

**Eighth Annual  
STRIKING A BALANCE  
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*MEMORY LESSONS:  
A Geriatrician Cares for His Aging Parents*

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(Template: FORUM or TOWERS—includes 60<sup>th</sup> anniversary story)

**[SLIDE: TITLE SLIDE]**

Before I get started I want to thank the two community groups who arranged for me to come today: Austin Groups for the Elderly and the Capital Area Agency on Aging and more specifically, Glenda Rogers and Bruce Kravitz. Thanks for this invitation to be with you today and for helping out with all the logistics.

**[SLIDE: JW with Patient]**

For the last thirty-three years of my life, the practice of medicine has been, for me, about relationships. Relationships with my colleagues, of course--the good ones--who have helped me whenever I needed them, middle of the night or not. But more importantly, more significantly, I am talking about my relationship with

Winakur--2

my patients. These folks who have put their trust in me over many years, who have taught me so much about living and enduring and fighting and dying with grace. It is this special relationship between doctor and patient—this nebulous thing, this golden ring, this uncodeable-for-insurance-purposes, magical therapeutic bond—that we all want—we all deserve--to have with those whom we entrust with our bodies--that I have been so fortunate to have with so many people for so many years. People like Dorothy here—we went through so much together before she passed on. In truth, this is why I am still doing what I have done for so long. The relationships are why I am still here.

Here is why those of us committed to our work in helping to care for our elderly, for members of our own families, have to keep at it:

**[SLIDE: GERIATRIC STATISTICS]**

Those of us involved in caring for the burgeoning population of elderly in our nation await the storm surge of the old old and oldest old : 72 million people, 20% of our populace in the next 23 years.

Between 1900 and 2030 those over 65 have grown and will grow from 3.1 million—4.1% of our populace—to 71.5 million, 19.6% of our populace.

Even more stunning are the numbers of old, old (75-84) and the oldest, old (over 85). The former group will more than double between 2000 and 2050 while the latter will more than quadruple—to 18 million.

Only one out of twenty of those over 85 is fully mobile, half have some degree of dementia. Seventy percent of these people have Alzheimer's disease.

THE REPORT OF THE ALZHEIMER'S STUDY GROUP has just recently been released. Let's look at some of the data they compiled:

**[SLIDE: ALZ STUDY GROUP #1]**

--Currently Alzheimer's disease afflicts more than 5 million Americans, and is the nation's sixth leading cause of death.

--Alzheimer's disease is a family disease. This year 10 million caregivers will provide 94 billion hours of physically demanding and emotionally draining uncompensated care.

Winakur--4

--Alzheimer's disease is already the nation's third most expensive disease costing the Federal government alone more than \$100 billion per year.

**[SLIDE: ALZ REPORT #2]**

--Alzheimer's cases will increase by more than 50 percent in 20 years and double again to as many as 16 million cases by 2050.

--Over the next 40 years, Alzheimer's disease-related costs to Medicare and Medicaid alone are projected to total \$20 trillion in constant dollars.

**[SLIDE: A Sobering Fact]**

And here is one more sobering fact: by 2020—only 11 short years from now--1.2 million people over 65 will have no living children, siblings or spouse.

**[SLIDE: Family in Comfort]**

Today I am going to tell you a story about my family. Here we are in Comfort about ten years ago. This story is a distillation of my life in medicine and my life as my father's son with an emphasis on caring for him in his older years.

**[SLIDE: Lizzie and Jacob]**

This is the only photograph I have of my paternal grandparents, Jacob and Elizabeth Winakur, who arrived in Baltimore about 1900 from somewhere in Russia. Neither spoke English. My father was not yet born when this picture was taken. He was the last of six children and he was born in 1919. His father, Jacob, pictured here, died when my dad was 7 years old.

**[SLIDE: DAD and Frank fishing]**

My father often went fishing on the Chesapeake Bay with his older brother, Frank, who became his surrogate father. This may be the earliest picture of my father that survives.

After my father's father died, each child was taken in turn to run the small shop he had opened. It fell to my father at the age of 16 to begin his turn. He was plucked from high school, six months before graduation and he never had the opportunity to further his formal education. This left him with an inferiority complex that lasted his entire life.

**[SLIDE: The Photo of Mom Dad carried in the War]**

He met my mother, Frances, who waitressed in the small corner restaurant operated by her family that was across the street from my father's shop. They didn't know each other well when my

Winakur--6

father entered the service during WWII, but he carried this picture of her in his wallet for five years and she wrote him every day, sealing each letter with a big red lipstick kiss. When he returned from the service, the first thing they did was get married.

**[SLIDE: Wedding Day, 1946]**

Here are my parents on their wedding day in 1946. It looks as if they have big plans for each other after the party, doesn't it?

**[SLIDE: Fran, Jerry DeSoto]**

I came along in 1948. Here I am with my mother and the old DeSoto.

**[SLIDE: Dad age 60]**

When my father was the age I am now he had his first heart attack.

**[SLIDE: DAD IN ARMY AIR CORPS]**

After surviving almost five years in the Army Air Corps during World War II,

**[SLIDE: STAR LOAN]**

building a small business

**[SLIDE: AFTER THE RIOTS]**

and then losing it,

**[SLIDE: MIKE AND JERRY]**

raising two sons, after re-discovering his passion for art

**[SLIDE: Fishing SELF-PORTRAIT]**

and painting dozens of vibrant canvases, my father began his slow decline. At age 65, the year he qualified for Medicare benefits, he had an even bigger heart attack that left him with a poorly functioning heart muscle. Then, when he was 75, he developed prostate cancer and underwent a series of radiation treatments. At 81 he became short of breath. His doctor admitted him to the hospital with congestive heart failure. Within two days he became confused and paranoid and delusional. His dementia had been unmasked.

I stayed with him every night fending off bed rails and IV poles, checking each pill he took, every fluid-filled bag plugged into his arm, running interference when he went to the bathroom and down to x-ray. When he became too agitated to rest I reassured him with my hand on his arm or shoulder; one night—to help subdue the delirium demons--I even crawled into bed with him and held him, comforted him, as he had in a long ago life done for me.

After four days I took him home--although he was not yet ready to leave--because I knew, as a geriatrician, that if I did not he would never come home again.

And so he remained at home for almost six years since after that last hospital stay. Even though I had practiced medicine for three decades and made rounds almost every day in the hospital where many of the nurses and I address each other by our first names and where the CEO is my patient and my friend, I never intended ever to put my father back in this hospital. I vowed to keep my father at home until the sounds of his breathing ceased in the bedroom where he had slept every night for the past thirty years.

**[SLIDE: COVER OF HEALTH AFFAIRS REPRINT]**

In 2005 I wrote an essay that many of you may have seen entitled, "What Are We Going To Do With Dad?" This essay talked about what it is like, from my vantage point as a doctor specializing in geriatrics to observe my father's descent into disability and dementia.

I was not expecting the response: calls for my appearance on NPR's *The Diane Rehm Show* and Terry Gross' *Fresh Air*, a visit from the producers of *Frontline*, interviews on local radio and television shows in my hometown as well as in other cities, invitations

to speak at national gatherings of health care providers, to present Grand Rounds at academic medical centers, to author a monthly column on aging and elder care, to write a book on my experiences as a geriatrician and the son of an old, old man.

But most of all, I was not prepared for the e-mails and letters—thousands of them--I have received from around the country and the world. I have spent my years as a doctor attempting to help solve problems—social as well as medical--that arise in my patients, one at a time, in my office examination and consultation rooms, or at the bedside in hospitals, skilled units, and nursing homes in which I work every day.

Suddenly I was receiving hundreds of messages a day—several thousand in all--pleas for help and advice for an elder parent or an ill spouse; heart-breaking stories of neglect and loneliness; bitter, disappointing encounters with other medical professionals; nightmarish tales of end-of-life suffering; deep expressions of guilt by children living far from home, expiations years after the fact; requests for appointments by elders living in other states; and advice on how to die quickly and painlessly. I brought up my e-mail each day with a feeling of inadequacy and dread.

I am fortunate enough—more fortunate than most --to be a physician with the knowledge and means to secure the help we need as my family proceeded on our journey. I insisted upon--and my father received--prompt, compassionate and ethical care during this process. I never looked for help from any agency of government, although I realize that federal and state programs such as they currently exist are all that most of us will have to look to in our old age and I am grateful for these programs and supportive of them. I remained my father's advocate until the end, just as I have tried to be—sometimes with more success than at others—the advocate for many hundreds of my patients over the years.

Being an advocate for your loved one at life's end requires patience, commitment, and empathy, your knowledge as to what your loved one would want as his or her illness progresses, open communication with the health care providers and the legal means—such as a Durable Power of Attorney for Health Care—to act as the surrogate decision-maker.

**\*[SLIDE: TEXAS LIVING WILLS]**

The groundwork to be in such a position when the time comes must be laid well in advance, as you might imagine. As an important

aside, here is a very useful website for patients and families developed by Prof Klugman at the Center for Medical Humanities and Ethics at the UTHSC in SA. We can all use some help with this process because for most of us, the subjects that must be broached with our loved ones to lay this ground-work—these decisions at life's end—are topics we in our culture find difficult to engage each other in. But we must try.

But please do not believe for a minute that I have all the answers to the myriad of problems that ambushed my family as we struggled each and every day with my father and now my mother at life's end. These have been difficult times and we continue to muddle through them together as so many families have done and are doing across America

But I did learn this: Relationships, human touch and interaction, affection, loyalty, love...that is what our elderly want and need. Not institutions, paper work, forms, committees. Relationships—ongoing and meaningful—even at life's end—are what my generation will demand. We all deserve nothing less.

Has anyone noticed that it is harder and harder to find a doctor—a non-specialist--one who will stand by you for a lifetime? I bring this up because as concerned citizens and caregivers this is a critical issue that an aware populace needs to speak out about.

Here are some statistics:

**[SLIDE: Primary care/Geriatric statistics]**

Right now primary care medicine is in—according to the American College of Physicians--a “state of collapse,” and the number of medical students choosing this field has fallen by 50% in just the last few years.

While every eight seconds a Boomer turns 60, the number of certified geriatricians in the U.S. has declined 19% in the last ten years—to only 7000. Physician ranks grow by a mere 300 new geriatricians each year, fewer than those headed into retirement. In 2003, only 2% of physicians in the residency portion of their training programs indicated an interest in geriatric medicine. In 2005 there was but one geriatrician for every 5000 patients over the age of 65. In 2008, there is but one for every 8000 patients. Currently America has a deficit of 14,000 geriatricians that will grow to 34,000 by 2030.

This critical deficiency is not even on the radar screens of most policymakers.

It is not only a doctor shortage that we face. All the members of the “geriatric team”—nurses, therapists, social workers, care managers, psychologists, and trained aides are scarce as well. A million RNs will retire in the next few years with few to replace them. Healthcare employees in too many long-term care facilities are often woefully overworked, underpaid, under-trained, and suffer the highest rates of depression of any group of workers in the nation. And yet, they are the ones primarily responsible for the hour by hour, shift by shift care of our loved ones in long term care facilities: our grandparents, our mothers and fathers—and soon we, ourselves.

**[SLIDE: CENTER FOR MEDICAL HUMANITIES AND ETHICS]**

Since one of my themes today is about relationships I want to speak briefly about a unique one—a rare and vanishing one—that exists in medical education. And that is the relationship between medical students and their mentors and role models.

**[SLIDE: CENTER STAFF]**

At one time in America, young men—women were largely excluded in those days to the detriment of my profession—learned

the art and science of medicine by apprenticing themselves to a series of mentors, practicing physicians and surgeons. Good mentors produced good doctors who worked to advance the field in which they were trained when the system worked as designed. Of course, it didn't always and there was little quality control. There was not much classroom didactic teaching.

This all changed early in the twentieth century and, indeed, the current situation is one in which students drown in vast databases of scientific knowledge taught all too often by academic research physicians who, while they excel in their own fields, may not be very interested in the "art" of medicine, the actual hands-on daily encounters with real people suffering with real diseases over time with all the social, psychological, economic, familial, and societal stresses and strains that illness entails.

**[SLIDE: MEDICAL STUDENTS]**

The real problem that we as patients are confronted with today when we have an unsatisfactory encounter with a doctor (anybody here ever have this happen?) is not that the students admitted to med school—and thankfully 50 to 60% of them today are women—are uncaring. One of the real problems, in my opinion, is the lack of

mentors who are skilled in the art of medicine, not just the science of medicine. The skill of touching patients—literally and figuratively—is endangered. The gentle, soulful examination of the abdomen where practiced fingers gauge the texture of the liver and the size of the spleen is being supplanted by the whirl and buzz and clang of the CT and MRI scanner. Touch has been supplanted by technology and although I am in favor of new technologies that are used sanely and judiciously, machines will never be a substitute for human contact. Not in medicine, not in any other realm of human experience.

So one of the things my wife, the lawyer-poet Lee Robinson—and I do is volunteer as “Associate Faculty” at The UTHSCSA’s “Center for Medical Humanities and Ethics,” that I referred to a few minutes ago and now dynamically directed by Dr. Ruth Berggren.

Our task at the Center is to work with small groups of first and fourth year medical students and nurture their innate compassion and idealism, a fragile commodity too easily lost today in this dehumanizing environment of a modern hi-tech medical education. We nurture them by sitting down together and discussing stories by Chekhov and Hawthorne, Mary Shelly, Richard Selzer, Ethan Canin, and Raymond Carver. Poetry by William Carlos Williams, Rafael

Campo, WS Merwin, John Stone, Jane Kenyon and Donald Hall.  
Essays by William Osler, Atul Gawande, Jerome Groopman and  
Sherwin Nuland.

**[SLIDE: CENTER “EXPERIENCE/FAMILY”]**

We—the students and us--learn much about each other, ourselves and the human condition as we read and discuss and contemplate these literary works. And it is my hope and currently my belief that we are making a difference in turning out young doctors who will, in time, be as sensitive and empathic as they are technically competent. The kind of physician you will want to go back and see again. A valued, trusted relationship that can last a lifetime.

The Center for Medical Humanities and Ethics is a unique medical educational endeavor—supported in major part by private contributions--and is worth your consideration if you have any interest in this regard.

**[SLIDE: Memory Lessons: A Doctor’s Story]**

I want to tell all of you here today—especially those of you who are caregivers, or have been caregivers—or will be caregivers one day—and this pretty much includes every single one of us in this room or for that matter in this nation, doesn’t it?—another bit of my

family's story. It is a story I tell in my book, *Memory Lessons*, and I believe that this personal family story holds great relevance for all of us who are trying to "strike a balance" in the midst of our difficult caregiving experiences.

**[SLIDE: MOM AND DAD WEDDING]**

February 24, 2006, was my parents' sixtieth wedding anniversary. My family planned a brunch for them in their home. We were keenly aware that this may be the last anniversary my parents will celebrate together. It won't be an elaborate party, just a bittersweet one.

My mother is still ticking along at 85. She is a breast cancer survivor. After the surgery, after the bandage came off, she looked down at herself and said, "It's not so bad." She has severe macular degeneration and is almost blind, adult-onset diabetes, and arthritis. Her hearing is poor. She will say, however, that her greatest disability is my father.

**[SLIDE: DAD AND JER WITH LETTER]**

For a week or two before their anniversary celebration, I remind my father about it whenever I visit. "Do you know what's coming up real soon?" I ask. "A special occasion."

"No," he says.

“Does the date February 24<sup>th</sup> mean anything to you?”

“Sounds familiar. What is it?”

“Your wedding anniversary, Dad. Sixty years you’ll be married to Mom.”

**SLIDE: MOM AND DAD PENMAR]**

“I don’t believe it,” he says. “I love your mother, you know.”

“I know you do.”

I do know this. I’ve known this since I was a child, known it despite the angry words I heard on many occasions. Afterward, my mother would be silent for days; my father, never blameless, would always relent, seek her forgiveness. The arguments were never really about the triggering incident--the unneeded purchase, the forgotten birthday, the messy bathroom--but always about something else entirely, some unnamed grievance, a deep, basic misunderstanding between them.

This pattern of non-communication is common in many marriages, especially in my parents’ generation before self-help books and talk therapy became popular. My mother wanted a father-protector; my father wanted a woman to love him with overt affection and quiet passion. Each knew what the other wanted, but

they were unable to give it. I, their son--the one always in the middle--tried to make it right.

I realize from my long experience of dealing with other families that mine could have been much, much worse. I believe that given my parents own upbringing and limited opportunities for self-enlightenment they did the best they could.

**[SLIDE: DAD OLD AND SICK]**

A few days before they are to celebrate their sixtieth wedding anniversary, my mother calls me in a panic. My father is bellicose and paranoid. He accuses my mother of all sorts of betrayals; he curses at Yolanda (our trusted health care aide) in Yiddish, strings of foreign profanities he has not uttered in seventy-five years. He will not be bathed or shaved. He will not eat, refuses his medications. He is raving.

**[SLIDE: JER AND DAD AT EVA'S]**

“Dad,” I say, “what is it? What’s wrong?”

“I want to go home. Please, take me home!”

“But, Dad, you *are* home.”

“I don’t know where I am. Please, Jerry-boy, take me home.

You know the way.”

“I don’t know where else to take you, Dad. You’ve lived here for thirty years.”

“You go to hell! You’re in with them!”

“Don’t talk that way to your son, Leonard!” my mother says.

“You’re out of your mind!” There are tears in her eyes.

“You go to hell, too, you, you lying bitch, goddamn bitch!”

**[SLIDE: MOM WITH ROSEBUSHES]**

For an instant I am transported back in time. My first instinct is to protect my mother. But this is a sad game I stopped participating in decades ago. “You two deserve each other,” I learned to say.

And then I would leave. They stewed. My mother was silent, refused to cook for a day or two. The next time I saw them, everything would be as it had always been—at least on the surface.

**[SLIDE: DAD WITH DUKE]**

There is no walking away now. My father is demented. His agitation and paranoia arise from distorted memories, nightmares he can no longer separate from reality. He is an abandoned child. He searches for his boyhood home on Boarman Avenue, or perhaps our first house in Forest Park. He hears voices but can’t decode what is being said and his mind assumes the worst: my mother is insulting

him, planning to run off, his sons are belittling him, his mother scolding him, his older brothers and sisters teasing him. He is lost, with no father to turn to. I see that he has wet himself; a dark ring marks his place on the couch.

**[SLIDE: DAD AND ME ON FLOOR]**

My brief flash of anger melts away. I have been through this before—not only with my father, but with many of my patients over the years. I have been cursed, spit on, bitten, pinched, and punched by demented old folks over the decades. A poor woman threw a shoe at me when I stepped inside the door of her hospital room. The day before, she thought I was the devil.

I assume my doctor role with my father; I retreat once again into the armor of my starched white coat. As a doctor I know what to do; as a son I am uncertain. “Talk therapy” will not work here; the time for psychoanalysis, for delving deep into his life has long since passed. It is time to acknowledge his fears at the moment, to let him know I will do whatever I can to ease his agitation.

**[SLIDE: DAD AND ME 1976]**

“Dad,” I say, “you’re all upset. Let me get you something that will help settle you down.” I look into his eyes, now wild with

suspicion, with fear. I pat him on the thigh. I take his hand in mine. He does not pull it away. I feel his pulse. It is strong and even. "I love you, Dad. Wait here just a minute."

I walk the few steps to the kitchen and check the daily pill slots to make sure he's been getting his regular medications. Sometimes my mother, unable to see, inadvertently leaves pills in the plastic containers I fill every couple of weeks. But now everything seems in order.

My father takes eight medications a day; my mother fourteen. They are both on vitamins and minerals, blood pressure medications, diuretics, and cholesterol-lowering drugs. My father also takes two pills for his heart. My mother takes drugs for her diabetes, a thyroid disorder, osteoporosis, and an antidepressant. This is not unusual for folks their age.

I spend my doctoring days prescribing medications for my patients, re-shuffling the ones they're on--a tiny dose change here, a re-timing of administration there. By now I have written or refilled hundreds of thousands of prescriptions, but my constant goal is to cut back on medications, stop them altogether if I can: less is usually more. Every geriatrician knows this. All of us have witnessed the

negative effect of “polypharmacy” in our patients. By simply taking the time to spread all the drug bottles out on the desk, noting each one, thinking a few moments about the patient and her symptoms, and saying: “Quit taking this drug!,” we can often bring about a rapid improvement in a patient’s condition.

In the parlance of the technology and pharmaceutical industries, doctors like me who are cautious, who do not immediately jump on the company bandwagon every time it trumpets its “latest and greatest” product, are known as “slow-adopters.” Now they have figured out a way to circumvent my judgment should I fail to join the chorus of cheerleaders for their latest breakthrough. On television, in magazines, they promise an end to arthritis pain, a good night’s sleep, a cure for incontinence, a firm erection. My phone rings off the hook; some patients feel I am blocking their path to the Fountain of Youth when I decline their request to prescribe a drug they have been convinced by an effective ad campaign that they must have. Some even change doctors, to one more pliable in this age of consumer-directed medical care.

**[SLIDE: MOM AND DAD GREENMEADOW]**

And yet here I am in the kitchen of my parents' home, rummaging through a basketful of medicines I take down from a high shelf. Here is where I store the unused pills--all the psychoactive drugs previously prescribed by my father's physician for his recurrent bouts of anxiety or agitation, for his depression and his insomnia, for his memory loss and lethargy, for his confusion and paranoia, for his belligerency and sadness.

I take down a dozen orange plastic pill bottles with white, almost-impossible-to-remove lids. My father's name is on every label: some are six months old, some several years. We have been dealing with this for a long time.

Haloperidol and risperidone. Olanzapine and quetiapine. Paroxetine and citalopram. Alprazolam and trazodone. Donepezil and rivastigmine and memantine. Organic molecules, various combinations of carbon and hydrogen and nitrogen, oxygen and sulfur—the atoms of which we are all made--bioengineered to slip across the blood-brain barrier, to stimulate one receptor or block another, precipitate a rush of ions through neural membranes, flood synaptic gaps with potent neurotransmitters, flip a switch here, throw a breaker there, block a surge somewhere else. All to make us

whole again, to bring us back to our senses, to jump-start us once more.

It is an act of faith for me to prescribe any medication and an even greater act of faith for my patient to fill the prescription—much more expensive than it ought to be--and then swallow it, take it inside, day after day, often year after year. I know that I am the professional, the “scientist.” It is my role to evaluate these drugs, vet them, understand their pharmacology, their interactions, their effects on physiology, their complications. I am the one licensed by the state to make these choices, monitor these therapies. I am the captain of the ship, the one responsible if things go wrong.

But now any physician who prescribes these “atypical anti-psychotic drugs” for his elderly patients does so at his peril. The FDA—after first granting approval--has recently withdrawn its blessing for these medications in the treatment of behavioral disorders in our elderly folks with dementias. For years geriatricians and psychiatrists used these drugs with some success. Medications like risperidone rendered perhaps a 20 to 30 percent benefit potential—often when nothing else would--when weighed against a 2 percent chance of serious peril..

Who should I believe when conflicts of interest so bedevil the institutions I must depend upon?\* Medical scientists whose grant monies spur them to turn a hypothesis about a class of organic chemicals into advancement and tenure and, nowadays, a piece of the action?\* My doctor colleagues who reconfigure their offices into lucrative clinical research mills, abandoning patient care except as a means to recruit the naïve, the unsuspecting, the uninsured who are desperate for free medications or the money they receive for “guinea-pigging” in drug trials?\*

And whom are *you* to trust? If you have a copy of the *Physician's Desk Reference*, if you go online, if you read the information that comes—mandated by law--from the pharmacist, would you ever put a drug like risperidone in your mouth, or in the mouth of your loved one? Here are but a few of the side effects you might experience from the first dose or the thousandth: low blood pressure and thus a tendency to fall or pass out; impairment of judgment and/or motor skills; tardive dyskinesia (a potentially irreversible involuntary movement disorder); neuroleptic malignant syndrome (a sometimes fatal reaction: high fever, muscle rigidity, sweating, altered mental status, and cardiac arrhythmias.) Of

course, some of these are very rare and therefore quite unlikely to occur, but at the same time they are entirely unpredictable.

**[SLIDE: DAD AND JERRY WHITEFACE MTNS]**

Nevertheless I am in my parents' kitchen searching for the bottle of risperidone tablets so that I can give one to my father, so that I can review with my mother how to use it during the times he is belligerent and agitated. Although I am reluctant to use this drug—any drug--in treating my father (and in you or your loved one), I often resort to them for two reasons only.

The first and foremost rationale, I tell myself, is that I have used it before in my father with success. It has worked. It has settled him down, albeit with an added degree of cognitive impairment he can ill afford.

The second reason is that I hope by using this drug—judiciously and in a closely monitored fashion--I can maintain the status quo and keep my father at home for a bit longer; because, in my judgment, the risk to my father in a long-term care facility is greater than the risk of asking him to swallow another risperidone tablet.

Still, there is a risk, a qualitative risk, one for which I cannot give statistics. All I have is my years of experience as a geriatrician. This is what I bring to the table as I face down the legions of pharmacologists and pharmacists and epidemiologists, medical scientists, smiling, attractive salespersons from Big Pharma, Medicare and Medicaid regulators, chart auditors and quality monitors, and, of course, lawyers, any of whom might be critical of my judgment at a given point in time. All are my allies when things go well; they quickly become my inquisitors when things do not.

**[SLIDE: CHARTS AT END OF DAY]**

There is one major difference between us, however, a difference that separates us now and always: I am the one with the patient before me, a patient--my father or perhaps your mother--who is paranoid or delusional or abusive and in danger of injuring himself or a dedicated caregiver. I am the one you trust, for the moment, to try something, anything, to ameliorate the situation, relieve the tension and the strain and the heartache, the one here now to help diminish the suffering of the old, old man before me and the members of his family. I am the one who must give the order, write

the prescription and face the consequences, for good or ill, of my judgment and my action.

**[SLIDE: MOM AND DAD DANCING]**

Sometimes, before I reach for a medication, before my father's agitation has risen beyond what he and my family can bear, I put on Sinatra. Or Benny Goodman or Tony Bennett. If I'm lucky that day, my father begins to hum, he taps his foot. Lyrics come, a few at a time: *It was a very good year. Pennsylvania 6-5-0-0-0. I left my heart.* Sometimes he even tries to whistle along with the melody but his sagging cheeks and weak facial muscles render him powerless to make a sound. He blows dry, dissonant air.

One afternoon I stop by and he keeps saying over and over in a singsong voice, *I beg your pardon da da da. I beg your pardon. Why* has my father latched onto this song?

The next day Yolanda brings him a CD of the complete song and when I next drop by he is singing the whole first line: *I beg your pardon, I never promised you a rose garden.* I sing along with him.

My mother, sitting in her recliner listening, says, "You never promised me a rock garden, either!"

My father starts laughing, a real guffaw. “You never had much of a sense of humor,” he says to her. “But Frances, that was a funny one you just made!”

She chuckles, but I’m not sure she meant to be funny.

**[SLIDE: MOM AND DAD AT PoPo’s]**

Just before my parents’ sixtieth wedding anniversary, I find the bottle of risperidone, cut a bunch of the pills in half, and bring my father one of these bisected tablets and a cool glass of his nutritional drink.

“Here, Dad, take this. I think it will make you feel better.”

His eyes, still wild, stare at me. “What’s this for?”

“Dad, you’ve got *shpilkes*,” I say. I use this Yiddish word, retrieved somehow from my own memory, because my father has lately been interspersing his speech with snippets of this language, his mother’s tongue—the *mamaloschen*--the first words he ever heard, and therefore, the last ones to abandon him.

He smiles. “*Az ich haben shpilkes*,” he says. And he swallows the pill. “For the *shpilkes*,” my mother and Yolanda tell him when it is time for the next dose. Before long he is back to his usual demented self, his pleasant self. This time I have made the right decision.

**[SLIDE: ANOTHER WEDDING PIC]**

It's time for the sixtieth anniversary brunch. My wife brings a dozen yellow roses and arranges the table. She knows it is the dining set that my maternal Grandma Bessie bought my mother the year before she died and that my family uses it only for special occasions. My brother stops at the grocery store for a side of sliced, smoked salmon, some cream cheese, a few tomatoes, and a red onion. I rise early that morning, drive over to the bagel bakery, and pick up a dozen—onion, poppyseed and sesame--just out of the oven.

Those of us who love my parents assemble in the brick one-story home where they have lived since first coming to Texas. Not a stick of furniture in it was bought after 1962. The house is in my name because, after my father lost his business and his confidence, he refused to have a mortgage hanging over his head ever again.

**[SLIDE: DAD's 85<sup>th</sup> BirthDay—Mom with card]**

It is a small gathering. My parents' siblings are long gone, save my father's lone surviving sister, in her mid-nineties and in bad shape herself, a half continent away in Baltimore. Family-oriented to the point of insularity, my parents have made no close friends in all the years they have lived in San Antonio.

Most elders, as they age, find their social connections narrowing: their kids move away, their brothers and sisters and close friends pass on. As their world implodes, many withdraw further into themselves and this dearth of social contacts only accelerates the decline in cognitive skills. It is a mean cycle, one I try to alter in my patients when I recognize that they are caught up in it. I query them about activities at their church, help them find senior centers, talk to them about volunteer opportunities at the hospital or the library. Over the years, I have had much more success with the folks in my practice than with my own parents.

So here we are: my wife, Lee, and I, my brother, his wife Gaye and their son, Adam—my father's only grandson. My daughter Betsy is here and, of course, my parents' devoted health aide, Yolanda.

**[SLIDE: YOLANDA AND MOM]**

Yolanda is the one who holds everything together in my parents' household and no family celebration is complete without her.

Everything is ready and I wheel my father into the living room.

"What's the fuss about?" he asks as he enters, seeing all these faces he recognizes but cannot place. For a moment he is

frightened. Something must have happened: perhaps someone has died and now he will hear the terrible news.

“Dad,” I say, speaking into his good ear, “today is a special day. You and Mom have been married for sixty years.”

He searches for my mother’s face in the small crowd around him.

“Really? Is that true, Mom?”

“Of course it’s true,” she says. “Do you think we made this up?”

“It sure doesn’t seem like sixty years,” he says.

“It seems like a hundred to me,” she says. We, the assembled family, laugh nervously.

My brother leans in and asks our father, “So what do you think about all this?”

“I just want to say that I love Mom more today than I ever have.” He reaches for her hand but she doesn’t take it. I want to believe that because of her terrible eyesight she can’t see this gesture, but I’m not so sure. We all applaud my father’s words.

I push him up to the dining room table, festive with cards. He picks out one. “Did you see these, Mom?” he says.

“I can’t read them,” she answers.

He begins to read to her. They remind him again that it is their anniversary.

“Have we really been married sixty years?” he asks her.

“Every bit of it,” she says.

“I hope you know I love you.”

“I know,” she answers.

“And she loves you, too, Dad,” I say.

“Of course she loves me. She’s our Mom. She’s gotta love all of us,” he says.

After the party, after we have cleaned up, the guests have gone home, and I have put my father back to bed, I find my mother sitting on the couch, sobbing softly.

“What is it, Mom? What’s the matter?”

“I’m just tired. It’s been a long day.”

“Mom, it’s only early afternoon.”

“You know what I mean,” she says. And I do. My father’s dementia has been progressing now for almost six years. He is getting worse. My mother, like so many spousal caregivers, is ground down, exhausted.\* My father demands her attention unless

he is asleep; she is constantly worried that he is not eating, fearful that he's going to fall, anxious over what will happen next. Most nights he wakes her at least once, maybe more. She has not gotten away on her own now in almost two years.

“Mom, why don't we make plans for you to visit your cousins Rita and Buddy in Baltimore for a week or so? It would give you a boost.”

“Your father gets worse when I'm not around,” she says. And this is true. The last time she went away my brother and I stayed with him, alternated days and nights, back and forth. Our father constantly paced through the house, first to the front door, then to the back, looking for her: “When's Mom coming home? Did something happen? Are you telling me the truth?”

Over and over we explained, told him where she was, called her on the phone so he could hear her voice. “I really miss you, Mom,” he said. “When are you coming home to me?”

“Dad,” we told him a hundred times, “Mom's in Baltimore visiting Rita and Buddy. She's coming back soon.” In the end I resorted to the risperidone. My brother and I were exhausted by the time our mother got home. And she is with him twenty-four/seven.

Family caregivers—mostly spouses--give their all, and their high mortality rates (wives often precede their demented or sick husbands to the grave) prove just how grueling this job is.

I take my mother's hand in mine, put my face right up to hers so she can see in my eyes that I mean what I am about to say.

**[SLIDE: MOM , MIKE AND I, FOREST PARK]**

“Mom, listen to me. I know we promised ourselves that we wouldn't put Dad in a dementia unit. But maybe the time has come. He's near the end. You must know this. Mom--it's *you* Mike and I are now most worried about.”

Her answer comes without hesitation. “No,” she says. “I can't do that. I won't do that.”

And then she starts to cry again. I hold her in my arms.

“He's so ugly to me sometimes. He says such terrible things. Especially when you aren't here.”

I don't have to ask her what he says. I have heard and I have not forgotten.

**[SLIDE: DAD'S LAST SELF-PORTRAIT]**

“Mom, please try to understand. He's tortured because he's lost himself. Most of the good memories are gone and he's left with

distorted ones. You know he's always been a little paranoid about certain things. In his state, these bad memories and feelings take over and he can't control himself. I could increase his medications..."

"No," she says. "It settles him down but only confuses him more."

We sit together on the couch for a while. Her mascara, which she has difficulty applying, has run all over her face. I hand her some tissues.

"You know that when Dad says he loves you, he means it, don't you?"

"I think he gets me confused with his own mother," she says.

"Not all the time. I know that he loves you. And even though you have a hard time saying it because you're tired and frustrated, I know you love him. He wouldn't be here in this house today if you didn't. And I want to tell you how much I love you—admire you—for this tremendous sacrifice you're making. But if you ever decide enough is enough, I'll find him a place right away."

My mother doesn't answer me. She hears me, has been bolstered by my words. And I have never loved her more than at this

moment. I can never make up to her what she has endured--until it is my time to care for her as she has for him.

That time is coming soon.

**[SLIDE: Mom and Dad's 60<sup>th</sup> wedding anniversary]**

My father died at home on February 28<sup>th</sup>, after turning 87 on the first of that month and just four days after my parent's 60<sup>th</sup> wedding anniversary when this picture was taken.

As I watched my parents age together, I saw what love means when life is waning, what love finally comes down to as we grow old with our life partners, descend together into disability and, for some, dementia. This was a true and great life lesson that I learned--strange as it might seem--from my elderly parents, one blind, one demented. A valuable lesson I hope to pass on to whomever will listen to my story.

I want to close my talk today with a poem by one of my favorite poets who, in the interest of full disclosure, happens to be my wife, Lee Robinson. It has been a privilege and pleasure to address all of you today. I thank you again on behalf of all of our patients, our

family members whom you have helped and will continue to help over the years. Please keep up your good work.

**[SLIDE: CREED]**

**Creed**

If you ask me what I believe in  
it is the body of the ninety year old  
straining to stand upright, each vertebra  
a testament, each muscle a miracle

It is the shape of her head  
a sculpture the artist  
has been working on for centuries,  
the skull visible

under the veil of skin  
and if you ask me for a sermon  
I will give you that skin,  
every wrinkle a parable

If you insist upon sacrament  
I say take her hand in yours:  
it is the only way  
to save yourself

fold your flesh into her bones  
until you do not have to ask me anymore  
what to believe in:  
it is the body

the body,  
Amen.

**[SLIDE: MOM AND DAD 60th]**