

Arctos Foundation / HCG Secure

Adults with Parents who Need Long Term Care

A series of qualitative discussions

November 2022

Approach

- **In an online survey conducted about long-term care issues, a sub-sample of 109 individuals were identified as those who had a parent (of their own or of their spouse/partner) who needed long-term care.**
- **These individuals were recontacted and invited to participate in a series of 1:1 remote (Zoom) interviews. The purpose was to let them tell their stories more fully and reflect on how the experiences impacted them at the time and now as they plan for their future.**
 - In-depth interviews were completed with 10 of these individuals between April 4 and April 12, 2022.
 - Each session lasted about 45 minutes.
 - Participants were given a \$100 gift card as a token of appreciation for their time.

NOTE: The online survey was done with the middle market, defined as individuals aged 40-64 With a household income between \$75,000-\$150,000. The vast majority were working but some were recently retired.

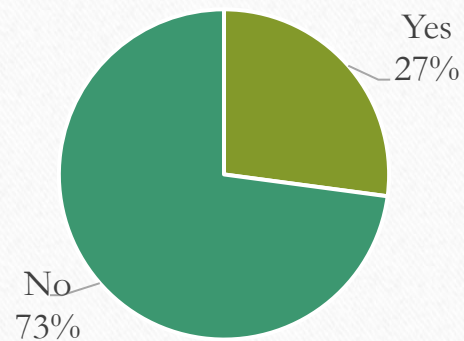
Previous Experience with Parents who Needed Long-Term Care

This section is based upon a smaller sample (n=109)

About one-quarter of this segment have a parent who needed long term care or assistance with daily living tasks.

- Those who are 50-64 are more likely to have had a parent who needed long-term care than those 40-54 (35% vs. 22%).
- A small subsegment (3%) experienced LTC needs for parents in more than one household. They were asked to focus on the household that needed care most recently for the following questions.
- Respondents who have experienced their parent's LTC needs are more likely to have had a conversation about their own wishes for potential long-term care than those who have not experienced this first-hand (51% vs. 40%).

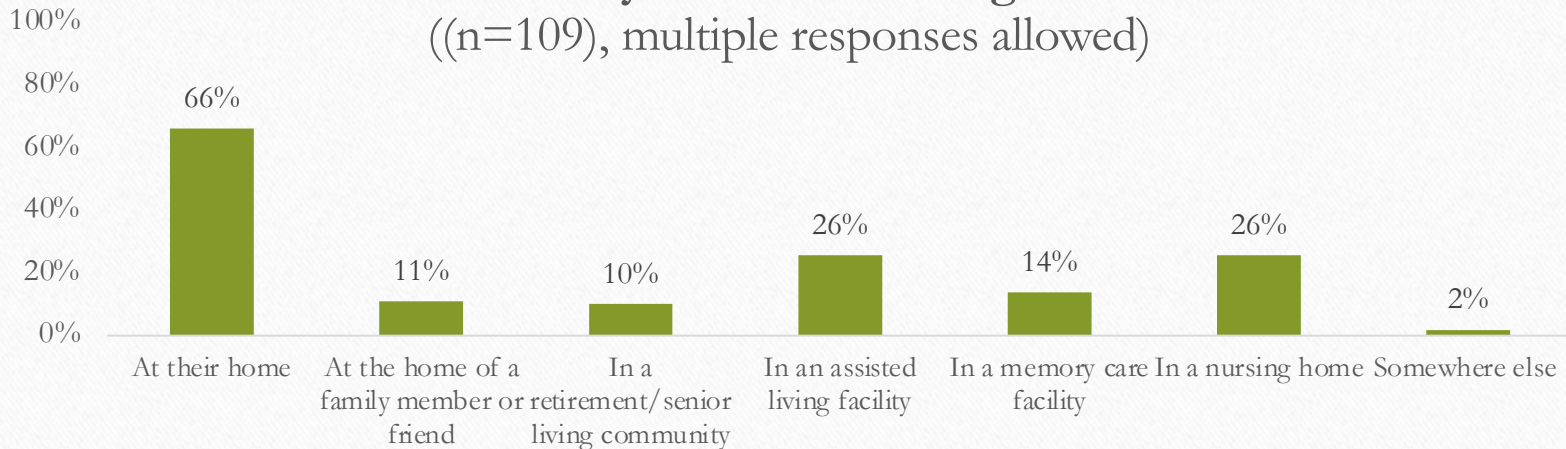
Has a parent of yours ever needed long-term care or care for daily living?



Two-thirds of these parents received long-term care in their own home, but about one-quarter were either in an assisted living or a nursing home.

- When looking at in-home and out of the home care:
 - Roughly three-quarters received at least some care at home.
 - About half received at least some care in a facility/nursing home.

Where did they receive their long-term care? ((n=109), multiple responses allowed)



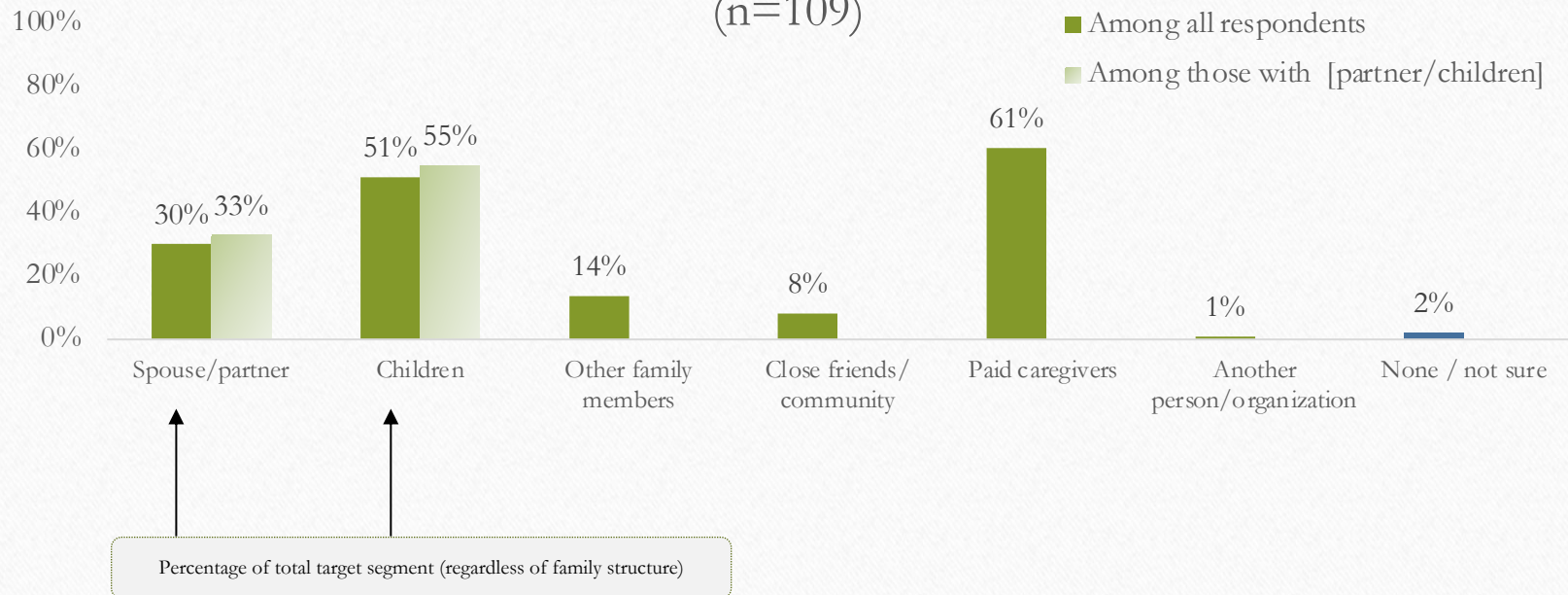
Those receiving care in home: 73%, or 78% if including senior living

Those receiving some care provided by any one of these (or multiples): 47%

Paid caregivers provided support for more than half, followed by adult children.

- This sample was too small to look at sub-segments.

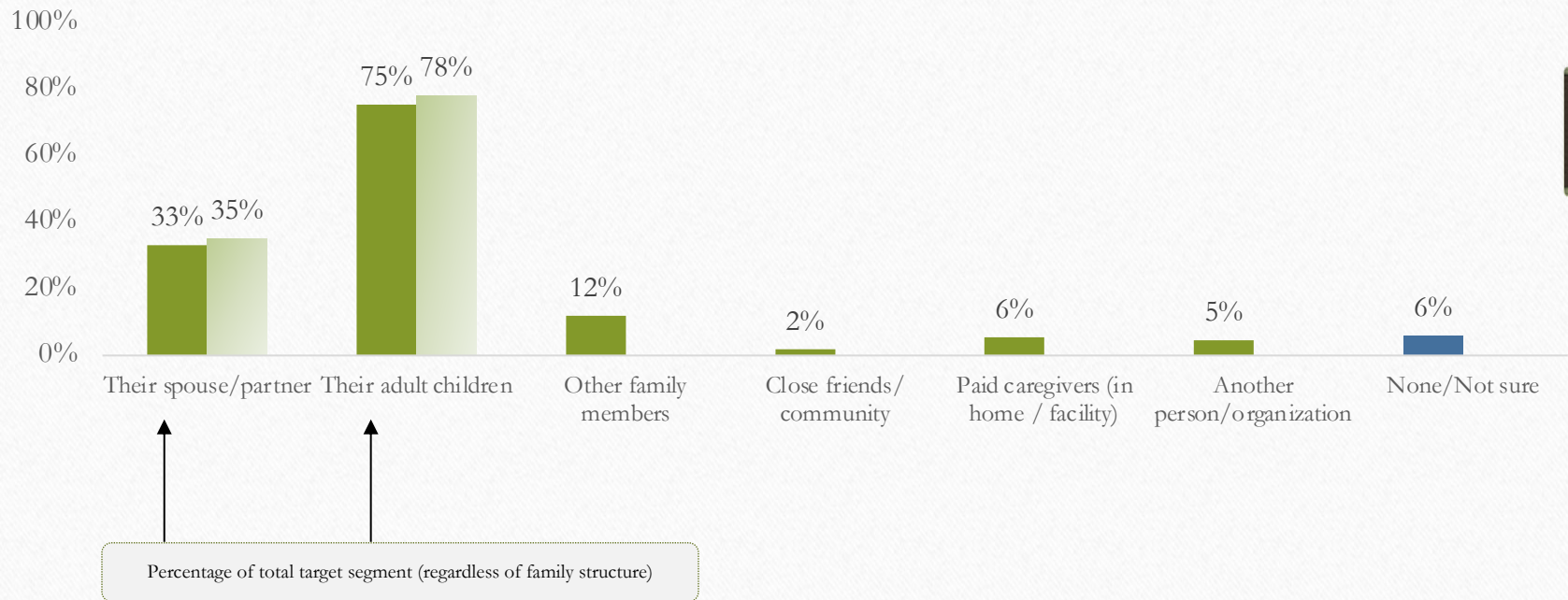
Who provided their physical support? (n=109)



Adult children predominantly navigated care options, followed by spouse/partners.

- This sample was too small to look at sub-segments.

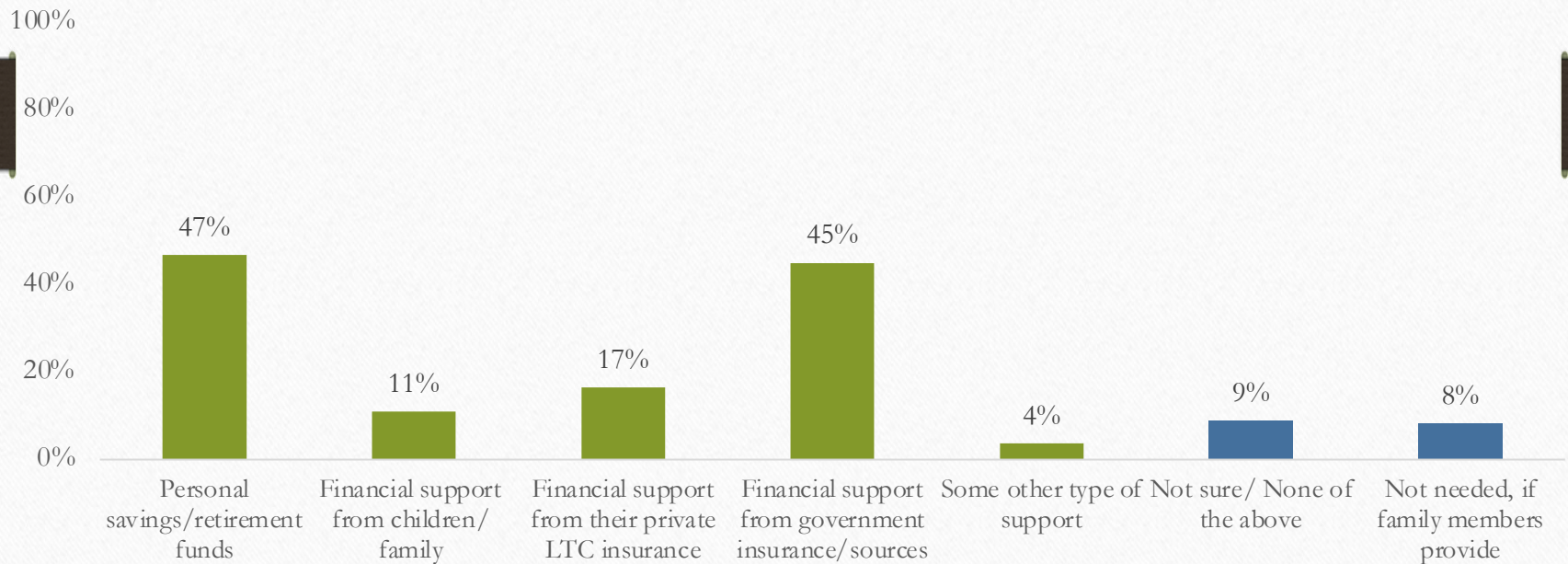
Who was involved in navigating care options for this parent? (n=109)



Costs were covered through personal savings/investments and then from government insurance/sources.

- This sample was too small to look at sub-segments.

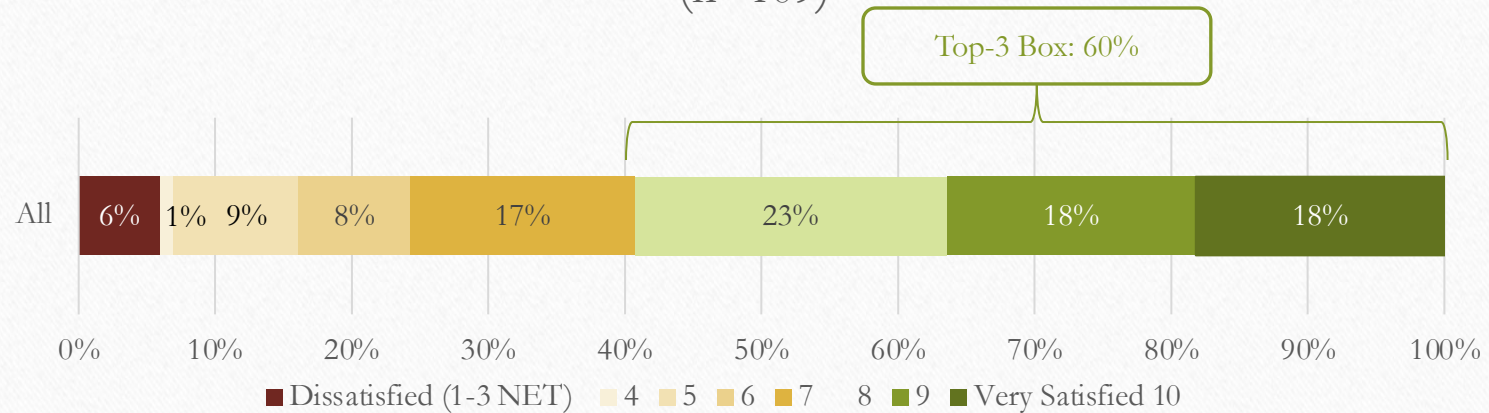
How did they cover the cost of their long-term care? (n=109)



Satisfaction rates are moderate: six in ten rate their satisfaction in the top-3 box range on a 10-point scale.

- This sample was too small to look at sub-segments.

How satisfied were you with the overall care they received? (n=109)

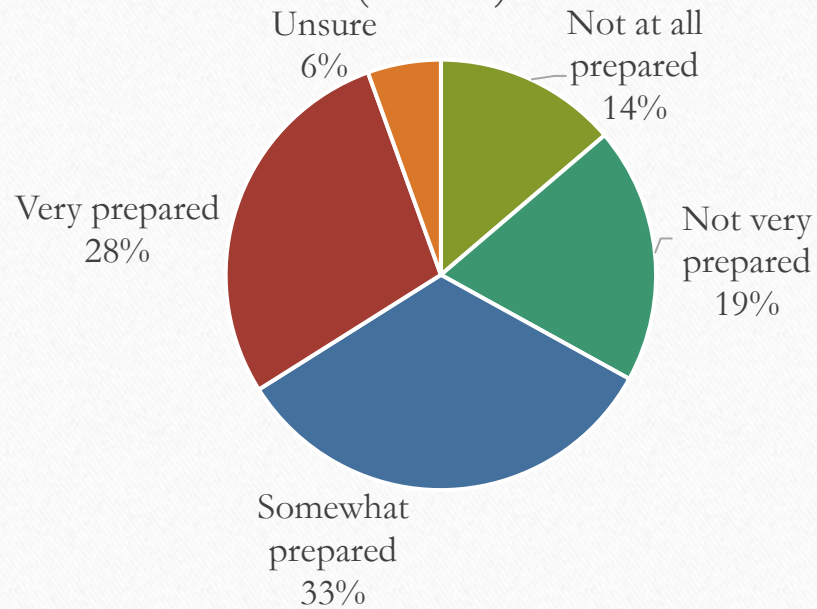


Only about one-quarter felt their parents were very prepared to cover the costs, and about one-third were not very or not at all prepared.

- This sample was too small to look at sub-segments.

How prepared were they to cover the cost of this care, as far as you could tell?

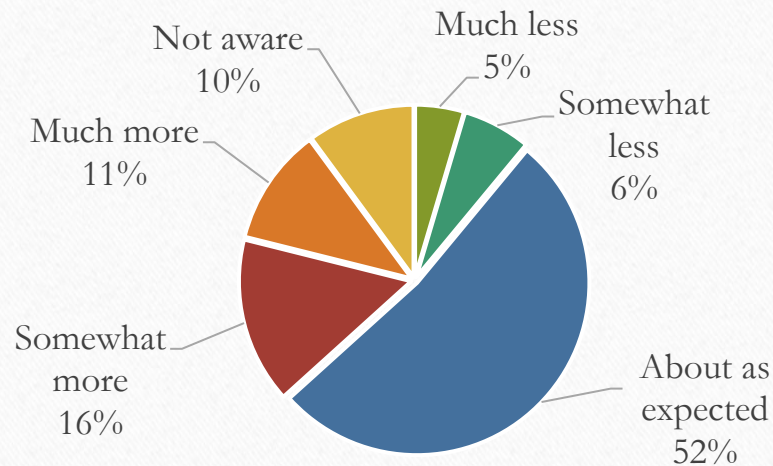
(n=109)



Half of the respondents felt the costs of their parent's long-term care were in line with what they expected; about one-quarter said costs were higher, about one-tenth said lower, and another one-tenth were not aware of the costs.

- Those who had a parent who received at least some care outside the home - in assisted living, memory care or a nursing home - were more likely to think costs were higher than expected (35% vs. 20%).
- All but one of those who feel costs were lower than expected were made up of those with parents receiving some care in the home (their own or the home of a family member or friend).

How did these actual costs for this care compare to any expectations you may have had? (n=109)



1:1 Interviews - Highlights

- **Many people with parents who end up needing care do not see it coming – the “unexpected” shows up in unique ways:**
 - Some are blind-sided with an emergency: a parent falling, a sudden accident, or an intense illness.
 - Some have parents who are young, active, or newly retired, and it wasn't on their radar.
- **Some see signs and watch a gradual decline, but may not know how or when to initiate care. This is especially true when their parents:**
 - Are fiercely independent and want to call their own shots and arrange for what they think they need.
 - Won't accept any outside help coming into the home.
 - Have spouses who feel they should provide the care without outside help.
 - Are not open to change.
- **Many parents specify the desire to stay in their home:**
 - Some demand it, in no uncertain terms.
 - Some adult children assume this is how it is supposed to be, even when they see it's not easy or ideal.
 - Parents living in a home that is easily navigable (all on one floor, first floor entrance, limited upkeep, a supportive community) or that can accommodate live in care, can stay longer.
- **As needs become more extreme or life-threatening, acceptance of the need for care often appears out of necessity. This may result in:**
 - More involvement by family members.
 - Care provided by paid care-givers.
 - A move to a community with more support or assistance.
 - A move to a facility with 24-hour care.

Highlights (continued)

- **Most caregivers talk about a busy, often chaotic, period where they need to put their own life on hold in order to get things under control with their parents.**
 - For some, this is during the busiest time of their life, with kids, jobs and limited free time.
 - For others, it's a reason (or an excuse) to retire early.
 - Some use their vacation time and/or spend their nights and weekends supporting the care-giving process in some way.
 - Some spend their own money and/or are prepared to cover more costs, if needed.
 - Some adult children providing or supporting the care of their parents have complicating factors of their own (an injury, an illness, a housing issue, their own spouse needing care or dying, etc.).
- **Family members step-up as best they can:**
 - Individuals make it a priority to get the best care they can with the time and money they have.
 - Those with multiple siblings, friends, and relatives involved, have an easier time.
 - In many cases, one sibling or another is not involved (because they are not capable, not local, or not interested).
 - Even when there is long-term care insurance or paid care involved, family members help when they can, spend much of their free-time with their parents, or may decide to provide as much care as they can through family first.
- **There is a pride in being able to deliver on their parents wishes and sometimes anguish about not knowing if they made the right decisions:**
 - Some realize that their parent's wants are not always feasible or not sustainable.
 - Those going it alone (as an only child, only in-law, or the only one in town) have more worries.
 - Those with parents who are able to ask for and accept help make it easier on their adult children.

Highlights (continued)

- **There is usually a period where a caregiver is completely stressed or overburdened. This can be:**
 - Financial stress, trying to figuring out what kind of funds and insurance is available.
 - Some realize that the person's documents, funds, and home are in complete disarray.
 - Some need to clean out and sell the home, some find random wads of cash scattered about, and some are uncertain what has been set-up and if they've found it all.
 - Stress caused by an inability to access funds that exist:
 - Getting the run around from LTC agencies.
 - Difficulty coordinating with family members, or dealing with siblings unable to make tough decisions.
 - Physical fatigue from providing care:
 - Some caregivers (often the spouse of the patient) end up having accidents or getting sick themselves (and may die before the adult they have been caring for).
 - Some caregivers realize that the person needing care is physically too big for them to move and/or help sufficiently.
 - Stress caused by difficulty finding services or facilities to provide quality care or piece together enough care.
- **Even among those with parents who have adequate funds, there are emotional stressors:**
 - Role reversal (the adult being more like the child).
 - Having a parent who does not want to discuss or accept care early on.
 - Watching a parent slowly die or become incapacitated.
 - Watching a parent lose their independence and be forced to live a life with no quality.

Highlights (continued)

- **Individuals who have witnessed or provided long-term care, understand the importance of “getting their ducks in a row.”**
 - Some have learned the hard way the importance of having a will, trust, financial POA, medical POA in place:
 - Some had to jump through hoops and even go to court to access funds.
 - Many wish they had been given a list of the financial sources and locations:
 - Bank accounts (ideally consolidated), rather than wads of cash hidden throughout the house.
 - Insurance, specifically long-term care, if it exists.
 - Financial plans (what funds will come in from retirement accounts, social security, Medicare, Medicaid, etc.).
 - Funeral plans and wishes.
 - Still, not all of these adult children have taken the same steps for themselves.
- **Regardless, almost all of these individuals had a period in which they were unsure how to provide or pay for care:**
 - They were not sure where to start and about what options exist.
 - Some did not know how certain conditions/events were classified nor what kind of insurance covered each type (health care, long term care, Medicare, etc.).
 - Some were unsure about the specifics of the coverage they had.
 - Some had projections that showed they would run out of funds if they did not move their parent to a different facility or care type.
- **When communication is clear, there is a support group, and connections can be leveraged, providing care is easier on all.**
 - Some had parents who were very clear about what they needed help with (moving/bathing their spouse, cleaning the house, driving/running errands, prepping meals so they could still cook, etc.).
 - Some were able to find a better than average deal for in-home care (through an existing connection) or had a large enough community to share the burden. Some ended up with live-in or consistent caregivers that were almost part of the family.

Highlights (continued)

- **Those with long-term care insurance do not all benefit the same way:**
 - Some “age out” or there is an attempt to buy them out, so they no longer qualify to get the monthly benefits (but can get cash at the end of the policy based upon what they paid in for premiums).
 - Some have trouble getting the funds they believe they deserve, referencing unfair criteria (e.g., you didn’t have this care in the past, so we cannot pay for it now).
- **The cost of care is higher than expected, and not something many can sustain for a long time.**
 - Most found ways to work with what they have/had, piecing together family care, intermittent in-home care, and in some cases 24-hour care either in the home and/or in a facility.
 - This was sometimes a stop gap until they figured out something they could afford.
 - At times, an emergency medical event where health care insurance kicked in (for hospital or rehab care) was almost a blessing in terms of funding but was also stressful if they lost their bed in a facility as a result.
 - Some were willing to dip into their own funds. They assumed if they had to do this, it would be for a short time. In some cases, it was a sibling or another family member with more resources who indicated a willingness to contribute if needed.
 - A couple of individuals were surprised how long a parent survived after they start needing care or became bedridden. Several said there is no way they could cover the cost of care without draining their own savings/investments.
- **Some describe it almost like a game - you can be smarter about it once you’ve played it:**
 - Understanding the look back period.
 - Shifting funds to other individuals for future use.
 - Figuring out what covers what and understanding how to qualify (Medicare, palliative care, long-term care, etc.).

Highlights (continued)

- **Those with experiences in facilities had mixed reviews:**
 - Some thought the environment was a step up from in-home living because of the social aspects, meal options, and having all types of care and services in one place.
 - A few felt a facility was the best option for their parent, based upon their needs – something they did not think they would say.
 - Many also saw that all facilities are not equal. Patients experienced different levels of care and staffing depending on the funding source or floor (short term, rehab, or long term).
 - Some saw shifts in care between units (better care for those in rehab or assisted living than in memory care or nursing home care, for example).
 - Some saw the loss of independence when moving into nursing home care (with very little choice left; patients not being able to do anything without permission).
 - Some felt there was not enough attention to detail in the higher support/24-hour care units.
 - Some felt like their parent was viewed as “ready to die” and witnessed a lack of assistance or follow-through.
 - Some were concerned their parent was not being kept clean or free from bed-sores, and that they were not sufficiently engaged mentally.
- **Even those who saw some advantages to senior living or assisted-living facilities have concerns:**
 - The best ones tend to be very expensive.
 - Some individuals get more confused or depressed when they are moved out of a familiar environment or community.

Highlights (continued)

- **It is interesting what decisions people make for themselves after being involved with the care of their parent:**
 - Many people still seem to think their own “good health” and “good genes” will get them through to the end.
 - This seems true of those whose parents lived to a very old age, even if they needed some care at the end.
 - Those who are generally healthy and/or feel too young to figure out what they need (even if 55+).
 - Many are hoping to stay in their own homes, but not all will require it.
 - Some are in a home that is conducive to aging, or have an adult child lined up to provide this care.
 - Even those with a parent who had a positive experience in assisted living tend to prefer the in-home option if it's feasible.
 - Some know that their current home/condo would not be advantageous for most in-home care and feel they would consider a senior community or a facility at some point.
 - Others feel they may exert their will to die by not eating or taking advantage of any legal options that may come to fruition in time for them, if their quality of life is gone and they are in a facility just being kept alive.
- **Those with long-term care insurance feel some relief that they have it:**
 - Although not all are not exactly sure how it works or what it will cover.
 - Others are not sure long term care insurance is an option for them. They have tried to get it and have been denied and/or have an existing condition.
 - Some do not think it is very readily available anymore (companies buying people out and getting out of the business) or have deemed current policies unaffordable or a bad investment (a wash at best).
 - Some are still evaluating and open to the idea, others assume new options will need to surface as the population ages. There is almost a “wait and see” attitude because they are unclear what the smart decision is, if there is one.

Highlights (continued)

- **These individuals see a need for care that can fill the gap between complete independence/no-care, and full time/facility care:**
 - Bringing care in earlier, to help people keep active and engaged without being burdened, could buy people more quality time in their homes.
 - Some mention that those with financial means have a lot of options; those with low net worth, or limited incomes have very few quality options for this type of care.
 - There is interest in a hybrid policy “concept.” They like the idea of cash payments to help cover some paid care costs and the idea of navigational support – a one-stop shop resource.
 - Some suggested allowing for more flexible care, without daily minimums, to allow for more days of care using the same funds.
- **Some would like a neutral source that can guide people on all the options without having “skin in any particular game.”**
 - Some states seem to have organizations and programs in place designed to do some of this (PN, FL, CA, etc.).
 - One person suggested an organization like AARP should take on this role, since they target the right audience and are seen as a trusted source. They also tend to provide information in a way that is understandable.
 - The youngest participant also emphasized that not all care-givers are old, and more resources need to be put in place for younger adults helping their parents when their own lives are very full.

Highlights (continued)

- **There are a few different long-term care planner “archetypes” that surfaced or are surmised from these interviews.**
 - **Family Rules:** There are those with larger families, living in close proximity, where they collectively work to stay true to their parents wishes (even when they are not sure it is the best solution). These families are better able to do it because there are enough bodies involved or there is a particular individual who has more flexibility (no kids, a flexible job/retired, lives next door, etc.). Even when they see some less-than-ideal circumstances or have witnessed other care that was in some ways better, these individuals tend to want the same thing: to stay in their home with family providing care. They assume whatever resources they have will be enough (often with no long-term care insurance in the mix) combined with the time/resources of their children.
 - **Giving More Than Their Share:** There is a sub-set who feel this way but also make it clear they are overburdened because they are doing this alone, without the help of other siblings or family members. They either don't have any siblings/relatives nearby or have siblings who are not willing or able to contribute equally.
 - **Good Genes and Healthy Habits Are Enough:** There are others whose parents lived into their 90s, who do not have many health concerns of their own, who are hoping (fingers-crossed) their end of life will be as good or better. They may not have children and/or do not have them lined up or earmarked to provide care. They more-or-less assume that the care they need will be limited or short-term enough that their retirement funds can cover it. It might be in the home, in a senior community or in an assisted facility of some kinds. They also are not sure what else to assume or do since they feel long term care insurance is not feasible. How care will be arranged or navigated doesn't seem to be on their radar.
 - **Smart Enough For or Smarter Than the System:** These individuals have been through enough that they know how to qualify for various types of care and save funds over time for incidentals, so that they can maximize the resources they have. They are on top of naming beneficiaries and specifying end of life wishes (DNRs, etc.) but not necessarily earmarking funds to be used for care. They realize they may end up in a facility that is covered by funds other than their own if things get extreme.
 - **As Prepared as Possible:** A subset of this group has long-term care insurance or is seriously considering it but may not be fully aware of what it will actually cover, whether they can get something that is actually a good investment, or if it will be enough to cover their needs in the end.
 - **Not Urgent Enough Yet:** Although individuals are aware that accidents and illnesses can happen to anyone at any age (even their own parents unexpectedly), it probably won't happen to them, and if it does, it won't happen soon. They may be traumatized by the events that transpired with their parents but are not necessarily motivated to take specific steps for themselves. They mostly seem humbled - more willing to accept that they have limited control over what happens and need to be more flexible in what they might accept for themselves than they thought prior.

Participant Summaries

Stories and quotes

Emmy: Her father needed care

- Emmy is in her 40s. Her mom passed away in an accident. Her dad had a brain tumor a few years later that led to erratic behavior (e.g., selling his house and getting married without informing his adult kids) and a chaotic process for providing care.
- He had money, but they had to go to court to access it because there was a new spouse involved and his will was never completed.
- He started out with in-home care, provided by his new spouse, rounded out with his adult kids (Emmy and her two siblings).
 - She had good coordination with her siblings but not his new wife.
 - It added stress to the situation.
- He eventually was moved to facility care, in and out of places (ER, palliative care, etc.), as his needs became more extreme, and he was eventually bedridden.
- In her words:
 - *It takes a toll to see your parent become incapacitated. It changed my outlook.*
 - *We have this stigma that you have to take care of your parent all the time. But living through that, with all my siblings here it was really tough, with jobs and families.*
 - *He did not finish the will. We had to go into a legal battle.*
 - *Having it all in one place for resources, would be very helpful. We were kind of shuffled everywhere. We had no idea where to go ... Having one place to go for all of that I think would be very beneficial, especially in my situation*
 - *I didn't know what was covered under Medicare or if I could use his 401K for this, or if he had long term care – that's the thing. Where do you find all this stuff? It goes back the person who has it to communicate it to you. But I think if he had had this insurance we would know where the funds come from and it would be there.*
 - *[I would tell people,] get your wills and estates and trusts in place. That is what screwed us up. My mom was in the process of getting the will and trust in place and she passed away and my dad didn't finish it. It never got done.*

Linda: Her mother-in-law needed care

- Linda is in her 60s. Her mother-in-law, who lived in FL, needed care.
 - Linda lives outside Pittsburgh and is retired from the healthcare field.
 - She took over as the primary person involved with her mother-in-law when her husband became ill himself.
 - Her husband ended up passing before his mom.
- Her mother-in-law lived in Florida, so Linda used her vacation time traveling south to provide support.
 - Her mother-in-law lived in a memory care unit after having trouble in other senior living facilities.
- She second guesses some of her decisions and hopes she made choices her mother-in-law would approve of. She felt like she was piecing things together all the way through – from identifying sources of funds (cash stowed around the house, multiple bank accounts, etc.) to determining what the best option was. She wondered what her mother-in-law might have wanted, or what her father-in-law or son might have wanted for her mother-in-law. It took a visible emotional toll on her.
- Her mother-in-law had some funds, but she also had to use some of her own money to pay for services and it was very expensive. It started out in the home with her brother, who lived in FL helping her find care-givers in the area. Eventually her mother-in-law needed more care and moved to and through a few facilities with varying degrees of success and levels of care.
- In her words:
 - *It was very demanding, and it was one of the reasons I decided to retire.”*
 - *I couldn't leave her unattended with her ability to walk and the fear that she'd get out and get lost. The expense for round the clock was horribly expensive, \$1500-2000/week, it wasn't sustainable. ... It was a mix of our money and her money – no LTC insurance.*
 - *I had used up all my vacation time. When husband passed away and I took some family medical leave. Then after that, I would go every 5-6 months a week at a time. It went on for 5-6 years.*
 - *I would tell others, sleep when you can, it won't be a lot. ... Just trying to find the resources and the time to get everything set up and spending all the free time that I had as far as vacation or time away from home devoted to taking care of what she had.*
 - *Coordinated care really would have been helpful.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Seth: His father needed care

- Seth is in his 50s and lives in CA. He is married and has no kids.
- His father had a live-in, long-term care giver, starting at 93 and he passed away at 99. He had problems walking and dressing himself. This 24-hour live in helper was on for 10 days and off for 2 and he had people coming in when he was off; there was always somebody there. His mom was also living in the home, and it helped her quite a bit. It was “ideal” as this care-giver was almost part of the family. Seth also said it was more cost effective than average, since it was a referral from another friend who had used him in this same capacity for years and they just continued the process.
- His mom was doing most of the grocery shopping and cooking, she still does. She’s still 100% functioning at 91. Seth’s brother has moved in with their mother and can provide the care she needs, when she needs it. He does not need to provide care now.
- Seth thinks he has “good genes.” He realizes he should prepare for LTC just in case, but it’s not a top priority right now.
- In his words:
 - *I’ve not set up anything specific for myself yet. Not right now, when the time comes. I guess I should start thinking about it.*
 - *They had long term care insurance that they had been paying into and right before he got care the insurance company gave him all the premiums back, \$30K. They were getting out of the business, or he outlived the policy or something. That amount of money they gave him back covered half a year of in-home care.*
 - *I think my dad had a good relationship with the caregiver. He would take him out during the day, drive him around, go to In-N-Out Burger. It was good; they had fun. My mom could keep doing her activities – she was active in women’s groups and could continue doing those things.*
 - *The caregiver took the burden off of us.*
 - *It is low on the priority list, but this interview is making me think maybe it should move up.*

Gary: His mother needed care

- Gary is in his 60s and lives with this wife in CO. They are empty-nesters, with 3 grown children. He has 5 brothers and his wife has 5 sisters. This close-knit, large family upbringing influences his perspectives.
- Gary's mom was 84 when she needed care, a few years after his dad passed away. She was getting older and becoming forgetful. She got lost driving one day which influenced Gary to get more involved and take her keys away. She needed someone to help cook, clean and run errands. Gary retired to help provide and manage her care. He was already planning to retire, but this made him do it sooner. His mom got LTC insurance many years ago and the company tried to buy her out of it since it was such a good deal. She got funds to cover 40 hours of care per week which could be used as desired without justification. She wanted help 2-3 days a week for a few hours at a time. He said she made money from the policy. She stayed in the home until she died in 2016 when she stopped taking her cholesterol/heart meds. His dad did the same thing. They both died within 6 weeks.
- His mom respected that he had POA when he took her keys away. He had made plans to tour a facility but she declined to go. He thought she would have benefited from being around more people and be held more accountable for exercising and rehab. She thought she needed to be home.
- Gary's wife's family went through a similar situation with her father who was paralyzed. They had no insurance to cover care, so they rotated care through the sisters and "made it work," although he acknowledged it was a big undertaking.
- Despite Gary thinking that his mom would have benefited from living in a facility, and that providing care for his wife's father was a lot, he and his wife also want to stay in his home until the end. They have communicated that to their children. He has a daughter with no kids who is already connected with their finances, and all are on board with it. They have taken care of their burials and have a living will. They don't have any LTC because it is unaffordable, They are hoping retirement funds will help take care of it.
- In his words:
 - *Actually, retiring was something I was looking forward to do anyway. Her needing help made me make that decision faster, let's put it that way.*
 - *I lived about 10 minutes away. I kind of did anything for her – bill paying, phone calls, etc. I did all of that. My younger brother actually bought the house right next to hers.*
 - *Before in-home care, after my dad died, she tried to stay independent. After she took the car to go shopping and got lost for 8 hours, we, as a family, decided she shouldn't have access to car keys anymore.*
 - *My mom said more or less "don't you dare put me in a home."*
 - *I think she believed that's what she wanted (to be home), but I don't think that was what she needed.*
 - *We don't have any LTC in place and I feel conflicted. I see what a benefit it was for my mother. The policies now are so unaffordable, it's out of reach.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Stan: His father needed care

- Stan is in his 60s and lives alone in a condo in Philadelphia, near his sister, and the home where they grew up. His dad was living in the family home up until recently. He was fiercely independent and reticent to accept help after their mother died. His house fell into disarray and his health deteriorated. One day they found him unconscious laying in the living room, after a fall on his way to the bathroom. This set off a cascade of medical issues and he was never able to return home.
- Stan and his sister each had designated roles that aligned with their strengths (his dealing with financials, hers dealing with the human side of things). Stan had to make quick and hard decisions about where and how to provide care for his father. Initially he had no idea where to start. He leveraged a large social network and was able to identify options. His father started out in a nice assisted living facility which Stan felt good about. When he needed more care, he was moved to a nursing home nearby. Stan observed a big loss in independence for his dad with this move. This was hard emotionally, but necessary.
- His father was a poor planner and made unwise financial decisions. Stan had to locate and organize his father's financial documents to figure out what he had to work with. This involved scanning hundreds of documents. His ability to do this benefited from his flexible schedule and his comfort with and access to technology. Still, this process was very time consuming and stressful for Stan.
- Stan had not thought about his own needs prior to this experience with his dad but has since. He has concluded that he has the assets/finances to be able to afford care should he need it. He worries more about his sister and has encouraged her to get more prepared. He would need to move if he needed to bring in care and would be willing to do that or may move into a more supported community.
- In his words:
 - *He was no where near where he needed to be to live in his house. He'd let his house fall decerped. We thought about home-care but it would require expensive work, there were mice running around. We decided to put the house on the market.*
 - *Same old story, he ran out of money, so we applied for and filled out the form for Philadelphia Corporation For Aging, to get him on nursing home Medicare and that was quite a process.. He should have had a lot more if he had managed his money. ... My dad's finances and his papers were in horrible disarray. They were statements shoved into folders. He had multiple accounts. It took me about 200 hours to get through that. It was very stressful.*
 - *I was a little angry with my father – he did no planning for any of this. He should have been more aggressive to plan better for his future. He didn't have a financial plan.*
 - *It was so stressful that I was literally having pain in my chest. I effectively had to do a long-term care plan for him and I didn't know this at all.*
 - *The biggest challenge was a lack of planning on the part of my family and the consequences of it.*
 - *[One word of advice?] PLAN! We live in a capitalist society and financial planning is the most important.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Marc: His stepfather needed care

- Marc is in his 50s and lives in Florida with his wife, and they have an adult son. Marc's mother lives in NY and is 20 years younger than her late husband, Marc's stepfather (who raised Marc). Both of his parents had LTC insurance policies but neither has used them. Marc's stepfather showed signs of Alzheimer's in his early 80s and his mother was able to care for him at home. She never brought in paid care, since she thought she could do it, and do it better. She also had a good social network of support. This set-up ended when his stepfather got the flu and ended up in the hospital and died. Marc believes he stopped eating on purpose to avoid ending up in a nursing home or hospice, which were recommended given the severity of his needs.
- Marc's mom has "good genes" and he thinks she may outlive him. She sold her home and now lives with her new partner. Marc is involved in her decisions and will spend summers near her when his wife retires.
- Marc had his own major health issues when he was in his late 30s. He is technically disabled due to an autoimmune disorder. This influences how he feels about death and end of life planning.
 - He believes we should all be open to discussing death. Marc and his family believe in euthanasia but know it's not an official option in the US. They hope this becomes an option in the future.
 - He feels it is better to prepare our loved ones as not to burden them with mismanagement. He feels he is set-up, living in a condo on one level, with no expenses. He spent a year in a wheelchair and this home can accommodate a wheelchair and in-home care, should he need it.
 - He is not a fan of current long-term care insurance policies. He is in the process of setting up tax shelters for himself to pay for care. He is a self-proclaimed "numbers guy" and when he does the math, it's a wash at best for what you'd be getting. He is open to exploring and discussing a hybrid insurance concept and comparing the numbers to what he has figured out with this current system. He wants a neutral source to help people better understand their options.
- In his words:
 - *I am not sure where that cut-off happens between the long-term care and Medicare supplements. I really need to find that out. ... It is confusing and hard to figure out.*
 - *For some reason, the conversation didn't happen about bringing care in for my dad, but then he went into hospital, and he was such a mess, and he was never coming home. ... We went from manageable to the only option is long term nursing home.*
 - *It's not a one-stop shop. People try to simplify things. It's very helpful that everyone is able to have conversations (in my immediate family). I have some family members who don't have a will and don't want to talk about anything. And, I say to them, "You're a selfish jerk."*
 - *Again, it goes back to not having enough resources and tools. I feel like that applies to LTC, people could get sold things that are not what they think.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Todd: His mother needed care

- Todd is in his 50s and lives in a condo in CA with his significant other of 20+ years (with no kids). His parents, lived in the same community for awhile. His mom (who was 12 older than her husband - 7 years older than they originally thought) was having memory issues. His dad was stubborn and didn't want to bring in paid help initially. Todd suggested they move into a senior community. His father was resistant, saying this was "a place you go to die." Eventually, they tried it and liked that some basic services were provided (laundry, etc.). His dad was concerned about the cost; they eventually moved to a facility in a neighboring city to get a cheaper rate.
- His father was still providing daily care for this mother, and this took a toll. He collapsed and ended up in the hospital. He eventually returned home with paid care covered through health insurance. His mother also needed long-term care, and this was paid for on their own. It was very expensive. His father died in the home. Todd kept his mom in the home as long as he could. When she developed a circulation issue, he moved her into a boarding care home (which took some legwork to find). The money was to going to run out the end of this year. He had plans to talk to an attorney to discuss options, but his mom passed away in June.
- This experience was "eye-opening," yet Todd has not made any plans for himself. He is 58 and healthy and hopes he doesn't have to consider this for awhile. He thinks options will change as the population ages. He does not think viable LTC insurance exists today so that is not an option for him.
- In his words:
 - *The first senior community was just a couple of miles, very nice neighborhood, shopping center a walk away, nice facility, everything taken care of. Just the cost. They kept raising the cost.*
 - *They found an assisted living / senior complex nearby where they lived for about 1 year, but it was getting too expensive. \$7000-9000/month. My dad was concerned he was going to run out of money pretty quickly.*
 - *My dad did not hire any help. It was a good solution until his health problems came crashing down. In the middle of the night, he got out of bed and collapsed. ... I didn't know how serious my mom's condition was until then – she had dementia – more advanced than I realized.*
 - *It was a learning experience, and I was surprised at how expensive it was.*
 - *If she was still around the middle of this year, someone said I should reach out to an attorney to figure out what to do when the money runs out. There was no way I could pay for it. It would drain my account in 2-3 months.*
 - *I don't know if places even offer LTC insurance anymore and if they do, it's outrageously high. It doesn't sound like that is going to really be an option for me.*
 - *Anything that could fill the small gaps would be helpful. Then, I could rely on investments, savings and social security for the rest. Certainly, any little help that I can get would be great. ... For those who can't afford full assistance or need just some assistance – house cleaning or meals, every day or a few days out of the week – a smaller plan would be good. There seems to be a gap. Whatever you try to get for yourself now, it's going to be costly.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Lauri: Her mother needs some care

- Lauri is in her 60s and lives alone. Her mother is 92 and lives on her own, nearby. She has some paid help to do yardwork and small household tasks. Lauri helps out with whatever they don't do, when her mom asks. Since COVID, Lauri feels her mom has lost ground because she cannot workout at the local gym and do other things that kept her going. She wants her to get help so she can keep cooking and doing things she loves. Her mom is also interested in getting more paid help and wants to use her LTC policy to pay for it, She's paid over \$200K over many years, but is getting the runaround when trying to use any funds. Based upon Lauri's observation, the firm is error prone and making it very difficult for her mom to qualify for the funds she needs to pay for additional help. Her mom made it clear that she wants to die in her home (and neither want Lauri to move in, unless it's absolutely necessary).
- Lauri is disabled after a spinal cord injury a few years back. She could not lift her mother but considers herself fully functional, in terms of what she can do for herself. She has been denied LTC coverage 3 times. After the experience with her mother, she thinks it may be a blessing since her mom has paid in a lot of money and is having difficulty accessing any benefits. They are working with an advisor now (accessed through her brother) to help them fill out forms in a way that her mom will hopefully qualify for benefits.
- Lauri's mom has documents in place (wills, trusts); Lauri does not. She is not worried because she does not have a family, her brother is well-off financially, and her sister is on her own. Lauri feels if she uses up all of her funds, it's fine. She is trying not to use government funding, which was suggested after her accident. That is why she was trying to get long term care insurance.
- In her words:
 - *They come up with every reason to not pay out. She has paid over \$200,000 into this LTC plan. We could not afford anyone more than a day week prior to accessing these funds. She wants to use the funds to cover more help. They are saying since she did not have someone more than 1 day a week up until now, she must not need it and they are not going to pay it.*
 - *The kind of care she is requesting, is what they cover but she just can't pass the screening yet. She's having difficulty cooking, standing for a period of time, and stuff like that. We'd like to bring someone into allow her to keep doing things she likes.*
 - *I'm hoping LTC will cover things – that's why she paid in to it for all these years, over \$200K, to get Long .. Term ...Care! It's supposed to cover what she's asking for. They asked us to give them info and fill out this form giving details and it was a major effort to pull it all together, to show what she's paid and services used. This process was not as expected. Not hardly. They way that they sold it, they made it sound like it would be very easy.*
 - *In a sense LTC is a misnomer. Yes, it's long term, because it's often lasting longer than a year or two. But the in-home stuff should have been thought of a long time ago. As the population ages, there are going to be a lot more people in that situation.*
 - *This process has opened my eyes to what is really going on in the background not what is being marketed. If asked, I would say, "go in with your eyes open." Make sure what they are promising is what you are going to get.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Marvin: His mom needs some care

- Marvin is in his 40s and lives in New York City with his 81-year-old mother, His mom had lived with his sister and her family, but they recently moved to Florida and his mom did not want to move there. They decided she would move in with Marvin because he was already managing her finances and taking her to appointments. Plus, she wanted to stay in NY. He describes his mother as being functional in terms of self-care but in need of assistance with transportation and managing finances properly.
- Earlier, Marvin also helped navigate the care needed for his father. He died 10 years ago after a long battle with Parkinson's. His dad lived at home until he needed more physical support than his mom could provide. Marvin helped with the decision and process to move his dad into a short-term facility before transferring him into a nursing home. Marvin helped his uncle in a similar capacity.
- His past experiences have educated him on how things work and what he might do differently to prepare for his mom's needs and his own. He had no legal documents for his father and learned a lot about "what not to do." He had to go back and organize 5 years' worth of financials to get care covered through Medicaid. They did/do not have long-term care insurance. He has listed his name on his mom's financial accounts and has specified beneficiaries. He stresses the importance of having documents in order..
 - He assumes his mom may have more needs down the road and is looking into options for in-home care assistance and potentially transitioning to a job where he is able to work from home more. He also knows he may need to use some of his own funds to care for his mother and/or move her to a facility if her needs get too great.
 - He tries to enjoy the quality time with his mom and takes pride in giving back to her, since she was a good provider for him when he was growing up.
 - He also thinks the system is not acknowledging or perhaps not aware of how many care-givers are young adults with full lives. He does not think there is adequate processes in place to support these types of care-givers, who also have families and/or are in key phases of their careers
- In his words:
 - *It was really one of the hardest decisions, putting my dad in a facility. ... He saw himself and was like 'I don't want to be here (in a facility), but I see why you did it.*
 - *I went to a bank and paid for 5 years of statements, which took some time. For a month or 2, I was covering his cable, his rent, until I could give up his apartment. I was putting money into an apt I'm not living in.*
 - *The system is so focused on caregivers who are like 50-60-70s, and they don't think about caregivers who are under 50, raising kids, and climbing the corporate ladder, having to do this.*
 - *Having something reasonably priced but gives you the care at home if you need it before going into a facility would be great. If you don't use the coverage, can I show it to the funeral home and use it toward expenses or something. Something flexible is needed.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Sheree: Her mom needed care

- Sheree is in her 50s, married, with no children. Her parents moved down to FL to get situated in a senior community before any illness was in the picture. Soon after, her dad got sick with cancer. Her mom was able to handle most of the care-giving for her father. Her mom got sick with leukemia shortly before her dad passed away. Her mom had supportive friends who came around to socialize, help, and stay over.
- Sheree's mom eventually hired paid caregivers for her dad, because he was a big man, and more than her mom could handle physically. She learned a lesson from her mom - be specific about what kind of paid help you need. In her dad's case, her mom asked for a person who could lift a larger person.
- Sheree visited regularly; her sister did not. In addition to spending quality time, she would give her mom's friends a break, and help with forms and financials. She said her mom had "chemo brain," which made it hard for her to work through long or complicated paperwork. Sheree felt the forms were laborious and not something you should subject a terminally ill person to, when they have limited energy and time left. She also got conflicting information on what drugs were covered and found the experience frustrating for a person in perfect health, let alone someone who is very ill. When it came to her mom's care, her mom specified that she wanted someone to clean, since she was told not to do that with her leukemia. She went through a few care-givers who placed too much emphasis on being friendly. Her mom said, "I do not need a care-giver to be my friend. I have plenty of friends." What she wanted was a worker – someone to come in and clean (and clean like she did), be friendly, but always be working. She found the perfect match, eventually. Sheree's dad suggested she move to FL and her husband would have been on board. Her mom did not want her to because she didn't want to disrupt her life. Sheree said that because of the long-term care insurance and her parent's network of friends she did not have to do that.
- Sheree valued the time with her parents, but the bimonthly trips were expensive and time consuming. Sheree was happy her parents had everything organized, in place and handled, including the funeral.
- In her words:
 - *I was in PN, and she was in FL. I would fly down twice per month.*
 - *I would help with her finances. When the doctor said she couldn't do this or that (clean, etc.) she would ask me to help her find services.*
 - *It was extremely tiring going down there twice a month and it was expensive, but it gave me quality time with her when the end was coming.*
 - *If it hadn't been for them having LTC, I would have had to move down there.*
 - *One of the drugs she tried was \$3800/month – and she could not afford it. The person handling it would say "we got you covered on this" and then someone would call back and say, "no you're not covered." If a person is alone (navigating), they are screwed.*
 - *[My advice to others is] plan. Don't be 60 years old and have nothing in place.*

Quotes may be paraphrased or modified slightly for clarity and conciseness.

Thank You



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