



SPECIAL REPORT: LONG-TERM CARE FROM THE INSIDE OUT

Revised and Updated Frequently

June 10, 2023

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¹ <http://www.magnusomnicorps.com/home.html>

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Original Publication Date: August 16, 2018

Revision/Update Dates:

2023: 2/23, 5/17, 6/7, 6/10
2022: 1/16, 2/24, 2/27, 3/4, 4/4, 4/27, 5/8, 8/31, 10/18, 11/3, 12/8
2021: 3/6, 5/11, 7/28, 8/7, 8/17, 8/21, 9/9, 11/28
2020: 1/17, 6/16, 8/11
2019: 1/3, 1/6, 1/16, 1/18, 3/30, 4/3, 4/26, 5/3, 5/24, 7/3, 7/24, 8/1
2018: 8/16, 8/27, 9/2, 9/5, 10/2, 10/8, 10/13, 11/9, 12/11, 12/21

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If you are experiencing difficulties of ANY KIND with a long term care community, contact your county ombudsman IMMEDIATELY – they are YOUR advocates and their services are free!! Go [here](#)³ or on the Internet simply search for “(your county’s name, your state’s name) ombudsman.”

1. INTRODUCTION

Recently I attended a [Senior Living Truth Series seminar](#)⁴ (which I **highly** recommend) conducted by Dr. Nikki and Chris Buckelew, (more info on them in **Section 6.**) One of the questions Dr. Nikki asked the panelist (all residents of senior living communities) why they moved there. One lady, 94, had an excellent response: **It’s much better to move sooner rather than later.** If you try to tough it out at home and move later, you may face health challenges that make the move significantly more difficult (to which I would add, or worse, possibly suffer a critical health incident, such as a fall, and wind up in a skilled nursing facility (SNF or “sniff”) or other long term care situation that may not be your ideal option). Also, if you wait too long, there may be issues with availability of help, etc., compounding the difficulty of the situation. Furthermore, if you make the choice to move when you are relatively healthy, you will have the time and energy to thoroughly investigate all your living options and that will significantly increase the chances of you being much more comfortable and happier with your decision. At these communities, you will be safer, more comfortable, and you will be able to better maintain your health because you will not be burdened and stressed with all the responsibilities you have with living on your own. At these communities, there is usually lots to do and you will be around a lot of people your own age with whom you have a lot in common, and that (being around people) is very important as it helps maintain our humanity. If you are a couple and, for some reason, one has to go to a higher level of care in another part of the community, it is much easier to visit and look after your spouse daily if you live in the same complex – think about the Covid years. Most of these places have welcoming committees to help get you acclimated to the community, so you’re not going in totally on your own. For individuals (relatives, professionals, etc.) who are trying to help seniors make these choices – you should be careful not to impress your views about what you think a person or persons’ living situation going forward should be

³ <https://ltombudsman.org/>

⁴ <https://seniorlivingtruthseries.com/>

like. You should be supportive, answer questions, politely offer alternatives and options and try to accommodate their desires and wishes and if a place doesn't fit, then step back and re-evaluate.

So, why this report? Because chances are very good that at some point in your life, you **WILL** have to deal with the private long-term care industry either for yourself or for a loved one and most people have **no idea** what they will be getting into. (As for government-funded Medicaid long-term care, that's a whole other animal but some things here still apply. Here's some good info.) It is a very confusing and complex system with all kinds of pitfalls and I saw the need for, but could not find, some kind of document that would provide this information for my family, friends and clients who would tell me of their trials and tribulations when dealing with caring for a loved one, not to mention many of my own. Yes, this is a long report, but if you want, you can skip to **section 14. Important Points to Remember**, for a summary. Or, if this just seems completely overwhelming, and in many cases, it is, you could employ the assistance of an elder case manager – there are usually some private companies that offer such services in most major metropolitan areas – do an Internet search, or see the [Aging Life Care Association's website](http://www.aginglifecare.org)⁵. **Exciting Update!!!** I have found an excellent resource to help caregivers and loved ones navigate this system. Please go to [Care Right, Inc.](https://carerightinc.com)⁶ and review their videos, products and service offerings.

I've been around the long-term care industry for a good portion of my life (about 30 years now) as my mom was a caregiver for 6 of our immediate relatives, including my father, over the course of that time. I quit my big corporate job and temporarily re-located to another state to help her care for my dad in their home for the last 2 years of his life. (We tried long-term care, but back then it was wrought with incompetence and indifference.) When I was young, she dragged me around to all the nursing homes where our relatives were and I have worked in the industry in a variety of positions and have been a licensed administrator. Eventually, I became her caregiver until she passed a few years ago.

Now, as a private detective, elder case manager, and former state-licensed administrator, I am in a similar position with my company as I assist families with running the long-term care gauntlet and care for individuals (clients) who have no family in the state or country who can do so. My consultant for this report has worked directly in assisted living communities and nursing homes for 35 years in every

⁵ <http://www.aginglifecare.org>

⁶ <https://carerightinc.com>

position from nurse's aide to director of nursing, to executive director in both for-profit and non-profit assisted living and nursing home communities.

The purpose of this report is not to give you a checklist of what to look for when selecting a community – there are plenty of those websites and services out there - they constantly advertise on TV, radio and senior-targeted media of all varieties. Also, [CARF](http://carf.org/)⁷ (Resources section) and [Where You Live Matters](https://www.wheretheyoulivematters.org/)⁸ are excellent places for you to start. I developed this report to give caregivers and prospective residents of long-term care communities some insight into the industry and provide you with some information and tips that you probably won't or can't get anywhere else. **If you have never been a caregiver, trust me, it is very time consuming and an extremely physically and psychologically demanding and difficult task and you need to go into that role knowing as much as possible and that goes double if you are caring for someone with memory-loss/dementia.** Prepare yourself for perhaps the most difficult, frustrating and stressful experience you've ever had and I'm not being melodramatic here. It will test your patience and relationships at home, work and with your loved one(s) and other family members. Even if you have been a caregiver before, I cannot strongly enough recommend that you join any of a number of caregiver support groups in your area. Most long-term care communities have them as well as major hospitals and they are usually conducted by mental health/geriatric care professionals. Also check with our county's areawide aging agency, the United Way and the Alzheimer's Association or even your church. In addition to support groups, many also offer classes to help you better understand what you and your loved one are going through and how to effectively cope and they are also great resources for the advice and services you will eventually need to get through this. **Please don't overlook this critical aspect of being a caregiver. Even if you are not providing hands-on care and may be geographically separated from your parent(s) or other loved one, join a group – you will thank me later!**

For the most part, I'll be discussing this subject as it relates to assisted living communities, but will touch on nursing homes, as well, and many aspects of this report can be applied to nursing homes. Assisted living communities were originally designed to provide simple assistance with daily living tasks – low levels of care, but because nursing homes have become so exorbitantly expensive (2 - 5 times or more that of most assisted livings) and their environments much less than desirable, the trend in the industry is to try to help the individual live as comfortably as possible with the minimum amount of assistance

⁷ <http://carf.org/>

⁸ <https://www.wheretheyoulivematters.org/>

necessary, as long as possible, but also make available the ability to move towards higher levels of care, almost at nursing home levels, when needed, hence the growth of assisted living communities. Lines between the two (assisted livings and nursing homes) are getting blurred.

An important point to keep in mind: Most nursing homes' residents' care is being paid for by Medicare (short-term rehabilitation stays) or Medicaid (long-term guaranteed government payments), but there may be some private pay residents, as well. In most places, other levels of care, independent living, assisted living, memory care are private pay only and are subject to the forces of the markets and competition.

2. FACING REALITY

“You can ignore reality, but you can’t ignore the consequences of ignoring reality.” Ayn Rand

Before I even get started, I want to address a very common factor in this subject: Denial. Yes, denial (and I’m going to lump ignorance in with that, too). It’s a great place to be until you’re forced out of it! As much as I am aware of it, I am still guilty of it, too – I try to do physical activities of a 20-year old when I know otherwise....and I usually pay the price for it physically and financially (to my wonderful chiropractor and his staff, who have “straightened me out” countless times, pardon the pun). The same goes for making decisions for yourself or a loved one. As you read this report, **be pragmatic** about prevailing health conditions and care needs. Sure, all of us would prefer to live out our lives and die in our homes, but that’s usually not realistic at all - latest statistics show that only 20-30% die at home with the rest passing in acute care hospitals, hospice homes or long-term care communities.

Invariably, you will receive advice and or information from a doctor, nurse, administrator or other health care professional that you do not want to hear – we will all get that information at some point in our lives eventually. **Live up to it and deal with it...and do so quickly because time is of the essence!** If you think you are getting bad advice, get a second or third opinion. And when it comes to getting advice, especially when assessing your long-term care options, trust those who have **experience in the field**. Trust, but verify, of course. What I mean is this, for example: You may have a nice niece who is a new RN and is whispering in your ear and giving your conflicting information (from what the other experts are telling you). It is nice that you have a nurse in your family who is helping and of course she has your best interests in mind, but she has a lot of book-learning under her belt, and very little, if any, practical experience (unless an LPN first) especially when it comes to long-term care. So, for example, if an assisted living director of nursing (DON) says that your mom or dad is having memory issues and needs to be moved to a memory care unit, discuss the situation with the staff at length and take them seriously irrespective of what the new RN says. No one wants to see their loved one’s condition deteriorate, but it almost always works out that way, so be ready for it and heed the medical professionals’ advice.

Another thing, if you are planning on caring for your loved one in your home, you really need to think it through carefully. Ask yourself, what kind of support system do I have? In other words, do you have a back-up plan in the event you fall ill or some other immediate caregiver-family member such as a spouse or child falls ill and you are unable to work because now you have 2 or more people to care for? Would

you be able to provide care to all who need your attention and assistance? How long before you run out of money or collapse from exhaustion (aka “caregiver burnout”)? This is especially true if you are caring for someone with memory-loss/dementia. Or what if there was a natural disaster? Think you can rely on relatives to help? Think again. I’ve seen more of them bug out than stick around to help and I also speak from personal experience, sad to say. Or worse, those relatives are constantly nipping at your ankles, second-guessing your decisions and making it very frustrating for you and your job that much more difficult. More on this later.

We live in a very mobile society and as such, we may not have family or friends in the immediate area or even state or country to assist with our care. So, parents, keep this in mind: It is unfair and selfish for you to expect one or more of your children to give up their careers, family and lives to move to where you are to care for you - it is not their fault that you did not plan and save appropriately for this phase of your life. Do not saddle them with that kind of decision and burden. From my experience, most children are not in any situation, financially or familially, to make that level of life-changing adjustment. Here’s a personal example: I briefly mentioned my mom’s history as a caregiver above, so she knew the score. For years I tried to get my mom to move close to me so I could help care for her, but she repeatedly refused saying that she didn’t want to be a burden on me. Well, as time went on and her health started to fail, I had to put my life on hold and spend months at a time, on and off, living with her in another state, caring for her and arranging for her care. Fortunately, I was retired (first time) and in a position to do so, but most are not. Near the end of her life, she admitted that she should’ve accepted my offer to move closer to me so I could care for her and apologized for being the burden on me she so much didn’t want to be. Of course, I told my mom not to be concerned about it and reflected on all the good times we did get to spend together in her later years that we probably would not have done otherwise.

However, if a family member (child) can provide care for a parent or parents, the task usually falls on the wife or daughter-in-law – for some reason, for the most part, men just don’t do “that stuff.” I just wanted to take this opportunity to tell the men of the family that you need to start stepping up to the plate and take a very active role in caring for your loved ones – opening your wallet just isn’t enough. And for those of you who just can’t bring yourself to go into hospitals or long-term care communities because you can’t stand to see sick people, you need to get over yourself, suck it up and get to work. Just think about how many times your mom or dad cared for you when you were sick! [See this report](https://www.usagainstalzheimer.org/sites/default/files/Dementia_Caregiver_Report_Final.pdf)⁹ on Millennials and

⁹ https://www.usagainstalzheimer.org/sites/default/files/Dementia_Caregiver_Report_Final.pdf

Dementia Caregiving in the U.S. from [UsAgainstAlzheimer's](https://www.usagainstalzheimer.org/)¹⁰ and consider these facts from the [Alzheimer's Foundation of America](http://alzfdn.org/wp-content/uploads/2017/04/Female_Face_High_Res.pdf)¹¹:

¹⁰ <https://www.usagainstalzheimer.org/>

¹¹ http://alzfdn.org/wp-content/uploads/2017/04/Female_Face_High_Res.pdf

THE FEMALE FACE OF ALZHEIMER'S DISEASE

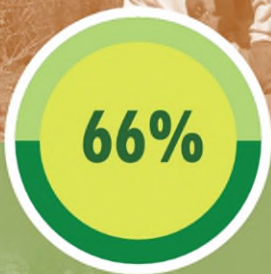
As Mother's Day approaches, our thoughts turn to all things "mom." The lives of an increasing number of mothers, grandmothers, daughters, granddaughters and other women have been touched by Alzheimer's disease – either through their own diagnosis or that of a family member. Here's a look at women and Alzheimer's disease:



MANY MILLIONS OF MOMS

85.4 MILLION = Number of mothers of all ages in the U.S.

(Source: U.S. Census Bureau, 2012)



SHOULDERING THE RESPONSIBILITY OF CAREGIVING



• **66%** of caregivers are female
(Source: National Alliance for Caregiving and AARP, 2009)

• Female caregivers' average age:

48

(Source: National Alliance for Caregiving and AARP, 2009)



THE AGING AMERICAN FEMALE

POPULATION 65+



(Source: U.S. Department of Health and Human Services, 2012)

LIFE EXPECTANCY AFTER AGE 65



(Source: Social Security Administration, 2013)

WOMEN AT 30% HIGHER RISK OF DYING FROM ALZHEIMER'S DISEASE

(Source: Centers for Disease Control, 2013)

75% of females who had a memory screening on the Alzheimer's Foundation of America's National Memory Screening Day reported memory concerns

(Source: Alzheimer's Foundation of America, 2010)



THE FINANCIAL AND EMOTIONAL COSTS OF ALZHEIMER'S CARE

Average cost of care per dementia case in 2010 was between

\$41,000 and \$56,000

(Source: RAND Corporation study, 2013)

48% Male

35% Female

Percentage of caregivers who feel they are well able to cope with the aggressive behavior of the person they care for

(Source: Alzheimer's Foundation of America/Harris Interactive, 2012)

76% of female caregivers report either physical or emotional exhaustion from their caregiving duties

(Source: Alzheimer's Foundation of America/Harris Interactive, 2012-61% of respondents female)

Caregivers' most common health changes as a result of behavioral and cognitive symptoms of the person they care for:

- Fatigue
- Difficulty sleeping
- Headaches
- Back pain
- Weight gain

(Alzheimer's Foundation of America/Harris Interactive, 2008)



ALZHEIMER'S DISEASE

5.1 MILLION AMERICANS HAVE ALZHEIMER'S DISEASE

(Sources: National Institute on Aging, 2013 and U.S. Department of Health and Human Services, 2012)

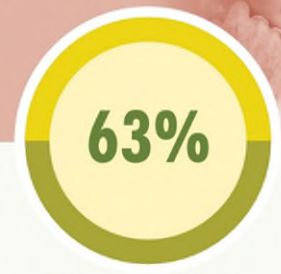


• Prevalence doubles every five years beyond age **65**

(Source: National Institute on Aging, 2013)

• **6th** leading cause of death in the U.S.

(Source: Centers for Disease Control, 2013)



AND A POSITIVE NOTE:

Sandwich caregiving (caring for child/children under 21 and someone with Alzheimer's disease) has positive aspects:

63% of women reported becoming stronger

(Source: Alzheimer's Foundation of America/Harris Interactive, 2008)

©2013 Alzheimer's Foundation of America

Now go back and re-read the first paragraph of **Section 1**.

Again, it is up to **YOU** to **be pragmatic** about your care needs, **plan appropriately and thoroughly** and make the necessary living arrangement changes **before** an emergency arises. ***You have to be your own first responder in all aspects of your life!***

More on planning in **Section 5**.

3. INDUSTRY TERMINOLOGY YOU NEED TO KNOW

When I was young, we called them, “the rest home,” or “the old folks’ home.” Then, they became “facilities.” Well, in our hyper-politically correct culture, none of those are acceptable now, so we call them “communities.” To be fair, the amenities offered by and the physical appearances of many communities have improved **significantly** over the decades, as have the costs. Also, I’m going to use the term administrator and executive director interchangeably to avoid confusion. Essentially this is the top person in charge of the community.

Before we start, for clarification purposes, here are some definitions. **Also keep in mind that what communities are referred to (nursing home, assisted living, etc.) can vary significantly from state to state as can staffing levels and licensure requirements for each respective level of care.**

However, skilled nursing and nursing home communities are regulated at the federal level, so their requirements should be approximately the same in most states, but in some states, states also have regulatory authority and requirements that may exceed federal requirements.

| | |
|--------------------------------|-------------------------------------|
| Old: DON (Director of Nursing) | New: Directors of Health & Wellness |
| Old: Activities Director | New: Life Enrichment Director |
| Old: Receptionist | New: Director of First Impressions |

And some other terms that need to be defined and again, terminology can vary from state-to-state:

55+ / 62+ Active Adult Communities (aka 55 and Better, Active Adult Living, Independent Living)

Yes, these are legal. You must have reached the age of 55 or 62, depending upon the community, prior to moving in and children are not allowed, which many seniors prefer. These are essentially apartment communities with some enhancements for seniors such as features for improved accessibility (e.g. sidewalks, elevators, indoor mail boxes, minimal steps to areas in the community and special features inside the apartment such wide doorways, ADA compliant bathrooms, kitchens, etc.). Of course, interior and exterior maintenance are included in your rent. Many communities have exercise rooms, clubhouses for social events, theater rooms, libraries, computer rooms, other common/social areas for community gatherings organized and hosted by the residents and not the management. The resident must still provide for their own meals, transportation, housekeeping, etc., however, some communities are strategically located in areas with excellent, inexpensive public transportation, close to major

shopping and medical services, etc. Some places may have a “concierge” who can assist you with arranging for services you may need. Depending upon the community and also state laws, they may have on-sight offices for a home health care contractor who can provide residents with additional assistance, if needed. These communities are usually NOT regulated by a state’s department of health as are other communities, but may be overseen by some states’ real estate commissions. Most are pet-friendly and have annual leases. Some communities may be partially subsidized by HUD meaning that rent fees may be on a sliding scale and the rent may be reduced for those with less income while others will have to pay the “market rate.” Do not pre-judge HUD-subsidized communities – my mom lived in one for several years and it was an absolutely wonderful place – 2 bedroom/2 bath, 1100 square feet, full-sized kitchen, full-sized washer and dryer, patio, etc. Other floor plans were available. May have a waiting list.

Independent Living Communities (Full Service)

Very similar to the above physically but with enhanced services (and cost). Some units may have full kitchens or kitchenettes, especially if 2 or 3 meals are included, which they often are at these places. Services also include interior and exterior maintenance, housekeeping, laundry, transportation to grocery shopping and medical appointments. Inside you will have emergency alert systems, organized (by staff) social activities, 24-hour staffing, security, etc. Some of these are non-profit faith-based owned while others are corporate owned or affiliated with a university or college. Again, in-house medical and personal care services are generally not provided, but as above, depending upon the community and also state laws, they may have on-sight offices for a home health care contractor who can provide residents with additional assistance, if needed. These communities are usually NOT regulated by a state’s department of health as are other communities, but may be overseen by some states’ real estate commissions. There are generally a variety of floorplans available, most have kitchenettes and community laundry machines (if you want to do your own). They may have covered parking or garages, patios, balconies, and all the common areas mentioned above. They may have annual leases or month-to-month and may be partially subsidized by or accept some governmental assistance. Fees can be expensive depending upon apartment size and amenities and there may be a long wait list.

Residential Care (aka Community Homes)

Not available in all states. A community, usually located in a single-family home setting in a residential neighborhood, where licensed staff care for a very small number of residents, usually 1 – 6, who live in

the house. Residents are usually required to be ambulatory and need a bare minimum of assistance with daily living tasks (aka ADL's). State licensed and inspected.

Assisted Living

A community where most residents are ambulatory, but need assistance with 1 or more daily living tasks [aka ADL's (Assistance with Daily Living)] such as dressing, bathing, personal hygiene, managing personal affairs, medication management, housekeeping, transportation to appointments, regular meal preparation, etc. Some assisted living communities can accommodate a wide variety of care needs (light to heavy) depending upon how they are licensed and corporate policies and procedures. The lines are becoming blurred between the levels of care provided by assisted living and long-term care (nursing home) communities. Much depends upon state laws, rules, and regulations. Most have all the common areas mentioned in the two above. In-house medical services are generally provided with a "house doctor" on staff as well as RN's, LPN's, CNA's, etc. Staffing levels depend upon state licensure requirements and corporate policies. The better ones have licensed nurses to assist with skilled care 24-hours a day, but that is rare. Some are pet friendly as long as the resident can properly care for the animal. Most are private pay and accept long term care insurance, depending upon your policy. Sometimes veterans' benefits can help with the rent. Medicaid assisted livings are rare. Some assisted living communities may have a separate section of the community for residents with memory care needs (see below).

Assisted Living Memory Care

Similar to assisted living above, but with strict ingress and egress security and unique design features for those who suffer from dementia/memory/Parkinson's/brain injuries, etc., conditions. Ideally, the staff should have received additional, specialized training, such as the Alzheimer's Association essentiALZ® training program, to better care for the memory impaired. These residents usually require significantly more care and close monitoring, so additional staff is generally required. All meals and services are provided. Rooms are generally smaller, semi-private, private pay and higher cost. Long term care insurance and other benefits may provide financial assistance, but these are generally private pay communities. Some assisted living communities may have a separate area of the community for their memory care residents or the community may be for persons with memory care needs only, i.e. a dedicated memory care community.

Skilled Nursing Facility [SNF (sniff)]

These are usually part of a long-term care nursing home or hospital. SNF's are for those who have been in the hospital and require short-term, usually 3 months or less, rehabilitation of some sort, after which they are discharged back to their prior living arrangement or to another community that can provide the appropriate level of care required. Depending upon your age and insurance status, Medicare and or your private insurance will cover most fees. Federally and state licensed, inspected (if not in hospital) and staffed by a full range of health care professionals including physical and occupational therapists to assist with your rehabilitation. Rooms are generally small, private or semi-private and all services are provided.

Long-Term Care/Healthcare Center

Also known as a "nursing home" and may also have an in-house skilled nursing facility (SNF). In most areas, these offer the highest level of long-term care provided. Residents are unable to living independently and require levels of skilled (nursing and other medical) care that is beyond the scope, capability, and licensure of all the aforementioned levels. Residents need 24-hour care and supervision with almost all ADL's. Levels of care vary from unit to unit within the same building. Rooms are either private or semi-private and general privacy is extremely limited. Cost for this level of care is very high and, in some cases, twice as much as assisted living. Federally and state licensed and inspected, private pay or Medicaid or both. Long term care insurance and veterans' benefits generally accepted when qualified. May or may not also provide long-term care for the memory impaired depending upon corporate policies.

Continuing Care (or Continuum of Care) Retirement Community (CCRC): (old term, now called Life Plan Community or Life Care Community)

There are other terms used, but this **usually** this means a community that provides **ALL** the aforementioned levels of care and living options at one location, but be sure to ask as that may not always be the case. Sometimes they offer a variety of special "buy-in" or "life care" contracts (very large initial deposit) meant to meet the unique needs for qualified individuals and these can help defer the high costs of long-term care by using a pre-determined and guaranteed pricing structure. Prospective residents must meet certain health and financial requirements and those vary greatly by community. May or may not allow individuals to skip levels of care. For example, if you want to live there and need assisted living care now, but you didn't start out in their independent living, they may not be able to accommodate you as they generally reserve rooms in advanced care levels for their long-term residents

who are advancing in their care needs. Private pay. More on this later. [CARF Consumer Guide to CCRCs, LPCs 2022](#)¹²

MAR: Medication Administration Record – A detailed record (paper or computerized log) of the medications administered to each resident – contains info such as medication, dosage, time, date, method of administration, initials of administering individual.

¹² <http://carf.org/Consumer-Guide-to-LPCs/>

4. WHY DO WE NEED LONG TERM CARE and WHO NEEDS IT?

People need care at levels provided by assisted living or nursing home communities for a variety of reasons; injury, infirmity, etc., but a significant amount of those individuals suffer from some form of dementia or Parkinson's disease and are no longer able to care for themselves at home or do not have a family support system who can assist.

When it comes to Alzheimer's and dementia, check out these statistics from the [Alzheimer's Association](#)¹³:

¹³ <https://www.alz.org/media/Documents/alzheimers-facts-and-figures-infographic.pdf>

2021 ALZHEIMER'S DISEASE FACTS AND FIGURES

DISCRIMINATION

is a barrier to Alzheimer's and dementia care. These populations reported discrimination when seeking health care:



of Black Americans



of Native Americans



of Asian Americans



of Hispanic Americans



1 IN 3

seniors dies with Alzheimer's or another dementia

MORE THAN 6 MILLION

Americans are living with Alzheimer's

Alzheimer's and dementia deaths have increased

16%

during the COVID-19 pandemic



OVER 11 MILLION

Americans provide unpaid care for people with Alzheimer's or other dementias



These caregivers provided an estimated 15.3 billion hours valued at nearly

\$257 BILLION

It kills more than

BREAST CANCER



PROSTATE CANCER

COMBINED

Between 2000 and 2019, deaths from heart disease have

DECREASED 7.3%

while deaths from Alzheimer's disease have

INCREASED 145%

In 2021, Alzheimer's and other dementias will cost the nation

\$355 BILLION



By 2050, these costs could rise to more than

\$1.1 TRILLION

alzheimer's association

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Also, [here is an excellent free report](#)¹⁴ from the Alzheimer's Association and more information is available from the [Alzheimer's Foundation of America](#)¹⁵.

America's population is aging – estimates are that people are turning 65 at a rate of 10,000 per day – that's 3,650,000 per year. Other contributing factors to need are:

- Simple aging and no longer being able to care for oneself – people need **assistance with daily living tasks** (aka **ADL's** in the industry)
- Mobility of our society and absence of close family in the immediate area who can help the individual continue to live on their own – run errands for them, take them to doctors' appointments, help them manage their financial affairs, care for the home, etc., etc.

Here's an excerpt and some additional statistics from a web article:

“Estimates are that somewhere between 50-70% of people over the age of 65 will require fairly significant long-term care services at some point in their life; meaning they'll need assistance with at least a couple of activities of daily living, such as eating, dressing, or bathing, and possibly even a higher level of care according to [this article](#)¹⁶.

According to the [National Center for Assisted Living](#)¹⁷, 59% of all assisted living residents will eventually move to a skilled nursing facility. The average stay in a nursing home is 835 days, according to the [National Care Planning Council](#)¹⁸. [For residents who have been discharged, which includes many who have received short-term rehab care, the average stay in a nursing home (SNF) is 270 days.]

In summary, it is not uncommon for someone to receive care at home for several months or longer, followed by a two and a half year stay in an assisted living facility, with almost 60% then requiring a nursing home stay of somewhere between nine months and a little over two years. All combined, this is a

¹⁴ <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

¹⁵ <https://alzfdn.org/>

¹⁶ <http://www.mylifesite.net/blog/post/so-ill-probably-need-long-term-care-but-for-how-long/>

¹⁷ <https://www.ahcancal.org/ncal/resources/Pages/ResidentProfile.aspx>

¹⁸ http://www.longtermcarelink.net/eldercare/nursing_home.htm

total of approximately 4-5 years of long-term care. In this scenario, the total cost of care could easily exceed \$300,000, depending on the cost of care in your region.

*This is daunting considering that it would be **in addition to** the approximately \$245,000 that Fidelity Investments estimates the average retired couple will spend on healthcare - other than assisted living or nursing care expenses— during the span of their retirement years.¹⁹*

The [U.S. Department of Health and Human Services \(DHHS\)](#)²⁰ says that approximately 70 percent of people over age 65 will require some degree of long-term care services during their lifetime.²¹ Some argue that this statistic is misleading because it includes not only those who require assistance with the six activities of daily living (ADLs)—bathing, dressing, eating, toileting, transferring, and continence—but also Instrumental ADLs (IADLs), such as everyday chores and homemaking. For example, if someone over age 65 hires a housekeeper to come by once per week, is that considered long-term care? Most would say no, but conceivably the DHHS statistic includes this form of assistance. Yet, a separate statistic produced by AARP suggests that the lifetime probability of becoming disabled in at least two ADLs, or of being cognitively impaired, is 68 percent for people age 65 and older.²²

Based on my personal experience, 100% of my immediate family (both parents, all grandparents, 3 uncles and great aunt) who lived past the age of 65 all required some form of long-term care. On a professional side, I've had 2 clients (husband and wife) who were functioning relatively normally and living independently one day and then literally overnight they required care in a memory care/assisted living community. Yes, it can happen that quickly. Would you know what to do in such a circumstance if you got “the call?”

The Alzheimer's Association has lots of [free online training](#)²³ to help families cope with Alzheimer's Disease and dementia. They also offer online training and certification for professionals through their [essentiALZ program](#)²⁴, which I highly recommend.

¹⁹ <http://www.mylifesite.net/blog/post/so-ill-probably-need-long-term-care-but-for-how-long/>

²⁰ <http://longtermcare.gov/the-basics/how-much-care-will-you-need/>

²¹ <http://longtermcare.gov/the-basics/how-much-care-will-you-need/>

²² American Association of Retired Persons (AARP). Beyond 50.2003: A Report to the Nation on Independent Living and Disability, 2003, (Washington: AARP 1 Jan 2005).

²³ <https://training.alz.org/>

²⁴ <https://www.alz.org/professionals/professional-providers/dementia-care-training-certification>

Since I'm on the topic of insurance plans, very briefly, if you are considering any kind of Medicare Assistance Program, be **EXTREMELY** careful about choosing one of these. Do your homework and talk to a knowledgeable, independent insurance broker (one who does NOT sell MAP policies) about the pro's and con's in your particular circumstance. Don't make a life-long, irreversible mistake when selecting your Medicare options.

5. PLANNING & COSTS

Bottom line: You need to make decisions about your care when you are able and before someone else has to do it for you!! The sad fact is that couples/families rarely talk about this at all. Ideally, you should start learning about your long-term care when you are in your 50's – planning and funding it **MUCH** earlier!!

Based on the statistics in section 4., it's obvious that as a society we must do much better at planning for our retirement years, not from just a financial standpoint, which ties in here, but from a healthcare aspect. This is critical if you are an “orphan adult” or are a senior and you have no family or friends in the immediate area, state or country who can come to your aid in the event of a life-changing emergency, such as a broken hip requiring an extended stay in a skilled nursing facility (SNF aka “sniff”) or the onset of dementia or other memory issues that can affect your ability to make rational choices or provide for your own care. This can also apply to senior couples – what if your spouse falls ill and you find yourself the lone caregiver – could handle it – physically, emotionally, financially?? And relatives of such at-risk individuals need to be prepared when you receive “the call.” Again, will you know what to do? Will you be immediately willing and able to come to the aid of a parent or loved one, even if they are in another state? Are you able to leave your family and job for an extended period of time (perhaps months) to handle such a situation? Who will handle your affairs while you are away? Is your life sufficiently automated that you can leave? Do you have a trusted friend or neighbor to take care of your house, bills, etc., while you are away? That is an especially important question for single people and doubly so if you are an only child.

When it comes to what I call “life planning,” at least from a financial aspect, most Americans are terrible about it. The sad fact is most Americans are living paycheck-to-paycheck and according to [this August 9th, 2017 article in USA Today](#)²⁵, we are only saving about 3.8% of our income and we are spending way more than we are earning. Also see: and [How Many Americans Live Paycheck-to-Paycheck in 2023?](#)²⁶ I recently attended a Money 101 seminar held by [Five Rings Financial](#)²⁷ and they had some interesting statistics on the state of savings and retirement in the U.S.:

²⁵ <https://www.usatoday.com/story/money/2017/08/09/americans-saving-less-income-lags-spending/549177001/>

²⁶ <https://www.meetbreeze.com/blog/how-many-americans-live-paycheck-to-paycheck/>

²⁷ <https://www.fiveringsfinancial.com/>

- There is \$10 trillion in U.S. accounts that is earning 1% (or less) interest. Factor in inflation and you are **losing** money, especially in these years of Bidenflation.
- Most people don't seriously think about or start saving until they are 53 – they spend most of their income paying bills and raising a family, but 53 is way too late, especially now in the age of Covid and “Bidenflation.”
- Just about anyone **can** save – statistics show the average person wastes about \$20 per day. (See the [Tip of the Day page on my website](#)²⁸ for great savings opportunities.)
- On average, a 65-year old retiree's IRA, 401(k), etc., will only last them 7 years, yet men and women are now projected to live into their early 90's.
- Less than 2% of individuals can retire at 65 and be financially independent – a bare minimum of \$1 million in savings is required and you have to manage it very carefully due to taxes
- 60% of bankruptcies are caused by health issues and 80% of those people had health insurance

Consider these other recent staggering statistics:

- [U.S. Census – Nearly Half of Baby Boomers Have NO Retirement Savings, 5/8/2023](#)²⁹
- [Jaw-Dropping Stats About the State of Retirement in America – GoBankingRates, 1/5/2022](#)³⁰
- [Ramsey Solutions Study: Today's Retirement Crisis, 9/27/2021](#)³¹
- [Americans are behind on saving for retirement. Here's how to get on track – CNBC, 9/1/2021](#)³²
- [1 in 4 Americans have no retirement savings — and those who do aren't saving enough – Yahoo News, 3/31/2021](#)³³
- [Bankrate Survey: Fewer than 4 in 10 Americans could pay a surprise \\$1,000 bill from savings, 1/11/2021](#)³⁴
- [40% of Older Americans Rely Solely on Social Security for Retirement Income, 1/13/2020](#)³⁵
- [WATCH: Why 78% of Americans are Broke & How to Prevent It! – The Minority Mindset, 8/2/2019](#)³⁶

²⁸ <http://www.magnusomnicorps.com/tip-of-the-day.html>

²⁹ <https://thehill.com/business/personal-finance/3991136-nearly-half-of-baby-boomers-have-no-retirement-savings/>

³⁰ <https://www.gobankingrates.com/retirement/planning/jaw-dropping-stats-state-retirement-america/>

³¹ <https://www.ramseysolutions.com/retirement/retirement-crisis-research>

³² <https://www.cnbc.com/2021/09/01/americans-are-behind-on-retirement-savings-heres-how-to-get-on-track.html>

³³ <https://www.yahoo.com/now/retirement-savings-us-193226292.html>

³⁴ <https://www.bankrate.com/banking/savings/financial-security-january-2021/>

³⁵ <https://www.nirsonline.org/2020/01/new-report-40-of-older-americans-rely-solely-on-social-security-for-retirement-income/>

³⁶ <https://www.youtube.com/watch?v=7MWyjGVN1kc>

- [Poll: About half of rural Americans cannot afford an unexpected \\$1000 expense -The Hill, 5/21/2019](#)³⁷
- [Half of older Americans have nothing in retirement savings – Yahoo Finance, 3/27/2019](#)³⁸
- [70% of Americans with credit card debt admit that they can't pay it off this year - CNBC, 3/19/2019](#)³⁹
- [New Report: How credit card debt impacts the average American – List with Clever, 3/11/2019](#)⁴⁰
- [Shutdown highlights that 4 in 5 US workers live paycheck to paycheck, CNBC, 01/09/2019](#)⁴¹
- [Millions of Americans working past 65, CBS, 12/12/2018](#)⁴²
- ["I Blame Myself" Retirement Remains Out of Reach for Millions of Americans, CBS, 12/12/2018](#)⁴³
- [Most Americans aren't financially healthy despite booming economy, survey finds - Los Angeles Times, 11/01/2018](#)⁴⁴
- [40% of American middle class face poverty in retirement, study says - CNBC, 10/12/2018](#)⁴⁵
- [1 in 3 Americans have less than \\$5,000 saved for retirement—here's why so many people can't save – CNBC, 8/27/2018](#)⁴⁶
- [Americans Still Aren't Saving, Despite the Booming Economy, 6/19/2018](#)⁴⁷
- [The World Isn't Prepared for Retirement – Bloomberg, 5/29/2018](#)⁴⁸
- [40% of Americans can't cover a \\$400 emergency expense – CNN Money, 5/22/2018](#)⁴⁹
- [Almost half of US families can't afford basics like rent and food – CNN Money, 5/17/2018](#)⁵⁰
- [A family was billed \\$937 for a baby's ointment and that's more than most Americans can afford – CNBC, 4/17/2018](#)⁵¹
- [65% of Americans save little or nothing – Bankrate, 3/15/2018](#)⁵²
- [Only 39% of Americans have enough savings to cover a \\$1000 emergency - CNBC, 1/18/2018](#)⁵³

³⁷ <https://thehill.com/policy/healthcare/444722-poll-about-half-of-rural-americans-cannot-afford-unexpected-1000-expense>

³⁸ <https://finance.yahoo.com/news/almost-half-older-americans-zero-210656147.html>

³⁹ <https://www.cnbc.com/2019/03/19/70-percent-of-people-with-credit-card-debt-cant-pay-it-off-this-year.html>

⁴⁰ <https://listwithclever.com/real-estate-blog/credit-card-debt-report/>

⁴¹ <https://www.cnbc.com/2019/01/09/shutdown-highlights-that-4-in-5-us-workers-live-paycheck-to-paycheck.html>

⁴² <https://www.cbsnews.com/news/retirement-age-changing-why-millions-of-americans-are-working-past-65/>

⁴³ <https://www.cbsnews.com/news/i-blame-myself-retirement-remains-out-of-reach-for-millions-of-americans/>

⁴⁴ <http://www.latimes.com/business/la-fi-financial-pulse-20181101-story.html>

⁴⁵ <https://www.cnbc.com/2018/10/12/40percent-of-american-middle-class-face-poverty-in-retirement-study-says.html>

⁴⁶ <https://www.cnbc.com/2018/08/27/1-in-3-americans-have-less-than-5000-dollars-saved-for-retirement.html>

⁴⁷ <https://www.bloomberquint.com/onweb/2018/06/20/americans-still-aren-t-saving-despite-the-booming-economy>

⁴⁸ <https://www.bloomberg.com/news/articles/2018-05-29/the-world-isn-t-prepared-for-retirement>

⁴⁹ <http://money.cnn.com/2018/05/22/pf/emergency-expenses-household-finances/index.html>

⁵⁰ <http://money.cnn.com/2018/05/17/news/economy/us-middle-class-basics-study/index.html>

⁵¹ <https://www.cnbc.com/2018/04/16/most-americans-cant-afford-a-937-bill-for-a-childs-toe-ointment.html>

⁵² <https://www.cnbc.com/2018/03/15/bankrate-65-percent-of-americans-save-little-or-nothing.html>

⁵³ <https://www.cnbc.com/2018/01/18/few-americans-have-enough-savings-to-cover-a-1000-emergency.html>

- [The Secret Shame of Middle Class Americans: Nearly half of Americans would have trouble finding \\$400 to pay for an emergency - The Atlantic, 05/2016](#)⁵⁴
- [63% of Americans don't have enough savings to cover a \\$500 emergency - Forbes, 1/6/2016](#)⁵⁵
- [More Americans are defaulting on their credit cards: analyst](#)⁵⁶
- [Study says older Americans going bankrupt more than ever, blames 'life in a risk society'](#)⁵⁷
(but essentially says more government is the answer, which it is NOT! How do you like your return on your Social Security "investment?")

[Financial experts](#)⁵⁸ say we should be saving about 10-15% of our income, but even those figures may be too low to fund our retirement or emergency needs. Retirement planning can be a very confusing task and best left up to professionals, in my opinion. Here is a good resource for finding a financial/estate planner (not stockbroker):

- [AARP: How to Choose a Financial Planner](#)⁵⁹
- [U.S. Securities & Exchange Commission: Investment Advisers: What You Need to Know Before Choosing One](#)⁶⁰
- [U.S. Consumer Financial Protection Bureau: Know Your Financial Adviser](#)⁶¹
- [Financial Industry Regulatory Authority \(FINRA\)](#)⁶²
- [Oklahoma Society of CPA's 2019 Financial Fitness Kit](#)⁶³

Most people I run across today think even less about planning for long-term care expenses (if they even do at all) than they do about for their general retirement, let alone actually do any real planning from either aspect. When confronted with the statistics and the very real possibility of the need for long-term care, the common responses I get are:

1. My health insurance policy or the VA will pay for all of it.
2. I'll never need it; I'll die from something else like cancer or a heart attack.

⁵⁴ <https://www.theatlantic.com/magazine/archive/2016/05/my-secret-shame/476415/>

⁵⁵ <https://www.forbes.com/sites/maggiemcgrath/2016/01/06/63-of-americans-dont-have-enough-savings-to-cover-a-500-emergency/#2f2a2d644e0d>

⁵⁶ <https://nypost.com/2018/08/11/more-americans-are-defaulting-on-their-credit-cards-analyst/>

⁵⁷ <https://www.theblaze.com/news/2018/08/07/study-says-older-americans-going-bankrupt-more-than-ever-blames-life-in-a-risk-society>

⁵⁸ <https://www.fool.com/saving/2016/10/03/heres-the-average-americans-savings-rate.aspx>

⁵⁹ <https://www.aarp.org/money/investing/info-03-2012/two-sides-of-financial-planner.html>

⁶⁰ <https://www.sec.gov/reportspubs/investor-publications/investorpubsinvadvisershtm.html>

⁶¹ http://files.consumerfinance.gov/f/201311_cfpb_flyer_senior-financial-advisors.pdf

⁶² <http://www.finra.org/>

⁶³ https://www.oscpa.com/writable/files/For_The_Public/2019finfitnesskit-web.pdf

3. My kids will take care of me.
4. Medicare will pay for it.
5. Plan for what??

Sound familiar? Here are the realities to those statements:

1. No, they won't.
2. If you're so sure of that, you should probably play the lottery or go to the casino.
3. What if they move away to another state or states and you have no other family nearby or they aren't in a position financially to do so, pre-decease you, are incarcerated, etc.?
4. Only if you're there for short term for rehab, but after 3 months, assuming Medicare approves your therapy for that long, it's usually all on you if you have to stay longer.
5. You've got a very rude (and expensive) awakening coming.

Now, I can't blame these people (too much) because when it comes to planning for our long-term care needs, most people have had little, if any, experience with the long-term care system and for the most part, couldn't care less. But, even if they've had no experience with long-term care, they've probably at least heard the rumors and I'm here to confirm to you that it is expensive, **painfully expensive**. If you do not fall into one of these categories,

- a. Are independently wealthy
- b. Have a private long-term care insurance policy (and most policies are cost-prohibitive these days, if you can even find them anymore)
- c. Have a private long-term care indemnity insurance policy
- d. Have a qualifying living benefit life insurance policy
- e. Are a federal employee or designated relative and have a [federal long-term care insurance policy](#)⁶⁴
- f. Qualify for the [VA Aid & Attendance benefit program](#)⁶⁵ or [VA Housebound Benefits](#)⁶⁶ (limited compensation) or [VA Long Term Care Services](#)⁶⁷ (see below)

⁶⁴ <https://www.ltcfeds.com/>

⁶⁵ https://www.benefits.va.gov/pension/aid_attendance_housebound.asp

⁶⁶ <https://militarybenefits.info/va-housebound-benefits/>

⁶⁷ https://www.va.gov/GERIATRICS/pages/VA_Long_Term_Care_Services.asp

g. Are destitute and qualify for Medicaid [More info on that here](#)⁶⁸.

..., then **YOU** are going to have to pay for your (or your loved one's) long term care 100% out of your own bank account and figuring out how to pay for long term care can be a **huge** challenge and may require multiple relatives kicking in for the individual's care, that is assuming you can convince them to do so or they are able to do so.

The good news: In most cases, these are out-of-pocket health care costs and may be tax deductible. Consult a CPA regarding the deductibility of **all** costs associated with long term care, including, but not limited to, care provided to an individual who resides in your home (could be considered a dependent) and irrespective of whether the care is from licensed/certified or non-licensed/non-certified providers, determine what is and is not deductible, who is paying for it, and develop a system to carefully track those expenses, receipts, etc., so you can provide that info to the CPA at tax time. [Here's a good article on this subject.](#)⁶⁹ *everyone should be aware and check with your CPA/tax professional.*

Some comments on the VA: The Aid & Attendance and Housebound programs can provide veterans and spouses some **limited** financial assistance to offset your long-term care costs and you cannot receive benefits from both programs - you must choose one or the other depending upon your unique needs. And keep in mind that the funding for these programs is dependent upon Congress renewing them each year, which I expect they will since they are some of the most underutilized federal benefits, believe it or not! And the application process can take a lot of time; several months in some cases, but benefits are usually retroactive once approved. However, understand that these benefits are **supplements** to your other (usually private) funding – they were never meant to pay for 100% of your care (you get that only if you are in a VA-operated or VA-contracted long term care facility – those spaces are highly limited and waiting times to get in can be very long). There are also [VA Long Term Care Services programs](#)⁷⁰ available to veterans (unsure about spouses, but I don't think so) if you qualify ([per VA.gov](#)⁷¹: "Veterans must be *enrolled* in VA health care before applying for VA long term care services. *Enrolled* in VA health care means you have applied for VA health care benefits and receive care through a VA facility on a regular basis.") **Do not** be under the false assumption that these benefits will cover all your long-term care needs because chances are, they will not! More on specific costs below.

⁶⁸ <https://www.medicaidplanningassistance.org/how-medicaid-counts-income/>

⁶⁹ <https://www.thecaringchoice.com/assisted-living-tax-deductions/>

⁷⁰ https://www.va.gov/GERIATRICS/pages/VA_Long_Term_Care_Services.asp

⁷¹ https://www.va.gov/GERIATRICS/pages/VA_Long_Term_Care_Services.asp

Here are some resources for additional info:

- [Dale K. Graham's Veterans Foundation](https://dalegrahamveteransfoundation.org/)⁷² (Helps Vets Understand Benefits and Navigate the System)
- [Your Complete Guide to VA Benefits for Long Term Care](https://www.aplaceformom.com/veterans-benefits-guide)⁷³
- [Eligibility info here](https://www.veteransaidbenefit.org/eligibility_aid_attendance_pension_benefit.htm)⁷⁴
- [2022 Veterans' Pension Rates](https://www.va.gov/pension/veterans-pension-rates/)⁷⁵ [VA Official link](https://militarybenefits.info/survivors-pension-rate-tables/)⁷⁶
- [2022 Survivors' Pension Rates](https://www.va.gov/pension/survivors-pension-rates/)⁷⁷ [VA Official link](https://www.va.gov/pension/aid-attendance-housebound/)⁷⁸
- [VA Aid & Attendance and Housebound eligibility info and application forms](https://www.va.gov/pension/aid-attendance-housebound/)⁷⁹
- [VA Nursing Homes, Assisted Living and Home Health Care](https://www.va.gov/health-care/about-va-health-benefits/long-term-care/)⁸⁰

If you are considering long-term care insurance, take your time, examine ALL your options and choose very carefully! Below are a couple of good, succinct articles on the subject. There are now other options to "traditional" policies and I think those are the options most seniors would have to explore versus the traditional policies, which are mostly cost-prohibitive for most seniors, especially one that would provide adequate coverage at today's rates. Again, you are really going to have to do your homework on this or get some independent, professional assistance since there are so many factors to consider when selecting a policy. Be sure to see the **Pro Tip** at the end of this section.

- <https://www.nerdwallet.com/blog/insurance/long-term-care-insurance/>
- <https://www.nerdwallet.com/blog/insurance/alternatives-long-term-care-insurance/>

But here's the real issue: Trying to project out decades in advance, we just don't know what, if any, insurance products will be available, or if we do take out a policy when we were relatively young and healthy or perhaps even later, what's to say that the insurance company that issued it won't cancel it (right when we need it) for some reason and for whatever reason(s), you might not be able to get another policy?

⁷² <https://dalegrahamveteransfoundation.org/>

⁷³ <https://www.aplaceformom.com/veterans-benefits-guide>

⁷⁴ https://www.veteransaidbenefit.org/eligibility_aid_attendance_pension_benefit.htm

⁷⁵ <https://militarybenefits.info/veterans-pension-rate-table/>

⁷⁶ <https://www.va.gov/pension/veterans-pension-rates/>

⁷⁷ <https://militarybenefits.info/survivors-pension-rate-tables/>

⁷⁸ <https://www.va.gov/pension/survivors-pension-rates/>

⁷⁹ <https://www.va.gov/pension/aid-attendance-housebound/>

⁸⁰ <https://www.va.gov/health-care/about-va-health-benefits/long-term-care/>

How would you pay for care in such a situation?? Note that I didn't mention anything about government-provided long-term care. Yes, they have it and it's called Medicaid and absent any kind of expertly and carefully crafted estate planning [(Medicaid Trust) **maybe**], done **years** in advance of need by a highly-skilled attorney, you practically have to be destitute in order to qualify for coverage and trust me, you do **NOT** want this to be your only option for long-term care. But if it is your only option, [here's some more info](#).⁸¹ And as for the politicians coming up with any other type of government-provided long-term coverage not currently in existence that would pay for your stay in a private assisted living, **KEEP DREAMING!!!** (see below)

According to [Genworth's Cost of Care Survey for 2020](#)⁸² costs can range from a (very) low of about \$4,300 per month (rarely that low, that's \$51,600 annually) for a private room in an assisted living to \$8,821 or more (usually more) per month (\$105,852 annually) for a skilled nursing (aka SNF or "SNIFF") or nursing home facility and the costs can be significantly higher in assisted livings depending on the level in of care required (more on that below) and the region of the country in which you reside. Nursing homes work a little differently – they usually charge a flat rate no matter what kind of care is required and they can be certified as private pay only, Medicaid only, Medicare (skilled nursing) only or a combination thereof.

Now, with those kinds of numbers, it's hard to look at it as a good value, but consider that in-home home health care would be significantly more expensive. Most providers charge \$20 - \$30+ per hour for a home health aide (not nurse), so, if you had home health care in your home to care for your loved one while you were at work, then for 8 hours per day for 5 days per week, that would cost \$3,200 - \$4,800 per month. [For 24/7/365 in-home care @ \$25 per hour: \$219,000 annually.] Keep in mind, you would still have to do some cooking, cleaning and laundry and wouldn't be able to leave the house on the weekends without someone to fill in for you. Also consider what you would do if you were running late getting home from work, had to go out of town on a business trip, got sick, etc., or if the home health person couldn't make it due to weather, sickness or some other issue and there were no alternates available from the agency – I know from experience that it becomes a very tedious, frustrating and stressful juggling act. And my experience with home health care providers has been marginal, at best – most were barely able to provide services much better than the neighborhood teenage babysitters and were less dependable due to their own life-drama issues. More on that part later. Once you average it

⁸¹ <https://www.medicaidplanningassistance.org/how-medicaid-counts-income/>

⁸² <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

out, care at an assisted living community runs around \$5 -\$7 per hour – pretty reasonable from that aspect, if you think about it, but they are by no means a panacea either.

One side note and a piece of advice my dad gave me when I was very young and something for you young folks to think about: Do not depend upon some union, corporation, state or federal government or the military for your retirement and health care needs – they may or may not have your best interests in mind and many times are at the mercy of political whims, so you just can't count on any of them to carry you through life or be there for you in an emergency – almost all will let you down in some manner or fashion. For example, just look at:

- The poor folks in Puerto Rico after hurricane Maria in 2017 who suffered so because the politicians had neglected the infrastructure for decades and mismanaged relief funds
- States that fail to properly fund or administer their employees' pensions
- Companies that are mismanaged and cut promised benefits
- Companies who violate their contracts with union workers
- Unions who mismanage their members' pensions
- Government shutdowns
- Millions of unexpected job losses from unforeseen factors like the Coronavirus and it taking months for those individuals and businesses who needed government support/stimulus checks to receive them, if ever, and the process was rife with fraud.
- Companies that forced employees to take the Covid vaccine or be fired.
- The poor people in Louisiana after hurricanes Katrina (2005) who lost power for weeks or months and then AGAIN after hurricane Ida (2021) because the power grid had not been reinforced after all those years!!!
- The first responders in Baltimore (just one example) who, in 2021, had 5 years added to the time-in-service required to qualify to draw their pensions because of mismanagement/shortfall of their pension funds.
- The complete incompetence of President Joe Biden and his administration's bungling of the Afghanistan pull-out that led to the tragic and unnecessary deaths of 13 U.S. Marines, dozens of innocent civilians, and the abandonment of hundreds of U.S. citizens, many children, and \$85 billion in high-tech military hardware that all fell into the hands of terrible terrorists, the Taliban.
- Cities and states that defund and fail to support law enforcement and leave citizens to fend for themselves, many of them in states that require citizens to be victims first and then district

attorneys and attorneys general who refuse to prosecute the criminals and won't even require bail before release.

Federal retirement plans are generally very good, but there are just so many choices and rules and regulations on them that it is beyond confusing. And without a real expert explaining all the advantages and disadvantages of structuring your retirement, chances are good that you won't optimize those benefits and that's especially true for any surviving spouse or heirs. Be very careful and get multiple opinions and options. And as for Social Security, Medicare and Medicaid being there for you when you retire, I wouldn't bet the farm on it – just look what happened to Greece and Venezuela and other socialist countries with extensive government entitlement programs. To paraphrase former Prime Minister Margaret Thatcher:

“Socialism is a great thing until you run out of other people's money.”

What that means is that the government that gives you everything eventually won't be able to give you everything and there will be drastic cuts to government-provided benefits – it's called **austerity measures**. So, if you've been depending upon government for your survival, you're eventually going to get the short end of the stick one way or another. Even with today's bustling economy and record labor participation rate, we still have way too many able-bodied people who are not fully-productive citizens, don't pay into “the system” and who just take and take and take from those who do produce and pay into “the system.” ([Over Half Of America Gets More In Welfare Than It Pays In Taxes](https://www.zerohedge.com/news/2018-10-24/more-half-america-gets-more-welfare-it-pays-taxes)⁸³). And don't forget the 15 - 25 million+ illegal aliens who consume approximately \$132 billion (net) in taxpayer-funded social programs/services every year [according to FAIR](https://www.fairus.org/issue/publications-resources/veteran-needs-vs-illegal-alien-costs)⁸⁴ [and here](https://www.fairus.org/issue/publications-resources/fiscal-burden-illegal-immigration-united-states-taxpayers)⁸⁵ (this was prior to the Biden Administration's open borders/mass migration policy that allowed in 7+ million more illegal aliens.) ([California: More than 7-in-10 Noncitizen Households Are on Welfare](https://www.breitbart.com/politics/2018/12/04/study-more-than-7-in-10-california-immigrant-households-are-on-welfare/c)⁸⁶) The government enables this behavior with their largess, constantly expanding and overly-generous entitlement programs, and failure to secure our borders and enforce immigration laws. And because of all that, the government will probably have no choice but to eventually implement austerity measures – will **you** be ready for it?? I particularly like this quote:

⁸³ <https://www.zerohedge.com/news/2018-10-24/more-half-america-gets-more-welfare-it-pays-taxes>

⁸⁴ <https://www.fairus.org/issue/publications-resources/veteran-needs-vs-illegal-alien-costs>

⁸⁵ <https://www.fairus.org/issue/publications-resources/fiscal-burden-illegal-immigration-united-states-taxpayers>

⁸⁶ <https://www.breitbart.com/politics/2018/12/04/study-more-than-7-in-10-california-immigrant-households-are-on-welfare/c>

“I am for doing good to the poor, but I differ in opinion of the means. I think the best way of doing good to the poor, is not making them easy in poverty, but leading or driving them out of it.

In my youth I travelled much, and I observed in different countries, that the more public provisions were made for the poor, the less they provided for themselves, and of course became poorer. And, on the contrary, the less was done for them, the more they did for themselves, and became richer.” — Benjamin Franklin, 1766.

Bottom line, folks: In addition to any company or government benefits, **YOU** have to plan **your** life carefully and **also** fund your retirement privately, that way **YOU** and only **YOU** will have control over it....and your destiny! **You** must be your own first responder!

So, when it comes to planning for your retirement and care later in life, you **MUST** plan **decades** ahead, even as early as your teen years, mainly because it is **SO** expensive – have “**the talk**” with yourself, your spouse, your loved one(s) and get all the legal and medical documents sorted out and in place **well before** care is needed. (More below.) Make plans **now** because if you don’t, you **will** eventually have to make all these decisions on short notice or in an emergency situation and complicated decisions made under duress are almost always poorly thought out and ill-advised, causing even more problems for all involved. Remember, in many cases your family is depending upon you to make the absolute best decisions for their care.

The Legal Aspect:

*If you do not speak for yourself **when** you can speak for yourself, then someone else will eventually do it for you.*

So, what does that mean?? Well, if you don’t communicate your health care wishes and desires, in writing in a legal document, then, if something happens to you – health incident, car collision, other catastrophic event – and you are unable to speak for yourself, then someone – relative, government agency, court/judge, will do it for you and they may or may not know your wishes and desires when it comes to providing the care and assistance that you would have wanted or not wanted.

This is a **critical** aspect of planning that **must not** be overlooked. You and or your loved one need to have all the necessary legal documents in place – will, trust, health care power of attorney, financial power of attorney and advanced care directive (aka, living will). Or, in some cases, guardianship or conservatorship. Copies of these documents should be on file with the community, medical providers and affiliated medical facilities (hospitals, clinics, etc.), bank, hospice, funeral home, etc. In the event of an emergency, having these documents in place will make providing care much easier, efficient and expedient for the patient, caregiver and other professional providers. Seek the assistance of an attorney familiar with or [certified in elder law](#)⁸⁷ to help you prepare these documents.

The two best books I've ever seen to help organize your life so people can help in the event of an emergency and or better help administer your affairs if you have to go to a long-term care community are:

- [Age Your Way – Debbie Pearson, RN](#)⁸⁸
- [The Blueprint to Age Your Way – Debbie Pearson, RN](#)⁸⁹
- [Also check out Care Right, Inc.'s Grab and Go Binder](#)⁹⁰

If you want a more futuristic, digital way to manage your estate planning and documents, consider services such as [Everplan](#)⁹¹, [My Life and Wishes](#)⁹², or [Cake](#)⁹³. Also, most banks and funeral homes have very comprehensive and free “personal information manager” booklets that can really help you get organized.

A word on health insurance: Be very careful if you are considering moving your loved one to another state to be closer to you or other relatives. I had one client whose children wanted to move him to an adjoining state to be closer to them, but his supplemental health insurance policy would not transfer to another state, so they couldn't not move the man and had to hire me to administer his affairs and look after him in a memory care community. In such cases and until the laws change, I would get a letter

⁸⁷ <http://www.nelf.org/find-a-cela/>

⁸⁸ <https://www.amazon.com/Age-Your-Way-Create-Unique/dp/0997853301>

⁸⁹ <https://www.amazon.com/Blueprint-Age-Your-Way/dp/099785331X>

⁹⁰ <https://carerightinc.com/grab-and-go-binder/>

⁹¹ <http://www.everplan.com>

⁹² <https://www.mylifeandwishes.com/>

⁹³ <http://www.joincake.com/>

from any primary or supplemental policy carrier confirming that the policy will transfer before making a move to another state. Another tip: There are a lot of companies out there advertising any number of Medicare Advantage programs and they promise you the moon. Be **EXTREMELY CAREFUL** when signing up for these – do your homework! What do they cover, but more importantly, what do they **NOT** cover. Call your current health care providers to find out if they accept these plans and if so, how good are they at paying? Keep in mind that when you initially sign up for Medicare and if you sign up for standard Part A, B and let's say D, then switch to a Medicare Advantage plan, but discover it wasn't everything it promised, you have 1 year to revert to your original plan or you are stuck with a Medicare Advantage for good, that is, unless the laws change. Also, be sure to check to see what happens if you move to another state, or have to seek care in another state.

Bottom line: You need to get other family members on board – **everyone** needs to take part or it will wear out a single person, leaving the loved one without a support mechanism.

If family members can't agree, for whatever reasons, or have problems figuring everything out, and that is frequently the case, seek out a mediator first and then attorney, if necessary, to help sort things out. It is very important that they are experienced with elder/long-term care issues. An example of such a firm that works with families nationwide is [Care Right, Inc.](https://carerightinc.com/)⁹⁴ – and they have several excellent videos to show to loved ones that can help explain and simplify many complex issues that everyone in this position faces. However, if a family member doesn't want to help and trust you, and there is always one or more in the punch bowl, write them off immediately; do not waste your valuable time and energy dealing with them and let them know very clearly up front that if they aren't going to help or are constantly confrontational over the issue, then they will have **no voice** in the situation. However, remember that residents of long-term care communities still have all their legal rights and absent a guardianship, it can be difficult to control who visits the resident (more on this in **Section 9**). However, if the visitor or family member creates problems (threats or disturbances) at a long-term care community, you can ask the administrator to ban them from the property or they may do so independently of a request from you. Again, worthless or troublesome family members can cause you as much, if not more, stress than actually caring for your loved one.

⁹⁴ <https://carerightinc.com/>

Pro Tip 1:

Re: Powers of Attorney. This is one aspect you really have to give some thought to and **must** discuss with your attorney – who are you going to give that power to? One person? One person (primary with full authority) with an alternate (secondary with full power if the primary is not available and what constitutes “not available?”). Two (or more) people with divided or full authority? The reason I bring this up is because I’ve seen cases where two people with full authority have a disagreement over a loved one’s care and that causes all kinds of problems. Your attorney will be able to construct several scenarios for you to consider based on the potential individuals you present and then you can make an educated decision accordingly.

Pro Tip 2:

Re: Long term care insurance. Back in the early 90’s when I was in my late 20’s and when insurance companies were just beginning to offer these types of policies, I took out a policy through my company, who, at that time, was one of the underwriters. I asked my dad, an insurance broker, among other things, about it and after he reviewed the policy, he exclaimed it was the best insurance deal he’d ever seen and to jump on it! I did and I got a fantastic, full-benefits policy for only \$127 per year. That’s right, per year! Flash forward 30 years and my premium is up to about \$2,100 per year, but the benefits the policy provides are the same – very generous (kept pace with inflation) and comprehensive. It will easily cover even the most expensive of long-term care communities, including nursing homes and or at-home care.

But here’s the twist I’ve been hearing from some: Getting these insurance companies to pay up can be difficult and here’s why: When these insurance companies started offering these policies, their actuaries really botched the cost projections when it comes to rising health care costs, human longevity, etc. My dad was absolutely right – those policies were bargains and hundreds of thousands of people like me took them out and we’re starting to exercise those benefits, costing the insurance companies **significantly** more than what they had expected (which is why they’re so hard to find now), so, they are sometimes making it very difficult for policy holders to qualify for coverage.

When trying to make a coverage claim, you need to dig out your policy and see what the prerequisites are. Is there an elimination (waiting) period? In other words, do you have to be in a LTC facility for a certain number of days before coverage will start? Sometimes as long as 6 months. That (elimination periods) is usually the case. Does the level of care you need meet the policy minimums for coverage?

In other words, has a doctor determined that you need assistance with a certain number of specific ADL (assistance with daily living) activities (required by the policy) before coverage kicks in? Have you been diagnosed by a doctor with certain conditions that require you to be in a LTC community and do you have that written proof? You really have to have your ducks in a row when it comes to this.

In most cases I've seen, the insurance company will dispatch a nurse to do an assessment on the policy holder to see if care/coverage is warranted. They will also review and collect supporting documentation from the doctor(s) and facility. In some cases, they may give the doctor and or facility lengthy questionnaires to fill out and this can take a long time, especially since most doctors and LTC facilities are overworked and understaffed. You **will** have to ride herd on everyone if this is the case. In other words, find out when the paperwork was sent to the doctor/facility and to whom. Then, follow-up with the doctor/facility to ensure that they received the paperwork. Follow-up with the insurance company after a few days to see if they have received it back and if not, contact the doctor's office/facility. I think you see what I mean here.

Now, if, after completing everything required by the policy on your part and if it is clear that the policy holder warrants coverage, but the insurance company drags its feet, you have some options:

Contact your attorney and have him/her send a letter to the insurance company. Be sure the letter includes time frames expected for payment as well as reminders that this matter, if not resolved promptly and to your satisfaction will be turned over to the respective state's Department of Insurance and the Attorney General's Consumer Protection Unit for investigations....and do file those complaints with those agencies promptly - most have online forms. Trust me, these insurance companies want no beefs with those two agencies and they will usually snap to after receiving nastygrams from them!

Here are a few other pro pointers (and this ties into the section below):

As I mentioned at the beginning of this section, you should really start learning about this industry in your 50's. Learn about the communities and cultures in your area where you think you will want to live before it becomes a crisis.

Attend community events such as open houses to get a feel for the community and staff. Take frequent tours over the years of your preferred communities to see how they are being cared for and staffed.

Is it a for-profit or non-profit? Many non-profits staff at higher levels. However, that does not necessarily translate to better care.

You may be saying to yourself, “I’ll move in when I need it.” But what does that even mean? What is your tripping/breaking point – when you have to give up your keys because you cannot drive safely? A weather event or power outage that leaves you in a bad situation? A medication or surgical error that changes your life situation? You have to engage in crisis planning! Play the “what if” game!

When you have a crisis, most people choose the cheapest and easiest place that will take you and you may (usually) have to move again when that place doesn’t work out for you. Also, hospital social workers/case managers may or may not have the education, background, experience and expertise to properly assist you with assessing your long term care options and they generally just don’t have the time to engage in that kind of “hand holding.”

Some couples may or may not be able to live together depending upon their care needs, so that is where a CCRC really works well so the other spouse can easily visit the other daily without having to get in the care and drive somewhere.

When your children come to town, get them involved in the process - take them on tours of communities where you might want to be. Remember, it is YOUR life – YOUR ideal place may not be the same as children’s, so communicate with them about your wishes and desires, or, better yet, clearly spell them out in your trust documents! It’s better for YOU to plan ahead so your children don’t have to do it for you – it is an enormous responsibility!!

Once you get to a community, do not stop planning – review your documents, care needs, etc.

Ask about your preferred communities’ waiting list and get on at least one or two, even if well ahead of need. Can you put down a deposit to secure your place? Is it fully or partially refundable? Under what circumstances?

What is a communities plan for natural disasters? Where would they relocate you? Is it a location where your loved ones can easily get to you? Most licensed facilities are required by law to have such contingency plans in place.

6. SELECTING A COMMUNITY, CONTRACTS, STAFFING CONSIDERATIONS & MISCELLANEOUS COSTS

Be sure to see **Section 13. Special Considerations for Senior Community Builders, Owners, Managers and Residents** of my related report: **Apartment Living: Selection & Guide** (including a special section for senior living communities) on the [Publications page of my website](#)⁹⁵.

Again, there are plenty of guides and services about this, so I'm going to address aspects that most do not. If you need assistance selecting a community, I suggest you first contact your county's Areawide Aging Agency – they will know where to point you and here's how you can find them:

- [National Association for Area Agencies on Aging](#)⁹⁶
- [U.S. Dept. of Health & Human Services, Administration for Community Living](#)⁹⁷

A brief note on those celebrity advertisements you see on TV about community locator/placement services: I've been told that they rarely actually tour communities, but rather get most of their information from communities' websites. Even though their services are free to the consumer, they do charge **very large fees** (usually the equivalent to one month's rent at that specific community) to the communities for each referral who winds up signing a contract and they can be extremely aggressive with the community when it comes to taking their referrals. In some cases, if a community has a waiting list, they may pass you over if they know they have to pay a large referral fee and just go on to the next person on the list for admission. Or, the community may even pass that locator/placement service fee expense along to you under the guise of some other fee, such as an "activity fee," "community fee," etc. Some communities refuse to take their referrals altogether because of those high referral fees and high-pressure sales tactics, so you may not be getting the whole market picture from them if some communities are omitted from their searches. If you have no idea where to go or what to do, they offer a good starting point, but always do your own homework before signing on the dotted line. Look for local companies that offer similar services but which usually have much more first-hand knowledge and contacts in your local market to help you find the community that fits your needs the best. Also, these national outfits

⁹⁵ <http://www.magnusomnicorps.com/publications.html>

⁹⁶ <http://www.n4a.org/>

⁹⁷ http://www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx

sometimes sell your contact information to 3rd party marketing companies, so as soon as you enter your e-mail into that form, or call them or otherwise contact them, expect to start receiving lots of long-term care marketing advertisements and calls. Another word of caution – with all the Internet cookies, tracking software, algorithms, etc., if you ever get a call from a locator service or marketing representative from a specific community and you did nothing other than visit their website(s), but they say that you had expressed interest in the community or that you were referred by a locator service, but again, you took no direct actions with either one other than perhaps peruse their website(s), be extremely cautious as it may even be a scam, although I haven't heard of that angle from the criminals,....yet! The best way to insulate yourselves from this type of nefarious Internet behavior is to use a VPN (Virtual Private Network) connection when surfing the Internet. [ExpressVPN](https://www.expressvpn.com/)⁹⁸ and [NordVPN](https://nordvpn.com/)⁹⁹ are two of the best. You can read more about Internet security and ID Theft in my free **ID Theft Problems and Solutions** e-book on the [Publications page of my website](#)¹⁰⁰. Caveat Emptor!

If you are in the Oklahoma City area, I strongly suggest you attend the free and informative [Senior Living Truth Series seminars](#)¹⁰¹ conducted by the [Buckelew Realty Group](#)¹⁰² and [OKC Mature Moves](#)¹⁰³ (both Chris & Dr. Nikki Buckelew, Realtors), who specialize in senior housing issues, downsizing and senior housing educational programs. If you're not in the area, you can see videos of their seminars on their [YouTube channel here](#)¹⁰⁴ or their [website here](#)¹⁰⁵ – I **highly** recommend them!!

Most communities are regulated by respective states' Departments of Health and Human Services and inspection reports/surveys can be reviewed there. And if the community accepts Medicare and or Medicaid, inspection reports/surveys can be found here: [Medicare.gov Nursing Home Compare tool](#)¹⁰⁶. A word of caution on these: Surveyors come and go and may or may not have extensive training or experience in the industry and the whole process. And, the inspections/reports can be very **subjective** for a variety of reasons, so scrutinize them very carefully. In most cases, when a community is cited (issued a deficiency or tag), the survey report is posted online at the health department's website. The community has a certain number of days (usually 7 – 10) to respond with a plan of correction, which

⁹⁸ <https://www.expressvpn.com/>

⁹⁹ <https://nordvpn.com/>

¹⁰⁰ <https://www.magnusomnicorps.com/publications.html>

¹⁰¹ <https://seniorlivingtruthseries.com>

¹⁰² <https://www.buckelewrealtygroup.com>

¹⁰³ <https://www.okcmaturemoves.com/>

¹⁰⁴ <https://www.youtube.com/c/SeniorsrealestateinstituteUSA/videos>

¹⁰⁵ <https://seniorlivingtruthseries.com/senior-living-truth-series-video-replays/>

¹⁰⁶ <https://www.medicare.gov/nursinghomecompare/search.html>

should ALSO be posted directly with the citation/deficiency report. Surveyors may delay or even fail to post these mandatory community responses/plans of correction, in which case you would only be getting half of the story regarding the deficiency. If you see a citation/deficiency report, but no plan of correction, contact the administrator and or regulatory agency for clarification.

Also, disgruntled employees can, and often do, anonymously call in bogus complaints, triggering mandatory inspections and reports and thus unfairly casting a bad light on the community. Frankly, I don't give these reports much weight when considering a community unless those reports are chronically bad, have clearly egregious violations, or repeated violations for the same complaint. I go by what I see, hear and smell when I visit a community and what other family members and residents tell me about their experiences.

It is important to keep in mind that selecting a community will be an exercise in compromise – you will not find everything you absolutely want and need in one place, so do your homework and set your priorities accordingly. And remember, no official survey or private review will be a substitute for you visiting a community and forming your own opinion(s).

Inside the Community Sales Office:

New communities are springing up so fast to meet the rapidly-increasing need that it'll make your head spin. Competition is rigorous and the owners and corporate management push their sales and marketing staffs to the limit to produce or be fired, so they are motivated to fill up the rooms (aka increase the census) at any and all costs!

Another point: Because of competition, some communities may admit your loved one for the wrong reasons. For example, let's say your loved one has dementia and is being physically aggressive towards the staff and other residents, creating safety concerns. The administrator may suggest (or in some cases require, based on state laws) sending him or her to a geriatric-psychiatric facility temporarily for evaluation and medication adjustment. The family doesn't want to subject their loved one to that process, but since they cannot remain where they are if they are deemed a threat to themselves, others, or fall outside the medical care capabilities of the assisted living community's scope of care (per their state license) and face eventual eviction, the family shops around and find a community who sends a nurse, assesses the person and deems him or her "acceptable" for admission to the other community and no need for a trip to the geri-psych unit. New admission achieved, box checked! Do you see the

problem there? Even if the person is admitted to the new community, if they create the same problems there, the family will still eventually be faced with the requirement for further evaluation at a geri-psych unit....and after all the stress and expense the family went through to move the person and the stress on that person who has to acclimate to a completely new environment.

This is why you want to do your homework, read the online reviews, research the administrator and DON's records (resources in **section 15. Internet Resources**) and make sure choose the right community and avoid unnecessary moves, stress and expense.

Contrary to popular belief and even though monthly rates seem outrageous to most, not all of these communities are enormous profit-generating machines, in fact, it's quite the opposite in most cases and some are actually non-profits.

As you will see, the majority of these communities have beautiful websites (some with music!), glossy, professionally produced promotional materials, and maybe even radio and TV ads. They'll even come pick you up and take you to their community for lunch and a tour! They make it sound as if their community is Shangri-La and by grace, you have found it. Halleluiah!! Go ahead and take the tour and listen attentively to the salesperson, but also be on the lookout for other things:

The Lease Contract/Service Agreement:

As I discussed in the previous section, be prepared as rent is very expensive at most places. Do not move in if you cannot afford the rent – as cruel as it sounds, if you do not pay your rent, the management **may** work with you for a while, but if you are consistently late or your check is short, just like at any apartment complex where you don't pay your rent, you **will** eventually be served notice to leave (evicted). This puts everyone in a very awkward position and is very unfair to the fragile resident who gets caught in the middle. In some rare cases, and mostly with non-profits, some communities may have a "hardship program," "charity care," or similar for residents with financial difficulties, but assistance is usually limited to a small number of cases and you must qualify first and usually that also includes having been a resident at the facility for at least a certain, minimum length of time. If it looks like you will have financial difficulties, be sure to discuss it with the administrator as soon as possible. Administrators be sure to pay extra close attention to cases of potential elder financial abuse from relatives and other caregivers and alert APS (Adult Protective Services) as appropriate.

There are two kinds of contracts, written and oral (verbal). One thing that was pounded into us in real estate school was that if it isn't written down, it doesn't exist. So, it should go without saying that you need to "get it in writing!"

Some states have certain requirements for contracts and communities must submit them to the respective governmental oversight authority for approval whereas others do not, and it may just be a boilerplate corporate contract.

Right up front, in most cases, you will be asked pay a sizeable **non-refundable** deposit, usually equal to one month's rent. I know it sounds like a lot, but it is used to cover/offset services such as: Room make-ready (painting, carpet, repairs, staff labor, etc.), nurses' and other staff members' time, travel and services for assessments, admission coordination, paperwork, etc. Only in some very extenuating circumstances may this fee be refunded and almost definitely not if the resident has stayed for at least a month. Of course, always ask to see if the administrator will work with you on this, if needed, but don't expect much leeway to be given.

Also, there will be a large **activity fee** and like the deposit fee, it is usually non-refundable, as well. This fee is used for exactly what you think – activities for the residents – paid 3rd party entertainers, speakers, etc., transportation to organized events, etc.

The particular areas you want to pay very close attention to are: Services provided, admissions and discharge criteria, involuntary discharge criteria and appeal rights and procedures.

Also scrutinize the "**notice to vacate**" instructions: In most cases, a 30-day notice is required, but have you ever wondered what happens if your loved one dies at the beginning of the month. **Most** communities will not require you to pay for a full month and will pro-rate the rent. However, I have been made aware in one particular instance and with one owner, that was not the case – the owner demanded the full month's rent even if the resident died on the first day of the month. In another case, an assisted living community agreed to admit a woman and the family paid the deposit, fees and first month's rent, around \$8,000.00. Then, before the woman was discharged from her other care facility and took actual physical possession of her room at the new community, there was a significant disagreement between the two medical directors regarding her course of care. The doctor at her current facility refused to discharge her without receiving doctor agreeing to his plan of care, so the doctor at the new community

refused to admit the woman. The facility then refused to refund the \$8,000.00 – not just the deposit and fees, but also the first month's rent and the woman had never even stepped foot on the property! Fortunately, the assisted living community discovered that one of the woman's relatives was a very prominent member of the community and realized what a PR nightmare it would be to fail to refund the money and they did eventually refund the full \$8,000.00.

Update I: Recently I've heard about a new trend – **60 day notices to vacate**. There are several, obvious problems here: If, by no fault of their own, a resident must vacate because the current community cannot provide the care needed, then the resident may be required to pay rent for time they are not living there, assuming the community does not agree to pro-rate the rent, which we already know does happen. Another example: If the community requires the resident to vacate immediately because the resident is unruly, breaks the community rules or there are family or friends who cause unacceptable disturbances, or anyone who otherwise creates situations that present an unsafe environment for other residents and staff, then the resident may again be stuck paying for up to 2 months' rent when they are no longer living there. Why do they do this? Again, competition for residents is very rigorous and as such, it takes time to re-rent the room of the resident who just left and a 60-day notice gives the community a paid "cushion" to find a replacement resident. I'm sure you can see what's going on here. So, what do you do? Well, you need to ensure that there is some kind of verbiage in the contract clearly specifying what happens in such cases so you don't get stuck paying a huge amount of rent when you are not present. If necessary, get an attorney to help you draft an addendum spelling this out. The local administrator may not have the authority to sign such an addendum, in which case you will contact someone higher up in the corporate chain for assistance.

Update II: This applies to **services provided** under the contract. I'm just going to provide you with an anecdote here, which best illustrates the point:

"I received a call recently that a facility told the family that they would have to hire a private HHA to feed their mother, who was in the memory care wing of the community. I laughed and said, well, then, what's the point of her being there? It is usually understood that these facilities, especially memory cares, will, at some point, have to assist in the feeding of residents, who, for whatever reason, can no longer feed themselves. In this case the mother had Parkinson's and couldn't manage the utensils. So here's what I said to the family:

- I assume the community sent someone to assess your mother before she moved in.

- I assume your mother had Parkinson's before she moved in.
- Therefore, the community knew of all your mother's conditions and limitations and care needs before she moved in.

If your mother was able to eat on her own when she moved in, but the Parkinson's has gotten worse since she moved in, they should have had an Occupational Therapist evaluate her and make recommendations for weighted utensils or other custom accommodations to help her eat on her own, if at all possible. If they thought that her condition might progress to the point that they could not provide adequate care for her at some point in the future, they should've counseled you about that in the beginning. More on this below.

Okay, back to the residency agreement. You need to pull that out and look it over. Specifically:

Services Provided:

- Does it address providing meals? How so? Health Dept. rules usually require residents to receive 3 meals per day, on a specific time schedule, with the nutritional contents (facility's menu) reviewed and approved quarterly (I think) by a registered dietician.
- Does it specify they do not provide feeding services or does it specify that the resident must be able to feed themselves? (If yes to either, then that would pretty much negate the purpose of such a facility since every place I've ever been in provided feeding services.)
- Does it address assisted feeding? If not, then you must assume that they will feed the resident, if needed.

Admission Criteria:

- If the agreement says they must be able to feed themselves (or that they do not provide feeding services) and he was able to feed himself when he moved in, then yes, they can require you to hire a feeding assistant, but that should've been clearly explained to you by now.
- If the agreement does not specify either of the above and since they are providing meals, you have to assume they will assist the resident with eating. (This is especially true if you see people getting "mechanical soft" or pureed foods - those people generally need assistance with eating and if they are making those kinds of food preparations/offer them

for residents, then it's highly likely they know that they will need to assist some residents with eating.)

Discharge Criteria:

- Review this to see if your mother falls under any of the stated categories that warrant discharge. I doubt it does and if it does not, then they don't have a leg to stand on regarding requiring you to hire a feeding assistant.
- I doubt this area covers feeding, but again, if the residency agreement states that they do not provide feeding assistance and the resident can no longer feed themselves, then they should recommend that you hire a feeding assistant or move him elsewhere - a place that offers a higher level of care that can accommodate her needs. This should've clearly been explained to you by the E.D. at this point instead of letting you twist in the wind over these issues.
- Be careful - if their care contract with the health department does not allow for 2-person transfer, you could be out on the street in fairly short order. Or if there is anything else in the discharge criteria that your mother falls under.

Okay, at this point, you don't want to be a shrinking violet (especially since you are paying so much), but you don't want to get tossed out either - you know what I'm talking about here. I think you can come at it from the angle, look, I'd like to keep my mother here and I want to work with you on this, but you have to tell me right now whether you can provide the care my mother needs and that to which you have agreed in the residency agreement for the fees you charge me or we need make an addendum to the agreement. I highly doubt the residency agreement says anything about residents being able to feed themselves or no feeding assistance provided. Again, at some point, a majority of residents need assistance with eating and that's what these places are there for. I think you can go in and talk with the administrator and, using the residency agreement and arguments I gave you above, make a case that **they should be feeding** your mother 3 meals a day AND providing all the other services listed in the residency agreement. If for some reason they give you the runaround, you might suggest calling the ombudsman in to mediate and if he/she deems fit, they will ask the health department to review your mother's case – the Ombudsman Program is administered through respective county's Areawide Aging Agencies (I provided specific phone numbers here.) Both of those numbers should be in your residency agreement and are required, by law, to be publicly posted at the community. I think if these facts are on your side, they are not going to want to do that because they would probably get tagged for a variety of

violations such as failure to adhere to the residency agreement, failure to provide adequate care and nutrition and possibly even neglect.

Again, I suspect they are like most all other facilities and have manpower problems. They may or may not be able to hire agency people to fill the gaps - ask them about that - that's a corporate call. If they refuse to answer, then that definitely warrants a call to the ombudsman or health department because it may be an indication that they do not have adequate staffing and therefore cannot provide appropriate care to the residents. If they cannot provide the care the residency contract specifies and do so safely (adequate staffing), then they should so state and either suggest another place for you to go or reduce your monthly commensurate to what you have to pay for private services to augment their staff. Because of Covid, almost all these places have significantly reduced census levels and want to keep all the residents they can for as long as they are able, but, of course, they have to (should) do so with the residents' safety and proper care and feeding being the foremost concerns, naturally. Unfortunately, there are unscrupulous outfits that are only looking at the money aspect.

If you want her to stay there, you really need to get this cleared up with the administrator. The residency agreement is key! Also, they must have a state-licensed administrator overseeing the community. Unless the regs have changed, they can operate under another (off-site) administrator's license, but that administrator must be on-premises for a certain number of hours per week and I can't remember what that number is." End of anecdote.

Okay, with that, I think you understand what I'm getting at here. This also goes back to my point that when selecting a community, you really need to engage in some forethought and try to project the care you or your loved one will need and make sure that the community you are considering will be able to provide you with all the care you need as time goes on and conditions deteriorate and more care is required. Ideally, you want to stay in one place as long as possible.

A little bit more on discharge criteria. I was recently contacted by a friend whose father was in a nursing home (not assisted living). She was told that she had to move her father immediately because he kept falling (fall risk) and had dementia and they could no longer care for him. Since he was private pay and this was a nursing home, the highest level of long-term care available, the daughter asked me if they could do this. The answer, in most cases and depending upon state laws, is yes. If a resident is a risk (aka "immediate jeopardy") to themselves or others, the Administrator can require immediate

discharge or a set number of days. Of course, there are very strict and specific corporate and Health Department rules that must be followed and reports must be filed by the Administrator in order to force this action. Families who get this call are often caught off guard and it is a difficult pill to swallow, but consider this: For example, every time a resident falls, the facility must file their own internal paperwork, then they must file a report with the Health Department, then they usually have to submit a care plan adjustment with the Health Department (and there may be other requirements) **every single time** the resident falls. In many cases with falls, the facility is required by to send the resident to the hospital for evaluation. Obviously, this is a huge time consumer and manpower drain on the facility. Furthermore, in this case, the nursing home didn't have a wing devoted to memory care and couldn't guarantee the safety of that resident or the other residents, so they had no choice but to ask him to leave. Trust me, in this day and age, no place wants to lose a paying customer, but sometimes they just have no choice and it is the best for all parties involved.

One other contractual item to beware of: **Prescription medications**. In most cases, you cannot bring in a bag of your prescriptions, hand them to a nurse and have the staff dispense them to you accordingly - most communities want you to use their preferred provider for your prescriptions – there are several valid reasons for this: legal, safety, efficiency, accuracy, cost-savings, etc. In most cases, however, a resident has the right to obtain their prescriptions from any pharmacy they so choose and have them delivered to the community's nursing staff for distribution and the community must abide by their wishes. A perfect example is where the resident gets their medications from the VA – the community must accommodate this. Conversely, in most states, a community **does** have the right to deny you admission if you refuse to use their preferred prescription service. But here's the catch: I have been made aware of some communities that have charged residents an additional fee, sometimes as high as \$500 - \$700 per month, to use a non-community-preferred pharmacy and you are not allowed to do that in most states. If you have to use a different pharmacy than the community uses, make sure you are not being charged an additional fee for it by the community.

If you're an owner, corporate officer or administrator and such practices as outlined above are your attitude towards business in general and this industry especially, you shouldn't be in it or at least go take the Dale Carnegie course on "How to Win Friends and Influence People!!" AND a course on business ethics! Again, this is a good example of clearly knowing what care a person needs and whether the assisted living community is ready, able and willing to provide what is needed.

Another word on medications: In most cases, you (your insurance or your Medicare account) paid for those medications, so they belong to you. If, for whatever reason, you have to leave the long term community you are in, they staff should return all your remaining medications that they have for you. This is true even if you have been in a SNF (skilled nursing facility) for rehab following a hospital stay.

Contract options for these facilities vary greatly depending upon the level of services offered by the community and are almost never an apples-to-apples comparison. For example, you may just be on a month-to-month rental contract or you could be on a “life contract” (aka “buy-in”) where you pay a significant amount of money up front to move in. In the latter case, these are usually at CCRC [Continuing Care Retirement Communities (offering independent living thru skilled nursing care/memory care)] communities. Again, it is very important for you to be realistic about your care needs on a long-term basis and research each community and its senior staff/board of directors very carefully.

Be sure to carefully read any contracts you will be signing and understand that these are **legally-binding** documents that **compel** you and the resident to certain **obligations** and **behaviors**. Certain breaches may constitute a dischargeable offense. If you have any questions, be sure to ask the administrator and contact an attorney before signing.

The “Buy-In,” “Life Contract” or “Life Plan Contract”:

Some CCRC’s are structured such that you have to plop down a sizeable lump sum fee to move in – sometimes it’s in the 6-figure range, **PLUS** there is still the monthly rental fee. I know a lot of the general population balk at such an initial expense, but I understand it and, in some cases, agree with the buy-in/life plan contract pricing model because those funds can eventually be used to pay for your care if and when you have to transition to an area of the community that provides higher levels of care, or in some rare cases, if you run out of money. And, in some cases, you may receive preferential/prioritized placement at significantly reduced rates in the higher levels of care areas) over someone who is not on a life contract, but rather wants to move in on a month-to-month basis. **However**, you should ensure that the money is housed in an FDIC-insured or otherwise insured account and audited regularly by an **independent** accounting firm and receive regular statements as to that account’s solvency. And understand what, if any, guarantees there are for the return of my money if an unscrupulous owner or employee misuse or abscond with the funds in that account. It has happened at numerous communities. Also, you need to understand under what circumstances and how much of that fee will be refunded, how and when it will be used for future care, what happens to it if you suddenly die, etc. Also note that if

there is a diagnosis of dementia or Alzheimer's Disease or perhaps other terminal illness, you may not be able to get a Life Contract. Before you invest that kind of money in a community, I strongly suggest you research it well and have an attorney review the contract and clearly understand how the money is used and what, if anything, could occur that would cause you to forfeit those funds. I also suggest checking online court records to see if the community, its owners, officers or employees have been named in any related lawsuits.

Community Staff:

Look, just like any other business in today's economy, and perhaps even more so, long-term care communities struggle with finding and retaining good employees and having a good, caring and attentive staff is really imperative when you are caring for the elderly, for obvious reasons. Employment challenges can vary from state-to-state, city-to-city, suburb-to-suburb, i.e., some states have much more of a problem in this area than others, but the administrators with whom I've discussed this issue really couldn't explain this phenomenon. Personally, I think a lot has to do with the quality, or lack thereof, the prevailing government (public) school system in the immediate area.

First line/floor level employee pay and benefits are, in my opinion, far from commensurate with the responsibilities and physical demands placed upon these individuals and they will frequently leave to go to another community or other line of work for just a few cents more per hour, or if they simply get in even a petty disagreement with management. Inasmuch, some communities have difficulty attracting and retaining good employees, so there is not much continuity and as such, familiarity with the residents. None of this is any good for anyone in the community. It is a delicate balancing act – problems with employee retention/turnover, marginal work ethics, and so much drama in their personal lives that a job becomes a secondary or tertiary priority. Sadly, government schools (and a lot of parents) these days have left these young adults woefully unprepared and ill-equipped to cope with the ever-increasing and complicated intricacies of life, let alone given them any type of instruction in self-control, morals, values, work ethics and the law (Oh, heaven forbid!). ([1-in-3 pass 'US Citizenship test,' just 19% for Americans 45 and younger](https://www.washingtonexaminer.com/washington-secrets/1-in-3-fail-us-citizenship-test-just-19-for-americans-45-and-younger)¹⁰⁷, [American University Tells Faculty to Disregard 'Quality' of Writing When Grading](https://www.breitbart.com/tech/2019/01/11/american-university-tells-faculty-to-disregard-quality-of-writing-when-grading/)¹⁰⁸) When holidays and income tax refund times come around, most communities are either short-staffed or have agency (contractor) personnel fill in and sometimes that is not always ideal since they aren't familiar

¹⁰⁷ <https://www.washingtonexaminer.com/washington-secrets/1-in-3-fail-us-citizenship-test-just-19-for-americans-45-and-younger>

¹⁰⁸ <https://www.breitbart.com/tech/2019/01/11/american-university-tells-faculty-to-disregard-quality-of-writing-when-grading/>

with the residents and their individual needs. During those times, it is very important that family or friends check up on their loved one(s).

My experience has been that most, not all, but most places provide basic, bare minimum care, at best. There are some good and very good communities with excellent, caring staffs and engaged management who go well above and beyond, but they are few and far between. Also, keep in mind that the quality of care provided doesn't necessarily correlate to cost or the newness of the community, etc. In other words, shiny and new aren't necessarily better and higher fees don't necessarily translate into better care.

Also, staff licensure requirements vary greatly from state-to-state and it depends upon the level of care offered by the community. Some states require licensure of almost all staff all the way down to the nurse aide level, whereas others do not.

I've seen a lot of administrators and directors of nursing (DON's) with some very impressive credentials – advanced and doctoral degrees in health care administration, nursing, geriatrics, clinical research, etc., etc., and I've seen other administrators who only have their administrator's license (and sometimes LPN or RN license). Don't let those fancy credentials fool you – one of the absolute best administrators I've ever seen falls into the latter category and I've seen some really, completely worthless ones with a lot of fancy parchment hanging on the wall behind their big, fancy desks and highly-polished chair seats, if you know what I mean. Just look them up on LinkedIn to see how many jobs they've had in the past 5 – 10 years.

Most administrators and DON's I've seen are **not** the “hands-on, lead by example” type – they rarely come out of their offices to supervise their staff's activities, visit the residents, or do spot checks of rooms, kitchen, medical records, MAR's (medication administration records), etc. On rare occasions, you will find an administrator who is also a nurse and they generally have a significantly better understanding of what it takes to properly operate a facility and provide good care to the residents. And when I say “nurse,” I mean an LPN or RN who has actually had **hands-on, direct care experience for years** and not just someone straight out of school with just a bunch of “book learnin'.” I don't lay all the fault on the administrators and DON's – they are usually so overburdened and overwhelmed with burdensome corporate/human resource make-work compliance B.S. and government regulatory paperwork that they have little or no time to do anything but push papers and deal with employee life-

drama management issues and that is one of the main problems with the industry. This is rapidly becoming the case for the floor-level/charge nurses, as well, so it is very important that the community staffs their building appropriately. Some states have specific staff-to-resident requirements, others do not. Some are required to always have nurses on duty, others are not. Ask. In some cases, even when state regulations do not always require nurses on duty, better communities have them anyway, just in case, and it's obviously a great selling point. You can ask what their staffing ratios are, but few will tell you – you will get the tired excuse that it is company proprietary information or that they conform to state requirements – I've heard this on numerous occasions. Ditto for agency (contractor) staffing percentages. It's all a bunch of B.S. and usually just an excuse to mask inadequate staffing. **Note to administrators:** Stop insulting the public's intelligence with this canned response. Most people can count quite well and it is relatively simple for anyone to walk around and do a cursory headcount of residents and staff and determine a fairly accurate ratio and you never know when a detective and former administrator will be sitting across the desk from you shopping your property for a family. Think about it – if you lie to me, I **WILL** make you famous! But also keep in mind that in some instances, state regulations may not actually spell out exact ratios required, only, “adequate staffing to provide proper care” or something of that nature. Talk about open to interpretation!

Sadly, most places, and even the best ones, struggle constantly with staffing, both in quantity and quality. So, you **will** have to ride herd on the entire staff from the administrator on down because, in my experience, they rarely do what you ask until the 2nd or 3rd time or under threat of a visit from the ombudsman or state inspector. However, we've all heard the adage, *“You attract more bees with honey than with vinegar.”* So, I always try to be as cordial, amicable and helpful as possible with the staff – yelling, screaming, threatening to call the state inspectors, etc., usually gets you nothing more than a case of indigestion, an ulcer, high blood pressure and won't necessarily translate into better care for your loved one and it may even get you banned from the community and or your loved one discharged. Please try to keep in mind that these people have very difficult jobs (as you will discover as a caregiver) and being part of the solution is always preferable to being part of the problem. The people providing the direct care to you or your loved one may or may not have advanced training, so before jumping to conclusions, pulling out your flaming keyboard and going on social media or review websites to unfairly lambaste a community, take time to assess and analyze the situation, calmly discuss it with the staff and help them understand you and or your loved one's concerns and or needs. Think about it, could you do their job full time?? Again, cameras in rooms can clear up a lot of conflicting information and or confusion, especially if a resident is telling a family member one thing and the staff another. Most

administrators should welcome the placement of cameras. Check state laws first before installing them – violating privacy and HIPAA laws could land you in a lot of legal hot water – consult an attorney if you are unsure.

Regarding employee background checks and drug testing:

Most state laws and corporate policies usually mandate that every employee be screened for certain convictions prior to or immediately after employment. You will hear the sales pitch about how thoroughly they screen their **employees**, for example, one company touts that they perform background checks with local, county and state police (usually through the respective state's bureau of investigation), and also fingerprint and sexual offender checks and in some cases, even interview the applicant's neighbors. That's all well and good, but who's performing the background checks and how thorough are they really? Do they perform ongoing (infinity) background checks and or drug screens on employees? If not, why not? I know a little about background checks and the problems with them are too numerous to go into here, but suffice to say that **a lot** can fall through the cracks. For example, perhaps the person has never been caught at whatever illegal activity they happen to be involve in or, it is possible that the records-keeping system has not caught up with them yet and doesn't reflect recent convictions or deferred sentences at the time they applied for a job. Also, a person doesn't necessarily have to have a squeaky-clean background to work at a community – they can have convictions of certain types (known as “**non-barrier offenses**”) that do not preclude them from working in long term care. And pending charges may not be considered “barrier offenses,” but the community's corporate policies may be stricter than state laws. Administrators would most likely **not** be able to discuss an employee's background check with you for privacy reasons. Again, laws vary from state-to-state, so check with the respective governmental oversight authority.

UPDATE: Here's the reason I emphasized **employees** in the previous section: Due to Covid (2019 and on) and other economic reasons, there is a critical shortage of front-line workers in the health care industry and it has severely impacted the long-term care industry. Many long-term communities have had to turn to **employment agencies** and apps like [Nursa](https://nursa.com/)¹⁰⁹, and others to fill the gaps in their staffing. Ditto for non-medical services such as housekeeping, food service, maintenance, etc. Laws and regulations regarding background checks vary from state-to-state. Some states require the long-term care employers to conduct the background checks and leave it up to the employer as to who performs those checks, whereas other states have a centralized, fingerprint-based background checking system

¹⁰⁹ <https://nursa.com/>

that employers are mandated to use. Obviously, the latter is the superior system, in my opinion. Now, whereas most states require background checks for the healthcare workers, some may not require non-healthcare workers to have background checks, but I've found that to be rare. Most long-term care employers, irrespective of government requirements, require all employees to be background checked in order to work at a community and that is for safety and liability reasons, of course. **Now here's the twist:** When a long-term care community contracts for non-healthcare related services like housekeeping, maintenance, etc., some agencies, especially ones that are not licensed by the state department of health, may not perform background checks on their employees, for example, a manpower agency that provides housekeepers. They are probably not required to do so and may not, since it is yet another expense for the company. However, personally, from a liability standpoint, I would certainly do so if it was my company. In this case, it is left up to the long-term care community to background check those agency staffers. This is where you have to be very careful when you inquire about background checks for a community's staff, since today, many are not direct employees of the long-term care company/community. And why is that you may ask? Well, when you work for a staffing agency or go through a pairing app like Nursa, you, the contract staffer, can pick the places, dates, and shifts you want to work and in the case with pairing apps, to a certain extent, you can essentially name your own price, to the extent someone will pay it, that is, and, in many cases, the going hourly rate is 2 – 3 times what you would be paid if you were a direct employee. Also, with pairing apps, taxes are not taken out. Now, that sounds like a pretty sweet deal to me. Of course, you don't have any benefits, etc., in those cases. So here's the questions you would ask an administrator regarding this:

1. Do all your direct employees, healthcare and non-healthcare-related, go through fingerprint-based background screening?
2. Who performs the background screens?
3. Are the employees allowed to start working prior to being screened and then screened soon thereafter, or must they be screened before starting work?
4. Do you employee agency/contract staffers?
5. Does the staffing agency provide you with proof of background screening for every staffer? Or,
6. Do you background screen the agency people? (Question 3 applies here, too.)
7. For non-healthcare-related agency staffers, (Questions 3., 5. and 6. apply.)

Basically, there should not be **anyone** working in that community who has not had their background checked.

Also see Section 8. **COMMUNITY & PERSONAL SAFETY AND SECURITY**

If you are fortunate enough to live in a state that puts their court and health department records online, I suggest you:

Check the administrator's license and the licenses of the senior staff such as the director of nursing – this info should be online in most states - check for expiration dates, sanctions and or disciplinary actions against them. If your state puts court records online, check their names in those databases, as well. Most state health departments require background checks for employees, but the problem is that many only flag convictions and not pending cases or offenses that were pleaded down or out which is why you must do this yourself. In one case, I had a client at a community who had an administrator who was named in 4 wrongful death lawsuits. To be fair, when you are the administrator, you are almost always named in any type of legal proceedings against the community, but in this case, the administrator quit after only a couple of weeks on the job and moved far out of town. There is no way someone facing that much court time could effectively administer a community with that kind of legal burden hanging over their head.

*(See the links under “**Facility and Long Term Care Staff Records Research**” in section 15.*

INTERNET RESOURCES *below.)*

Below are a couple of places you can go to find public records in your state and run a criminal background check on someone. If you do this and find questionable information on an employee, discuss it with the administrator and if they are the one in question, ask to speak with a regional supervisor or other corporate officer. I've seen cases where employees passed background checks because a charge was pleaded down and they were convicted of a lesser, “non-barrier” offense, but the original charge itself constituted a barrier offense and the employee had to be discharged. Unfortunately, the service providing the background checks may not scrutinize an applicant's background to that degree and they may not be required to do so. Also, look the person up on Facebook – what a resource it has been for people in my industry - people LOVE to blab about themselves and expose behaviors that are not conducive to their continued employment in the long-term care industry.

<http://www.blackbookonline.info>

<https://www.crimesmasher.com>

Pre-employment drug screening – unless required by law, many communities do not do these because they are expensive and there would be as much as a 50% fallout rate, usually because of marijuana use, and employees are getting hard enough to find as it is. Marijuana laws and court decisions regarding how it effects employment are constantly evolving – here are a couple of excellent articles:

- [Medical Marijuana and the ADA](#)¹¹⁰
- [Noffsinger v. SCC Niantic Operating Co.: What Does the Connecticut Ruling Mean for Employers?](#)
- [Considerations for Employers as Medical Marijuana Approaches](#)¹¹¹
- [Employers Dropping Marijuana Tests](#)¹¹²

On a side note - don't think legal marijuana is a serious problem? Check out these reports:

- [Rocky Mountain High Intensity Drug Trafficking Area \(RMHIDTA\) - Downloadable, annual reports and other information on the impact of marijuana legalization in the state of Colorado](#)¹¹³
- [Marijuana Devastated Colorado; Don't Legalize it Nationally – USA Today, 8/7/2017](#)¹¹⁴

When it comes to having people come in your house to provide home health care services, I would want someone who has at least been with the company for a year and who has had a recent background check performed and not just at the time of hire, again, just in case there were pending cases or recent convictions that hadn't been entered into the record when they were hired.

When you visit a community, look around the business areas – are the desks neat and clean or covered with food, food containers, drinks, employees sitting around playing on their cell phones, etc.? If so, I wouldn't waste any more time there.

¹¹⁰ <http://www.currentcompliance.org/2017/01/26/medical-marijuana-ada/>

¹¹¹ <https://www.law.com/thelegalintelligencer/sites/thelegalintelligencer/2017/11/14/considerations-for-employers-as-medical-marijuana-approaches/?slreturn=20180025231959>

¹¹² http://hosted.ap.org/dynamic/stories/U/US_EMPLOYERS_DROPPING_MARIJUANA_TESTS_CTOL-?SITE=TXMCA&SECTION=BUSINESS&TEMPLATE=DEFAULT&CTIME=2018-05-02-15-31-59

¹¹³ <http://www.rmhidta.org/default.aspx/MenuItemID/687/MenuGroup/RMHIDTAHome.htm?AspxAutoDetectCookieSupport=1>

¹¹⁴ <https://usat.ly/2vHw0kJ>

Food Service:

For safety, liability and health department regulation reasons, most communities won't allow you to go into the kitchen, but there should be absolutely no reason for them not to let you at least stand in the doorway and look in. If they won't let you at least do that, that's another reason for immediate departure from the premises. However, don't expect the kitchen to look like something out of a celebrity's home on the Food Channel – this is a real, working kitchen that provides dozens, if not hundreds of meals per day, so expect it to appear somewhat chaotic. What you want to know is how many of the kitchen staff have their food safety certification – there should always be at least one person present at all times who is certified and the credential should be prominently displayed in or near the kitchen or at least available for you to inspect, just like the administrator's and facility's licenses are and any facility worth their salt should be more than happy to produce those credentials.

Most places I've seen tout their "chef-prepared" meals, etc. Some places do have **real** chefs and others have cooks and or CDM's (certified dietary managers) – there's a BIG difference and I know, because I have been a cook in restaurants and long-term care communities. Real "chefs" are graduates of accredited culinary arts programs/institutes and have diplomas with the word "chef" on it to prove it. This business about having "worked under a chef" or been a "chef's assistant" is complete nonsense and does **NOT** make one a "chef" nor confer the right to call oneself a chef. Trust me, there is a HUGE difference between being a great cook and being a **real** chef!!!

Get a good understanding of how a community's food service works, ask:

- Does the resident have to get fully dressed (dress code) to come to meals?
- Can meals be delivered to the room? How often? Additional cost?
- Is there an "open kitchen," i.e., can a resident get food at any time?
- Are snacks offered? What kind? How often?

Stay for a meal and ask other residents and their family members about food quality, variety, accommodation for special dietary needs, timeliness and professionalism of presentation and service, etc.

Monthly fees PLUS:

By far, most assisted livings have a basic monthly rate for their rooms **PLUS** a basic monthly fee for different levels of required care, medication management, incontinency supply program, etc. In assisted living communities, this basic monthly care fee will obviously go up as the resident requires more care and attention and the salesperson **should** explain these to you – they are frequently referred to as points, levels of care, or tiered levels of care. Here's where you have to be careful about the old bait-and-switch: After the staff nurse does an initial assessment and gets the prospect moved in, amazingly the next month they (new resident) require more care than they had initially determined so they will raise the monthly care fee to the next level. In some cases, additional level costs increase by \$200 - \$700 per month increments!!!! Obviously, this can be a real shock if you are barely able to make the monthly payments to begin with. Also keep in mind that assessment criteria can vary from community-to-community. Another note on assessments – be completely honest with the RN about your loved one's condition - do not try to fool or lie to the assessing nurse about any special care needs, propensity for violent behavior, etc. Doing so will eventually make the whole situation very bad for everyone and in the end, it will be the person who needs the care the most who suffers.

Remember, in nursing homes, there is usually only one flat fee and the only difference would be in a semi-private versus private room. On rare occasions, you may also find some assisted living communities that have “all-inclusive, no surprises” monthly pricing models.

Since some of these communities are not-for-profits, they sometimes have financial assistance programs available, so ask the administrator for details.

Salon/Barber Shop Fees:

Some places have employees in their salons and add any fees to the monthly bill. However, **most** salon staff are independent contractors usually you have to make arrangements to pay the hairdresser, barber, etc., directly. Some salons offer manicures and pedicures – ask. Ask them if they can take PayPal, Apple Cash, Zelle, etc.

Podiatrist fees:

This is probably another service your loved one will need. Again, this will probably be through an independent contractor physician. Be sure to get it set up and get them on a regular schedule.

Medical transportation fees:

It used to be free, but now most places charge per trip because they have to pay a full-time employee, then there's insurance, fuel and maintenance on the vehicle, etc., etc. Some places I've seen charge as much as \$25+ one way! Considering their monthly rental fees, I find such transportation fees obscene! The best communities work **to** the **residents'** schedules, but most make you adhere to **their** schedules, which usually aren't very flexible at all. If your loved one has to go to a lot of appointments or go to appointments outside the general vicinity of the community, be sure you understand the community's policies beforehand and usually be prepared to pay an additional nominal fee for each time you use their transportation services. Also, it is rare that a community staff member will accompany your loved one to his/her appointment and depending upon the driver's schedule, you or your loved one may have to wait a very long time to be picked up. If there are no relatives in the area that can perform this function, you will have to establish an account (well ahead of anticipated need) with a home health care agency that can accompany the resident and or provide the transportation (if they are insured to do so – ask) and assist him or her during the appointment and return them to the community. Again, you or your loved one will need an advocate, especially if the person has vision or hearing limitations or memory issues. Ask around about home health agencies – there are many out there and they will give you the slick sale, too. You want to make sure that when they are needed, there are no glitches. In this case, I suggest you provide your cell phone number to the aide so he/she can text you when your loved one has been picked up, they have arrived at the appointment, are returning to the community, etc. Unfortunately, my experiences with these outfits has been less than inspiring. Again, you will have to ride herd on this process – alternately, you could call the community to make sure the caregiver/aide arrived and that your loved one departed for their appointment on time and call the doctor's office to ensure that they arrived and then call the community to ensure that they returned.

In the event of a medical emergency, your loved one will be transported to the hospital by an ambulance, but, in most cases, the long-term care community will **not** send a staff member to the hospital with your loved one in this case either. They may arrange for a “med-ride” taxi to bring them back, but not always – be sure you understand how this works and make contingency plans accordingly.

7. RESIDENT CARE

There are differences in care levels and applicable state and federal regulations. Keep in mind that higher levels of oversight and regulation does **NOT** necessarily translate into better care. Nursing homes provide the highest levels of care and are regulated by state and federal authorities, assisted livings provide mid-level care and are regulated by the state, residential care provides low-level care in residential home settings and are regulated by the state, independent living communities provide little or no care and have some state regulations, but usually not oversight from the respective states' departments of health like the other levels of care. In some states you may have recourse through the real estate commission, if they have oversight, or you may just have to file a suit in civil court.

Assisted living communities were originally designed to provide assistance with daily living tasks – low levels of care, but because nursing homes are so exorbitantly expensive (2-5 times that of most assisted livings) and the environment usually not as desirable as that in an assisted living community, the trend in the industry is to try to help the individual live as comfortably as possible with the minimum assistance necessary, but also move towards providing higher levels of care, almost at nursing home levels, when needed, hence the growth of assisted living communities. Lines between the two are getting blurred.

State health departments are evolving – political and budgetary pressures can change the focus on their missions which can affect their oversight of communities. For example, if they run short of money, staffing can be reduced, therefore community inspection frequency can be lengthened and when they receive complaints, they may only visit a community if it is an “immediate jeopardy” issue.

Most families I've seen have unrealistic care expectations especially in light of the high amount of money paid for that care. If a loved one has had problems at home, whose behaviors are set (won't brush teeth, eat, etc., fighting with bathing, falls at home), then they probably won't be resolved at assisted living or nursing home – they will continue, unless medication can mitigate the behaviors. However, using medications to manage behavior has inherent legal, moral and ethical issues and the medications themselves can create a host of unwanted, secondary problems, such as dizziness, falling, constipation, confusion, hallucinations, etc. This is obviously an area where extreme caution is advised. Here's a perfect example: A friend, who suffered from Parkinson's Disease, began having hallucinations after a change to his medication to help calm him. I suspected a medication conflict, but his sister assured me that the DON, house doctor, neurologist and pharmacist had all reviewed and approved his medication

regimen. I showed the regimen to a nurse-friend who had been in the long-term care industry for years and she immediately pointed out that there were 2 medications on the list that were absolutely not to be taken together and she proved it to me with her Nurse's Drug Handbook. I immediately notified the sister who brought it to the attention of the nursing home staff and they discontinued the offending medication, substituted another and my friend's condition improved almost overnight. In this case, I believe the nursing home staff was just paying lip service to the sister and didn't really review the man's meds as they should have – it was just too glaring of an error. Again, this is why you have to ride herd on the staff and why every resident needs an advocate. More info on medications in **Section 9.e.**

When you are choosing a community, be certain that the care offered (what services they do offer and what they do not) is appropriate for what you and your loved one need right now **and**, if you think you will be remaining in that community long-term or perhaps indefinitely, evaluate if they will be able to provide the services you or your loved one will need later as their health and health care needs change or, essentially, increase over time, which they almost always do. For example, some communities I've been in have RN's and LPN's on staff and even though they are thoroughly trained and eligible to administer injectable medications or perform blood sugar finger sticks, tube feedings, etc., in the eyes of the state, the community's policies may not allow them to do so and they will have to have a contract home health nurse come in to perform those types of functions thereby adding additional costs to your monthly bill. If you are the resident, be honest with yourself and your situation – I've experienced personally and seen and heard of way too many cases where a resident and or family members have unreasonable and unrealistic expectations of degrees of recovery which, in the end, never manifest themselves. In other words, they think they will recover to the point they can return to living alone and it turns out not to be the case....in most cases.

Keep in mind that laws vary greatly from state to state as do levels of licensure as to what kind of care/services a community can provide. A community may be licensed to provide certain (higher) levels of care, however, corporate policies may limit that care to lesser services for a variety of reasons.

Here's an example of terminology confusion: A potential resident of an assisted living in state "A" needed mechanical soft/ground (but not pureed) food because he didn't have lower teeth. The son, from state "B," asked if they could provide a "mechanical soft" diet for his father and they said that state law didn't allow them to do so. In reality, they could provide "ground up" food, but in state "A," "mechanical soft" meant pureed to them and their state licensure didn't allow them to provide pureed food to residents

in an assisted living, only in a nursing home setting could that be done. In state “B,” where the son was from, assisted living communities were allowed to provide both ground up (mechanical soft) and fully pureed food. In the end, the son moved the father into that community because they could meet his father’s dietary needs, but initially, because of differences in state laws and terminology confusion, neither side thought they could meet the man’s dietary needs.

Be very careful – if you get into a community that only provides basic care and your health condition changes over time or you have an incident (such as a fall) that changes your care needs immediately and the community cannot provide that care, you may have to move and do so quickly. Occupancy rates at communities can fluctuate wildly due to a variety of factors and the place where you would like to go or place your loved one may be full and have a waiting list, leaving you with scrambling to find a place that may have not been your most desired location and or services. However, if hospice is involved and the family is helping, the community may allow the resident to remain in place – all that is contingent upon state laws, corporate policies and if you have a good relationship with the community and its staff.

OTC (over-the-counter) emergency medication – for constipation, upset stomach, diarrhea – you need to ensure it is available on the medicine cart in the event it is needed. If not, depending on state regulations and corporate policy, a family member or friend may be able to purchase the necessary OTC medication themselves and give it to the staff for administration. State laws and facility rules come into play here – some may be able to keep such OTC meds in stock and can be administered by a nurse and others may require a written doctor’s order. In some cases, a doctor may give blanket authorization for all the residents under his care to have these medications at the nurse’s discretion. You need to check on this so your loved one will not have to go without something relatively simple while awaiting a doctor’s order – get the order in place ahead of time.

When it comes to prescription medications, if able, some assisted livings will let you self-administer most medications, but usually not narcotics or other “high-pilferage” medications, things like Lortab (Norco, hydrocodone), Atavan, Xanax, Valium, Marinol, Morphine, liquids, etc. This is usually due to prevailing laws, facility rules, their contracts with pharmacies, the high potential for pilferage, as well as concern for residents’ health and safety. So, if you or your loved one is prescribed one of these medications and you are currently self-administering your medication, you will probably have to pay an additional fee for medication management. I think this is generally wise – if you or your loved one accidentally takes a double dose of some of these medications, it can lead to a life-threatening situation. If your loved on

requires an opioid-related drug, ask the DON if they have NARCAN (naloxone) readily available to counteract an overdose. Due to the nationwide opioid crisis, NARCAN is now available to civilians without prescription, so there should be no excuse not to have it on hand.

You will have to keep a close eye on medications, especially if you suspect your loved one is not receiving their medication for some reason. This is especially true if they are taking any of the aforementioned drugs, which may be stolen by staff to be sold on the street for significant profit. Be sure to report any suspicions of theft to the DON and administrator. Also, when medication changes are made, be sure to double check with the dispensing individual to ensure that the MAR (Medication Administration Record) has been updated accordingly.

Recently I received a call from a friend asking for advice – the facility (memory care section) her father was in told her that she needed to hire a full-time sitter (licensed home health aide from a 3rd party agency) to watch and help care for him because he was a fall risk. She was considering it, but was lamenting the cost because a 12-hour per day HHA can run \$250 - \$500 per day, that's \$7500 - \$15,000 per month, and that is **in addition to** the monthly rental fee the family was already paying, which I estimate was approximately \$6,000 per month!! I told her that was outrageous on so many levels. First, he is in the highest level of care available, a small, secured, memory care unit. His situation was not unique and they should be well-able to care for her father, plus, he was already on hospice, too and they were coming in to check on him and provide care at least twice weekly. Here's what I suspect is going on: Like every other business during the Covid pandemic and it is especially true in long term care communities, they are chronically short-staffed and, in many cases, are having difficulty getting 3rd party agency staff because they are in the same position, too. To complicate matters, right now census levels (occupancy rates) at communities are very low and they obviously want to retain as many residents as possible because they need the revenue. However, primary in this situation should obviously be the health, safety and proper care provided to the resident. I told my friend that she should have a meeting with the DON and administrator and ask them straight out whether they think they can provide the care her father needs. If not, they should be honest and so state and recommend another community or nursing home. Any administrator worth his or her salt would recognize the community's shortcomings and admit it to the family, less there be some disaster where the father is injured and the situation devolves into a hospital stay, or worse, and possible lawsuits. Again, in this situation, you may have to enlist the assistance of the ombudsman and or local governmental oversight authority. Risk management, administrators, risk management!!!! And yes, I know it can sometimes be difficult to get

your corporate bean counters to understand this, but most of them have never had any operations experience and are just relying on a bunch of fancy, but worthless, nicely framed pieces of parchment paper hanging on their walls. I sympathize with you!!

Also see **Section 10. THE HOSPICE COMPONENT** for info regarding the facility cutting back on care services after hospice becomes involved – this is **NOT** acceptable.

Pro Tip:

Most assisted livings are starting to reserve a section of their buildings for memory care residents, however, they are usually limited in the number of people they can accommodate, usually 15 - 20 and there's usually a waiting list to get in. So, if you have a loved one in a community's assisted living and you think that they will eventually need to be moved to a higher level of care, such as the memory care unit, be sure to talk to the administrator and get their name on the waiting list. If their name comes up and they are not at the stage where they need to move, just have the facility pass them over and go to the next person in line, but you maintain your number 1 position so when the time is right, you won't have any problem getting them in and you won't have to go through the struggle, expense and confusion (especially to your loved one) of moving them to an entirely new place. If the care at the community is good, it is generally best to keep them at a place with a staff with whom you both are familiar.

8. COMMUNITY & PERSONAL SAFETY AND SECURITY

When considering a community, some things to ask about:

- Is the community controlled access? In other words, is/are there secure door(s) and or a gatekeeper you have to pass to gain access to resident quarters? On duty all the time?
- Does it have a dedicated (state-licensed), armed security officer patrolling the grounds? At what times?
- Is there a monitored, recording camera system? Dedicated employees to monitor?
- Are cameras allowed in rooms? (Check state laws.) Accessible via facility's Wi-Fi?
- Also, find out how the call light system works. Go in a room and pull the cord and see how long it takes someone to respond. Most places are slow to respond to call lights and this is mainly due to employee shortages.

Personal Relationships:

Okay, kids, here's the scoop: Just because your mom, dad, or other loved one is old and or has memory issues, it doesn't mean that their desire for companionship (if you know what I mean) necessarily disappears. Some of these folks are more "active" than you care to imagine, trust me.....and get used to it. And remember, they are still adults with full rights (in most cases) to do whatever they wish, so let them be happy, within reason, of course. The administrator or DON should have discussed such policies before admitting the person. Discuss any concerns with the administrator and DON, where necessary, especially when it comes to the STD issue - yes, they're still a concern even at that age and don't be shocked if you "get the call" one day from the administrator informing you that your loved one is "getting busy," or, absent any problems or dangers to the resident, a facility may not notify you, again out of privacy rights concerns. Just think about this: Would you want someone notifying your parents of your behaviors (as an adult)?

Safeguarding Against ID Theft:

As a caregiver, the absolute last thing you need to deal with is a case of identity theft, either personally or with your loved one. Our personal information is "out there" and statistically speaking, it's just a matter of time before we must deal with this kind of crime, so the best thing we can do is take proactive steps to secure and insulate ourselves and our information. And just because you or your loved one may have

no web presence, i.e., no online accounts, this does not mean that your information is safe – far from it. [See this article](#)¹¹⁵ from security expert Brian Krebs at Krebs on Security.

With so many people having access to you or your loved one's personal information, it is imperative to take steps to protect it against criminal activity (financial fraud, exploitation, identity theft, etc.).

- Establish a “mySocialSecurity” account here: <https://www.ssa.gov/myaccount/>
- Establish a “myMedicare” account here: <https://www.mymedicare.gov/>
- Establish an “eBenefits account here (if military, a veteran or civil service worker: <https://www.ebenefits.va.gov/ebenefits/homepage>
- Establish an account with [USPS.com](https://usps.com) if your loved one is still receiving important mail that their former residence. Yes, it is **USPS.com** and not **.gov**.
- Lock credit files with the big 3 credit reporting agencies and the [NCTUE](#)¹¹⁶: [Clark Howard's Credit Freeze Guide: The best way to protect yourself against identity theft](#)¹¹⁷
- On your smart device, set up text or e-mail notifications for any transactions that occur with your loved one's banking and credit card accounts.
- If you or your loved one are victims of identity theft, report it to the police and go here for more information on how to proceed. [Federal Trade Commission's Identity Theft Resource website](#)¹¹⁸.
- [Protecting Residents from Financial Exploitation: A Manual for Assisted Living and Nursing Home Facilities – U.S. Consumer Financial Protection Bureau](#)¹¹⁹
- If you have home health care services in your own or your loved one's home, secure or removed all financial statements, any valuables, collectibles, firearms, etc. Install surveillance cameras (check state laws, first). Report any suspicious, malicious or other criminal activity, missing material, etc., to the home health agency and police immediately.
- For more detailed information, see my 104-page **“Special Report: Identity Theft, Financial Fraud & Cyber Crime – Problems, Solutions and Mitigation Strategies”** on the [Publications page of Magnus Omnicorps' website](#)¹²⁰.

¹¹⁵ <https://krebsonsecurity.com/2018/06/plant-your-flag-mark-your-territory/>

¹¹⁶ <https://www.nctue.com/consumers>

¹¹⁷ <https://clark.com/personal-finance-credit/credit-freeze-and-thaw-guide/>

¹¹⁸ <https://www.identitytheft.gov/>

¹¹⁹ <https://pueblo.gpo.gov/Publications/pdfs/6178.pdf>

¹²⁰ <http://www.magnusomnicorps.com/publications.html>

New Medicare ID Cards:

Because of the prevalence of ID theft, Medicare has begun (in April 2018) sending out replacement ID cards with a new, unique numbers on them – they will no longer be using your Social Security number. Your old number will still be good for 2 years, but you should notify all your medical service providers of your new number once you have received it. Beware of scam phone calls requesting any information or payments regarding this. You do **NOT** have to pay for your new card, nor confirm anything to anyone over the phone to receive your new card. BE CAREFUL and safeguard your new number – new scams are popping up daily from criminals trying to gather as many of these new numbers as possible to sell on the Dark Web.

[Center for Medicare & Medicaid Services \(CMS\) Official webpage for new card rollout information and updates](#) (you can also sign up for e-mail updates here)¹²¹

Elder Financial Abuse:

I recently attended an 8-hour training seminar for law enforcement on this subject and they had some sobering statistics: 1 in 6 seniors will be affected in some way. 47% of elders are abused and or exploited in some manner by their caregivers and 85.5% of the abusers are usually family members. I've seen other, different statistics, but all agree that it is a growing problem that we are way behind in addressing. This type of abuse takes various forms and sometimes it is very difficult to spot since the senior may be too afraid to communicate their concerns or unable to do so. This is outrageous and should not be tolerated by our society. Anyone who suspects this may be happening should contact the police and or adult protective services immediately. (See **section 14. OTHER RESOURCES** for more information on how to spot abuse and statistics.)

Other Considerations:

Before discussing or moving your loved one to a long-term care community, be sure all weapons have been removed from the home and or they haven't snuck any weapons into their personal effects destined for the long-term care community. I knew one lady who kept a stiletto on her nightstand for months and none of the staff ever realized what it was (fortunately she wasn't violent). And consider this terrible story in the news recently:

¹²¹ <https://www.cms.gov/Medicare/New-Medicare-Card/index.html>

- [13 Guns Found in Home of 92-Year Old Mother Who Allegedly Killed Son Over Nursing Home Dispute – CBS News, 7/6/2018](https://www.cbsnews.com/news/anna-mae-blessing-red-flags-before-woman-92-allegedly-killed-son-over-assisted-living-dispute/)¹²²

Also, please read: **Regarding employee background checks and drug testing** in Section 6.

¹²² <https://www.cbsnews.com/news/anna-mae-blessing-red-flags-before-woman-92-allegedly-killed-son-over-assisted-living-dispute/>

9. PARTICIPATING IN YOUR LOVED ONE'S CARE

Bottom line: No one will care for your loved one as well as you will and give them the individualized care and attention that you would. And in fairness, we cannot expect the staffs of these communities to know your loved one as well as you do, nor do they have the time to spend one-on-one with your loved one, so you will have to help out.

Okay, let me make a couple of things perfectly clear here: Residents of long term care communities are still citizens of the United States with full Constitutional rights, which, of course, includes civil rights. You do not, you **cannot**, abrogate those rights simply because you are in a long term care medical facility. I'm bringing this up because I have seen instances where a facility will ban certain relatives from visiting a loved one, relative, friend, etc., at the direction of a resident's designated power of attorney. *(Note that a resident with a court-appointed guardian/guardianship may be able to limit visitation – **consult your attorney!**)* Simply put, they cannot do this. A resident has the right to see whomever they wish as long as that person/visitor is not a threat to the staff or other residents and is not a disruptive presence. The Center for Medicare and Medicaid Services (CMS) has a standard list of residents' rights as do most individual states. This document is usually required, by law, to be conspicuously posted in a public area of the facility, along with other information such as the administrator's license, facility license, ombudsman contact info, etc.

- [CMS Resident Rights and Quality of Care](https://www.cms.gov/nursing-homes/patients-caregivers/residents-rights-quality-care)¹²³
- [Know Your Rights – Residents' Rights in Nursing Homes, Assisted Living and Residential Care Facilities](https://oklahoma.gov/content/dam/ok/en/okdhs/documents/okdhs-publication-library/86-58.pdf)¹²⁴

Again, if you have never been a caregiver, prepare yourself for perhaps the most difficult, frustrating and stressful experience you've ever had and I'm not being melodramatic here. It will test your patience and relationships at home, work and with your loved one(s) and other family members. Even if you have been a caregiver before, I cannot strongly enough recommend that you join any of a number of caregiver support groups in your area. Most long-term care communities have them as well as major hospitals and they are usually conducted by mental health/geriatric care professionals. Also check with our county's areawide aging agency, the United Way and the Alzheimer's Association or even your church. In

¹²³ <https://www.cms.gov/nursing-homes/patients-caregivers/residents-rights-quality-care>

¹²⁴ <https://oklahoma.gov/content/dam/ok/en/okdhs/documents/okdhs-publication-library/86-58.pdf>

addition to support groups, many also offer classes to help you better understand what you and your loved one are going through and how to effectively cope and they are also great resources for the advice and services you will eventually need to get through this. **Please don't overlook this critical aspect of being a caregiver. Even if you are not providing hands-on care and may be geographically separated from your parent(s) or other loved one, join a group!**

State laws and corporate policies usually mandate that there be some kind of written care plan for your loved one and that it be reviewed and updated on a regular basis. This plan will cover their biographical history, hobbies, family members, likes, dislikes, medical care specifics, etc. When you or your loved one are admitted, the community will present you with a number of questionnaires to fill out – don't neglect to take care of this important detail as it will help all involved – resident, staff, caregivers, etc., provide for a better experience for all, especially the resident. And be sure to let the staff know that you want to be notified when the care plan is coming up for review so you can participate – be part of the care team and part of the solution.

Every resident needs an advocate (especially those who are hearing, vision and or memory impaired) whether it be a family member or someone else who will be checking in on them weekly, at the very least, and ideally every other day.

Also, be aware that staffing levels are usually significantly decreased during the 3rd shift since most residents are in bed during those hours, but there still needs to be adequate staffing. It is imperative that you visit your loved one regularly “after hours” (usually sometime after the evening meal is served) to check up on them to ensure they are being cared for in a timely fashion and not left to sit at the dining table for extended periods of time after they have finished eating. This is especially important if your loved one has incontinency issues.

Again, when holidays and income tax refund times come around, most places are either short-staffed or have agency (contractor) personnel fill in and sometimes that is not always ideal since they aren't familiar with the residents and their individual needs. During those times, it is very important that family or friends check up on their loved one(s) as frequently as possible.

If you cannot get satisfaction from the community staff, you have legal rights and avenues of recourse – ombudsman, state health department inspectors, corporate management, cameras in rooms in certain

jurisdictions (check state laws), which I highly recommend. Most administrators should welcome the placement of cameras. Check state laws first before installing them – violating privacy and HIPAA laws could land you in a lot of legal hot water – consult an attorney if you are unsure. Most problems I've had, however, can be resolved by **respectfully** bringing them to the attention of the appropriate department head (honor the chain of command) and, if necessary, the DON or administrator.

Mind Your Manners:

Long term care communities' mission is to care for the health and safety of their residents. Inasmuch, aggressive or abusive behavior by the resident's family members, friends, etc., or the resident towards staff and or other residents could cause the resident to be discharged immediately (including if they are a danger to themselves) or given a 30-day notice to vacate – read your contract and have an attorney explain it to you if you have questions!!!

If a resident exhibits aggressive behavior, strikes another resident or staff member, in many cases the community will recommend sending the resident to a geriatric-psychiatric facility for brief (1-2 week) evaluation which may include medication adjustments. This may be required by law in some states. Family members need to be prepared to provide the same oversight and supplemental care at these facilities as they have at the long-term care community, i.e., taking clothing, personal hygiene products, visiting, etc. Most long-term care communities will not provide those extended services. Also, I am not a doctor and don't give medical advice, but it has been my experience that if a loved one has memory care issues coupled with aggressive behavior, it is very helpful for them to be under the care/supervision of a neuropsychiatrist or geriatric psychiatrist, especially one who specializes in treating memory care patients and really knows how to fine tune the medication so that the patient is calm, but not lethargic – there is a very, very fine line when it comes to prescribing those types of medications.

The long-term care community is very tight-knit and word travels quickly, so other places may not take problematic residents or residents with troublesome families. The alternative is a long-term geriatric psychiatric unit and in most states, options are extremely limited and many of these places are not very desirable at all. The legal authority of a community to keep such residents is a conundrum for the community – they must look after the safety of the staff and other residents, but legally cannot retain aggressive residents, yet families are afraid to upset the relative by moving them, but often have no choice.

Caring for Personal Effects:

You know, it's a sad testament to humanity that I even have to address this, but it is a very important point. A long-term care community is going to be you or your loved one's home. You **should** feel safe and secure in your person and personal effects in your home, and you **should** be able to have jewelry, keepsakes, expensive items, etc., in your home, but then that's when reality comes into play. When you or your loved one are admitted to a community, the staff will undoubtedly counsel you to the effect that they are not responsible for lost, damaged or stolen clothing, jewelry, hearing aids, dentures, etc. The odds are good that you or your loved one **will** suffer some kind of loss and or damage while at one of these communities – it's almost inevitable. If they insist on having expensive jewelry, etc., check with your insurance company to ensure they are adequately covered while your loved one is in the community. And I strongly recommend you get any such items appraised, **with photographs**, prior to moving into a long-term care community. And photograph any other expensive items, especially jewelry, etc., and other small items that can be easily stolen. Some communities have lockboxes in each room for securing valuables, or there are any number of different lockboxes you can get from companies like [First Alert](https://www.firstalertstore.com/)¹²⁵, etc. Also, there are a lot of small firearm safes (handgun vaults) that function well for this purpose. Try [Liberty Safes](https://www.libertysafe.com/)¹²⁶, [Gun Vault](https://gunvault.com/)¹²⁷, [GunBox](https://thegunbox.com/)¹²⁸, etc., and they are carried by many of your larger sporting goods stores like Academy, Bass Pro, Cabella's, etc.

Regarding hearing aids, consider trying one of those \$20 “bionic ears” you get at the local drug store or sporting goods stores. If your loved one repeatedly loses hearing aids, sometimes those can be a viable and affordable alternative. **You have been warned!!**

Be sure to properly mark anything and everything you take in to the facility and you will have to re-mark clothing frequently because even the best “permanent” markers fade over time. Make sure your loved one has comfortable, easy to put on clothing (take into consideration range of motion and other limitations) and items that are not so delicate that they will be ruined in the community wash. I've purchased some very nice used and even new/never worn clothing items at the local Goodwill stores for very reasonable prices.

¹²⁵ <https://www.firstalertstore.com/>

¹²⁶ <https://www.libertysafe.com/>

¹²⁷ <https://gunvault.com/>

¹²⁸ <https://thegunbox.com/>

Unless the family or a friend is doing the resident's laundry, don't take expensive clothing – it **will** get ruined or lost. Most places don't take much care when doing residents' laundry so expect lots of lost and ruined items.

If the family is providing incontinency products and they seem to be getting used more quickly than usual, it is possible that they are being stolen by aids for use on other residents either out of convenience or when shortages occur with in-house incontinency program supplies such as end-of-month shortages that happen when someone forgets to place the monthly order in a timely fashion or the supply company fails to deliver on time. Such misuse/theft of personal supplies should be reported to the DON and administrator.

For any credit cards, credentials, critical paperwork, etc., you may have in your room, be sure you have the respective issuers and account numbers written down and stored elsewhere. In case they go missing, especially in the case of credit cards, checks, etc., you will be able to contact the issuer to let them know to put a stop on those accounts and issue new cards, etc. I suggest a password manager like [LastPass](https://www.lastpass.com/)¹²⁹ or [Dashlane](https://www.dashlane.com/)¹³⁰.

Pro Tip:

Buy a box of Sharpie markers and conspicuously mark all items with the resident's name, including and especially consumable items such as Depends, absorbent pads, etc., and you can also number them, 1 of 5, 2 of 5, etc. For items where markers don't work well, get some laundry tape and mark them with that. You can usually find it at most hobby and craft stores.

Time marches on – fading memories:

If your loved one is admitted to a long-term care community with their faculties intact, it doesn't mean that they will always necessarily be so. As time passes, the potential for dementia onset is very real – be prepared emotionally and financially for when you get “the call” from the administrator or DON informing you that they have to move Aunt May to a different ward/hall where there's a higher level of care,....and increased cost. At this point, many families are in denial and accept the diagnosis and reluctant to move their loved one to a memory care wing or community, but it is an unfortunate inevitability that I want you to be prepared for. Listen to the medical and nursing professionals carefully and take their advice

¹²⁹ <https://www.lastpass.com/>

¹³⁰ <https://www.dashlane.com/>

seriously. People with even mild memory loss may be a danger to themselves and others and problems are relatively easy to avoid if proper care is given in a timely fashion. Also, there have been some advancements in medications and the sooner early-stage dementia is diagnosed and the appropriate medications are administered, the better. [Here's an excellent article](#)¹³¹ from the Alzheimer's Association. More about this in **THE HOSPICE COMPONENT** section below.

Common Health Issues, A Brief Word On:

a. Urinary Tract Infections (UTI's). I know, this is a strange topic to include, but follow me on this as I've seen it countless times before. If for some reason your loved one seemingly goes bananas overnight, starts falling/has balance problems, becomes uncharacteristically aggressive, has seizures, slurred speech, etc., then they may have a UTI and or bladder infection. Note that these can also spike blood sugar, causing its own additional set of complications, especially in diabetics. Seniors, especially women, are very susceptible to these. Most long-term care communities are well-familiar with this issue, but many hospitals are not and frequently overlook this very common problem, leading to a misdiagnosis of the patient. Do not discount these as a mild problem! If the community calls and indicates that your loved one is having symptoms normally associated with a UTI, get there immediately and follow their recommendations. Untreated infections can quickly lead to sepsis and death. Again, this is why it is essential that your loved one have an advocate to go with them to the hospital and that is critical for anyone whose loved one is unable to speak for themselves for whatever reason. Remember, in most cases, the long-term care community will not send a staff member to the hospital with your loved one, nor will they arrange to bring them back from the hospital – it is all left up to the family. And family, if you are trusting the long-term care community and the hospital social worker to coordinate these things, **good luck with that!!!** In some cases, they may arrange for a “med-ride” private transportation company to bring the resident back to the community, but that can be very expensive. Ask the administrator or DON how the community handles such situations **before** they arise! Another point on this, if the hospital or anyone tells you it takes 24-48 for the urine specimen culture to grow to determine if the person actually has a UTI, that is wrong! The lab can tell almost immediately if a foreign agent is present in the urine sample, however, it **does** take some time for the culture to grow to the point that they can positively identify the bacteria so that they can prescribe the most appropriate antibiotic to counteract it.

¹³¹ <https://www.alz.org/help-support/caregiving/stages-behaviors/early-stage>

b. Skin: Another item to pay close attention to, especially if your loved one doesn't walk very much or is bed-ridden – bruises, bed sores and other skin ulcerations. Take time once a week to examine their skin, paying close attention to the buttocks and feet (heels especially) areas. Bring any abnormalities to the **immediate** attention of the DON and check back **daily** to see if the situation is being addressed appropriately. It can be extremely difficult to get the staff to turn residents every 2 hours, as is usually required for bed-ridden residents and that is why I strongly recommend installing a Wi-Fi camera (if laws allow – check first) in your loved one's room so you can monitor their care. There are many options out there – just visit any Best Buy or other electronics store or check Amazon.com and be sure to read the product reviews from other customers for tips when buying a system. A note on bruising: As we age, our skin becomes thinner and more prone to easy bruising. Certain medications, especially blood thinners (anti-coagulants) can **significantly exacerbate** this, medications such as Coumadin (Warfarin), aspirin, etc. So, if you go to visit your loved one and you see bruises that you haven't normally seen, bring it to the attention of the nursing staff, but do not immediately assume it is abuse related.

c. Broken Hips: They can be caused by an impact from a fall or falls or a failing hip can fracture causing a fall. In either case, and if the resident did not hit their head and is still able to walk, it is usually standard protocol to have the hip x-rayed and that is usually done at the community by an in-house mobile x-ray service contractor. (Obviously if the resident is in so much pain they cannot walk or move, or anytime they hit their head, they are sent to the hospital and most state laws require it.) There have been some cases I've heard about where the x-ray did not reveal a fracture or breakage, but it was there. The only symptom was persistent pain. Eventually, there was a full break requiring hospitalization and surgery. The key here is to very carefully monitor the resident after a fall, take their complaints seriously and do not hesitate to send them to the hospital for further evaluation.

d. Constipation: People taking opiate pain-relieving drugs such as Norco (aka hydrocodone, Lortab, Vicodin, Lorset, etc.), tramadol, morphine, etc., have a risk for constipation – be sure to discuss this with the doctor and care staff so you or your loved one are getting the appropriate counter-preparations (stool softeners, laxatives, etc.) to keep things moving. Most of the time, this is covered if you or a loved one has to start taking these pain relievers, but it can be overlooked. Also, it is probably not a good idea to try to self-medicate with over-the-counter stool softeners – always consult the medical professionals.

e. Medications: Medication errors and pilferage are one of the most commonly cited problems in long-term care communities. As such, it is a good idea for you to frequently review medications with the

Director of Nursing, Wellness Director, charge nurse, etc., **especially if you notice a change in your loved one's condition.** Often doctors' orders are improperly transcribed to the MAR (Medication Administration Record), so you or your loved one might not be getting the correct medication, right amount, frequency, etc. Also, unfortunately, there are some high-pilferage drugs, such as Norco (Lortab, hydrocodone), Ativan, Xanax, Vicodin, Tramadol, Marinol, etc., which are stolen for sale on the street or to feed an employee's habit, while you or your loved one go without. Sad, but true. Another point on this: As we age, our body processes medications differently – a 100 mg dose of a particular Rx might not be appropriate for someone 80 years of age, or even vice versa. Medications are a tricky aspect of our care – things that can influence our physiological and psychological well-being as it relates to prescription medications are: Age, weight, body type, genetics, allergies, other OTC medications, vitamins, minerals, and other herbal supplements, dosages, when medications are taken, how they are taken (orally, injected, sublingually, etc.), with or without food, combination of medications, and so on. I think you see the point. Again, if you notice any changes in your or your loved one's behavior or anything else out of the ordinary that occurs over a short period of time, a thorough review of the prescription and OTC medications should be one of the first things done and by more than one nursing or medical practitioner, just in case. See my example in **Section 7.**

f. Bed Bugs: This problem seems to be getting worse everywhere and these pests are very difficult and expensive to eradicate. Previously it was thought that they were mostly an annoyance and hadn't been found to carry and or transmit any diseases or other pathogens, **however**, some recent studies (see citations below) indicate otherwise and contradict the CDC's official position as of 2017, so there is even more reason to take precautionary measures to avoid these insects. Almost any public facility has problems with these as eggs can stick to clothing and be dropped just about anywhere and carried elsewhere. Long-term care communities are no different – people moving in and out and bringing their furniture, clothing, etc., which could be contaminated. Also, medical equipment used in other facilities/communities that could have colonies hidden just about anywhere – bed rails, wheelchair pockets, etc. Be aware that they could be an issue anywhere, but are **NOT** an indication of facility cleanliness and hygiene. If you see them, bring it to the immediate attention of the staff and follow up to ensure that they are treated immediately. Note that you may have to replace your loved one's furniture, usually at your own cost.

g. Diabetes: If a person has diabetes and cannot manage it themselves, then most likely your only option for long term care is a nursing home. Why? Because taking finger sticks several times a day,

administering the proper dose of insulin, etc., requires **skilled care** and that requires at least a licensed nurse, not a nurse's aide or assistant. Also, most communities below the level of nursing homes are not required to have 24-hour licensed nurses on duty. A few rare ones do and they may be able to accommodate your or your loved one's diabetic care, but they are few and far between. This holds true for any other medical conditions that require 24-hour skilled (nursing) care. *(If a community **seems to advertise or imply** that they have 24-hour nursing coverage, make absolutely sure that they do and put it in writing.)* So, do not be surprised if an assisted living or memory care community declines to admit you or your loved one or, at some point, tells you that they are no longer able to care for your or your loved one because the care required for you exceeds their capabilities. And those capabilities are often defined by state law in their licensure, so they have no choice in the matter. This is again yet another reason to look to the future and your future care needs when considering a community.

h. Internal Implants, etc.: If the patient has, for example, metal rods, plates, etc., inside their body or a device like a defibrillator, etc., sometimes hospitals will refuse to do an MRI until they not only see the physical card indicating such **AND** talk to the physician who placed the device and get a copy of his or her notes. They do this for liability reasons, but sometimes it can hinder care, especially if the surgeon is in another state and if the emergency falls on a weekend or holiday. Or, even worse, if the surgeon is no longer practicing or has moved. So, if you ever have this kind of surgery, you need to carry copies of the surgeon's records with you and include them with any documents you provide to your new doctor and any potential medical care facilities you may go to.

Related articles:

- [CDC's FAQ's on Bed Bugs](https://www.cdc.gov/parasites/bedbugs/faqs.html)¹³²
- [Penn Study Shows Bed Bugs Can Transmit Parasite that Causes Chagas Disease](https://www.pennmedicine.org/news/news-releases/2014/november/penn-study-shows-bed-bugs-can)¹³³
- [Study Offers Further Evidence of Bed Bugs' Ability to Transmit Chagas Disease Pathogen](https://entomologytoday.org/2018/01/30/study-further-evidence-bed-bugs-transmit-chagas-disease-pathogen/)¹³⁴
- [PPMA Survey Highlights Bed Bug Prevalence Nationwide, 6-14-2018](http://www.pctonline.com/article/ppma-survey-bed-bug/)¹³⁵
- [Orkin Releases New Top 50 Bed Bug Cities List, 1-12-2018](http://www.pctonline.com/article/orkin-top-50-bed-bug-cities-list/)¹³⁶
- [Pest Control Professionals See Summer Spike in Bed Bug Calls, 6-4-2018](#) (See InfoGraphic)

¹³² <https://www.cdc.gov/parasites/bedbugs/faqs.html>

¹³³ <https://www.pennmedicine.org/news/news-releases/2014/november/penn-study-shows-bed-bugs-can>

¹³⁴ <https://entomologytoday.org/2018/01/30/study-further-evidence-bed-bugs-transmit-chagas-disease-pathogen/>

¹³⁵ <http://www.pctonline.com/article/ppma-survey-bed-bug/>

¹³⁶ <http://www.pctonline.com/article/orkin-top-50-bed-bug-list/>

- [Bed Bug Treatment Site](https://bedbugtreatmentsite.com/)¹³⁷

¹³⁷ <https://bedbugtreatmentsite.com/>

10. THE HOSPICE COMPONENT

Another word on hospice – don't discount their services for you or your loved one. The traditional thinking and public perception of hospice services is that they don't kick in until someone is clearly at the end of life. Today, that is not true. For example, a lady who was living on her own qualified for hospice because she had COPD (but rarely used supplemental oxygen) and atrial fibrillation, but had difficulty preparing meals and had some range of motion limitations in her shoulders and hands due to arthritis. She received hospice services – twice a week bathing and personal care services (in her home and when she went to an assisted living) and weekly nurse visits for 17 months before she died. Hospice also provided her with all the equipment she needed to help with life – walker, oxygen concentrator and portable tanks, shower chair, hospital bed, incontinency supplies, health condition-related medications (delivered to her door the same day). Note that hospice will usually only provide medications related to the condition for which they were admitted onto hospice. Hospice may also provide what is called “palliative care” if full hospice care is not warranted at the time. The following links explain the differences between hospice care and palliative care:

- [Hospice vs. Palliative Care – National Caregivers Library](http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgroup-hospice/hospice-vs-palliative-care-article.aspx)¹³⁸
- [Palliative Care vs Hospice Care: A Quick Reference Guide by Vitas Healthcare](https://www.vitas.com/~media/files/pdfs/palliative%20vs%20hospice%20care.ashx)¹³⁹

Hospice provides a true on-call, 24 x 7 x 365 medical team, so if you need anything, you call a single number and get help immediately – the nurse comes and if necessary, consults with the on-call doctor to get you the assistance and or medication and equipment you need. If you move to a long-term care community, they also work closely with them to supplement your care. If you are unsure if you or your loved one will qualify for hospice, just contact any hospice provider and talk with them – if you know enough about your loved-one's medical history, they will probably be able to tell you over the phone and if there are any questions, they will send out an RN to perform a free assessment. Remember, all hospice services are free of charge to you – Medicare pays their fees. Hospice service providers are private businesses contracted with Medicare and it is big business and there are usually dozens of different providers in most major metro areas, so ask around the community to see which they've used or had experience with – which ones work best with the staff, which are more responsive, etc. – they will

¹³⁸ <http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgroup-hospice/hospice-vs-palliative-care-article.aspx>

¹³⁹ <https://www.vitas.com/~media/files/pdfs/palliative%20vs%20hospice%20care.ashx>

know and will tell you which are the best and which are the worst. Also keep in mind that hospice eligibility rules change from time-to-time, so if you have someone who has been on hospice for long term, such as the case mentioned above, be very careful about switching providers without ensuring the person is still eligible under present-day criteria. Again, call a couple of hospice providers and ask them. The same goes for contacting multiple providers when attempting to determine eligibility for hospice care/coverage – not all agencies are the same and it often pays to double-check.

Again, one problem I have seen in long-term care communities is the theft of hospice or privately supplied items, especially consumables such as incontinency supplies. This can be out of convenience – a nurse's aide needs gloves to assist with another resident or maybe a pull-up (Depends), but if there are none in the room, they may just use the gloves or pull-up of the person on hospice since they know hospice will keep re-supplying them. Or, if it is near the end of the month and the facility hasn't placed an order for their consumable supplies, they may take from the person who has hospice-supplied items. Obviously, if you see this or too many supplies are being used, you should inform the administrator and or director of nursing and the hospice provider. This is theft, plain and simple, and the employee(s) engaging in it should be reprimanded and or fired and reported to the respective state licensure authority.

Another common problem is that once hospice is involved, the facility staff stops providing the same level of care that they had prior to hospice coming in, because hospice is now providing some of that care. For example, hospice staff will bathe the patient. If the facility aides bathed the resident twice a week before hospice, they may not continue to bathe the resident since hospice is doing it. This is wrong, unless, of course, the facility discounts your monthly rent, which is highly unlikely. Let me be clear – you contracted (usually in writing) with the facility to provide certain levels of care for a specific amount of compensation – the presence of hospice does **NOT** alter that contract nor the facility's obligations for care of any kind. If you see that happening, you should first contact the DON and administrator. If they do nothing, then call the ombudsman assigned to the facility (they usually are located at the county's areawide aging agency) and most states' laws require that name and number to be conspicuously posted in a public area of the community. Further, you can contact the state health department or respective governmental oversight authority and report them to Medicare. Remember, hospice comes into the picture when there is care required that is **IN ADDITION TO** that which is already being received.

11. FUNERAL PLANNING

The average length of stay in an assisted living or nursing home is between 1 – 2 years. Inasmuch, if you have a loved one in a long-term care community, the likelihood of them passing is obviously high and you need to prepare for that, as well.

I cannot overemphasize the need for this. Immediately following the death of a loved one or close to it is absolutely no time to be engaged in this process, which can be extremely complicated and usually expensive, even if there is only cremation involved, especially in highly regulated states, such as “blue” states. It becomes even more difficult if there is a death near or on a major holiday and especially at the end of the year. You may have to wait weeks in some jurisdictions (“blue” states) for the appropriate paperwork to be processed and permits obtained.

A funeral plan should be in place and contact information for clergy and the funeral home should be in the resident’s file and also probably with the hospital and primary care physician. Be sure to notify the clergy and the funeral home, as well, of the resident’s location. Also, if no relatives are close by, desired burial clothing should be in a separate garment bag and stored in the resident’s closet and clearly marked as such. Most state insurance departments regulate funeral insurance policies, so check with your respective agency if you have questions.

12. OTHER TIPS

Legal Documents & Medical Records:

For caregivers, it is critical that you have all the necessary financial and medical powers of attorney, guardianship, conservatorship, advanced care directives (living wills), etc., paperwork in order and copies in your loved one's file at the community. I even suggest carrying multiple copies in your car with you in the event you have to go to the hospital with your loved one. Even better, make sure any doctors of record and the hospital have these records on file – this will save you and the medical providers a lot of headaches when you're trying to deal with a crisis. Also, in the event you have someone like me looking after your loved one, be sure that in the care provider's contract, there is verbiage that allows that person to receive medical information on behalf of the family and your loved one, etc. You may also need to fill out HIPAA release forms with the respective medical service providers naming the caregiver.

HIPAA is probably one of the worst, most restrictive, complicated, confusing and confused laws ever passed. I understand why it was enacted, but many times it hinders prompt care and the medical community uses it as a pathetic blanket excuse not to communicate with other facilities and health care providers. I even heard of one case where the hospital said that it didn't have a patient's records even though the patient was admitted to their emergency room. Their excuse was that the ER was a separate entity and HIPAA prevented them from sharing records. **BULLSH*T!!!!** HIPAA specifically **allows the sharing** of records between medical providers so they can provide the best care possible to the patient. Now, it could be that their electronic systems/records software are not compatible with each other, but when it is the same facility, physically connected to each other, I find that very hard to believe. Don't take that as an excuse, either. When visiting with your doctor, ask him or her which hospital they have admitting privileges with and if they share records with those hospitals. In any case, as I mentioned before, you should provide your doctors and any medical facilities you may visit with copies of your medical records and pertinent legal documents (PoA's, advanced health directives, DNR's, etc.) before you have a medical emergency. Most facilities have a central documents repository where you can take such documents and have them scanned in for you. In an emergency, this can remove and questions and be a real life-saver when time is of the essence with you care. However, never ass-u-me that the medical staff is smart enough to check for your records and if they do, do not ass-u-me they have thoroughly read and understand what is in those records. Again this is where you almost always need an advocate to speak on your behalf and that person/those persons should be named in your medical PoA. Or, if your advocate is a third-party professional guardian or caregiver, such as myself, a copy of

the caregiver's contract with you should be on file and in that contract should be a line item allowing medical facilities to disclose any and all information regarding your medical condition to that individual. Note to professional caregivers, you should always carry hardcopies of your clients' contracts with you in the event of any emergency. Electronic copies are okay, but the hospital may not have a way for you to e-mail it to them or print it out from a flash drive.

Also, if your loved one has real estate or other real property in their name, and especially absent a will or trust with clear disposition instructions for the property, it is imperative that you contact an attorney and make adjustments to the title, deed, etc., to provide for a smooth transition of property ownership. This especially must be done before your loved one starts to exhibit signs of dementia. Remember, you must "have capacity" in order to contract.

Travel Emergency Bag:

If you take your loved one away from the community from time-to-time on outings and they have incontinency issues, need assistance in the restroom and or cannot clean themselves, you need to be prepared to deal with that situation. I always carry a bag with the following contents:

- 2 – 3 pair surgical gloves
- 2 – 3 surgical masks
- Safety glasses
- Hand sanitizer
- Package of baby wipes
- Roll of toilet paper
- Roll of paper towels
- 2 pair of underwear or pull-ups
- 2 – 3 incontinency pads (for car seat and or wheelchair)
- Pair of loose-fitting sweat pants
- Loose-fitting, button up shirt
- 2 pair of socks
- Extra pair of Velcro clasp tennis shoes (Walmart \$10)
- Small (13-gallon) plastic trash bag to put soiled clothing in
- 2 or 3 plastic shopping bags to dispose of used gloves, wipes, soiled pull-ups

State ID's:

Everyone regardless of age should have one. In the event you lose your driver's license, a state ID will serve as a "primary ID," otherwise you will have to produce a passport or notarized birth certificate along with a secondary form of ID in order to get a replacement driver's license.

For those who no longer drive or cannot get their license renewed for health reasons, they will still need some form of official government-issued ID – starting with a new doctor, admitted to a different hospital, for your power-of-attorney to conduct business on your behalf, etc. It is important to obtain a state ID before one's driver's license expires because if the individual does not qualify for driver's license renewal, a tag agency may decline to issue a state ID until they get a letter from the DMV authorizing it. This will require taking your loved one down to the DMV to see an examiner. We all know what a hassle it can be down at the DMV and the last thing you want to do is needlessly subject your loved one to that whole process. However, if you must do so, check the DMV's website – you may be able to schedule an appointment and cut down your wait time at their office.

Most states provide state ID cards free or at low-cost to seniors.

13. FINAL THOUGHTS

I apologize if this report has been like getting a cold bucket of ice water thrown in your face, but that's pretty much what it was meant to be. I've seen too many families struggle terribly, internally and externally, because their first introduction to the long-term care industry was during an emergency situation and they had no idea what they were facing or how to deal with it. I want **you** to be **prepared** if you ever have to deal with the long-term care industry and chances are you will.

I was at a senior conference recently and one of the speakers told the group that if we (the world) don't find a significantly viable treatment or cure for dementia-related diseases in the next 20 years, every penny of our annual national budget will be consumed by the health care costs needed to provide care for those afflicted and it will bankrupt countries....as if we weren't in already bad enough financial shape as it is. [The Alzheimer's Association](https://www.alz.org/)¹⁴⁰ is going to be one of your best resources to help cope with this and there are many others – see **section 15. Internet Resources** below.

Again, we must start taking responsibility for planning not only for our retirements, but for our long-term care needs, as well. We need to be pragmatic about our needs and have open and frank discussions about those needs with our family and seek out professionals to assist us with that planning and heed their advice.

¹⁴⁰ <https://www.alz.org/>

14. IMPORTANT POINTS TO REMEMBER:

I know there is a lot to remember in this report, so here is a brief outline:

- a. Being a caregiver is a very difficult task. If you have never been one, you **will** need professional assistance, not just for your loved one, but for you, too! Even if you are not directly involved with caregiving, but a concerned, close relative who is geographically separated, you should join a local caregiver support group or groups – they are usually available in long-term care communities, major hospitals, churches, and United Way-affiliated organizations.
- b. Be pragmatic about your situation. Listen to and heed (trust, but verify) the advice of medical and nursing professionals who have experience in the long-term care field.
- c. Know and understand the terminology/jargon used in the industry – it can be confusing and can vary from state-to-state.
- d. Estimates are that somewhere between 50-70% of people over the age of 65 will require fairly significant long-term care services at some point in their lives.
- e. Long-term care costs are very high and most frequently borne by the consumer (private pay out of their bank accounts). Even if you are young (in your 20's), **NOW** is the time to talk to your financial and legal professionals and family to plan for these expenses. Start saving at the earliest possible time, even if it is only a few dollars per month. Do you **really** need that \$7 cup of coffee every day??
- f. If you live far away from a parent, relative or other loved one, will you know what to do if you get “the call?” Will you be ready, willing and able to help immediately? Is there someone you trust to act as a highly involved advocate in your absence? **Plan ahead!!** Start learning about this industry and the process in your 50's, earlier if you have aging parents/loved ones who have not prepared.
- g. Selecting a long-term care community will be an exercise in compromise. Do your homework: Take community tours, eat lunch with the residents and ask them questions, read community

reviews, review state and federal official survey reports, research the backgrounds of the management staff. And remember, shiny and new, high-priced or highly regulated does not always translate into better care!

- h. Beware of the “slick sale” and scrutinize lease contracts (especially “life plan” contracts) very carefully with close attention paid to: Admissions and discharge criteria, involuntary discharge criteria, appeal rights and procedures, notices to vacate, community bankruptcy. Contact an elder law attorney for assistance. Also pay attention to fee structures and additional fees that you will have to pay for services.
- i. Understand what levels of care a community can and cannot provide. Think ahead and decide if a particular community can meet all of your current needs as well as possible future needs – would you be willing to move if higher levels of care were needed?
- j. Be cognizant of crime: Personal effects and ID theft, elder abuse (personal & financial), etc. and take steps to mitigate any exposure. Install cameras (with sound and recording capabilities) in the room where allowed – they can clear up a lot of conflicting information and confusion. Most administrators should welcome the placement of cameras. Check state laws first before installing them – violating privacy and HIPAA laws could land you in a lot of legal hot water – consult an attorney if you are unsure.
- k. LTC community residents still have full rights under the law. Check in on your loved one frequently – every other day, if possible and at varying times throughout the day and night. Check their personal effects, skin, bed bugs, etc. Take complaints about pain, care, etc., seriously and discuss them in a calm and respectful manner with the staff while honoring their chain of command. You will have to ride herd on the staff and if you can't get satisfaction, there are other official avenues you can pursue – corporate chain-of-command, governmental oversight authorities, ombudsman programs through [your respective county's Areawide Aging Agency](#)¹⁴¹.or more directly [here](#)¹⁴².

¹⁴¹ <http://www.n4a.org/>

¹⁴² <https://ltombudsman.org/>

- l. Don't rule out assistance from hospice – in some cases, they can provide assistance even if end of life isn't imminent (palliative care). Medicare pays and there are many, many private companies that provide it and will perform free eligibility assessments.
- m. Do your funeral planning well ahead of time – it will save your loved ones a lot of stress and anxiety when the day comes.
- n. Have all your legal documents (PoA's, wills, trusts, DNR's, living wills, etc.) in order and provide copies to all related service providers. Seek the assistance of an attorney familiar with or [certified in elder law](#)¹⁴³ to help you draw up these documents.
- o. If you are having problems with insurance companies, etc., getting them to give coverage, contact your attorney and also file complaints with your respective state's Insurance Department and Attorney Generals Consumer Protection Unit.
- p. And don't forget to join that support group!! Do it NOW!!!

AND ONCE AGAIN:

We must start taking responsibility for **planning** not only for our retirements, but for our long-term care needs, as well. We need to be pragmatic about our needs and have open and frank discussions about those needs with our family and seek out professionals to assist us with that **planning** and heed their advice. ***You must be your own first responder in almost all aspects of your life*** these days!

¹⁴³ <http://www.nelf.org/find-a-cela/>

15. INTERNET RESOURCES:

Here are some websites and guides that you will hopefully find beneficial:

For Family:

[Alzheimer's Association](#)¹⁴⁴

[Alzheimer's Foundation of America](#)¹⁴⁵

[Bank of America's U.S. Trust - Memory & Your Family - Capital Acumen, Spring 2015](#)¹⁴⁶

[\(Coach\) Broyle's Foundation – service Alzheimer's Caregivers in Crisis](#) (be sure to get “The Playbook” – this is excellent if you are caring for someone with dementia)

[The Calm Before the Storm - Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia](#)¹⁴⁷

[Care Right, Inc.](#) – Assistance with senior life planning – great video resources on website, amazing services to help caregivers and their loved ones!!! Available nationwide!!

[Caring for a Person with Alzheimer's Disease - Your Easy-to-Use Guide from the National Institute on Aging](#)¹⁴⁸

[The Conversation Project website](#)¹⁴⁹

[Dale K. Graham Veteran's Foundation \(free service helping vets apply for benefits\)](#)¹⁵⁰

¹⁴⁴ <https://www.alz.org/>

¹⁴⁵ <https://alzfdn.org/>

¹⁴⁶ <http://www.ustrust.com/publish/ust/capitalacumen/spring2015/features/memory-and-your-family.html>

¹⁴⁷ <http://www.cvcoa.org/assets/files/CalmBeforeTheStorm.pdf>

¹⁴⁸ <https://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide>

¹⁴⁹ <http://theconversationproject.org/>

¹⁵⁰ <https://dalekgrahamveteransfoundation.org/>

[FamilyAffaires.com Guiding Families Through Life Changes](http://www.familyaffaires.com/)¹⁵¹

[InsureUOnline Special Section on Long Term Care Insurance](http://www.insureuonline.org/insureu_special_longtermcare.htm)¹⁵²

[Let's Talk: Starting the Conversation About Health, Legal, Financial and End-of-Life Issues guide](http://www.n4a.org/files/Conversations.pdf)¹⁵³

[myLifeSite](http://www.mylifesite.net/)¹⁵⁴

[Magnus Omnicorps' Helpful Info and Links page](http://www.magnusomnicorps.com/helpful-info---links.html)¹⁵⁵

[National Academy of Elder Law Attorneys](https://www.naela.org/)¹⁵⁶

[National Elder Law Foundation](https://www.nelf.org/)¹⁵⁷

[National Caregivers Library](http://www.caregiverslibrary.org/home.aspx)¹⁵⁸

[National Long-Term Care Ombudsman Program Locator](https://ltombudsman.org/)¹⁵⁹

[Oklahoma Society of CPA's 2018 Financial Fitness Kit](https://www.oscpa.com/writable/files/For_The_Public/2018-financialfitnesskit.pdf)¹⁶⁰

[Senior Transitions of Edmond & OKC \(specialized moving services for seniors\)](http://seniortransitionsokc.com/)¹⁶¹

[Where You Live Matters \(community selection\)](http://www.whereyoulivematters.org/)¹⁶²

¹⁵¹ <http://www.familyaffaires.com/>

¹⁵² http://www.insureuonline.org/insureu_special_longtermcare.htm

¹⁵³ <http://www.n4a.org/files/Conversations.pdf>

¹⁵⁴ <http://www.mylifesite.net/>

¹⁵⁵ <http://www.magnusomnicorps.com/helpful-info---links.html>

¹⁵⁶ <https://www.naela.org/>

¹⁵⁷ <https://www.nelf.org/>

¹⁵⁸ <http://www.caregiverslibrary.org/home.aspx>

¹⁵⁹ <https://ltombudsman.org/>

¹⁶⁰ https://www.oscpa.com/writable/files/For_The_Public/2018-financialfitnesskit.pdf

¹⁶¹ <http://seniortransitionsokc.com/>

¹⁶² <http://www.whereyoulivematters.org/>

Oklahoma Resources:

[OKCares](#)¹⁶³ (resources for caregivers)

Oklahoma Long Term Care Laws (Statutes), Rules and Regulations, all facilities¹⁶⁴

Central Oklahoma Counties Senior Nutrition & Mobile Meal Programs¹⁶⁵

Legal Aid Services of Oklahoma¹⁶⁶

Legal Aid Services of Oklahoma- Senior Legal Help¹⁶⁷

Medicare's Nursing Home Ratings¹⁶⁸

Mobile Meals of Oklahoma County¹⁶⁹OKDHS Aging Services Publications¹⁷⁰

OKDHS Guide - Nursing Home or Alternative Care in OK¹⁷¹

OKDHS Long Term Care Options and Resources¹⁷²OKDHS Long Term Care – Know Your Rights¹⁷³

¹⁶³ <https://www.okcares.org>

¹⁶⁴ <https://oklahoma.gov/health/protective-health/long-term-care-service/rules-regulations-and-statutes.html>

¹⁶⁵ <http://www.areawideaging.org/fundedprograms/nutritionprograms.html>

¹⁶⁶ <https://oklaw.org/>

¹⁶⁷ <http://www.legalaidok.org/senior-legal-help>

¹⁶⁸ <https://www.medicare.gov/nursinghomecompare/search.html>

¹⁶⁹ <https://www.211ok.org/locations/areawide-aging-agency-inc-479/mobile-meals-of-oklahoma-county-1>

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<http://www.okdhs.org/sites/searchcenter/Pages/okdhspublicationresults.aspx#Default=%7B%22k%22%3A%22%22%2C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString06%22%2C%22t%22%3A%5B%22%5C%22%2C%7%82%2C%7%824167696e67%5C%22%22%5D%2C%22o%22%3A%22and%22%2C%22k%22%3Afalse%2C%22m%22%3Anull%7D%5D%7D>

¹⁷¹ <http://www.okdhs.org/OKDHS%20Publication%20Library/87-83.pdf#search=nursing%20home>

¹⁷² <http://www.okdhs.org/OKDHS%20Publication%20Library/15-52.pdf#search=nursing%20home>

¹⁷³ <http://www.okdhs.org/OKDHS%20Publication%20Library/86-58.pdf#search=nursing%20home>

[Oklahoma Assisted Living Association \(OKALA\)](https://okala.org/)¹⁷⁴

[Oklahoma City/County Areawide Aging Agency](http://areawideaging.org/)¹⁷⁵ [\(incl. Life Alert & ombudsman programs\)](#)

[Oklahoma City Community Foundation Oklahoma County Senior Nutrition Program](https://occf.org/ocsnp/)¹⁷⁶

[Oklahoma County Senior Services](https://ariisp1.oklahomacounty.org/tga/SeniorCitizenResources/SeniorCitizenResourcesTxt.htm)¹⁷⁷

[Oklahoma Insurance Department – Regulated Industry Services](https://www.oid.ok.gov/regulated-entities/regulated-industry-services/)¹⁷⁸

[Oklahoma Nurse Aide & Non-Technical Service Worker Registry \(check to see if a person is on the registry\)](https://www.oid.ok.gov/regulated-entities/regulated-industry-services/)¹⁷⁹ [DOH Full Page](https://www.phin.state.ok.us/NARSWBSearch/Views/LandingView.aspx?id=6202)¹⁸⁰

[Oklahoma On Demand Court Records Search](http://www1.odcr.com/)¹⁸¹

[Oklahoma State Board of Examiners for Long Term Care Administrators \(OSBELTCA\)](https://www.ok.gov/osbeltca/)¹⁸²

[Oklahoma State Court Network Docket Search](http://www.oscn.net/applications/oscn/casesearch.asp)¹⁸³

[Oklahoma State Dept. of Health Nurse Aide and Nontechnical Services Worker Information](https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/index.html#NTSW)¹⁸⁴

[Oklahoma State Dept. of Health, Protective Health Services Provider Survey/Inspection Search](https://surveys.health.ok.gov/)¹⁸⁵

¹⁷⁴ <https://okala.org/>

¹⁷⁵ <http://areawideaging.org/>

¹⁷⁶ <https://occf.org/ocsnp/>

¹⁷⁷ <https://ariisp1.oklahomacounty.org/tga/SeniorCitizenResources/SeniorCitizenResourcesTxt.htm>

¹⁷⁸ <https://www.oid.ok.gov/regulated-entities/regulated-industry-services/>

¹⁷⁹ <https://www.phin.state.ok.us/NARSWBSearch/Views/LandingView.aspx?id=6202>

¹⁸⁰ https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/index.html#NTSW

¹⁸¹ <http://www1.odcr.com/>

¹⁸² <https://www.ok.gov/osbeltca/>

¹⁸³ <http://www.oscn.net/applications/oscn/casesearch.asp>

¹⁸⁴ https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/

¹⁸⁵ <https://surveys.health.ok.gov/>

[Oklahoma State Department of Veterans Affairs](#)¹⁸⁶

[Oklahoma Board of Nursing – Nursing License Verification & Disciplinary Actions](#)¹⁸⁷

[Oklahoma State Dept. of Health List of Nurse Aides with Disciplinary Flags/Convictions](#)¹⁸⁸

[Oklahoma City Areawide Aging Agency Senior Resource Directory](#)¹⁸⁹

National & Federal Resources:

[Centers for Medicare and Medicaid Services - Your Guide to Choosing a Nursing Home or Other Long Term Care](#)¹⁹⁰

[Medicare.gov Long Term care page](#)¹⁹¹

[Medicare's Nursing Home Ratings](#)¹⁹²

[National Adult Protective Services Association – Elder Financial Exploitation](#)¹⁹³

[National Association for Area Agencies on Aging](#)¹⁹⁴

[National Caregivers Library](#)¹⁹⁵

[National Council on Aging – Elder Abuse Facts](#)¹⁹⁶

¹⁸⁶ <https://oklahoma.gov/veterans.html>

¹⁸⁷ <https://apps.ok.gov/nursing/verify/index.php>

¹⁸⁸ <https://www.phin.state.ok.us/nar/>

¹⁸⁹ <https://www.areawideaging.org/survival-kit>

¹⁹⁰ <https://www.medicare.gov/Pubs/pdf/02174-Nursing-Home-Other-Long-Term-Services.pdf>

¹⁹¹ <https://www.medicare.gov/coverage/long-term-care.html>

¹⁹² <https://www.medicare.gov/nursinghomecompare/search.html>

¹⁹³ <http://www.napsa-now.org/policy-advocacy/exploitation/>

¹⁹⁴ <http://www.n4a.org/>

¹⁹⁵ <http://www.caregiverslibrary.org/home.aspx>

¹⁹⁶ <https://www.ncoa.org/public-policy-action/elder-justice/elder-abuse-facts/>

[National Center on Elder Abuse](#)¹⁹⁷

[Nursing Home Abuse Center](#)¹⁹⁸ [Statistics](#)¹⁹⁹

[Nursing Home Ratings](#)²⁰⁰

[StopFraud.gov](#)²⁰¹

[Senior Housing Crime Prevention Foundation](#)²⁰²

[U.S. Government's National Center on Elder Abuse](#)²⁰³ [Statistics](#)²⁰⁴

[U.S. Dept. of Health & Human Services, Administration for Community Living](#)²⁰⁵

[U.S. Dept. of Health & Human Services Long Term Care Resources page](#)²⁰⁶

[U.S. Dept. of Health & Human Service Long Term Care website](#)²⁰⁷

[World Health Organization Elder Abuse Statistics, 6/8/2018](#)²⁰⁸

Facility and Long Term Care Staff Records Research:

[Commission on Accreditation of Rehabilitation Facilities \(CARF International\)](#)²⁰⁹

¹⁹⁷ <http://www.ncoa.org/public-policy-action/elder-justice/>

¹⁹⁸ <https://www.nursinghomeabusecenter.com/>

¹⁹⁹ <https://www.nursinghomeabusecenter.com/elder-abuse/statistics/>

²⁰⁰ <https://nursinghomerating.org/>

²⁰¹ <https://www.stopfraud.gov/sf/elder-fraud-and-financial-exploitation>

²⁰² <http://shcpfoundation.org/>

²⁰³ <https://ncea.acl.gov/>

²⁰⁴ <https://ncea.acl.gov/whatwedo/research/statistics.html>

²⁰⁵ http://www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx

²⁰⁶ <https://www.hhs.gov/aging/long-term-care/index.html>

²⁰⁷ <https://longtermcare.acl.gov/>

²⁰⁸ <http://www.who.int/news-room/fact-sheets/detail/elder-abuse>

²⁰⁹ <http://carf.org/>

[Medicare's Nursing Home Ratings](#)²¹⁰

[Oklahoma Nurse Aide & Non-Technical Service Worker Registry \(check to see if a person is on the registry\)](#)²¹¹ [DOH Full Page](#)²¹²

[Oklahoma On Demand Court Records Search](#)²¹³

[Oklahoma State Board of Examiners for Long Term Care Administrators \(OSBELTCA\)](#)²¹⁴

[Oklahoma State Court Network Docket Search](#)²¹⁵

[Oklahoma State Dept. of Health Nurse Aide and Nontechnical Services Worker Information](#)²¹⁶

[Oklahoma State Dept. of Health, Protective Health Services Provider Survey/Inspection Search](#)²¹⁷

[Oklahoma State Laws, Rules and Regulations governing long-term care facilities](#)²¹⁸

[Oklahoma Board of Nursing - Nursing License Verification](#)²¹⁹

[Oklahoma State Dept. of Health List of Nurse Aides with Disciplinary Flags/Convictions](#)²²⁰

If you have a loved one or client who is also experiencing mental health/behavioral issues, I have a special resource list for those cases – see the [Mental Health Resources for Central Oklahoma list](#)²²¹.

²¹⁰ <https://www.medicare.gov/nursinghomecompare/search.html>

²¹¹ <https://www.phin.state.ok.us/NARSWBSearch/Views/LandingView.aspx?id=6202>

²¹²

https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/index.html#NTSW

²¹³ <http://www1.odcr.com/>

²¹⁴ <https://www.ok.gov/osbeltca/>

²¹⁵ <http://www.oscn.net/applications/oscn/caserearch.asp>

²¹⁶

https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/

²¹⁷ <https://surveys.health.ok.gov/>

²¹⁸ http://www.ok.gov/health/Protective_Health/Long_Term_Care_Service/Rules,_Regulations_and_Statutes/

²¹⁹ <https://apps.ok.gov/nursing/verify/index.php>

²²⁰ <https://www.ok.gov/health/pub/wrapper/nrsaid.html>

²²¹ <https://nebula.wsimg.com/ecdf5a30c1a578f491466474929140cd?AccessKeyId=602ED0BF003FFC4E99AF&disposition=0&alloworigin=1>

APPENDICES

A. MANAGING YOUR RELATIVE'S AFFAIRS

In previous sections, I mentioned the need for having all your legal documents in order:

- Trust or will
- Pour-over Will (if trust)
- Financial power of attorney
- Medical power of attorney
- Do Not Resuscitate (DNR) order
- Advanced Care Directive (aka living will)
- Insurance plans
- Funeral Instructions/Plans
- Other

Before I start, obviously keeping all these documents and information straight, organized and easily accessible is a daunting task in itself. I have recently found some software programs that can help immensely with this task:

- [Cake](https://joincake.com/)²²²
- [Everplans](https://www.everplans.com/)²²³
- [My Life & Wishes](https://www.mylifeandwishes.com/)²²⁴

In this section, I will go over this in a little more detail, but since I am not an attorney and do not give legal advice, you should always contact an attorney for assistance in this area! I do not recommend using boilerplate forms off the Internet or from the office supply store. Every person's and family's situations are different and very unique and that is why you need a legal professional experienced in elder care to

²²² <https://joincake.com/>

²²³ <https://www.everplans.com/>

²²⁴ <https://www.mylifeandwishes.com/>

help walk you through these steps to ensure all your bases are covered adequately and appropriately. Trust me, having all these documents in place will make the task of caring for your relative unbelievably easier.

Irrespective of your position, caregiver or patient, you will still have personal affairs that need to be managed such as:

- Paying bills [house related (mortgage, rent, gas, electric, insurance, cable, etc.)]
- Other bills (health and or auto insurance, credit cards, subscriptions, clubs, memberships, etc.)
- Annual tax filings, quarterly estimates

The list can go on and on, but I'm sure you see my point. Eventually, you will be able to whittle all these down, especially if your relative becomes a resident of a long-term care community. These PoA (power of attorney) documents need to be in place and up-to-date AND they need to be on file with all the respective service providers so when you need to act, you don't have to do the paperwork shuffle, too. In the case of a trust, it needs to be "funded," in other words, items you want in the trust, need to be titled in the name of the trust. Talk to your attorney about this.

First, I want to focus on the PoA's. Even an 18-year-old needs a PoA. Why? Well, they are adults and parents may not be able to speak for them in an emergency when they cannot speak for themselves. Select your PoA's early on – you can always change them as needed. You NEED to have these in order and you NEED to have someone you trust implicitly named so they can take over in the event you are unable to act or speak for yourself or in the event of a cognitive disorder such as dementia, etc., are having difficulty with confusion and or making sound decisions.

I've seen PoA's that are immediate and others that are "springing." With immediate PoA's, your designee has the power (enumerated in the PoA) to act on your behalf the moment those documents are signed and notarized. For "springing" PoA's, that usually means that the individual requires some type of written certification from one or more medical professionals and or a court that they are unable to act/speak for themselves and only at that point is the designated PoA given authority to act on his or her behalf.

Obviously, every family's situation is different and unique, which is why you need to discuss this with your attorney and go through all the "what if" scenarios and draw up your documents accordingly.

The problem I've seen is that in emergency situations and especially with early onset dementia cases, springing PoA's can be somewhat of a hurdle to getting things done in an expedient manner. Again, this is why, as we age, we need to be pragmatic about our situations and review these documents with our attorneys and family members and have them updated accordingly. Legal professionals and notaries are absolutely correct to be overly cautious and suspicious of family members who bring in a relative who is clearly suffering from a dementia-related condition and ask that PoA's be modified to give them authorities not previously granted in other documents. In those cases, you will probably not be able to get modifications made and will have to adhere to the stipulations in the original documents and that may put the caregiver in a real bind, especially if time is of the essence when dealing with certain financial and or care situations.

Now, thanks to technology, Internet, smartphones, etc., managing another person's affairs has become much easier. Even if PoA's are not in place with service providers, if the relative/account holder can give the customer service agent verbal authorization to discuss his or her account with the caregiver, then the caregiver can usually get things done easily. Again, this is something you can do ahead of time – you can call the respective customer service lines and tell them to make a note in your account file that they are allowed to discuss your account details with Jane Q. Caregiver. Banks and other financial institutions may not be able to do this and may require a copy of the PoA.

As the caregiver, you should have copies (either photocopies or pictures on your smartphone of your relative's credentials):

- Driver's License or State-issue ID card
- Medicare ID card
- Medicare supplement plan ID card
- Any other health insurance card
- Auto insurance card (if you are driving their car)
- Any other credential frequently required when conducting business on their behalf
- PoA's

There are a lot of apps for smartphones that act as mobile scanners – you take a picture of the item/document and it will convert it to a PDF file and allow you to e-mail, text, fax it to whomever. Personally, I use [TurboScan app from Piksoft](https://turboscanapp.com/index.html)²²⁵, or [Clear Scanner from Indy Mobile App](https://indymobileapp.web.app/)²²⁶, but there are many others out there. This can really come in handy if you need to provide a copy of a PoA to a new medical service provider who doesn't have it in their system.

When it comes to paying bills, it is fairly easy to automate their payment:

- Go to the respective service provider's website and using information from a monthly paper statement establish an online account, if not already established
- Set up paperless billing to your e-mail address
- If desired, have the monthly bill automatically debited from the respective bank account
- You can pay the bill electronically every month, but that will require you to have online access to person's bank account
- Instead of debiting the bank account, you can direct the bill to be paid by a credit card, but, most utilities still don't allow this and must be paid via bank account debit.

Since you will have a lot of passwords, etc., to keep track of, I suggest a password manager program such as Dashlane, 1Password, OnePass, LastPass, KeePass, etc. Most offer free options for one device, but charge to install the software on multiple devices and keep the information synchronized – a very handy service and worth the small annual fee.

Obviously, if you are carrying around this much personal information in your smartphone, you need to have it secured – the last thing you need at this point is deal with a case of identity theft. I recommend an alpha-numeric password only. Yes, I know there are fingerprint and facial recognition options available, and those are very convenient, but those have obvious vulnerabilities. With an alpha-numeric passcode, you **must** enter it. Also, without a court order, current law prevents law enforcement from compelling you to speak or provide the passcode, but they can get your fingerprint or hold the phone up to your face. Think about it. **UPDATE:** Laws are always changing and vary from jurisdiction to jurisdiction – please read this article: [Feds Can't Force You To Unlock Your iPhone With Finger Or](#)

²²⁵ <https://turboscanapp.com/index.html>

²²⁶ <https://indymobileapp.web.app/>

[Face, Judge Rules](#)²²⁷ This is just one ruling in one jurisdiction and it may or may not hold in your area. I suspect this particular issue will eventually make it to the U.S. Supreme Court, but until they rule on it, I advise you to keep using an alpha-numeric passcode to secure your devices.

Additional articles:

- [Know Your Digital Rights, Electronic Frontier Foundation, 10-2014](#)²²⁸
- [US Judge Rules That Police Can't Force You to Unlock Your Phone by Iris, Face or Finger, ZDNet 01-15-2019](#)²²⁹
- [Can Police Force You to Unlock Your Phone?, Android Authority 06-14-2019](#)²³⁰
- [The Police Want Your Phone Data – Here's What They Can Get and What They Can't, Vox 06-04-2020](#)²³¹
- [Protecting Your Privacy If Your Phone is Taken Away, Electronic Frontier Foundation 06-04-2020](#)²³²

You also need to have your smartphone's information backed up – most operating systems have a way for you to do that. Of course, any place you back it up should also be secured with a passcode or other device and that device should also be backed up, especially if it is a laptop or external hard drive.

Any online accounts you have access to should be secured with a strong password and two-step (two-factor) login authentication – that is where after entering the e-mail and password, a 6-digit passcode is sent to your smartphone which you have to enter on the screen to gain access to the account.

Again, if you want a more futuristic, digital way to manage your and or your loved one's estate planning and documents, consider services such as [Everplan](#)²³³, [My Life and Wishes](#)²³⁴, or [Cake](#)²³⁵. Or, for a

²²⁷ <https://www.forbes.com/sites/thomasbrewster/2019/01/14/feds-cant-force-you-to-unlock-your-iphone-with-finger-or-face-judge-rules/>

²²⁸ <https://www.eff.org/issues/know-your-rights#:~:text=The%20Fifth%20Amendment%20protects%20you,or%20unlocking%20your%20electronic%20devices.>

²²⁹ <https://www.zdnet.com/article/police-cant-force-us-citizens-to-unlock-their-phone-by-face-or-finger/>

²³⁰ <https://www.androidauthority.com/police-unlock-phone-rules-rights-998683/>

²³¹ <https://www.vox.com/recode/2020/2/24/21133600/police-fbi-phone-search-protests-password-rights>

²³² <https://www.eff.org/deeplinks/2020/06/protecting-your-privacy-if-your-phone-taken-away>

²³³ <http://www.everplan.com>

²³⁴ <https://www.mylifeandwishes.com/>

²³⁵ <http://www.joincake.com/>

more basic, but also comprehensive system, ask your bank or funeral home for a personal information management booklet – most have something like that and they are usually free.

There is much more to computer security, so I strongly recommend you read the related sections in my **Identity Theft report** on the [Publications page of my website](http://www.magnusomnicorps.com/publications.html)²³⁶.

²³⁶ <http://www.magnusomnicorps.com/publications.html>

B. CARING FOR A LOVED ONE IN A LONG-TERM CARE (LTC) COMMUNITY IN THE AGE OF COVID

March 6, 2021

Thanks to former New York Gov. Cuomo (D) and his debacle with nursing homes, this issue now has national attention.

The best way for me to relate this issue to you is via a personal story:

The daughter of a long-time senior estate management client of mine recently moved her mom to her home state so they could be closer together. She found her mom a very nice apartment at a very nice assisted living community only about 1 mile from her place. Of course, as in most states, because of Covid, the daughter was not allowed into the building to visit her mom, check up on her, verify that she was being properly cared for, eating well, etc., etc. Even though the community was one of the nicest and most expensive in the area, the daughter repeatedly had difficulty getting the staff to respond to her calls, questions, etc. The mother, who had mild-to-medium cognitive impairment, (mostly short term memory loss) wasn't a reliable source of feedback, either. So, the daughter had to hire a 3rd party "sitter," who was allowed into the community to assist her mom and provide her (the daughter) with intel reports.

Flash forward a couple of months and sadly, Mom became ill and was hospitalized for a while then released to a skilled nursing facility (SNF) for rehab. The daughter's problems getting feedback from that facility, and even the attending physician, were even worse, to the point she finally called me for advice. In this situation, her mom's care was being paid for by Medicare while she was in the SNF, so that took the hospice option off the table. After some thought and consulting with my expert on this issue, here's what we told the daughter:

1. Depending upon the facility's policies, you may be able to get a sitter in there to evaluate and report on the situation.
2. Since the mother's health is clearly declining, the daughter should inquire about "compassionate care" visits - most places allow that, but that is dependent upon the respective governmental

oversight authority's and the facility's rules and regulations. In most jurisdictions, the city/county/state departments of health have oversight over assisted living and nursing home communities.

3. If neither of those are options, she should contact the respective county's areawide aging agency and ask to speak with the ombudsman who is assigned to that facility. Most facilities are required to prominently and publicly display the ombudsman's contact information.
4. Concurrently, she should contact the governmental oversight authority, explain her situation and inquire about the options available to her. (Never assume an LTC community is telling you the truth about anything - sorry to be so cynical here.)
5. Call any hospice provider and ask them to go evaluate the mother - they are at least able to do that and are generally very happy to do so because that business is very competitive and they are always looking for clients. **[Sidebar:** Hospice is a great option for such situations and contrary to popular belief, you don't need to be knocking on death's door to enlist their services. Another client of mine was on it for 15 months and they were extremely helpful. Hospice services are usually operated by private companies, hence the competition, but are 100% paid for my Medicare. Hospice services must be ordered by a doctor and the patient's need for their services must be periodically re-assessed and the doctor's order renewed. However, only about 50% of hospice's annual funding is used and this is because the public either doesn't know about hospice and their services, are not told about it by healthcare "professionals" or just don't really understand hospice's mission.]
6. The final option would be to arrange for 24/7 sitters, get a doctor to approve her discharge from the SNF, get hospice involved immediately and move her back to her apartment at the assisted living. With the hospice involved, sitters and in-house therapy, the mother would get the best care and the daughter would have significantly more control over the situation. Obviously, all this would have to be coordinated with both the SNF and assisted living communities, their respective staffs and their respective discharge and intake personnel, Medicare and the hospice provider of choice. Yes, that's a tall order, but it can be done - you just have to keep after them to get the paperwork completed and even in some cases, you will have to hover over them to get it done and may have to hand deliver some of the paperwork yourself to the involved parties. **(Tip:** I've

had many of them use the excuse, "Well, I faxed it to them" and then the recipient say, "Well, I never got it." Ugh! Who knows who's telling the truth?? It can get so frustrating because there is no ownership or follow-up by anyone. Basically, they just don't care about you or your loved one, sad to say. Yep, I've had to hand-walk the paperwork myself because some of the staff is that incompetent and lazy.) For hospice provider suggestions, I would ask the assisted living community whom they recommend. They usually have a couple of providers with whom they work closely and prefer and probably also know the ones who aren't as good, but the final decision is always up to the family -the facility cannot deny your access to your chosen hospice provider. And, this option would also be enormously expensive - with the private sitters, her monthly rent and additional, private therapy, I estimated around \$25,000 per month. Yes, that's correct. However, if she improved, the sitter hours and therapy sessions could potentially be scaled back, as necessary.

7. If you are facing a long-term care need, please see my ***"Long Term Care from the Inside Out "*** report on the [Publications page of my website](http://www.magnusomnicorps.com/publications.html)²³⁷. Two points I would like to reinforce here:
 - a. Anyone in an LTC community needs an advocate - spouse, family member, private senior case manager, guardian, etc., to check on their welfare no less and 3 times per week.
 - b. Fancy, new and expensive doesn't necessarily translate into better care from any aspect.

²³⁷ <http://www.magnusomnicorps.com/publications.html>

C. ROBIN FISHER BROKEN LEG CASE STUDY

This story is true. The names were changed to protect the innocent and incompetent – you know who you are!

Among other things, I'm an elder case manager. I take care of seniors who are in assisted living or memory care communities and who don't have any family or close friends in the area upon which they can rely.

This is the story of Robin Fisher, a client whom I helped navigate the medical service gauntlet following a broken leg incident.

Robin was 90 years of age and lived in her home alone with no real family or friends in the state. I had worked for her in a variety of capacities over the course of about 15 years and developed a nice relationship with her and stopped by frequently just for social visits. She was an extremely well-educated and interesting person, so we had many wonderful conversations and I always enjoyed hearing about her life and travels since we had several things in common.

Around April 2015, I noticed Robin repeating things she had told me even just the day prior. I had seen this pattern before and knew it was early-onset dementia. However, she was still getting along by herself just fine. Later, in October, she tripped over a chair, fell and broke her arm. I took her to the urgent care clinic and then the orthopedic doctor and about 8 weeks later it had healed and she was fine, physically, that is. The only reason I mention this incident is because immediately following it, I noticed a significant reduction in her recall – she was having difficulty remembering things that had happened the day before and even the broken arm event itself.

Following her broken arm, her son arrived to help with her care and he noticed the memory problems, as well. After he departed, I started doing Robin's grocery shopping for her, taking her to doctors' appointments, etc. She continued to live on her own and was doing well.

Flash forward to September, 2016. I was volunteering at a large annual event when I saw Robin's caller ID come up on my cell phone around 12:30 pm. I answered, but I could only hear some faint moaning and something I thought was, ".....elp." I couldn't get Robin to respond, so I hung up, dialed her

landline and there was no answer. Then I tried her cell phone and there was no answer. I knew at that point something was wrong, so I immediately left the event and got to her house 10 minutes later. I unlocked the front door with my key, opened the door and saw her on the floor. As I had been trained, I checked the scene for dangerous/broken objects, obvious wounds/blood, etc. Everything was fine from that aspect, but her speech was slurred and she couldn't move her lower extremities and complained of pain in her left leg. She insisted that I get her on her feet so she could go to the bathroom and that I get her some water, but I refused both requests. From the slurred speech, I suspected a possible TIA or stroke which may have precipitated the fall and from her leg pain complaint, I suspected a broken femur or hip. She continued to demand action and became quite verbally adamant about it, if you know what I mean, but I declined and grabbed a couple of cushions off the couch, propped her up a little and stepped away and called the ambulance. The paramedics arrived and I gave them a brief assessment of the situation. They entered the house and one questioned Robin and put one finger on her left hip area, to which she responded, "OUCH!" and he simply responded, "You're going to the hospital." Robin continued to throw a fit, but didn't have much choice and the paramedics loaded her up in the ambulance. I instructed them to take her to the West-Central City Hospital nearby since I knew her primary care doctor was affiliated with the hospital and they would have all her records on the computer. But, I grabbed her purse anyway and headed to the ER.

X-rays in the ER confirmed the broken femur – a circumferential fracture on the ball that goes into the pelvis. She was eventually moved to a regular room upstairs to await surgery.

I made my way from ER to her room and when I got there, there were two young RN's questioning her about everything. I got in on the part of the conversation where Robin was telling them that she had fallen and broken her arm. The RN's were dutifully taking it all in. Robin is hearing impaired and didn't have her hearing aids in at the time, so I whispered under my breath to the RN's that she had dementia and it was a broken femur, not broken arm, which occurred last year. One of them exclaimed, "Ohhh, that explains a lot!" My point here is that since Robin's records were in the system, the diagnosis of dementia should've been quite prominent and these RN's should've known to be skeptical of anything Robin told them and that it might be incorrect. After I got everyone on the medical staff on the same page, everything was fine, or so I thought.

As I normally do in such situations, I review my client's medical records with the nursing staff to ensure that all the information is current and correct. During this process with Robin's files, we discovered that

her DNR (Do Not Resuscitate) order was not on file. Obviously, that is something very important that the hospital needed and should've had since it was on file with her doctor's office. I immediately went to her home and retrieved a copy and took it to the nurses' station for them to copy, scan in and place in her hard copy and digital files. Unfortunately, the nurse didn't know how to operate the printer to scale down a legal sized document, so I asked her where the central document office was and took it there to have them scan it in. When I arrived and explained the situation to the clerk, she informed me that she didn't know how to scan in documents, but she would make a copy and have someone help her do it later. I had to get back up to Robin's room so I left the clerk with a copy and crossed my fingers.

Back in Robin's room, I asked the nurse if Robin's admission status was as an in-patient or out-patient. At that time, she was an out-patient. I asked if that would be changed, since she was going to be there for more than 3 days and the nurse said that was up to the doctor. I told her that I wanted to make sure that Robin was listed as an in-patient so she could get her physical therapy and other rehabilitation services covered by Medicare. Eventually she was classified as an in-patient, as she rightfully should have been.

Robin was supposed to have surgery the next morning, but, due to a miscommunication between the two orthopedic surgeons on staff, neither was on-call – both thought the one was going to cover for the other, when in fact, that was not the case. Eventually the hospital got in touch with one of them and the surgery was scheduled for later that evening.

Later, around 5:00 pm In the pre-op room, the surgical nurse came in to do all the prep work and review the records. At that time, I double checked to see if the DNR had been placed in her file – it had not. Surprise, surprise!! She was obviously very concerned about that and ran out to the office area and pulled up Robin's file on the computer and the DNR had been added, but, a hard copy had not been inserted into her file. She was very appreciative of me bringing this to her attention, obviously. The anesthesiologist and surgeon eventually came in at separate times to discuss the procedure with us and they took Robin to surgery. All went very well with the surgery and Robin was back in her room, awake and talking about 3 hours after the surgery began.

The next day, I was visiting Robin and she was complaining about not getting any decent food – all fat and full of sodium. I thought that was odd since the hospital was known for their good food. I started looking around the room for a menu, but could find none and that was because there was no menu in her

room!! Keep in mind that when she was admitted, I told the admissions clerk that she had a very strict diet, commonly referred to as a “heart healthy” diet in medical facilities, and I wanted to make sure that everything she got was low fat and low sodium. I eventually got a nurse to get me a menu and helped Robin make several selections that were acceptable to her.

Robin’s son eventually arrived from out-of-town to assist.

Robin continued with in-hospital rehab for 4 more days and then was discharged to skilled nursing facility (SNF). Unfortunately, hospitals usually only give you 48 hours’ notice, at best, to find a place and make arrangements for the transfer. In our area, SNF bed space can be at a premium, so you may not be able to get into your preferred facility and you just have to take what you can get. Such was the case with Robin. Anytime a transfer like this occurs, paperwork has to be coordinated between the hospital and the SNF. Of course, the limiting factor here are personnel on both ends and how efficiently and accurately they do their jobs. Usually a family member has to ride herd on the whole process to keep everyone on track and on schedule and this was no different, but everything went relatively smoothly.

Robin arrived at the Shady Rest Skilled Nursing Facility (SNF) and Nursing Home. Of course, I was there to oversee the transition. We got her all settled in. The place had a stellar reputation in the community and even though it was a nursing home and really felt like it, I was confident that she would be well taken care of, or so I thought.....

Her son spent most of her waking hours with her at the SNF and I went about my other business. Eventually, the son had to leave, so I took over. One night around 9:30 pm, I got a call from Robin saying that she was stuck on the side of the bed, couldn’t get her other leg into bed, had to use the bathroom and no one came to answer the call light, which she had pressed 20 minutes earlier. She also said that she saw staff pass by her door and she called for help, but they just walked on by. Knowing about her dementia and how Sundowner’s can affect people, I wasn’t too concerned, but nevertheless, I got dressed immediately and drove to the SNF as quickly as I could. I was shocked to find Robin STILL sitting on the edge of her bed and the call light was still illuminated, so she had obviously pressed the button. Her voice was still quite strong and her bed was only about 7 feet from the entrance and immediately across the hall from the nurses’ station, so I know someone had to have heard her pleas for help, but did indeed ignore them. I found the nurse who called the aide and the aide reached in his pocket and pulled out the call light pager and exclaimed that he’d been having problems with it and that

was why he didn't see her call light. I suspect he either had it intentionally turned off, forgot to turn it on or failed to charge it.

After that incident, I knew I had to keep a much closer eye on Robin and the staff.

While we were there, her hospital records and doctor's instructions said that she was to see the surgeon again 10 days later for a follow-up examination. I called the doctor's office the day before to confirm and they told me that they had no record of Robin having any follow-up appointments scheduled. Since everything seemed to be going well otherwise, they waived the follow-up unless we thought it was absolutely necessary and no one thought it was.

2 days later, I got another call from Robin again around 9:30 pm. She said she was freezing cold and couldn't get anyone to answer the call light. Earlier in the day I had been there and made sure she had 6 blankets on her bed because she is always cold. Again, I got dressed and went up to the SNF and discovered that someone had left the air condition turned to its lowest temperature and highest fan setting. It was indeed freezing in her room and the call light was still illuminated. I fixed the A/C setting and reset the call light since I knew I'd get the same story as before. I didn't bother to speak to anyone about it because I knew the on-duty staff caused it and any complaining I would do to that shift would be pointless and they might have retaliated further against Robin, so once I got her settled back in, I left for the evening.

The next day when I went in, I was just about to walk in her room and I witnessed a nurse's aide slam Robin's food tray down very aggressively and I called her on it. She had an extremely thick African accent, so I could barely understand a word she was saying, but I could tell from the tone, timber, cadence and volume of her words and the expressions on her face that she was very angry about something. I explained to her that I couldn't understand her but whatever the problem was, there was no call for her to slam Robin's tray on the table nor raise her voice to me or Robin. She left in a huff and I called the two on-duty nurses and another aide to the room and was in the process of reading them about the whole situation regarding the three incidents and I was rather loud, but not profane, about it. Coincidentally, at the same time, the Administrator and Social Worker were coming down the hall and they promptly did an about face and left the area. At that point, I knew I had to get her out of there before she suffered some kind of catastrophic fall or contracted pneumonia.

I contacted a nearby community, Whispering Oaks, the one I really wanted her in to begin with, and thankfully, they did have an opening coming up. So, I shuttled between both SNFs and got all the staff on the same page and started getting the document shuffle in progress for the transition. Everything was going well at Whispering Oaks, but I had to constantly be in the social workers office at the Shady Rest SNF because she wasn't sending complete and correct paperwork to Whispering Oaks, and never did, but we eventually got Robin transferred.

The day before Robin was to be discharged to Whispering Oaks, I called Med-Trans to schedule transportation for her. I got everything scheduled for the next day, or so I thought. The next day I arrived an hour ahead of schedule to start getting Robin ready and pack up her belongings. When the time to leave came, I wheeled Robin out to the lobby and we waited for the Med-Trans, but after 15 minutes passed, it became apparent that something had happened. So, I called Med-Trans and they saw her name on the schedule, but apparently someone had forgotten to inform/schedule a driver. Fortunately, they were able to get someone there right away and took Robin to Whispering Oaks and they took very good care of her and she was later discharged to a memory care community where her recovery continued.

I think it goes without saying that I was extremely disappointed in the care we received at Shady Rest, but I didn't understand why as they had always had a stellar reputation in the community. I later found out that about a year prior, they had been sold to another company, but for some reason, they were allowed to keep the original name and therefore, the reputation. Interestingly, the company that purchased them has a very poor reputation in the community for their quality of care at their numerous other communities. Had I known who really owned Shady Rest from the outset, I would've never let Robin be placed there. Being the detective I am, I later discovered that the person who purchased Shady Rest had significant ties to an affiliate organization of the previous owners, so it all started to make sense at that point.

LESSONS LEARNED:

The lessons learned from Robin's ordeal are many:

First and foremost, everyone in **any** type of long-term care community needs not just an advocate, but someone who knows the system, knows how things should be operated and knows who to contact in the

event there are problems. And if you are the advocate, carry plenty of cards and make sure everyone involved with your client's care knows how to reach you and that they can contact you at any time with any questions. Usually, professional advocates/guardians/case managers have contracts with their clients, so it is important that the medical providers have a copy of your contract so they know that you are allowed to receive your client's medical information, etc., and that fact should be clearly spelled out in the contract, among other things.

If you are a single individual (and probably a good idea even if you have a spouse), you **must** do proper estate planning with both medical and financial PoA's and very careful thought must be given to whom you grant authority over you and make provisions for contingencies so someone or group of people can act on your behalf and take care of your affairs if you are unable to do so. Not having these in place can hinder your care and wind up costing you significant legal fees.

All your health records should be on file with your doctor(s) and the hospital, including PoA's, DNR's, Advance Health Care Directives, etc. Even if you **think** they are, double-check and make sure the front-line medical staff has all the current and accurate documents they need.

If possible, before being discharged to a SNF, research the ratings and reviews (survey results) for long term care communities with Medicare.gov and the respective city/county/state oversight authority, usually the State Department of Health and Human Services. It is usually very obvious which are the good ones and which are the bad ones.

Always call at least 24 hours in advance to confirm any appointments, tests, etc.

Pro Tip: No matter how bad the care is in a facility, **IF** your bills are currently being paid by Medicare, for example, after a qualified hospital stay and your transfer to a SNF, **do not** leave that facility without receiving proper authorization (official discharge or transfer from the medical provider who authorized and ordered your care at that facility). If you leave without being discharged or transferred properly, Medicare may hold you financially responsible for a significant portion of the medical fees related to that incident. Furthermore, if, for some reason, you have to receive additional care (hospitalization or rehab) for the same health issue, Medicare may not cover it. Be sure to discuss this with the facility social worker/discharge rep/authorizing doctor/physical therapist and Medicare. And contact the ombudsman if

you are not receiving care in a timely and appropriate fashion and have not received assistance from the facility's staff and management.

Finally **never, ever** underestimate the incompetence of “the system” as a whole. It will let you down almost every single time and more than likely, in multiple instances, so you must be prepared.

D. CASE STUDY: THE DISASTROUS EFFECTS OF NOT PLANNING AND NOT KNOWING **(AKA IGNORANCE)**

One day I was having a conversation with a friend and she was lamenting to me a terrible situation her friend, Louise, had found herself in. Louise was in her late 70's and still lived at home alone and had recently taken several falls and fortunately, no broken bones. Despite the pleadings from her daughter, Samantha, Louise refused to get one of those "fall alert" devices – oh no, she didn't need that, that was for old people!!

Well, the day came that Louise took another fall and landed in the hospital for several days and she had a UTI, sepsis and pressure (bed) sores on her lower extremities. After treating her, she was released to a SNF (sniff), or skilled nursing facility for rehab. The SNF they sent her to was all the way across town, a long way from where Samantha lived, and in a very bad area of town. The reason for this was availability of space and the fact that other places did not accept her Medicare supplement plan. I know most SNF's in the area, but I had never heard of this one. I checked nursing home ratings at Medicare.gov and the state health departments website's survey page and although both recognized the name of the facility, neither one had any documents available on the facility. At first I thought that was odd, but then I checked another website and found that the name of the place was just a "dba" (doing business as) and the actual name of the parent company was something else and was owned by an out-of-state entity. I searched for the parent company's name at both places again and nothing. I also checked the Secretary of State's website for business registration and it was current and reflected the parent company's name. Okay, so, I went to the County Assessors website and found that the place had been under another name two years ago. Now it all started to make sense – a change of ownership which was somewhat recent and that was why no documents were available under the new name. I checked the previous name at Medicare.gov and the state health department's website and it became crystal clear as to why the place went out of business. Now, that in no way necessarily meant the new owners operated the facility in a similar fashion.

Fast forward – Louise was transferred from the hospital to the SNF and Samantha reported that the place was absolutely horrible and they offered no wound care at all, but she didn't know what to do. Folks, let me tell you, pressure sores can rapidly get out of hand, become infected and create a septic condition in the body. If you don't know what sepsis is, it can rapidly create a life-threatening infection in one's body and cause death. Unfortunately, people (and especially the elderly) who have to spend even

a short amount of time in the hospital can develop these – as we age, our skin become thin and susceptible to tears, sores, etc. This is why I go into this in detail in **Section 9.b**. And I will re-emphasize here, anyone who cares for an elderly person needs to examine their skin over their entire body on at least a weekly basis to see if there is any evidence of these sores manifesting and bring it to the **immediate** attention of the Director of Nursing. Any place worth their salt should have very specific wound care protocols (ask) in place and a dedicated nurse who monitors and treats that condition – **it is that serious!!!**

Let's go back to the Medicare issue. When you are discharged from the hospital, if you are admitted as an in-patient for a designated period of time and have to be discharged to a SNF for rehab, Medicare will pay 100% for your stay up to 90 days. The key words there are “up to.” If the rehab staff determines that you have met the rehab goals and there is no possibility of you improving further, they must discharge you and my experience has been that you're very lucky if they give you more than 48 hours' notice of the pending discharge. Now, depending upon your health diagnosis, you may be discharged back to your home, or, your medical team may discharge you to an assisted living community or nursing home, again, depending upon your circumstances. Most assisted livings are private pay, so Medicare doesn't come into play here. Some nursing homes are private pay, but many accept Medicare as well and sometimes exclusively – it depends. Once you are notified of the discharge, you must find a place for the person to go, assuming they must go to some kind of long-term care setting. Usually, the SNF will help you find a place. However, in some cases, SNF's are located within nursing homes or CCRC's (continuing care retirement community) and, if space is available and if you so desire and the financing meets your needs, you can just move down the hall to another room with the appropriate level of care.

However, there are a couple of caveats here: Where you are eligible to go also depends upon what type of Medicare plan you have and which facilities take it – do you have the standard “Part A and Part B” and a Medicare supplement insurance plan to pick up what Medicare does not pay? Or do you have a Medicare Advantage plan or some other kind of Medicare alternative plan? If you have adequate funds and can pay the difference for what Medicare does not (usually an 80/20 split), then your options can be expanded, obviously. Or if you have some kind of long-term care insurance or similar plan to cover your long-term care costs, but for the purpose of this case study, we'll stick to Medicare.

Remember, just because the hospital discharges you to a particular SNF, it does not mean that you have no choice but to remain at that one – you can transfer to another. I advised Samantha that she should

immediately start calling around and trying to find a place for Louise in a different skilled nursing facility with a reputation for good care and I suggested a couple, since she didn't know and trying to make that kind of decision in an emergency is never good – you simply don't have time to “do your homework.” If you do make the choice to move, chances are you are going to have to “ride herd” on the transfer process. See the **Robin Fisher Broken Leg Case Study** in the previous section for more details about this.

Samantha said that she had a social worker helping her, which I thought was odd – so I asked, at the SNF? No, it was the social worker from the hospital. I explained to her, no, Louise is out of the hospital – this person has no obligation to further assist you, nor can she, really. To ensure Louise got as good a care as possible at the first SNF, I told her she should immediately contact the ombudsman for assistance – she had no idea what that was or how to contact them. I provided that information.

I also advised her she should contact at least a couple of hospice providers to come out and assess Louise to see if she was eligible for hospice or at least palliative care. Again, most people are unaware of the incredible service hospice can be in such circumstances and you do not have to be on death's doorstep to qualify for their assistance, which is 100% paid for by Medicare and you can have them when you are in a long-term care community. Be advised that if a person is on hospice, you must keep them apprised of everything and allow them to coordinate with the facility or you risk losing coverage for that incident or hospice care and you have to start over – it's a very tedious thing – just keep hospice informed.

What are the lessons here? Numerous!

Going back to **Section 2.**, you must, you **MUST** be realistic about your life situation and **plan** accordingly. I hate to project my judgement upon someone's situation, but after multiple falls, it is clear that Louise was long past the time where she should/could continue living alone. At the absolute very least, she should've purchased a fall-detecting device.

The need for long term care can strike anyone at any age. That need can arise out advanced age, disease, unexpected injury, or any other reason that can cause a permanently debilitating physical or mental condition that requires round-the-clock monitoring, assistance or medical care. I think the youngest person I saw in a nursing home was 21 years of age. He was an otherwise very healthy young

man who was trying to change a tire on a semi-truck when the tire exploded and put him in a permanent coma and on a ventilator and sadly, he never came out of the coma and passed a couple of years later. Another young man I saw was in his 50's and he was suffering from advanced stages of Alzheimer's Disease. (**Note:** *The earliest diagnosed case of AD was in a 17-year old young man according to [this CBS story](#)²³⁸.*) However, more often than not, though, it is the result of advanced age. Inasmuch, all of us, especially the children of elder parents, need to discuss their parent or parents' care and avail themselves of the information readily available to them from a variety of sources about long term care and prepare themselves for the eventful day which will come. If you've read this entire report, though, it is clearly obvious that the planning part is just one component – knowing who to call and what to do once that day arrives is a whole other story. Unfortunately, I have yet to see any family who does this.

As I've mentioned before, if you find yourself in a long-term care situation, you need a personal advocate to ensure that you get the care you need. Clearly, most of us are not nurse's aides, nurses or doctors, so we have to leave the health care up to those people who are. However, there are a few things we can look out for and bring them to the attention of the care staff, when needed. And if the resident doesn't get the attention required, we have to know the third parties to whom to turn to get assistance and those being the ombudsman, local health department, adult protective services, etc. I've been in multiple instances where I've had to tell nursing staff over and over and over about a problem before it got corrected. Sometimes I would correct it myself, if it was within my abilities.

SNF TRANSFER PROCESS:

This assumes you have found another location with space available to take the patient. At this point, you have already contacted them, apprised them of the situation, and are gathering the information they need to make the transfer.

Documents you will need to get from the primary facility's intake/discharge coordinator:

- Hospital records/doctor's orders
- List of medications
- Rehab plan and records of treatment thus far

²³⁸ <https://www.cbsnews.com/news/early-onset-alzheimers-on-the-rise/>

Other documents you may need:

- Powers of Attorney documents/contract authorizing you to act on behalf of the person or the person's written consent
- Patient's state-issued, valid (not expired) ID
- Patient's Medicare card or at least the number

I know what you're thinking – doesn't/shouldn't the primary facility take care of all this? To which I reply, HA! Not in my experience. You see, if you take a patient away from a facility, you are taking away a significant amount of income they will receive. Get the picture? Okay, so if you want to trust them to take care of this process, here's what happens: Maybe today or tomorrow or the next day, they will say that they faxed the info to the secondary facility and then the secondary facility will say they never received the documents. This is what I call the fax machine shuffle – it's a "he said, she said" kind of thing – you don't know what the case really is and meanwhile the clock has been ticking. Look, you don't have time for this kind of shenanigans and my experience has been the level of incompetence and foot dragging is epic at these places, so **you have to do all this yourself**. You will have to essentially follow the discharge coordinator to her office and wait for her to gather the documents, make copies and give them to you – make sure she knows you are waiting for them – this is sometimes the only way you can get them to move in any sort of expeditious fashion. So, with documents in hand, you head over to the secondary facility and hand them over to the intake coordinator.

At that point, they will start making arrangements to receive the patient. You may have to arrange a Med-Trans transportation for the patient. If you do, on the night before and on the morning of, be sure to call the transportation company to ensure that you are on their schedule. Yes, you have to ride herd on them, too, because I've had them drop the ball on me, twice.

Look, I know what you're thinking if you've read up all the way down to this point – is it really as bad as this guy is saying?? Well, I generally have a "glass 3/4 full" outlook, but in this case, it's the opposite. And I don't necessarily fault the people/staff at these places completely. Ever since Obama(Does Not)Care passed, the system has become **really** mucked up and significantly more expensive. We were warned about this and I've discussed it in previous sections here – the staff is just so overwhelmed with corporate, local, county, state, and federal compliance issues, paperwork, records-keeping, etc., that they just can't keep up with everything and quality of care ultimately suffers. I'm sad to say that I don't

have any expectations that anything will ever get any better because the issues I've discussed here doesn't affect our policymakers (politicians) because they have the money to pay for this kind of care privately, so it's no skin off their noses, sad to say. Most will never have to know firsthand the struggles the rest of us go through. Think about that next time you go to the ballot box and don't stop voting!!

E. WHY YOU NEED A LOCK BOX ON YOUR HOUSE

Over the years, I've had to assist friends and clients with personal emergency situations. Today, I want to address one step ALL of us can take to make the job of people like me and any other first responders MUCH easier and make your life much safer.

We never know when disaster will strike our lives. I've seen young couples in their 40's leave multiple children parent-less due to unexpected disease. I've seen a 21-year-old young man in a permanent coma and on a ventilator because of a truck tire that exploded while he was trying to change. I've seen young people also in their 40's and younger just drop due to undiagnosed heart conditions. And I've seen seniors have strokes and die or have their hips spontaneously break, leaving them completely incapacitated, or just fall and need assistance getting back up. And I know of one case where it took a lady fell, broke her hip and spent almost 2 days attempting to crawl to a phone (battery was dead) before someone noticed she was missing, couldn't reach her, and went to check on her. In another case, a friend had a stroke and when no one could reach her and no neighbors or friends had a key, the police were called to do a welfare check, but they declined to forcibly enter her home, even upon the insistence of her daughter in another state. Eventually the daughter had to drive 8 hours overnight, entered the residence with her key (the police still wouldn't enter) and she found her mother deceased. If the police ever refuse you, call the fire department.

What are a couple of strategies that could've been put in place that might have helped these people avoid these dire situations or at least better cope with them? A couple of things:

No matter what your age, see your primary care physician on a regular basis. Do what he or she tells you, get the appropriate inoculations and routine exams such as a heart scan, EKG, colonoscopy, and other gender-specific diagnostic tests/exams.

Get a fall alert device. Most smart wristwatches, like the Apple Watch, have this technology already built in. Or a less expensive, even better option that I like is the [Lively Medical Alert Mobile Plus emergency alert system](https://www.livelydirect.com/mobile-plus/alert-system)²³⁹, available at Best Buy, Walgreens, etc. – from the folks who bring you the Jitterbug phones. And program your smartphone with your ICE (In Case of Emergency) information – emergency responders know to check this.

²³⁹ <https://www.livelydirect.com/mobile-plus/>

Place a simple, inexpensive, Realtor-type lock box for your front door, such as the Masterlock 5400EC or equivalent. Amazon has many varieties for \$20 on up or you can get them at just about any hardware store. Yes, I know a lot of people have keypads on their garage doors to open them in case the battery in your car's remote fails, but when was the last time you tested that keypad to see if the battery was still good? Ah ha!! Okay, so if you change it regularly and have given a trusted individual the code, good. But, some (wise) people lock the door from the garage to the house (and everyone should). Have you hidden a key somewhere in the garage where your trusted individual can find it? Will they remember where it is? I think you see what I'm getting at here.

In many of these cases, such as with a heart attack or stroke, seconds count and the **IN**ability of emergency responders to access you as expeditiously as necessary can literally mean life or death. In several of the aforementioned instances, the affected individuals had not made arrangements for a trusted neighbor or relative living close by to have a key to their homes for just such an emergency.

So today, I'm asking everyone to find that trusted friend, neighbor, or relative and get them a key and emergency codes to your home. If you get the lockbox, program a code in that your trusted individual can easily remember and have them program it into their phone somewhere. If you don't have someone like that whom you can trust, at least put the lock box on your front door, call 911 and provide them with the code so in the event first responders do ever have to come to your aid, the 911 dispatcher can give them the code and they can get immediate access to and also avoid causing costly damage to your home and have to leave your home unsecured if they have to take you to the hospital.

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