Dementia Dialogues:

11.09.21 Navigating and Choosing Housing/Supports as we Live with Dementia
Jen Rynbrandt, MA, CMC-Clinical Team Leader, Ferretto Eldercare Consulting, Inc.

Planning and Education = More Autonomy and Control for memory loss individuals and their caregivers. Be prepared when investigating/seeking care, and "line up your ducks".

1. Optimize choices by seeking care/housing options when symptoms initially surface, if possible, if you meet the age and fiscal criteria for a CCRC or CCAH. You may have more options (such as a CCRC and CCAC) before testing reflects cognitive deficit. That said, testing should not be avoided once symptoms/changes are definitive and consistent.
2. Determine symptoms and needs (assessment, ADLs, testing for cognition to determine stage of dementia and forecast needs for coming months/year).
3. Ensure that legal designations are already made for Health Care and Financial POAs for the individual experiencing memory loss and the spouse/partner/primary caregiver. Advocating for a vulnerable person includes making determinations for yourself as well.
4. Look at resources and current sources of income to pay for the appropriate care and determine an optimal budget to include guaranteed monthly income as well as investments or community-based resources to draw from/supplement.
5. Move only once, if possible, when memory-loss is present. Folks with memory loss may have more difficulty acclimating to new environments/people the further along they are in the disease process.
6. Don't present any ideas as permanent or set in stone. Being flexible and open to modification may help the individual with dementia transition better into care.

Know what care models are available to you and costs for your area

1. Independent Living (IL): Apartment-style living that may offer meals on site, security, pull-cords and emergency pendants, activities, and some transportation. Usually, the most affordable model but offers no built-in care or oversight. Staff may be reluctant to offer help with interventions due to liability issues. These models generally start at $2500+

2. Assisted Living (AL): Usually smaller units or suites that may include a private or shared bath, a kitchenette or minifridge. All independent living provisions (rent) are included as well as all meals. Additional costs and added in for medication management, coordination of physician's visits or psych/behavioral support, and help needed with personal care (ADLs include bathing, dressing, toileting, ambulating, feeding, etc.) Care costs are determined by an assessment by an RN from the desired facility. Medical history will also be used in the evaluation, resources will be reviewed (to ensure payment for services rendered), and community fees are standard and generally start at one month's rent. An RN is on-site and there is a medical director or visiting physician or CRNP who can treat the residents if desired. Also on-site is behavioral health (therapists/mental health medication management), PT, OT, podiatry, dental cleanings,

ophthalmologists, and mobile X-rays through vetted vendors (with an Rx from a physician or CRNP). Private and semi-private rooms. Costs start at approx. $3k a month for semi-private or shared suite and can reach $9k+ care depending on community and size of unit (larger units command larger monthly rates). There is a discount for the second resident if two people are admitted together in the same unit.

3. Group Home Assisted Living- Assisted living on a smaller scale. Generally, licensed for 15 or less total beds in a residential community. Offers similar supports as larger ALs but are commonly locally owned and operated so more flexible for changing needs of residents. Also, more affordable and a family-like atmosphere in a renovated home that is ADA compliant or similar, elevators or chair lifts are installed, and meals are prepared in a standard home kitchen on-site. Many of these models accept county subsidies or "waivers" for low-income seniors who might otherwise be institutionalized in a nursing home. Check your local county Dept. of Aging to find out if there is a waitlist for waivers in your area. Waiver criteria is similar to Medicaid criteria for a skilled care facility (nursing home). In many group homes, there is one flat rate that is all-inclusive of care, room and board. May not be appropriate for wanderers unless all one level and fenced in yard with security measures on doors. Many group home ALs successfully care for folks with dementia who are not combative or pose an elopement risk. Group homes offer private and semi-private rooms and start at $2400 for a semi-private room. Residents in these models are also more likely to have access to outdoor spaces such as front porches and lawn/garden areas with oversight.

4. Memory Care- Memory Care can fit under both Assisted Living and Skilled Nursing depending on the funding. Memory care in standard private pay communities are generally assisted living. These are set-aside units/floors in an assisted living community. Because the staff ratio is higher and the environment is more suited for wanderers, memory care in assisted living is more expensive than the general population. Memory care in AL also have smaller units and may not offer semi-private or shared rooms /bathrooms due to behavioral needs or increased likelihood of needing hands-on full-assist with personal care activities. These units have large bathing rooms on each floor, not in the individual rooms, to accommodate the need for 2:1 caregivers with a larger floor space without barriers to enable less fall-risks. Memory care at assisted living also work in conjunction with hospice services in the very later stages of dementia if the resident/family does not wish to be transferred to a SNF for total care needs and if funds allow. Again, if elopement risk or combativeness is not a concern, the individual with dementia may be able to remain in the general AL population or reside in a group home with greater oversight. Memory Care at AL allows for folks with dementia to age in place but can be quite pricey. Expect monthly rates of approx. $6500+ There may also be a request from the facility for "private duty" caregivers to be engaged if the individual is up at night or requires more oversight due to high fall risk. Many times, this prompts families to seek Medicaid funding for the individual as care can exceed $12k+ per month including private duty or high level of care at the memory care AL.

5. Skilled Nursing Facilities (SNF or “sniffs”)-These are the priciest models of care and often offer the least amount of privacy and autonomy. $10k-$12k+ a month for folks that do not qualify fiscally or physically for Medicaid. However, most SNFs accept Medicaid for reimbursement, so it is often the only option for low-income folks with dementia and their families. SNF may also be the only safe option for individuals with dementia that cannot be managed in a less restrictive environment. SNFs often have “secure” dementia units with higher staff ratios, specific activities for folks with memory loss, and can accommodate wanderers as the dementia units are locked 24/7. Staff will also be familiar with psych issues and behaviors that often accompany dementia and there is a medical director on-site to make Rx changes in a timely manner. As dismal as some SNFs are, there are some others that offer good care and a more pleasant environment than others. These SNFs often have a lengthy waitlist (6mo-2 years), so we recommend getting on the waitlist, even if you change your mind and ultimate pursue another option. Always have a “Plan B” in the back pocket!

6. CCRC- Continuing Care Residential Communities. Also called Life Care Plan Communities. These communities encompass the IL, AL, and SNF offerings at one location or campus. Prior to covid, most CCRCs required entry as functional independent adults. They also made contracts confusing and exceedingly complicated for couples who were not equally well, or when one had a diagnosis such as dementia. These CCRC communities offer peace of mind for individuals and couples who can afford a hefty up-front fee, a physical and medical history review, cognitive testing, and rigorous fiscal review. Reason being the Type A contract that they offer may include caring for you after you have exhausted your resources. There are also Type B contracts that offer modified wording/care, and Type C contracts that are a fee-for-service contract where care is out of pocket at market rate and these residents would have access to the SNF on-site for rehab or nursing care if there are no Type A contract residents in need of available SNF beds. Some CCRCs have Medicaid contracts for the SNF area of the community to fund care after resources are depleted. Most all CCRCs have Medicare contracts so that residents can have rehabilitation on-site rather than having to go to another SNF off campus after a hospitalization. Some CCRCs also have memory care on-site. This is a good option for couples (or family members) who wish to be in the same community but need varying levels of care. CCRCs offer couples discounts that can often apply to domestic partners, siblings, or even a parent and disabled adult child.

Should I Stay or Should I go Now? Pros and Cons to Staying in Your Home

PROS to Staying Home:
Community (neighbors, place of worship, favorite restaurants, grocer, banker, etc.)
Familiarity
Budget Friendly *if home paid off
Privacy
Location
No Cost to Move
No Downsizing Required
Space
Family and Friends can visit easily and have accommodations

CONS to Staying Home:
Upkeep of home and insurance Costs, Taxes (!). I will have to drive to get where I want to go. Supportive services will be needed at some point and waiting until after decline will limit my choices. Housekeeping ($20+hr.); Meal Prep, Shopping, escort/transport, Doc's office, specialists, lawncare and seasonal services, in addition to personal care ($25+hr.) Autonomy at the risk of Isolation; Relying on kids or family members, safety in the event of an emergency such as a fall; not having anyone to check on me daily, not having health care providers or professionals able to see me immediately, lack of social stimuli, nutritional intake can go down (less access to nutrient-rich and fresh foods); Safety in numbers! TOO MUCH TV! Too much space to manage. Kids worried and it's causing tension—visits are no longer social—You are determined to remain independent but becoming increasingly dependent on kids. Weigh what your independence is costing others in time and efforts over the course of a week/month/yr.

OPTIONS FOR REMAINING AT HOME:

1. **CCAH-Continuing Care at Home**. A new model of care that brings the CCRC model and levels of care to seniors who own a home (and willing to modify for accessibility) or rent their home (that can be modified as needed or is already accessible). This model might also apply to folks over 60 who live in an independent living building/community. Like CCRC but with more affordable entry fees, the CCAC offers all levels of care but in the home. CCACs often have relationships with outside providers for placement if complex medical needs demand on-site care (such as on-site dialysis, infusions, extensive wound care, etc.) or behaviors pose a safety risk to the resident or caregivers provided. Like long term care insurance, CCACs provide several options for maximum daily rate as well as varying entry fees as low as $21k. This model targets seniors who are still well and living in the community who may not want to or be able to afford steep CCRC upfront fees and do not wish to move unless it is medically necessary. This model allows seniors to age in a place that is infinitely familiar, without changing medical providers, in a community where they have cultivated friendships, and by family members. This model also offers similar concierge services as the CCRCs including social workers to help once formal care services are active, a medical director, caregiver oversight by an RN, etc. These models may also pay family members (minimum wage or similar) who wish to serve as the primary caregiver of a member receiving care. CCAC models also offer a modified Type B contract for couples with one well spouse and one spouse with preexisting age-related disease or dementia that might disqualify them from a standard Type A contract.

2. **In-Home Care through an individual or agency**: As defined above as care provided in the home vs. in a formal care setting or community. Rates through an agency are approx. $25-$30+ per hour, although some agencies provide live-in caregivers who might work round the clock at a reduced rate. With live-ins the caregivers would tag-team with one or more other caregivers on 24 hour-48-hour shifts. Others alternative weeks. States determine parameters for hours worked/overtime. Some clients opt for finding their own caregivers in the community through friends, family, or online at sites such as Care.com. In the past, we've steered families away from these arrangements but again, Covid has pushed the paradigm and some of the better caregivers are leaving agencies to work for themselves at twice the hourly wage. If you desire to seek these

folks out, please perform a background check, and be sure they are licensed by the state, bonded, and insured! You will also want to check with your attorney and CPA for withholdings and taxes paid for hired employees. Each state differs on the definition of employees so again, please do your homework to protect yourselves and your assets!

3. **Home Sharing/ Co-Living for Seniors**- In this model, more than one senior in need of assistance would live as roommates or suitemates and share the cost of a caregiver. This option is gaining popularity as the cost of caregivers have increased to $25+ per hour (incl. night shift when the caregiver may be sleeping). Caregivers can provide light care, meal prep, light housekeeping, and transportation for seniors that are not in need of 1:1 care.

   In some areas of the country, savvy seniors are building multi-family homes in urban areas and sharing space within walking distance to their favorite shops/grocer/doctor. In other cities, Seniors are finding places to share a home with others to combat isolation and increase community. Online services such as Seniornest pair people with homes and even provide auto pay for rent, renter's insurance, and lease formats to utilize. Seniors in search of a younger person to help with chores and light care tasks in exchange for rent may want to consider this type of arrangement.

   There are also university and trade schools with students who may be willing to help with care in exchange for rent or at a more reasonable rate. This is how I got my first caregiving job as an undergrad for a tiny woman from Scotland, Helen, who was 95. I prepared lunch for her three times a week and helped her into bed for her afternoon nap after tidying up. I also provided company for her, which she really needed. It gave her daughter a much-needed break while allowing her mom to remain in the community, longer. Helen was able to avoid a SNF until she was 98! Her goal in life was to make it to the year 2000, and she did!

   I'd also recommend checking with a local nursing school, CNA/GNA training center, or undergraduate programs for PT, OT, or nutrition students. They need experience and may be willing to offer caregiving services in exchange for an hourly fee and a great recommendation! That said, be sure anyone you hire is bonded/insured or have your attorney write up a contract to protect yourself from caregiver injuries, abuse, and the dreaded IRS! Agencies are the safest method of acquiring qualified, trained caregiver, but again, Covid has created a nationwide caregiver shortage and even the better agencies are strapped and less than stellar.

4. Want to stay home but your home is not user-friendly for dementia**? There are certified home remodelers who modify existing homes using a PT/OT approach** to ensure proper floorplans, accessible bath/kitchen/entrance, install lifts, ramps, grab bars, and even replace slippery tubs with a stream-lined shower that is wheelchair accessible. Contact a certified Aging-In-Place Specialist through the National Association of Home Builders for a provider in your area at: www.nahb.org

5. Should I stay in my own community or move closer to an adult child? Oh boy, this is a loaded question! My first inclination is "yes", particularly if your adult child is also your POA for healthcare and finances and you are already feeling isolated and overwhelmed. But keep in mind-If you have more than one child, this determination may hurt some feelings or cause suspicion if family dynamics are less than ideal.

   But you will also want to consider the fact that unless you share the same zip code, this will mean finding all new docs, new friends, and new meaning in life, particularly if your child is busy with work and family. Has your adult child been begging you to consider? Then by all means, do! But you are settled and happy, have connections, and good supports where you are, this may not be the best thing for you.

   Things to consider:
   -How do I drop hints to the kid I'd most like to be nearby?
   -Are there motives to a child wanting me around more? (i.e., will I be expected to be an as needed babysitter?)
   -Is there any chance my child will have to move elsewhere for work after I move closer?
   -Are they available to me now when I need them? If not, this may be a pattern.
   -Do I have a child that I trust without reservation that wants me closer?
   -How often can I plan on visits from them if I do move?
   -Will I still need to engage the same supports I would need if I stayed put?
   -What will it cost me to move, and can I afford it?
   -Are there comparable community-based resources and supports available to me after I move (i.e., what is the wait for waivers, etc. after you declare residency?)
   -Make several trips for shopping senior communities before you decide. They may not have your preferred flavor. Have a professional help you whittle down the list beforehand.
   -What will a senior community cost me? Can I afford the one I like best?
   -Are there specialists there that are good and taking new patients?
   -There may be some initial awkwardness as you redistrict family and activities… (Amanda's mom doesn't like her church and wants her own. But this is a good thing!)
   -Take a test drive on a respite stay before putting all your eggs in one basket!
   -Reconsider living with a child unless their home is safe for your needs (i.e., accessible bathroom and entry, one level, etc.) and you will have your own private space for self-initiated time-outs, having guests over, making a mess, and decorating to your liking.

ODDS AND ENDS for housing, whether in your home, or venturing elsewhere…

The Alzheimer's Association also offers a free guide to "dementia friendly" homes at www.alzheimers.org.uk that addresses the need for good lighting, organization, reducing fall risk at home, eating and drinking, and tips for safety and furnishings.

An accessory dwelling unit might also be a possibility and can be purchased as "kit-homes" for a backyard granny flat to add square footage to a family home of a child or trusted friend. These are one-level, easy to navigate, and can come with a small kitchen and accessible bathroom upon request. Considering the price of 2x4s right now, these little, tiny homes may be a quick, affordable, and viable option and add value to the home and lot it sits on. Getting a permit may also be easier than a new build as the square footage is petite. Studio Shed is one of my favorite sites for these granny flat ADUs. These tiny living solutions may not be appropriate for four seasons living in cooler regions but being outdoors with touch, color, fresh air, greenspace, and wildlife can offer stimuli like no other as well as reduce anxiety.

Consider utilizing medical adult day programs when the individual is further along the dementia spectrum, but the well spouse or family members need respite during work hours. These day programs are often subsidized or private pay, and offer meals, transportation, snacks, and meaningful activity so that the individual with dementia has a full day of activity translating to better rest at night. Many times, the primary caregiver ends up being up all night and getting so worn down from lack of sleep that placement becomes a consideration. Rather than decline with the memory loss individual, have that loved one go out for the day so that you can rest. If they resist at first, present it like a job. Pack them a lunch and help them get "dressed for work". Adult Medical Day Programs can also be accessed through some SNFs. Check with your local Dept. of Aging for listings.

Join a support group! I'm certain most of you have already done this but it is never too early to plug into a group for support for both now and the future. Couples battling early onset can even attend together in separate groups but at the same location so that transport is easier. Find a list of free support groups near you through the Alzheimer's Assoc. website.

Mental health supports for both the person with memory loss and the spouse, partner, and family members are recommended. Loss of a spouse, partner, friend, or family member to dementia is a long and heart-breaking journey. A therapist can help work through inherent changes in communication and intimacy, transitions, steep declines, and decision-making as well as provide a safe place (aside from friends and family) to share feelings that you fear others may judge you for. Ask your doctor for a referral! Many therapists will come to you at home for an nominal charge and most accept insurance.

If you are already in need of care, then have a pow-wow with friends and family about your needs and see if someone you know and trust would like to be reimbursed by the fed/state for caregiving if you qualify fiscally and medically. Otherwise, ask people in your circles if they know of a responsible person that provides care, is responsible, and pleasant to be around. Also contact nearby agencies who may be able to fill in hours or provide round the clock care for a high level of needs.

One way to lessen the burden of high-cost care and low caliber caregivers, is to have a family calendar (online!) and engage immediate and extended family and friends to each pick a two-three-hour time slot during the month to give the primary caregiver a break to care for themselves, run errands, or even have a night or two away! Spread the love and ask for help with this. Even high schoolers and college aged family members can participate. It's a wonderful opportunity for them to contribute to their elders and know them beyond snippets of time during holidays. Sometimes people are too busy to commit to taking someone to a doctor's appointments, but they may be able to shop, pick up groceries, or help with some light housekeeping or laundry if they aren't able to be a sitter once a month. If the needs are spread out, then willing helpers are less likely to get burned out.

The holidays are coming up! Ask for caregiving hours instead of gifts from friends and family if that is what you would really love! I recently had a client who loved decorating the family home for Christmas. She had three trees decorated, music on, and lots of lights. It drove her minimalist husband NUTS, but it made her so happy! I realize that this may be a safety hazard for some so use your own judgement when choosing home décor tasks, but it may keep your loved one busy and smiling! If there are holiday displays in your town or neighborhood, drive around after dark and look at them together! This is also a great time of year to drive by senior communities who may have also decorated for the holidays and offer a great excuse to tour and have lunch!

Most importantly, be flexible! Be willing to make modifications if your ideal housing/care scenario doesn't work out. Rigid folks do not age well, and a laid-back caregiver attitude is best for the environment of an individual with dementia. With that in mind, enable humor whenever possible! Watch funny movies/stupid movies that will help you and the person you are caring for laugh and let go! If there is one thing I tell families that are battling memory loss, it is to turn the news off, bundle up, and go outside. Exercise. Take care of your body (and theirs!) with good brain-healthy food, drink lots of water, and when those overwhelmed feelings begin to creep up, ask for help before your circuits overload. Try a meal delivery service for a month such as Sunbasket or Blue Apron and cook together (premeasured ingredients make it fast and easy!). Look at cookbooks together, design magazines, art, or watch your favorite performers live-stream for a concert on the couch. Consider a therapy pet from a local shelter or browse on Petfinder.com. Or consider for a couple's message, if safe and the individual with dementia responds well to therapeutic touch.

There are so many more options for living with memory loss than there were even ten years ago. New models of care and care delivery during Covid have only increased the need for greater education and exploration of supports such as housing and care ahead of time. If you have legal determinations established, have investigated planning with your attorney and financial professional and have a budget in mind, you can better determine whether staying put or initiating your next adventure is in order. Know what your choices are ahead of time. Put your name on waitlists even if you aren't sure that a

move is for you. Seek out communities that fit your flavors in size, culture, food, location, and price point. Tour and remember to be on your best behavior because while you are interviewing them, they are also interviewing you!

Most of all, go at your own pace and educate yourselves well beforehand. Don't wait for a crisis to decide where and how you plan to live with dementia.

Questions???