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PRESENTS

VITAL ELDER CARE RESOURCES™

by **Betthni Jiggs and LadyJaye**

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Knowing the immense responsibility it can become, and while the drama of such an undertaking in your life such as caring for your elderly parent(s) or other loved one(s) can seem insurmountable and complicated; our hope is that this booklet of vital resources will help lighten your load. With a combined total of decades of health care experience - and experiences - we at Spirit Wine Publications™ had become increasingly concerned at the lack of information and the difficulty in locating what was available. Constantly it resulted in tremendous burdens upon the families and care givers. Pooling our concerns and years of experience, then, this booklet was born in the hopes of relieving the stress, confusion, and frustration on those of you to whom the care giver charge has been given. We strove to cover all areas of needs for which you may be searching.

In the organization of this booklet of resources I was myself often overwhelmed with memories and the reality of my own inevitable destiny. With age 63 creeping up on me, making me about 20 years older than those around me and 20 years younger than most of the persons we are writing about, I feel like the center of a sandwich . . . hmmm, let's sugar-coat it a bit and I'll be the Oreo center, instead. I have been the Queen of Denial up until the writing of this book, but, funny, isn't it, how sometimes life 'just up and smacks ya' with reality when you least expect it!

And the truth of that hurts in more ways than one. Having been a Certified Nursing Aide and Home Health Care Aide off and on for a few decades, I was able to slide right into the new venture of this book. Of all the positions of employment I have held over half a century in the workforce, caring for the elderly has been by far my favorite, stopping me only occasionally because it was so hard on the joints; especially the elbows, feet, back, fingers, and . . . and . . . well, let's just say I hope I've given you a whole new appreciation for our nursing aides! They are the one person in your loved ones life that can care for them and fall in love with them as they are because they have no emotional baggage or history with them. In my experience, most residents of nursing homes have been long dismissed by their families, except on dutiful occasion. Understandably, and sadly, too many families are unable to cope emotionally with the steady and obvious decline of their loved one and find it difficult to make regular visits, especially when they are not recognized. Having gone through some tough times, myself, I often found myself crying with one or more of them at holidays, and then finding some way to cheer us both up again. I loved seeing their eyes sparkle and their smiles return! Indeed, I become emotional even now, at the dear faces flowing before my eyes as I write.

And I can attest to those in my circle not understanding why the body has to decline, while we still feel so mentally young and capable. I feel no different in my mind and heart than I did as a young adult. But, now that I have a four-year-old granddaughter who wants me to kick the soccer ball around with her, I find myself unfamiliar with what is happening to my entire body as I am trying to play out what my mind has been planning for years!

As I have been writing along on this book, my mind cannot help but personally recognize many of the symptoms the aging process has already begun taking on my body. (AHA, you see, there's still an element of denial, exposed by that word 'already'!) Truly, I had been believing I had about two more decades of 'youth' left in me and before my children have to begin watching over me a little closer. Truth is, I am already finding myself just wanting to tell them to back off. I'm learning – as an 'aged' – to be more cautious about the words I speak to them because they misunderstand and think the

worst about any little twinge I slip up and report. Looking through their eyes, though, as I write, I do understand what they must be feeling . . . but – shhh! – it only succeeds in making me even more cautious!

One of the most important things for me, as time has made me realize, is to keep my mind and time constructively busy. In that way, time passes delightfully; but when those little things show up that betray the body of memory, bringing to reality the slow decay of the human body just as surely as a ripening fruit, it sometimes is more emotionally difficult to deal with in the comparison. In those times, and I do not believe I am alone in this, my focus begins to stray to the negative of my future, to the picture of that ripening fruit, and what may lie ahead. If I don't stop that straying from the positive, my world becomes dark and foreboding . . . simply NOT part of who I am or how I choose to live out the rest of my life.

Fortunately, I am successful in abstaining from such debilitating mind-trips, but it gives me great compassion for those who have not been able to master the technique. It brings to mind all the tasks required of me as a CNA, caring for those elderly ladies who could not escape the constant reminders of their impending future. Though at the time I could not relate, I am so glad I was compassionate with them, because as I have matured I have come to understand the reality of 'you reap what you sow' and now I am right in line for the harvest.

That's what those of us who are Spirit Wine Publications jointly embrace about the life we live and what we did with it by the end. Some of us take a lifetime to understand life, but the important thing is that the closer we get to that meeting in Bliss, we've been able to make the paradigm shifts of the heart and soul required to get us through this last season on earth. I say this so you will perhaps understand a bit more of how important it is to have patience, perception, intuition, and compassion for the ones ending up in your care. Your decision to care for your parent(s) or other loved ones, no matter which direction you must take them, the 'caring' will NEVER go unrewarded . . . and your turn is coming.

Oooh yes, we all get our turn.

It is my fervent prayer that your heart can remain in delight of your new calling, or will grow to be so, and that when it is all over you will recognize it to be the most delightful experience of your life. That's really all that matters.

Shalom, dear ones.

Bethni Jiggs, your author.

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Disclaimer: Spirit Wine Publications™ is not responsible for any adverse activity resulting from any external links in this book. Information resulted from high integrity research, accepting each as legal and viable resources.

THANK YOU: To all custodians of each and every website whose hyperlink was utilized in this booklet of voluminous information and resources intended for the public to the benefit of those courageous care givers of the elderly and unwell.

~ Chapter One ~

Discuss Primary Care Giver First

The very first thing that should be done is that your parents need to designate one child or person who will be in charge of their care. Law-Glossary.com defines a primary care giver as the "person who is primarily responsible for looking after someone's health, safety and comfort." A primary care giver intervenes only when their charge cannot fully care for him/her self and may be a specified family member, a medical professional in a care facility, or a trained professional living outside the home. This person should be given a <u>durable power of attorney</u>, which includes financial power of attorney. (http://www.freedocumentbase.com/doc/durable-general-power-of-attorney-form) This website also includes a form for a <u>living will</u>:

If your parents do not have the financial means put away for their care, decisions need to be made as far as transferring any real estate and valuable possessions to the person who will be in charge of their care. Medicaid has a 'look back' period of five years which they use to determine if someone is eligible. So if you are able to plan ahead, now is the time! However, they will not collect from estates valued at under \$25,000 and no recovery would be sought while the spouse or certain dependents are still living. Likewise, you can petition for hardship exemption, which may be considered.

In planning ahead, it is also very important to obtain copies of any life insurance policies that your parents may have. Hind sight is always 20/20; no matter how difficult this subject is, it is always best to talk BEFORE something happens to those communication channels.

There are several websites that offer free information about estate planning. Two of those excellent site links are posted below and will provide instant answers to any question you may have:

Step by Step Guide to Estate Planning

(http://www.wills.about.com/od/preparingtodraftaplan/Step_by_Step_Guide_to_Estate_Planning.htm)

Durable Power of Attorney (http://www.freedocumentbase.com/doc/durable-general-power-of-attorney-form)

Powers of Attorney can be done by using programs on the internet. It is not necessary to spend hundreds of dollars in attorney's fees. One very important fact to note is that a power of attorney is no longer good after the person granting the power has passed away. So it is equally important that the executor's name be added to all accounts: checking, savings, CD's, mortgages, etc. You can file a copy of your power of attorney with the mortgage company and banking institutions; however, once death has occurred, they do not have to honor the power of attorney. If there is any real property, i.e. home, land, etc., you should make sure to file a deed of joint tenancy with right of survivorship. In other words, should death occur, the ownership automatically rolls over to the joint tenant. This will make things much easier in the long run. There are many websites that offer assistance with powers of attorney, including the options to purchase computer software that will enable you to complete the necessary documents. Here are two excellent sites to check out, if you choose to work on the internet: Rocket Lawyer (http://www.rocketlawyer.com) and Legacy Writer (http://www.legacywriter.com). For those less inclined, a 50-state list of Legal Aid can be found on Chapter Five.

When a crisis occurs, it is often difficult to obtain accurate or timely information. It is always better to have complete and accurate information and update it regularly while you still have that option. If you are reading this book, chances are you are already aware of changes that are affecting your

parent(s). Even if you are just starting to see little changes, it will seem that a lot is happening all at once. There are so many situations and variations that they would never be able to fit in any one book; but throughout this information our intention is to give you several broad – and most common – examples that may closely describe what you are experiencing.

Perhaps one or both of your parents or loved one seem to be having some difficulty with day-to-day functions, whether that would be hygiene, mobility, memory, prescription stability, or other. Too often, the spouse nobly takes up the position as care giver, not realizing the strain and stress hastening the decline of their own body.

Be prepared to meet much resistance when you attempt to step in and control the care of one or more of your parents or other elderly charge for which you may be responsible. It is not always possible to reason with them, especially when dementia is involved; as much as they want to make good decisions, sometimes it is just no longer possible. Work to make it a joint effort with them; respectively allow them as much dignity as they may need for as long as they are able; and compassionately keep in mind they are aware they will inevitably lose their battle for independence.

It becomes more difficult when things like incontinence, memory, and mobility become serious issues. I think this is truly the hardest part. It is demanded of you mentally, then, to make the leap at this point into the 'parent of your parent' role. Be assured that difficult moments pass more quickly if you can remain calm and try to stay pre-educated of those situations that may arise so you will be able to understand what is actually happening in any given difficult moment. Your must not take the behaviors of your charge personally or it will devastate you emotionally. In the greatest majority of situations, they are not aware of their actions.

While we have tons of information available at our fingertips on how to raise our children, as you can see there is very little instruction on how to 'parent a *parent*' or care for any elderly . . . *precisely, the inspiration for this book!*

~ Chapter Two ~

In-Home-Care

When trying to decide if in-home care would fit your parent(s) needs, there are several questions you need to ask yourself. First, remember this is a personal choice that the care giver has to make, depending on their own needs and abilities. Many will unquestionably make the decision to keep their loved one(s) at home until all resources have been exhausted. In this case, there may be some resource and moral support assistance available through the Administration on Aging, the NFCSP - National Family Care giver Support Program

(http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx). This program provides support and services to family care givers who are caring for persons 60 years old and older as well as grandparents who are raising their grandchildren full time. Some of the services provided are:

- Free information to care givers about available resources
- Assistance to care givers in accessing what services are needed
- Individual counseling, support groups, and/or care giver training
- Respite Care (either in-home, adult day care, or short-term in an institution)

If you do choose in-home care, your first concern is whether or not your parent(s) will even allow someone other than yourself to come into their home. You have to realize that for most aging adults this feels invasive and - again - they do not want to relinquish their independence. It is helpful to sit down and have a heart to heart talk with your parent(s) and explain to them your concern for their safety and well-being; this will more often than not ease their fears. Be aware that you may run into a complete road block where this is concerned and your parent may not be willing to budge. If the answer is an absolute 'No,' you may want to find out about adult day services in your area and, if you work, it would be helpful to check into adult day care facilities in your area where they could be dropped off and enjoy other activities and companionship for the day. This information can be found through your local senior citizen centers or online for your local Council on Aging (http://www.ncoa.org/).

Perhaps your loved one may be in a situation where they really only need someone to come in for a couple of hours each week to help with errands or housework. There are services available locally; check out Elder Care (http://www.eldercare.gov/) to locate services in your area.

For the safety of your loved one, we strongly recommend that you interview any potential care givers thoroughly. Be prepared to obtain at least 3 personal references and to check with those references. Be sure to also Google that person's name on the internet for any info 'hits' that might show up, as well as check on Facebook or Myspace to see what other information you might glean about the person. We also strongly recommend that you consider using a home health agency that actually provides training, supervision, and background checks for their employees, through the local Sheriff's Office. You'll also want confirmation that the agency you chose to deal with is insured and bonded.

When interviewing a potential care giver, there are signs to look for. We strongly recommend that your parent/loved one be present during the interview if at all possible. It is beneficial to your relationship, in easing them into this new 'chapter' in their lives, to encourage them to engage in questioning the potential care giver. Some of the questions that you will want to ask are:

- Have you ever cared for older adults before?
- What kind of clients have you cared for before?
- What made you decide to care for older adults or disabled persons?
- Has he/she received training in CPR or other healthcare procedures? (Get documented proof!)
- Does he/she have any specialties? (Copy of certifications!)
- How long has he/she worked at their current job? (Call them and confirm/get referral.)
- Try to find out if there is a history of this person switching agencies. (This can be done by online search of the CNA Registry (http://www.ncdhhs.gov/dhsr/hcpr/links.html). (All 50 states plus the District of Columbia have a Nurse Aide Registry. This list includes addresses and phone numbers for all of them, as well as links to online registries if available. The list was last double checked for accuracy in October 2010.)
- Confirm how many hours this person is willing to work? (and DAY or NIGHT?)
- Outline and discuss specific duties with the potential care giver. (Have a list for both of you, both copies initialed and dated by the care giver you choose.)
- Ask whether or not he/she has any questions for you or your relative about their care and what is expected?
- What is the expected salary? (Put it in writing.)

DO NOT BE TIMID about getting confirmations and documentations; you are letting this person into your home and turning your parent(s) care over to them . . . your parent(s), who are as helpless as an infant at this point. Always remember their vulnerability and fragility! 'Hindsight' in this case would be devastating and does happen; whether in the home or a facility, there is always the potential for elder abuse.

Also, while the potential care giver is answering questions, it is good to assess the person and note how he/she addresses you or your relative. Is he/she warm, well groomed, attentive, and happy?

Costs for in-home care are going to vary from state to state. You can contact your local Council on Aging or the <u>eldercare locator service</u> (http://www.eldercare.gov/) and ask what services may be available for your relative. Some of the services provided by these organizations are free, while others may depend on the resources of your parent or loved one, or on community-based waiver services.

~ Chapter Three ~ Assisted Living

Hard as you try, it is nearly impossible to convince an aging person that they can no longer do everything. When you look through their eyes, they truly believe they should be able to carry on as always.

Having been made aware of all this, please always remember to keep your parent's feelings in mind. Removing their every freedom can often do more harm than good. It is seldom possible to come to every decision without one or more of you feeling hurt and frustrated . . . you are trying to protect your parent and your parent is trying to protect their independence. Keep in mind that the tables have chronologically turned; you probably knew it was coming eventually, and now *they* are the 'rebellious child'!

When the leap is made to assisted living, there are many things for which to be prepared. The first is the adjustment period; most people take three to four weeks to make the adjustment. You more than likely will receive calls from your parents, wanting to come home. This experience can be compared to when we first have to leave our child at day care or the first day of school. In a word: heart - wrenching!

There is a great misunderstanding about assisted living facilities; that they are considerably more expensive than a nursing home. That is seldom the case, so be sure to add them to your list as you check out the many choices. Called Personal Care Homes, Group Homes, Senior Housing, Long-Term Facility, or by any other name, they each have their own specific qualifying criteria, but most are usually reasonably flexible in their requirements. Costs vary, also, and can reach to several thousand per month; however, if you shop around carefully, there are very nice facilities that can allow you to stay within your budget.

Per new laws, there are advocates for the older person, protecting them from being evicted because of declining health or mobility. When it comes to choosing assisted living facilities, one must be prepared to always 'think ahead.' If your charge is terminal and you know that his/her health is going to decline and the level of care is going to increase, confirm at the outset the facilities policy for tenancy in such cases. Moving your loved one from facility to facility is displacement and extremely traumatic and disorienting to an older person, threatening their emotional stability. So keep a mindset of choosing a place where your loved one can stay from the beginning to the end. Explore the laws in your state so you are prepared when interviewing for that perfect place. State Laws (via specific agency) and national survey of facilities: (https://aspe.hhs.gov/system/files/pdf/76086/sfconst.pdf)

(And don't forget your **Legal Aid** resource; we've listed all 50 states in Chapter Five.)

Every facility will most likely tell you that as the care for your loved one progresses, so likely will the cost. The majority of assisted living facilities are very willing to work with families and try to keep the cost within the guidelines of the person requiring the care and their budget. Choosing a place that is reasonably close to family and friends is also important, so visitations can take place at least weekly.

If you have a handful of places you are considering, visit them more than once. Just 'pop in' unannounced, wanting to 'see the facility'; you will more likely see the standard level of care, be able

to meet the staff, and see firsthand how they will be treating your loved one. Also, you want a facility that cares not only for your loved one, but cares enough to keep the facility in shape so it is safe for the residents, so be looking for signs of disrepair.

It is always a good idea to check with the <u>Better Business Bureau</u> (http://www.bbb.org/us/find-a-bbb/), a good resource, as well as your advocate and/or Ombudsman for recommendations of possible records of complaints. Do your research and homework on the facility; you'll have ten times the peace of mind for the time it takes to do this. If the assisted living facility is attached to a nursing home, be sure to include it in your research.

The National Center for Assisted Living (NCAL) recently compiled a summary of the assisted living regulations in all 50 states. *The Assisted Living State Regulatory Review* can be found at this web page (http://www.ahcancal.org/ncal/resources/Documents/2009_reg_review.pdf.) The Review noted that about one million Americans are now residents in assisted living facilities. Of those, about 115,000 received assistance from Medicaid programs in the various states. Until recently, there was little or no oversight for these homes. Unfortunately, while there are some federal laws which impact assisted living facilities, the primary responsibility is in the hands of state governments.

~ Chapter Four ~

Medicare and Medicaid

MEDICARE ELIGIBILITY: (http://www.medicare.gov/MedicareEligibility/)

Medicare is a federal health insurance program that serves people aged 65 and older, people under age 65 with certain disabilities, and people of all ages with end-stage renal disease.

Who administers Medicare plans?

Medicare Parts A and B (sometimes known as "Original Medicare") is run by the federal government. With Medicare Parts A and B, the government pays fees for your health care directly to the doctors and hospitals you visit.

Other types of Medicare plans, such as Medicare Part C (also known as Medicare Advantage), Medicare Supplement Insurance and prescription drug plans (Part D), are operated by private insurance companies that are contracted by the government. The government pays a fixed fee to your plan for your care, and your plan then pays your doctors and hospitals.

What are my Medicare coverage choices?

You can choose the type of Medicare plan you want, based on what's available in your area and your coverage needs. Here's an overview of what each coverage plan offers:

- Medicare Part A and Part B (sometimes known as "Original Medicare")
- Helps cover hospital stays, preventive care, doctor visits and other medical services.
- Run by the federal government.
- Can be paired with a Medicare Supplement Insurance plan to help pay your share of costs.
- Can be paired with a stand-alone prescription drug plan (Medicare Part D), to help pay for medications.

Medicare Part C (Medicare Advantage):

- Provides the same coverage and services as Medicare Parts A and B, often with additional benefits that vary by plan.

Some plans include Medicare Part D prescription drug coverage:

- Run by private insurance companies that are contracted by the government.
- Works similarly to an employer-sponsored health plan.

Medicare Part D (prescription drug plans):

- Helps cover the costs of your prescription drugs.
- Run by private insurance companies that are contracted by the government.
- Can be added to Medicare Parts A and B or a Medicare Advantage Private Fee-for-Service (PFFS) plan.

Medicare Supplement Insurance:

- Helps pay your cost of Medicare-covered services, such as copays and deductibles.

Some plans offer additional benefits not covered by Medicare Parts A and B.:

- Run by private insurance companies. These plans are regulated by the state in which you reside, and are not a benefit offered by the federal government.
- Can be added to Medicare Parts A and B.

A Medicare Advantage Plan (like an HMO or PPO) is another Medicare health plan choice you may have as part of Medicare. Medicare Advantage Plans, sometimes called "Part C" or "MA Plans," are offered by private companies approved by Medicare.

If you join a Medicare Advantage Plan, the plan will provide all of your Part A (Hospital Insurance) and Part B (Medical Insurance) coverage. Medicare Advantage Plans may offer extra coverage, such as vision, hearing, dental, and/or health and wellness programs. Most include Medicare prescription drug coverage (Part D).

Medicare pays a fixed amount for your care every month to the companies offering Medicare Advantage Plans. These companies must follow rules set by Medicare. However, each Medicare Advantage Plan can charge different out-of-pocket costs and have different rules for how you get services (like whether you need a referral to see a specialist or if you have to go to only doctors, facilities, or suppliers that belong to the plan for non emergency or non-urgent care). These rules can change each year. Your local Department of Children and Family Services can bring you up to date, help you determine if you qualify, and guide you to those local resources.

Help with Medicare and Drug Costs:

You may be eligible to <u>save money</u> (http://www.kyequaljustice.org/file/view/MSP+Webpage.pdf) on medical and drug costs with these programs:

Medicare Savings Program (SCAN Foundation)

(http://www.thescanfoundation.org/sites/default/files/scan_factsheet_17_medicare_savings_0_0.pdf)

Extra Help/Low-Income Subsidy (https://www.ehealthmedicare.com/medicare-part-d-prescription/low-income-subsidy/)

State Pharmaceutical Assistance Program (SPAP)

(http://www.xmarks.com/s/site/www.medicare.gov/navigation/medicare-basics/medical-and-drug-costs.aspx)

<u>Good Rx – (Coupons and discounts)</u> (https://www.goodrx.com/?gclid=EAlalQobChMl09OC9pjG1QIVDYl-Ch2YygZMEAMYAiAAEgldgvD_BwE)

PACE (https://www.medicare.gov/your-medicare-costs/help-paying-costs/pace/pace.html)

Medicaid (www.BenefitsCheckUp.org)

MEDICAID, the nation's largest health coverage program, covers nearly 60 million low-income individuals, including children and families, people with disabilities, and seniors who are also covered by Medicare. Indigent clients – that is, a person who needs Hospice care but has no insurance at all -across the country, can discuss their options with their local Hospice agency.

To help you see if you may be eligible for a variety of governmental programs, you may want to access the GovBenefits (http://www.benefits.gov/benefits/browse-by-state) and BenefitsCheckUp (http://www.benefitscheckup.org/) websites. Check it out, the information on these sites is great and may surprise you by their comprehensive list of qualifiers!

~ Chapter Five ~

Legal Aid - All 50 States

This is a list of **Legal Aid** sites for all 50 states and the District of Columbia. You do NOT have to break your meager budget on attorney's fees, should you need legal advice on benefits; each state has their forms listed *for your FREE download and use*.

Follow their instructions carefully, making sure to keep at least two or three original copies for yourself and making copies for those places that will take them, as some will not require an original.

For free legal aid referrals and information, choose your state:

Alabama, Alaska, Arizona, Arkansas

California, Colorado, Connecticut, Delaware

Florida, Georgia, Guam, Hawaii

Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana

Maine, Maryland, Massachusetts, Minnesota

Mississippi, Missouri, Montana

Nebraska, Nevada, New Hampshire, New Jersey

New York, North Dakota, North Carolina

Oregon, Ohio, Oklahoma, Pennsylvania, Puerto Rico, Rhode Island

South Carolina, South Dakota

Tennessee, Texas, Utah, Vermont, Virgin Islands, Virginia

Washington, Washington D.C., West Virginia, Wisconsin, Wyoming

~ Chapter Six ~

Common & Little-Known VITAL Benefits

Military Benefits:

If either of your parents served in the military, it is very important that you obtain copies of their military service records or discharge papers. The discharge papers are important and show the dates of service, which is very important when trying to determine if they are eligible for additional benefits due to their service. You can take those records along with your parent to any local Veterans Administration Office and they will be able to tell you if any benefits are available.

Another excellent resource for veterans is <u>Veterans Benefits</u> (http://www.ebenefits.va.gov) and it will allow you to browse benefits and tell you exactly what you qualify for, both you and your family.

American Indian Benefits:

This website will answer questions regarding qualified benefits for the American Indian senior citizens, as well as direct you to your individual Tribe's information:

Elder Care Initiative Long-Term Care Grant Program – 2010 (http://www.ihs.gov/)

Each Tribe has its requirements and qualifications, should you want to apply for membership to their Tribe. For more on American Indian Benefits, <u>click here</u> (http://www.ihs.gov/)

Minorities Benefits:

This <u>fact sheet</u> examines Medicaid's role for <u>Black Americans</u> – as of May 2011. It includes data on Medicaid's coverage of black Americans and the program's impact on their access to care, as well as the impacts of the recent recession and the coming expansion of Medicaid under health reform on enrollment in Medicaid among Black Americans. The fact sheet also has a chart showing state-by-state data on health insurance coverage of Black Americans.

(NOTE: It is a PDF file, requiring Adobe on your computer and sometimes takes a few minutes to download; OR you can call your local library and ask them to print it out for you – they charge a per page fee – from web address http://www.kff.org/medicaid/8188.cfm)

This <u>fact sheet</u> examines Medicaid's role for <u>Hispanic Americans</u> – as of May 2011. It includes data on Medicaid's coverage of Hispanic Americans and the program's impact on their access to care, as well as the impacts of the recent recession and the coming expansion of Medicaid under health reform on enrollment in Medicaid among Hispanic Americans. The fact sheet also has a chart showing state-by-state data on health insurance coverage of Hispanic Americans.

(NOTE: It is a PDF file, requiring Adobe on your computer and sometimes takes a few minutes to download; OR you can call your local library and ask them to print it out for you – they charge a per page fee – from web address http://www.kff.org/medicaid/8189.cfm.)

There are so few <u>Asian-Americans/Pacific Islanders</u> in available statistics, that benefits are generally subject to individual qualifications and state-to-state requirements. Contact your state's <u>Office of Minority Health (http://www.minorityhealth.hhs.gov/templates/browse.aspx?lvl=3&lvlid=200)</u>.

For more information on State Health facts, click here: <u>State Health Facts</u> (http://www.statehealthfacts.org/profile.jsp)

Alzheimer Benefits:

An unbiased source of information on Alzheimer's Disease is <u>ADEAR</u> - Alzheimer's Disease Education and Referral (http://www.nia.nih.gov/alzheimers). The Alzheimer's Disease Education and Referral (ADEAR) Center Web site will help you find current, comprehensive Alzheimer's disease (AD) information and resources from the National Institute on Aging (NIA). The Department of Health and Human Services also offers comprehensive information for seniors including news, benefits and government programs on this site.

<u>Cancer Information</u> - Accurate, up-to-date, comprehensive cancer information (http://www.cancer.gov/) can be found from the U.S. government's principal agency for cancer research.

<u>Disability.Gov</u> (http://www.disability.gov/home/i_want_to/disability_benefits/where_to_look_on_disability.gov) provides a number of ways to find information about Social Security disability benefits and other benefit programs for people with disabilities. You can start by learning 'where to look' on the Disability.Gov website or select one of the links below for more information about each topic:

Social Security's Disability Programs (https://www.ssa.gov/OP_Home/handbook/handbook.html)

<u>Social Security Administration's Definition of Disabled</u> (https://ssabest.benefits.gov/benefits/benefit-details/4382?_ga=2.95117852.184128752.1502146720-67488718.1502146720)

Applying for Benefits (https://www.benefits.gov/benefits/browse-by-category/13

Children's Benefits (https://www.benefits.gov/benefits/browse-by-category/category/13)

Reporting Disability Benefits Fraud (https://www.justice.gov/actioncenter/submit-complaint)

Benefits for Veterans & Service Members (https://www.benefits.gov/benefits/browse-by-category/category/13)

Other Benefits Programs (https://www.acl.gov/programs)

FDA: (Info for future planning, health issues, etc.)

A listing of articles, brochures, and other publications of general interest to seniors, can be found on this Food and Drug Administration site. Explore it closely; it can assist in early planning. (http://www.fda.gov/oc/seniors)

Community Care Service Program:

For the functionally impaired and meeting Medicaid requirements, this program sets up Meals on Wheels, Adult Day Health, Alternative Living Services, Respite Care, and other services.

Contact your local AAA – <u>Area Agency on Aging</u> (http://www.n4a.org/about-n4a/?fa=aaa-title-VI). Recuperating services are also available through this organization, paid for Medicare, Medicaid, or private insurance.

<u>Senior Citizens' Resources</u>: Find government resources for seniors, on money, housing, health, consumer protection, and more: (https://www.usa.gov/topics)

<u>Care Givers' Resources</u>: (http://www.usa.gov/Citizen/Topics/Health/caregivers.shtml) Help providing care, benefits, long-distance care giving, legal matters, support for care givers.

<u>Consumer Protection for Seniors</u>: (http://www.usa.gov/Topics/Seniors/Consumer.shtml) Consumer fraud, elder rights, advocates for nursing home residents.

<u>Education, Jobs, and Volunteerism for Seniors</u>: (http://www.usa.gov/Topics/Seniors/Education.shtml) Adult education, AARP working options, Senior Corps.

End-of-Life Issues:

(https://webarchive.library.unt.edu/eot2008/20081103234437/http://www.usa.gov/Topics/Seniors/EndofLife.shtml)
Advance directives, estate planning, hospice.

<u>Federal and State Agencies for Seniors</u>: (https://www.usa.gov/topics) Administration on Aging, Social Security Administration, Veterans' Health Administration.

<u>Grandparents Raising Grandchildren</u>: (http://www.usa.gov/Topics/Grandparents.shtml) Benefits and assistance, health and safety, state resources.

<u>Health for Seniors</u> (http://www.usa.gov/Topics/Seniors/Health.shtml) Disease, health care facilities, Medicare, nutrition.

<u>Housing for Seniors</u> (http://www.usa.gov/Topics/Seniors/Housing.shtml) Reverse mortgages, in-home help, nursing home comparison, and more.

<u>Laws and Regulations Concerning Seniors</u> (http://www.usa.gov/Topics/Seniors/Laws.shtml) Age Discrimination in Employment Act, Medicare Modernization Act, Social Security Act.

<u>Money and Taxes for Seniors</u> (http://www.usa.gov/Topics/Seniors/Taxes.shtml) Investing, tax counseling, estate planning.

<u>Retirement</u> (http://www.usa.gov/Topics/Seniors/Retirement.shtml) Pension plans, benefits calculator, retirement ages.

<u>Travel and Recreation for Seniors</u> (http://www.usa.gov/Topics/Seniors/Travel.shtml) Amtrak senior discount, older drivers, travel tips.

Elder Abuse:

The National Center on Elder Abuse (NCEA – FAQ's), directed by the U.S. Administration on Aging, is committed to helping national, state, and local partners in the field be fully prepared to ensure that older Americans will live with dignity, integrity, independence, and without abuse, neglect, and exploitation. The NCEA is a resource for policy makers, social service and health care practitioners, the justice system, researchers, advocates, and families. (https://ncea.acl.gov/)

Senior Citizens 60+:

This easy-to-use website features basic health and wellness information for older adults from the National Institutes of Health: (http://www.nihseniorhealth.gov/)

Exercise and Physical Activity

Topics A-Z

Healthy Aging

Diseases and Conditions

Memory and Mental Health

Bones and Joints

This tool has detailed information about every Medicare- and Medicaid-certified nursing home in the country. Before you get started, though, you or your family member may have other long-term care choices like community-based services, home care, or assisted living depending on your needs and resources. For more information, see Alternatives to Nursing Homes (http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteriaNEW.asp)

Otherwise, follow these steps when choosing a nursing home:

Step 1: Find nursing homes in your area. Search by name, city, county, state, or ZIP code.

Step 2: Compare the quality of the nursing homes you're considering using the 5-Star Quality Ratings, health inspection results, nursing home staff data, quality measures, and fire safety inspection results.

Step 3: Visit the nursing homes you're considering or have someone visit for you. Use the Nursing Home Checklist and other resources under "Additional Information" below.

Step 4: Choose the nursing home that best meets your needs. Talk to your doctor or other healthcare practitioner, your family, friends, or others about your nursing home choices. Contact the Long-Term Ombudsman (list on Chapter 8) or State Survey Agency for a referral before you make a decision.

Be aware that if you come up against a nursing home that claims not to have any Medicaid nursing home beds available, but that it does have private pay beds available, it is against the law for Medicare to discriminate based on source of payment. It is hard for the state to regulate that sort of situation, but it should be reported to your local Ombudsman, who will investigate.

Social Security Resources/Disability:

It is nearly impossible to get someone on the phone at Social Security, so you may not want to waste time even trying. Everything can be done online or, better yet, visit the Social Security office nearest you. It has been my experience that the office visit is much quicker and takes a LOT less patience.

Social Security office locator (https://secure.ssa.gov/ICON/main.jsp)

Get Extra Help with Medicare prescription drug costs (http://www.ssa.gov/prescriptionhelp/)

More Long-term care info:

A <u>clearinghouse of information</u> (http://www.eldercare.gov/), nationally; information for FUTURE long-term planning . . . what's available; how to plan; average cost per state; how to find the services; etc . . . a wonderful tool!

AARP (Medicare Plans from United Health Care):

<u>AARP Health Centers link</u> (http://www.aarpmedicareplans.com/) provides helpful information on over 1,000 of the most common diseases and conditions, as well as providing up-to-date information on the following:

Cancer

Care Giving

Diseases & Conditions

Symptoms

Treatments

Prescription Drug Tools:

A-Z Drug Directory

Drug Interactions

Pill Finder

Diabetes

Emotional Health

Falls Prevention

Fitness

Find a health program that is right for you:

Health Management Program

Health Risk Assessment

Health Calculators and Quizzes

AARP can help select a plan that may fit you perfectly; OR call 1.855.229. 9068 for help in selecting. It also has a link for 'understanding Medicare.'

Your Medicine: Be Smart. Be Safe: (http://www.ahrq.gov/consumer/safemeds/yourmeds.htm)

You can learn more about how to take medicines safely by reading this guide. It answers common questions about getting and taking medicines and has handy forms that will help you keep track of information. Keep this guide with your medicines in case you have any questions, concerns, or worries. (Use the Wallet Card at the end of that site.)

This guide was developed by the Agency for Healthcare Research and Quality (AHRQ) and the National Council on Patient Information and Education (NCPIE).

ADULT DAY CARE:

It works just like a day care for a child: they are dropped off in the morning; they provided meals and snack; entertainment and recreation; and picked up by you at the end of the work day. Most facilities function during normal business hours, but some can be found that provide this service for the evening.

Basically, not all states regulate adult day care centers, so you want to be extremely cautious to investigate the centers in your area, get recommendations and referral from others/families receiving care at that facility, and talk with the staff. Cost can vary greatly, from about \$25 per day to \$125 per day, depending on what kind of service it is, the needs of client, and even geographic location. It is not normally covered by Medicare, but there are federal and state financial assistant programs for this service. Both the OAA and the VA have programs in place to help cover adult day care costs. (http://www.aoa.gov/aoaroot/aoa_programs/oaa/index.aspx) and (http://www.ebenefits.va.gov/)

The best way to discover what you may qualify for is to contact the Administration on Aging at 1-800-677-1116, or the National Adult Day Care Services Association - NADSA - at 1-866-890-7357, or go to their website to explore the enormous amount of information available to you, as far what to look for and what's available to you for financial assistance. (http://www.nadsa.org/) and OAA (http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx)

OAA :(https://fas.org/sgp/crs/misc/RL33880.pdf)

The **Older Americans Act of 1965** was the first federal level initiative aimed at providing comprehensive services for older adults. It created the National Aging Network comprising the Administration on Aging on the federal level, State Units on Aging, and Area Agencies on Aging at the local level. The network provides funding - based primarily on the percentage of an area's population 60 and older - for nutrition and supportive home and community-based services, disease prevention/health promotion services, elder rights programs, the National Family Care giver Support Program, and the Native American Care giver Support Program. In 2006 congress reauthorized the Act in its entirety, effective now through FY 2011.

The OAA was passed as a part of Lyndon Johnson's Great Society reforms. It followed closely behind the Civil Rights Act and the Economic Opportunity Act which included many similarly structured programs, based around a centralized network of funding for a decentralized (community level) service delivery system. The OAA was a response to Congressional concerns about the lack of community social services for senior citizens.

Funding for many Great Society programs as well as Johnson's political capital, dwindled during the Vietnam War. Some programs and agencies were dismantled by later administrations, such as

Nixon's and Ford's slow dissolution of the Office of Economic Opportunity. Other programs, such as those under the OAA, Medicare, Medicaid, and initiatives in the arts and humanities continue to survive.

The stated purpose of the OAA is to ensure equal opportunity to the fair and free enjoyment of:

- Adequate income in retirement;
- The best possible physical and mental health services without regard to economic status;
- Suitable housing;
- Restorative and long term care;
- Opportunity for employment;
- Retirement in health, honor, and dignity;
- Civic, cultural, educational and recreational participation and contribution;
- Efficient community services:
- Immediate benefit from proven research knowledge;
- Freedom, independence, and the exercise of self determination;
- Protection against abuse, neglect, and exploitation.

Headed by the US Administration on Aging, OAA - The National Aging Network — established this network of state and federal agencies to plan and provide services that enable older adults to live independently in their homes and community. The network includes 56 state agencies on aging; 620 Area Agencies on Aging; 246 Native American Aging Programs; over 20,000 service providers; and thousands of volunteers, just to name a few of these advantages. Some of the services that are available through this Older Americans Act of 1965 is:

- Adult day care (offers supervision in a protective setting to people who cannot be left alone during the day because of healthcare, social needs, or disability)
- Care giver programs (includes support groups for care givers and also for grandparents who are raising grandchildren)
- Case managers (work with the family and older adults to evaluate and be supportive to the seniors and their families so they can try to remain independent)
- Elder abuse prevention program
- Financial assistance (local area agencies work with the elderly and their families to see if they are eligible for any financial assistance)
- Home Health Services are included in this Act (wound cleansing, providing feeding tubes, cleaning catheters, etc.)
- Home repair program (to help the elder people to keep their housing in good repair: patch a leaky roof, fix faulty plumbing, etc)
- Home modification program (helps to put in wheel chair ramps, new railings on steps, for safety and security, etc)
- Specialists available for financial consultation and evaluation of needs
- Legal assistance (includes a legal advice representative, etc, for anyone 60 and older; advice on tenant rights, consumer problems, etc.)
- Nutrition services (Meals On Wheels, etc.)
- Personal care (daily duties such as bathing, grooming, etc.)
- Aging services (respite, Hospice, volunteers, etc)

- Housing programs (helps discuss and research housing options, etc)
- Special senior social programs
- Transportation services (to get to doctor's appointments, etc.)

This is a phenomenal resource for you, so take time to explore within the entire site; we have barely touched upon the advantages of this program.

Aging and Disability Resource Center (ADRC): (ftp://ftp.tjcog.org/pub/aging/tjaaa/Updated Info J/Fiscal Monitoring first package/1. Region J AAA Policy and Procedure Manual/Section 2/AgingNetwork_Structure_Program.pdf). The US Administration Resource Center and Centers for Medicare and Medicaid Services streamlines access for long-term care, a bit like a 'one-stop-shop' for local communities that help older adults. The ADRC program provides states with an opportunity to effectively integrate the full range of long-term supports and services into a single, coordinated system. By simplifying access to long-term care systems, ADRCs and other single point of entry (SEP) systems are serving as the cornerstone for long-term care reform in many states. Access this site – it will allow you to check your local community for what's available – or call 1-800-677-1116. It's also located in the elder care website, in the aging and disability resource centers. (http://www.eldercare.gov/)

~ Chapter Seven ~

Your Ombudsman - Your Best Friend!

An Ombudsman is a person who acts as a trusted intermediary between an organization and some internal or external constituency while representing not only - but mostly - the broad scope of constituent interest. The Office of the State Long-Term Care Ombudsman seeks to improve the quality of life for residents of long-term care facilities (nursing homes, intermediate care facilities for the mentally retarded, personal care homes, and community living arrangements). The State Office certifies and trains community Ombudsman who work to resolve concerns of long-term care facility residents statewide. We emphasize residents' wishes in assisting to resolve problems. This link lists the Ombudsman in all 50 states and other countries

(https://www.longtermcarelink.net/eldercare/ref_ombudsman.htm), OR:

(If your state, or all its information, is not listed it is because they have not registered or perhaps chanaged. Remind them.)

Alabama: Virginia Moore-Bell, State LTC Ombudsman AL Dept. of Senior Services, 770 Washington Avenue, RSA Plaza, Suite 470, Montgomery, AL 36130; Tel: (334)242-5770 Fax: (334)353-8467; http://www.ageline.net

Alaska: Robert Dreyer, State LTC Ombudsman, Office of the State, LTC Ombudsman, AK Mental Health Trust Auth. 3745 Community Park Loop, Suite 200, Anchorage, AK 99508 Tel: (907)334-4480 Fax: (907)334-4486 http://www.akoltco.org

Arizona: Jan Cardoza, State LTC Ombudsman, AZ Aging & Adult Administration, 1789 West Jefferson 2SW 950A Phoenix, AZ 85007 Tel: (602)542-6454 Fax: (602)542-6575 http://www.de.state.az.us/aaa/programs/ombudsman/default.asp

Arkansas: Kathie Gately, State LTC Ombudsman, State LTC Ombudsman, AR Division of Aging & Adult Services P.O.B. 1437 Slot 1437 Little Rock, AR 72203 Tel: (501)682-8952

California: Joe Rodrigues, State LTC Ombudsman, CA Department on Aging, 1300 National Drive, Suite 200 Sacramento, CA 95834 Tel: (916)419-7510 Fax: (916)928-2503 http://www.aging.ca.gov/html/programs/ombudsman.html

Colorado: Shelley Hitt, State LTC Ombudsman, The Legal Center, 455 Sherman Street Suite 130, Denver, CO 80203 Tel: (800)288-1376 ext. 217 Fax: (303)722-0720 http://www.thelegalcenter.org/services_older.html

Connecticut: Nancy Shaffer, State LTC Ombudsman, Office of the State LTC Ombudsman, CT Department of Social Services, 25 Sigourney Street, 12th Floor Hartford, CT 06106-5033 Tel: (860)424-5238 Fax: (860)424-4808 http://www.ltcop.state.ct.us/

Delaware: Victor Orija, State LTC Ombudsman, Division of Services for Aging & Adults, 1901 North Dupont Highway, Main Admin. Bldg. Annex, New Castle, DE 19720 Tel: (302)255-9390 Fax: (302)255-4445 http://www.dsaapd.com/ltcop.html

District of Columbia: Gerald Kasunic, State LTC Ombudsman, Legal Counsel for the Elderly, 601 E Street, N.W., A7-500 Washington, DC 20049 Tel: (202)434-2140 Fax: (202)434-6595 http://www.aarp.org/Articles/a2003-05-08-lce-longtermcare.htm

Florida: Brian Lee, State LTC Ombudsman, Department of Elder Affairs, Florida State LTC Ombudsman Council 4040 Esplanade Way, Tallahassee, FL 32399 Tel: (888)831-0404 Fax: (850)414-2377 http://www.myflorida.com/ombudsman

Georgia: Becky Kurtz, State LTC Ombudsman, Office of the State LTCO, 2 Peachtree Street, NW 9th Floor, Atlanta, GA 30303-3142 Tel: (888)454-5826 Fax: (404)463-8384 http://www.georgiaombudsman.org/about_program.asp

Guam: Evelyn Cruz, State LTC Ombudsman, Division of Senior Citizens, Guam DPHSS PO Box 2816, Hagatna, GU 96932 Tel: (671)735-7382 ext.5 Fax: (671)735-7416

Hawaii: John McDermott, State LTC Ombudsman, Executive Office on Aging, 250 South Hotel Street Suite 406, Honolulu, HI 96813-2831 Tel: (808)586-0100 Fax: (808)586-0185 http://www2.state.hi.us/eoa/

Idaho: Cathy Hart, State LTC Ombudsman, Idaho Commission on Aging, P.O. Box 83720, 3380 American Terr., Suite 120 Boise, ID 83720Tel: 208-334-3833 Fax: 208-334-3033 http://www.idahoaging.com/programs/ps_ombuds.htm

Illinois: Sally Petrone, State LTC Ombudsman, Illinois Department on Aging, 421 East Capitol Avenue Suite 100, Springfield, IL 62701-1789 Tel: (217)785-3143 Fax: (217)524-9644 http://www.state.il.us/aging

Indiana: Arlene Franklin, State LTC Ombudsman, Indiana Division Disabilities\Rehab Services, 402 W. Washington St., Room W 454, PO Box 7083, Indianapolis, IN 46207-7083 Tel: (800)622-4484 Fax: (317)232-7867

Iowa: Jeanne Yordi, State LTC Ombudsman, Iowa Department of Elder Affairs, Jessie M. Parker Building Suite 2, Des Moines, IA 50319 Tel: (515)725-3327 Fax: (515)242-3300 http://www.state.ia.us/elderaffairs/

Kansas: Gilbert Cruz, State LTC Ombudsman, Office of the State LTC Ombudsman, 900 SW Jackson Street Suite 1041, Topeka, KS 66612 Tel: (877) 662-8362 Fax: (785)296-3916 http://www.kansasombudsman.gov

Kentucky: Jane Chapman, Interim State LTC Ombudsman, Office of The Ombudsman, Eastern Region LTCOP, 1844 Carter Avenue Frankfort, KY 40621 Tel: (606) 776-0384 Fax: (606) 920-2026 http://www.cfc.ky.gov/agencies/ombudsman

Louisiana: Linda Sadden, State LTC Ombudsman, Office of Elderly Affairs, 412 N. 4th Street, 3rd Floor, P.O. Box 61 Baton Rouge, LA 70821 Tel: (866)632-0922 Fax: (225)342-7144 http://www.lousiana.gov/elderlyaffairs/LTC ombudsman.html

Maine: Brenda Gallant, State LTC Ombudsman, Maine LTC Ombudsman Program, 1 Weston Court, P.O. Box 128 Augusta, ME 04332 Tel: (207)621-1079 Fax: (207)621-0509 http://www.maineombudsman.org

Maryland: Alice H. Hedt, State LTC Ombudsman, State LTC Ombudsman, Maryland Department of Aging, 301 W. Preston Street, Room 1007, Baltimore, MD 21201 Tel: (410)767-1067 Fax: (410)333-7943 http://www.mdoa.state.md.us/Services/Ombudsman.html

Massachusetts: Mary McKenna, State LTC Ombudsman, Massachusetts Exec Office of Elder Affairs, 1 Ashburton Place, 5th Floor, Boston, MA 02108-1518 Tel: (617)727-7750 Fax: (617)727-9368 http://www.mass.gov

Michigan: Sarah Slocum, State LTC Ombudsman, Michigan Office of Services to the Aging, 7109 West Saginaw, P.O. Box 30676 Lansing, MI 48909 Tel: (517)335-1560 Fax: (517)373-4092

Minnesota: Deb Holtz, State LTC Ombudsman, Office of Ombudsman for Older Minnesotans, P.O. Box 64971, St. Paul, MN 55164-0971 Tel: (651)431-2604 Fax: (651)431-7452 http://www.mn.aging.org/admin/ooom.htm

Mississippi: Anniece McLemore, State LTC Ombudsman, MS Dept. of Human Services, Div. of Aging, 750 North State Street, Jackson, MS 39202 Tel: (601)359-4927 Fax: (601)359-9664 http://www.mdhs.state.ms.us

Missouri: Carol Scott, State LTC Ombudsman, Department of Health & Senior Services, P.O. Box 570, 2023 St. Mary's Blvd., Jefferson City, MO 65102 Tel: (800)309-3282 Fax: (573)751-6499 http://www.dhss.mo.gov/Ombudsman/

Montana: Kelly Moorse, State LTC Ombudsman, MT Dept. of Health & Human Services, P.O. Box 4210 111 N. Sanders, Helena, MT 59604 Tel: (406) 444-7785 Fax: (406)444-7743 http://www.dphhs.state.mt.us/sitc/index.htm

Nebraska: Patty Pierson, State LTC Ombudsman, Division of Aging Services, P.O. Box 95026, Lincoln, NE 68509-5044 Tel: (402)471-2307 Fax: (402)471-4619 http://www.hhs.state.ne.us/ags/itcombud.htm

Nevada: Teresa Stricker, State LTC Ombudsman, Nevada Division for Aging Services, 1860 E. Sahara Avenue Las Vegas, NV 89104 Tel: (702) 486-3081 Fax: (702) 486-3572 http://www.nvaging.net/ltc.htm

New Hampshire: Don Rabun, State LTC Ombudsman, NH LTC Ombudsman Program, 129 Pleasant Street, Concord, NH 03301 Tel: 603.271.4704 Fax: 603-271-5574 http://www.dhhs.state.nh.us/DHHD/BEAS/ltc-ombudsman.htm

New Jersey: Debra Branch, State LTC Ombudsman, Office of Ombudsman for Institutionalized, P.O. Box 807, Trenton, NJ 08625 Tel: (609)943-3451 Fax: (609)943-3479 http://www.state.nj.us/health/senior/sa_ombd.htm

New Mexico: Sondra Everhart, State LTC Ombudsman, New Mexico Aging & LTC Services Department, 2550 Cerrillos Road, Santa Fe, NM 87505 Tel: 505-476-4790 http://www.nmaging.state.nm.us/vlunteer.html#ombuds

New York: Mark Miller, State LTC Ombudsman, New York State Office for the Aging, 2 Empire State Plaza, Agency Building #2, Albany, NY 12223 Tel: (518)474-8718 Fax: (518)474-7761 http://www.ombudsman.state.ny.us

North Carolina: Sharon Wilder, State LTC Ombudsman, North Carolina Division of Aging & Adult Services, 2101 Mail Service Center, Room 307, Raleigh, NC 27699-2101 Tel: (919)733-8395 ext. 227 Fax: (919)715-0364 http://www.dhhs.state.nc.us/aging/ombud.htm

North Dakota: Helen Funk, State LTC Ombudsman, Long Term Care Ombudsman Prog. Aging Services Division, 1237 West Divide Avenue, Suite 6, Bismarck, ND 58501 Tel: (800)451-8693 Fax: (701)328-8744 http://www.nd.gov/humanservices/services/adultsaging/ombudsman.html

Ohio: Beverley Laubert, State LTC Ombudsman, Ohio Department of Aging, 50 W Broad Street, 9th Floor, Columbus, OH 43215-3363 Tel: (800)282-1206 Fax: (614)644-5201 http://www.goldenbuckeye.com

Oklahoma: Esther Houser, State LTC Ombudsman, Long Term Care Ombudsman Prog., DHS Aging Services Division, 2401 N.W. 23rd Street, Suite 40, Oklahoma City, OK 73107 Tel: (405)521-6734 Fax: (405)522-6739

Oregon: Mary Jaeger, State LTC Ombudsman, Oregon Office of the LTC Ombudsman, 3855 Wolverine NE, Suite 6, Salem, OR 97305-1251 Tel: (800) 522-2602 Fax: (503)373-0852 http://www.oregon.gov/ltco

Pennsylvania: Wilmarie Gonzalez, State LTC Ombudsman, Penn. Dept of Aging, 555 Walnut Street, 5th Floor, PO Box 1089, Harrisburg, PA 17101 Tel: 717-783-7096 Fax: 717-772-3382 http://www.aging.state.pa.us/aging

Puerto Rico: Dania Vazquez, Diaz State LTC Ombudsman, Puerto Rico Governor's Office of Elder Affairs, PO Box 191179, San Juan, PR 00919 Tel: (787)725-1515 Fax: (787)721-6510

Rhode Island: Roberta Hawkins, State LTC Ombudsman, Alliance for Better Long Term Care, 422 Post Road, Suite 204, Warwick, RI 02888 Tel: (401)785-3340 Fax: (401)785-3391 http://www.stateomb@alliancebltc.org

South Carolina: Dale Watson, State LTC Ombudsman, Governor's Office on Aging, 1301 Gervais Street, Suite 200, Columbia, SC 29201 Tel: (803)734-9898 Fax: (803)734-9986 http://www.aging.sc.gov

South Dakota: Jeff Askew, State LTC Ombudsman, Department of Social Services, SD Office of Adult Services & Aging, 700 Governors Drive Pierre, SD 57501-2291 Tel: (605)773-3656 Fax: (605)773-6834 http://www.state.sd.us/social/ASA/services/ombudsman.htm

Tennessee: Jerry Blasingame, State LTC Ombudsman, TN Commission on Aging and Disability, Andrew Jackson Bldg., 500 Deaderick Street, Ste. 825, Nashville, TN 37243 Tel: (615)741-2056 Fax: (615)741-3309 http://www.state.tn.us/comaging/ombudsman.html

Texas: Patty Ducayet, State LTC Ombudsman, Center for Consumer and External Affairs, Texas Department on Aging, P.O. Box 149030, Austin, TX 78714 Tel: (512)438-4356 Fax: (512)438-3233 http://www.dads.state.tx.us/news info/ombudsman/index.html

Utah: Daniel Musto, State LTC Ombudsman, Department of Human Services, Utah Division of Aging & Adult Services, 120 North, 200 West, Room 325, Salt Lake City, UT 84103 Tel: (801)538-3924 Fax: (801)538-4395 http://www.hsdaas.utah.gov/ltco.htm

Vermont: Jacqueline Majoros, State LTC Ombudsman, Vermont Legal Aid, Inc., 264 N. Winooski Avenue, P.O. Box 1367, Burlington, VT 05402 Tel: 802-863-5620 Fax: (802)863-7152 http://www.akoltco.org

Virginia: Joani Latimer, State LTC Ombudsman, VA Association of Area Agencies on Aging, 24 E Cary Street, Suite 100, Richmond, VA 23219 Tel: (804)565-1600 Fax: (804)644-5640 http://www.vaaaa.org

Washington: Louise Ryan, State LTC Ombudsman, State LTC Ombudsman Prog., So. King Co. Multi-Srvc Ctr, 1200 So. 336th Street, P.O. Box 23699, Federal Way, WA 98093 Tel: (800)422-1384 http://www.ltcop.org/index.htm

West Virginia: Suzanne Messenger, State LTC Ombudsman, Aging & Disability Resource Center, 9541 Middletown Mall, Fairmont, WV 26554 Tel: 800-834-0598 http://www.state.wv.us/zseniorwv.us/seniorservices/

Wisconsin: Heather Bruemmer, State LTC Ombudsman, Wisconsin Board on Aging & Long Term Care, 1402 Pankratz Street, Ste 111, Madison, WI 53704 Tel: 608-246-7014 Fax: 608-246-7001 http://www.longtermcare.state.wi.us

Wyoming: Deborah Alden, State LTC Ombudsman, Wyoming Senior Citizens, Inc, 865 Gilchrist, P.O. Box 94 Wheatland, WY 82201 Tel: (307)322-5553 Fax: (307)322-3283

~ Chapter Eight ~ End-Of-Life Care

HOSPICE:

The Hospice philosophy is to allow all persons end-of-life care in many different settings.

Hospice agencies provide symptom and pain management to terminally ill individuals and emotional, spiritual, and bereavement support to the individual and family, in the home or places of permanent or temporary residence.

Hospice Agencies are licensed by the state to provide care within the minimum health and safety standards established by statute and rule. Hospice services may also include the provision of home health or home care services. The Department of Health enforces the standards by periodically conducting unannounced surveys of these agencies.

Medicare may pay for services provided by Hospice Agencies who voluntarily seek and are approved for certification by the federal Health and Human Services Centers for Medicare and Medicaid Services (CMS). CMS contracts with the Department of Health, Facilities and Services Licensing to evaluate compliance with the federal hospice regulations by periodically conducting unannounced surveys of these agencies.

To be qualified for Hospice services, a person must be referred by a doctor believing that the person's disease or illness would likely runs its natural course within 6 months. That doesn't mean that if the timeline is extended beyond 6 months, the Hospice service ends; it just means that every re-certification period, usually through Medicare every 90 days, some indication of continued decline is noted. Generally, loss of weight, mental decline, and other obvious symptoms are present in the client to secure the continuity of Hospice services. Any in-stage organ disease, from the brain to the toes, can make a person eligible for Hospice care; it is not just for cancer.

Hospice services are available 24-hours a day and seven days a week; the client's call results in a timely response. Generally, your doctor's office or hospital will have a contact number for your local Hospice agency, to initiate contact and solicit a visit from Hospice to determine eligibility. In most situations, Medicare pays 100% for Hospice care that is related to the Hospice diagnosis. Hospice care can be facilitated through several different settings, with a favored approach to the home setting. There is a whole team of Hospice staff to work with each client: the doctor – most often, the clients doctor is able to be retained; nurses; volunteer coordinator; social worker; home health aide – to help with daily care and light housework, as needed; and a chaplain, if the client desires. The person in charge of this team is always the client, making the decisions for his own care.

Once a client has been diagnosed and receiving Hospice care, all services and needs for that diagnosed illness will be covered; it does NOT, however, pay for services and needs for a secondary illness – i.e., diagnosed terminal with lung cancer, yet living with diabetes: only the lung cancer is covered by Hospice services. It is important to get the client into Hospice care as early as possible, in order to more effectively manage the clients symptoms. Sometimes a client will improve under the Hospice care and graduate from their services . . . a special feather in the Hospice cap! If their health declines later, they may opt to use the Hospice services again.

Some clients are in nursing homes, with Hospice care, and get the majority of their care from the nursing home personnel, but with the backup of the Hospice services. The same thing applies in Hospice care through an assisted living facility, hospitals, and those who are in Alzheimer units and not able to be home by themselves.

The nation's largest health coverage program, Medicaid, covers nearly 60 million low-income individuals, including children and families, people with disabilities, and seniors who are also covered by Medicare. Indigent clients across the country – that is, a person who needs Hospice care but has no insurance at all - can discuss their options with their local Hospice agency. If the Hospice agency is certified and qualified under the state guidelines, Medicaid generally follows their guidance in the decision-making regarding caring for the indigent clientele. It is not a practice of Hospice to refuse care due to lack of finances; their philosophy is the SANCTITY of life – anyone's life.

A myth about Hospice care has been that a client has to be a 'DNR': 'Do Not Resuscitate' – or 'AND': Allow Natural Death - but that is not true. Many clients have not come to that decision, yet, and should a heart attack or other issue arise, they would want to be resuscitated. Another myth about Hospice is that they 'hasten death.' That is the complete opposite of the truth: Hospice is about the sanctity of life and allowing the client to live as fully and as comfortably as they can, despite their illness.

There are very few 'residential' Hospice facilities, where the client may live as though in their own home, but is Hospice-run. These facilities are funded as non-profits, usually through church ministries. You can inquire about this type of facility through your local Hospice agency. There are other Hospice facilities; however, that contract with the Hospice agency and where the client may go if in crisis at home, such as pain. They retain their Hospice nurses, but would be in the facility for a period of five to seven days, until the client is stabilized and can be returned back home, if possible. Often they must make the move to a long-term care facility, such as a nursing home or assisted living.

Hospice educates the client and family continually, from the first day, to prepare them emotionally. Upon a client's death, the family does not have to call 911 or any other emergency service, but simply calls the Hospice nurse, who comes to the home or facility to make the official pronouncement of death. The nurse then makes the calls for the family and stays with them until the funeral home director arrives. It is a very calm and peaceful procedure, maintaining the dignity and care of the family and the client's body.

LOCATE A HOSPICE AGENCY NEAR YOU

(http://www.nahcagencylocator.com/index.asp)

~ Chapter Nine ~

Care Giver Support, In-Home or Facility

There are tax benefits for care givers. If you pay over 10% of the support for an older adult you may be eligible for tax deductions. There are also deductions for qualifying relatives; go to care giver deductions to see if you qualify for the <u>deductions</u>.

(http://www.irs.gov/publications/p17/ch03.html#en us 2010 publink1000170857)

It will be greatly beneficial to you to quickly identify your local support services. A great way to do this is by going to the eldercare website (http://www.eldercare.gov/), an excellent resource which also covers these matters:

Aging Organizations

Care Giving

Disease Specific Organizations

Elder Rights

End of Life

General Health Resources

Housing & Living Options

Mental Health

Also, locate your local respite care providers at <u>National Respite Care</u> Network & Resource Center or you can also call 1-800-473-1727 for more information. (http://www.archrespite.org/)

It is imperative that you make connections with other people and share your experience. Doing so will reduce your feelings of stress and will also help you to overcome the feelings of being overwhelmed by the task at hand. It is vital to your own well-being to find someone you can talk to about your feelings in this new sojourn. You may find that connection in friends, clergy, or other family members.

Take extra good care of yourself! Both your mental and physical health are very important, in this chapter of your life especially. It is extremely important that you eat right, exercise, and get as much rest as possible . . . and find time at least once a week to do that something you love, just for you!

Another great resource for care givers is the FREE Medicare bi-monthly newsletter
(https://www.medicare.gov/Publications/Search/Search/SearchCriteria.asp?version=default&browser=Firefox%7C54%7CWinNT&Language=English&pagelist=Home&comingFrom=13) which gives valuable medical updates, stories, and videos that can help you deal with your care giving responsibilities. They also allow you to ask questions online that may be answered in their newsletter as well as in direct REPLY to you.

It is true that the very best resource for support comes from other care givers or people that have 'been there, done that.' It is very hard to put into words the feelings that arise from care giving: there are both the wonderful feelings of fulfillment and then there are the awful feelings of guilt and inadequacy . . . that great 'emotional roller coaster' that has hit us all! It is a genuine relief to find out you are normal, whatever you are feeling, and that there are thousands of people who have gone through this before and thousands of people who know just what you are going through right now! So, take heart, you are in great company and we're here for you.

Care giving can cause an unbelievable strain within families. It is imperative that you all realize you are on this journey together. The burden should never fall on any one person. If you don't have any options in the way of family support, I urge you to reach out to your church family or your local community for a support group; even check with your Chamber of Commerce, who may be able to lead you to a support group. The help is there, all you have to do is ask. Pride has no place in the life of a care giver; it will only keep you from getting the relief you so desperately need.

ADULT DAY CARE: If you, as the care giver, have a full or part time job and cannot find a service to come into the home to sit with your charge while you are at work, adult day care is a viable option. Be sure to take advantage of this service for your own occasional respite.

~ Chapter Ten ~

Supportive Websites

For those preferring, an excellent source of natural health information is <u>Know the Cause</u>, (http://www.knowthecause.com/) my personal favorite, with advice on skin, mental, fungal, and many, many other mysterious and miserable issues that may be plaguing you or your elderly charge.

An excellent place to start and to find excellent information, step-by-step, in caring for your loved one(s) is <u>AARP</u>. As well as confirming many of the resources in this booklet at hand, it provides emotional and mental support. Between this booklet of resources and this AARP website pretty much everything you will need is covered.

A delightful source of spiritual encouragement and quality reading for all ages is <u>Spirit Wine</u> <u>Publications™</u> (http://www.spiritwinepub.org) and its bookstore Spirit Wine Books™. We invite you to peruse the other categories of books flowing into our library.



Thank you.



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