

# Advisory Council on Aging and Disability Services

*Creating choices for elders and adults with disabilities in Seattle-King County*

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www.adsadvisorycouncil.org

## MONTHLY MEETING JUNE 11, 2010

### MEMBERS PRESENT

City of Seattle	King County	United Way
<input checked="" type="checkbox"/> Diane Snell, O&A Chair	<input checked="" type="checkbox"/> Art Mussman, P&A Chair	<input type="checkbox"/> Amy Astle-Raaen
<input checked="" type="checkbox"/> Jacqueline Deerr-Lord	<input checked="" type="checkbox"/> Cathy Von Wald	<input checked="" type="checkbox"/> Michael Miller, V Chair
<input checked="" type="checkbox"/> Duong Nguyen	<input checked="" type="checkbox"/> Kaylene Moon, At large	<input type="checkbox"/> Lorna Stone, Secretary
<input type="checkbox"/> Nick Licata, elected official	<input type="checkbox"/> Vacant	<input checked="" type="checkbox"/> Timmie Faghin, Chair
<input checked="" type="checkbox"/> Bev Clark	<input checked="" type="checkbox"/> Marsha King, Communication Ch	<input checked="" type="checkbox"/> Katty Chow
<input type="checkbox"/>	<input checked="" type="checkbox"/> Dave Rogers	<input type="checkbox"/> Dr. Elizabeth Phelan
<input type="checkbox"/>	<input checked="" type="checkbox"/> Ava Frisinger, Elected	<input checked="" type="checkbox"/> George Dicks
<input type="checkbox"/>	<input type="checkbox"/> Berta Seltzer	<input checked="" type="checkbox"/> Lillian Tang
<input type="checkbox"/>	<input checked="" type="checkbox"/> Kris Fredrickson	<input checked="" type="checkbox"/> Tom Minty

<b>Excused Absence</b>	Nick Licata, Berta Seltzer, Dr. Elizabeth Phelan, Lorna Stone, Amy Astle Raaen,
<b>Guests:</b>	Mary Anderson,
<b>ADS Staff</b>	Karen Winston, Gigi Meinig, Rosemary Cunningham, Doug Ricker, Margaret Casey
<b>United Way Staff</b>	Linda Woodall
<b>King County Staff</b>	
<b>City of Seattle</b>	Pamela Piering

### Welcome and introductions:

**Timmie Faghin, Chair**, welcomed Advisory Council members and ADS staff to the meeting. She asked those present to introduce themselves.

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## **Program: Family Caregiving**

The Executive Committee is in the process of making changes to the Advisory Council Meeting format. These changes will result in a more efficient meeting and give the Advisory Council time for discussion: Pam Piering, ADS Director, agreed to pilot this approach and modeled a short presentation. Advisory Council members may use her PowerPoint, and personalizing as needed. The template can be customized based on each speaker's skill set, professional background and personal stories.

Pamela Piering defined family caregiving as an act of providing unpaid assistance and support to family members or acquaintances who have a variety of health and social needs. Caregiving is typically provided by family, friends and neighbors.

Over 210,000 unpaid family caregivers live in King County which is 14% of the population. Baby boomers are often caught in the middle caring for an aging parent and children at the same time. In the future, as baby boomers age the number of potential caregivers for each person will shrink. In 1990 there were 11 potential caregivers for each person needing care. By 2050 the ratio will shrink to 4 caregivers for each person.

A recent BRFSS survey asked King County caregivers to prioritize the greatest difficulties they faced when caregiving. "Creates stress" was the most frequent response. Besides stress caregivers often feel isolated and many don't know where to turn for advice or support. Jonathan Rauch, author of the Atlantic article "Letting Go of My Father" described his journey as a caregiver for his elderly father and the isolation he felt. See the link to the article: <http://www.theatlantic.com/magazine/archive/2010/04/letting-go-ofmy-father/8001>

According to Jonathan Rauch, What we need even more of "is for our nameless problem to be plucked out of the realm of the personal and brought into full public view, where help can find us." In King County a recent BRFSS study found that information about local programs or services is the most desired help needed by caregivers. The good news is Washington leads the nation in developing a system of family caregiver support services. In King County these services include:

- Information and Assistance
- Care coordination and consultation, temporary respite care
- In-home mental health counseling
- Support groups

Without the efforts of family caregivers long term care costs through Medicaid and other public spending would be much higher. One of the biggest problems facing the Family Caregiver Support Program is its low profile among caregivers, medical providers, general public and the media. ADS funded services reach about 5% of primary caregivers. Pam asked the Advisory Council to help identify ideas to get the word out about services to unpaid family caregivers. The Council answered the following questions. (Please see attached results from the groups)

- a. From your experience, what additional challenges do family caregivers face today?
- b. How can the AC help bring family caregiver concerns into "full public view"?
- c. What actions would you be willing to take to improve the reach and effectiveness of family caregiver support programs?

## **Business Meeting**

### **Minutes**

The May 14, 2010 minutes were approved as written.

### **City Council Report - no report**

### **Planning and Allocations Committee see attached report**

### **Outreach and Advocacy Committee see attached report**

### **Communications Task Force**

Marsha King, Chair of the Communications Task Force, gave a brief update and asked for volunteers. She reported the task force will meet in the next couple of months to draft a communication policy. The policy will be presented during the September Advisory Council meeting. During the meeting council members will have an opportunity to review and make final recommendations. Task Force members include: Marsha King Chair, George Dicks, Diane Snell, Bev Clark, Kaylene Moon, Dave Rogers, Tom Minty, and Timmie Faghin.

### **State Council on Aging**

Don Moreland reported the funding picture in 2011 continues to look bleak and reminded everyone about the importance to continue their communication with legislators.

### **NW Universal Design Council – no meeting**

### **Director's Report**

1. Pam thanked the Advisory Council for raising the visibility of senior centers with Councilmember Nick Licata at the April meeting. Their ideas were incorporated into a draft report which will be used during the stakeholder session June 7<sup>th</sup> and the final report to be sent to the Mayor and City Council. The report suggests that the City prepare for the demographic increase in the over 60 population expected in the near future. Additionally, the report emphasized no cuts to senior programs. Pam noted the report did not use the word seniors, but instead used more inclusive language.
2. Pam commented that the feedback received from today's discussion on Family Caregiving will be used to increase access of family caregivers and to inform a future Family Caregiving RFP expected in January 2011. Pam asked for a couple of volunteers to participate in bi-weekly RFP planning meetings. The next RFI meeting will be held June 22<sup>nd</sup> at 2:30 PM.
3. The Older American's Act Reauthorization Forum was held Thursday, June 10 in Olympia. Diane Snell represented the Advisory Council. The morning session focused on the OAA and the diverse array of programs the OAA provides in three States including Washington, Oregon and Idaho. During the afternoon session participants broke into discussion groups to provide feedback on policy changes to the Older Americans Act. It is hoped that future changes to the OAA will advance the aging network and suggest how it fits within the context of the health care reform. The discussion topics included

- How can caregiving among diverse populations be enhanced?
- How to encourage collaborative Social and medical chronic care management?
- What options are available to enhance the future role of information and access services?
- How can technological innovations for services delivery be incorporated?
- What can be done to support planning for aging-friendly communities?

**Adjourn**

The meeting was adjourned at 2:00 PM

**NEXT REGULAR MEETING:**

**Friday, July 9, 2010**

**Noon – 2:00 PM**

**700 5<sup>th</sup> Ave., Suite 4060 Seattle, WA**

[www.adsadvisorycouncil.org](http://www.adsadvisorycouncil.org)

# Letting Go of My Father

His elderly father insisted that he could manage by himself. But he couldn't. The author found himself utterly unprepared for one of life's near certainties—the decline of a parent. Millions of middle-aged Americans, he discovered, are silently struggling to cope with a crisis that needs to be plucked from the realm of the personal and brought into full public view.

By [Jonathan Rauch](#)



IMAGE CREDIT: JON KRAUSE

MY FATHER CAME to live in Washington, D.C., near me, in the spring of 2009. I went with my partner, Michael, to Phoenix, to fetch him and bring him east. He had Parkinson's disease, or so everyone thought. He was falling regularly, which he insisted was no cause for alarm, because falling is something people with Parkinson's learn to live with. In Phoenix, when he fell on the sidewalk or in the front driveway, passersby would stop to help him. This sometimes elicited visits from the police, to whom he would not open the door. He refused entreaties to use a walker, feeling that it made his balance worse. He insisted on driving, though his weakness and tremor defeated the mechanics of the right-hand turn. Through it all he would insist—*insist* is a verb I find I must work hard in this context—that all he needed was to be left alone. He would “relearn” how to walk and drive and live. Accepting help, he believed, would only cause his function to atrophy. “Use it or lose it,” he said.

Still, knowing all this about him, I was not prepared for the weakness I saw when we arrived in Phoenix last spring. He could barely dress himself, and only glacially at that. His stride had

become a Parkinsonian shuffle. His shaky hands were frustrated by pens and silverware. He could not cut his own nails or shave or keep his face clean. Hearing he was leaving Phoenix, one of his friends there had called me. "Oscar needs help," she said. "He needs someone to come in every day. He cannot live alone." Living alone, however, was exactly what he insisted on doing. I was dubious but game to try. I imagined checking on him by phone every day, stopping by his apartment several times a week, and regularly going out with him to restaurants and theater. It could work!

Three days after he arrived, I entered his apartment and found in the bathroom a plastic bowl full of feces and urine and soiled baby wipes. The vanity and floor were smeared with brown. This, apparently, was part of his process of relearning how to use the bathroom. He insisted he would clean up the mess himself, forbidding me to touch it, an instruction I defied, since he tended to fall when he bent down. In the kitchen, most of a pint of two-day-old ice cream lay hardened into a sticky goo on the floor where it had fallen, out of his precarious reach. He insisted he would clean that up, too, and just hadn't got around to it. Meanwhile, he had dropped a sheet of paper towel over the mess.

That was just day three.

My father was 80 then. He was a bright man, strong-willed and willful, and his strength of mind had served him well. Despite having been raised in poverty by a single mother, he got himself through college and Yale Law School, then built a successful law practice in Phoenix, where he lived for more than 50 years. After his marriage failed, he raised three children as a single parent. For decades, people had sought his counsel. You could not tell him what to do. He looked at me once, on one of many occasions when I was pleading with him to accept help, and said levelly, "I want you to consider the possibility that I am right and the whole rest of the world is wrong."

In the late 1990s, after retiring from law and traveling the world, he had gotten into the habit of spending summers in Washington, where he had converted a midtown studio apartment I owned into his second home, nine miles from my house in suburban Virginia. He and Michael and I would spend weekends exploring Asian film festivals and Jewish theater and esoteric restaurants. As he got sicker, it made sense for him to move his base from Phoenix to Washington, because he could get around Washington without driving.

Before he arrived last spring, I did my best to prepare. I had set up an emergency-alert button, which he accepted as an aid to independence (but did not consistently wear). After a week or two of coming in and finding urine-soaked jeans on the floor and sometimes on him, I bought him some adult diapers, which he also accepted as an aid to independence (but did not consistently wear). I asked the condo building's maintenance man, whom my father liked, to do housekeeping twice a week, an arrangement my father accepted because it struck him as ingenious and inexpensive. Through a friend at work, I arranged periodic visits from a social worker with the Jewish Social Service Agency, whose competence and intelligence my father respected. I thought I was ready, and for a few weeks, despite my initial shock over his condition, it seemed to work.

I should say that my description so far must make my father seem nothing but stubborn. He was stubborn, but he was also charming, resourceful, generous, kind, funny, uncomplaining, and good at making friends and allies of those around him. By enlisting friends and learning to cope, he had managed on his own longer and better, certainly, than I could have done. He had consistently proved wrong those who told him what he couldn't do. And Parkinson's, his doctors assured us, was a slow-moving disease. Expect only gradual change.

By last year, however, the disease was moving fast. He would eventually be rediagnosed with a particularly nasty neurological torment called multiple system atrophy, but that was later, near the end. Until the last couple of months, no one realized how sick he was, and so his resistance to impingements on his independence was understandable. Shame was another reason he wanted to be left alone. As he confessed to me more than once, he felt ashamed of his condition. One of the few times he ever cried in my presence was when he saw me on my knees, scraping hardened ice cream or jam, or whatever it was that day, off the floor. "I'm sorry," he said. "I'm sorry. I never meant for you to scrub the floor for me."

In the early weeks, I was protective of his independence. He believed that confinement in a nursing home would kill him, and I understood that his autonomy was the thread by which his emotional health hung. But his motor control was not cooperating. By summer, he was having trouble getting out of bed. Many days, he relied on the maintenance man to dress him, or never managed to dress properly at all. On several occasions, I arrived in his apartment to find him lying on the floor, unable to get up. He was no longer able to manage his own mail or appointments. Often his slurred voice on the phone was barely intelligible. When I called, he would manage to pick up the phone but said only "I can't hear you! I can't hear you!" before hanging up.

I came to dread the ring of the telephone: it might be my father on the floor, asking me to come over and pick him up, or it might be emergency medical services, summoned by a neighbor or the call button. Once, when I arrived amid a commotion of paramedics and flashing lights, a neighbor, herself elderly, was standing in the hallway, her face flushed with fear, yelling to me, "He can't live here! You've got to move him!" In the midst of it all, my father would be entreating everyone to leave him be.

My professional work all but stopped. Finding doctors for him and getting him to appointments and coordinating escalating medical needs swallowed entire days. I managed until one hot July afternoon. I was at my desk closing a column when Michael called from Costco, where he had taken my father shopping. My father had gone stiff on one side, become incoherent and unable to stand, and didn't know where he was. I had to get over there, Michael said, in a quietly frightened voice. I jumped up and ran out, but by the time I arrived my father had recovered and did not remember anything untoward happening. "Do you need to see a doctor?" I asked, stupidly. He just gave a dismissive wave of his hand. "I'm okay," he said. I stood there, in the produce aisle, with no idea what to do, frightened by my incompetence and, worse, furious at my father for putting me in this impossible position.

That was the day I realized that he could not cope and I could not cope and, emotionally, he could take me down with him. And I discovered in myself an awful determination not to let that

happen. From that moment, I was determined to get him out of his apartment and under professional eyes, or, failing that, to protect myself. How to protect myself, I didn't know. Hire help over his objections? Take him to court and seek to have him declared incompetent? Report him to Adult Protective Services? Use my ownership of his apartment to force him out? All I knew was that, at that point, I believed myself capable of doing such things, or even of washing my hands of the situation if he would not listen to reason. I imagined telling an indignant world that I had tried my best and could do no more. You have no idea what a thing it is to have that sort of conversation with yourself about a parent.

In hindsight, I was ripe for post-traumatic stress syndrome or anxiety disorder or depression. According to the Rosalynn Carter Institute for Caregiving at Georgia Southwestern State University, family caregivers face elevated risks to their physical health, mental health, finances, employment, and retirement. I can attest to the mental-health risk. That I managed to keep myself together owes itself largely to a coping strategy of my own—one that brought with it a peculiar discovery.

For whatever reason, and quite against [my usual introverted nature](#), I talked. To almost anyone. A provocation as simple as “How are you?” would reduce an answer like, “Bad. I'm at my wits' end coping with my father.” Out could come the whole story. Though I tried not to be too socially inappropriate, I must have discomfited a lot of people. But I discovered that I *had* to talk. And I discovered that when I talked, other people talked too.

I got advice and tips: mix coffee with yogurt if he likes the taste of coffee but has trouble swallowing it; here's the name of a geriatric case manager who's really good. This kind of practical wisdom was useful. But why, I began to wonder, did I have to collect it on the street?

I got amateur counseling: take care of yourself first; don't try for perfection. Good, tough, compassionate advice, but randomly proffered. How much more was there that I needed to hear but that no one happened to tell me?

Above all, I got stories. Some were in the past tense, but a surprising number were in the present, and they gushed forth with the same kind of pent-up pressure that I felt. Washington is a city of middle-aged careerists like me, proper and dignified and all business. Yet time and again the professional exteriors would crack open to reveal bewildering ordeals.

A lobbyist. At a reception hosted by his trade group, he asks what I am working on, and I reply, “Taking care of my father.” Without missing a beat, he tells me of having spent that morning in tears, sobbing in a meeting with the staff at the care facility where his 100-year-old father now lives.

A scholar. He is working on a book about interest groups and we go out for coffee to discuss it. He asks how I am. When I tell him, our original agenda melts away and he tells me that his life's work, now, is flying back and forth to remote Wisconsin, where he takes care of a father with Alzheimer's. He has had to move his father, sell the house, find a care place, deal with his father's affairs, all while trying to do his professional work and raise his own kids. I tell him that,

for me, the biggest problem is not so much the time spent on my father's crisis as the distraction, the inability to concentrate or focus. "It's my work which is the distraction," he replies ruefully.

A journalist. He stops by my office, plops in a chair, tells me he has heard about my situation and wants me to know he admires what I'm doing for my father. Thanks, I say. But he continues. His parents are 80-ish. They are managing, but just barely. The situation is teetering toward crisis. They need to move or accept help, but his father is too proud to consider it, and the journalist and his siblings don't know how to raise the subject. He needs advice, which, with the benefit of my several months of experience, I do my best to give. Don't wait any longer to deal with this, I tell him. Push your parents harder than you feel inclined to push, I say. What I am thinking, of course, is: *What you really need is a better adviser.*

As I walked the streets, did interviews, conducted business, I took to wondering which of the middle-aged people I encountered were quietly struggling to cope with their own crisis. How many of them felt utterly out of their depth? How many others, having come through an ordeal, had experience that they had no ready opportunity to share? According to the National Alliance for Caregiving, about 50 million Americans are providing some care for an adult family member. I was swimming in an invisible crowd of caregivers every day, but, like streams of photons, we passed through each other.

Many years ago, when I was 12, my parents divorced and my mother left our suburban Phoenix home and her kids to start a new life in Berkeley. Later, when I was a young adult trying to understand why she had left, a friend of my mother's told me: "You've got to understand. Back then, women didn't *talk*." I didn't get it. Meaning? Meaning, she said, that in the 1960s and early '70s women felt it was part of their job to pretend to be content in the house with their kids. If you were dissatisfied, you kept it to yourself. Each lonely, bored housewife faced her unhappiness on her own. In those days, she told me, a woman like my mother, who was brilliant and college-educated and felt trapped, was on her own, and in some cases the strain was simply too much.

This was the conversation that came back to me last year. So many stories. So much experience. So much need for help! Yet until I volunteered my own story, usually in a socially inappropriate setting, it stayed quiet, "personal." It was as if we were being graded on coping stoically. Broaching the subject and confessing desperation was like uttering the password to a secret brotherhood of beleaguered, overwhelmed, weary, or sometimes just resigned adult caregivers. But the sect seemed ashamed to be seen.

As I reached my own breaking point, two things happened. First, my father caught sight of my distress. He would not accept assisted living on his own account, but when I told him that he was already in assisted living but that I was the assistance; that I was overwhelmed, underqualified, and barely hanging on emotionally; that I wanted to be his son again, not a nurse and nag and adversary—when I told him all that, and when his sister and the social worker chimed in, he acceded. He was still, after all, my father, and it was still his job, he understood, to care for me. Second, the inevitable happened. As his disease overtook him, not even he could deny his incapacity. And so he moved, reluctantly, to a nearby assisted-living place, which gave me the help I needed and, to no one's surprise but his own, gave my father more rather than less

independence. Another phase of the story then unfolded, ending with his death in December. His last gesture to me, so very characteristic, was to wave me away. He wanted me to go on with my life rather than hover by his bedside.

I did go on, but I emerged from the whole experience not a little indignant. The medical infrastructure for elder care in America is good, very good. But the cultural infrastructure is all but nonexistent. How can it be that so many people like me are so completely unprepared for what is, after all, one of life's near certainties?

I am now convinced that millions of middle-aged Americans need more help than they are getting, and that the critical step toward solving the problem is a cultural change akin to the one demanded by feminists in the 1960s. Betty Friedan, in her landmark 1963 book, *The Feminine Mystique*, famously called the housewife's endemic loneliness and boredom "the problem that has no name."

Suddenly they realized they all shared the same problem, the problem that has no name. They began, hesitantly, to talk about it. Later, after they had picked up their children at nursery school and taken them home to nap, two of the women cried, in sheer relief, just to know they were not alone. Gradually I came to realize that the problem that has no name was shared by countless women in America.

Though their situation is obviously different, today's invisible caregivers face their own version of a nameless problem. They are being asked to do alone and out of sight what in fact requires not just private sympathy and toleration but public acknowledgment and proactive assistance.

I would put special emphasis on the word *proactive*. There are resources out there to tap, to be sure. Once you begin looking, you can find them. Thanks to a personal connection, I was able to find the invaluable social worker. Banging around on Amazon, I found a few books on elder care, which were mildly useful (but really too generic). Had I looked harder, I might have discovered the Web site of the Family Caregiver Alliance ([www.caregiver.org](http://www.caregiver.org)), which offers a wealth of fact sheets; the National Alliance for Caregiving ([www.caregiving.org](http://www.caregiving.org)), which offers an online tool to help coordinate care; [strengthforcaring.com](http://strengthforcaring.com), which offers "Share Your Story" and "Meet Other Caregivers" bulletin boards. To get this stuff, however, you have to go look for it, which means you have to have some idea of what you need, and I didn't. What I needed was for the experts to find me and tell me what I needed.

And, indeed, to explain why I needed it. I can say, from experience, that convincing caregivers they need help is not easy, at least not until they need it too much. Americans pride themselves on resilience and independence. We don't want to burden others with our problems. We don't like to acknowledge that a crisis is happening or imminent. Above all, we prefer to assume that our own and our parents' declines will be smooth and uneventful. By keeping the problem out of sight and consigning it to the realm of the "personal," the culture enables our natural tendencies toward denial, procrastination, and silence.

At one point, as I struggled with my father's crisis, I joked to friends that we should all be given time off work at age 40 to take a course on elder care. I no longer see this as such a joke. A few

big companies, realizing that caregiving responsibilities drain employees' time and productivity, are making available seminars like Powerful Tools for Caregivers, a six-week course on subjects like "Taking Care of You" and "Mastering Caregiving Decisions." That seems like exactly the right idea. If employers can provide seated massages and host blood drives, surely they could be a conduit for elder-care training and information. Surely toll-free hotlines would not be so hard to set up and publicize ubiquitously. Surely HR departments and health providers and clergy could be trained to respond, on learning that an employee or patient or congregant has an elder-care "issue," with a nudge toward resources, rather than just, "I'm so sorry for what you must be going through."

What we need even more than that, though, is for our nameless problem to be plucked out of the realm of the personal and brought into full public view, where help can find us. In the years after Betty Friedan named their problem, women who work in the home (formerly "housewives") demanded and got a new infrastructure for support: opportunities to study and work at home, part-time job opportunities, public and private help with child care, social networks, and so on. Perhaps more important, they demanded and got society's recognition that they were providing an indispensable public good. As a result, they are not isolated or silent anymore, and they do not need to put up with being lonely or bored. Keeping today's invisible infrastructure of caregivers out of sight is as stressful and wasteful and pointless as leaving millions of women feeling stranded at home once was. My mother's friend and the feminists of her generation fundamentally had it right. There should be no need for anyone to go through this alone, and no glory in trying.