SPECIAL REPORT:
LONG-TERM CARE FROM THE INSIDE OUT

Revised and Updated Frequently

September 5, 2018

This report, as well as others, are available for free in PDF format on the *Publications* page of Magnus Omnicorps' website.[1]

[1] http://www.magnusomnicorps.com/home.html

Disclaimer Summary: *The information in this publication was obtained from various sources. While it is believed to be reliable and accurate, Magnus Omnicorps, LLC does not warrant the accuracy or reliability of the information. This publication is for informational purposes only and is far from all-inclusive or a complete review of the topics discussed. These suggestions are not a complete list of every loss control measure. Use this information at your own risk and discretion. Magnus Omnicorps, LLC makes no guarantees of results from use of this information and assumes no liability in connection with the information nor the suggestions made.* ***The author is not an attorney and does not give legal advice.*** *If you need legal advice, contact a competent, licensed attorney who specializes in the area of law in which you need assistance.* ***The author is not a medical doctor or nurse and does not give medical advice.*** *If you need medical assistance, contact a licensed medical professional.*

See full Disclaimer at the end of this report.

Original Publication Date: August 16, 2018

Revision/Update Dates:

September 2, 2018
August 17, 27, 2018

TABLE OF CONTENTS

1. INTRODUCTION

Why this report? Because chances are that at some point in your life, you will have to deal with the long-term care industry either for yourself or for a loved one and most people have no idea what they will be getting into. 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.

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. 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 positons and have been a licensed administrator. Eventually, I became her caregiver until she passed recently.

Now, as a private detective, 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 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 printed media. 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.**

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 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.

2. FACING REALITY

Before I even get started, I want to address a very common factor in this subject: Denial. Yes, denial. As much as I am aware of it, I am still guilty of it – 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. 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 (unless an LPN first), if any, practical experience 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.

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? 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? 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 on.

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 has the cost. 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:

Independent Living: Essentially an apartment complex for seniors that also offers additional amenities such as regularly scheduled meals, transportation to shopping, community activities, barbershop, salon, business/computer center, activity rooms, etc. May or may not have on-sight offices for a home health care contractor who can provide residents with additional assistance. Usually not regulated by a state's department of health as are other communities.

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 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).

Assisted Living: A community where most residents are ambulatory, but need assistance with 1 or more daily living tasks such as dressing, bathing, personal hygiene, managing personal affairs, medication administration, transportation to appointments, regular meal preparation, etc. Levels of care available in assisted living communities can vary greatly 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.

Assisted Living Memory Care: Similar to assisted living, but with strict ingress and egress security and for those who suffer from dementia/memory issues. 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.

Skilled Nursing Facility (SNiF): Usually part of a long-term care nursing home, SNiF'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.

Long-Term Care: Also known as a "nursing home." In most areas, the highest level of long-term care provided. May or may not also provide long-term care for the memory-impaired.

CCRC: Continuing Care Retirement Community **(old term, now called Life Plan Community)**. Usually this means a community that provides all levels of care at one location, specifically, independent living, assisted living, assisted living-memory care, skilled nursing (SNiF – skilled nursing facility), long term care nursing, long term care nursing-memory care. Sometimes offer special "buy-in" or "life care" contracts that can help defer the high costs of long term care. More on that later.

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.

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 that can assist.

When it comes to Alzheimer's and dementia, check out these statistics from the Alzheimer's Association[2]:

[2] https://www.alz.org/facts/

Also, here is an excellent free report[3] from the Alzheimer's Association.

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 **a**ssistance with **d**aily **l**iving 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[4].*

According to the National Center for Assisted Living[5], 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[6]. [For residents who have been discharged, which includes many who have received short-term rehab care, the average stay in a nursing home (SNiF) 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 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.[7]*

The U.S. Department of Health and Human Services (DHHS)[8] says that approximately 70 percent of people over age 65 will require some degree of long-term care services during their lifetime.[9] 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

[3] https://www.alz.org/documents_custom/2017-facts-and-figures.pdf
[4] http://www.mylifesite.net/blog/post/so-ill-probably-need-long-term-care-but-for-how-long/
[5] https://www.ahcancal.org/ncal/resources/Pages/ResidentProfile.aspx
[6] http://www.longtermcarelink.net/eldercare/nursing_home.htm
[7] http://www.mylifesite.net/blog/post/so-ill-probably-need-long-term-care-but-for-how-long/
[8] http://longtermcare.gov/the-basics/how-much-care-will-you-need/
[9] http://longtermcare.gov/the-basics/how-much-care-will-you-need/

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.[10]"

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 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.

5. PLANNING & COSTS

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 SNiF or the onset of dementia or other memory issues that can affect your ability to make rational choices or provide for your own care. And relatives of such at-risk individuals need to be prepared when you receive "the call." 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 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," Americans are terrible about it. According to this August 9th, 2017 article in USA Today[11], we are only saving about 3.8% of their income and we are spending way more than we are earning. I recently attended a Money 101 seminar held by Five Rings Financial[12] and they had some interesting statistics on the state of savings and retirement in the U.S.:

- There is $10 trillion in U.S. accounts that is earning 1% (or less) interest. Factor in inflation and you are **losing** money.
- 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.
- 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[13] for great savings opportunities.)

[10] 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).

[11] https://www.usatoday.com/story/money/2017/08/09/americans-saving-less-income-lags-spending/549177001/

[12] https://www.fiveringsfinancial.com/

[13] http://www.magnusomnicorps.com/tip-of-the-day.html

- 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:

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[14]
65% of Americans save little or nothing – Bankrate, 3/15/2018[15]
Almost half of US families can't afford basics like rent and food – CNN Money, 5/17/2018[16]
40% of Americans can't cover a $400 emergency expense – CNN Money, 5/22/2018[17]
The World Isn't Prepared for Retirement – Bloomberg, 5/29/2018[18]
Americans Still Aren't Saving, Despite the Booming Economy, 6/19/2018[19]
More Americans are defaulting on their credit cards: analyst[20]
Study says older Americans going bankrupt more than ever, blames 'life in a risk society'[21]
(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[22] 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 stock broker):

AARP: How to Choose a Financial Planner[23]
U.S. Securities & Exchange Commission: Investment Advisers: What You Need to Know Before Choosing One[24]
U.S. Consumer Financial Protection Bureau: Know Your Financial Adviser[25]
Financial Industry Regulatory Authority (FINRA)[26]
Oklahoma Society of CPA's 2018 Financial Fitness Kit[27]

---

14 https://www.cnbc.com/2018/08/27/1-in-3-americans-have-less-than-5000-dollars-saved-for-retirement.html
15 https://www.cnbc.com/2018/03/15/bankrate-65-percent-of-americans-save-little-or-nothing.html
16 http://money.cnn.com/2018/05/17/news/economy/us-middle-class-basics-study/index.html
17 http://money.cnn.com/2018/05/22/pf/emergency-expenses-household-finances/index.html
18 https://www.bloomberg.com/news/articles/2018-05-29/the-world-isn-t-prepared-for-retirement
19 https://www.bloombergquint.com/onweb/2018/06/20/americans-still-aren-t-saving-despite-the-booming-economy
20 https://nypost.com/2018/08/11/more-americans-are-defaulting-on-their-credit-cards-analyst/
21 https://www.theblaze.com/news/2018/08/07/study-says-older-americans-going-bankrupt-more-than-ever-blames-life-in-a-risk-society
22 https://www.fool.com/saving/2016/10/03/heres-the-average-americans-savings-rate.aspx
23 https://www.aarp.org/money/investing/info-03-2012/two-sides-of-financial-planner.html
24 https://www.sec.gov/reportspubs/investor-publications/investorpubsinvadvisershtm.html
25 http://files.consumerfinance.gov/f/201311_cfpb_flyer_senior-financial-advisors.pdf
26 http://www.finra.org/
27 https://www.oscpa.com/writable/files/For_The_Public/2018-financialfitnesskit.pdf

Most people I run across 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 will pay for it.
2. I'll never need it; I'll die from something else like cancer or a heart attack.
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, it 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 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[28]
f. Qualify for the VA Aid & Attendance benefit program[29] (more info here)[30]
g. Are destitute and qualify for Medicaid

…, 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.

According to Genworth's Cost of Care Survey for 2016[31] costs can range from a (very) low of about $3,800 per month (rarely that low) for a private room in an assisted living to $7,700 or

[28] https://www.ltcfeds.com/
[29] https://www.benefits.va.gov/pension/aid_attendance_housebound.asp
[30] https://www.veteransaidbenefit.org/eligibility_aid_attendance_pension_benefit.htm
[31] https://www.genworth.com/about-us/industry-expertise/cost-of-care.html

more (usually more) per month for a skilled nursing (aka SNiF) 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, 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. 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 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 out, care at an assisted living community runs around $5 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. Just look at the folks in Puerto Rico after hurricane Maria in 2017, or states that fail to properly fund or administer their employees' pensions or companies that are mismanaged and cut promised benefits – the news is full of such stories. 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. 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." And don't forget the millions of illegal aliens who consume approximately

$116 billion (net) in taxpayer-funded social programs/services every year according to FAIR[32]. 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 have no choice but to eventually implement austerity measures – will **you** be ready for it?? I particularly like this quote: *"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:
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[33] 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[34]

The Blueprint to Age Your Way – Debbie Pearson, RN[35]

[32] https://www.fairus.org/issue/publications-resources/fiscal-burden-illegal-immigration-united-states-taxpayers
[33] http://www.nelf.org/find-a-cela/
[34] https://www.amazon.com/Age-Your-Way-Create-Unique/dp/0997853301
[35] https://www.amazon.com/Blueprint-Age-Your-Way/dp/099785331X

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 from any primary or supplemental policy carrier confirming that the policy will transfer before making a move to 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, 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 is ElderPeace Partners[36]. 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. 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.

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

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[37]

U.S. Dept. of Health & Human Services, Administration for Community Living[38]

A brief note on those celebrity advertisements you see on TV about community locater/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 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. 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. Caveat Emptor!

[36] http://www.elderpeace.com/
[37] http://www.n4a.org/
[38] http://www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx

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[39]. 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), 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 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 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.

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.

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 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 scope of the assisted living communities scope of care 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.

[39] https://www.medicare.gov/nursinghomecompare/search.html

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 sales person, but also be on the lookout for other things:

The Lease Contract:
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.

The particular areas you want to pay very close attention to are: 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 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 If you're an owner, corporate officer or administrator and that's 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!!" 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.

Contract options for these facilities vary greatly depending upon the level of services offered by the community. 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 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. Before you invest that kind of money in a community, I strongly suggest you research it well and have an attorney review the contract. 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, 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.

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 morals, values and work ethics (Oh, heaven

forbid!). 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 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 isn't necessarily better and higher fees don't necessarily translate into better care.

Also, staff licensure varies 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 worthless ones with a lot of fancy parchment hanging on the wall behind their desks and highly-polished chairs, if you know what I mean. Just look them up in LinkedIn to see how many jobs they've had in the past 5 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, 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. 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 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 have nurses on duty at all times, others are not. Ask. In some cases, even when state regulations do not require nurses on duty at all times, 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. 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? 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.

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[40]
Noffsinger v. SCC Niantic Operating Co.: What Does the Connecticut Ruling Mean for Employers?
Considerations for Employers as Medical Marijuana Approaches[41]
Employers Dropping Marijuana Tests[42]

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

[40] http://www.currentcompliance.org/2017/01/26/medical-marijuana-ada/
[41] https://www.law.com/thelegalintelligencer/sites/thelegalintelligencer/2017/11/14/considerations-for-employers-as-medical-marijuana-approaches/?slreturn=20180025231959
[42] 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

reports and other information on the impact of marijuana legalization in the state of Colorado[43] and this article: Marijuana Devastated Colorado; Don't Legalize it Nationally – USA Today, 8/7/2017[44]

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.

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 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.

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.

---

[43] http://www.rmhidta.org/default.aspx/MenuItemID/687/MenuGroup/RMHIDTAHome.htm?AspxAutoDetectCookieSupport=1

[44] https://usat.ly/2vHw0kJ

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 they do an initial assessment and get the prospect moved in, amazingly the next month they (new resident) requires 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.

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. 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 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 the 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.

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. 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. 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 opiod-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 the double check with the dispensing individual to ensure that the MAR (Medication Administration Record) has been updated accordingly.

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 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 have to 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[45] 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 if your loved one is still receiving important mail that their former residence.
- Lock credit files with the big 3 credit reporting agencies and the NCTUE[46]: Clark Howard's Credit Freeze Guide: The best way to protect yourself against identity theft[47]
- 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[48].
- Protecting Residents from Financial Exploitation: A Manual for Assisted Living and Nursing Home Facilities – U.S. Consumer Financial Protection Bureau[49]
- For even more information on protecting yourself from this type of crime, get my free, 64-page report[50] on identity theft, cyber-crime and fraud on the Publications page of my website.
- 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

[45] https://krebsonsecurity.com/2018/06/plant-your-flag-mark-your-territory/
[46] https://www.nctue.com/consumers
[47] https://clark.com/personal-finance-credit/credit-freeze-and-thaw-guide/
[48] https://www.identitytheft.gov/
[49] https://pueblo.gpo.gov/Publications/pdfs/6178.pdf
[50] http://www.magnusomnicorps.com/publications.html

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 ***"Special Report: Identity Theft, Financial Fraud & Cyber Crime – Problems, Solutions and Mitigation Strategies"*** on the Publications page of Magnus Omnicorps' website[51].

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.

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)[52]

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:

13 Guns Found in Home of 92-Year Old Mother Who Allegedly Killed Son Over Nursing Home Dispute – CBS News, 7/6/2018[53]

[51] http://www.magnusomnicorps.com/publications.html
[52] https://www.cms.gov/Medicare/New-Medicare-Card/index.html
[53] 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.

Again, if you have never been a caregiver, get ready for a very difficult, frustrating and stressful experience, especially if memory/dementia issues are involved. 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. 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. In our area, Sunbeam Family Services[54] has some great programs. **Please don't overlook this critical aspect of being a caregiver.**

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

[54] http://sunbeamfamilyservices.org/

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 family members 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 very 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:
When you or your loved one is 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. 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.

Unless the family or a friend is doing the resident's laundry, don't take expensive clothing – it **will** get ruined. 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.

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 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[55] 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 many times before. If for some reason your loved one seemingly goes bananas overnight, becomes uncharacteristically aggressive or has seizures, they may have a UTI. 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 common problem, leading to a misdiagnosis of the patient. 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 the arrange to bring them back from the hospital – it is all left up to the family. 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.

b. Skin: Another item to pay close attention to, especially if your loved one doesn't walk very much or is bed-ridden – 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.

[55] https://www.alz.org/help-support/caregiving/stages-behaviors/early-stage

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.

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.) 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. 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.

Related articles:
CDC's FAQ's on Bed Bugs[56]
Penn Study Shows Bed Bugs Can Transmit Parasite that Causes Chagas Disease[57]
Study Offers Further Evidence of Bed Bugs' Ability to Transmit Chagas Disease Pathogen[58]
PPMA Survey Highlights Bed Bug Prevelance Nationwide, 6-14-2018[59]
Orkin Releases New Top 50 Bed Bug Cities List, 1-12-2018[60]
Pest Control Professionals See Summer Spike in Bed Bug Calls, 6-4-2018 **(See InfoGraphic)**

[56] https://www.cdc.gov/parasites/bedbugs/faqs.html
[57] https://www.pennmedicine.org/news/news-releases/2014/november/penn-study-shows-bed-bugs-can
[58] https://entomologytoday.org/2018/01/30/study-further-evidence-bed-bugs-transmit-chagas-disease-pathogen/
[59] http://www.pctonline.com/article/ppma-survey-bed-bug/
[60] http://www.pctonline.com/article/orkin-top-50-bed-bug-list/

Bed Bug Treatment Site[61]

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 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." The following links explain the differences between hospice care and palliative care:

Hospice vs. Palliative Care – National Caregivers Library[62]

Palliative Care vs Hospice Care: A Quick Reference Guide by Vitas Healthcare[63]

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 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 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.

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, but if there are none in the room, they may just use the gloves or pull-up of the person on

[61] https://bedbugtreatmentsite.com/

[62] http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgrp-hospice/hospice-vs-palliative-care-article.aspx

[63] https://www.vitas.com/~/media/files/pdfs/palliative%20vs%20hospice%20care.ashx

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.

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. A funeral plan should be in place and contact information for clergy and the funeral home should be in the resident's file. 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:
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 HIPPA release forms with the respective medical service providers naming the caregiver.

Also, if your loved one has real estate or other real property in their name, 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 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 ID. 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 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 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[64] is going to be one of

[64] https://www.alz.org/

your best resource 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.

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! 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, NOW is the time to talk to your financial and legal professionals and family plan for these expenses. Start saving at the earliest possible time, even if it is only a few dollars per month.

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? Plan ahead!!

g. Selecting a long-term care community will be an exercise in compromise. Do your homework: Read community reviews, review state and federal official survey reports, research the backgrounds of the management staff. And remember, shiny and new 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. 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. 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.

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 you 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[65] to help your draw up these documents.

o. And don't forget to join that support group!! Do it NOW!!!

[65] 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[66]

Bank of America's U.S. Trust - Memory & Your Family - Capital Acumen, Spring 2015[67]

(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[68]

Caring for a Person with Alzheimer's Disease - Your Easy-to-Use Guide from the National Institute on Aging[69]

The Conversation Project website[70]

FamilyAffaires.com Guiding Families Through Life Changes[71]

InsureUOnline Special Section on Long Term Care Insurance[72]

Let's Talk: Starting the Conversation About Health, Legal, Financial and End-of-Life Issues guide[73]

myLifeSite[74]

Magnus Omnicorps' Helpful Info and Links page[75]

National Academy of Elder Law Attorneys[76]

National Elder Law Foundation[77]

---

66 https://www.alz.org/
67 http://www.ustrust.com/publish/ust/capitalacumen/spring2015/features/memory-and-your-family.html
68 http://www.cvcoa.org/assets/files/CalmBeforeTheStorm.pdf
69 https://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide
70 http://theconversationproject.org/
71 http://www.familyaffaires.com/
72 http://www.insureuonline.org/insureu_special_longtermcare.htm
73 http://www.n4a.org/files/Conversations.pdf
74 http://www.mylifesite.net/
75 http://www.magnusomnicorps.com/helpful-info---links.html
76 https://www.naela.org/
77 https://www.nelf.org/

National Caregivers Library[78]

Oklahoma Society of CPA's 2018 Financial Fitness Kit[79]

Senior Transitions of Edmond & OKC (specialized moving services for seniors)[80]

Oklahoma Resources:

Central Oklahoma Counties Senior Nutrition & Mobile Meal Programs[81]

Legal Aid Services of Oklahoma[82]

Legal Aid Services of Oklahoma- Senior Legal Help[83]

Medicare's Nursing Home Ratings[84]

Mobile Meals of Oklahoma County[85]

OKDHS Aging Services Publications[86]

OKDHS Guide - Nursing Home or Alternative Care in OK[87]

OKDHS Long Term Care Options and Resources[88]

OKDHS Long Term Care – Know Your Rights[89]

Oklahoma Assisted Living Association (OKALA)[90]

Oklahoma City/County Areawide Aging Agency[91]

---

[78] http://www.caregiverslibrary.org/home.aspx
[79] https://www.oscpa.com/writable/files/For_The_Public/2018-financialfitnesskit.pdf
[80] http://seniortransitionsokc.com/
[81] http://www.areawideaging.org/fundedprograms/nutritionprograms.html
[82] https://oklaw.org/
[83] http://www.legalaidok.org/senior-legal-help
[84] https://www.medicare.gov/nursinghomecompare/search.html
[85] https://www.211ok.org/locations/areawide-aging-agency-inc-479/mobile-meals-of-oklahoma-county-1
[86] 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%C7%82%C7%824167696e67%5C%22%22%5D%2C%22o%22%3A%22and%22%2C%22k%22%3Afalse%2C%22m%22%3Anull%7D%5D%7D
[87] http://www.okdhs.org/OKDHS%20Publication%20Library/87-83.pdf#search=nursing%20home
[88] http://www.okdhs.org/OKDHS%20Publication%20Library/15-52.pdf#search=nursing%20home
[89] http://www.okdhs.org/OKDHS%20Publication%20Library/86-58.pdf#search=nursing%20home
[90] https://okala.org/
[91] http://areawideaging.org/

Oklahoma City Community Foundation Oklahoma County Senior Nutrition Program[92]

Oklahoma County Senior Services[93]

Oklahoma Insurance Department – Regulated Industry Services[94]

Oklahoma Nurse Aide & Non-Technical Service Worker Registry (check to see if a person is on the registry)[95] DOH Full Page[96]

Oklahoma On Demand Court Records Search[97]

Oklahoma State Board of Examiners for Long Term Care Administrators (OSBELTCA)[98]

Oklahoma State Court Network Docket Search[99]

Oklahoma State Dept. of Health Nurse Aide and Nontechnical Services Worker Information[100]

Oklahoma State Dept. of Health, Protective Health Services Provider Survey/Inspection Search[101]

Oklahoma State Laws, Rules and Regulations governing long-term care facilities[102]

Oklahoma Board of Nursing - Nursing License Verification[103]

Oklahoma State Dept. of Health List of Nurse Aides with Disciplinary Flags/Convictions[104]

Oklahoma City Areawide Aging Agency Senior Resource Directory[105] (downloadable PDF)[106]

---

[92] https://occf.org/ocsnp/
[93] https://ariisp1.oklahomacounty.org/tga/SeniorCitizenResources/SeniorCitizenResourcesTxt.htm
[94] https://www.ok.gov/oid/Regulated_Entities/Regulated_Industry_Services/index.html#cemeteryforms
[95] https://www.phin.state.ok.us/NARSWBSearch/Views/LandingView.aspx?id=6202
[96] https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/index.html#NTSW
[97] http://www1.odcr.com/
[98] https://www.ok.gov/osbeltca/
[99] http://www.oscn.net/applications/oscn/casesearch.asp
[100] https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/
[101] https://surveys.health.ok.gov/
[102] http://www.ok.gov/health/Protective_Health/Long_Term_Care_Service/Rules,_Regulations_and_Statutes/
[103] https://apps.ok.gov/nursing/verify/index.php
[104] https://www.ok.gov/health/pub/wrapper/nrsaid.html
[105] http://www.areawideaging.org/
[106] http://www.areawideaging.org/images/2017_Resource_Directory_for_website_updated_March_2018.pdf

National & Federal Resources:

Centers for Medicare and Medicaid Services - Your Guide to Choosing a Nursing Home or Other Long Term Care[107]

Medicare.gov Long Term care page[108]

Medicare's Nursing Home Ratings[109]

National Adult Protective Services Association – Elder Financial Exploitation[110]

National Association for Area Agencies on Aging[111]

National Caregivers Library[112]

National Council on Aging – Elder Abuse Facts[113]

National Center on Elder Abuse[114]

Nursing Home Abuse Center[115] Statistics[116]

StopFraud.gov[117]

Senior Housing Crime Prevention Foundation[118]

U.S. Government's National Center on Elder Abuse[119] Statistics[120]

U.S. Dept. of Health & Human Services, Administration for Community Living[121]

U.S. Dept. of Health & Human Services Long Term Care Resources page[122]

---

[107] https://www.medicare.gov/Pubs/pdf/02174.pdf
[108] https://www.medicare.gov/coverage/long-term-care.html
[109] https://www.medicare.gov/nursinghomecompare/search.html
[110] http://www.napsa-now.org/policy-advocacy/exploitation/
[111] http://www.n4a.org/
[112] http://www.caregiverslibrary.org/home.aspx
[113] https://www.ncoa.org/public-policy-action/elder-justice/elder-abuse-facts/
[114] http://www.ncoa.org/public-policy-action/elder-justice/
[115] https://www.nursinghomeabusecenter.com/
[116] https://www.nursinghomeabusecenter.com/elder-abuse/statistics/
[117] https://www.stopfraud.gov/sf/elder-fraud-and-financial-exploitation
[118] http://shcpfoundation.org/
[119] https://ncea.acl.gov/
[120] https://ncea.acl.gov/whatwedo/research/statistics.html
[121] http://www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx
[122] https://www.hhs.gov/aging/long-term-care/index.html

U.S. Dept. of Health & Human Service Long Term Care website[123]

World Health Organization Elder Abuse Statistics, 6/8/2018[124]

Facility and Long Term Care Staff Records Research:

Medicare's Nursing Home Ratings[125]

Oklahoma Nurse Aide & Non-Technical Service Worker Registry (check to see if a person is on the registry)[126] DOH Full Page[127]

Oklahoma On Demand Court Records Search[128]

Oklahoma State Board of Examiners for Long Term Care Administrators (OSBELTCA)[129]

Oklahoma State Court Network Docket Search[130]

Oklahoma State Dept. of Health Nurse Aide and Nontechnical Services Worker Information[131]

Oklahoma State Dept. of Health, Protective Health Services Provider Survey/Inspection Search[132]

Oklahoma State Laws, Rules and Regulations governing long-term care facilities[133]

Oklahoma Board of Nursing - Nursing License Verification[134]

Oklahoma State Dept. of Health List of Nurse Aides with Disciplinary Flags/Convictions[135]

---

123 https://longtermcare.acl.gov/
124 http://www.who.int/news-room/fact-sheets/detail/elder-abuse
125 https://www.medicare.gov/nursinghomecompare/search.html
126 https://www.phin.state.ok.us/NARSWBSearch/Views/LandingView.aspx?id=6202
127 https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/index.html#NTSW
128 http://www1.odcr.com/
129 https://www.ok.gov/osbeltca/
130 http://www.oscn.net/applications/oscn/casesearch.asp
131 https://www.ok.gov/health/Protective_Health/Health_Resources_Development_Service/Nurse_Aide_and_Nontechnical_Services_Worker_Registry/
132 https://surveys.health.ok.gov/
133 http://www.ok.gov/health/Protective_Health/Long_Term_Care_Service/Rules,_Regulations_and_Statutes/
134 https://apps.ok.gov/nursing/verify/index.php
135 https://www.ok.gov/health/pub/wrapper/nrsaid.html

Full Legal Notice & Disclaimer:

The author is not an attorney and does not give legal advice. If you have questions of a legal nature, contact a licensed attorney who specializes in the area of law in which you have questions. The author is not a medical doctor or nurse and does not give medical advice. If you need medical assistance, contact a licensed medical professional.

Limit of Liability and Disclaimer of Warranty: Magnus Omnicorps, LLC has used its best efforts in preparing this publication and the information provided herein is provided "as is." Magnus Omnicorps, LLC shall in no event be liable for any direct, personal, commercial or otherwise, indirect, special, incidental, consequential or other losses or damages arising out of any use of this publication or the performance or implementation of the contents thereof. Magnus Omnicorps, LLC, makes no representation or warranties, expressed or implied, including, but not limited to, accuracy or completeness of the contents of this publication and specifically disclaims any implied warranties of merchantability or fitness for any particular purpose, non-infringement, or title, that the contents of the publication are suitable for any purpose, nor that the implementation of such contents will not infringe any third party patents, copyrights, trademarks, or other rights.

Please note that parts of this publication are based on personal experience and anecdotal evidence. Although Magnus Omnicorps, LLC has made every reasonable attempt to achieve complete accuracy of the content in this publication, it assumes no responsibility for errors or omissions. Also, you should use this information as you see fit, at your own discretion and at your own risk. Your particular situation may not be exactly suited to the examples illustrated here; in fact, it's likely that they won't be the same, and you should adjust your use of the information and recommendations accordingly.

Any trademarks, service marks, product names or named features are assumed to be the property of their respective owners, and are used only for reference. There is no implied endorsement if we use one of these terms.

Trademarks: This publication may identify product names and services known to be trademarks, registered trademarks, or service marks of their respective holders. They may be used throughout this publication in an editorial fashion only. In addition, terms suspected of being trademarks, registered trademarks, or service marks have been appropriately capitalized, although Magnus Omnicorps, LLC cannot attest to the accuracy of this information. Use of a term in this publication should not be regarded as affecting the validity of any trademark, registered trademark, or service mark. Magnus Omnicorps, LLC is not associated with any product or vendor mentioned in this book nor does it necessarily endorse its product(s) or service(s).

Finally, use your head. Nothing in this publication is intended to replace good sense, legal, medical or other professional advice, and is meant to inform and entertain the reader.

The name and trademarks of copyright holders, author and publisher may NOT be used in advertising or publicity pertaining to this document or its contents without specific, written prior permission. Title to copyright in this publication will at all times remain with copyright holders.

SHARING:

Unless this report was offered free-of-charge from my website, the following applies:

Much work that went into putting together this publication. I can't tell you how many hours were spent compiling it. That means that this information has value and your friends, neighbors, and co-workers may want to share it.

The information in this publication is copyrighted. I would ask that you do not share this information with others-you purchased this publication and you have a right to use it on your system. Another person who has not purchased this publication does not

have that right. It is the sales of this valuable information that makes the continued operation of Magnus Omnicorps, LLC possible. If enough people disregard that simple economic fact, these types of publications will no longer be viable or available.

If your friends think this information is valuable enough to ask you for it, they should think it is valuable enough to purchase on their own copies. After all, the price is low enough that just about anyone should be able to afford it.

In all cases, it should go without saying that you cannot post this publication or the information it contains on any electronic bulletin board, website, FTP site, newsgroup, etc. You get the idea. The only place from which this publication should be available is Magnus Omnicorps, LLC's website. If you want an original copy, visit Magnus Omnicorps, LLC at the following address: http://www.magnusomnicorps.com/