COMMON MYTHS ABOUT ASSISTED LIVING AND ELDERCARE OPTIONS

By: Elizabeth Eardley
Myth #1

Myth: Most assisted living communities offer pretty much the same levels of care.

Reality: In West Michigan we are blessed with well over 100 different assisted living communities. Not only do each of these communities look different and offer different amenities, more importantly they are licensed differently (or not at all), offer different care levels, and are qualified (or unqualified) to accept different funding and insurances.

Let’s look at a couple of examples:

Julie is looking for a place for her dad. Dad is in a wheelchair due to a stroke but his cognition is still relatively good. Julie went to visit a couple of assisted living communities and was told by the admission representative that her dad needs skilled care because he could not walk. Because of that information, she had shifted her search to skilled nursing facilities.

Reality: Assisted living facilities offer different levels of care either due to their license, or their business model. Many assisted living communities can provide two person transfers and have trained staff members to operate mechanical lifts to help non ambulatory residents.

Why it matters: Assisted living communities often offer a more home like and private setting and cost between 30 to 50% less. If given the choice most people would prefer to live in an assisted living instead of a skilled nursing facility, and should be given the tools to understand their options to make the best choice for their loved ones.

Tom’s dad was recently widowed and wants to move into an assisted living so he isn’t so lonely and has someone to help prepare meals and make sure he takes his meds on time. He has chosen an assisted living, but after moving there he tried to use his long term care policy and was rejected because the assisted living community does not hold a license.

Reality: Assisted living communities can legally operate and be licensed as Adult Foster Care, Home for the Aged, or be unlicensed. Many different funding options only work in licensed communities.

Why it matters: In order to avoid moving again, people need to be aware of how a community is licensed and how that affects their ability to use Medicaid Waiver, Long Term Care insurance and Veteran’s Benefits.

Karen’s mom and dad want to move together to an assisted living. Dad has a feeding tube due to radiation damage to his esophagus, and he is able to manage the tube on his own except for setting the timer. Mom is pretty independent and will mostly be a companion to dad. Karen has been calling around but has been told no either due to her dad’s feeding tube or the shared room with two distinctly different levels of care. At this point they feel like dad will have to move to a nursing home and mom will stay home alone. This is hard for Karen as her parents will become very depressed without each other.

Reality: Some communities cannot have two people needing care in the same room due to the license they hold. Some communities cannot accept people with a permanent feeding tube due to the license they hold. A handful of communities can and will do both.

Why it matters: If this family does not get the right information, a couple that has been happily married for 62 years will sadly have to live their last years apart.
Myth #2

Myth: Medicare will cover the cost of my hospital stay and rehabilitation.

Reality: A hospital admission can be classified as “under observation” and will then not be covered by Medicare Part A. Understanding the status of a person admitted into a hospital or a rehab has always been confusing, but in recent years it has become increasingly difficult to predict and understand. Rehab stays are reimbursed differently depending on whether you have Traditional Medicare or a Medicare Advantage plan, and also whether you were admitted under observation or as an inpatient.

Why it matters: MONEY!! Medicare reimburses in vastly different ways and at different levels depending on how you have been classified during your hospital stay. Qualifying for Medicare benefits in rehab also depends on the status of your hospital stay and/or the type of Medicare plan you have. Your quality of care will be the same in either case.

Let’s look at an example: John and Julie have been caring for John’s mom Sarah at home. Sarah has advanced dementia and is really confused much of the time about who she is and where she is. She no longer is able to properly bathe herself and is getting rashes. Most alarmingly she is now too weak to walk. John and Julie had Sarah brought to the ER by ambulance where she was examined in ER and brought to a room for further tests. After two days in observation and further tests the care manager told John that his mom was not found to have any treatable conditions but she is also unsafe to go home and it is recommended she be transferred to a rehab to get stronger.

Myth: Sarah’s hospital stay will be covered by Medicare part A (hospital insurance and rehab insurance) so the entire cost of her stay will be covered. Since Sarah isn’t safe to go home she can go to rehab to get stronger and Medicare will pay for that as well.

Reality: Sarah was under observation status at the hospital so she is considered an outpatient and is covered only under part B (medical insurance). She will be billed as an outpatient for her hospital stay. She may choose to go to rehab but she will pay privately around $300 per day if she has traditional Medicare. If Sarah has a Medicare Advantage plan she may still qualify for Medicare benefits at the discretion of the insurance company.

Why it Matters: It is very important to know how you are classified as a patient at the hospital so that you are not surprised by your bills and so that you can make decisions to minimize the cost.

Observation status defined: Observation services are hospital outpatient services that a physician orders to allow for testing and medical evaluation of your condition. While under observation care, your room may be located anywhere in the hospital. However, the quality of care is exactly the same regardless if you are an observation patient or inpatient admission. Within the first 48 hours of your stay, the physician will decide whether you require an inpatient stay, or may be discharged home for care in another setting. Observation services are typically ordered for conditions that can be treated in 48 hours or less, or when the cause for your symptoms has not yet been determined. Some examples are nausea, vomiting, weakness, stomach pain, headache, kidney stones, fever, some breathing problems, and some types of chest pain. Since observation stays are billed as an outpatient service, your insurance co-pays and deductibles, along with any additional costs, will probably be based on the outpatient terms of your policies. Your out-of-pocket costs may change depending on whether your stay is designated as observation or full inpatient admission and your qualification for rehab may differ due to the type of Medicare plan you have; Traditional Medicare or a Medicare Advantage Plan.
Myth #3

Myth: Independent living communities are designed for seniors who want to downsize but are still able to do everything else for themselves.

Reality: In the past, Independent living communities were places that seniors would move to after retirement. Except for offering a sense of community, most residents were still completely independent. Now, independent living communities offer on-site home care to help with activities of daily living, meals, transportation, and many other amenities and activities to help seniors who really can no longer live safely home alone, either physically or emotionally.

Why it matters: Many people postpone moving when it is clear they need assistance because they do not want to, or can’t afford to, move to “a nursing home”. It is important to have accurate information on your senior housing options, and to clear up any preconceived ideas, so that a move that could potentially greatly improve the quality of life of a senior isn’t unnecessarily postponed.

Let’s look at an example: John’s mom Delores is 79 and suffers from arthritis, making it difficult for her to get dressed in the morning and to take showers on her own. She also struggles to keep the house clean and doesn’t cook much anymore. John and his wife are exhausted with having to come over and help her all of the time, but Delores is dead set against a move and claims she will never move to a “home”. John and his wife are concerned too, because they called a few places and they were told the cost was over 3,000 per month, an amount that Delores can’t afford for long. They have put off the move and continue to be Delores’s caregivers.

Myth: Delores’s options are to stay home with help from her family and home care, or move to a nursing home because she can’t afford assisted living.

Reality: Because Delores’s care needs can be anticipated and scheduled, she can move to an independent living apartment that has homecare on site, 3 meals a day and offers light housekeeping. The cost could be 50% less than an assisted living*

Why it matters: It is important for the caregivers almost as much as the seniors themselves to not limit their options or get stuck in a cycle of worry and ruminating due to incomplete and inaccurate information. When seniors stay home and rely on assistance from family members the end result can sometimes be frustration, resentment and burnout for the caregiver. If possible, the adult children of seniors needing assistance should be able to enjoy their relationship with their parents and not see it as another source of stress and hard work. Being aware of suitable and desirable housing options for seniors can improve the quality of life for the whole family.

*An important caveat – Independent living, no matter how many services are purchased, is NOT equivalent to assisted living. Assisted living communities are generally licensed, are inspected for care quality and staffing ratios by the State, and have 24/7 awake staff. The key difference between independent living and other housing options is the level of assistance offered for daily living activities. If you require around-the-clock help with eating, dressing, transferring and using the bathroom, or require regular medical assistance, other housing options such as assisted living facilities or nursing homes may be a better fit.
Myth #4

Myth: Assisted living is private pay only and is too expensive for many seniors.

Reality: A licensed assisted living is expensive, but usually runs at least 30% less than a nursing home. Also, in addition to private pay funds many residents can qualify for VA benefits (even as a spouse of a veteran) or Medicaid waiver. There are also bridge loans offered by some companies that can loan a person money while their house is being sold, using the value of the house as collateral. Some properties run specials that can last up to twelve months, or can help residents to share rooms to reduce costs.

Why it matters: It all comes down to having options. When seniors and their family members are making the very important decision of where to spend their last years so they are safe and comfortable, they need to be aware of all possible options. With incomplete information seniors needing help can end up prematurely in a nursing home or choose not to move at all, when it is to their benefit to have around the clock supervision to maintain their safety, health and quality of life.

Let’s look at an example: Edward is 88, has an income of $1,000 per month and is a Veteran. He has Parkinson’s and is having a hard time walking, getting dressed and taking showers. He also cannot drive. He has about 15,000 in his checking account. Edward’s son Steve is looking for assisted living for him and has called around a bit. He is being quoted prices averaging $4,000 per month. He can’t afford to help his dad financially and has decided to have him move in with him, even though he works full time and will rarely be home, and Edward would prefer to move to an assisted living.

Myth: Edward can’t afford assisted living and will have to move in with his son or make other arrangements to get the care he needs.

Reality: Initially Edward could choose an assisted living and start paying privately with his income and savings. He would immediately apply for VA benefits and would receive approximately $1,911.00, including retroactive funds from the date of application. This would slow down the rate at which his savings are depleted. He can apply for Medicaid and once he is approved and his savings are spent down, he can be assessed for the Medicaid waiver program and the community can start receiving funds to cover the cost of some of his care. Even though the income limit for Medicaid waiver is currently $2,349.00 per month, his higher income still qualifies, because approximately $700.00 of the VA benefit is excluded from the income count. With the two additional funding sources and his income, Edward can afford assisted living.

Why it matters: Choice! Applying for these funding programs isn’t easy or quick and not everybody has the time or energy. Also, it is certainly possible to not be approved for various reasons. But these are very valid, legitimate programs that are available not only help the resident but also to keep people out of skilled care and on full Medicaid. Families need to know about these programs as part of the resources that are available to them so they can decide for themselves how to proceed.

Basic qualifications of funding programs: Medicaid Waiver - Must be qualified for Medicaid, must meet a level of care determination, and must make less than $2,349.00 gross income. VA benefits - Must have served or be a spouse of a Veteran who has served at least one day (at least 90 days total active duty) during a qualified time of war, must have been honorably discharged, must have not been divorced from the veteran or remarried after their death (if the widowed spouse of a veteran), must have less than approximately $129,000 in assets not including a house or car, and must have documented care expenses exceeding income.
Myth #5

Myth: Medicare pays for 100 days of rehab after a 3 night qualifying stay in a hospital.

Reality: Traditional Medicare pays for up to 100 days of rehab after a 3 day qualifying stay in a hospital. Medicare Advantage (for example, Priority Health, BCBS etc.) pays for up to 100 days of rehab for reasons determined by the physician and the insurance company, sometimes a hospital stay is not even required! The average length of stay in a rehab is from several days to several weeks depending on rehabilitation needs. Generally, continual progress in rehabilitation must be made for Medicare to continue to pay. This progress is documented by the therapy and social work team.

Why it matters: It is not unusual for people to be told they will receive up to 100 days of rehab but instead to hear that they definitely will get 100 days in rehab after being qualified. This leads people to suspend or never begin working with the care management team to create a plan for discharge. Not surprisingly, they are alarmed and frustrated when they get a call from the discharge planner at the rehab (who has been trying to warn them!) to be notified that the discharge date is coming up in 3 days. A lack of awareness of benefit eligibility also creates distrust between the rehab and the family, because they feel they are being denied their rightful Medicare benefit. This animosity and frustration makes an already stressful time even worse.

Let’s look at an example: Steve and Julie’s mom Laura has a Medicare Advantage plan. She has suffered a pretty severe stroke and is unable to use her right side, cannot walk without assistance, and can’t dress and bath herself. Before her stroke Laura was relatively independent. Laura is going to rehabilitation now and Steve and Julie have heard that she is covered for 100 days by her Medicare plan. Laura is fine cognitively and is ready to work hard in her rehab, so her kids feel confident she will be able to regain a lot of strength over the next 100 days and hopefully return home, maybe with some assistance.

Myth: Laura will be able to be in rehab for 100 days to give her time to fully recover from her stroke so she can go safely home.

Reality: She may be in rehab a much shorter time, depending on her progress and her insurance company’s (Medicare) judgement. While traditional Medicare leaves it to the medical professionals to make decisions about the type of, duration, and location of treatment, Advantage companies control many of these decisions. Case managers at the insurance company make many decisions about the care provided and what will be covered. Traditional Medicare will cover the cost of inpatient rehabilitation for up to 100 days, assuming the patient continues to progress toward a measurable goal, and with some co-payments if there is no supplementary insurance. There tend to be fewer Medicare Advantage providers that will routinely agree to pay for 100 days of care.

Why it matters: If Steve and Julie think that their mom is going to have 100 days of rehab they may significantly delay their planning of her discharge with the care management team. It may be necessary to have multiple family meetings, make improvements to the home, line up home care or visit assisted living communities and nursing homes. This takes a lot of time and emotional energy and can seem overwhelming when rushed unnecessarily. Also, if they are aware of the terms dictating the length of her stay, they can be prepared to understand how to appeal it to try and gain more days, or they can ask the care manager at the rehab to better explain the parameters and keep the lines of communication open between the rehab and the family so that the discharge will proceed smoothly.
Myth #6

**Myth:** There are two choices when your loved one needs help to continue living safely at home, home care or moving to an assisted living.

**Reality:** There are many, many options for seniors to receive socialization, care and support without having to hire home care or move to a community.

**Why it matters:** It is not uncommon for a caregiver to feel that if only they could get some help with their loved one they could continue to care for them at home. Also, many caregivers are aware of the cost of home care or assisted living and feel they just can’t afford it. By understanding options for senior centers, adult day care and PACE programs; working or overwhelmed caregivers can have a substantial and affordable break from their caregiving duties during the day while still having their loved one remain home.

**Let’s look at an example:** Julie lives next door to her parents, George and Helen who are both in their mid-80’s and desperately want to remain at home together. Laura would like that too, but is overwhelmed with having to come over every day to help her parents with many of their daily needs such as cooking, cleaning and personal help. George has mild dementia, is a bit unsteady on his feet, and needs help with bathing and dressing. Helen is still pretty independent but has heart disease and doesn’t have the energy to care for George, although she is very lonely and bored. They live on a fixed income and have minimal savings. They can’t afford home care at approximately $20 per hour and also cannot afford to move to an assisted living because their income is too low. Laura is resigned to the fact that she will have to continue to care for her parents even though she is risking her own health due to the demands of caregiving.

**Myth:** Helen and George can’t afford home care or assisted living so must remain home and have family care for them.

**Reality:** George needs quite a bit of help and would be a great candidate for either the PACE program or an Adult Day Care. Adult Day Care can provide meals, life enrichment, and bathing services. There are some that also have a nurse on staff to handle medical needs. These programs typically cost about ½ of what home care does, generally around $10.00 per hour. Participants can go from 7 am or so until about 6 pm up to six days per week. If this is still too expensive, George can apply for Medicaid and instead join the PACE program (Program of all-inclusive care for the elderly). PACE offers all of the same benefits as the Adult Day Care but also includes a pharmacy and doctors on site for all medical needs, eliminating the need to be brought to doctor’s appointment or to pick up prescriptions. Both Adult Day Care and PACE programs can arrange for transportation as well. Since Helen is becoming isolated and depressed, she may benefit from going to a senior center where she can enjoy companionship and a meal with other seniors on the days that George goes to a day program. She can get transportation services through RideLink or the GoBus. With a combination of these programs Helen and George can get much of the care they need and still live at home on the nights and weekends with their daughters help.

**Why it matters:** Many adult children or spouses promise their loved one that they won’t ever make them move, and many others simply can’t afford a senior community or homecare. These caregivers can be overwhelmed with guilt and sadness knowing that they made a promise they can’t fulfill. They struggle to make things work, jeopardizing their health and the relationship with their loved one; resentment often follows. By being aware of day programs, a large portion of the daily responsibility of caregiving can be shifted and the caregiver can feel like they can now be successful with the promise of keeping their loved ones home.
Myth #7

Myth: If you talk with your parents in advance of their need for assistance or a move to a care community, they can tell you what they want and eliminate the need for you to make unwanted decisions on their behalf.

Reality: The reaction of most seniors when asked how they would like to be cared for when they can no longer be independent is “I want to stay home no matter what!” Many times they make their family members promise never to move them. Unfortunately this is often a decision based on fear and a lack of information and the promises made cannot be kept; adding stress, guilt and resentment to all involved.

Why it matters: If family discussions regarding senior care could be restructured to focus on how the chosen power of attorney is going to do everything possible to provide the very best care and living environment and will give their best efforts to make decisions that align as closely as possible with the wishes of the senior loved one, while not making any promises, it would provide more freedom to the POA to find options for care and support that truly address the care and safety needs of the person in question.

Let’s look at a few examples: Susan is the medical power of attorney for her mother Barbara. When Barbara was 75 and still quite independent she and Susan had a discussion about her future needs and Susan ultimately ended up promising her mom she would not move her from her farm home that she loved so dearly. Now at age 83 Barbara has developed moderate dementia, has suffered a broken hip that has left her very unsteady on her feet, and is unable to take her medications properly. Susan still needs to work full time and cannot be her mother’s caregiver, and her mom cannot afford the cost of 24 hour home care. She really wants to have Barbara move to an assisted living near her but knows that she has made the promise to have mom remain home.

Myth: Susan made a promise to her mom that she would keep her home, and she should fulfill that promise.

Reality: Susan had all of the best intentions when making the promise to her mom, but only now understands that having her mom remain alone in her home will place her at great risk. Also, she feels that her mom would actually enjoy the social aspects of a senior community instead of being home alone in an isolated area. If she and Barbara had been aware of how things can sometimes change in our health and care needs beyond what we would ever expect, they could have had a more realistic discussion on being open to the idea of alternative forms of care and housing and Susan could have felt better about making these difficult decisions, even if her mom is still against the idea of a move.

Why it matters: Being the medical power of attorney for a senior loved one is a very stressful position to be in. The majority of people appointed the decision maker in their loved ones care plans love the person they are helping and are doing everything in their power to make the best decision possible not only for the person needing care, but for the caregiver, spouse and the rest of the family. Adding unreasonable promises to the mix can cause undue stress and guilt and make an already difficult decision much harder.

Talking with our parents about their wishes is extremely beneficial and important. Listening with love and attention is a way to learn from them, honor them and show we care about what they envision for themselves as they age. Equally important however is to help your parents understand that you love them and as the chosen medical advocate you will do your very best to make informed, loving decisions that match their desires as closely as possible, but that you can’t be held to any specific promises.
Myth #8

Myth: My mom can no longer live at home and she wants to shelter her assets to leave to her grandkids so that she can go on Medicaid and move to a facility.

Reality: Not so fast, or easy! There are limited (and expensive) ways to shelter assets unless you have preplanned 5 years in advance (that is expensive too!). It is important to know Medicaid only pays the full cost for care in a skilled nursing home, and only pays partial cost in certain assisted livings. Also, just because you are no longer safe to live at home does not mean you will meet the care requirements to qualify to live in a skilled setting on Medicaid.

Why it matters: The first thing many people do is make a visit to their lawyer the first thing they do when they realize that their loved one needs to move to a senior care property. It is common to have people first retain a lawyer to help them get on Medicaid for their parents and then find out the hard way (through multiple phone calls and tours) that their loved one doesn’t meet the Level of Care Determination (LOCD) necessary to use Medicaid to live in a nursing home. Also, without prior investigation or assistance, many people are unaware that Medicaid can only be used to cover all costs in a nursing home – not an assisted living, and many popular and well known nursing homes that are a part of continuing care communities have rarely have openings for people who aren’t already living within their continuums.

Let’s look at an example: Joan’s father Fred is living at home but has been having many problems taking care of himself. He isn’t eating well, showering as often as he should, and he doesn’t always take his medications correctly. He has also taken a couple of falls where he was not able to get up and had to wait for help. He hasn’t broken anything yet but Joan is very concerned and both she and Fred’s doctor feel he should no longer live home alone. Fred has decided that if he has to move to a nursing home he would like to apply for Medicaid and shelter his remaining savings to leave to his kids as an inheritance. He wants to move to the place in his neighborhood that one of his friends recently moved to. Joan has visited there in the past and agrees that he should move there after he gets on Medicaid. Joan and her father plan to meet with an elder law attorney to start the process.

Myth: Fred can shelter his assets, qualify for Medicaid and move to the facility he knows in his neighborhood.

Reality: Fred doesn’t meet the level of care determination to qualify for Medicaid, the property down the street is not a nursing home and doesn’t accept Medicaid, and to shelter assets he would have to retain an attorney for a potentially expensive fee to preserve less than half of his assets.

Why it matters: Without proper information people may hold mistaken beliefs about Medicaid such as:

1. Medicaid will pay for my care in a senior facility if I am elderly and out of money. The truth is you have to need skilled care for Medicaid to pay for it.
2. Medicaid is accepted in all senior facilities. The truth is only nursing homes can accept Medicaid for the entire monthly obligation. This can be an unhappy surprise as skilled nursing homes are medical facilities with shared rooms, often not what people envision as their new living environment when deciding to apply for Medicaid. Some assisted living communities can accept the Medicaid waiver, which pays for a portion of the care costs, but the resident still has to pay for room and board.
3. It is easy to shelter assets for an inheritance for my kids. The truth is that you either have to plan five years in advance by establishing an irrevocable trust that you cannot be the trustee of, split assets with your spouse, or give away a portion and use the remaining amount to pay the nursing home the penalty you incurred with the divestment. It isn’t difficult but it is expensive and greatly limits your options as explained previously.
4. Once I have Medicaid I can use it at any skilled facility. You can, but the truth is that many of the more well-known and popular skilled communities rarely have openings.
Myth #9

Myth: The Veteran’s Aid and Attendance benefit is available to all Veterans, has no financial lookback period, and can be used in any senior care community or at home. Spouses of Veteran’s can always get benefits as well.

Reality: There are many qualifications that need to be met to be approved for this benefit including dates of military service, assistance needed, and income and asset amounts. Regarding a financial lookback, the Veteran’s administration is advising families not to transfer assets within the 2 year period prior to applying to avoid having the application delayed or denied. This is a cash benefit provided to the family and can be used to help pay for care, but it is much harder to qualify for the benefit at home or in an independent living situation, and the application is most successfully processed by the Veteran’s Administration. A widowed spouse of a Veteran needs to have been married to the Veteran at the time of death and not have remarried and meet the same financial and care qualifications the Veteran would need to meet.

Why it matters: Many times people move their loved ones into communities with the assurance that they will qualify for VA benefits. When they end up not qualifying because they don’t have accurate information, they often cannot afford to stay in the community.

Let’s look at an example: John served proudly in World War II and is now 90 and has a hard time living home alone due to being socially isolated and not always taking his medications correctly. He has agreed to move into a senior community that has assured his family that they can use VA benefits there. The community he has chosen offers meals and light housekeeping and has a home care company on site that he is going to pay $200 a month to remind him to take his medications. John’s income is $1800 per month.

Myth: John is a World War II veteran and is moving into a senior care community that offers meals and he also is paying for medication assistance so he should qualify for VA benefits.

Reality: John does not need the level of care necessary to trigger the benefit and will probably be denied. In John’s case he is only spending $200.00 per month on care which is lower than his monthly income. One of the standards the VA looks for, that John does not meet and is that the cost of care needs to be higher than income. The reason it can be easier to obtain the benefit in a licensed assisted living community is because the whole monthly cost of the community is counted as a care cost, rather than just the cost paid to a home care in an independent community or at home.

Who is Eligible?
Any War Veteran with 90 days of active duty with at least one day during active War time, with Honorable Discharge is eligible for this benefit. A surviving spouse of a War Veteran may be eligible if married at the time of death. The individual must qualify both medically and financially. The amount of assets are considered when qualifying for this benefit however, many things, including their home, vehicle, pre-paid funeral expenses and other items may not be included in this number.

Eligibility dates are:
- World War I 5/9/1916 - 11/11/1918
- World War II 12/07/1941 - 12/31/1946
- Persian Gulf War 8/2/1990 - present

This is only a brief introduction to VA benefits and there is much more to learn and consider when applying. The Veteran’s administration is available to answer additional questions.
Myth #10

Myth: Moving into an assisted living requires a long term commitment and contract.

Reality: Almost all assisted living communities offer for respite or short term stays based on availability which are billed at daily or weekly rates and can be anywhere from 1 week to 3 or 4 months. Sometimes the daily rate can be a bit higher than the rate for a resident under contract but it can also sometimes be lower because communities are trying to use respite stays as a way to attract new residents. A respite resident receives identical care and services to a contracted resident but is not required to pay an initiation fee or sign a long term contract because the intent is to have the stay be short term. A respite resident still has to meet the same admission criteria as a permanent resident.

Why it matters: For some people, the idea of moving from home to an assisted living is overwhelming and scary and for that reason they decide they will just stay home. If given the opportunity to stay at an assisted living for a respite or temporary stay they may be able to alleviate some of those fears and move forward with the decision to move. Also, caregivers can often feel overwhelmed by their responsibilities or have an obligation or illness that makes them unable to be there for the person they are caring for. Respite stays can provide safe care and housing for their loved ones so that they can either rest or attend to their obligations. Also, respite stays can be used as a temporary solution when a crisis has occurred and more time is needed to determine a permanent solution.

Let’s look at two examples:

Barbara has been caring for her mom Sally at her home since Sally’s husband died. Her mom relies on Barbara to help her with many of her activities of daily living as well as provide companionship to her by sharing meals and watching TV. Unfortunately, Barbara needs a hip replacement surgery for herself and will be unable to provide care for her mom for up to two months and also wants to really be able to rest and not worry so she can heal as quickly as possible. She has been asking family for help but no one is available and she is very concerned with how she is going to deal with her mom’s needs and her own recovery.

Myth: Barbara will need family or in home care to be able to get the help she needs for her mom.

Reality: Sally can move to an assisted living community for a short term stay and pay week to week until Barbara is healed enough to begin providing care for her again.

Why it matters: If caregivers are not aware of the options for respite care, they can postpone or neglect their own healthcare or personal needs. This can lead to burnout, resentment or a health decline on the part of the caregiver so that they can no longer handle their responsibilities.

John and Kathy’s mom was brought to the hospital on a Friday night after being picked up by the police wandering down a busy street without a coat on in the middle of winter. She was checked out in the emergency room but found to have no issues other than her dementia and cannot be admitted to the hospital. The discharge planner has recommended that she does not go back home alone and John and Kathy are frantically trying to rearrange their schedules at work so that one of them can stay home and care for her and the other can start figuring out a long term plan.

Myth: John and Kathy have to make a quick decision which community to move mom into, or care for her at their home.

Reality: With the proper assistance, John and Kathy could quickly identify communities that could immediately take Joanne as a temporary resident into their memory care unit. This would allow them time to still manage their work and personal obligations while taking their time to be sure to choose the right permanent solution that will be a good fit for mom’s financial, clinical and emotional needs.

Why it matters: Without knowledge of temporary respite stays families may be pressured to sign contractual agreements to communities that are not the best option, or bring their loved ones home and struggle to find time to care for them while simultaneously looking for a permanent solution and attending to their own family and work obligations. A difficult and unnecessary scenario!
Myth #11

Myth: Dementia care communities are just like assisted living communities but have locks on the doors.

Reality: Dementia communities can and should be designed and staffed in ways that address the specific needs of a resident that has memory loss. The staff should have training in how to care for a person in a way that reduces their anxiety and improves their quality of life. This can include knowing how to distract, cue and redirect someone when they are becoming confused and agitated, in a way that doesn’t make the situation worse and that retains the resident’s dignity. The community should have special life enrichment programs and activity stations that the resident can enjoy and keep busy with and that are proven to be of interest to people whose memories have taken them back in time. These would include areas that have pictures, clothing and memorabilia that are from the resident’s younger days, stations to fold towels or clothes or have other hands on activities to distract a resident or make them feel like they are contributing, quiet rooms with pleasant soothing sounds and aromas to relax an agitated or worried resident. Activities that are within the ability or interest of the resident, such as talking about a farm or war time, life in the old days or maybe enjoying some gardening can create confidence and well-being. Some communities that have been built more recently also have design features that help a resident to orient themselves and increase their independence, such as hallways and doors in contrasting colors, and areas to walk around a community, inside and outside, rather than just up and down a hallway.

Why it matters: Unfortunately very little can be done to stop or reverse memory loss. In fact reducing the anxiety of people suffering from dementia is often the most important consideration. Being in a community that specifically addresses the unique needs of these residents can go a long way towards accomplishing these goals.

Let’s look at an example: Laura is looking for a community for her father Steve who is 90 years old. Steve was diagnosed with dementia several years ago and as his memory loss has progressed he has started getting very confused as to time and place, and where he should be. This has led him to leave the house in the middle of the night thinking he has an appointment at his former place of employment. Recently he was picked up by the police wandering without a coat on a cold winter’s night. Laura realizes she must now find a community for him to move to where he can be safe and comfortable.

Myth: Laura needs to find a community that her dad cannot elope from for him to be safe and comfortable.

Reality: Safety should be a top concern, but the search for the right community for her father should not stop there. There are assisted living communities that have locked and alarmed doors or use wander guard systems for the resident’s safety, but that do not have the extras that can make such a difference in their quality of life. The right community for Steve might also include an activity area that can partially replicate his work, a secure area outside that he can walk around, trained staff that know how to redirect him from his plans to leave without creating unnecessary agitation, and that have other residents that are experiencing similar issues so that he is not singled out as an unusual case and potentially excluded or avoided.

Why it matters: Every year of a person’s life is special and all efforts toward improving quality of life should be strived for at all costs. Choosing the right type of care can make an enormous difference in the quality of daily life of a person with dementia.
Myth #12

Myth: My neighbor’s mom had a horrible experience at the assisted living in my neighborhood so I would NEVER have my mom move there.

Reality: There are so many variations to this statement such as “They let my dad fall and he was on the floor all night”, “My mom hasn’t been given a shower in a week”, “My wife needed help and had to wait for an hour after ringing a call button” and “They took all my parents savings and then when they ran out of money they kicked them to the curb!” Accusations regarding senior living facilities often are a result of unrealistic expectations, miscommunication and sometimes emergencies that occur unexpectedly. There are of course situations in which errors, sometimes tragic errors, are made. But the idea that senior care facilities are staffed by people who don’t care or are purposefully neglectful is just not true.

Why it matters: Many times these stories take on a life of their own and are still being told years after the “incident”. At worst the stories are just not true and at best the error was unintentional and has been learned from and corrected by the community. Without further investigation and knowledge, these unsubstantiated rumors can paralyze a senior housing search due to fear and people that may have otherwise greatly benefited from living in a senior community, remain at home alone.

Let’s look at a few examples:

They let my dad fall and he was on the floor all night waiting for help! The first question is whether dad is in an assisted living that has 24 hour awake staff. These sorts of incidents are more likely to occur at independent living communities where the care has to be scheduled. If care has not been scheduled at night then no one will know that someone has fallen until breakfast, when they didn’t show up.

My mom hasn’t been given a shower all week. Resident’s in senior living communities retain all of the rights they enjoyed before moving. One of these is the right to decline a bath. Unfortunately, either due to dementia, fatigue or modesty, many seniors are very resistant to bathing. If they refuse, the community cannot force them. So in many cases, a person refusing a bath is not the fault of the community, although it would be important to see whether the caregivers are trying different approaches and to communicate concerns with loved ones.

My wife needed help going to the bathroom and had to wait an hour after using the call button. This is one those situations that can happen when there is another emergency happening in the building. Unfortunately there are times when the staff members that are present need to prioritize who they help based on whether a situation is life-threatening or the person is in pain. There are times when everyone needs something at once, and sometimes people have to wait longer than promised. As long as this is not a pattern, it does not mean the community is understaffed or the caregivers are lazy.

They took all of my parent’s money and then kick them to the curb when they ran out. There is usually much more to these stories. All senior living communities have some form of a contract that clearly spell out the financial obligations of the resident, and under what conditions the resident might have to move, whether it be level of care, financial, dementia etc. These parameters are not often clearly communicated or heard, but should be in writing. A closely read contract can usually help avoid these issues. As far as being kicked out to the curb, the family member of a resident is almost always consulted with at length about strategies to stay or ideas about other options for new housing. A minimum of a 30 day written notice is required to force someone to move. Communication both before and during the residents stay can alleviate many of these issues.

In summary, it is best to keep an open mind when searching for a senior care community, don’t believe everything you hear, ask questions, and don’t cross a potential community off of your list until you get the truth.