# The **Eldercare** MONOLOGUES



A HIPPIE-ADJACENT GOOD SON TELLS YOU ALL ABOUT IT!

Tips on doin' right by Mom 'n Dad without it bein' a buzzkill

How I winged it - Stories of my experience taking responsibility for the quality of my Parents' lives and caring for their welfare.

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This is not a comprehensive "guide" to all aspects of eldercare. It's just my own ad hoc story via vignettes and musings. If you need such a guide, I suggest "When Someone You Love Needs

Nursing Home, Assisted Living, or In-Home Care" by Bornstein and Languirand.

This is designed to be a loose, rambling and informal attempt at describing how I arrived at best practices that pared the amount of MY actual movement and time / energy expended to the minimum, while maximizing the sensitivity to THEIR well-being and satisfaction. It also is an attempt to lighten the mood surrounding taking care of your geriatric parents and illuminate how noble, sacred and rewarding it is to do it.

#### THE DECISION

- So the decision to take responsibility. (It's not for everybody in my case, I had accumulated barely enough money [and no personal relationship] to compel me to conclude that I couldn't afford to take the risk of later knowing that, despite being able to afford and take on the job of caregiving, I'd likely end up regretting not doing it.)
- As in many families the time came when it was obvious that my Dad, Mort, was ready to capitulate to the idea that he could no longer handle managing his and my Mom's independent lifestyle, and that I should take over his and my Mom, Marilou's affairs, both financial and lifestyle. They were retired in the Tampa Bar area for 22 years, and I'd made regular pilgrimages from Southern California over the years, and I'd helped resolve a mini-crisis involving Marilou's adverse reaction to taking the sleep aid Ambien (which nobody had remembered she had even been prescribed on an "as needed" basis well before side

- effects became alarmingly noticeable), but by age 85, they both were exhibiting frailness, absentmindedness and anxiety about independent living. I knew then the time to step up and take responsibility was upon us.
- Their parental instinct is to keep pushing the kid out of the nest and to resist the offer to re-engage in such a significant way, so make sure you mean it, can communicate the love and commitment you feel honestly and completely, and then get their permission to take control. In my case, they were relieved, gratified and proud of me for stepping up. At that age (85) they were becoming anxious on a daily basis on how their futures were to unfold. I kept reinforcing that "there is no reason to be anxious any more, but you will anyway, so I'm going to keep reassuring you." I've found that repetition is a good formula for success repetition of everything: healthy daily living routines, reassurances, medical information, etc. Just keep repeating stuff periodically. You'll be surprised how much they don't remember you telling them.

After deciding that I wanted to be responsible for Mort and Marilou's future, my strategy was to move them from Florida to a senior living community within 25 minutes of my house and then making daily visits after getting them situated.

- First, a little family biography:
- I'm the only surviving son of a two-child family. My sister Janet was mentally ill with <u>schizophrenia</u>, which was

discovered in her early teenage years, quite typically. She struggled with her schizophrenia until age 27 and died tragically in an accident in 1985 involving a moving train. She was in a manic phase of her illness and was impatient, while on foot, to not wait for a slow-moving freight train in our home town of Fort Wayne, Indiana as it was passing by behind the old newspaper building on her walking path to a coffee house that had just opened. The coffeehouse was geared towards the Alcoholics Anonymous community members with whom Janet bonded in her mental illness, having convinced herself that she was alcoholic and not seriously schizophrenic. In her effort to run through the railroad traffic crossing before the train could block her path {for 15 minutes}, she miscalculated, and although she dashed across the tracks to the other side, looking up triumphantly (the horrified witnesses in cars at the crossing arm said), the engine was wider than she knew, and it caught her from behind and threw her aside, killing her instantly. She didn't know what hit her, mercifully. From that moment on in 1987, I realized I was going to have to be very careful to make sure I survived my parents and was going to be the person who would take care of them in their elder years, when the time came. I liked to joke that I looked both ways, after 1987, a hundred percent of the time. Anyway, when my father produced some brochures about an assisted living community near where they were living in retirement, in Florida for 22 years, I knew the time had arrived to start taking over for their benefit.

• After my Dad turned 62, he was sort of "edged out" of his career in Personnel Administration by Beatrice Foods, who

had recently absorbed the cheese factory called County Line Cheese, where he was working in his fourth, and last, industry, of his rather remarkable career. He was transferred to Milwaukee in order to keep working, and found upon arrival there that they would prefer to have him just take a retirement. They made his life kind of miserable in order to communicate that desire, and he picked up on the cues and took an early retirement at 62.

When Mort and Marilou sized up their possibilities economically, Florida made the most sense, and they ended up buying a manufactured home in Ellenton, Florida, outside of Bradenton, which is in the Sarasota area on the Gulf Coast. (Tampa Bay Region). When I discovered that my dad, at age 85, was looking at brochures of a brochure for a continuing care community near them that many people in their manufactured home community seemed to find preferable, he came to me on one of my visits, and he admitted they were beginning to slow down enough that he didn't feel comfortable having Marilou continue to prepare meals much longer, as her ability to do so was quickly waning. I told them clearly that I'd welcome taking the role of decision - maker and their chief caregiver, and that I'd like them to re-locate to California, (Los Angeles), where I lived, and while they were understandably reluctant to impose on my life, they were quite happy that I was willing and insistent that they come to California to live in an assisted living community that I offered to find for them, rather than in Florida. So we began planning how that might happen.

They were both 85 when I made my commitment and moved them from Florida to California, where I lived.

Their physical condition: Mom had a history of <u>TIAs</u> (<u>Transient Ischemic Attacks - mini strokes</u>) which affected her <u>ability to swallow (lost her gag reflex</u>). She was also diagnosed with <u>atrial fibrillation</u> much earlier and put on Cumedin (blood thinners) as a result. Later, at 93, I discontinued it in favor of baby aspirin at the suggestion of the hospice nurse. We could have done that much earlier, but she had decided that she preferred to not change her medication routine until I finally contravened during her chest congestion bouts. By then she was in agreement.

Swallowing for her was difficult, more deliberate than automatic, and fluids entered the airway easily, resulting in a lot of coughing. She had about 27% kidney function, so she was considered by her Doctor in Florida to be "in declining health." Dad / Mort was a nervous / anxious personality type and wanted the security of knowing the future would unfold without physical risk for them both, but he was largely very healthy for his age. He had been diagnosed with an enlarged prostate in his 70s, but his Doctor advised "watching it" rather than a biopsy. He ended up dying at age 91 of natural causes, but his historically enlarged prostate did cause him to get an in-dwelling catheter for the last year and 2 months of his life.

<u>If there are other family (brothers and sisters)</u> I can't advise <u>you</u>. I was alone. But I hear it's important to agree among yourselves what the roles of each member of "the team" are, who gets the most inheritance for doing the most work, etc. Don't fight in front of them. Figure it out, make the

commitments and don't look back. It's largely wonderful, especially if you embrace it wholeheartedly at the beginning.

## GIVE YOURSELF OVER TO THE PROGRAM

I get a big kick out of the <u>Jason Bourne movie scene flashback</u> at the indoctrination Center. When that scientist <u>Looking guy says to David Webb give over give yourself over to this program completely</u>. Taking on full-time Elder Care responsibilities is sort of like that. You stop being who you were and you start being a new kind of person- a caregiver.

I possessed self diagnosed 'manic' aspects to my personality that I mitigated with over-work in the movie industry - on the set as an assistant director and as a location manager for a number of years, so when this change presented itself, I was ready to give over to a program of more contemplative and meditative aspects.

You may think your attentiveness to their needs is going to be adequate when you get started, but soon you'll realize it's really not enough. You have to give yourself over completely to the program and be there. And watch TV with them, and listen to them, and watch them, and then make the 37 minute commute home. At first I deliberately over-compensated with the time commitment thing - hanging with them until late in the evening every day, 7 days a week (after doing my work, which was freelance location scouting - I would scout in the days and upload and organize pictures at their place in the evening with the cable tv provider/internet provider high speed web which I paid for). Giving over to doing most everything at their place

paid dividends, as I developed healthy routines for them and really learned how their energies ebbed and flowed.

I built balance into my life in stages, but after the first year, I was pretty comfortable with understanding how time passes for both them and me and how to optimize my energies.

When my dad finally, after about 7 years in California, took to bed & chair (and limited walking) at my house, and when 6 months after he came home, I brought my mom home, too, it became a lot easier because all that commuting time was given back to me. After Mort died in August 2018, it became time for Marilou to rejoin a community - in her best interests and mine. She didn't need a caregiver by her side like Mort did, and I was ready to do some renovations on my house, so I moved her to a Senior Living Community 15 minutes from my house. Home in 10 minutes late at night when there's no traffic.

But I still spend almost all of my time over there - I break away for a couple, three, maybe 4 hours a day to do yard work, marketing, light scouting, or projects at my house, and then I come back. (Only after Marilou was admitted to hospice did I hire a caregiver to be there with her when I would leave - up til then I left her alone in her apartment with a "pendant" that, when the button was pushed, would alert the front desk that she needed something. My routine was somewhat solitary and socially isolated as a result. But like I say I was at a point where giving myself over to the program and becoming more contemplative and meditative was in my best interest. I do want to say thank God for Facebook, which allows me ample

opportunity to share my experience with relatives who have a persistent interest in Marilou's well-being, and it also provides a free archive for me to store photographs to share and look back on for the rest of my life. It also allows me to stay informed and keep up with the goings ons of old and new friends. But it has to be said again. You have to give yourself over to the program.

Embrace the role of their "life manager." Don't resent it, or you'll not make it work. Learn Patience. Listen a lot, but don't be afraid to frame the discussions clearly. Be supportive and loving. Unpack the neuroses you grew up with due to their imperfect parenting and inspect them, then discard them. Invent a "new normal" supportive, patient, loving role for yourself in their lives. Convince them that you want the role. It will be gigantic time commitment for you and a big lifestyle change, so be certain it's what you want to do. If you have job and family obligations that preclude taking a large "hands on" role, consult family about forming a "team approach" and split the shifts and responsibilities.

# ADVANCE HEALTH CARE DIRECTIVES FOR THEM BOTH

It is really important to get these drawn up along with the Durable power of attorney — also know as "health care proxies", these documents put into legal writing the desires of the family member. In our case they both wanted: No extraordinary intrusions or life-extending treatments. No hydration - just to be kept comfortable and be allowed to die. Another form, the "Do Not Resuscitate" form - bright pink or

yellow sometimes, depending on the state - also needs to be drawn up. It travels with the patient. This might fall by the wayside or in the cracks, as computers and databases keep the records (as Kaiser our HMO does, for example), but I think you should have one physically present wherever they are so that when the time comes, you can produce it, hand it to the ambulance or ER staff, and everyone is on the same page. Their lawyer drew these up too.

These forms will often allow you to keep your family members at home, or in an assisted living facility rather than have them taken to the hospital when downturns happen. If the assisted living facility makes a federal case out of wanting them to go to the hospital, and you know you want them "just kept comfortable," you can produce the forms and insist that they respect your wishes. If they won't I suggest you keep a single bed ready at your home so that you can evacuate them to your house, even for one or two nights until you can regroup and find a nursing home. They have no business going to the hospital if you have your shit together. If the protocol at the facility where your parents live compels them to call 911, you can dialogue the EMTs and refuse them to be taken to the hospital, but if the facility insists, you can meet the ambulance at the hospital and confer with the doctors there and show them the DNR and take them home. It shouldn't have to come to that, though. The doctors at the hospital know that they can't really help them, and there's tons of sick people there, so your elders will just be exposed to more germs for hours and hours. You'll pull an unpleasant all nighter just trying to get them discharged, which they'll do, but it takes a while to get seen, tested and then discharged. I'd avoid it at all costs if possible.

Pick a Medicare Program for them.

<u>I chose Kaiser (HMO)</u>. I didn't have to get supplemental health insurance policy. Part D (Meds) required enrollment (we had to do late enrollment, because Dad was buying meds from Canada direct and didn't enroll in Part D). Result: About \$20 / month payment each for late enrollment above and beyond Medicare co - pays.

Advantages of Kaiser:

Coordination of Care

No Supplemental insurance needed - Medicare covers 100% except for co-pays

Co-pays are pretty reasonable - about \$15 for most visits \$200 for surgeries, etc.

Every year, Medicare evaluates plans based on a 5-star rating system. In 2020, Kaiser Permanente California, Colorado, Georgia, Hawaii, Mid-Atlantic and Washington regions received 5 out of 5 stars. Northwest region received 4.5 out of 5 stars.

## Kaiser website.

.....is great. www.kp.org. You can email your doctor, as well as specialists. A nurse reads all the emails and gets the doctor to respond if he/she cannot. You can order medications on the site, read test results (they are almost instantly loaded on the site within a couple hours of the blood draw / urine sample ), see past test results in a variety of ways / charts, and make appointments. All the specialists look at the same chart, so the coordination of care at Kaiser between specialties is excellent.

#### From Kaiser to Caremore

When Marilou moved to a Senior Living Community (which saved me money and the food improved ) — I went from a 24 hr / day - 7 days a week caregiver for Mort (and some help w/ Marilou, at my house - w/ no "community" and 'meals on wheels' / "Mom's Meals" [with a discount for Kaiser Plan members]) to a nice one bedroom apartment at Pasadena Highlands with 3 meals/ day, activities/entertainment, and a 'panic button/ pendant that summons the front desk to radio a caregiver - my costs went from 6k a month to 5k a month. Later when I added Natasha, my caregiver, back to the mix (when Marilou weakened with chest congestion I decided to give myself a break and hire Natasha for 7 hours a day / 5 days a week - I paid her for 8 hours (travel time allowance) @ \$200 / day.

We cut back to 3 days a week when Marilou re-gained strength, but I'm always prepared to bring her back when Marilou needs real help dressing, transferring from bed to walker/toilet/commode/chair, etc. Eventually she may need help with feeding, toileting, etc., but since she has a swallowing disability and flirts with chest congestion frequently, at age 93, she was admitted to hospice care (Medicare covered "extra" vigilant care) with the understanding that it could be a long hospice period. I switched her from Kaiser to Caremore at the advice of the Pasadena Highlands Medical Director. (from a website:) "CareMore's "Touch" model is to bring interdisciplinary teams of medical professionals such as physicians and nurse practitioners into people's homes — including senior living communities — to provide more rapid and coordinated services.

CareMore receives payment for these services via health plans, including Medicare Advantage plans, which view coordinated care as a way to increase beneficiary satisfaction and reduce hospitalizations and other expensive episodes.

CareMore is affiliated with Anthem — one of the nation's largest health insurers — but is part of the company's Diversified Business Group. So, there is a firewall between CareMore and the insurance side of Anthem, and CareMore partners with both Anthem-operated health plans and those offered by competing insurers, Jain told SHN.

For over a decade, CareMore has <u>worked with</u> senior living providers on a facility-by-facility basis, bringing services to residents enrolled in partnered health plans."

It was a good move, since the Caremore Doctor assured me that he could get Marilou admitted to Hospice quickly and easily than if we stayed with Kaiser, where I had to transport her to appointments. Caremore Doctor and Nurse team come to Pasadena Highlands for "housecalls." Kaiser was great for years, but when frailty and ill health became more prevalent, Caremore and the subsequent Hospice care admission were a much better fit.

## MONEY AND STUFF

Mort was an administrator, a manager, a business school graduate and a "detail guy." He made checklists, underlined profusely in what he read, clipped articles, wrote letters to the editor - very empathetic, sensitive and community - minded. But he was also, understandably, a neurotic — he was brought up by his Grandmother and 7 Jewish Aunts and an Uncle, as his

mother, the oldest of 10, died tragically in his infancy. I think his upbringing inevitably shaped his neuroses. He was always prone to mood swings, sensitive to slights, and could enter deep funks that took days, sometimes weeks to emerge from, I remember while growing up. But he was a problem solver, a coalition builder, a negotiator for organized labor agreements (he worked for the management side) who loved the rough and tumble world of contract negotiation and arbitration. We were always middle class - I don't think my Dad made more than \$22,000 - \$25,000 a year in salary in the 60s and 70s - but he was an avid student of careful investing and taught me the fundamentals of compound interest, stocks and bonds at an early age. His career spanned four industries, and his last industry cheese manufacturing - was subject to the vicissitudes of corporate leveraged buyouts: his company was absorbed by a large corporation and he was given an unpleasant option to move to a job in Wisconsin from our home town of Fort Wayne, Indiana, or face termination. He accepted the assignment but quickly learned that the management's strategy was to make life unpleasant for him so that he would quickly opt for an early retirement, which he did at about age 62.

Mort sized up his situation and took Marilou to Florida where they purchased a manufactured home in a gated community, rented the lot, joined a Unitarian Church, and lived within their budget. He used Canadian Pharmacies to buy their medications (and didn't opt for Medication Part D when it came into the Medicare Act.) Later when I enrolled them in the Kaiser HMO, they were required to have Part D and to use the Kaiser Pharmacy, so a "late enrollment penalty" was assessed

and I paid approx. \$22 a month each for them for the duration of their lives for that.

Mort's attention to detail and dutiful thriftiness resulted in their ability to maintain and grow their life savings and take only the minimum required distributions on their IRAs. By the time I took over control of their affairs, they had an accumulation in total (2 IRAs - Marilou worked, too & a Cash Management Account at Merrill Lynch, with a wonderful broker/advisor, Andrew Minor) that totaled just over \$550,000.

When I moved them to California, The British Home Rent was \$3,000.00/ month for their room in Independent Living which included 3 meals a day and all utilities. (It is up to approx. \$3,900/mo for double occupancy - which is not bad 8+ years later!) Mort & Marilou's combined Social Security, a baby pension Mort had from work for ITT in the Aerospace Industry (during my elementary school years), and Interest/Dividend income from their Savings equaled \$3,000.00 / month (not including required minimum distributions from the IRAs), so I was in good shape. I used the required minimum distributions from their IRAs to cover all other expenses, like medical copays, the Part D late enrollment penalties, miscellaneous drugstore purchases, Grocery store goodies to supplement their diet (snacks and sweets), clothing, furniture from thrift stores and senior mobility aids (and I re-invested the rest of the RMDs in their cash management account). Later when they moved into Assisted Living and the costs were higher, I tithed from my own income to prevent the need to sell out of their investments (diluting the "seed corn") to make up the shortfall. But also, as they aged, the required minimum distribution from their IRAs

went up in predictable dramatic fashion - the government wants those traditional IRA accounts to be zeroed out by age 100, so the distribution bites get much bigger in the latter years. Only now, that Marilou is 92, am I facing having to nominate select investments for liquidation to make the minimum distributions (not just be able to accumulate enough interest and dividends from within the IRAs to equal the RMD amount, which has been the case thus far!).

# Durable Power of Attorney <u>DURABLE POWER OF ATTORNEY</u> - forms link

They gave me this - we visited their lawyer and got it drawn up.

This is one of the earliest things to get done. If they aren't ready to do it, then you should not commit to the role until they are. It allows you to make decisions for them in their best interests. Talk it over with them in the presence of their attorney, and then return to the attorney later, if necessary, to sign the papers. They shouldn't feel rushed or pressured into this decision, but it's important that they give you the DPOA. (A Power of Attorney for health care or Health Care Proxy, by contrast, authorizes someone to make medical decisions.) This is probably a hot topic in some families - Dads want to retain their control and autonomy - that's understandable. But in my opinion, the discussion of taking over for them on the important stuff is only possible if they trust you, and if they trust you, they should trust you completely and give you the DPOA. If they aren't ready to do that, then perhaps you shouldn't over-involve yourself in

their daily affairs, etc. Don't be a "fair weather friend," though - by that I mean, don't offer to help them out when it's convenient for you and then abdicate for great periods of time, because Dad wants to retain control and stiff arms you from getting involved with financial decisions, or other stuff that require you to have DPOA-level of responsibility. Offer what you can of yourself consistently, and limit that level of involvement consistent with the level of responsibility they will give to you. When you have DPOA, it will be incumbent on you to be fully involved in their lives.

MERRILL LYNCH DURABLE POWER OF ATTORNEY - a separate form to give me control of their funds. Essentially, putting my name on all the accounts (including controlling their IRAs - [traditional - not Roth]}. As opposed to the "durable power of attorney" form for Florida and then California, the brokerage needs their own paperwork for you to have control of the money.

CABLE TV W/ ON DEMAND / RECORDING FEATURES
I subscribe to cable TV. For my parents immediately upon
moving them to the British home. I got the on-demand feature
working where I could go and look up episodic TV shows that
they liked and play them for them on demand period we
watched seasons of Chicago Fire from beginning to end as well
as Blue Bloods, which was my father's favorite. Downton
Abbey was a lifesaver when it came on. I tested them by
playing shows over again (repeating entire seasons of Downton
Abbey) a couple of months later from beginning to end, and they

enjoyed watching them all over again on more than one occasion, spaced apart by a couple of months. I found that they really enjoyed the familiarity of the characters and have basically forget the storylines, and so they get to enjoy them all over again.

#### MOVING AND DOWNSIZING

Here is a punchiest I made to get my shit together upon getting ready to move Mort and Marilou from Florida to California. I'm big on "re-capping" and "checklists".

re·cap

informal

verb

verb: **recap**; 3rd person present: **recaps**; past tense: **recapped**; past participle: **recapped**; gerund or present participle:

recapping

/rē'kap/

1. state again as a summary; recapitulate."a way of recapping the story so far"

noun

noun: recap; plural noun: recaps

/'rē\_kap/

1. a summary of what has been said; a recapitulation."a quick recap of the idea and its main advantages"

#### Punchlist:

- \* Establish Durable POA way in advance of the process
- \* Gather all Advance Directives, Wills, Bills, Accounts, Investments, etc. into Database
- \* Change SS payments, pensions, dividends to auto deposit.
- \* Establish online banking logins, passwords
- \* Shop for Independent / Assisted Living Settings w/in 15 min. of my house
- \* Take Pix / Video
- \* Check references / Management tenure & approachability / Talk to Residents during visit / Residents' Council? / Clean?
- \* Sample Meals
- \* Rent Discussion / Room for negotiation?
- \* Assisted Services added fees? / Skilled Nursing or not? / Alzheimers care Licensed? (what do we want/need?)
- \* Find out where nearest hospital(s) is/are
- \* Find out what HMOs and Medicare Plans dominate for our area
- \* Check ratings of Medicare plans and HMOs
- \* Find out how close medical offices and referral specialists' offices are to the setting
- \* Any Pre-requisites for Acceptance (Chest X-rays for State TB screening, applications, DPOA, Advanced Directives, etc.
- \* Take 5 month break from visiting Florida (absence makes the heart grow fonder) Buy plane tix for one way trip to Florida for Visit.
- \* Buy Tempurpedic bed on Craigslist and store in my garage
- \* Put a friend on notice to help transport and install bed and temporary furniture

on morning of my parents' first day in California while they sleep at my house.

- \* Designate furniture at home to be temporary furniture for their new setting while shopping
- \* Visit with Pictures / Video Stay one full month to accomplish everything
- \* Blindside them with "I support any decision you make, but it would break my heart if you chose to move into Independent Living in Florida and not Southern California near me."
- \* Guide their decision on which Independent / Assisted Living Institutions to consider.
- \* Offer to schedule a trip to California from Florida to "visit" several options.
- \* Let a couple of days go by and then offer to turn the "visit" into a "move" suggest they try out their favorite (from pix/videos) and if it doesn't feel right, they can move to my house while we decide on which one to try next.
- \* Guide their decision on which Institution seems like the "favorite"
- \* Pick a date for moving "sooner rather than later"
- \* Buy plane tickets for one-way trip for us three to California from Florida
- \* Google and schedule movers (they are pretty much competitive and reliable)
- \* Google and schedule car mover
- \* Buy Boxes and bring them inside 3 at a time for filling. Let them fill them at the last minute if they want. Limit to 15 "China" sized boxes. Hold up items: "Into a box or give to Goodwill?" & "If you think you MIGHT want it, let's put it in the box & decide later."

- \* Make no less than 12 full carload trips to goodwill
- \* <u>Schedule Going away party with neighbors</u>. Pick who will empty the fridge, put out the trash, & enjoy a last dinner out together.
- \* Use online floorplan software to imagine <u>furniture floorplans</u> <u>in new setting</u> (No Couch <u>Use Recliners</u>) (Make <u>"snapshots"</u> so they can visualize)....Later when <u>it turns out to be similar</u>, it won't be a surprise!
- \* Create timeline showing them that the first night to be spent at my house, the 2nd night and onward at their new home at "The British Home"
- \* Repeatedly look at pictures and floorplans, but do enjoyable diversions like movies and outings
- \* Schedule car service for to airport and from airport to Home
- \* Have ice cream and sugar cones ready for last snack before car service to airport ride
- \* Buy 50" Plasma TV at Bestbuy and schedule installation
- \* Buy Recliner chairs (<u>"standing" recliner</u> for Mom, <u>LaZBoy</u> for Dad)
- \* Order cable TV
- \* Schedule sales/counselling house call by HMO / Medicare representative
- \* Enroll in HMO midmidMedicare plan
- \* Identify and schedule Dental appointments
- \* Schedule online DMV drivers license test and application for Dad and California ID for Mom (and register them to vote)
- \* Cancel homeowner's and auto insurance in Florida
- \* Cancel Phone and change address at Post Office
- \* Meet Movers and load boxes and extra furniture into my garage, then take their furniture to British Home

- \* Hang Pictures ASAP
- \* Save old family pictures in my spare room ("The Shrine") and bring them over for visits to browse through the memories.

I found The British Home in California for Mort and Marilou while touring several other communities found in guides and online. I stumbled on the British Home - it wasn't listed! Too small and mismanaged up until just before I discovered it! But what a find. I took location scouting pictures of the room which the administrator suggested might be barely big enough for a couple to fit into, and I measured it and used an online floorpan application (free) . Roomsketcher is simple to use, and I taught myself easily. <a href="https://www.roomsketcher.com/">https://www.roomsketcher.com/</a>.

When I got to Florida with my pictures, I sat down and laid out the floorpan for their lifestyle and printed out the floorpans (several variations) to reassure them that it would work out. Since we did a lot of "family camping," Mort and Marilou were well suited to prepare for a downsizing of living space. As elders get older, their world naturally gets smaller - they move less easily, so less distance to cover in the living space is a welcome thing. Moving my parents was pretty easy. I rented the room at the first of July and quickly put in the bed, TV set and desk and chairs, and then I flew to Florida to pack them up and move them out. Previously I had flown to Florida to show them the pictures and sketch the floorpans, list their mobile home for sale, and hire the movers and the company that moved their car on a car carrier. When I came back to move them, all the appointments for the movers and car mover were in place, and in a matter of a few days, I had them packed up and ready to travel. I had the refrigerator empty and only Ice cream and cones were on hand for snacks when we loaded up into the cab I'd hired to take us to the airport. There was a car service ready to take us to my house upon arrival in Los Angeles. From there I transferred everything into my car and we drove immediately to the British Home by way of a pizza parlor for lunch. We met the administrator and they signed paperwork and then went to their room to settle in. There was no looking back.

#### THRIFT STORES

When Mort and Marilou agreed to let me relocated them to Southern California from the Tampa Bay Area of Florida, I set about downsizing their possessions.

I went to the movers and bought large cardboard boxes. Then I started playing a game of show and tell - I'd show them something and ask them - "Goodwill or Moving Van?" I took the stuff to Goodwill that they were ready to part with and packed the stuff that they weren't. When we got moved into the British Home, there was a Queen sized Tempurpedic mattress and platform with sheets and pillows waiting for them. I had also purchased at the thrift store a desk and chair for Marilou, and I'd bought from another thrift store a "standing" Lazboy recliner for Mort. (Lucky find - it had been on the floor for ONE DAY when I found it!). The rest of their stuff was in the moving van taking the slow 10 day trip west (the movers bundled several families into one van, so it takes a while to get it full and then on the road). I picked up lamps and other stuff to make them comfortable from the thrift store, too. Marilou

wasn't comfortable with the first couple of chairs I got for her desk - she's got osteoporosis, so its important to find the right "fit" for her. I just kept haunting the thrift stores until I found the right swivel desk chair for her. Later, the swivel chair became too unstable for her, so I switched to a a lightweight armchair - like a dining room chair. Always from a thrift store. When the King sized tempurpedic mattress and platform arrived, I took the Queen sized bed home and absorbed it into my house's furnishings. Many of the stuff they thought they wanted to keep, however came out of the moving van and went straight to the thrift store as donations, since their space was limited. Back in Florida, I also used the thrift stores as sources of used large suitcases to pack up my parents' clothes to cover the several weeks we'd be waiting for the moving van to arrive. Later I donated those suitcases back to thrift stores in California.

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## THE END OF THE BEGINNING

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## SENIOR LIVING COMMUNITY

Finding the place: I am a location scout / location manager in Hollywood, so when I set out to find a place for them, I used those skills. I not only used the guide books for senior living communities, but once I saw one or two in Arcadia, CA, I drove around to see what the shopping, doctors offices, etc. proximities were like. In doing so I stumbled on a small place that, at that time, wasn't in any of the guidebooks! It was fun by a women's charity - The Daughters of the British Empire, and it was called "The British Home in California." The original DBE British Home is in New York, where wealthy British Doctors' wives teamed up to "do something for the nannies." (Nannies, when they aged out of their jobs, were left penniless and homeless, since they were paid with room and board in the 19th century. They couldn't even afford a ship ticket to go back to England or Ireland where their families might be willing to care

for them. So the British Home was formed. I found it to be a perfect fit for my parents.

After 6 years of living independently in The British Home (an en-suite room with meals provided in a community dining room - no Assisted Living services to help with the tasks of daily living), Mort bumped his head in a fall, recovered, but got an in-dwelling catheter, and then needed to live with close supervision, so I brought him home to my house, and 6 months later, Marilou joined him there (she was getting frailer, too, and although she benefits from a community setting, the costs compelled me to consolidate their care to my house).

Mort died 15 months after moving in, and three months later I moved Marilou to another (even closer) senior community, Pasadena Highlands, where I spend most days hanging out being her companion and entertainment directorshe has a "pendant" with a button she can push for help when I'm not there, and the meals are prepared daily, with a good dining room experience for her to mingle with other residents.

But I've found that my presence makes her quality of life excellent, and otherwise, like most all of the other residents, her time would be spent entirely alone. For most of them, they can socialize, but Marilou is largely deaf, and quite frail, so I've concluded that my commitment to being there for her is worthwhile. After 13 months at Pasadena Highlands on an assisted living floor, but without needing to use their caregivers' aid (and pay for it on a tiered system based on the amount of time the caregivers give direct personal service), I hired the caregiver who took care of Mort at my house to come to this

place for 7 hours a day to have a constant "lifeguard" on Marilou, and I work the morning and evening shifts.

#### HEMP OIL AND CBD

Let's talk about CBD Marilou has restless leg syndrome, which plagued her for years. It manifests itself by causing spasms in her whole body after she goes to bed, usually within the first half-hour. I never really understood why, and they didn't have much to give her for it but Carbidopa, which is basically an anti Parkinson's Med and has lousy side effects. So she was taken off of that few years ago, and I experimented by buying CBD THC oil in a three to one ratio, and it was like a Eureka moment. It completely cured it and helped knock her out to go to sleep soundly. So we have a bedtime ritual where I administer the vapor pen. And she does 3 tokes before going to bed and it seems to have cleared up all restless leg syndrome. It may be good to couple this with an over-the-counter medication that helps sleep called melatonin. And I administer that also in a double dose (10mg) to Marilou at night. She really sleeps deeply for about 9 to 10 hours. Although she does get up to pee every three hours or so, but that's a fact of life for most of us after 50 anyway, but she does get her rest and this restless leg syndrome doesn't torment her. I buy it at the marijuana store for \$50/ capsule that screws onto the Battery pen and it lasts for quite a while, because she only does two or three puffs. I put water by her bed with thickener in it and refresh her water daily, and it's good to have a couple of sips of water in between puffs of the CBD THC, because it does irritate the throat somewhat.

Marilou has had "restless leg syndrome" for years. In Florida she self-medicated by taking a quarter tablet of a sleep medication called <u>Ambien</u> (!) and taking it with a serving of Ice cream with Bailey's Irish cream drizzled over it. But eventually, she started exhibiting side effects - 'sleep-eating' - being awake (seemingly) and half eating and half "wearing" her food (only getting half a spoonful in her mouth at a time). It freaked out Mort, and I arrived on one of my frequent vacations shortly after the onset of these symptoms, so I took her to the hospital for evaluation. They ruled out stroke and her principal physician remembered an old Ambien prescription, which she was stretching by splitting the pills into quarters.

Once the Ambien was ceased, and then the move to California shortly thereafter, she was tormented by restless leg syndrome, so they prescribed <u>Carbidopa levodopa</u>,

Carbidopa is for Parkinsons, and it is used for restless leg syndrome, lacking any other reasonable alternative, I guess. It has side effects for some, including confusion, tiredness, headaches, swelling in arms or legs, dizziness, dry mouth, sleepiness, etc. I ceased this med for her and started her on THC/CBD 3:1 vaporizer - about 5 puffs a night before bedtime, and it seems to have completely cured her symptoms! When it ran out once and she did without, the symptoms returned instantly, so whether this is a placebo effect or a real effect, it sort of doesn't matter - she sleeps much more soundly now without being woken up (usually in the first few hours) by Restless Leg syndrome.

# WHITE BOARDS, GRABBERS, COMPRESSION SOCKS

My friend Joan Grossman gets the credit for suggesting I get a couple of white boards with erasable pens - one for the bedroom and one by her eating station in the living room of her apartment at the Pasadena Highlands because I've noticed that on the occasion when I'm late arriving, she gets anxious. So by seeing the message from me from the night before that I'll be arriving late that morning, she gets an instant update. I put the date and the day of the week on the Whiteboard and what time I'm going to be arriving so that when she wakes up she can read it and be reassured. She does lose track of what day it is. So this is helpful for that too. Otherwise, she always looks at the newspaper to decide whether she knows what day it is or not. These white boards can also be good for putting down some future appointments like upcoming dentist appointments, Etc, so that they can begin to look forward to them, and there isn't as much surprise and anxiety when you spring it on them that "today's the day they're going in for that root canal."

GRABBERS - These - 32" Grabber Reacher 2-Pack | Magnetic Tip Helps Pick Up Small Objects | Fitted with Post to Assist with Dressing | Mobility Aid Reaching Assist Tool, Arm Extension (32-inch) - are about the best. I bought two so there's one in the bedroom near clothes and one in the "cockpit" for dropped or out of reach items. The "post" is cool 'cause it holds open socks for pulling on (this is an acquired skill, but encourage them to practice. It is a good grabber.

COMPRESSION STOCKINGS - I think pretty much all of these elders need these. Swelling in the ankles is super common, and so you should have them wear these all the time AND encourage them to elevate their legs when seated. I like these new "copper fit" kind are easier to put on and off and work just fine.

# **HEARING AIDS - COSTCO**

You can't beat the deal on hearing aids from Costco. Here is a review from someone that mentions tons of detail, but I'll just share a few tidbits. First, both my folks got sets of hearing aids at Costco shortly after arriving in Southern California, and I was very pleased with the price and performance, after doing some basic comparison shopping with other audiology sources locally. Eventually, Marilou was getting too deaf to get much out of hers, so after Mort died I scheduled her for another appointment and the opinion was to get her the more expensive "turbo" hearing aids that also required a mold of her ears for the earpieces. They were more expensive, but it had been about 6 years since the first set was purchased, so whatever. When we got them home and started using them, it became clear that Marilou was uncomfortable putting them in (she could do the old style okay, but couldn't manage the coordination required to twist the new molded earpieces into her ear. I had to do it for her), and also, frankly, her hearing was not benefitting from the new aids. They amplified, sure, but her problem was that clarity was permanently gone. Costco has a generous policy that allows you to try out the hearing aids for, like, 3 months or something and then return them for a full refund no questions asked. Just can't be beat. We returned hers and got the thousands of dollars back and went back to using her old ones (when she'll wear them). Since discovering the new Google app called "Live Transcribe" for our android devices, we have an

enhanced ability to communicate which makes her hearing aids no longer really necessary!

# INTERNET AND FACETIME, EMAIL, FACEBOOK, Etc.

I'll be blunt. My parents, while really really smart and without an ounce of dementia, just were too much of <u>luddites</u> to be successfully converted into the 21st century as users of personal computers, smart phones or any of the applications (<u>apps</u>) that <u>might have made their lives more stimulated</u>. I got them cellphones (simple ones) in Florida a couple of years before they moved to Southern California. They never used them once. The little buttons, their eyes (cataract surgery notwithstanding), — they just never took to them (and this was before smart phones).

I have friends whose folks became power users of their phones and computers, but no matter how I tried — <u>tablets</u>, even — they just had no interest in trying them. That's why I am so thrilled to have "<u>live transcribe</u>" now - I can set up a tablet and turn it on and prop it up and it automatically transcribes whatever is spoken in the room. Marilou doesn't have to touch it. The font size is changeable and you can even save the transcriptions on the web for 3 days and refer to them later, copy and paste them into emails or documents, etc.

I personally found <u>Facebook to be really handy for sharing</u> <u>pictures and news about them</u> easily with family members back East, and several of my FB friends also enjoy keeping up with my posts about them.

## LETTERS, CARDS, POSTAGE ADDRESS BOOKS

Marilou is an avid correspondent with family and friends via snail mail. Her address book, kept for years, is very important, and I'm diligent to make sure that I know where she stashes it, as that is her habit - sometimes <u>putting it in her walker</u>, sometimes under some papers on a shelf next to her, sometimes over by a chair where she writes letters. I also know that she likes the <u>American Flag postage stamps</u> which fortunately are the default ones that the machines at the post office print out and vend, so I can always buy them without standing in line. She's a real patriot and likes displaying the flag at patriotic holidays, and we have a little one in the apartment that is kept in a prominent spot where she can see it easily.

# CAR TRUNK: FOLDING WHEELCHAIR, FOLDING WALKER

The trunk of my car has a <u>portable wheelchair</u>, a <u>folding walker</u> (tennis balls on the rear feet - we don't use it anymore, but it was handy to use when going to restaurants, etc. so that their <u>bulky walkers</u> could be left at home. I would always use a wheelchair to transport my folks to the car and then fold it up and put it in the trunk after getting them loaded in the passenger seat when taking them to appointments or outings.

#### DIGITAL PICTURE FRAMES

These digital picture frames are neat. They only cost about 40 bucks and you can transfer tons of family pictures onto them via USB. Both of my folks really enjoyed seeing the slide show of all their memories. I varied the duration - but never less than 30 seconds. They seemed to respond best to the 10 minute durations, as they would bring up memories in conversation more readily when I changed the duration to the longer period.

# EMPATHY, MENTAL TOUGHNESS, COPING STRATEGIES, AND ENJOYING THE ROLE

This is an important section of my sharing - When I realized that the time had arrived when my Dad was not able to stay independent with Marilou in Florida much longer, by virtue of his actively shopping for a senior living community there and sharing with me that he was too anxious about Marilou's personal safety from falling/fainting and his inability to "catch her or pick her up" without assistance, I fairly quickly had to make a decision: Either a) assist him in shopping for a supportive community there in Florida and essentially abdicate myself from any day to day role in their continued survival - or - b) step up and offer to find a senior living community near me in Southern California and thereby commit to a time-consuming day to day role in their lives.

It's psychologically daunting to be in this position, so I knew that if I was going to survive the commitment I was about to

make, I had to give myself a mindset that was going to be agreeable and enjoyable for all concerned. I decided that a way to do that was to use my show business background and "play to my strengths:" I'm a location scout / manager and my main job is to "sell intrusion" to unsuspecting location owners or to quickly check availability for intrusion with established location owners. It's a salesman's job, essentially - I have to be "jovial under pressure," and not take no for an answer - "close the deal." It becomes a "character" that I play - a very empathetic but insistent nerd with a heart of gold who only wants to make them richer and happier while getting myself out of the trouble I'm finding myself in — needing desperately to find a location to rent to bring a large crew to for filming one project or another.

Mort and Marilou were clear about NOT wanting me to feel obligated to devote myself to such an extreme degree — they were willing to "go it alone" in Florida, as they had been for 22 years, but I quickly disabused them of that notion and "sold" them on my happiness to a) not have to worry about them, b) to not have to stay in hotels when visiting them, and c) to not having to wonder how they were doing every day. In so doing, I was ALSO selling MYSELF on this truth. I knew that I was signing up, potentially, to a lot of anxiety, but I also knew that if I stayed "in character-" the happy, over-compensating, absentminded professor son — the list-making, deal-closing, forwardmoving, over-organized fussy but funny guy who was determined to make them feel reassured, less anxious about the future, and listened to — I'd SUCCEED at the task at hand (in both the short and long run) and that I could have faith in my ability to make myself happy for having made the commitment.

I also had the personal circumstances present that sort of 'cornered me' into stepping up: I wasn't in a relationship, so there was nobody else depending on me on a full time basis. I had barely enough money saved, and my career was slowing to a point that I kind of couldn't afford NOT to step up, or I'd run the risk of regretting that I DIDN'T do so for an honest, compelling reason. It was an "Aw shucks, I'm 'all in" moment.

And for 8 years and counting, I have pretty much stayed "in character." During my work life, my character had to be more impatient, efficient, relentless and "not suffering fools gladly" as an <u>Assistant Director in Television</u>. I was a very effective Key <u>2nd AD</u> - running a shooting set with a First AD and Key Crew Members and getting a lot of work done in a hurry. Taking on eldercare is all about being patient, flexible, careful, attentive, calm, sweet and forgiving.

Now, I am fortunate that my parents are/were intelligent, kind, funny and sweet people in their own right. My upbringing was not characterized by the kinds of pathologies I hear about from others, so I was quite clear-headed about my feelings of obligation and gratitude that accompanied my personal courage to step up and grow up/into this role.

Make no mistake: if you become a caregiver, you WILL get frustrated and impatient. This is why I think it's important to have strapped on a fun and invigorating "character" to role-play within in all circumstances — one that is true to your inner nature, but one that is certainly a moment by moment conscious

pretense that masks your feelings of frustration and impatience. Remember - you don't have to answer to these people or prove anything to them anymore. That was when you were a kid. Now, your role is to be supportive, nurturing, reassuring and kind. You might feel momentarily "put upon," angry, and rebellious (those are familiar reactions that you got to exercise a LOT when you were a teenager, but just because they are easy habits to fall back into - they aren't helpful), but by staying "in character," you can fulfill your noble role on this new stage - a smaller and more compact stage.

For their worlds have become momentously smaller as they have become geriatric - they play more feeble and vulnerable roles on this smaller stage, and they will certainly stay "in character," even as you might "go up" on your lines and improvise awkwardly, employing old habits that exhibit sharp edges. Don't worry. It's just "family stuff," and they understand that. They watched you try on ALL your roles from infancy onward. When you regain your new nurturing character, you both can go back to running through your mutually healthy "routines" and enjoy this latter-day "Vaudeville" era of your time together.

## **BEDS**

When I brought Mort home with his catheter for Fathers Day 2017, and when Marilou moved from Independent Living into Assisted Living at The British Home in California, I availed myself of the convenience and value offered by the Convalescent Aid Society in Pasadena. They offer free loans of

mobility aids, hospital beds, bedside commodes, and other stuff for the elderly. I borrowed hospital beds for both of them. They are single rail beds only in Assisted Living Facilities (only a rail allowed on one side only - by regulation in California to avoid entrapment \*). When Mort was disoriented and getting used to his catheter, the bed was pushed against a wall and the rail was used to prevent him from "sleep walking" (trying to get out of bed to go to the bathroom - his sense of urgent need to go haunted him). Later, as he calmed down, I lowered the rail. Usually it is best to have the bed accessible on both sides to facilitate making the bed.

## \* Entrapment Zones

The FDA guidance characterizes the head, neck, and chest as key body parts at risk of entrapment. It also identifies these seven potential "zones of entrapment" in hospital beds:

- 1. within the rail
- 2. under the rail, between the rail supports or next to a single rail support
- 3. between the rail and the mattress
- 4. between the rail, at the ends of the rail
- 5. between split bed rails
- 6. between the end of the rail and the side edge of the head or foot board
- 7. between the head or foot board and the mattress end Rachlin says that proper fitting rails can be useful. However, health care professionals and patients need to assess whether rails are necessary in each instance. "In addition to entrapment, there are other potential hazards associated with bed rail use,

including serious injuries from falls when patients climb over rails, and having patients feel isolated or unnecessarily restricted," he says.

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## Mental stimulation

Mort was an avid NY Times Crossword puzzle completer right up until about age 86. He was an avid reader until about age 88. By then his eyes weren't cooperating very well with reading, despite having had the cataracts surgery around Age 84. I got them cable TV package with HBO premium channels from the beginning of their time in California, and I taught my Dad how to use the remote control, although they both were pretty well versed with remote controls from their retirement years in Florida. But I noticed that they needed to brush up on remote control instructions frequently, even from age 86 onward. I would review the simple stuff and not over complicate the options the remote had. I typed up a large guide to the favorite channels with their numbers and taught them how to punch in the numbers while aiming the remote at the TV (the aiming part was important - they habitually wouldn't do that very well, and then they'd get frustrated and just stop trying to use the remote. If you catch them giving up on something, or just not doing something they used to do, be sure to review it with them and not assume they've lost interest. It's. More likely that their frustration has gotten the better of them.

Marilou loved and still loves to write letters to her friends. I keep a supply of stamps on hand and help her find her address book, which she misplaces easily. Their worlds get very small in their assisted living rooms/apartments, and it is easy to assume that they are okay with that. But truthfully, in my opinion, they naturally start to "shut down" mentally out of simple frustration with something so banal as not finding the stamps the moment they reach out for them, and then get a little "mini-depression" that distracts them from trying, and then their natural fatigue will kick in, and they just sit around. I like to continuously re-arrange the desktop around my Mom and present things, magazines, articles, her address book, the stamps,

the pens, etc. so she knows I'm trying to make sure she knows where they are, and then she kicks in and starts writing or reading or re-arranging things herself. As for Mort, I would look at his crossword puzzles and compliment him on finishing them, and marvel at how hard they were, etc. He'd get a kick out of that and take pride in trying to complete them every day, even when it got too hard. I'd make sure he had the puzzle in the same place every day. Making up routines - defining them for them, then adjusting them on purpose for no good reason, then re-defining the routines again, as if it was the first time....all kinds of little routines - where food is stored, their dresser drawers - putting away clothes, folding clothes for them but asking them "is this the way you like your shorts folded," just anything that feels like a reliable routine that they can be interested in and then rely on (even if they are going to forget it shortly, which, of course, is what is going to happen!), are good habits to fall into. It keeps them mentally stimulated and interested in their "smaller" worlds - BECAUSE YOU ARE INTERESTED IN MAKING THEIR SMALLER WORLDS INTERESTING! It's all just a game, but without the game, there is just "warehousing" tired old bodies and shut-down minds. There is dignity in taking care of old folks, and a nobility in doing it, but only if you are working at making them smile. Otherwise, its just a duty, and chores.

## **SKIN**

As they age, you begin to see the emergence of <u>"age spots,"</u> large dark discolorations on the skin - they appear in abundance on the arms, hands, and also on the chest, legs and back to a lesser degree - but more and more as advancing age takes place.

They appear on the face to a lesser degree. Both of them asked me to buy <u>flesh colored cover-stick</u> makeup to apply over the spots on the face and neck, especially my Dad. Eventually Marilou accepted that there was just too much discoloration to try to cover and she accepted her aging more. They don't like to see the shocking appearance of dark blotches in the mirror.

I bought a bunch of stuff for wound care to keep on hand - gauze, tape, bandages, Neosporin, large bandages, etc. I also found this great product, tubular elastic retention netting. This stuff is great! It holds gauze pads over cuts and abrasions so you don't have to use tons of tape (which is no fun on their old, papery skin — high tack tape can even tear their skin when its taken off). I also use it on Marilou's forearm to protect her skin from her wristwatch (which she loves - it's an oldie with a metal springy band. I also keep a lot of moisturizer of several types around. I apply it liberally to Marilou's back at bedtime a couple nights a week (and used to do this for Mort, too).

DERMATOLOGIST VISITS - FREEZING OFF THE SPOTS Mort and Marilou were both redheads in the generation prior to sunblock lotion's invention, so they sunburned a lot as kids. Later in life, skin cancers began to emerge like clockwork. They dutifully visited dermatologists in Florida, and I kept up with those regular appointments in California. Some of their cancers required "Mohs" surgery (an out-patient surgical procedure where the top layer of the skin is carved off and the patches of skin sent to the lab while they wait in the chair - the patches are

analyzed for cancer cells and the edges should be cancer-free, of the doctor comes in and carves away some more until he/she has gotten all the exposed cancer on the surface of the skin. The doctor then stitches up the wound and those areas heal slowly, and I was watchful to make sure that no infections appeared on them. Smaller cancers can be treated with liquid nitrogen and burned off, causing little scars to appear, which fall off. Vaseline was recommended as the best thing to put on their old, thin skin. I liked to apply gobs of it and did so for both of them. I didn't count on them doing it themselves, but over time, they got better about it. Its greasy and they don't like their favorite clothes to have to be put in the laundry so quickly, but I insisted for the health of their skin. I also made sure to change their sheets more often than I might have if they weren't old redheads with thin dry skin that required a lot of vaseline. All other lotions are not that helpful, but they liked them better, so I made sure they always had what they liked in their bathroom.

## **HYDRATION**

In assisted living facilities I believe that state law requires the caregivers there to check in on 30 minute intervals and make sure they are hydrated (have a glass of water beside them, kept full). I'm not 100% sure, but <u>Assisted Living facilities are definitely regulated</u> in California. At the British Home, the aides were pretty diligent to make sure the trash was emptied and that water was beside them.

I learned that despite having water beside them, they won't necessarily be good about DRINKING the water, because it makes them need to get up and pee, and that is work, and they

are tired and don't want to work! (at least in my Dad's case. He developed urinary retention problems which I wasn't really aware of until the last two years of his life). Once I was clued in, I started adding lemonade powder sometimes, hydration powder from Costco other times, to make the water palatable. Also for Marilou, adding thickener (honey consistency is better and more concentrated than nectar consistency. I mix it up with my favorite <u>blender</u> instantly and keep a pitcher in the fridge). Adding Ice on a regular basis is also a good practice. I lift up their glass often and regularly and offer it up to their mouth to make sure they take a drink. Marilou eventually developed a genuine taste for staying hydrated without needing reminding, which was great. Mort would not touch the water glass by himself and I and Natasha were in the habit of offering him a drink regularly. Despite a nasty dehydration episode, he was the type of elder that just sort of devolved back toward an infant / toddler mentality and was dependent on us for everything, dietwise. He would just sit there and watch TV and zone out all day. He still had his intellect, but he just didn't want to try to do or take an interest in anything other than watching his Blue Bloods episodes. Oh well. You learn to just accept them the way they present themselves as they age. The line that stuck with me was when Mort said, "I'm tired of being challenged. I just want to be supported." God bless him!

The best and typical cups are <u>large plastic cups with snap-on</u> <u>lids and large plastic straws</u>. I replace the plastic straws with <u>flexible silicone straws</u>. Marilou needs thickened liquid to avoid getting water in the airway, so I use <u>"Simply Thick,"</u> which was suggested to me by a friend whose wife was a sales rep. I like

the packets better than the pump bottle - the stuff doesn't spoil and the amount is pre-measured. I use two packets (honey consistency) in each 20 oz container with snap on lid and straw. I use a blender to mix for ease, but the new formula is "easy mix" and is much easier to get into suspension in the liquid. Marilou is very good about drinking her water ever since I introduced Simply Thick - it is the best product - better than starch-based thickeners, which have been around forever. This product is newer, within the last decade. "Dysphagia" is not a normal condition in aging, but you should get your elder checked for it if you suspect they aren't taking hydration willingly.

## **PEEING**

"It's a guy thing." Those were Natasha's memorable words, spoken when I met her on the porch of a Board and Care Home, which was on a list provided to me by the assigned Social Worker at Kaiser Permanente when Mort was hospitalized with the subdural hematoma in his head, incurred in a fall in his bathroom at the British Home. She was responding to my description of Mort's urinary challenges - he had bad <u>urinary retention</u> while in the hospital and rehab and was fitted with an indwelling foley catheter and collection bag, and he was very neurotic about just letting go and letting the catheter do it's job. He didn't want to wet himself and gave voice to his worries ad infinitum. Marilou, on the other hand, is very practical about her urinary issues. She coughs - she squirts. She sometimes "doesn't make it" to the bathroom in time. She gets up a lot at night to pee. So it goes. Natasha was generalizing about how

elderly men seem so much more concerned about their peeing than women. They can be real babies about it. And Mort was a big baby about a lot of "getting too damn old" stuff. He would rather lament about it than man up and cope. Every older personality is different, so you just have to adjust - there is no changing them. In my case, I made sure he had a caregiver by his side 24 hrs a day, 7 days a week. His catheter situation made it necessary in his case. He took getting it as a cue to enter an infantile phase of life. While Assisted Living Communities are precluded from allowing men with indwelling catheters from living there unless they are "self-regulating," meaning the men have to empty the collection bag into the toilet themselves (it's easy), Mort was never going to be one of those guys, and I knew it. He was in rehab for the 10-14 days after the 2 days in Neuro Intensive care at Kaiser from the bump on his head, and since the catheter was now a fact of life going forward (probably for the rest of his life was the prognosis - if they need one, they need one, and they'll continue to — in Mort's case, his Urologist finally recommended the "roto-rooter" surgery to open up his urethra and let him pee "like a 12 year old" again, because the monthly changes of the catheter were getting more and more problematic. He had a blockage where the prostate was in the way of the opening to the bladder. This was what caused his retention problems, but it got worse and the nurses weren't able to get past it with the rubber catheter tube, and the Urologist himself had to be called in every month at the appointment to use a "guide wire" to get past the blockage. After the 3rd month of that struggle, he suggested that Mort was stable enough to pass pre-op and get the surgery. He got it in June and was able to go to the bathroom with Natasha assisting him standing and

negotiating his walker and sitting him down, where he could go void. Mort was comfortable spending up to a half hour or more at a time on the toilet at this stage, and his neuroses about his personal toilet needs included over-reacting to every gas pain as a "need to go," so he'd get his exercise going to the toilet to fart and wait, usually to no avail. On the occasion he had a poop it was cause for great mutual celebration and he would be relaxed and content in his chair watching TV since he was so glad "to get that out of the way."

Marilou is like a lot of older women. They squirt, leak, whatever. Deal with it. Depends absorbent underwear with an added Poise Pad is her recipe. We also got absorbent adult briefs with tape tabs from the Hospice agency (for free!) and Marilou likes those better than Depends, because they are easier to put on (no struggling to pull them up). She'll pitch the Poise pads and keep wearing the shorts / briefs until the accident is too profound. Mort liked wearing Depends before he got the catheter, even though he would NEVER wet himself. He would demand the Depends, but he would writhe in bed clenching his bladder with retention rather than unclench even a little bit to let urine flow into his diaper... But he liked the security of knowing that he was wearing Depends because he imagined that he needed them to stay dry. Whatever. "It's a guy thing." Every old dude is different - you roll with their personalities and love them for being true to themselves - that's my philosophy. You're lucky to have them at this age (so many don't), so count your blessings.

Since Mort had a catheter, he didn't need (or want) a <u>bedside</u> <u>commode</u>. After his operation, I could have gotten him one, but he was so neurotic about going to the toilet that unless it was a real toilet, he wouldn't use it. (!) Marilou, on the other hand, ASKED (at age 91) for a commode at bedside when she knew she was ready. She has a righteous fear of falling, and with her being 93, with osteoporosis and on blood thinners - she knows it's cheap insurance against falling and likes the commode right beside the bed. If I had to do it over again, I'd push the commodes on them much earlier and "sell" them on the concept. Mort might have adapted to it and made all our lives easier if he had. Who knows?

## **POOPING**

I like <u>Senna</u>. It's gentle on them and easily administered - a small tablet (or you can get the syrup and put it in their food). I also like making sure there is a lot of fiber in their diet. I like canned pineapple for that - it tastes great and provides fiber. Constipation is common - especially because it accompanies the dehydration which is also common. (They hate to drink 'cause they hate to pee 'cause it's a lot of work to pee and they pee all the time and they're tired 'cause their old so they hate to drink....). Marilou kept <u>nitrile gloves</u> by the toilet and manually reached in and loosened hard stools herself. She did this all the time. I was freaked out at first upon learning she needed to do this, but heck, it's practical and gets the job done. Mort did the same sometimes, but his style was to sit and push and push and groan and groan until he produced. If that didn't work, he'd resort to using his fingers, wearing a glove.

Since keeping them hydrated was such a challenge, I coped by making sure there was Senna and fibre in the diet as much as possible, but still - it didn't always work. But once regularity could be re-established, it would hold for a while as long as they kept hydrated. SMOOTHIES are a great way to get this done. Protein, fiber, hydration - a good combo. I would nag them to drink the smoothie by saying "Hey, I made this for you fresh. It's my own recipe - custom made just for you. Please drink the smoothie - you make me feel proud and happy when you drink your smoothie....." - and on and on. I cop a character and make them smile and make them drink. It's a little ridiculous, but it works for me.

#### **SAFETY**

Walkers are cheap insurance against falling, and the sooner I could convince them to adopt them, the better. I started with the folding aluminum style, with tennis balls on the rear feet but quickly graduated to a Costco model with large wheels, hand brakes, a memory foam seat with a large storage compartment beneath. I sent the back rests to an Artist and had them "yarn bombed," a folk art that sprang out of a hybridization of Grafitti and crocheting. They came out amazingly great!

It's important to make sure they know how to use the walker safely. I always repeat, "lock it" and pantomime pushing the hand brake levers downward to illustrate. I'm diligent to make sure they always lock the brakes before letting go of the walker to transfer to holding on to other handholds.

In their rooms, I made sure to place furniture strategically so that they can tag in and out from handhold to handhold and walk to their destinations - chair, bed, bathroom, walker, etc. I am very big on saying "We do everything the same. No new ideas." What I mean is that they need to park the walker in the same place and use the same handholds to move around. I establish multiple parking places in the room for the walker so they can use the flat seat as a "wheelbarrow" to carry things around the room. At the beginning I make sure I'm watchful and consistent with coaching where to park the walker, how to place things on the walker, which handholds to use. Even if they get irritated and impatient and rebellious, I just say the same things, "in character" (the slightly anxious, sort of absent-minded, wellintentioned loving son character, that is), "Always lock it, for safety." "We don't carry stuff in our handg s - we put them on the walker, unlock it, and take them safely where we want to go." It becomes an inside joke, this character. They just roll their eyes, but they comply, which is the point. I want them to establish safe practices that will become 2nd nature (hopefully) even when I'm not around.

There has to be a handrail by the toilet, number 1. <u>I bought</u> mine at Target. This item is genius. Marilou likes to stand up after going Number 2 and then do all her cleaning up in a football crouch, so this item provides grab bars on both sides of her, and it has a place for her newspaper, even! Only \$40.

I also use the metal foil tape to tape down the bathroom rugs. You can get a standard three-piece bath rug sets from Walmart. I taped all three together on the edges and to the floor so that the entire area from the toilet to in front of the sink is one secured rug. I made sure Marilou saw how easy it was to BRING THE WALKER INTO THE BATHROOM and park it in front of the bathtub opposite the toilet, lock it, and then transfer her grab bar from the locked walker to the stand-alone grab bar next to the toilet. From there, she can sit down, loosen her pants, stand back up, lower her pants, underwear, and then sit back down and commence the process. BUT IT TAKES REHEARSING! I compelled her to do the whole process in front of me (right up to lowering her pants) from outside the bathroom door - bringing the walker in, parking, locking, etc.

And like all the other routines, she deviates and I catch her leaving the walker outside the bathroom door and creeping in without it. Sometimes she feels like she won't "make it" to the toilet in time if she takes the walker all the way in. I don't accept that, though, and try to gently apply an "elderscold" to remind her logically that "there's a little too much risk involved in NOT taking the walker into the bathroom, for the distance from the walker to the grab bar stand is just a little too far, and you might fall." If she leaves the walker outside, I just bring it in for her and interrupt her "process" - it's a quick moment and then I shut the door behind me. She gets it. I really mean it. The walker has to come inside. Period. (We use a more nimble 3-wheeled walker inside and take the 4 wheeled walker with the seat for longer walks when she might need to take a break and sit down.

Another tip I found and adopted was to supply them with "gripper" socks like they give you at the hospital. Cheap insurance against falls when they don't have shoes on. It's best to get their shoes on though, right away upon rising. They need the consistency of using their abilities to stay upright under the same and safe conditions all the time. Otherwise, they will trip on their shoes more easily if they get in the habit of walking without them. I say get rid of slippers, but supply them with two different pairs of good shoes for walking, with one of them being New Balance Sneakers and the other a decent leather upper, rubber soled comfortable lighter weight shoe.

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## **EYE DOCTORS**

I had my parents checked for new glasses every two years or so, and I had their bifocals made with the hard line - not progressives. Better for reading and distance once they got used to it. They both got tired easily and complained about not seeing as well as they used to, but I just keep reassuring them that their prescriptions are up to date. I also regularly clean their glasses. Both of them got new lenses due to cataracts in their early to mid 80s. Kaiser did the surgeries and the cost was \$250

to us per surgery. They do one eye at a time, with a gap of time in between surgeries.

STANDING CHAIRS / STANDING RECLINER CHAIRS LaZboy makes a line of "lift recliners," which has an electric motor that raises and lowers it into a reclining position. I bought two of them - one for each of them, but Marilou couldn't use hers due to arthritis - it put her in an uncomfortable position that was painful - she thrives in a simple dining room chair with arm rests to hold on to getting up and down. So I adopted her lift recliner several years ago and maintained my own throne in their midst. I love my power lift recliner! I added a seat pillow and a coverlet over the back rest. I take naps in it and spend hours upon hours in it being a quiet companion to Marilou in her room at Pasadena Highlands while she eats (an all day process), reads the paper, and watches TV. We have internet with our cable tv package, and so I get my work done doing location scouting photos uploading, file pulling, website building, etc. Having a comfortable recliner with space to set my laptop and a kitchenette a few steps away has made for a comfortable "preretirement" Live/work space. Marilou is deaf, largely, so we don't spend much time talking to each other, but she loves having me next to her, and I derive a lot of meaning out of my time spent being her caregiver/companion.

As for purchasing one of these babies, I suggest using craigslist or offerup. New, they are pricey.

People often buy these for their elderly relatives near the end of their lives, and it is not uncommon that the person dies shortly after acquisition. They often are happy to sell the chair for a deep discount to get the estate liquidated and get the chair out of the way. The back detaches from the seat, so if fits into a cheap U-haul pick up truck or any van. I got mine for \$400 and \$250 respectively. I have had to replace the hand controller on one of them (bought it on eBay), but otherwise, they are pretty bullet proof. I put casters on one of them to make moving it around easier.

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## THE END OF THE MIDDLE

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A TRANSCRIPTION OF AN "ELDER-SCOLD" - What is an "Elder-scold?" It is a gentle tune-up with some firmness - only used on issues of personal safety. This one was to my Mom on

the reason why she can't use the bathroom un-observed any longer............
(Dictated into Google app "Live Transcribe")

"I think you misunderstand. The whole idea of hiring Natasha from 1:00 to 8:00 pm - is so that when you go into the bathroom.... you can shoo her away for privacy... but I want her to know when you're getting up from the toilet, because that little Crouch that you go into is unstable. And when the day comes where that doesn't succeed for you and you're alone in here, you're going to teeter back and crash either backwards or forwards. So the whole idea is that she peeks at you while you're doing that and if you start to Go over Backwards or sideways she's there to catch you. So yeah, it's great that you can do everything by yourself in the bathroom. But when you get up from the toilet and kind of look like a football player and are working on yourself with both hands off of The Walker...... That's an unstable time..... I don't mind that you don't want her to help you then... but I got to have her watching you through a crack in the door so that she could catch you in case you lose your balance.. You know if your left leg decides on its own to go out then, well, you know you're getting older, and I can't even have one fall. We got close last Sunday night, right? You almost keeled over! No Falls! So that's why she's been hired. But it's a waste of money if you chase her out of the bathroom and shut the door and then you end up falling. I'll feel like an idiot for spending all the money and then you break your hip anyway, because you shoo her out of the bathroom. So I'm telling her that if you shoo her out of the bathroom, I'm making the rules— The Door has to be partly open and she has to watch you. She's a

professional. She's a woman. Your privacy is shared with Natasha not "Complete privacy" any longer, All right?"

#### FALLS AND THE URINARY SYSTEM

A quote from a study on frequent urination and it's association with fall risk:

"The mechanistic inference is that these symptoms may force abrupt, unexpected alterations of daily physical routines and compel affected individuals to engage in potentially risky behaviors, such as arising several times a night to urinate. Thus, if this association is confirmed, urinary symptoms may be a potential target for preventive interventions to reduce fall risk in community dwelling men and women."

My translation: "They need to pee a lot and often, and when that's the case, they make sudden moves toward the toilet, awaken in the middle of the night too often and stagger out of bed to go to the bathroom — all this adds up to increased fall risk for sure."

My take on how to deal with this:

1) Put a <u>commode by the bed</u>. Tell them it's "cheap insurance" against falling. Tell them it's no problem for you to clean it, and you welcome them to use it a lot- it gives you peace of mind. And they want you to have peace of mind, right? To clean it, just remove the bucket, dump it into the toilet, flush the toilet, put the lid back down, hold the collector under the bathtub spigot and fill it a tiny bit, turn off the tub, swirl the collector and dump it in the toilet, then put the collector bucket on the

floor in the bathtub, squeeze some liquid soap from a reused shampoo dispenser on the corner of the tub into the bucket, fill the bucket to overflowing, dump 1/2 the liquid out of the bucket, and then put the bucket back on the commode. That simple - and you don't have to smell or touch very much at all, and there's clean soapy liquid in the commode bucket to receive the next deposit(s).

2) Make sure they do the same thing over and over to get to the bathroom - use the same hand holds, look down at their feet, pick up their feet, and don't rush. Rehearse this with them using your "corny too-earnest worry-wart kid trying to make a meaningful difference in their lives" character. They will appreciate the attention and it will sink in that you are making sense when you say, "You'll be groggy, only half awake, so you won't be able to think about what you are doing. If you do it the same way every time, your body will remember the safe way for you to get to the bathroom.... let's rehearse it again. Please! Indulge me! I'm only doing this because I love you and don't want you to fall down." (I was an assistant director in episodic television and had to prepare important "call sheets" under highly sleep-deprived conditions. These documents called all the people and elements together for the next day's work and there was 0 tolerance for mistakes on them - or some person or important prop would not show up if they/it were missing from the callsheet, so I developed repetitious routines for preparing the callsheet that guaranteed accuracy even if I was delirious from lack of sleep. That's why I use the same philosophy for grooving them into repeated patterns of behavior that might save them from injury). They have to be able to use the commode or

get to the bathroom "in their sleep," after all. Since I'm from show business, I'm a firm believer in REHEARSE REHEARSE REHEARSE REHEARSE. And RECAP RECAP RECAP, too: Every week or so I like to "re-cap" with them the things we have set up as safe and healthy routines - such as, Going to bed: (putting the walker in the same spot, the hearing aids in the same spot, where the water will always be beside the bed, the TV sleep timer on the Golf channel for 60 minutes to put them to sleep, turning the thermostat down for cooler sleeping temperatures, etc. By recap'ing they will be reminded of the reliability of the routine and it's component parts, and heck, often they will let you know about an improvement in the routine that they need and had thought about earlier but forgot to tell you! Re-cap'ing and rehearsing are super valuable habits to fall into.

# OTHER QUOTES ABOUT FALLING FROM THE MEDICAL STUDY:

"One-third of adults over age 65 fall each year. Unfortunately, fewer than half of these people discuss falling with their health care providers. Among older adults, falls are the leading cause of both fatal and nonfatal injuries. In 2013, 2.5 million nonfatal falls among older adults were treated in emergency departments and more than 734,000 of these patients required hospitalization. In 2012, the direct medical costs of falls in the United States were \$30 billion when adjusted for inflation. Falls are the leading cause of injury-related visits to emergency departments in the United States, as well as the primary etiology of accidental deaths in people over age 65.4,5 The mortality rate for falls increases dramatically with age in both sexes and in all

racial and ethnic groups, with falls accounting for 70% of accidental deaths in people aged 75 years and older.4,5 Falls can be indicators of declining health and deteriorating motor function, and they are associated with significant morbidity. More than 90% of hip fractures occur as a result of falls, with most of these fractures occurring in people over age 70 years.4,5 One-third of community-dwelling elderly persons, and 60% of nursing home residents, fall each year. 5 From 1992 through 1995, 147 million injury-related visits were made to emergency departments in the United States. 6 Falls were the leading cause of external injury, accounting for 24% of these visits. 6 Emergency department visits related to falls are most common in children under age 5 years and in adults over age 65 years. Compared with children, elderly persons who fall are 10 times more likely to be hospitalized and 8 times more likely to die as the result of a fall.7

Trauma is the fifth leading cause of death in persons older than age 65 years, 4,5 and falls are responsible for 70% of accidental deaths in persons age 75 years and older. 4,5 The elderly, who represent 12% of the population, account for 75% of deaths from falls. 4,5 Annually, 1800 falls directly result in death. 8 Approximately 9500 deaths in older Americans are associated with falls each year. 9"

## **URINARY TRACT INFECTIONS:**

The above quote about falls illustrates again, as mentioned earlier, that old folks are FALL RISKS - it's a matter of degree, but they all are. My Mom got a UTI several years ago and it snuck up on her (symptoms don't show up immediately, but

when they do, the infection is in full bloom and collapsing/fainting is not uncommon), and she fainted. Nothing got broken, but because she was on blood thinners, the protocol at the British Home was that such a resident who faints and is on blood thinners is no longer allowed to be in "Independent Living" but must be in "Assisted Living" if they are to be allowed to continue to reside there. I had to split them up and Marilou had to go to the assisted living cottage, and I moved Mort down the hill to the Independent Living Cottage next door to hers. So one Urinary tract infection that snuck in compelled the big unfortunate change in lifestyle of having to separate them. If I had know more earlier, I'd have been regularly getting her tested for UTI's so that they could be attacked before they caused the weakening that can be severe.

Avoid urinary tract infections. Here's an apocryphal observation: I have had ten "trigger finger" surgeries over the years, and so I've become pretty friendly with my orthopedic surgeon. I was sharing with him my stories of my Dad falling in the bathroom and how I was taking care of him and Marilou, and I mentioned that she had a UTI at the British Home and lost consciousness, though didn't injure herself in the fall, fortunately. He told me that in his time as an orthopedic surgeon, he's seen a LOT of over 90-year olds come to his operating room with bone breaks from falls, and he said, "You know, I've NEVER seen one of these 90+ year old patients show up at the emergency room with a bone break without also having an accompanying urinary tract infection. We both agreed that it seems like it goes hand in hand: UTI's sneak up on them (they don't show symptoms until they are advanced), and when they

weaken from the UTI's, they tend to faint, fall and often break something.

Encourage them to wear <u>Depends</u> to bed. That way, when they wake up to go to the bathroom, if they practice NOT RUSHING, there may be occasions when they don't "make it in time" and wet their pants. If they are wearing Depends, no harm - no foul. They just pull them off at the toilet and throw them away. Keep a supply of Depends near their bedside (bedside table drawer, for example) as well as beside the toilet (under the sink, or in the cabinet next to the toilet, for example).

Guys might be funny about Depends, but as time goes by, they'll appreciate how they work and keep them dry when accidents happen.

#### **BUMPED HEADS AND REHAB:**

6 months after Marilou's UTI, her fainting, and her having to be relocated to the Assisted Living cottage at The British Home, Mort fell in his bathroom, and there was an accompanying dehydration episode that settled it: we all agreed he was ready for assisted living, so he moved into the room next door to hers in the assisted living cottage. It was a nice arrangement until a few months later he fell again in his bathroom and hit his head. He was fine in the morning when they found him on the floor, but after breakfast he became confused and started talking funny, so From there I took him to the hospital (they wanted to call an ambulance, but those are expensive and I agreed to take him myself — I really suggest not using ambulances, and you should put your foot down and insist on taking them yourself, if possible. If you have power of attorney, they can't say no, really

- appeal to them that their risk management hats are on a little too tight, and that you are responsible for them and will take them straight to the ER

Mort got diagnosed with a hematoma, spent 2 days in the ICU and then went to rehab for a couple of weeks, and then we would see if the British Home would have him back. It's their decision if the resident is healed enough to integrate into the community and thrive with the level of care and assistance available there. As it turned out, Mort's urinary problems advanced during rehab and he was a candidate for an indwelling catheter, which precluded him living in assisted living community any longer (state regulation - nobody but an LVN can touch the catheter or the bag, so since the caregivers cannot, the resident must be "self regulating" or go live elsewhere - like a skilled nursing facility).

So I brought him home and utilized resources provided to me by the assigned social worker at the Hospital ICU to visit a nearby to the British Home "board and care" home in the hope that it might be an option to keep him and Marilou close to each other so that my attentions could be made more manageable. The result of that visit was meeting the caregiver who I hired to come to my house and take care of Mort. She answered the door and I explained my situation. The clock was ticking. Rehab only lasts 10-14 days generally, and since the catheter meant he couldn't go back to the British Home, he HAD to live SOMEWHERE, so my house beckoned as the best option, providing I could hire a 24 hr / 7 days a week caregiver in time and get the place ready. Since Natasha, the caregiver who

answered the door, was just working there on weekends, nights part time, and stitching together a living by juggling that job with a weekday caregiving shift somewhere else, she brightened right up and offered her services. It was like winning the lottery for her. She offered to take the job for \$180 a day, 24 hours, and find a "b-team" for the weekend (another caregiver to live there and watch him). I knew that \$220 a day was considered a fair price, so I jumped at her offer. Didn't check references or anything. Just invited her over to look at the room and house situation and trusted my instincts. She was a woman from Zambia, a Christian, and eager to take the gig. I'd recommend checking out Board and Care homes for recruiting purposes to anybody in a tight spot looking for a caregiver to take on a 24 hr task. They are already doing the job and not being paid very much. They just might jump at the chance to take a 24 hr gig and make some real money. It worked for me.

But back to UTI's (urinary tract infections). The reason I didn't get a catheter recommendation for Mort in the Hospital ICU is still a mystery to me. He was exhibiting major symptoms of retention: couldn't stay in bed more than 15 minutes without demanding to go to the bathroom, and then not producing much when on the toilet, sometimes for 20 minutes or so. I escorted him back and forth in the ICU until it became obvious to me that he was most comfortable sitting on the toilet, so I told the nurses that I had decided to let him sit/sleep there for long periods of time, for his own comfort and to break the routine of back and forth back and forth to the bed. They probably should have suggested getting and ultrasound in there and checking his bladder for an unhealthful amount of urinary retentions, and then

they would be medically compelled to do an "in and out" cathetization, but I didn't know anything about caterers or urinary retention for that matter, at that point, so the fact that the ICU nurses, at the highest level of care unit in the hospital, didn't do that medically responsible thing is a mystery.

It may be, as I later learned, that the whole health care system in the U.S. has evolved to de-emphasize catheters because they always mean a likelihood of urinary tract infections, and UTI's are sneaky bastards that don't show up with symptoms until the patient is weakened to such an extent that they may lose blood oxygen, faint, break something, or have complications in their old weakened immune systems from the advancing infection. Nurses used to give catheters willy nilly, as it made life easier for them. They didn't have to escort weak, elderly unstable patients slowly to the bathroom over and over - a huge time suck. But UTI's were rampant, and I assume there were hospital people who wore risk management hats that said "enough!" If the family doesn't ask, don't go offering catheters, or something like that.

The caregivers at the rehab didn't mess around. I had to go home and get some sleep that third night after he got transferred to rehab, and Mort was in agony with urinary pressure, so they wheeled in the ultrasound and discovered he was overly full and applied the catheter. He hated it (his first), but the relief was just that - RELIEF. He ended up getting a 2ND catheterization that night (!), since he was producing a huge amount of night time urine (not unusual). Also, and perhaps contributing, I googled and found out that head traumas can rattle the pituitary gland

and the result is an abnormally large amount of night time urine production. Car accident victims who hit their head on the windshield for example, supposedly, have that symptom sometimes, and I guess they go tot he bottom of it. (<a href="https://www.brainline.org/qa/hypopituitarism-after-brain-injury">https://www.brainline.org/qa/hypopituitarism-after-brain-injury</a>)

So I suggest to anybody in my situation that you be real watchful for UTIs. Get them checked out (blood draw / Urine sample) frequently if you want to be thorough, since symptoms don't show up til it's too late to prevent weakness/dizziness/falling. Pester their principal physician to authorize the tests whenever you suspect something. Watch out for funny smelling and cloudy urine - tell your parents NOT to flush the toilet so that you can look at it and flush it for them, and tell them why — that you are watchful for signs of UTI. Heck they might be forgetting to flush anyway due to absentmindedness!

## **LIVE TRANSCRIBE**

I'm CRAZY about Live Transcribe. To help right a couple chapters for my book. First of all live transcribe is an app for the Android device put out by Google in February 2019 for beta testing and by June 2019 for download on Google Play Store. It is a game changer for communicating to the hearing impaired. And since Marilou is practically stone-deaf, now, this app came in the nick of time. I think it's actually valuable for almost anyone who's communicating with their seniors to at least try it out. You may find that having a visual aid in the middle of important conversations, especially ones like this, that saves the transcription for three days on the web, and allows you to scroll

back copy and paste it into documents, emails, etc can be very valuable when having important conversations about planning the future for your elderly parents.

It allows them to review what's being talked about in real time and prevents confusion or defensiveness. When discussing things like Downsizing out of the home or relocating to a senior living community or giving over durable power of attorney to one of the children Etc. It might be best to have the transcription in writing so that you can hand the phone or tablet to your parent scroll back and let them read what's been said and consider it again without having to spend the energy of trying to hear and keep up. Especially since people naturally tend to speak too quickly when they're anxious, and It's hard to imagine these conversations being anything less than anxiety-filled.

# MEALS - Munchies and "Elder <u>Tapas</u>"

Kaiser had a relationship with <u>Mom's Meals</u>, which we subscribed to along with <u>Meals on wheels</u>. <u>Meals on wheels</u> is sponsored by the federal government and you have to research who has the territory where you live. They bring hot lunches daily Monday thru Friday for about two bucks a meal. They are pretty basic, but we helped them along with canned green beans, fresh fruit. But all in all, they were a godsend. Here's a tip: Get <u>Thai Chili Pepper Sauce</u>. Use it like ketchup as a dipping sauce for almost any entree. They love it and it helps them increase their appetite. THIS TIP IS A KEEPER - TRUST ME!

When my folks lived at the British Home, the meals were included, naturally, but they also had a refrigerator to share in their cottage and a cabinet in the kitchen. I kept cookies, cereal,

Marilou's <u>Starbucks Frappuccinos from Costco</u> (wait for the sale), milk, some cheese, some yogurt, crackers, and some <u>canned soups</u> (I prefer Amy's) in their cottage for quick snackmeals, especially late at night when they might be hungry and not able to sleep.

Fresh Hot Food Tastes Better To Everybody. It's true. We all know it. So I emphasize serving it piping hot and telling them to eat it while it's hot. I also don't mind picking up a plate that is half eaten and heating it up in the microwave, adding a little garnish to it, and re-present it as "new" for them to finish. It helps their appetite. When we were at The British Home, they had a system - everybody came to the dining room, even if they had to be helped (wheeled, if they were sick) and the servers brought the same entree to everybody (the place was small, so options weren't an option). There was always a salad, sometimes a soup, and always a dessert. They did a great job the portions were small, but very delectable. At Pasadena Highlands, with a census of over 200, they offer options (2) entrees at every meal) and you can custom order off the menu, too, if you don't like the entrees. I order a cheeseburger for Marilou frequently, and nowadays we've realized that the ritual of going to the dining room (down the elevator) and then giving our order, waiting, being served and then being able to only eat a tiny bit, so then packing it up into styrofoam (which we recycle and pack into the belly of her walker and bring down with us) has become too tiresome. I used to think it was a fine way of spending time - and still do - she gets to socialize on the way to the table, get some exercise, and then be in community in the elevator. We will get back to doing it I think, after she fully

recovers from a bout of pneumonia (3-4-2019), but I go down now and order it to go on china under cellophane and bring it back up to the room. I cut up the food a little - offer her a tiny portion of everything arrayed on a plate and serve it to her.

Ginger ale Keep ginger ale around. Every time there's a hint of an upset stomach or a sense of nausea offer ginger ale maybe not on much ice too much cold can trigger phlegm and constriction of Airways. But Ginger Ale. Mick The orange juice We're just by itself. Can be a real Panacea for the elderly.

## THE COCKPIT

Marilou's room has a large glass top desk/table which serves as her "cockpit," where she takes meals, reads the paper, and writes letters. She sits on a thrift store wicker backed, cushioned dining room armchair on wooden legs - no wheels or glides. It sits firmly on the floor. She sits with a pillow at the small of her back. There is an old-school "hot plate" - rectangular metal, no dials - just a plug - one setting: HOT.

I like to provide a generous supply of ICE at her cockpit. I empty half a tray of ice into the styrofoam lid of a to-go dinner container - it's a good size, has a wide lip, and I can set a glass of juice, a mocha Frappuccino, a protein shake carton (preopened - they can't open those plastic caps that 'snap' open the first time - too stiff), and a single serving squeeze pack of apple sauce (also pre-opened with a plastic cap - she uses apple sauce to take her medications - makes swallowing pills possible without crushing them into a foul-tasting powder).

For Breakfast or brunch, I've moved to giving her soup for breakfast every other day instead of her favorite hot cereal and sweet roll with poached eggs every day - I like Amy's organic soups, mixed with a few meatballs, some frozen portions of soup from the dining room and, importantly, a good dash of MAGGI SEASONING

This stuff is essential - makes everything taste better. I put it all in a <u>commercial blender</u> that I've had forever. I put it in a bowl under cellphane and put it on the hot plate. Her solid food entree is generally Poached eggs, runny and a large slice of dark rye bread. Let's talk about taste for a moment: They are old. Their taste buds are old. Pungent, strong flavors are better - subtle stuff is lost on them.

Rye bread, - dark, strong rye - is a favorite. Bleu Chees dressing on salads is preferred. Mini cornichons pickles, olives, sharp cheddar cheese in small slices, a variety of nice crackers, freshpopped popcorn — anything that I like to eat I'll make a cornucopia, mini-sampler plate and offer them. Oh, and Salt on the table (screw the bland senior-safe diets that reduce salt - they've earned the right to salt their food if they want). Like their clothes, they will tend to tell you they want to eat the same things over and over — I accommodate that, but I also always make sure they get new things foisted on them, too. If their hungry, they'll eat it.

Back to breakfast: Every other day I capitulate to Marilou's preferred bowl of Cream of wheat with a glass of warmed milk, banana standing by - which she peels and cuts one out of 5 times - and 1/4 of a large sticky cinnamon roll (<u>Costco</u> and <u>Ikea</u> both sell them in packages - I separate them, cut them into quarters,

and shove them into ziplock sandwich bags and freeze them. I also make a batch of healthy smoothie and freeze paper cups w/cellophane for a half-week's worth.

Ingredients: frozen blueberries, frozen strawberries, frozen banana (overripe ones peeled and saved), chocolate protein powder, honey, yogurt, milk, apple juice, and canned pineapple. I thaw and re-blend a smoothie portion every morning. I put a styrofoam take home dinner lid with half a tray of ice cubes in it and put the smoothie glass in it, along with her favorite: Starbucks Mocha Frappucino. I buy them when they go on sale at Costco - a good deal - I buy ten at a time when they are on sale. She lives for them. Importantly, she doesn't get them after 3pm, but can have as much as she wants before then. I've found by depriving her of her first one until after she has had some fruit/protein smoothie, and hopefully some soup, prevents a sugar bomb drop that makes her take an early nap. Getting protein in her early has paid benefits - she takes less naps and has more overall energy throughout the day. I also put a small glass of orange juice in the ice pond (plastic tub with frozen water in a plastic bottle). After breakfast, I'll change the offering to cream of wheat, if she's still hungry, or I'll wait til afternoon and then put out the leftover soup (there's always some) and a small offering of dinner with sides (veggie, starch, salad). My whole style can be characterized as "Elder Tapas" small portions, appetizingly presented, and offered all day long.

I have my own philosophy. That I kind of nicknamed "Elder tapas." It's sort of like Raising children, you just keep putting snacks out and let them graze and eat them when they want. I put out small portions of food (not spanish, like true Tapas, but a

variety - little servings - and clean up every once in a while and replenish with something new and different. Like a couple slices of cheese and some cut apple slices, then clean that up (eat it yourself) and replace with a small yogurt (take off the foil and replace with saran wrap - so they can see the food and struggle to open it themselves - just pierce it with small pair of fingernail scissors kept tray-side to cut away stretch plastic wrap.) Maybe surprise them with a cookie, or some chips, or a few crackers, or a scoop of ice cream — just vary it and keep them guessing. Their appetite is non-existent in a traditional sense, so they won't ask for food, but if you offer tiny portions, they will eat it, and not get overwhelmed with a large portion - they don't feel hungry and don't think they can finish a large portion, so they won't want to even eat a little of it - they'll push it away and be negative. But if you delight in delighting them with small portions pushed at them unexpectedly, they will "get it" and appreciate that you are making nutrition more of a "game," that they feel obligated to participate in and "play along." (Plus you can snack away along the way!)

Marilou has a swallowing deficiency. So it's important to keep her food hot the way she likes it. And so I have a hot plate - very old school. It only has one setting plugged in and super hot or unplugged and off no switches no dials. The newer models have a simple dial to vary the temperature. But I like that it's very hot! It makes for an "area heater" near her chair (which is good because she chills easily). I moderate the temperature by simply putting layers of tinfoil on the surface to keep some areas a little cooler than others.

I put out an "elder tapas" (various small portions) buffet in the morning for her to eat all day, which can include some chicken from the \$4.99 roasted loss-leader chickens from Costco. I buy those \$4.99 rotisserie chickens and cut them up and de-bone them when I get home and store them individual servings in the refrigerator or freezer or both. I also include her favorite, Cream of Wheat (quick cooking farina cereal) which I recommend you over-salt, because they don't have the same taste buds we do, and cream of wheat is too bland when it's not salted enough with some milk and butter in it and heated up in the microwave under Saran Wrap.

I also buy the <u>Costco gooey cinnamon rolls</u> and cut them into about 25 pieces and put in the freezer. I can just peel off one and wrap it in some foil and throw it next to the hot plate (not on it - it will bake into a rock hard crust!)

There's also little bit of yellow cheddar cheese, some yogurt, some orange juice, A mocha Frappuccino from Starbucks mixed with a <u>protein shake</u> and poured back into the bottle.

I keep a tub with a frozen quart of ice in a couple inches of some water and have all the cold stuff basting in there — and all the hot stuff on the hot plate, and all the normal temp stuff next to the hot plate.

She also likes two poached eggs in the morning BTW - an egg poacher from sharper image is great and easy - to - use. Marilou read in a book called "The Fountain of Youth" that one secret to youthful energy was to each the yolks of two eggs every day. Poached eggs are the easiest way to provide them to her.

There's a little wheat toast. Sometimes I include a little whole grain toast. And she picks and chooses what she wants to eat throughout the day eating very slowly with her swallowing deficiency. But Having her swallowing deficiency gave me the idea of creating a kind of mini Buffet of small courses with a large variety, and it gives her something to do — unwrapping everything and deciding what she's hungry for, or not.

I've noticed that their appetites as they get older become very subdued, so having this kind of Exploratorium of tiny portions helps enhance their desire to go ahead and eat—but putting out too large of portions food is a dis-incentive—they aren't THAT hungry, and they see all that food and interpret it as a challenge that they certainly can't rise to — they're never going to eat all that, and they know it, so they push it away and don't want to eat any of it. Much better I think to just offer tiny portions and maybe refresh them throughout the day and let them eat what they want when they want.

• Routines are the key. I have a routine for the morning that consists of setting up the breakfast buffet of "Elder Tapas" (small portions under plastic wrap, some kept warm on a <u>electric warming tray</u> with two china plates - not one - to keep the poached eggs from overcooking over the great amount of time it takes her to getting around to eating everything.) BTW - an <u>egg poacher from sharper image</u> is great and easy - to - use. Marilou read in a book called "The Fountain of Youth" that one secret to youthful energy was to

- each the yolks of two eggs every day. Poached eggs are the easiest way to provide them to her.
- After setting up the food I then moving on to cleaning. I love an electric broom with an easy to empty small filter canister.

  And I use <u>T-shirt carry out bags</u> for all of the wastebaskets which are scattered everywhere, and I use <u>10 gallon waste basket bags</u> for the kitchen waste basket. It's really smart to empty the trash often and tie them up tight and just pitch them out the door and take them to the can later.
- I like having a scrubbing sponge at the sink and a glass top table for Marilou's breakfast set up. It's really easy to clean spills even after they dry on glass. And just use a little detergent in the sponge and some paper towels and done. As for her chair, a straight backed dining chair with a padded seat is perfect. I found one with arms at the thrift store, but without arms is fine for most people. The arms give her something to push up from when standing, which is pretty important when the chair is pushed out from the table. (She grabs hold of the edge of the glass table to stand when the chair is close enough so the arms are really optional, and cheap dining room sets from Walmart don't have arms on the chairs.

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# • A COUPLE MISCELLANEOUS TIPS:

- I put a few layers of <u>metal repair tape</u> on the feet of the chair to make it easier to slide. The oldsters don't have a lot of strength themselves, so an easy to slide chair is real important. I keep a pad for the small of her back on the chair.
- I empty the <u>commode</u>, which is kept next to her bed into the toilet and then rinse it a little in the bathtub, empty it again,

and then set in the bathtub fill it again & squirt some soap/ water mix from a shampoo dispenser on the corner of the tub, and let it overflow before emptying some of the soapy water out into the tub drain and then taking it back. I always leave several inches of soapy water in the commode to take the curse off the #1 and #2 excrement it will receive when they get up at night to pee.

• I keep an <u>air freshener spray</u> in the bathroom in case the urine smell sometimes bugs me but not so much lately. It's always good to have <u>air freshener plugin units</u> keeping the room smelling nice around the commode and in the bathroom. I don't use very much laundry soap on her clothes. Her skin is very sensitive, and I found that if you just use a tiny bit of soap, the clothes don't irritate her skin as much. Essentially, you're just rinsing these clothes with a tiny bit of soap. It makes a difference. Their skin is really thin and sensitive to soap residue. It makes them itchy. I also give her back a generous rubdown with <u>skin moisturizer</u> before bedtime.

## **HEALTH CARE**

We just enrolled in "Caremore" which is a Medicare Advantage plan that specializes in providing elderly people in institutional settings like this one with Healthcare— a doctor and a nurse practitioner make regular visits. The nurse practitioner comes once a week and does the blood draws for her clotting Factor test - the first week she wisely counseled me to take her off of

cumedin and just give her a baby aspirin daily — by 93 the risk of stroke from A-Fib (atrial fibrillation). And the doctor comes once a month for a checkup. Another upside to this is that if she were to fall and hurt her hip or something, they would bring a x-ray machine to the facility and up to her room to check and see if she broke anything and avoid a trip to a hospital.

Also the doctor, during the first visit when I was testing the waters, suggested that he has the flexibility to recommend hospice care for Marilou when he wants to, and much earlier than a big institution like Kaiser, which would be compelled to follow a stricter protocol and delay admission to hospice until they could document from measurements (blood ox, weight loss, etc) that the patient was entering or in the last year of life. The upside of having Hospice Care prescribed early is that you get more medicare-covered visits from nurse practitioners more often and they keep closer track on the blood pressure and offer comfort aids For skin irritations, like bed sores, or they can be watchful for early indications of bed sores if Marilou becomes more bedridden, which luckily is not yet the case. With Kaiser we would have to wait until she was much further debilitated before qualifying for hospice care.

This doctor makes it sound like She could be qualified, in his estimation, right now and stay in Hospice Care indefinitely until the end of her life, unless she rallies without any lung infections and has super stable vital signs, in which case they'd be compelled ethically to discharge her from hospice and re-admit her again when she gets sick. But the Doctor opined that she'd likely just stay in hospice, even if that were to be a couple years

or longer. They Outsource hospice to another agency, and as long as everybody's being compensated nobody asks any questions or makes any changes in the diagnosis, is the way I understand it.

# A couple of Mobility tips—

First of all having a portable foldable wheelchair in the trunk of the car is an essential. If also doubles as a wheelbarrow for bringing food and stuff up from Costco to the room from the car.

The protocol for getting in and out of the automobile. I've noticed with both more and Mary Lou. Compels some discussion. First of all, they're very hesitant and uncertain and anxious because they don't get in the car very often and their fear of falling is fairly profound. So my suggestion is do what I do- bring the chair parallel to the car very close to the open door have the passenger seat pushed back all the way back providing the most foot room in the car possible. Then encourage them to stand slowly and grab the back of their belt waistband and firmly pull up to let them know you won't let them fall. You've got them in the center and hold on tight through this entire procedure. After they stand encourage them to turn and face you and let your hand kind of wrap behind them around their waist and then encourage them to sit down as deep into the seat as they can on the first try but slowly and hold their waistband tight and let them press your arm against the backrest of the car as they lower themselves down then extricate your arm. And encourage them to scoot back a little bit before twisting and turning and bringing one leg at a time into the car.

Their natural inclination is going to be to face the car and stick one leg in the way you always do when you get into the car and kind of sidesaddle Mount the seat. It's much more Awkward for people at this Advanced age to try that although if they feel confident that that's what they want to do. You can hold their waistband and kind of let them guide themselves in but I noticed with both mert and Mary Lou there's a little twisting and Wrenching of the hip socket doing it this way. And it caused sharp pain in both of them something like straddling or widening their stance that much and putting one leg in high and keeping one leg on the ground low and trying to lower themselves into the seat was awkward to a fault and causes hip pain. So I recommend against it.

I say coach them into doing the easier safer route, which is face you and sit into the seat facing you, and then twist in the seat, and then bring their legs into the car.

You might also want to put something slippery on the seat of the car so that there's less friction for their butts when they do the twisting in the seat, maybe some plastic. It seems like a small thing to spend this much time and attention on, but when you need to put them in the car, it may often be for medical appointments when they're under the weather or other more stressful situations, like going to the dentist, etc.

It's good to have a procedure that you both agree is safe and secure and provide some peace of mind so that it's not a freak out getting into the car or there isn't a moment of carelessness where someone gets hurt doing something that we consider ordinary. This is another thing worth "re-cap'ing" about - back

in the house/apartment. Review the procedure step by step away from the car so they can use their imagination. Then when you get to the car they might better remember the steps naturally and be more proud and happy about getting into the car - not stressed out and ashamed at having something so simple, but in public, be so hard and embarrassing.

Just because you like to go to bed at a normal hour. Don't be surprised if they don't. Mary Lou, for example really only hits her stride after about 9:30 p.m. We have our ritual. At night at bedtime, which is usually somewhere between 10:45 and midnight. A couple of eye drops and three hits off of three two one CBD THC vaporizer cartridge She gets up every two hours to use the bedside commode. And Often times has hip pain at night, which I attribute to her sleeping on her right side. I've encouraged you to sleep on her back and when she does trained herself to do it, there's almost no complaining of hip pain. So I think I'm on to something. But at 9:45 p.m. She's Wide Awake having eaten pretty much all afternoon her brunch. And had an exercise walk somewhere around 6:30 to 8:30 p.m. Somewhere in there. That's when she likes to write letters or watch TV or read the newspaper. And it's kind of a shame to ask her to try to go to bed earlier than when she actually gets tired, which is somewhere around 11 p.m. So I've adjusted my body schedule to hers. It's difficult. But I fling myself home which takes about 15 minutes and try to make short work of getting ready for bed myself. I enjoy my beauty rest in the morning, though. And try to make it back to the retirement home by about 10:15 to 10:30

at the latest. To get breakfast ready? My pattern is to hang out with her after she finally gets up around 11:30. Until she's fully underway eating in her little command post with the TV playing MSNBC and her newspaper. At arm's length Before I break away for a few hours in the afternoon to do some housework or run some errands or do some shopping. I'm usually back around 4:30 or 5:00 p.m. To make sure I pick up the dinner. At around 5:15 to 5:30 and then the evening hang out begins.

Hospital beds are free at the convalescent aid society, but they're too high and have hard bruising rail edges while getting in and out. But they "sit you up" making getting out of bed easier in your 90s. I prefer a cheap and low Ikea twin bed with double ikea cheap mattresses dressed slightly over the entry edge to prevent bruising and a gait belt screwed firmly to the end so Marilou can pull herself up to seated and swing her legs over for successfully leaving the bed.



Once Marilou was admitted into Hospice treatment, she qualified for a more modern hospital bed that Medicare would pay for, so we wouldn't have to depend on the free/donated older hospital beds that the Convalescent aid society provides, bless them. The more modern beds lower down almost to the floor! But I left the gait belt/strap pull up option in place, screwed to the bedside table at the foot of the bed, because if Marilou misplaces the control box with the up/down arrows, (on a coiled cord hanging on the side of the bed - it can come un hooked and dangle near the floor - she's not able to retrieve it by feeling for the cord and reeling it in) she can use the gait belt pull up strap to sit up and swing her legs over the edge of the bed to get up and use the commode next to the bed. It's a good back-up plan to the automated controller for the hospital bed.

# SENIOR LIVING OPTIONS AND "HOUSE RULES"

I feel like talking a bit about the need for social interaction. It seems like with all these commercials for stair lifts and others devices designed to make living at home alone easier for the elderly, these are all part of a misguided ruse that doesn't actually enhance the quality of life. First of all, the whole issue of meal preparation isn't something that people take into consideration when they think their family members would prefer to live alone rather than in a Senior living community. It's difficult, as one gets older, to make nutritious meals fresh and hot, sit down and eat them alone, and then clean up after yourself. It's a lot of work.

Not only that but it's very lonely living alone and even I'm married couple who have gotten used to a routine in the house are they take care of each other and enjoy having the familiar familiarity of their circumstances it's not the best practice for staying healthy staying safe and having a good quality of life. After putting my mom Marilou into the Pasadena Highlands Senior living community in October of 2018, and spending basically every day there hanging out with her for much if not all of the day, fetching her meals, accompanying her on her nightly walk in the courtyard, arranging the furniture and getting her lifestyle ergonomically situated, and partaking of the food left overs, I've become a convert to the idea that a Senior living community is actually a very good value. Even limited social interaction with other residents is a tremendous thing to have.

Senior Living Alternatives:

#### **Board and Care Homes**

These are like houses in neighborhoods with no signs or anything identifying them as care facilities. But they have up to 6 (I think, by license/regulation) residents and 2 or 3 caregivers inside. Usually these are dignified alternatives to nursing homes for Alzheimers patients and cheaper than larger facilities with memory care units. Sometimes (often) there are pets in residence. Meals are cooked there, and residents hang out and watch TV mostly, near as I can tell. You can expect to pay between 3 and 5 thousand a month for these in rent.

# Senior living Communities

Up to 200 residents is about normal. It seems like this is the magic number for an economy of scale so they can make money. The British Home was only 36-38 persons, but it was a charity and the ladies' chapters would tithe to the Home to help make it pencil out. But I inferred that it was tough to make the numbers work there with only 36 folks. The meals were good, but there were no "choices." The menu was fixed and everybody got the same entree each day (but it was excellent). The folks don't eat a lot, and portions are sort of skimpy, but that's normal. You can always get second. At Pasadena Highlands with about 200 folks, there's two choices on the menu for entree and you can order off the menu - burgers, salads, etc. if you don't like either of those.

We pay about \$5000 a month including a small "care package" for services (showers, in our case - I do the escorts to dinner - she walks with a walker, but I like to accompany her / motivate her / guide her). The price for services goes up the more you

need - help with toileting, dressing, going to bed transferring to a chair from wheelchair, etc.

Memory care for Alzheimers patients is pretty high - around 6000 a month I think, or more.

## At home 24 hour caregiver

I was pretty tolerant of Natasha using the cellphone all the time - its pretty boring work being present 24 hours with a senior who spends so much time sleeping. I supervised her though, in that I made up "house rules" for Mort:

- 1) He had to do 7-9 walks a day from the room, down the hall, into the living room, and back. Natasha would stand him up and help him get up on his walker and accompany him down the hall and back. It was a lot of walks I wanted, but it was a short distance, and it gave more meaningful structure to his days, apart from just being healthy to keep him moving.
- 2) He had to eat the food we brought him, at least some of it. I wanted him to understand that it would break my heart if he were to "stop trying" (the medical establishment calls that out on their evaluation sheets in the facilities "won't try."). I told him that if he were to go there, I'd be forced to opt for a board and care home where I wouldn't have to watch him give up. He got the picture and was a good sport for a long time (about 18 months until he ran out of steam and passed). Also the caregiver had to handle the TV and the DVD player Mort liked to watch all 8 seasons of the TV show "Bluebloods" over and over. "It keeps me from going crazy," he would say. I also went to the video store and got movies for me and Marilou and shared them with Natasha for her to watch when Mort was asleep.

When Mort gravitated to Palliative care and was bed bound (about 5 weeks before he died), I bought lots of incense so that his poop wouldn't make Natasha gag. She appreciated that a lot.

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#### THE BEGINNING OF THE END

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## AMBULANCE SERVICES

This is an important story. When Mort fell in his assisted living room and hit his head, I took him to the hospital and he spent 2 days in the ICU while recovering his speech and mental faculties successfully. Then he was transferred to a "rehab" facility (typical) for physical therapy and further evaluation before potentially being accepted back at the Assisted Living facility (The British Home, where Marilou was still living). Because he got an "in-dwelling catheter" while in rehab (story told elsewhere in this volume), there was some bleeding in the collection bag after the insertion of the catheter (not unusual).

BUT - because the amount of bleeding was more than average, the protocol is that they have to go back to the hospital emergency room to be evaluated by an MD (urologist) to make sure they don't need surgery to stop bleeding - it's rare, because most of the time the bleeding resolves itself, but just in case, the rehab folks follow this protocol. They call an ambulance service to "taxi" the resident back to the hospital, and I watched as the guys loaded Mort up and then I drove to the hospital to meet them when they arrived. BUT - he never made it! Because of his bleeding (maybe), and because he was the type of guy who would just "zone out" when placed on a gurney (probably more likely the reason), AND BECAUSE THE REHAB FOLKS PRINT OUT INSTRUCTIONS FOR THE AMUBLANCE GUYS THAT INCLUDE THE "DO NOT RESUSCITATE" STATUSE (HIS MEDICAL DIRECTIVE), BUT THEY **DIDN'T INCLUDE A BRIGHT PINK "DNR" FORM WITH** HIS TRAVEL DOCUMENTS, (which is traditional going back before computers were in such constant use everywhere!!), THE AMBULANCE GUYS REACTED TO A DROP IN MORT'S BLOOD PRESSURE (INTO THE HIGH 80s) BY TREATING HIM AS A "FULL CODE" PATIENT INSTEAD OF A "DNR" PATIENT —

That meant that they pulled the ambulance over and called the 911 operator to ask for a fire department ambulance to come to them to transfer the patient and take him to the nearest hospital to the spot where they pulled over! The fire department EMTs can treat the patient en-route w/ IVs, etc, which the ambulance transport company guys are not permitted to do. That 's why there is this protocol. Mort was taken to a different hospital than the one at Kaiser where I was and I didn't get the word about

this FOR HOURS! He wasn't fed there, (typical of all ERs - they just don't think about food and don't want stuff in their patients' stomachs anyway), but was treated well and kindly. I talked on the phone w/ the ER doctor and eventually we were reunited, but a 45 minute ambulance ride became a 6 HOUR process!

The moral of the story is GET A PINK DNR FORM FOR YOUR FOLKS AND KEEP IT WITH THEM WHEREVER THEY GO, AND MAKE A POINT OF MAKING SURE IT ALWAYS FOLLOWS THEM WHEN THEY ARE TRANSPORTED BY AMBULANCE.

If the guys had read their notes more carefully, they should have IGNORED their protocol for "full code" patients and just proceeded to take him to Kaiser. (His blood pressure revived by the time he got into the fire department ambulance because he "woke up" from his "zone out" and they gave him some IV saline, which helps boost blood pressure. His bleeding resolved, as expected and after 4 hours at Kaiser, he was transported by ambulance back to the rehab facility. Truthfully, a nurse told me that these ambulance drivers, and hospice nurses, too, for that matter, are largely motivated by trying to avoid having to "report an incident." They know that too many "incidents" reflect poorly on their agency/company, because the paperwork is not only laborious to fill out, but gets reported to the State. So EVEN IF your parent has a DNR, the drivers may over-react to a drop in blood pressure and will pull over and call the fire department, because they don't want them dying in THEIR ambulance and causing an "incident report" to be necessary. If I

had to do it over again, I'd have a face to face with the drivers before departure and tell them explicitly, "No matter what happens, take him to Kaiser. He has a DNR and if he doesn't show up there directly, I will need to have your company file an incident report on why it didn't happen." Hindsight is the best sight. What a day!

#### ON NOT EATING

This is a transcription of an "ELDERSCOLD" (my tease), that I lovingly laid on Marilou during her most recent chest congestion / cough period in mid-November 2019, when she indicated that she was tired of coughing and went into a funk. She told the social worker, during her intake interview upon being admitted to hospice treatment by the Doctor/Nurse team with Caremore, the Medicare Advantage provider outfit that visits senior living communities, that she was "tired of coughing, and tired of eating (which exacerbated her coughing, since she normally aspirates a certain amount of what she eats or drinks, even when she doesn't have a cold) and wanted her life to end soon." (Bear in mind, Marilou's career was an Administrator for the Retired Senior Volunteer Program in Fort Wayne, IN, our home town for 12 years, an Activities Director at a skilled nursing facility before that, and a Clinical Gerontological Social Worker for a large Senior Living Community in Florida after retirement (She got her Masters in Social Work at Age 60 in Wisconsin as my

Dad was approaching his early retirement — she is very mature about what she's facing at age 93 and knew who she was talking to, and that it was being written down, and she has many times reassured me that she is more than ready for "this phase of my life to be over.").

I spoke to her after the social worker left, thru the Google App "live transcribe"):

"Mom, If you do stop eating and make the Sovereign decision to end your own life by refusing nutrition, then this whole hospice team will make you comfortable as you weaken. If you choose to sit and eat with me, though, even a little bit, even with difficulty, then that's your choice. And that nurse said "if she'll eat a little, even through her difficulty, she could easily live 18 months... two years... or much more, unless she takes a fall." And she has seen a lot of old people. That was her expert opinion. It's all about if you aspirate food and cough, or if you get bad mucus deposits, like a pre - pneumonia, or any bad congestion, you might weaken anyway and die. But you might "tough it out" and the mucous may back off and you'll be okay again. The coughing and mucous are the things that make you want to stop eating, but if you're in a weakened state from a bad cough, well, that's the worst time to stop eating. Because you need to build some strength to give your body a chance to bounce back one more time.

So it's about being strong enough to want to "pretend to want to eat" (because you probably aren't going to really want to eat, because you don't feel hunger anymore). But it's a life necessity,

and it's either you accept it, and use the time to extend your life by eating - even if it's unpleasant to you, well, that's one choice that would extend your time with us.

And If you stop eating and start coughing, and don't stop coughing unless we give you, you know, medication to calm you, but you don't eat anymore, it will be a very slippery slope and won't take long..... four days, which you know.

If you stop eating, if you won't get out of bed and go and eat, we can sit you up and offer you nutrition, ensure shakes, and if you sip at them in bed (because your body is actually hungry, and you will probably drink it), you may find yourself bouncing back, and then being back at this table eating again in a couple of months, because you'll realize, it's a hell of a lot easier to eat and not feel miserable than it is to pretend to think that this "not eating" will be a quick-and-not-miserable experience.......

It is actually kind of a slow and miserable experience. So people in your spot will generally start eating again.

So you can just accept what I'm telling you is true, and eat now, a little, even while you're just starting to regain strength, but still coughing a lot, and trust that you're probably around for a while.

It's really more a matter of attitude than anything else. So it's fine for you to make the dramatic announcement to the social worker that you hope this doesn't take much more time but until the end of the month...... and it's fine for you to tell me that you're like Mort - ready to go.... but it's, it's a different thing to pull it off.

So I'm going to keep offering you food and shakes, and trying to cajole you into taking nourishment, and you can tell me "no stop doing that. I don't want to eat anymore," and it'll all get written down in a binder over here."

She smiled while reading all of the above.

(She was admitted into hospice treatment the day before we had this conversation — started 3x daily <u>nebulizer breathing</u> <u>treatments</u>, an <u>oxygen machine</u>

for continuous oxygen, day and night, her cold went away, she kept eating, and as of this writing in January 2020, is a cheerful, if frail, tough and self-described "lucky old lady" who eats (and drinks my protein smoothie) every day and is happy to be hugged by her friends......and me.

# URINARY RETENTION IN MEN AND IN-DWELLING CATHETERS

• Mort, my Dad was quite a "clencher" when it came to holding back urine flow. Over time his enlarged prostate and his disposition resulted in a chronic case of urinary retention. This was discovered in the hospital after he bumped his head in the bathroom of his assisted living room on one of his frequent trips to try to go. He had taken a spill and hit the back of his head, and he began talking funny hours later, which was the indication that he had a head injury and needed to go to the hospital. I took him in

- my car and admitted him to the emergency room, and they quickly ran some tests and
- realized he needed to be put in the Intensive Care Unit for observation for a couple of days. The special ICU was for stroke and head injury patients. The effects of his small "brain bleed" wore off, just as the neurosurgeon / neurologist assigned to him told me would occur. Apparently men of advanced age who bump their heads like he did usually don't have to have any surgical intervention, because the brain shrinks with age, and the space inside the cranium allows for these bleeds to be absorbed and normal brain function to resume naturally. In younger people, where the brain fills the cranium to capacity, the pressure of a head injury-created bleed is very serious, and they will do surgery to relieve that pressure to avoid strokes and other deleterious effects.
- So as predicted, in the two days he spent in the Intensive Care Unit, Mort recovered his ability to speak and think clearly (to an extent). But his urinary retention problem was so pronounced and evident, that I had to sit up with him all day and night while he sat on the toilet in the ICU and would take naps. Sitting on the toilet seat, rather than laying in bed, was his "comfort zone," because every time I took him to bed he insisted on going back to the toilet. He couldn't produce much urine, but he was more comfortable sitting there trying to go, than in bed feeling the need to go.

• After recovery in the ICU, the normal course of action is to next be transferred to a "rehab facility," (a skilled nursing facility, or SNF - "sniff") which is like a nursing home that is designed for short-term stays of residents (along with long-term residents, too) that need physical therapy after say, maybe breaking a bone in their wrist when falling or that sort of thing. Going to "rehab" after the hospital is quite typical before they are returned to their home or assisted living facility. The rules are that the Assisted living facility has to "accept them" back from the hospital once they're discharged. And generally, the assisted living facility and the doctors think going to rehab for a week or 10 days or (two weeks maximum, customarily -

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I think that might be the Medicare limit for coverage of "rehab") is the best course of action to transition them back to their normal lifestyle because physical therapy is available at the rehab facility on a daily basis. In my dad's case. He didn't need Physical Therapy too much but was given it. He just needed to kind of "bounce back" from his head injury, which really only took those first two days to completely bounce back, but nonetheless they knew he would benefit from a stint in "rehab." Now, at the rehab facility, they don't screw around, and if you have a bad urinary retention problem, they will do a quick ultrasound to see how much urine you're retaining in the bladder, and if it's above a certain amount (I think the amount was 40 milliliters), they will introduce what they call an "in and out catheter" to drain the bladder. So my dad had his first in and out catheter his first night at rehab - a shocking

"welcome"! In fact, they had to give him two "in and outs" that night because he was retaining so much urine. Later, I discovered that "Head injury can damage the pituitary gland and reduce production of two important hormones. ... The part of the pituitary gland that makes antiduretic hormone (ADH) is also vulnerable to injury. Reduced production of ADH can cause diabetes insipidus, which causes excessive urination and extreme thirst." who knew?

- So he may have had an exacerbated situation because of his head injury. Or his urinary retention problem was just finally coming to light which I think is really the case because he was trying to go to the bathroom too much in assisted living and did slip and fall in the bathroom where he hit his head. Anyway, after a couple of days in rehab and my research online, I realized I should ask. The question is my dad a candidate for an indwelling catheter. The doctor was relieved when I asked the question.
- And I realized that during the two days in intensive care, the nurses never mentioned a catheter once, even while they watched me march him back and forth to the bathroom and sit him there from 45 minutes to 2 hours at a time sometimes because he was more peaceful and rested there. I don't know why they didn't mention catheters to me and I don't know why the doctor didn't suggest an indwelling catheter, but waited for me to ask but I suspect it has to do with the fact that there was a lot of overuse of catheters 95 in the profession. Until the really recent past when they realized that urinary tract infections were just epidemic in

catheter patients and that nurses were over catheter Rising their patients because it made life easier for the nurses. They didn't have to help people with bed pans or get them up and down to the bathroom frequently.

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And so the philosophy may have changed to the point where if the family members ask, then the medical profession will go ahead and accommodate catheters. But otherwise they tend to resist it. I assume they don't want to be accused of causing urinary tract infections, which can be very serious. Their seriousness is partly because urinary tract infections appear to incubate without a fever or real symptoms for quite a while and then suddenly the patient is overcome with weakness fainting. A Light delirium or confusion And often will fall. Down In fact the orthopedic surgeon who worked on my trigger fingers. Of which I had 10 small surgeries to release. Locked tendons in my hands. The surgeon I became friends with over the years. In a conversation where I was mentioning my dad's fault and my mom's urinary tract infection. And the problem about getting catheters to him. Without asking He shared with me that. In his practice, he sees a lot of older people naturally who break hips or fall and break bones and they always do a workup on them. And he said a hundred percent of the time his patients have always had urinary tract infections. So he agreed with me on my theory that Broken hips are often caused by people fainting because they have a urinary tract infection that makes them lose their balance.

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## CLOSENESS, AND OBSERVATION

As far as subjects like "closeness", I believe that it's nice to give them a back rub or a back scratching while you're walking with them. They get a big kick out of it and it develops a nice intimate routine where you're keeping a close proximity to your mom or dad and actually helping their muscles relax while taking them for a walk with their Walker. Don't be too rough on them, but don't be afraid to give them a good scratching and rub down through their clothes while walking.

Eldercare is like baseball. It's a game of inches. Closeness is something to aspire to, from the beginning if possible. I came a little late to achieving more closeness with my folks. But I always gave them a hug hello and a hug goodbye every day. I have a recliner that I placed in my parents room upon arrival at The British Home and we all sat around and watched TV and snacked together (and I used the internet and my laptop to do my location scouting and managing work). Once my dad died, and I moved my Mom to Pasadena Highlands, I moved my recliner, too, and now I sit close to her while we watch TV. When she gets a cold or a bout of pneumonia, I sit in a different armchair directly next to her and offer the occasional pat on the back or let her hold my hand. It's quality time, better spent closer, and it promotes her healing.

See, she really has no reason to "try" to enjoy her life except for because of my willingness to encourage her and offer her companionship, so I've gotten used to the "mission" of just "being there" as much as possible. When my dad was bedbound in his last month, I spent several 30 minute sessions sitting next to him and holding his hand. He would squeeze it as hard as he could to express his appreciation for the odyssey we shared of leaving Florida and setting up life in California together. The closeness we nurtured allowed us to really reconnect before dying.

In Marilou's bedroom, in the morning when I wake her, I give her a morning hug - (and we have a goodnight hug every evening). I got into the habit of hugging my Dad, Mort a lot, too, especially in his last two years of life. I learned from my cousin, who told me, that when My Uncle was told he was dying, he made up for lost hugs by hugging and smothering her with kisses. They had never really hugged much during her whole life, she said, and it stuck with me that his instinct was for making sure his love for her was expressed in a fury of hugs and kisses. I think all elderly parents yearn for the hugs of their kids at this phase of life.

As for privacy issues, when I'm in my Mom's room, I will avert my eyes when she goes to use the commode, but I don't run out of the room like I used to. She's a little too unstable, so in case she starts to tip over, I can keep an eye on her. After watching her, if I spot some carelessness in her "technique," I "coach" her now and then - reminding her on how to use the hand rail net to the toilet for safety while still able to crouch and clean herself up - and where to position the handi-wipes package, and maybe even "anchor" it to the sink with tape so she can pull a handi-wipe out with one hand.

You never really "check off the boxes" once and for all on the checklist of eldercare — it's a process of setting up healthy routines and then basting them in reminders of how the routines work for their comfort and safety, and why they work. Their memories are pretty iffy at this phase, so just build it into YOUR routine - that you are going to be repeating yourself - your

"speeches" about how to stay safe, etc. This process of observation and adjustment is transferable for all manner of tasks of daily living -for example: I positioned a chair close to a small bookshelf inside the closet with clothes hanging above it. Marilou can sit and reach most items on the shelf (underwear, pajamas, socks etc. - and a package of handiwipes taped to the shelf). From this "dressing chair," she can then stand up carefully and pull a shirt off a hanger, and then sit back down to put it on. She cal also access all of her underwear, pajamas, shoes and socks and stand up and sit down using the arms on the chair, with her walker opposite her, locked. This setup grew out of observation and "rehearsal" of the safest way of using the space in her room and her abilities.

"Don't Fall Down," is my parting shout before blowing her a kiss every time I leave my Mom's room for any significant length of time. It's our little joke, but it's based in my philosophy of observation, coaching, repetition, adjustments and the fact that almost all of the deaths of folks over 90 result from falls or pneumonia. Strokes hit them younger, cancer kills them even younger. If they make it to 90, they'll live until they fall and break a hip or catch a bad pneumonia. That's the impression I get.

According to the U.S. Centers for Disease Control and Prevention:

• One in four Americans aged 65+ falls each year.

- Every 11 seconds, an older adult is treated in the emergency room for a fall; every 19 minutes, an older adult dies from a fall.
- Falls are the leading cause of fatal injury and the most common cause of nonfatal trauma-related hospital admissions among older adults.
- Falls result in more than 2.8 million injuries treated in emergency departments annually, including over 800,000 hospitalizations and more than 27,000 deaths.
- In 2015, the total cost of fall injuries was \$50 billion.

  Medicare and Medicaid shouldered 75% of these costs.
- The financial toll for older adult falls is expected to increase as the population ages and may reach \$67.7 billion by 2020.

It does a lot of good knowing that she'll use the commode privately in the middle of the night more safely because I closely observed and made adjustments in its position. And I can keep score on her abilities more accurately, and I can see if there is any decline in those abilities by choosing to be close much of the time.

So for example, if I want to fold a load of laundry. I could do it away from her, but I do it right there on her bed while she's in it, so that when she wakes up, I can watch how she gets up, and take notes on how she moves when she's still half asleep. These

little moments of instability will creep up on you, and they won't have a chance to call out - they'll just fall down.

At this age Marilou is like a potato chip on edge: I can't let her fall down. And I can't let her get too wet because she'll crumble - meaning she can't fall and break a hip. She's too crispy. And, she can't get any more bad chest colds or pneumonia, because she will expire from the struggle against pulmonary Edema .

A RAMBLE ABOUT BRINGING MORT HOME WITH AN INDWELLING CATHETER AND HIRING A 24 HOUR LIVE-IN CAREGIVER:

After Mort bumped his head during in May, 2018, on one of his myriad trips to the bathroom, and had a <u>brain bleed</u>, and thus had to go to the hospital, where he was correctly diagnosed and given two days in the neuro-ICU for observation while it self-resolved, he was sent (quite typically) to a <u>rehab facility</u> for 10-12 days for PT (physical therapy) and assessment before returning to (in his case) an assisted living facility. Once we realized in rehab that my dad couldn't go back to assisted living with his new <u>in-dwelling catheter</u> (also called a Foley catheter).

This kind stays put. A tiny balloon filled with water, keeps one end inside your bladder. The other end drains out into a bag that's either strapped to your leg or hanging from the side of a bed or a stand. An indwelling catheter needs to be replaced at least every 3 months or so. — regulations prohibit caregivers in senior living communities from touching the catheter or the collection bag - the resident has to be "selfregulating" [emptying his bag himself into the toilet], and the State must be notified that a catheter patient is in residence only an LVN [licensed vocational nurse] or an RN [registered nurse] can touch a catheter or bag in an assisted living facility) ..... the Clock Was ticking. Rehab usually is about 10 days maximum ordinarily and the facility will release them / discharge them: "our work is done." They've had their Medicare covered allotment (Medicare covers a limited amount of rehab) of physical therapy and rehab, and it's time to go home or to the assisted-living facility or wherever they live.

In my case since he couldn't go back to the British Home, - he was too weak and confused to deal with his own catheter - he had been wanting to "just die," for a long time, being pretty miserable with the challenges of being over 90 years old, so he was unable to try to learn how to adjust to his catheter. As of this injury and its aftermath, it was clear: He needed a caregiver by his side prompting his every act - from waking up/getting up, getting dressed, walking, etc. So I decided to bring him to my house after rehab and hire a caregiver to make him comfortable for the rest of his life.

At the Hospital, they give you a social worker and a case manager, and the case manager will pick a rehab place (a skilled nursing facility -SNF for short - one that specializes in rehab patients, but one which will also have permanent residents - 70% of Americans in skilled nursing facilities are on Medicaid - meaning that they have been drained of all financial assets and the State has to pay for their nursing home care in conjunction with the Federal Government's medicaid program) that has an available bed for your relative, because the patient's being discharged from the hospital, and he has to go somewhere, so time is of the essence.

They don't screw around - they (the hospital case managers) have the right to pick the rehab for you, but they will take your desire to have the rehab facility be close to your house into consideration if possible (remember - you can ALWAYS pull rank and insist on having the patient discharged into your care, if you have durable power of attorney - and you can take him straight home and skip rehab. In my case, I didn't know he would have to come home rather than return to The British Home, since I didn't yet know the rules about catheters. Besides, I didn't have a room ready. (This is a good moment to digress and say that it's probably a good idea to get a room ready early in the process of taking charge, even if they are going to live elsewhere — you never know when you'll need to make a quick decision and bring them home for some reason. I had to scramble to get Mort's room ready, and it was an

emotional time to be spending that much energy emptying a bedroom and retrofitting it for an elderly father!) .

They also will give you some brochures and referral information about housing options which include Assisted Living placement Specialists and the like. Many times families are dealing with these decisions for the first time when their family member takes a fall at home and break something or needs to go to the ER like my dad and get admitted to the Intensive Care Unit with a brain bleed head injury. And everyone gets focused on "they can't live at home" suddenly, and "where shall they go?" One of the options that the placement specialist might alert you to is what's called a Board and Care House. These are Anonymous looking houses in regular neighborhoods that have generally up to six, generally Alzheimer's elderly residents living in them with caregivers. These houses are privately owned and have been remodeled to accommodate that kind of residential use. It's cheaper than a nursing home, more intimatem and less bleak in many cases. The price on those was between 3000 and 4000 bucks a month, and when I looked into them, there was one near the British home. A small Bungalow that had four people in it and an open bed in a room designed for two roommates, which is not uncommon.

These are often very very seriously Advanced Alzheimer's patients living out their lives. My thought was maybe my dad could live in one for a period of time near the British home, and realize that if he could learn to self manage his catheter, he could

maybe go back to the British home where my mom was living. So I knocked on the door of this Board and Care house on a Friday night, well after Sunset, which is when I finally could get over there, after visiting my dad in his rehab facility and my mom at the British home.

Since I'm a location scout and manager, I don't have any real discomfort knocking on doors, even after Sunset. I stand back, produce a business card, smile politely and try to reassure people who answer that "this is not a intruder knocking." The woman who answered the door was an African-American woman who was really an African actually, from the country of Zambia as it turned out, named Natasha.

She was working part-time - the weekend shift- at this Board and Care House.

I explained myself and told her about how I had about a week to figure out what to do with my dad, and I had decided to bring him home, and was just beginning to empty a room for him. But I had to figure out a caregiver strategy.

Since a few months earlier, my dad had an episode where he wouldn't wake from a nap after walking up to breakfast and back, and would just murmur and refuse to open his eyes. And when I reported it to the assisted living facility nurse, she said "if they won't Rouse from a nap, we have to send them to the hospital, that's the protocol. It's the rules the protocol." It turned out Mort was very seriously dehydrated, which he brought on himself by just not drinking enough water, because he didn't like

the sensation of having to go to the bathroom all the time (because of his growing urinary retention problem.) Since this was months before the fall that bumped his head, I didn't realize how serious his urinary problem was developing to be. At the hospital they gave him an intravenous introduction of fluids and he bounced right back, but my dad was feeling quite sorry for himself and figured after the ambulance ride to the hospital that it must mean he was dying and he was sort of playing the role of the "dying man on his deathbed" quite convincingly.

And so the case manager at the emergency room was scratching his head and consulting with me and saying, "look if I send him to a SNF (Skilled Nursing Facility) tonight for Rehab, they'll probably just send him back to the hospital, because he's being persistent with this "I'm dying" presentation - laying on his back with his mouth wide open, and being non-responsive to verbal prompting. And I said, "Well, I'll just take him back to the British home, to his room. I have my car here - I'll just take him back." He came in the ambulance, but I had my car and offered to take him back. Little did I know that the protocol is that the hospital is supposed to call the assisted living facility medical director / nurse, even if it's over a weekend or late at night, and get "permission" to send him back. And generally, the assisted living home will refuse until he/she has been through rehab first - they want to be sure the resident is stable enough to resume their lives at the community. But when we loaded my dad into the ambulance when he wouldn't rouse from his morning afterbreakfast nap, the nurse/director forgot to tell me the protocol

and didn't say anything to me in the driveway about "they have to call me before he can come back," or some such thing. So I didn't know, and I think the case manager at the hospital took advantage of my ignorance, because when he came back from Consulting with the doctor, he said "the doctor and I think that's probably the best idea - for you to take him back." I didn't understand his question earlier, which was "will they take him back?" I just answered, "Well, I'll take him back - I have my car right here." It was then that he sort of clammed up and didn't give me any more information that night about "they have to agree to take him back" or anything like that. So I didn't know.

Anyway, I took him back. And the next morning, because I stayed there all night with him in his room, I mentioned to the nurse, when she asked me sort of plaintively, "How is Mort doing?" - that "Mort's fine - it was just bad dehydration." She said "Well, where is he?" - thinking he was at some rehab facility or another, and I said, "Oh he's in his room," and she freaked out and said "What? he's in his room? I didn't get a call!" and I said, "Well no one told me to call you, and I just brought him back because they let me."

So she made me get him a caregiver in his independent living room for a couple of weeks, because the Assisted Living Cottage was full, and he had just come back from the hospital and clearly couldn't be considered an independent living guy for the time being since he didn't go through rehab, and he wasn't given a clearance to go back to Independent Living. So I hired a

caregiver whose business card was dropped off at the Pasadena convalescent Aid Society nearby, where I got hospital beds and wheelchairs, and the like, free of charge. They are a real godsend to the community. And they happened to have, when I asked, the name of a woman who did caregiving services, so I called off her business card and hired her to come over to the British home and take care of my dad for a couple of weeks until everybody was in agreement that he could live independently or they found room for him in Assisted Living.

At that time I realized the style these caregivers apply is "Sleep in the same room as the person you're taking care of, so that when they wake up you wake up and you can attend to their needs." She was quite devoted, and kind of obsessive - a Filipino woman who had some language difficulties, but I was able to communicate with her, and she had quite a lot of experience, and for \$220 a day she would spend 24 hours taking care of the elderly person in her charge. She had spent 14 years taking care of a woman in her house in the rich community of San Marino near where I live, and the woman hadfinally died. She had Alzheimer's disease for 14 years and this woman lived in the house and took care of her, and the nephew would come and visit and see his aunt with her hair made up, Cosmetics on, clean pressed clothes, Clean and Comfortable. She did this for 14 years, 24 hours a day living in this woman's home.

So I'm talking with Natasha at this Board and Care Facility and mentioned that I had hired one caregiver for two hundred twenty dollars a day for 24 hours - to sleep in the room with him and provide caregiving, and that I was given to understand that \$220 was a fairly reasonable rate for that, and Natasha, without missing a beat, said "Well, I would do it for a hundred and eighty." And I said, "Well you seem like a pleasant and qualified woman. Why don't you come and take a look at the room and we'll talk about it." She did just that, and without checking references or anything. I just liked her - and I hired her.

Natasha slept in a twin bed next to my Dad's hospital bed and was with him 24 hours a day, 5 days a week (with another older Zambian woman handling Saturdays and Sundays), emptying his catheter collection bag, showering him in the bathroom, helping him dress, handling his meal preparation and presentation (I helped a lot with that)all in a room in my house for 14 months until he died peacefully with us surrounding him.

#### **CREMATION**

Mort and Marilou were well-organized with their last wishes — they both had wills drawn up and they communicated to me years ago that they had selected cremation and had contracted with National Cremation Service to make the process trouble-free.

Here are the particulars of their arrangements and a quote from the National Cremation Website: Josue H. Najera

**Cremation Arranger** 

National Cremation Service (local contact - they made their contracts in Florida)

10559 Victory Blvd., North Hollywood, CA 91606

E: Josue.Najera@sci-us.com

P: 818.755.5030 F: 818.755.5039

www.NationalCremation.com

2/28/05 cash receipt - payment to contract \$586.98 - conv47360958 - ref# 00006320 - marilou mendel 2/28/05 cash receipt - payment to contract \$586.98 - conv47360959 - ref#00006319 - mort mendel orig contract date 8/19/91 \$550.00

"When we founded National Cremation in 1973, we set out to help families that choose cremation for their final needs by providing a simple and affordable cremation service. Today, 160,000 families later, we are the nation's oldest and largest provider of cremation services, still helping families plan.

We have learned from our client families along the way. We have learned that individuals and families choose cremation for a variety of reasons. Many choose cremation for the low cost and simplicity; others to reduce their eternal land use. Over the years, we've become not only cremation specialists, but cremation experts.

## Perspective: Five Actions to Address the Crisis in Long-Term Care Services and Supports



Media Contact
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#### September 16, 2019

The eldercare crisis is among the top policy challenges facing the nation, yet the scope of the response to the crisis continues to fall short, even though the health and well-being of millions of Americans are at stake. What can states and their partners do to change this?

National Cremation appreciates the opportunity to work with you and your family and show you how simple cremation can be. Whether you have an immediate need at the time of death or are preplanning cremation for a future need, you are sure to find that our cremation services meet your needs.

Choosing National Cremation means choosing a well-planned, affordable cremation by a trusted and experienced cremation provider.

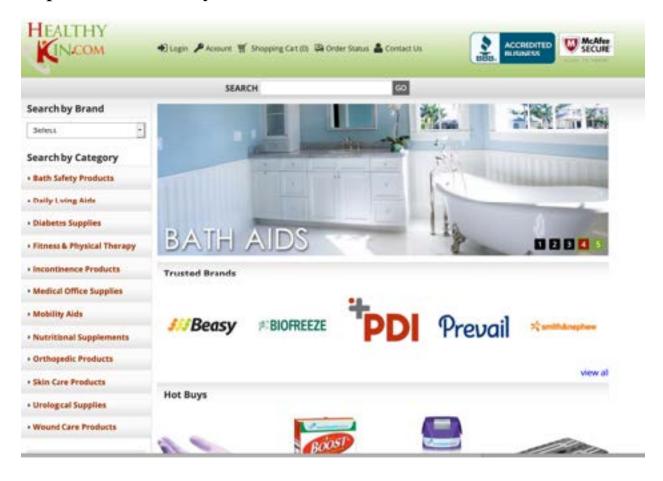
To learn more about National Cremation and our services contact us by calling one of our offices, filling out the contact form on this page, or calling (855) 469-9474."

#### **APPENDIX**

## QUOTES AND LIFTS FROM OTHER READING MATERIALS OF INTEREST

#### LINKS OF VALUE:

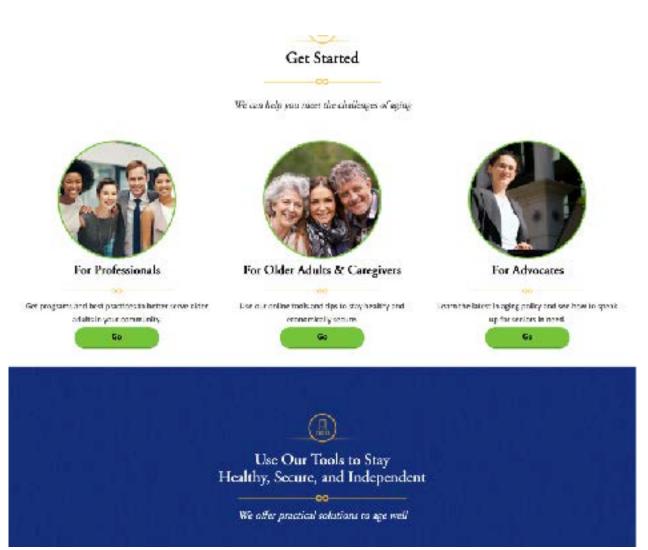
https://www.healthykin.com/ -



#### **NATIONAL COUNCIL ON AGING**

https://www.ncoa.org/

#### START THE CONVERSATION



The right time to talk about the future is now—even if it's uncomfortable. Ask your loved one about their wishes, values and preferences on things that matter, from health to finances. If you wait until a fall, accident or serious diagnosis, your choices may be more limited and more difficult to evaluate when everyone's stress levels are sky-high.

ather than bringing up a tough topic out of the blue, it can help to point to a newspaper story or a relevant comment as a conversation-starter. (Example: "You mentioned your eyes are bothering you. Is this causing problems with reading or driving?")

- **Don't forget to talk about money:** It's often at the heart of decisions you'll make as a caregiver. Respectfully ask them to review their bank accounts and health insurance so you can know how much is available to cover potential costs.
- **Listen to and respect your loved one's desires:** The person you're caring for should always participate in discussions about their needs and plans for their future, to the extent that it's possible.
- **Bring others into the conversation:**Once you've started the discussion, you may wish to ask a few other people close to your loved one—family members or friends—to be part of the process. There may be conflicts, but don't be afraid to talk through them. Better now than in a time of crisis.

#### 2. Form a Team

Don't go it alone. Trying to handle the responsibilities of caregiving yourself can lead to burnout and stress-related health problems. It's important to reach out to form a larger network of friends, family and community resources that can help you. Remember to consider your loved one part of the team.

- **Go deep and wide:** Team members' need not all live nearby or have huge blocks of time to be of value. Family or friends living at a distance with limited schedules can pitch in with meal organizing, bill paying, or financial assistance. The computer whiz in the family could set up an electronic calendar for dinner delivery or chores.
- **Decide who's in charge:** It's important to have a point person to keep the process moving and make sure everyone on the team understands the plan and priorities. In most families, one person assumes the primary role because he or she lives nearby, has a close relationship, or simply is a take-charge person. That may be you.
- Consider a mediator: It can be useful to engage an unrelated facilitator, such as a social worker or minister, to help keep everyone focused, manage potential disagreements and communicate difficult subjects when meeting with your team.

#### 3. Make a Plan

Now it's time to work with your team to develop a plan, thinking both short term—such as determining who will be responsible for each caregiving task—and long term. You can't anticipate every detail or scenario, but being forward-thinking now will help you respond more quickly and effectively in an emergency. It also helps assure that everyone keeps the focus on what's best for your loved one.

- **Determine roles:** Ask your caregiving team members about what tasks they can and are willing to take on, while considering key points. Who is free to travel to medical appointments? Who can prepare meals a few times a week? Who can be responsible for bill paying? If you're the primary caregiver, delegating even small tasks can make a big difference in your busy schedule.
- **Be honest with yourself:** What are you prepared to do? If you are uncomfortable with hands-on caregiving tasks, such as helping a loved one bathe, ask if another team member can step in. Or discuss whether there is money available to hire assistance.
- **Summarize the plan in writing:** A written record will assure that everyone is on the same page and avoid misunderstandings (while remembering, of course, that the plan will likely change as time passes).
- **Find the best way to communicate:** You may want to set up an email group to keep everyone up to date. And consider using an online scheduling tool such as <u>Lotsa Helping Hands</u> to organize and stay current on who's doing what, when.

#### 4. Care for Your Loved One

This step encompasses the others, of course, and every caregiver's situation is different. But there are a wide range resources and tools that can make your job easier, whether you're caring for a parent from another state, a spouse with a long-term illness or a family member with dementia. In any caregiving situation, it's important to know where to get information and assistance.

- Advocate for yourself: Let the doctor know that you are the primary caregiver and need to be informed about your loved one's condition and the treatments prescribed. Ask for training if you are expected to do procedures you've never done at home, such as injecting medication or changing bandages.
- **Keep the home safe:** If the person you're caring for has more difficulty getting around or their vision or hearing fades, some simple changes can be made to make their home less hazardous. Consider installing things like handrails, grab bars, nightlights and adjustable shower seats.
- **Stay organized:** It can feel overwhelming to try to keep track of all the information involved in caregiving—emergency phone numbers, medical appointments, health records.

#### 5. Care For Yourself

As a family caregiver, it's easy to forget about your own needs—which is why caregivers are more likely to report high stress levels and suffer from depression, and other health problems. Don't neglect exercise, sleep and healthy eating, and take time for activities you enjoy. You'll need to keep up your energy and stay well to care for others.

- Understand caregiving's costs: Your personal finances can take a hit from family caregiving—which might require time off of work, cutting back on hours, or passing up promotions, as well as paying for things like groceries and prescriptions for your loved one from your own pocket. Try to calculate these costs when budgeting.
- Find out if your workplace is accommodating: Your employer may be fine with your working from home part-time or making certain adjustments to your schedule. If you need more time off, consider asking whether you are covered by the Family and Medical Leave Act. (Many are, but if you work for a small company or haven't worked for your employer long, you may not be eligible.)
- **Give yourself a break:**Sometimes caregivers feel guilty about taking time to have fun. Find ways to reduce your stress and enjoy yourself. Many turn to yoga or meditation, or arrange a weekly movie outing with friends. Think about what activities you find relaxing and/or energizing and put them on your to-do list.

### Caring for a Loved One at Home

Caring for a Loved One at Home Nearly half (48 percent) of family caregivers are caring for someone who lives in his or her own home, while an additional 35 percent are sharing a home with the loved one for whom they're caring. Some are caring for a spouse or partner, many for a parent — all working to help that person stay at home for as long and as comfortably as possible. Your caregiving role might involve simply stopping by to check in every few days (if you live separately) or assisting with everything from bathing and meal prep to medication management and administering injections.

#### 1. Develop A Plan

It's important to always think both short term (prescriptions are due for refill) and long term (the "what ifs"). You can't anticipate every scenario, but being forward-thinking now will help you respond more quickly and effectively in an emergency. And don't go it alone. Reach out to form a larger team of family, friends and others who can help you.

- **Determine tasks and find consensus.** Ask team members what they're willing to do to contribute to your loved one's care. Even if they live far away, they can handle jobs like paying bills, ordering prescriptions and scheduling medical appointments. Work with the team on a plan.
- **Be honest with yourself.** What are you prepared to do? If you are uncomfortable with hands-on caregiving tasks, such as helping a loved one bathe, ask if another team member can step in. Or discuss whether there is money available to hire assistance.
- **Summarize the plan in writing.** A written record will ensure that everyone on your team, including your loved one, is on the same page and avoids misunderstandings (while remembering, of course, that the plan will likely evolve as time passes).

#### 2. Make Safety Adaptations

If the person you're caring for has difficulty getting around or compromised vision or hearing, you'll need to consider ways to make home less hazardous. If you're unsure, consult a professional who can assess the home and make recommendations — an occupational therapist, geriatric care manager or aging-in-place specialist. Be alert to changing needs as time passes.

- Make simple fixes for fall prevention. Some basic, low-cost changes include removing trip hazards, such as throw rugs, making sure the home is well lit (use automatic nightlights) and installing things like handrails, grab bars and adjustable shower seats.
- Make adjustments for dementia. Dementia brings with it particular worries about selfinjury, though there are many ways to lower the risk. They include installing remote door locks, using GPS devices, disabling the stove and lowering the water heater temperature to 120 F or less.
- More extensive modifications may be necessary. When physical limitations are more severe, you may need to hire a contractor to make structural changes, such as installing wheelchair ramps and adjustable countertops and widening doorways.

#### 3. Manage Health Care Needs

Because hospitals have been discharging patients more abruptly to cut costs, tasks once reserved for nurses are now often handed off to caregivers, who sometimes get little or no training or instruction. Meanwhile the caregiver may be trying to keep track of a confusing mix of medications for a range of different ailments. The key is to stay organized and know how to get the help you need.

- Stay on top of meds. Create and maintain an updated medication list, with the name, dosage, prescribing doctor and other relevant information a handy document to bring to medical appointments. AARP's Rx app is one easy way to manage both you and your loved one's prescriptions.
- **Be ready to handle medical tasks.** Many family caregivers are required to handle challenging tasks at home, such as injecting medicines and inserting catheters. It's important to get detailed instructions and even a demonstration of how to perform the procedure before you leave the hospital.
- **Set up home health services.** Medicare will cover certain in-home services deemed medically necessary such as doctor/nurse visits, X-rays, lab tests or therapies. A patient who is considered homebound, or unable to make an office visit, qualifies for these services on an ongoing basis.

#### 4. Create a Healthy Lifestyle

Especially if you are sharing a home with the person you're caring for — most likely a parent or spouse — caregiving can become all-consuming. You may find yourself playing nurse, coach, nutritionist and social director. All of these roles are important for maintaining your loved one's mental and physical health. Just don't neglect your own.

- Address social needs. Isolation and loneliness are associated with poorer health so helping your loved one (and yourself!) avoid them is a key part of caregiving. You might find a community arts program for seniors, invite friends and family members to visit, or go out to eat together.
- **Manage nutrition.** Be conscious of any dietary restrictions, and encourage your loved one to maintain a balanced diet, avoiding processed foods. Look into home-delivered meal programs and be sure your loved one drinks plenty of fluids; dehydration can cause fainting, headaches and more.
- **Encourage exercise.** Staying mobile is crucial for maintaining among other things strength, balance, energy and brain health. Your loved one's abilities will vary, and you should check with a doctor, but the routine may include activities such as walks, seated yoga, swimming or lifting small weights.
- **Establish boundaries.** Especially if you and your spouse/partner are living with the person you're caring for, it's important that everyone has a level of privacy. Ideally there is some separation between living areas and you can manage some time together as a couple.

#### 5. Get Help

Depending on the severity of your loved one's problems, if you're the primary caregiver you're going to need either a bit of assistance or a whole lot of it. Rely on your team for help with some caregiving tasks and to fill in so you can take breaks. Don't feel guilty: Your own health — and the quality of your caregiving — will suffer if you try to do everything and don't take time to care for yourself.

- Ask friends and family members for help. There are plenty of people in your life who may be happy, or at least willing, to lend a hand if you simply ask. Maybe someone can pick up a prescription for you on the next trip to the store, or a neighbor might stop by with dinner once a week.
- **Farm out some household jobs.** Consider paying for relatively small services that will take a big load off, such as a weekly housecleaner, yard care or grocery delivery. If you live apart from your loved one, you might do the same for your own home.
- **Hire in-home care.** You can go through an agency or hire a caregiver directly, but either way, be sure to check references and background, then monitor performance carefully (cautionary tales abound). It's smart to rely on word of mouth; ask fellow caregivers for recommendations.
- Watch your mental health. As a caregiver, you are at a higher risk for stress and depression. If either grows serious, seek help from a mental health professional. And consider reaching out to other caregivers for support and advice.

#### **HACKS**

Does your loved one shuffle their feet or easily trip over things? To help cut down on trips and falls you can place red tape on all thresholds in the home. The red captures the brain's attention and forces the eye to look down, helping to prevent trips. You can also outline the edges of steps,

coffee tables and doorways with colored (plumber's) tape to help prevent bumps and bruises.



Use from tubing and a cable file to improve the usability of a doorinob. Cut the foam tubing to fit around the coorknob with excess at the ends to tie off. Whap the fraim tubing around the close knob and the off the ends with a cable rise.



Use a cardioperd tube and caple ties to create a case holder that effacties to the leg of your chair for easy access.



One way to note to evoid falls on supporty floors is to wear socies or support with rapper grips for better flection.



One way to help fall proof year home is to have a same in every room, You can get precise and have different styles of cames are lable for your levels one to provide stability white walking and to social in proventing falls.



histalling a metal kidle rick in your battarions makes accessing tweezers, fingernal outlers, scissors and other small motal items cuick and easy.



A convenient way to spere your leves one from walking through a dark house at night in serech of a snack or a drink of water from the kitches is to keep a mini findge in the bedreom. You can stock the fridge with juice, water and their feverite snecks to help your loved one avoid high time trip hazers.



A good way to help keep your leved one from falling an slippery floors is to apply non-alip point or finish to slick walking surfaces in and around your nome. The critiq texture can help prevent strong and falls.



Make thin handled objects no sits and easy-to-grasp by inserting the handle into a springe halr roller. Simply response the pleatic clip from the roller and insert the handle.



Leaning slows to put on a pair of shoes can be a difficult measurer for some. It help with the process, you can buy a couple of 21-inch for longers shoehoms and leang them where you put on and taxa off your shoes. This will make chessing much occur.



# Perspective: Five Actions to Address the Crisis in Long-Term Care Services and Supports

https://www.altarum.org/news/five-actions-address-crisis-long-term-care-services-and-supports

## **Top 5 Solutions to Aging and Long Term Care Crisis**

http://www.altcp.org/aging-long-term-care/

## How to plan care for your later years when you're aging solo

https://www.iona.org/how-to-plan-care-for-your-later-years/

## The Forgotten Middle: Many Middle-Income Seniors Will Have Insufficient Resources For Housing And Health Care

https://www.healthaffairs.org/doi/full/10.1377/
hlthaff.2018.05233



HOW WE WORK OUR PROJECTS

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#### **Long-Term Care Financing**

> OUR PROJECTS > LONG-TERM CARE FINANCING



Convergence Long-term Care Financing Collaborative

The Challenge



expanded to accommodate people with more complex needs. These settings provide housing in a community environment that often includes personal care assistance services. Unfortunately, these settings are often out of the financial reach of many of this country's eight million middle-income seniors (those ages seventy-five and older). The private seniors housing industry has generally focused on higher-income people instead. We project that by 2029 there will be 14.4 million middle-income seniors, 60 percent of whom will have mobility limitations and 20 percent of whom will have high health care and functional needs. While many of these seniors will likely need the level of care provided in seniors housing, we project that 54 percent of seniors will not have sufficient financial resources to pay for it. This gap suggests a role for

network of friends and social groups, as well as a cellphone app, to make sure she is checked on periodically. Jeremy M. Lange for The New York Times

By Susan B. Garland

### **Long-Term Care Financing**

https://www.convergencepolicy.org/latest-projects/long-termcare-financing-collaborative/



We must note that advantage plans siphon off funds from the Medicare program into private insurance companies; generally restrict users to their private networks and don't cover all that regular Medicare does.

The coverage of Medicare Advantage Plans can now automatically and smoothly renew for beneficiaries each year. For those who have no desire to make changes in their Medicare Advantage Plans, no further action will be required as the renewal will be automatic.

Some of the cost-sharing requirements of Medicare Advantage plans will be different. The changes are meant to offer more benefits for Medicare beneficiaries.

Medicare Advantage plans may have certain medical criteria that let the plans charge different annual deductibles. Private carriers are no longer required to submit certain accounting info when they bid to offer Medicare Advantage plans. This may lead to more carriers offering Medicare Advantage Plans.

https://onecentatatime.com/changes-in-medicare-for-2019-you-should-know/#comments

## Medicare Allows More Benefits for Chronically III, Aiming to Improve Care for Millions

June 26, 2018

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Source: New York Times

Congress and the Trump administration are revamping Medicare to provide extra benefits to people with multiple chronic illnesses, a significant departure from the program's traditional focus that aims to create a new model of care for millions of older Americans.

The changes — reflected in a new law and in official guidance from the Department of Health and Human Services — tackle a vexing and costly problem in American health care: how to deal with long-term illnesses that can build on one another, and the social factors outside the reach of traditional medicine that can contribute to them, like nutrition, transportation and housing.

To that end, the additional benefits can include social and medical services, home improvements like wheelchair ramps, transportation to doctor's offices and home delivery of hot meals.

The new law is a rare instance of bipartisan cooperation on a major policy initiative, embraced by members of Congress from both parties. The

### Medicare Allows More Benefits for Chronically Ill, Aiming to Improve Care for Millions

https://jrreport.wordandbrown.com/2018/06/26/medicare-allowsmore-benefits-for-chronically-ill-aiming-to-improve-care-formillions/



## The SCAN Foundation is an independent public charity devoted to transforming care for older adults in ways that preserve dignity and encourage independence.

https://www.thescanfoundation.org/chronic-care-act-2018-advancing-care-adults-complex-needs

## **Health Affairs**

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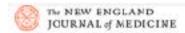
### Medicare Advantage Flexibility: Improving Care For Seriously Ill Beneficiaries

Allison Silvers, Torrie Fields, Anna Kytonen, Diane E. Meier

JULY 6, 2018

10.1377/hblog20180702.641853





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### Perspective

Integrating Medical and Nonmedical Services — The Promise and Pitfalls of the CHRONIC Care Act

Amber Willink, Ph.D., and Eva H. DyCoff Ph.D.



## Medicare Advantage Flexibility: Improving Care For Seriously Ill Beneficiaries

https://www.healthaffairs.org/do/10.1377/hblog20180702.641853/
full/#

# Integrating Medical and Nonmedical Services — The Promise and Pitfalls of the CHRONIC Care Act

https://www.nejm.org/doi/full/10.1056/NEJMp1803292

https://www.aginginplace.org/how-to-select-a-long-term-care-insurance-plan/