, nor a typical full gospel voice either. Almost had a singing voice that was pure, soft and gentle like her spirit, yet it nevertheless, inexplicably, somehow penetrated the room. She sang with a fine tremolo, like music from the gods. If you had to think of a popular singer to compare her to, I think it might be Billy Holiday, but sweeter. Sometimes that voice would rise as if to say the softness

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was tempered, not physiologic; but most of the time it was just so soft that its distinctive presentness broke through in any crowd of singers.

Almost had a hefty body. She had been able to keep plenty of meat on her bones over the years. While with us her life became more and more sedentary and she was less and less aware of things around her, including her own sensation of pain and pressure. Unfortunately, late stage dementia patients, like diabetics, lose sensation, or at least the cues of unpleasant sensation. Any one of us, if we sit still in one place for more than 15 or 20 minutes begins to feel uncomfortable because the pressure of our body weight upon our bony prominences begins to interrupt the circulation to skin, muscle and fat. This eventually causes pain and if we don't squirm, move or get up that pressure goes on to destroy soft tissues and we get skin ulcerations. These ulcers, particularly in people who lack sensation such as some stroke patients, some diabetics, and people with leprosy can destroy vast amounts of tissue under the skin and go on to gangrene and blood infections. PACE doctors have come to realize that "skin failure" in the demented is like any other organ failure that people suffer—a potentially fatal event. Late stage dementia patients are particularly prone to skin failure unless they are observed and repositioned every hour if they don't move on their own initiative.

Toward the end of her life, Almost became so much of a burden on her daughter that she could no longer be managed at home in a community setting and we had to place her in a Skilled Nursing Facility. The staff at the SNF was kind and cared about their charges in my estimation, but they did not have adequate nursing personnel to deal with moving such sedentary inert dementia patients as frequently as necessary.

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Almost stopped moving, was unable to protect herself and so developed an ulcerating area on her low back (over the sacrum). Efforts by us to treat her ulcer at its early stage were not successful at breaking the cycle of pressure, tissue death, more pressure, more tissue death. One day she showed up at the Center with a large hard black “escar” ---a thick leathery scab of dead tissue over the area—replacing what had been a much smaller and more superficial ulcer. I tried to cut through some of the thick escar tissue to remove it, but was not very successful. It was clear that she had more dead tissue and infection deep underneath. I put her on antibiotics, but the next day her infection was worsening (because dead tissue is a great food for bacterial infections). Almost was sent to the hospital for examination by the “burn specialist”, a surgeon who also did grafts in ulcer cases.

The surgeon recommended a major surgical procedure to clean out a “grapefruit sized” area of dead tissue down to bone and move both her buttock muscles (the glutei) into the hole to cushion her skin from the pressure of her pelvic bones in the future. He was also quite angry at the nursing home for allowing this to happen. Even then, I was not convinced that the situation was so easily avoidable as he proclaimed. Had I known then what I learned over time, I would not have allowed Almost to undergo that extensive surgical procedure—which I, myself, observed. I think the surgeon’s righteous indignation was misplaced. Many dementia patients, well cared for in general, will develop and die from skin failure. The kind of muscle and skin graft surgery that he performed required a lot of post surgical care and nutrition to heal well. And what would protect this 250 pound immovable and inert woman from the same cycle recurring? How

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did he think that would play out? She had become too sedentary and impervious to pain and discomfort. It would be close to impossible to assure that she was turned enough in bed and got adequate nutrition to prevent or heal such wounds.

For several weeks the grafts looked like they would take, but then began to open up again because it was so hard to keep pressure off the area. Now she was placed in a different Nursing facility which had a higher staffing level and a better care reputation. But to no avail. Meanwhile we had also followed this intensive intervention algorithm for her care by making a second sad mistake-- one that families and physicians of severely demented people must try to avoid or cause great suffering.

Almost's oral intake had dwindled to inadequate calories for her sustenance and healing ability. At Kate's request we had placed a nose to stomach feeding tube and she was being fed through this tube in her nose round the clock. Thankfully we did not go on to place a permanent feeding tube through the stomach wall, which many dementia patients will pull out when they notice this alien thing hanging out of their body. But that would be small consolation to Almost because a nasal (nasogastric) tube causes more local discomfort in the nose and throat than the Gastrostomy tube.

Now, day by day Almost's wounds were becoming larger and deeper again. She was in a bed where a special wound nurse could use an attached pressurized jet of water, minor surgical debridement, and chemical agents to try and stop the inexorable process. The wound was staying clean, but the process was relentless. The hole was back down to the bone again and then it began to become infected again also. I was in to the SNF almost every day, either observing or participating in the cleaning of the

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wound. By now Almost was beginning to whine and complain where previously she had just been stoic. She did nothing much else, because she no longer was participating in her own life. All that was left was her discomfort, pain, the feeding tube, the wound and the visits from her daughter who had never seen this gaping hole in Almost's back.

From the time that Almost went into the hospital and had her wound graft surgery I was in constant touch with her daughter, Kate. Her mother was the only important person remaining in her life, though she was also active in CEI affairs. Whenever I discussed a change in Almost's condition I always told Kate the possible options for care and support and asked her--as her mother's spokesperson--what she wanted us to do. I tried not to be directive but to give her the best assessment of alternatives and likely outcomes. Months had passed and things were daily more distressful to Almost and distressing to me.

I then realized something was missing. Kate, distressed, worried and upset, still had some hopes for her mother's recovery, despite my frequent reiteration that Almost's dementia would not get better and was the major factor contributing to the circumstances of her life threatening decline. I was getting nowhere in these discussions even though I could see that Almost's suffering was becoming more intense by the day.

Finally, one day I became too upset with myself to go on protecting Kate from the reality that I saw every time I looked at the wound and Almost's inability to do anything other than lie there in pain. Many months had passed since Almost had been to the Center to see friends and familiar faces, to participate in even basic childlike activities or

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to sing gospel songs. It was a long time since Almost had been able to be loved by anyone but Kate. On this day I asked Kate to meet me at the Nursing Facility and after I had examined and treated the wound I went out to the waiting room where I had asked her to wait. I had been trying to win Kate over to let me remove the feeding tube and let Almost's will, and her own body determine the outcome.

Almost could swallow and eat if she had the will to live. She was not a stroke victim with swallowing dysfunction. She could be fed. But Kate had refused. This time I told her straight up that I was seeing her mom suffering terribly and that she needed to actually see the wounds that we were treating to understand what I meant. I took Kate to the bedside and uncovered the wound for her to see. She gasped. Nothing she had heard about the wound over the previous months, nothing she had imagined had prepared her for what she saw. That day Kate asked me to pull out the feeding tube. Free to take oral fluid and food Almost did not, would not. Who knows if this was a willful choice or a part of Almost's dementia process? I don't. Nevertheless, I am close to certain that Almost's "decision" to not eat and Kate's "decision" to withdraw the NG tube were the most ethical and medically sound thing to do to minimize the suffering of a woman who did not deserve to have her life end this way. If anything, we had already passed the stroke of midnight at the ball.

This was when I realized that force feeding people to keep them alive under such conditions (when their decline is not reversible and their suffering is sure to increase) is really a form of torture. I also realized that I had to work harder to prevent these deadly pressure ulcers and to intervene with aggressive local sharp surgical

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debridement in the CEI centers at the earliest sign of significant tissue death in our participants. And that I needed to convey the message of this experience to our other docs as well.

Using such techniques we were able, in future years, to rescue a number of people from the danger of ulcers penetrating down to bones in the feet and pelvic and back areas. But participants who lose as much contact with the world around them as Almost did always present a near impossible challenge and, as in this case, some do not have enough mental, emotional or physical reserves to come back. I imagine that Kate may have passed nights second guessing her various decisions, but I think that there is no doubt that she helped make her mom's death easier at the end. And that's important.

Health care professionals who fail to get inside the beliefs, values, and relationships that exist between disabled, very ill and dying people and their families and loved ones will often fail to provide the key ingredient of support. There is no rule, algorithm, or perfectly right time to tell a family that they ought to let a person they love die. And yet, a sensitive professional will find that right time, when that moment of necessity of potential acceptance by all involved arises. With Almost, I believe I waited too long.

Almost's dying was a particularly difficult challenge for me because I knew her daughter so well in another context at CEI and I had personal reasons to not want to intrude into her strong feelings of connection to her mother, who was up over 90. Katy

was already about 70 herself, suffering her own medical problems, and living alone. -I'll fly away-

She was an important community supporter of CEI. And I almost let the very last moment for reprieve for Katy, for me, for Almost, slip by.

Had I the chance to reverse time and treat Almost differently I would have debrided those wounds aggressively myself in our clinic in the first place, despite not being a surgeon, and made every effort to keep this friendly demented woman under my charge and away from the operating room. Even had I failed to stop the relentless process, I would then have assured that Katy understood the trajectory of Almost's dying earlier on. That would have been the best decision. The few months that the surgery gave Almost were months of suffering, not quality months of life. They were months of isolation and suffering within a mental abyss. They were probably the most difficult and distressing months of her long wonderful life.

A Loving Son Reaches His Limits

The first time that Lettie's son applied for her to enter CEI I personally kept her out. She was in her 80s, severely demented, delusional and on a trajectory to rapid and imminent death. When I met her at her CEI visit she was withdrawn, almost non-responsive and very resistant to attention. I remember Lillian saying at the next morning's briefing that she wouldn't eat even a bite at lunch. Although she was under the care of her only son who lived with her, Lettie had deep and infected ulcers in her hips and back (sacral and coccyx area), had been in and out of hospital continually over many months and had just been released to home after a 2 month stay; now she was refusing to eat; not just at CEI, but at home also. She had lost a good percentage of her body weight and was very asthenic (wasted).

I opposed the team beginning its multi-disciplinary complex time consuming evaluations of her on the following point alone: if she would not eat, it meant she lacked the will to live. If a demented delusional woman lacked the will to live and would not eat, it was a kind of statement that her quality of life was not acceptable to her, and there was little, I argued, that anyone could do to change that other than feeding her by force. I foresaw her going back into a nursing home soon after admission to CEI and dying from complications of her wounds and malnutrition. I did not think there was much we would be able to do to change this course of events and I was unequivocally opposed to force feeding demented patients with feeding tubes. Experience has shown that the whole feeding tube process is fearful to the dementia patient and often leads to

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them pulling the tubes out of their stomach as a result. Plus, by this time the notion that losing swallowing is a natural part of the physical decline in Alzheimer's disease was less and less supported by the evidence.

Of course, Lettie's son Robert was discouraged by the CEI rejection and our view that she might not survive living in the community, because he had finally got his mother home from medical institutions. But he also was determined get her better with or without CEI. "I'll get her eating and I'm already changing her wound dressings twice a day under the training of the Visiting Nurses Association. You'll see her get better," he offered.

"If you bring her back and she's eating and seems to have some ability to interact and some will to live I'm sure the team will be happy to help support your efforts," I told him. "Good luck".

Perhaps two months later, there was Robert back at the door with Lettie. He had done the seemingly impossible. Lettie was now less withdrawn, would smile and interact and was no longer resistant to eating and drinking. Moreover her vast and deep decubitus ulcers were healing well. Of course she was still just as demented and delusional, but she seemed, to any observer, more or less content and well on the way to medical stability and acceptable (both to her and us) quality of life. That was around 1994.

The team was excited that Lettie was to enter the program and amazed that she had such a supportive and caring son who had worked these miracles. As her first CEI doctor I got to perform complete evaluations and physical exams on Lettie (as we did on

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all of the participants) every 3 months, even after her wounds were fully healed and she no longer needed regular acute medical attention. I think it was during my second examination after she had been at CEI 3 months that I asked Lettie how things were going with her at home. Of course I knew that she could not rationally answer such questions, but it was both interesting and sometimes useful to engage the dementia patients in such discussions. Sometimes useful information about their care needs surfaced by chance.

This time Lettie responded, “you wouldn’t know, would you? You don’t even come by to see the kids. You’re good for nothing”. I was at first taken aback and somewhat flabbergasted.

“What do you mean”, I asked her? “What do I mean? Are you going to act like we haven’t been married all these years and you don’t have to pay any attention to me and your own children?”

From that moment on for the next few years Lettie acted out that I was her former husband. Whenever I greeted her in the hallway or in the activities rooms she would always jibe with me or criticize me for unloving and unsupportive behavior. “What good is having a husband like you?” she would conjecture out loud for everyone to hear. Maybe she was righting the injustice of my keeping her out of the program after our first interaction.

Robert, meanwhile, would come by the Center fairly regularly to visit with his Mom on her Center days or to talk with staff and give and receive pointers in her care. He really doted on her and was determined to do whatever it took to keep his mom

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going, more or less forever. Robert was a nervous, sometimes anxious, but very attentive African American man, probably in his late 30s. He was a quick learner and wanted to be involved in all aspects of Lettie's care. I don't know what else was on Robert's mind at this point but he was very much opposed to the idea that his Mom be allowed to die peacefully when her heart stopped sometime in the indefinite future. Later, even as her age passed 90 and she became more and more oblivious to reality, and to who he was, he remained adamant that resuscitation be attempted when her heart stopped. Robert wasn't hostile or suspicious that I continued to raise this issue with him year by year. He accepted my wondering about her quality of life issues. He would just say to me time after time, "I don't think I'm mentally ready to let her go yet, but it's ok to discuss this." From his point of view as her son, her quality of life was good enough for him and he was entrusted with her care. Moreover, the idea that if successfully resuscitated she could likely lose major physical functions afterward, in combination with her mental losses, and would face more pain and suffering, or that if unsuccessful she would die in unnecessary pain, did not phase him. His mother was the most important thing to him and he saw his role as refusing to give her up, even to nature's inevitable jaws of death.

Well, maybe that was all well and good as long as Robert was there giving his entire life to his mom's survival, but things were going on that we were not aware of. A couple of years into Lettie's time with CEI she missed a few regular days in attendance at the Center and when last seen was not doing too well, in retrospect. At first, however, the clues did not raise any suspicion. I am not sure if I have the correct

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sequence of events that followed. But to my recollection someone in the apartment building may have noticed things awry or a smell from their apartment. Somehow either 911 or Adult Protective Services were notified and when they went in they found the apartment in a shambles, with feces smeared around and Lettie lying on the floor in the mess. Robert, I believe was unconscious nearby though these details are murky.

I recall that luckily CEI was quickly notified and we were able to intervene to prevent Lettie's being placed by the authorities. It took some explaining to make clear that we had no idea the situation had gotten out of control and that we would never allow someone in the program to live in such conditions. You see Robert, who was somewhat suspicious as well as over-protective, had been doing all the homecare for Lettie and we did not have a regular CEI homecare person going in there and reporting back to a nurse and the team.

Once the smoke cleared the story of Robert's personal tragedy began to unfold. He had been diagnosed with HIV, unbeknownst to us, and had become quite ill. He was also a drug user and had been drifting in and out of his dependency even while he was taking great care of Lettie and becoming sick. This acute crisis for him and Lettie was mainly the result of him becoming acutely ill and being hospitalized, near death. Lettie had to be temporarily placed in a Nursing Home, and he was removed as her Guardian. The team and staff in general were not sure how to respond to this crisis and this powerful information. There was reluctance to allow Robert to come back into Lettie's life as her main caregiver because of the level of neglect that he had

participated in. However, as in our earlier wonderment at Robert's determination, he was able to again turn the corner, building and restoring trust and even confidence. -I'll fly away-

The way Robert did this was to get himself clean, get into regular medical care for his HIV and successfully get onto a complex drug regimen that arrested his disease. He then re-established his own personal autonomy and a life style that included not only good personal care for himself but a renewed concern for the well-being of Lettie. But this transformation did not happen overnight. By the time that Robert was back on his feet and allowed into his Mom's life on some level, CEI had taken on a more global role in her life management which was never to be relinquished. Through all this Lettie herself remained unfazed, largely oblivious to the disappearance or illness of Robert. She lived on and on for several more years in a state of delusional bliss, making wise cracks to various staff including her doctor and acting like life was just a bunch of roses. In the last years of her life Robert was always consulted about decisions concerning her care including her end of life care wishes.

A Hidden Identity: Steadmon

The struggle to find and word-sculpt some richness, fullness, identity of these elders who I only knew so late in their lives and only after they had suffered devastating losses, complicates my remembered tales and my writing. I often just don't know enough about their lives, who they were at earlier ages. But on several occasions I had the good fortune to have family members and friends tell me an in-depth life story of a participant (Barbara F. was one example in this book; Leroy another). Hearing those fleshed out stories with their insightful details always fascinated, and enriched, my appreciation. My need to know more motivated the reading and reminiscences group that I formed and led on and off for 9 years. Here are traces of the missing history I didn't know or understand about two very different men, married together in this book only in my own imagination.

Steadmon cared for his mom who was developing dementia. He entered the CEI program simultaneous with her enrollment. They lived together. Surprising that he lived at home with her, but on the other hand she did need his support as she aged and had become progressively more confused. Maybe she had long standing mental problems? I remember that their electricity had been turned off by the power company when she refused to pay the bill in a dispute that was trivial and over only a few cents or dollars. But was this irascible counterproductive behavior part of her mental decline or was it basic personality, the way she had always been? Maybe she had needed Steadmon's

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help always, and that was why he had never moved out. At first glance, that had to be considered a possibility.

Steadmon died before his mom. He had had a heart valve replacement some years back, and I believe he died a sudden death related to his heart. When he died, he was only about 65 years old and not that long in the program. He was my patient. Earlier though, I had heard something about Steadmon directly from his CEI health worker who visited to help out in their house. She sought me out privately one day (outside of team meeting) to report that Steadmon holed himself up in his room and watched gay pornographic movies endlessly.

I remember Steadmon at the Day Center as a very personable, intelligent and not withdrawn, fellow. I particularly enjoyed talking with him and he often commented positively on my clothes. I was surprised however that Steadmon had lived with his mom his whole life. It wasn't like he had moved back home because she now needed assistance due to her confusion. He had never left. Did the home care worker's report, in stark contrast to his Center persona, provide an explanation? Those were times when most gay men were "in the closet." And Black communities, like many traditional cultures, were quite hostile to gays in their community.

When I attended Steadmon's funeral at Chapel of the Chimes, I found myself seated next to an attractive well-dressed woman probably around 50 to 60 years of age. At the end of the service I asked her how she had known Steadmon. Her story filled in some of the missing pieces of a life, the man who I had only known on the surface.

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Steadmon was a professional jazz pianist of some repute in the Bay Area. He had a band and played at well known houses, sometimes traveling to LA and elsewhere to perform; these facts were alluded to in the memorial service. My pew mate now told me how she had dated Steadmon and fallen in love with him. In fact, she had gone and proposed to him that they marry. But he had refused her. She'd never gotten over him. Here she was, despondent--not only because of his death--but over a life that might have been with a man who told her he would not marry her because he had to care for his mother. This woman was confiding intimate details of her life to me—someone she didn't even know-- perhaps because of her vulnerability at that moment. What to do? I could not—would not dare—to reveal the secret of Steadmon's apparent sexual orientation; I did not even imagine asking her if she had considered then the possibility, or realized later, that Steadmon was gay, or whether she had had a sexual relationship with him. I was in no position, had no relationship with this woman that would permit me to speak of such things. That would have been terribly intrusive and cruel and unlikely to help her with her own closure even if it explained his rejection of her love in a less painful way.

Though good judgment restrained me from speaking out, I marveled at the clarifying light she shined on Steadman, the jazz musician's life, there to me, a total stranger, in the Chapel of the Chimes. I wished that Steadmon might have been there with us to tell his own true story to us both.

A few years later as his mother lay dying in her apartment in a severely demented state I spent some time with her in her bedroom and while there I studied the

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many photos on bureaus and walls of her jazz pianist son, Steadmon, looking robust and quite handsome. As I type these words I am again looking at a one and one half by two and one half inch snapshot of him, about the size of a passport photo, among the many photos of various sizes and various people posted on the walls of my own study. I am mindful that for all the intimacy with participants the CEI environment provided, there is such a vast hidden world of details and complexity in every person—in every life—that we barely can scratch the surface when trying to know and understand the people in our own lives. And in that I don't mean patients, but even the people who created us, even the people we love, rejoice in, hold dearly as close friends.

There is a constancy, a thread that each life is strung upon, and yet despite that constancy, that thread can be torn all too easily by events, by traumas big and small. Identity remains a mystery, a mystery so deep that we even struggle to untangle our own motivations and behaviors whenever they defy the rationality we grasp at with our mind's eye, the thread we, often desperately, try to hold onto that explains us to ourselves as well as to others.

Stevie revisited

Remember Stevie from CEI Live, the fellow who quit the theater project? Stevie's survival—in his late 80s when I drafted this sketch—is one of those miracles we recognize but can't understand. At first, if you met Stevie, you might not notice the evidence of his extreme disabilities as he presented his friendly persona. You would notice that he resides in an electric wheelchair and that both his legs are gone. You might also notice the disturbing tremors in his hands and arms as he tries to work the controls of that wheelchair. But why is it miraculous that Stevie lived to a ripe old age?

In medical terms the causes of Stevie's amputations and his tremors are straightforward. He's a diabetic and that's the main cause of his amputations; and he's done a fair bit of drinking in his day which caused his bad tremors. Still, not everyone who has diabetes has to have both their legs cut off. Not everyone who drinks has their fine muscle control go totally whacky.

Many readers will know the well defined list of things that diabetics must do to control their blood sugars effectively. This starts with a controlled diet spread out over at least 3, but better 4 or 5 small meals a day; avoiding all refined sugars and concentrated sweets, controlling fat intake, avoiding alcohol and a good dose of regular exercise, which reduces insulin resistance; then, as needed, various medications; sometimes doses of injectable insulin, one, two or more times a day.

Stevie had frequently told us all at CEI about certain incidents in his earlier life, though who knows how much to believe. Even at his advanced age and high degree of

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dependency he remains proud of his days as a hustler and street soul. He wore his drinking and poor eating habits like a badge of courage. Stevie still spent several nights a week down at the local jazz bar where patrons, staff and the owner treat him like a regular guy, a friend, and help him deny that he is as frail and dependent as he is despite his total dependency on home care staff to change diapers, help him to bed, help him with his meals and fit his specially adapted eating utensils, bathe him and so forth, It says something positive about humans and culture that the bar crowd protected and supported Stevie. The bar folks accepted him as one of the guys and didn't shy away from the fact that he needed "mothering". And there's something to be said for Stevie's human spirit too-- that he continued to hold onto his proud self-image tenaciously. He could still do a little gambling and drinking and they could take his money, so he really was one of the guys and belonged. He took meals down there and someone or other made sure he got back to the apartment house if he needed help.

Though "denial" seems a harsh and judgmental word, we all live in denial. You can't face daily life too easily if inevitable deterioration, suffering, pain, death, are on your mind and kicking you in the teeth every waking minute. Imagine the lives of Palestinians, Syrians, Iraqis and so many others in these times. It's another miracle that people can survive incessant war and bombing and displacement.

It's human nature to look to the brighter side for our own survival. But some folks just have a system of thought—of reality--where denial sits more in the center of their identity rather than just a helpmate off to the side. Stevie's denial was one of these.

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Denial was his core--and that is how he'd done so much damage to himself that death was always blowing its cold harsh breath down Stevie's neck. And yet he survived.

Stevie was likeable. He had a smooth friendly manner, in the typical hustler style. But beyond that he was quite boyish, humble and seemingly respectful. Even though he tried to proposition some of the young attractive female staff, he wasn't the first fella to do that and he wasn't persistent. People got used to saying no. When he was told it wasn't appropriate to proposition the nurses and health workers Stevie seemed embarrassed and apologetic; he promised to stop the offensive behavior and he did.

But Stevie would test the night staff whose help he needed to put him to bed and clean him up and who needed to finish up this work by 10 p.m. or so. He'd stay out at the bar until late hours and then complain to Home Care supervisors about how he was being abused and neglected by the staff who were supposed to be there for him at his whim.

Within the persistent taught chord of Stevie's fight for self-defined independence arose his request to have help with sexual dysfunction. This was before Viagra as an oral pill went on the market, but there was a small pill that could be gently injected with an inserter into the urethra at the tip of the penis. We (I) had no problem with providing this medicine, or later Viagra, to men who might benefit as long as they accepted the risk of heart attacks and angina that they would be taking, given their frailty, and understood the risks of sexually transmitted infections if they practiced unsafe sex.

(More recently the Viagra associated heart attack risk has been downgraded substantially from earlier warnings).

In Stevie's case, with diabetes and severe vascular disease, once Viagra was available I thought the risk of his using it would be significant. In our first discussion about his sexual behavior (initiated by Stevie) he told me that he had a female friend/partner who wanted to have sex with him--but he was having trouble with erections.

Loss of libido, loss of erections and/ or ejaculation are common findings in diabetics, especially those with documented end organ disease like Stevie. Unfortunately medications are helpful in a much smaller proportion of diabetics than with other causes of impotence. But sometimes it does work. Knowing that Stevie was a hypster, I thought I should try to find out what kind of a sexual tryst he really had going. There might be all kinds of denial mixed into this situation but I was willing to go along with whatever seemed to work for him, so long as he did have a willing partner who was able to consent. From the team's standpoint, when we discussed these intimate details however, some thought that if Stevie's sex interest was for prostitutes there could be a danger to him (mainly in terms of getting rolled by a pimp since he was defenseless). Another concern related to the fact that we had found another male CEI participant in the same apartment house who had been cajoling severely demented but sexually complicit women into his apartment (see Jamie's story elsewhere in this book). I needed to assure myself that Stevie wasn't following that route, especially because some of the children of dementia patients living in that building knew of those previous

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episodes with Jamie and we'd promised to protect the dementia patients. And third and equally important, in that pre-Viagra era Stevie was going to need his partner to use the inserter to delicately place this little pill inside the opening of his penis since his tremor made such an effort impossible.

So I arranged with Stevie to interview his partner and him together to get the picture, to be assured that this was a consensual relationship, and to instruct her in this procedure. Though this may seem intrusive and embarrassing, this is the logical realm of special rights that are the province of doctors working as facilitators in this type of situation. Meanwhile I tried the insertion of the pill on Stevie and sent him out of the clinic. He reported that it helped him get an erection. I didn't either believe or disbelieve him. I was agnostic about it.

We three met in Stevie's room and the first thing that became apparent was that the woman was also a CEI participant, one of the younger women about 60 years of age, living in the same building. I did not know her well and so I did not immediately know what disabilities she had that qualified her for CEI, but she did not seem to me demented and was able to carry on a conversation with me. She reported that indeed she was willing to have sex with Stevie and she understood from him the purpose of this discussion and meeting.

At first everything seemed fine, but when I began to show her the device she became anxious and we had to abort the training effort without a demonstration. Imagining that my presence might well have embarrassed her, I left Doris and Stevie alone to try it themselves. However, that did not improve the situation and she decided

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to leave. Confused by the unclarity of what had happened, I left Stevie and reported these events back to team briefing the next morning.

When I described (without these explicit details) the meeting with Doris and Stevie and her flight from the training, I learned from Doris' physician and other team members that she was considered somewhat mentally retarded and also had some psychiatric issues. Moreover she had already told her own physician—a woman--after the episode that she never intended to have sex with Stevie but didn't know what to say or how to say it in my presence with Stevie there. The situation had become quite complicated. A series of meetings with Doris and her doctor (and with Stevie) followed to make clear to Stevie that he apparently misunderstood Doris' friendship; and that I had only worsened the confusion, making her feel pressured.

Stevie, in his own inimitable way, said that he too had been misunderstood and that he had never done anything to pressure or intimidate Doris and would certainly leave her alone if that was what she wanted. I hoped I hadn't wrecked their friendship.

Later that very year Viagra was approved and in a short time Stevie came to me and asked to try it. I authorized a very small supply but never again asked him about his intended sexual liaisons. By then, I had convinced myself that Stevie's sex trips were more fantasy than reality, I didn't think he would or could physically hurt anyone, and I regretted the results of my earlier intervention. I thought: maybe I shouldn't have tried to get in the middle of, and support, his earlier efforts. I just hoped he wouldn't get himself into some kind of trouble.

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Later, around 1999, Stevie hit a spell where he was particularly frustrated with his dependency and decided he might like to move away from Oakland and CEI and go off on his own. For all intents and purposes this was physically impossible. However, Stevie's first effort was fairly rational. He proposed a trip to LA to visit old friends from decades earlier. Since Stevie was 100% dependent upon a home care aid, this was going to be a difficult trick. But he was adamant, and the team was of course interested in protecting his rights if it could be done. His solution to the difficulties was that he would contact these old friends, make sure they would meet him at the plane, handle all his transportation, have him stay with them, and they could look into his getting a support worker, a nursing assistant, for the several days he would be in LA. The team had a lot of misgivings but finally agreed that CEI would provide transportation for him to and from the airport and out to the plane locally if the other details were successfully arranged by him and he bought his own ticket.

The plan collapsed before a disaster could occur. When contact with his old friends was established, they reported they didn't want to have anything to do with him since they knew him back when he had badly messed up his own life. They were rather hostile, held him fully responsible for his own amputations and said he'd have to stay on his own if he came to LA. If he did arrive, they might drop by and visit him if he told them where he was staying, but nothing more. Stevie's trip was, by his own choice, then canceled.

The ever hustling con man, Stevie, a veteran, was one of several CEI participants who tried double dipping from the VA. Stevie had VA benefits that might

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have afforded him home care had he not been part of the CEI program paid for by Medicare. We were financially responsible for his home care services. Nevertheless, he applied for, and did receive (for a year or so until detected), money for home care from the VA that he never received. (Stevie wasn't the only CEI participant to pull this scam, but they all got caught when we refused to fill out deceptive forms). The fact that CEI had warned him against this practice didn't sit well with Stevie, nor with Harry, another streetwise participant. For this and/or other reasons he decided he wanted to apply to a VA home for independent living up in the Northern California Wine Country and leave CEI. However, he was in fact too dependent for that program as defined, and was declared ineligible.

But Stevie was still hoping to flex more muscles of independence. Maybe part of it was resentment that CEI had blasted him for his efforts at double dipping from the government, but more likely it was just an awareness that CEI would not desert him and he was trying to challenge his dependence on us. I wrote earlier about Stevie's acting career with the CEI Live theater group. He did a great job acting in several of the skits about the lives of participants, and was especially pleased by the incorporation of a piece about himself in which he beat the famed Minnesota Fats in a hustler's pool game. Inexplicably, Stevie quit the group after having great success and public acclaim.

Why? The fact that Stevie was still alive when I retired is testimony to a personal life strategy based upon denial and hustling that somehow kept him going, yet this sad man spent the last 15 or 20 years of his life in a condition of near total dependency that

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none of us would wish upon even our enemies. Even with his successes in the theater group that promoted his autonomy and independence, Stevie apparently saw CEI as a mirror that reflected his terribly dependency back to him—a Stevie he doesn't want to live with. Whether or not Stevie ever shot pool with or beat Minnesota Fats is only something we can guess at. It might have happened. Whether an invention or not, it lay at the heart of Stevie's belief in who he was—the streetwise hustler. But one thing for sure, Stevie's longevity defied the judgments of anyone and everyone, myself included, who would blame him for the actual state he lived in. Survival strategies can be like that.

The Washingtons—a name in common

During the 1990s CEI admitted George Washington and Isadore Washington, both of them African Americans, to the San Pablo Avenue center. Most African Americans' family names in the U.S. derive from the plantation owners—the masters-- under whom their ancestors were enslaved, bought and sold. I have no idea whether either George's or Isadore's families, back in the early 19th century, were slaves held by our first U.S. president, the national hero George Washington. However, that would not be surprising if true. We know, of course, that both President Washington and our third president, Tom Jefferson were plantation and slave holders and they both had children by women slaves. Both George and Isadore Washington were up in their 90s when they joined CEI. They had not known each other previously nor did they become fast friends, though they did meet.

George Washington

George Washington joined CEI a couple of years before Isadore. He was slender and sly and very well married. That is to say, George had been married about 60 years to Bennie, a fastidious woman who was still spry, youthful and beautiful with wavy white hair and smooth unblemished skin. She was almost 20 years younger than George. Just to be in their presence you could see the enthusiasm with which George and Bennie loved life and loved each other. They both had youthful personalities. They had

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few complaints about anything despite George's disabilities—he was wheelchair bound and his legs hurt constantly and he could just barely stand on them.

If I remarked to George that he and Bennie were a wonderful couple and what a beauty his wife was, George, more than once retorted: “Now don't you go payin attention to my wife, unless you want to deal with me. You hear that?”

Although George was occasionally confused he had that wry sense of humor. His comment about Bennie was spoken with a straight face, but you could see the gleam in his eye, reflecting both his pride in Bennie and his own self-mockery. He was putting you on and after a few seconds you appreciated his comment as humor, not as jealousy. And Bennie was as loyal a devotee and lover of George as the world has known despite her younger years.

I had not been George's primary physician when I had the occasion to perform his 2nd or 3rd quarterly exam after his admission to CEI. Quarterly exams were comprehensive. A complete review of all preventive services, interim history, review of interim progress notes, review of all medications and laboratory work and a full physical exam. George did his usual bantering back and forth with me. He was a pleasure to “rap” with and listen to for the rapid rhythm of rapping is kind of what he'd do. He and Bennie were planning a trip to the Southwest to visit relatives. They intended to drive in their Cadillac into the Southwest summer heat. Not without risk at his age. I advised them to be sure the air-conditioning was working and that they had sufficient water to drink in the car.

On George's physical exam that day I noted that his penis was almost rigid. I absorbed this fact with great seriousness. I must have been a bit unplugged that day. I didn't even stop to ask myself (or George) how this could be. When his doctor returned later that week I told her about this. There were nurses present as well at the time. I was more than a little embarrassed when Lyn, his doc, giving me a little smirk and a half smile said sarcastically, "well he does have a semi-rigid penile implant." Everyone laughed and I probably turned red as a beet before guffawing myself. No doubt that George and Bennie weren't going to give up sex. He had had the operation years before the advent of drugs for erectile dysfunction and long before he entered CEI.

In summer, Bennie and George did set off on their trip to the Southwest by car and, simultaneously, I was off on a nice vacation myself. Bennie must have driven all the way to Texas herself in the summer heat through the desert. But the air conditioner on their Cadillac did give out and so they traveled through much of the desert heat under rather extreme conditions for a 95 year old man with heart and blood vessel disease.

When they got to Texas, George was weak and obviously ill. Bennie took him to a hospital and he was admitted. Though we were responsible for his care, CEI learned about this only two days later when Bennie called. She had been told that George's main diagnosis was heat stroke and that he was responding well to treatment, but she was also told by the physician caring for him that George had such bad circulation that they would have to amputate his legs to save his life.

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It was at this point that Bennie knew she needed to call CEI and get advice. The call went directly to Dr. Stromberg in the clinic and Bennie explained what was happening. As George's primary physician Lyn already knew that George had terrible arterial circulatory disease. That's why he was wheelchair bound. But this was a long-standing problem and she doubted, given the details she now heard from Bennie and the Texas doctor, that emergency amputation was indicated. At the very least Lyn was going to bring George home and see what she, and if necessary CEI's local vascular surgery specialists, thought of this situation before authorizing any such dramatic measure. She heard nothing to suggest George had gangrene or an acute vascular crisis from a blocked artery.

Lyn went immediately to Peter Szutu and together they worked out a plan. She took full responsibility from the Texas physician with his agreement. They hired an ambulance to take George directly to the airport. They bought first class tickets for him and Bennie and notified the airline for needed support. In just 12 hours George and Bennie were back in town and in the CEI clinic under CEI's watchful care. I suppose family in Texas took the Cadillac.

Although it was true that George's legs were cool and his circulation very compromised, Lyn found that, as she had expected, there was not a change in his condition when compared with earlier exams she had done. George was in moderate, not severe pain from the insufficient blood supply. He showed no signs of an impending crisis. This was one of many lessons in how continuity in primary care medicine can make all the difference in the world. Peter and Lyn had spent thousands of dollars

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getting George home safe, but they had saved George from losing his legs and possible complications of unnecessary surgery and the menace that any extended hospitalization represented to someone over 95 years of age. Lyn's aggressive intervention (to prevent the aggressive intervention by the Medical System) was an important achievement in maintaining George's life and quality of life.

When I returned from vacation and learned all that had happened I understood not only that Lyn had done a great job, but that she had shown that she was a logical successor to the Medical Director role for CEI when I retired. Lyn however, was of another mind, deciding that she did not want the burden of that role. In fact she and I had a little contrarian sparring game going on between us. It seemed that the more I pushed her to take the idea seriously, the less likely she was to want the position. At my retirement Lyn remained the physician at the San Pablo site but did not ask to be considered for Medical Director. Later, she also left CEI.

George Washington lived about 2 more years in the program. Nothing ever had to be done about his legs. His terrible peripheral circulation was not the cause of his death. George died before the turn of the 21st century, before I retired. I was later in touch with Bennie by phone to see how she was doing and I saw her at the Center once when she stopped by CEI to visit with all the staff. She still looked as young and beautiful. "Now don't you go payin no attention to Bennie," George told me.

Isadore Washington

Isadore Washington, though unrelated to our George Washington, seemed to me to have that same fiercely rooted independence and sense of humor, characteristics that often power survival among the disabled. These Washingtons were determined to enjoy whatever quality of life they could seize. Isadore was so proud that he never admitted to any illness. That was his strength, yet it also contributed to his demise.

Isadore had a big family, but most of them lived in the Seattle area. The only close relative around Oakland was his sister, Ruth. I think that Isadore lived with Ruth until he moved into the San Pablo Senior Apartment building. They were very close—as in day to day--but as with many folks in such close relationships they had some pretty intense arguments. Ruth tried to care for Isadore, but he usually felt she was interfering with his freedom and his right to make his own choices. From my vantage point, Ruth's concerns were justified, but I also knew Isadore's resentment was predictable. He needed his own autonomy.

Isadore was another CEI participant with diabetes and heart disease. He was prone to heart failure—had past hospitalizations for this-- and was under medical advice not to eat salt. But he did eat salt and he did more than that. Not only did Isadore eat salt, but he secretly carried a salt shaker in his pack and took it to lunch at the Day Center. Being a friendly fellow Isadore shared his salt shaker with others under the table, including other folks with heart disease and at risk for the heart failure salt will promote.

Once Isadore could no longer walk, he spent his time in a wheelchair. Eventually he got an electric wheelchair. I can't remember how he obtained an electric wheelchair because CEI worked very hard to limit electric wheelchairs to people who were both severely incapacitated and who could benefit significantly from the additional mobility beyond a regular wheelchair. The cost of an electric wheelchair can be upwards of 8 thousand dollars. That cost amounts to a big chunk of the capitation for all services and care for program participants. Early on we learned that once a few people in the program had powered wheels a whole crowd became like little kids who all want what their friends have, regardless of actual need. Perceptions of being short changed lead to resentments. So we tried not to authorize many electric wheelchairs without a particularly strong reason and purpose that could justify this.¹³ For example, some participants are unable to move a regular wheelchair because of paralysis or weakness of the upper extremities.

Peggy Elms OT and rehab director and Susan Musicant PT had relationships with some organizations that would sometimes donate electric wheelchairs to CEI. But even with those donated chairs which cost the agency nothing, their allocation to participants increased the pressure on the team from other participants. Isadore may well have been given one of the donated chairs as his mobility faltered.

¹³ A 60 year old paraplegic woman, a friend of mind not a CEI participant, lives alone and uses a manual wheel chair. She would not think of using an electric wheel chair so long as she has the strength to push herself around town and even up and down hills. Her physical independence and her ability to live alone depend upon maintain sufficient upper body strength by using her wheel chair regularly as a form of exercise. But to understate the impact of aging, it is considerably easier to be self-motivated like R.S. at 40 or 50 or even 60 than at 85 or 95 years of age.

At a certain point toward the end of his life Isadore got restless and became a wreckless driver with his electric wheelchair. He ran it straight full speed into a wall in clinic. Just two feet above the solid wall base were huge windows up to a height above 7 feet. The chair started to climb that wall, dumping out Isadore in the process. He didn't reach the windows with his vertical climb. Luckily he suffered no severe injuries in the fall but much to his chagrin, Isadore was forced back into a regular wheelchair, his license revoked.

Isadore became wheelchair bound because of his diabetes and not paying close attention to his own health and well being. He was now careless and walked into things, especially banging his feet. With diabetic neuropathy he felt little or no pain when he injured his toes. Unknown to us he had a toe injury that developed into an infection. Isadore, proud as ever, saw it but tried to ignore this infection. By the time we found out about it he had a tunneling abscess. We worked hard and got that first one under control. Then the same thing happened again, with Isadore again not telling us he had a problem until it was noticed by staff, too late.

Like George Washington, Isadore never complained when he was in pain or felt poorly, but when told he was going to need an amputation he became badly depressed about it. He resisted and pleaded so much to avoid it that, against my better judgment, I agreed to have the surgeon perform a partial amputation of the foot rather than the usual below the knee amputation. The vascular surgeon advised that it was best to go higher up in this situation because poor circulation (and loss of sensation) in the diabetic often leads to failure of the partial effort, leading back to a second surgery, or a third or

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even a worse outcome. But the hope of just removing his toes to preserve both his dignity and possibly allow him to ambulate with a walker seemed worth the risk because of how upset Isadore then was. He was still walking on his own two feet at that time. I say it was a mistake because I defied the sensible logic of the vascular surgeon.¹⁴ Indeed, Isadore's amputation failed and he had to have the second surgery later. But how to judge if it was as mistake or a reasonable risk, I don't know.

Isadore loved to read. Nurses and other staff would help find books for him. He read fiction. Though he didn't particularly favor top quality writers, I was impressed at how much he enjoyed reading because I do read also and there weren't that many CEI participants who were thus engaged. Gregarious, he enjoyed teasing the nurses, but—unlike Stevie-- he was never inappropriate. Isadore was one of the most respectful elders I'd met. For his 95th birthday his entire family came down from Seattle. Unfortunately, Isadore was in poor shape by then. But he was happy, ebullient, to be so honored and loved; and proud that they all came down. However, he never stopped grouching about Ruth. She was one of the dearest people, and thought only about his well being, but he rewarded her like a pre-teenage kid rebelling from his mother.

¹⁴ There were times at National PACE Association Primary Care group meeting when the importance of PACE docs not letting specialists—such as vascular surgeons—take charge and do advanced procedures we understood as of little value to the functionality or quality of life of our patients. That was good advice also, but in this case my outcome expectations were unrealistic, not the surgeon's.

Macario

In July of 2002—a year after my “retirement”—I dropped by to meet CEI’s new Director of Services, Judy Hunt, and ran into some participants I knew outside the San Pablo Day Center and updated a bit with them. John, still with his bicycle in hand, welcomed me saying he continued to think of me as his doctor even though “I’m happy with Dr. Stromberg”, because “you were my first doctor here and the first to help me”(See John’s story elsewhere). I left John, greeted several staff, was starting to walk out and ran into Macario who I barely recognized. He was somewhat disheveled, but that wasn’t so different. He was a bit bent over and tremulous but that I attributed to his neuroleptic (anti-psychosis) medicine, also not really startling. No, it was his full shaggy grey beard. It made him look older and more unkempt than usual.

Como estas? Bien.

Su corazon? Muy bien.

Ya tiene la barba. Si, pero voy a razurar.

(How are you? Well. Your heart? Very good. Now you have a beard. Yes, but I’m going to shave it off). He smiles and shuffles away in the opposite direction from me, departing.

Macario was referred to CEI around late 1998 or early 1999 by a local Catholic agency (St. Mary’s) that services very severely impacted elders. He had a long history of psychiatric illness and disability and their staff protected him and tried to keep him on his medications. Macario is a permanent resident of the U.S. He emigrated from one of

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the Latin nations terribly torn by wars. The U.S. is implicated in supporting a death squad government there in past decades. We found, in addition to mental illness, that Macario had very severe and progressive heart failure related to his blood pressure. His paranoia made medication compliance for his heart disease a recurring problem.

Macario had a comprehensive delusional system that he at first concealed from us. But once he got accustomed to talking with us and trusted CEI enough he told of the men disguised as doctors and auto repair men who capture him when he goes out and stick a disc in his abdomen (like a disc brake, or maybe a CD player) that controls him and can make him sick and also prevent him from leaving town. His tale reminded me of Nobel Prize winner, John Nash, whose delusions are documented in ***A Beautiful Mind*** (the book by Sylvia Nasar and the film featuring Russell Crowe as Nash).

Macario was bilingual but he preferred that I converse with him in Spanish. In fact, when his psychiatric condition was unstable he lost his ability to communicate effectively in English.

Macario's heart failure was a serious concern. It would get so bad that off medicine he had difficulty breathing even at rest and was in constant danger of hospitalization. However, his heart condition was remarkably well controlled on the 5 drug regimen used for his low ejection fraction cardiomyopathy.

In late 2000 Macario announced that he had to go back to his home country to take care of a house that the family owned, and to visit family. It wasn't the first time he had talked about going home despite his over 10 year residency status, but this time he was very adamant. He said his adult son would go with him. I had previously told him

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that the issue would have to wait until his heart condition was under better control. He'd accepted my decision, but now he correctly assessed that his heart was doing better and the medicine was helping. Unfortunately he also was sure that the CIA was trying to prevent him from leaving and that the men with the discs were still working on his innards.

I was nonplused but tried to be consistent. If he went he would have to take his medicine every day and he would have to return in less than a month, I said. He agreed. Moreover, I told him, I'd want/need the opinion of our Ethics Committee about this; whether he would be safe leaving the country. How would he feel about coming before the Ethics Committee and telling them about his plans? The Team agreed with this approach and so did Macario. I had thought he might bail out but, in fact, he was quite enthusiastic about this appearance, as if he was going to audition for a part in a play (though in this case, his own life).

The sister at St. Mary's, across the street, who had long ties to Macario was not nearly as enamored of the plan. She, and her cohort, felt that leaving the area would endanger Macario's life, because he would immediately stop taking his medicine. She thought him not in a state of mind to handle meaningful decisions about his life; his delusions made him highly irresponsible and a potential danger to himself. I owned that this was possibly true, but wondered about the impact of taking away a man's right to visit the land of his birth and upbringing. And Macario was very consistent about his plans; he seemed to have the details down pretty well, despite his paranoid delusions. I

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was leaning toward supporting his right to go, but waited to hear what the Ethics Committee thought. The social worker from St. Mary's was invited to participate.

To the amazement of some staff, Macario attended the Ethics Committee meeting dressed impeccably with a tie and jacket, well groomed, and highly coherent. He did a beautiful job of presenting his case. The Ethics panel was very impressed.

Discussion: Two panelists pointed out that Macario was not conserved and had legal rights that include freedom to travel. In response to a question, the Committee was told that when out of the country, CEI has no responsibility for his medical care. Social workers on the panel pointed out the CEI philosophy is to assist in maintaining independence without placing serious restrictions on peoples' ability to make meaningful decisions in their own lives. A panelist thought that trying to stop him seemed too paternalistic since his cognitive state is high enough to make his own decisions even if they might be bad ones, so long as he is able to understand the potential ramifications. Several panel members took the pragmatic approach: let's give him a letter in Spanish about his heart condition that he can use if necessary; let's contact his sister in Central America. Let's try and assure that his son does really go with him (as he claims will be the case). Though we have a responsibility to try and reduce/ minimize the risk, the Panel concluded, intervening to prevent his ability to leave the country was inappropriate.

The St. M.'s social worker expressed satisfaction with the discussion and its outcome.

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Recommendations of the Panel: ***The Panel is unanimous in its view that M's autonomy rights and independence be respected even though there is an acknowledged risk that he may decompensate medically and/ or psychiatrically and that this risk could lead to serious consequences up to and including hospitalization, incapacitation or death. The Panel agrees that M. be permitted to travel to x for a month and to remain in the program; that CEI do everything possible to assure him a safe trip and return by: 1) holding a meeting with M. and his son who he has said he will go with him to assure that he gets all possible assistance in medication compliance and medical necessities, 2) making contact with M's sister in x, 3) translating the medical documentation he will carry along with his medications into Spanish, 4) providing an explanatory letter from Dr. Sapir also. M. has successfully demonstrated to the Panel that he has the capacity to make meaningful choices and understands the possible consequences being discussed. Dr. Sapir will further reinforce these risks in forthcoming discussions with this CEI participant.***

A few days later I told Macario that the Team, the Ethics Committee and I supported his right to visit home. He had earlier claimed he was getting his passport renewed and only needed to arrange his papers before making reservations. I told him St. Mary's which was his representative payee for his disability income would give him his own money for the purchase of the tickets.

But Macario responded that there was a problem with his passport. "What is the problem?" I asked. "Well its expired", he answered.

"I thought you were working on renewal", I said. "There's a new problem", he reiterated. He acted confused and this confusion reflected a much different Macario than the one who presented so well, kempt and coherent with his hair greased and clean neat clothes before the Ethics Committee.

"I have an idea", I offered. "Let's have a little meeting with you and your son. Can you have him come in and talk with me? I'm sure we'll work it all out with you."

Macario never got his passport renewed. Who knows if it was expired or lost or what? He didn't bring in his son, although I would have found a time suitable to their needs. And in another week or so Macario appeared in clinic to tell me that he had decided not to go home at all. What had been an urgent and pressing need, had become a non-issue.

Someone might suggest that this outcome was all foreseeable; or even that we-- myself and all the others involved in this situation—had been wasting our time needlessly, idealistically, while putting Macario at risk. The man is, after all, a chronic paranoid schizophrenic whose delusions are persistent and ever present. But I don't think that I was (or we were) wasting my (our) time, and I don't really think there was anything else that one might do except to turn one's back on Macario and walk away. That is what often happens to difficult people in these difficult situations. Indeed, it is what we tend to do with most of the homeless panhandlers on the street. "Sorry, I really can't help you," I've said all too often.

But here is Macario and I think we did help him. He got to do an act, a presentation, and get himself together enough to represent himself exceedingly well before a panel of staff and community folks and professionals. He was able to get an affirmation from all of us, his community, that he was capable and entitled to make important decisions for himself. And then he made the right decision, the one that preserved his life and his continuity of care and support. He made the decision that kept him nurtured by a system of concern that could not conceivably be matched by

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whatever he had in store back home. He made the same decision that many of us would have made in his shoes had we the clarity and presence of mind to do so.

In 2002, the grey bearded Macario I encountered, was the somewhat unstable, semi-delusional Macario, living alone in his apartment; but unfettered, free, and out on the City or to the CEI day center as he pleased; yet Macario survival required the check-ins and check-ups readily available from the people at St. Mary's and CEI, the people of his adopted family and community.

Driving Under Divine Influences

Robert, Walter, James, Eva, and Sylvester

Like most American teenagers, as I approached my 16th birthday in New York in 1957, I couldn't wait to get my drivers permit and my license. Then as now, driving a car was a badge of adulthood and independence, autonomy and power. Indeed, cars aren't just symbolic. A car is a magical vehicle that can take a teenager almost anywhere, even to outer and inner space, and very far from maternal and paternal watchfulness and guidance. My mother had recently bought a used car for a few hundred dollars, I think it was a 53 Chevy or Oldsmobile, and I was thrilled. In those days few families around had a second car, but we lived in a suburban area where a working woman would find public transportation and carpooling difficult. And my mother had become a school psychologist and needed wheels.

My dad had begun to teach me how to drive on weekends, but I just couldn't wait out the long weekdays in between with him at work for my chances. I soon convinced my mother to let me take her car out to practice. The law said that you had to have a licensed driver in the passenger seat. I argued that my friend Steven Sumner already had his license and he would help me with my parking. I pleaded my case successfully and off we went. But as per her instructions, not far. About 6 blocks away, right near Steve's house I decided to practice parking. As I began to back in to parallel park, Steve opened his door to see how close I was coming to the curb. Apparently no one taught him that generic rule: don't open the car door while moving, and besides that he

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didn't even look around. So surprise, surprise there was a telephone poll right back there 8 or 10 inches from the curb and the steel of the passenger side door was well folded after door met poll. On my first solo run without parental oversight I now had to explain to my mom how her new car got crunched, and that the whole sorry mess wasn't really my fault.

Now fast forwarding 45 years to CEI where there are a number, though a small number, of disabled participants for whom driving was also a badge of maintained independence. And one or two of them did indeed rival my prowess as an initiate of sculpting doors. First was the group of proprietors of aging Cadillacs. These included Robert A with his old monster Cadillac the size of a boat. Likewise, our second MD, Walter Peters with his satiric allusion to African American attachment to Cadillac status. Walter's Cadillac was even older and more beat up (maybe something around the 1975 vintage), but no larger than Robert's. And James W. also, I think had a huge cadillac---or was it a big old Pontiac Bonneville? Anyway, Robert would drive his monster right up to the loading ramp behind the county hospital and take one of the spots reserved for the CEI vans to unload clients.

Robert was a veteran who'd had a stroke and had received his care at the VA. I think he joined CEI in part because of persistent residual shoulder pain from his stroke and arthritis. From his vantage point, he wasn't getting the attention he wanted from the VA docs who couldn't make it go away. He undoubtedly got more attention for his shoulder from CEI therapists and sympathetic ears but nothing was likely to free up his

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partially frozen shoulder; and his pain, though treatable with many different modalities and sometimes with great success, was not going to go away permanently.

Anyway, Robert was proud and he loved to drive that car up to CEI. We always tried to focus on maintaining participant independence but the team and the transportation staff weren't so happy with Robert's remedy for transportation. Would CEI be liable if Robert, with his hemiparesis, had an accident going to and from the Center on his lonesome instead of by van? And clearly there was no place for him to park his Caddy that was close enough for him get himself into the center. Robert couldn't be allowed to block the van unloading area. He was told he would have to leave his car and his driving at home.

Robert wasn't the first interesting driver at CEI. Before him, with a greater drama was Eva H a friendly if somewhat confused and mildly demented woman who had, in the past been married to David H., another participant in the program who usually seemed to be on a trip of his own. Eva was getting to the point where managing daily affairs was becoming more difficult due to confusion.

I think it was before she dropped a hot pie on her foot while cooking, causing serious second and third degree burns that her driving incident occurred. One morning we arrived at briefing to hear this overnight story from staff. The previous day Eva had decided to take her car for a spin. Although she had some home care support from CEI, most of the time—as on that day-- she was alone. That day she went out to the garage got in the car, started up the engine, put the car in gear and stepped on the gas--crashing through the back wall of the garage, stopping just before crashing into the

main house. Eva was unhurt, (her badly damaged car and garage were less fortunate) ^{-I'll fly away-} but the team decided to explain to her that she would have to give up her keys and stop driving to prevent worse danger to herself. Eva didn't resist.

Many years later, however, my own mother would resist. I had to take the car away from her because, at the age of 91, she had become too confused to be allowed on the road. However she refused to give up her car. When I reported her to the Department of Motor Vehicles they had her come in for a driving test—which she failed. Mother then proceeded to drive without a license until I physically took the car away to protect her and others on the road. By then she was showing ever clearer signs of dementia and my sister and I realized we had to act. But our mother became so angered at my affrontery that she called the police department and told them I had stolen her car and run off with it. It took us quite a while and some tense moments for my sister and I to convince the authorities we were acting in our mother's behalf. We send in all the documents to the authorities that proved we had power of attorney over mother and that because she was unsafe on the road we had no other choice but to take her car. (a lesson here to all: have your aging parents give you power of attorney to act for them while they still have the mental capacity to do so).

Sylvester H. was a different kind of driver altogether. He was an impressively intelligent and accomplished man who had had both his hands burned in a fire at the age of 2. All that were left of his hands were balls of skin and bone, stubs where his fingers had been. He did have partial thumbs that were scarred down but of use for

grasping. Sylvester went through life learning how to use his attenuated “hands” to perform essentially all normal daily functions and beyond that to drive tractors and other farm equipment and, ultimately, to be licensed to drive big rig 18 wheelers. He spent a good deal of his life as a long distance truck driver. To see his hands, it was hard to believe his accomplishments. He was quite humble (and also proud) of what he had done and become. No braggadocio. Sylvester only joined CEI because, getting on into his 70s, he was beginning to have more trouble doing things. With arthritis and slow physical decline on the backdrop of those hands without useful fingers it seemed a wise decision to look for collaboration in his aging days.

But joining CEI didn't stop Sylvester from driving. One hot summer day after visiting family and friends out in Fairfield, about an hour's freeway drive into the very hot central valley from Oakland, Sylvester got a flat tire and was out on the freeway trying to change it. The temperature was between 95 and 100 degrees. I can't say if he was angry and fuming and frustrated, but the heat and the crisis may have pushed up his blood pressure. Sylvester suffered a stroke there on the shoulder of Interstate 80 and was taken to the local hospital. As his health care provider we were notified. He was kept in hospital a few days, stabilized well and we then transported him back to Oakland by ambulance and put him in a Nursing facility for a while. We had him coming into the center for physical therapy and rehabilitation. Sylvester recovered fairly well but the additional loss of function had a dampening effect on both his spirit and independence. He was very happy to have the CEI family---staff and participants---around him for his

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support, but the pride of the independence that he had built into his life from the age of 2, undoubtedly with the support of his own family, had take a big hit.

Another driver, Mr. G, was a homeless man who attended the San Pablo Center and despite his homelessness owned a car which he slept in. When his derelict car was towed away soon after he joined CEI, Mr. G was furious with good cause. Only a few weeks went by and Mr. G had taken his disability check—the money that he lived off-- and rented a truck with it. A few days later I saw him at the Emergency room for minor injuries suffered when his truck was broadsided coming out of a driveway. The scuttlebutt was that it really wasn't his fault; his driving had been faultless. Perhaps Mr. Gs driving was superb, but I can't forget that my own mother tried to convince me she still had her driving acumen, when everyone around her could she was losing her mind.

Taking Risks on the long trip home

Gus

Gus was one of the original members of CEI. He was an 80 year old man then. Gus was slender attractive, youthful, with a fine upright posture, a small but well defined dimpled chin and fine lips, over 6 feet tall and quite shy. He stuttered a little when anxious—though never while singing--and had to be drawn out in conversation. He had a high smooth forehead and a mostly bald pate with short side-hair and an engaging smile. He dressed smartly but not ostentatiously often with a camel hair vest sweater over his collared shirts. One of Gus' greatest consternations was people thinking he was white, especially Black people. He was very fair complexioned and his features did not suggest his ethnicity. He did feel excluded and offended when he was not taken for African American by other African Americans because he was proud to be Black and let that be known. What Langston Hughes might call a "race man," Gus was embedded in Black culture and politics.

With quite a good number of participants having varying levels of dementia with memory loss, you can imagine the frustration of telling people what and who you are and to have them forget a few minutes later. Part of the issue here was that Gus too had a little dementia; not bad, but enough to confuse things a bit. But I'm getting ahead of myself.

Anyone paying attention knew that Gus had a beautiful gospel singing voice and that voice and the songs he sang might clue them in that he was African American. Gus' favorite song was "Ne'er by God to Thee" and he loved to solo in a group or the

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choir on that piece, straining his natural tenor for the high notes. His voice was strong enough that someone decided to capture it for posterity on CEI's professionally made video, "Still Singing," and you can still hear him singing today many years gone if you can get a copy of that video from the organization. As an aside, we learned that even severely demented participants can retain their musical talents and gain great enjoyment from singing (just as we learned from Almost).

I don't think Gus had family and so he was living at a Board and Care home. Gus loved Oakland. He was like a wandering minstrel. Whereas many dementia patients take to wandering in their confusion, Gus was a wanderer long before he had memory problems. CEI had other great travelers in the program, such as William B., a purposeful traveler, always on his way somewhere in particular, often by bus, sometimes on foot, but always out there. Gus on the other hand just liked to wander the highways and byways, without a defined goal. Maybe he missed the independence of living alone, or the friends who had passed or moved away, or family. But in any case he just loved to walk.

Staff all knew he could be seen almost anywhere around town and that became a concern for the Team as his memory slipped away to be replaced by confusion. Reports began to be fielded from the Board and Care of Gus missing in action at night, of his being picked up and brought home by the police at odd hours. Naturally we tried to talk with Gus about this situation. He didn't see the problem, just shrugged his shoulders and gave his shy friendly grin. Then one night he was mugged and wound up at the ER with, luckily, only minor injuries—cuts and bruises to his face.

The Team had been working with the Board and Care to try and have them not let him leave at night. They tried to monitor his coming and going but it was a large home with several exits and they were not successful. He kept disappearing. He often made his way home, but the risks and dangers grew over time. As Gus' memory slowly worsened the Team discussed whether to put him into a nursing home to protect him. After a lengthy debate the Team agreed that wandering was so integral to Gus' identity and quality of life before he had memory loss, that institutionalizing him beyond a Board and Care where he still had some autonomy, would be an attack on his personhood, his remaining identity, his joys. Instead a new Board and Care, thought to be more attentive and protective of its residents was found. The new smaller home had few doors and a staff member always at the main exit/entrance, so Gus could be allowed out at reasonable hours of the day and otherwise talked into staying home.

For a while the Team lapsed into a sense of false security for a job well done. We had protected Gus' quality of life and found a solution to a difficult problem. Then we learned that he was getting out again. Whether it was his cleverness or our misjudgment that the level of monitoring and concern at the new home was adequate, we will never know. Gus had been able to subvert the system in place in a fairly short time but it took longer for us to learn about this.

Perhaps a few weeks or a month went by after we recognized the recurrence of the problem. One night Gus went missing. The next day he was found dead face down in a creek. He had apparently tumbled down a small embankment and hit his head on a rock. There was no evidence of foul play. Gus was not ill at the time. He

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didn't really have any serious life threatening illnesses. The Team was shocked, heartbroken, and felt a great loss and sense of responsibility.

The next day we carried out a “debriefing” or review of the case. We gnashed our teeth and wondered and worried. But in the final analysis the logic of who Gus was pulled us back to ourselves. We had done well for Gus. We listened to him. He knew what he wanted and he was always clear on the importance being able to roam. In supporting him we had taken a risk that was necessary to make his life worthwhile. We had assessed the risk, tried to understand and quantitate it. His death did not mean that the risk was inappropriate or inordinate. We affirmed Gus. The Team also acknowledged that our commitment to honoring who Gus really was—still was-- reflected how deeply human and humane an interdisciplinary Team approach to the care of the frail elderly really is. Gus died doing the thing he loved most to do, walking the City's streets.

In Search of People No One Else Can Serve

Mavis

In its enabling legislation PACE was granted an exception for substance abusers. That is to say, although the Program sites have to take in all disabled elders seeking entry who live within a given site's catchment area and are Medicare and Medicaid eligible, programs do not have to take in chronic substance abusers including alcoholics. Only a few programs ignored this exemption and threw their doors open to these difficult management problems. From the very beginning CEI was one of these. Indeed, I informally reported on our experiences to other physicians and medical directors at national PACE conferences and urged others to follow this example. We thought PACE could work successfully with this population, although we had made a few mistakes that hadn't worked out well.

For example, CEI had, around 1994, admitted a woman in her late 60s who was in a chronic methadone maintenance program due to a history of heroin use. I became Mavis' first physician and, at the time, was not a fan of methadone maintenance (though this case caused some evolution in my thinking); so I asked her if she'd like to detox off methadone in our program. We would require that she agree to occasional testing of her urine to assure that she was staying clean. We would be in a position to monitor her closely. Mavis enthusiastically agreed to this plan. In retrospect one might wonder

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if she thought that she had to agree or we would not keep her in the program; she wanted the program. There was no such conditionality, of course; but addicts often get interesting ideas about what they have to do to get you on their side.

Mavis did detoxify off methadone and there was a big celebration, but her abstinence was fairly short lived (a few months). When she slid back into heroin use an adversarial relationship developed between her and staff as she lied and tried to cover up. Ultimately, in a mutually beneficial move, she disenrolled from the program because the working relationship had broken down.

Ironically, special provisions in the State's managed care regulations allow for substance abuse treatment to be paid for by Medicaid to a second program even when a person is enrolled in a total care package such as CEI. We were not liable for the costs of her care under a specialized drug program and had no financial incentive to take her out of that program when we did so. It was little more than my own desire to see Mavis get free of dependency on methadone that led to her failure to integrate fully into the CEI culture and her return to use of heroin.

‡
John

On the other hand CEI had taken in many alcoholics and some of these continued to drink, sometimes uncontrollably and even while at the Center. We slowly evolved strategies for dealing with the problems that such folks caused us. One response was formation of a group (called Step Zero) that met every Saturday morning run by an outside substance abuse counselor. Group members did not have to

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acknowledge any problem to participate and were referred in by their Team, their physician or social worker. The group gave its members mutual support in trying to cope with various kinds of problems and stresses but the explicit focus was education and discussion about chemical substances. The leader was a believer in the traditional 12 step program made famous by Alcoholics Anonymous, even though some of her participants did not even admit to having any problem.

A couple of years after the experience with Mavis, CEI hired a social worker, Sue Jacky, who, by good fortune, had experience working in substance abuse programs. Sue provided the professional staff at CEI with its first systematic exposure to the concept of "harm reduction." She provided an inservice and organized discussion and in-services with outside expert resources. Acting on advice from a task force we formed, CEI then adopted a policy of developing collaborative strategies with our alcohol and substance users aimed at minimizing the harm that can result from problematic use of alcohol and drugs. The strategies/plans were based upon the participants own personally established goals worked out with their social worker. No one would be pressured out of the program for using alcohol or other substances unless our relationship with them deteriorated to the point of no return. In eschewing the idea of externally set goals, such as abstinence only, we went against the advice of our Step Zero counselor. Along with the general policy on harm reduction came specific policy and guidelines about how to deal with people whose inappropriate behaviors were not re-directable at the Day Center.

All this activity was part of an agency wide discussion about throwing the recruitment net out even more widely and the likelihood of dealing with even more people severely impacted by drugs and alcohol.

Despite this preparation, when John showed up as a CEI candidate there were still staff who believed in their hearts that some people are just “low lifes” and nothing can be done for them because they don’t give a damn about themselves. John was a young man of about 60, a homeless severely impacted alcoholic. Suprisingly, John didn’t look the part. He was attractive, looked younger than his age, vigorously rode a bicycle, smiled easily and was friendly to most people.

Of course a comprehensive health program like CEI cannot effectively provide services to someone living on the street with no address or telephone or means of contact. Part of getting John into CEI involved facilitating his obtaining a low income apartment. When he joined us John was, for the moment, living somewhere in particular. But John had some attitudes about the process we proposed and so, in response to John’s assertions, did his social worker. “I’m the fittest 60 year old around” John insisted, “and I can handle all my own affairs. I’ve got it under control.” None of it was real, but covering his dependency, and his feeling “one down” was an obvious aspect of John’s historical drinking problem.

One couldn’t deny that John, now sober, looked youthful, muscular and apparently physically fit. But with underlying hypertension and cirrhosis the looks were deceiving. Not only that, something I didn’t know as John’s new physician--he had had

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a couple of hospitalizations for chest pain in the months before entering CEI which he didn't tell us about.

A month or so after joining CEI, whether due to drinking or not I cannot recall, John began to have problems with his housing. He failed some rent payment deadlines. The house manager gave him a warning that he could be evicted. His social worker offered to help him out, to help him manage his money and set aside the rent payment and negotiate with the housing manager. John got defensive, claiming he knew how to handle his own affairs and didn't need the help. I recall the social worker coming to the clinic one day to tell me his attitude was hopeless and she was washing her hands of it. He'd undoubtedly be evicted and would become homeless again because he wasn't going to let her help, she asserted.

"Where is he?" I asked.

"He just headed out the front of the building after telling me off," she said.

I ran out of the clinic and caught up with John, about to get on his bike. "What's going on?" I asked him.

"The Social Worker wants to run my life," he responded. "I know what I am doing. I can take care of myself, but she wants to take over."

"Look John I retorted assertively. You're screwing up. You need help, yet you push away the help that we offer. What's the sense of being in the program if you aren't going to use the help it provides? You say you can handle all these issues, like your rent and housing, but you've been homeless a lot. Obviously that hasn't worked out

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well before. Why let it happen again? Why not let the social worker protect your housing?”

We can lecture our own kids--or other people who need a lesson-- a million times and get nothing more than some egg in the face, but I guess this was the right time for John to hear this from his own doctor, someone he respected and felt had respected him. He turned around, went back inside and told the social worker he'd work with her on his problem. He didn't lose his housing, he stopped drinking altogether, and John and I became pals.

A few months later, during a night I was on-call, John was riding his bike and got chest pain. He stopped riding, got on a bus and went to the ER and after I was called he was admitted to rule out a heart attack. I was glad that I was to be his attending physician in the hospital. Although his cardiac enzymes were suggestive of a small heart attack, his cardiogram did not show any changes and his rhythm was stable. In reviewing his old hospital chart I found that John had been admitted before with a similar picture. Although under the care of good hospitalist physicians, no one had consulted a cardiologist or suggested that he have a coronary arteriogram to study his heart blood vessels for blockages. Not even a standard treadmill stress test had been ordered. I wondered if this could be the result of John's homeless status, his drinking history, his age and/or maybe his history of regular exercise.

I called our cardiology consultant, Dr. Earl Holloway, who recommended that catheterization was advisable. After a day's delay John was found, at catheterization, to have severe narrowing of two coronary arteries and underwent angioplasty and

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stenting. About a year and half later John had had no recurrence of his chest pain. However, he did somehow lose his housing again a couple of times though and, when I saw him briefly in a visit to CEI in July 2002, he was temporarily staying at a nursing home while CEI helped him find yet another place to live. I don't know if he was drinking again, but he seemed to be doing well. By then he was one of the participants who used the program less for the Day Center social environment than for medical care and social worker support.

Role Reversal: Luann rules the Team

Were you to ask staff at the Center for Elders' Independence to rank a few of the most irksome, annoying, difficult participants to deal with, quite a few would have put Luann right up top of the list. Here was a woman with a patent on driving people crazy. Young (then in her 50s) and not particularly physically disabled, though she sidled her 250+ pounds along dazedly with a walker, Luann had been at CEI from the days of the old Adult Day Health Center program before the program joined the all-inclusive care model (PACE). She was one of a very few people grandfathered in below the required age of 55. I remember her age clearly because it is the same as my own. And Luann has now, in 2004 (when I drafted this essay), been a CEI participant almost 12 years.

So, you may wonder, what was her disabling illness that, even despite her young age, qualified her for a special program for disabled elders. What made her dependent to the level of otherwise requiring nursing home level of care? If you're guessing mental illness, you are partly right, but that wouldn't be enough to make Luann's case for PACE entry. However, you'd be right because the name of Luann's condition is found and described in psychiatric texts and in the DSM V (the diagnostic manual of mental illnesses). To a psychiatrist that probably would make her a psychiatric case. In fact Luann became my patient after years of treatment with anti-psychotic drugs and care under psychiatrists that, in my view, did little for her. I particularly remember she came to us on Prolixin 30 mg (an anti-psychotic) and Elavil (tricyclic anti-depressant)

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but she was on several other medications as well. That was in 1992 when I performed Luann's entry exam. Upon expressing my hope that we would be able to get her off some of these possibly unnecessary medications, I remember Luann throwing a minor temper tantrum; something to the effect that she would die without every one of those medicines. My explaining to her that Elavil (amitriptyline) was probably making her sometimes troublesome urinary incontinence worse did not interest her in the least.

Luann's diagnosis according to a psychiatrist earlier in her life was/ "borderline personality disorder". What in the world is that, you may wonder. At least I did. And here we enter the twilight world of nosology (naming) and categorization of mental illness.

Googling BPD (Borderline Personality Disorder) you will find a rich world of descriptive information and data that shows that "personality disorders" are a grab bag of conditions encompassing a potpourri of symptoms, signs and concomitant conditions and morbidities. Below are excerpts from Wikipedia's discussion of the borderline personality diagnosis. In the chart labeled "Comorbid Axis II Traits" below I've underlined the traits that describe Luann.

Borderline personality disorder

emotionally unstable personality disorder –
impulsive or borderline type, emotional intensity
disorder^{[1][2]}

The essential features include a pattern of [impulsivity](#) and instability of [behaviors](#), [interpersonal relationships](#), and [self-image](#). There may be uncontrollable [anger](#) and

depression. The pattern is present by early adulthood and occurs across a variety of situations and contexts.^[3]

Other symptoms usually include intense [fears of abandonment](#), extreme anger, and irritability, the reason for which others have difficulty understanding.^{[3][4]} People with BPD often engage in [idealization and devaluation](#) of others, alternating between high positive regard and great disappointment.^[5] [Self-harm](#), [suicidal behavior](#), and [substance abuse](#) are common.^[6]

The [Diagnostic and Statistical Manual of Mental Disorders, DSM-5](#)

proposes "Alternative DSM-5 Model for Personality Disorders." These alternative criteria are based on trait research and include specifying at least four of seven maladaptive traits.^[76] Luann particularly fit the Cluster B characteristics in the following chart.

Comorbid Axis II disorders

Percentage of people with BPD and a lifetime comorbid Axis II diagnosis, 2008^[89]

Axis II diagnosis	Overall (%)	Male (%)	Female (%)
Any Cluster A	50.4	49.5	51.1
Paranoid	21.3	16.5	25.4
Schizoid	12.4	11.1	13.5
Schizotypal	36.7	38.9	34.9
<u>Any Other Cluster B</u>	<u>49.2</u>	<u>57.8</u>	<u>42.1</u>
<u>Antisocial</u>	<u>13.7</u>	<u>19.4</u>	<u>9.0</u>
<u>Histrionic</u>	<u>10.3</u>	<u>10.3</u>	<u>10.3</u>
<u>Narcissistic</u>	<u>38.9</u>	<u>47.0</u>	<u>32.2</u>
Any Cluster C	29.9	27.0	32.3
Avoidant	13.4	10.8	15.6
<u>Dependent</u>	<u>3.1</u>	<u>2.6</u>	<u>3.5</u>
Obsessive-compulsive	22.7	21.7	23.6

Luann fit well enough the picture above, particularly the “Cluster B” type, but, naming aside, the key point is Luann’s problem was near total dependency stemming from her personality itself . She substituted the idea of manipulating people around her

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to get whatever she wanted instead of making any effort to cope with real life relationships and problems. I think this substitution of needs can be likened to the behavior of infants and small children. All of their needs are met at first by their mother. The infant cries for milk, or to be changed, or because it is uncomfortable and sure enough mother responds. Eventually a communication system develops wherein the mother (and then father or other partner) learn which needs are being expressed. Of course the young child is unable to meet any of its own needs except by this form of communication. A child going through the terrible twos and troublesome threes confronts parents with the task of beginning to teach the child that needs are not always so easily and automatically met; and that over time children have to learn to both adapt to less responsively faithful environments, and to the reality that everyone else has needs too so getting needs filled has to be a give and take, a cooperative, collaborative and sharing process.

For reasons obscured from me, Luann was stuck back in the infantile way of dealing with people. She had projected her own difficulties in coping with life and its problems into her relationships with those around her, including her three daughters. She could do nothing for herself. She acted out only childish behaviors to attract attention, and that is the way that she presented herself to others. If acting out like a child could get her little more than attention and some basic needs met that was enough because it also served to mask Luann's deep personal sense of inadequacy and failure in her own life.

-I'll fly away-

Those who knew/know Luann might be tempted to think her mentally retarded, for much of the time she acted like she didn't even understand what people were saying to her. I wouldn't try and convince anyone that Luann is highly intelligent, if only because she has so attenuated her interactions with her environment that she stymies her own learning capacity. I honestly have no idea what her native intelligence capacity was. But over the years, through neglect of those learning, coping, and adaptation skills, Luann has undoubtedly lost some of her intelligence. She is, has become, like a sensory deprived animal, living in a self constructed dark cave with invisible walls. She pays attention only to her own immediate feelings, perceived needs, issues, and wants. She is, for practical purposes almost unaware of what is going on around her among other program participants, staff, family, her community, our world.

That's Luann at a distance, but why would many staff put her atop their list of distracting participants? And what kinds of reciprocal behaviors did that hairpulling lead to in the San Pablo Avenue team of CEI?

Every PACE program has system-abusing participants who call 911 for the most trivial concerns and complaints, pulling vital ambulances out of circulation and forcing their own transport to the Emergency Rooms for a runny nose or because they want a laxative and homecare didn't respond to their phone call. Such problem cases often became teaching lessons in the PACE Primary Care committee at national meetings. Hospital ER visits cost thousands of dollars, but an "All-inclusive Care Program" cannot refuse to pay for emergency room care, even when it isn't justified and even though there are physicians and nurses available by phone at all times, because the right to

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that care is more important. Participants who abuse that right time and again despite warnings and lectures are a persistent problem for teams. Luann was such an abuser, but she raised the abuse to the highest power.

Before we opened the CEI second center in 1996, Luann had already been evicted from many living arrangements due to behaviors that drove housing managers to distraction. She would scream and argue and refuse to follow rules. At one point one of her daughters tried to live with her in a Board and Care facility, a small home with 5 or 6 beds. The two of them could not get along and the fighting between them only added a third dimension to Luan's fights with the management. She was evicted again. Just in time, CEI opened a new center below a new independent senior housing building and Luann was able to get a room and to transfer to the new Day Center.

But having Luann closer to the Center she attended and under closer supervision by home care staff actually brought out the worst in her efforts at manipulation. Many times in 1996-7, as soon as the Center and clinic had closed for the day and Luann had gone to her apartment, she would "collapse" on the floor and scream out at the top of her lungs as if she were dying and in serious pain. What she was screaming for, she would make clear when someone arrived, was for people to get her up off the floor. This woman has no significant physical disabilities. She had the capacity to get up off the floor. For a while people responded supportively to this acting out in hopes of calming her. Still, she "fell" more often, at later hours, raised the pitch of screaming, causing alarm by the building management. She began to call 911 for these falls.

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One night when I was on call the home care staff called me to tell that she had called 911 again and the paramedics were there about to take her to the ER (Luann's "falls" never caused injury). I had staff put the paramedic on the line. It was about 10 p.m. "She's been doing this a lot," I told him. "Can you abort the transport and let us handle it? I'll take responsibility". Paramedic: "We know about her. It's getting around the Emergency staff, and I had her myself last time, but the only way to not take her if she wants to go is if you come down and assume the care." "Sure," I said. "I'll be there in 15 minutes". I drove to the San Pablo. I signed for Luann and she stayed home that night. But the next day we were bound to have one in a long series of our own distracted discussions in team about how to set limits and maintain consistency with Luann. We had tried regular meetings with Luann to make clear certain rules and expectations and to set clear lines and limits. Unfortunately, our team performance was not sticking rigorously enough to our own plans for her and Luann, despite her simplistic and infantile way of manipulating us, was actually out maneuvering an entire team of health workers including many professionals.

There was an episode with another daughter who lived in the area. The daughter wanted so much to show her love for her mom that she would call us to ask if it was ok for her to take her mom home with her for a weekend or several days. The team said "yes." Why would we have any objection to this? Moreover, there was no requirement that the daughter even ask us. Luann's apartment house was not restricted in any way. But the daughter was apparently under the impression that her mother was a lot sicker than we believed she actually was. So off Luann went to her

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daughter's for the weekend. At the end of the weekend, on Monday morning, there was no Luann in her apartment nor at the Day Center. Luann had not returned. Luann had pleaded with her daughter that she not have to leave her home. She'd insist she wanted to stay and to live with her daughter. The daughter felt so obligated by her love for her mother that she succumbed despite her better instincts from past experiences that solace would be short lived. Within hours of the daughter agreeing that Luann could stay with them, having gotten her "foot in the door" Luann began acting out and the situation became a nightmare. The daughter then grabbed Luann's things, bundled her into the car and dropped her back at the apartment house. The son in law would then ridicule the daughter for putting up with this. Several times these events repeated themselves—a daughter (one the three) trying to reconcile with her mother and taking her home supposedly on a visit; then followed by the daughter's understanding of the impossibility of coping with Luann collapsing in the face of the mother's beseeching to move in and stay there; then in no time the relationship would come crashing down.

We counseled the daughters quite sternly to set limits and not to give in but to bring Luann back on the day and time as planned in advance. They went through periods of total disaffection from and non-communication with Luann. Luann, who precipitated these situations would then complain to me that her children hated her and no one cared about her. I tried to get her to call the daughters and keep up relationships, loving relationships, but also to maintain some distance. She was immune to my proposals. She lost their phone numbers, occasionally called and left

messages but generally couldn't get it right and either stayed disaffected or pushed herself on them. -I'll fly away-

These messy relationships reached a crisis point with the most involved daughter, Jane, during a visit on the Thanksgiving holiday—1997. The son in law had not wanted Luann there as they were having guests as well as family. She had been so disruptive in the past, but Jane was set on trying. Luann was overjoyed that her daughter invited her. She had felt so rejected, and here was vindication, and love. So she went out to their home and in no time she was acting out again, right in front of their guests. Her behavior peaked with her taking off her underwear and urinating on the floor. Hearing that, it isn't hard to imagine Luann as a psychotic, I think. But, her behaviors were not based upon delusional thinking and were resistant to typical neuroleptic (ant-psychotic) meds. It didn't matter how much medicine Luann was given, it didn't change her behavior. You could knock her out with drugs like Droperidol but by the time she was alert she was the same Luann. Luann never had delusions or hallucinations in her entire life.

By that summer I think I was the only person around who thought Luann's act was so absurd that it was funny. We had tried seeing her in the clinic every day for counseling, therapy, and catheterization for her intermittent urinary retention. We had tried every other kind of attention and support that people could think of. Although the situation was, on one level, ridiculous, the greatest concern was that Luann was distracting us all from dealing with the many very complex and needy participants who required our undistracted attention. She was siphoning off hundreds of hours of staff

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time. I pressed the team to let go of Luann; to not let themselves be so upset by her. We could see that she was single-handedly damaging the whole system, and we were becoming co-dependent in the process.

Summer arrived and my wife and I went off on a 3 week vacation. When we returned I was shocked to find out what had happened with Luann. Almost as soon as I had left the team had put Luann on the list to see the psychiatrist the next week; although she was my patient, nothing had changed and so I was not part of their decision. They felt they had reached their limit and wanted her to bail them out. They believed they were hoping to treat Luann, but in my retrospective view they were trying to treat the Team itself.

Luann had seen the psychiatrist before at least twice and there had been no new acute changes to warrant the referral without my input (except that the team was distracted and that too was not really new). Then the final straw. In my absence, the psychiatrist saw her and offered that, as one of the researchers in a newer anti-psychotic drug trial, he was always looking for potential research subjects. He suggested that if he thought Luann was psychotic he would like to enter her into the trial. The team agreed. The psychiatrist certified that Luann was psychotic and she was begun on one of the newer atypical neuroleptic anti-psychotic drugs. I think that the ethics involved in these decisions requires serious and critical introspection by those involved.

Upon my return, learning of this, I intended to have Luann disenrolled from the drug trial. But upon calling the psychiatrist I found out that she had started acting out at

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his office on the second visit anyway, had begun screaming and demanded to go home. As a result, ironically, she was found to not be able to stick to the protocol and he had already disenrolled her. But I became so distressed upon hearing about how the team had tried to treat it's own upset with Luann by getting her drugged that I ultimately took the matter to our Professional Medical Advisory Committee and issued a policy that program participants are not to be entered into any clinical research protocols through CEI where there is no clearly expected benefit to the participant based upon published research and standard practices. Although our goal was to maintain the autonomy and maximize the independence of program participants, giving informed consent as a research subject to CEI—the program in which you are enrolled--seemed to me to be an ethically suspect procedure. Luann was certainly not capable of giving informed consent at any rate.

Shortly after this team-inspired psychiatric episode CEI had the good fortune to hire a social worker, Sue Jacky, who had worked in drug rehabilitation and also in group settings with borderline personality disorder people. Hearing the terrible tale of Luann she brightly responded. "That's not such a big problem. With borderlines you just have to set clear limits and really work hard to adhere to them. Just like with a difficult child." Sue took on supervision of both Luann and the team's efforts with her. She met regularly with Luann and made sure that other team members did not fall down on their roles in the care plan and agreements. She de-emphasized the clinic, though that was one place that Luann had loved to collapse and insist upon medical attention. Sue took a basic behaviorist approach to Luann and to the extent that Sue was able to assure

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and enforce the contracts and limits, Luann calmed down and became a manageable if not always lovable character. Her urinary retention decreased significantly and she rarely needed catheterization. She no longer needed regular appointments in clinic. She stopped calling 911. Her relationship with her daughters, however, did not improve, but her relationship with the team did. We had learned that people like Luann (borderline personality people, if that naming can be trusted) can destroy a team by playing off people against each other, treating the team members as if they were the parents of an infant with unreadable needs.

Sal's daughter

Sal was tall and handsome. She had a straight back and stood upright. She held her head up proudly. But there was a bewildered, befuddled look on her face, always. And her eyes often seemed glazed over. Even though her smile was warm her face communicated that she wasn't exactly there. It was tempting to want to believe this was from her stroke. After all, she had garbled speech (dysarthria) and sounded as if drunk (which she obviously was not). But her look wasn't just the stroke. Only the speech problem was added on after that event. She really didn't have much to say beyond her basic friendliness which was indisputable. She could walk, but after a little while in the CEI program she just sat down and stopped walking altogether. She had lost ambulation. This was the way Sal was.

I can't say if Sal's daughter, Carmella, had been abused the way Jolene's daughter was ---physically---nor if Sal had had a problem with alcohol, but she apparently was a woman who hadn't given her kids much of the love and attention that they needed. I don't think that it was her "fault" though. She seemed to be "challenged", probably both emotionally and cognitively. She had been as much a child as her children—a child trying to take care of a house full of her own kids.

One day in the early 1990s Carmella, in her late 30s, was driving down a main street in Oakland and passing a bus stop she caught sight of someone who looked pretty disheveled and down and out. She stared hard at the figure sitting there on the bench looking so forlorn and was sure it was her mother, Sal. She made a U turn and

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pulled over. Sure enough it was Sal. Carmella hadn't been checking in much on her mom; she didn't have much good feelings about her own upbringing by Sal or their adult relationship either, but down inside she did care. She believed that one of her sisters or brothers had taken her mom in after her small stroke. It hadn't been a bad stroke, but Sal wasn't all that self-sufficient even before that happened. She obviously needed support and Carmella had been re-assured that all would be ok.

Finding Sal out on the street, disheveled and disorganized, was very upsetting to Carmella; tears began streaming down her face. It made her feel somehow responsible. Why hadn't they even told her that her mom was living on her own again. Was her relationship with her sibs that deteriorated? She knew her brother on the peninsula didn't care, not even enough to share some of his wealth for his mom's care. She had issues with all the siblings, though the others weren't as bad. Even before she was in touch with them all, Carmella made the decision that she would take her mom in and care for her. She owed her Mom at least that much.

Caring for a disabled elder is hard enough for any of us. But Carmella didn't really like her mom much. She had deep resentments, feelings of having been neglected mixed with emotional attachment, and besides that she was struggling for her own success. She had become a fashion designer and ran her own business, working long hours, traveling around the state, with clients everywhere. Taking on Sal could put a big crimp into her work schedule and her plans for herself and her children. Her husband was unemployed, but he wasn't able or willing to do much for Sal.

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Carmella looked around and found CEI and knew this was an answer. She could manage her business and her mom would attend the Center and have home care too. She enrolled Sal and immediately started pressuring for 5 days a week at the Center¹⁵ and a large home care¹⁶ time allocation. The fact that CEI did not customarily provide custodial home care, but only care for medically necessary purposes, did not phase Carmella. She kept pushing. It was her only option to losing her own freedom.

Of course it was not really her only option. There were her siblings, her husband, and the possibility of the family paying for a part time attendant when Sal was not at the Center and Carmella was at work. But Carmella believed that she could get what she wanted and needed from CEI. She didn't have money to spend on a private care worker and she was in no position to force her siblings to pay either.

The team resisted Carmella's manipulative attempts to obtain more home care services and more days at the Center than other participants with similar issues would have been allocated. This standoff continued until a medical error threw the balance in Carmella's favor. Sal developed a urinary tract infection that caused some behavioral changes which Carmella noted, and reported to the clinic. At the clinic her urine was tested but the results were not acted upon the same day as they should have been. Sal was taken to the emergency room by Carmella that night (something that might have

¹⁵ Center days in PACE programs are variable and based upon the teams assessment of participant needs. Care plans, including number of Center Days can be changed as medical or other conditions require, but only by the team's decision.

¹⁶ Home care is not guaranteed by PACE. Homecare allocation by the team is based upon medical need. Many participants do not have home care when they are well and stable and, upon entry, the families are told that homecare is not an entitlement but dependent upon patient status, not family needs.

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been preventable) and she was admitted with a kidney infection. Sal recovered uneventfully, though we learned afterward that she usually didn't drink enough fluids and we found that she was prone to recurrent infections when not pressed to keep up oral intake. However, Carmella was enraged at her CEI Center doctor and threatened to take legal action. She went to Peter, the Executive Director, and demanded that her mom be moved to a different doctor.

Peter and I conferred and then met with Carmella. She was right, we had to admit, that the infection should have been caught and treated earlier. If she insisted upon it we would transfer Sal to the other Center under a different physician (that was her right), though we thought her present doctor was dependable. In any case, however, we told Carmella, the number of days she attended the Day Center or her hours of home care are team decisions, not to be made by administration. She should not expect more help than others in similar situations received.

Carmella calmed down and accepted our apology and had her mom transferred to a different Center. But within a few weeks Carmella and the new physician were at loggerheads too, though not over care issues. Carmella was again trying to dictate that her needs (not her mom's) be met by CEI. The doctor told her these were team decisions and there was nothing else to say. Carmella did not take being talked to so directly by a professional white woman-- physician or not--very well. And was frustrated in the failure of her agenda. Both she and the doctor asked me to take over Sal's care at that same center where I too saw patients.

Our home care manager, an African American woman, as was Carmella, saw her as a manipulative and selfish person out for herself. On a superficial level I couldn't argue with that assessment. The evidence was all there. Yet, there really were more interesting nuances to this situation than those vague generalizations suggest. Remember Carmella, the conflicted daughter who had earlier walked away from her mother and now felt she was the only child willing to take on the responsibility. Remember Carmella, with 3 children of her own (one only 8 years old) trying to make a go of a difficult business, without business training. Remember Carmella, with a nice enough fellow of a husband who was of no use to her in this situation.

The team eventually increased Sal's Center days upward when it became apparent that she was simply being left alone to sit and stare. By this time she was severely depressed and wheelchair bound from lack of human interaction. Over a year's time it became apparent that Sal was being neglected at home even on days she attended the Center, after she came back home. Without her assent she was being put in front of a TV set in her room or put to bed right after dinner. Had Sal been in her 80s or 90s she might have needed that rest. But she was younger. At the Center Sal spoke of her love for her daughter and plaintively and passively pleaded for us to have her daughter spend more time with her. She also was pleading with her daughter at home.

At a conference with Carmella two things became clear: she didn't know how to communicate with her mom and did not enjoy sitting with her and working hard to have conversations that weren't really conversations; and Sal was so emotionally immature that she was tending to cling to Carmella and want her present at every moment, like a

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love starved child. Her passivity was driving Carmella even further away. This was not working. Yet Carmella insisted over and over that her Mom would stay with her and was not to be placed in a nursing home or anyplace else. We kept trying to get Carmella to be there more, to allocate even just 30 minutes a day to interact with her mom. The plan had only some meager success. In a short while we were back to Sal sitting home in isolation, acting the role of a victim child, doing nothing for herself and becoming ever more passive and depressed and infantile. In fact, she became so withdrawn that, despite no loss of sensation or paralysis, she developed pressure ulcers from not moving at all.

Sal would/could do nothing to help relieve the pressure from her pressure sores. Her daughter and family were not able to do enough. She was placed in a nursing home despite the intense resistance of Carmella. She improved and then we let her go home. The situation reoccurred. Sal went back into the nursing home. After two or three cycles we were losing the battle. The wounds became deeper and infected and Sal became more and more oblivious to her own pain and suffering. She dwindled away. She stoically tolerated daily surgical debridement of her wounds and packing, special mattresses, turning her regularly, supplementation with the usual things like zinc and vitamin c and extra nutrition; and did nothing but lie there, uttering a few friendly amenities to me---“how are you? How is your wife? Yes, I saw Carmella,” when I came to treat her wounds. And indeed Carmella and her husband too were visiting her.

It never seemed to me that Sal had to go this road. It seemed all wrong. She didn't have severe dementia like Almost or personality disorder like Luann or diabetes;

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she wasn't badly paralyzed; she didn't have major loss of feeling in her body. She was just regressing and regressing and severely depressed, unresponsive to various antidepressant medications, waiting for someone to rescue her from her own fate, from herself. At a few junctures Carmella's other siblings showed up at CEI to voice their concerns, and sometimes suggest we were not doing enough. They spent little or no time with Sal, offered little help to Carmella. Carmella insisted they were worthless and just trying to rid themselves of their own guilt by blaming others. In truth they made little effort for Sal.

Yet, at the Center Sal did not isolate. She sat there amidst the other participants generally paying attention to what was happening; sometimes obviously enjoying the activities and camaraderie. Nevertheless, to me at least, she always looked a bit lost and she rarely, if ever, took any initiative. You had to work at drawing her out. And the positive affect was transitory. I could imagine her then sitting at the bus stop, alone, disheveled, hopeless, on the day that Carmella first found her back on the streets.

Sal faded away and died from complications of her wounds. We were unable to stop the process. I think she (reminiscent of Cornelio) demonstrated the difficulty—even for an intensively supportive system of care like CEI--in trying to change a certain course of events lacking the subject's will and desire to participate in improving their own quality of life, and also lacking the collaboration of all the loved ones around that person. We did try to motivate Sal—I haven't mentioned the ever hard working physical therapy and occupational therapy staff who worked with her--but on some fundamental level, beneath the surface, she was resistant and we failed.

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I got to know Carmella very well over the several years of Sal's declining health at CEI. I think we understood each other. Her support of Sal fell way short of what she might have done under ideal circumstances, but I couldn't blame her any more than I could blame Sal. I saw she cared. I saw her love of Sal and how it coupled with neglect (but not abuse). And I saw some of Sal in her--the frightened, immature, grown-up child. Ultimately, working in collaboration, Carmella relaxed and let me do whatever I thought was necessary for Sal's care and best interests; in the last months she let us decide where Sal lived and how we treated her. Carmella did achieve that level of collaboration with CEI. But by then both the wounds and Sal's mental state were irreversible. You can't turn a locomotive around on a single track and we lacked a switching yard, a roundhouse or the tools to stop Sal's inertia propelling her off the end of the track into the deep chasm that lay ahead.

Ron¹⁷

A Final Riff

Ron was a particularly unique member of the Center for Elders' Independence staff. A big dude--I'd say 6'1 or 6'2" and 240 pounds—he was about 45 years old then. After starting out in the Home Health department, he later worked both in the San Pablo Day Center and in Home Health simultaneously. Then he was elevated to Day Center lead health worker for a while. He worked hard, had skills and leadership ability. He spent several years at CEI and I saw him do amazing things with and for the elders. But he got taken off that lead position in a disciplinary move.

In home health Ron's care was marvelous to see. One of the best workers at helping participants through dying and in many other difficult situations, I always hoped he'd be assigned to those of my patients who were badly compromised and in distress. He was an incredible, supportive and empathetic nurse. Like the LVN Samantha, aggressive in her efforts for the participants, willing to put an elder's well being and safety above her own, but who got booted for doing too many things her own way and being unable to cede some of her autonomy to the authority and documentation regimen of her Department head, Ron too was able to perform many functions usually

¹⁷ Ron is a pseudonym. In many cases in this book I've used real first names which make the individual sufficiently anonymous. But in this case I kept even the first name out of the narration because I have revealed personal things that Ron might not want publicly shared.

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reserved for RNs. He had a sharp mind, life spirit, and wit. In a previous job he had been an EKG technician.

Though African American, Ron drove a lowered Camaro reminiscent of a Latino/Chicano Cholo low rider's car. I rode in that car with him a couple of times and thought of Dr. Walter Peters in his beat up old Cadillac. Walter's car was clearly a form of self-satire. It reminded me of some of my own exhibitionist jokesterism when I was his age. I'm not sure if Ron viewed his wheels that way, though it's possible he did also. Ron grew up in Berkeley and was a Berkeley type person. By that I mean he had a social conscience, was politically astute, analytical and well read. He knew a lot about current and past world events and had strong opinions about imperialism, racism and the various injustices of our purportedly democratic system.

On the practical side, day to day, Ron was a good cook. He loved cooking, working with and for the community of elders and doing things for people in general. He would cook up a storm for both participants and staff right there in the Day Center. The San Pablo Avenue Day Center has a kitchen but regular daily lunches are catered and brought in from outside. However, whenever there was a celebration, a staff party or a special activities event Ron would go out and spend his own money on ribs or various other things that he'd prepare for everyone.

Imagine him working at about \$10-\$20 an hour and spending a hundred bucks or more on food to cook for everyone more frequently than he could afford. On the other hand, there's no denying that Ron was quite an individualist who was going to do things his own way. He prided himself in that too. And he got into trouble trying to appear self

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important. One time Ron got himself into trouble involving poor judgment—nothing to do with job performance. There was a staff party at the home of the Human Resources Director, the only Staff party I'd attended that was at a private home. Another staff member who worked in Human Resources brought her 20 year old son along to the party. He got drunk and got himself into a compromising position with a young woman on a bed with the door to the bedroom open to hall traffic. Though a consensual activity, the flagrancy of the scene was obviously inappropriate. Ron passed by and saw what was happening and instead of either closing the door or otherwise lessening the inappropriateness of this situation he made it worse by circulating through the house telling various people to go and look at what was going on. After that, Ron was taken off the lead Health Worker position.

Sometime later I heard that he got surly with his supervisor and said he “wasn't going to take any more shit”. There's always two sides to a story and I didn't know either side of that. What I did know was that Ron was proud in that way that men can be, especially men whose value to society has not been recognized because of their ethnicity or because others take credit for their fine work. Ron had a bit of attitude, yet I regularly marveled at his humanity as I watched him work with and support very frail and disabled elders.

Ron touched, cleaned, lifted and carried, listened to, fed, spoke with-- dying men in a way that I would long for if it were me dying. Having had the pleasure to work with and besides him while serving these amazing elders was an honor for me. That jumble of contradictions that was Ron, is just what it is, what we humans are about.

-I'll fly away-

I am now past 75, almost the average age of participants at CEI when I served there, but lucky to still be in good health and fitness. An atheist Jew I have no thoughts of flying away to heaven as some of my religious friends and patients have. But I do know that life and death play out their tussling game in unpredictable ways, as they do in my tales. And if life and death were predictable life would lose its majesty and get quickly boring.

Frequently, I think of—can hear--the beautiful tenor voice of Gus, the wanderer who died in a shallow creek in Oakland, his perfectly striking high notes singing Ner by God to Thee, of Almeatie whose ethereal gospel singing voice penetrated to the heart right through her dementia, of Odille chuckling at the funereal story of the wife chucking those hussies out of the funeral procession. I think of Barbara, (see How Death Saved Barbara's Life) and her brilliantly arranged after-death "greeting" to me, a testimony to a quite real and remarkable transformative ending, an affirmation of her own life. I hope that all of us, despite the craziness of the uncivilized civilization we inhabit, can laugh at ourselves in that way; laugh at life's ironies and beauty, and find comfort in the joys of song. Do you laugh at yourself? I hope so. Take this prescription from a doctor please, for if you do you'll find it so much easier to fly away on gossamer wings.

ⁱ The Gospel song I'll Fly Away was written by Albert E. Brumley in 1929. It is sung frequently in the churches of many Protestant denominations in white, Black and integrated churches. I'll Fly Away has been recorded numerous times by a bevy of recording artists. It was included in the soundtrack of the film *Oh Brother, Where Art Thou*. When I chose this title for the book, I knew the song but was unaware of Mr. Brumley's authorship, and of the fact that he was a white Oklahoman who grew up picking cotton on his father's farm. I've learned from Wikipedia that the Brumley farm went bankrupt during the Depression and the well known dust bowl drought that devastated the middle of the country; that Brumley was one of the most prolific writers of gospel music in our history. Brumley took the theme for I'll Fly Away from a prisoners' song that spoke to the hope to fly from prison (not to heaven) and be free again, but he transformed it into a religious theme. In sense it was, indeed, a kind of religion from the mouths of prisoners.