caregiving THE CAREGIVER **JOURNEY WORKSHOP**

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To care always.































Overview of the Caregiver Landscape

Susan Ponder-Stansel, President & CEO

Alivia Care

Linda Levin, CEO

ElderSource











Overview of Caregiving Today

Susan Ponder-Stansel
President & CEO
Alivia Care, Inc.



Caregiving is being called a "Life Stage"

This is an issue that is not going away

- 7 in 10 Americans turning 65 today will need care for prolonged periods of their lives.
- 68% of Americans say they will turn to family members to provide the needed care.





Who are we?

- Old, young, married, single, employed, retired, from a big family, only children, wives, daughters, husbands, brothers...
 - We are your neighbors, work, colleagues, friends, church members...
 - We live alone, we live with others, we are long distance caregivers, we live close to our loved ones...
- What we share in common is that we are all on a journey that has challenges, rewards, and many unknowns.
- But everyone's care journey is unique.















The Caregiving Journey





Health problem emerges



Stress and steep learning curve



Work/life adjustments



Needs escalate: Financial caregiving



Recovery/ death







- Relationship between the caregiver and care recipient
- The presence or absence of others on the caregiving team
- Nature of the help or care needed
- Care recipient's health condition and prognosis



• Factors influence our caregiver journey:

 Duration and intensity of the care

• Financial resources available

Onset of caregiving responsibilities

Impact of caregiving responsibilities





Serial caregiving is a reality and can add stress



Children out of Home (18+ Years)

Parents and/or older relatives need care

Spouse needs care







- The timing of becoming a caregiver is usually not up to us:
 - Even those who expected to become caregivers can be thrust into this role unexpectedly.
 - Learning curve is steep and there is often little to no training or preparation.
 - Many aren't prepared with how their relationship with the loved one receiving care will change.
 - Many aren't prepared for how they will feel about being a caregiver.







41% of caregivers say they entered the role suddenly.

59% entered the role gradually as the needs grew.





Top goals as a caregiver:

- Preserving the dignity of the care recipient
- Providing the quality and quantity of care needed.
- Keeping their loved one out of an institution*





*Caregiving circumstances that can bring additional stress:

Institutional Placement

Long-Distance Caregiving









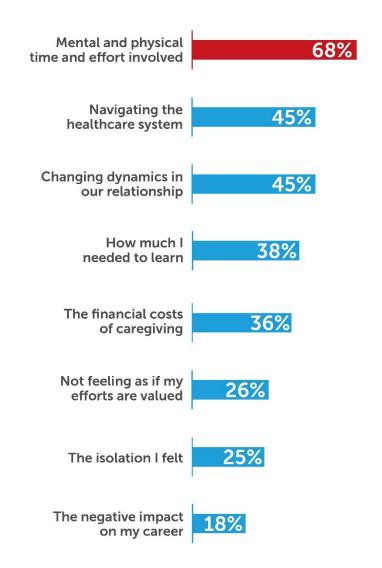
Caregiving can become an identity as well

Loss of identity as a caregiver can cause grief and disequilibrium



The Biggest Challenges of Caregiving











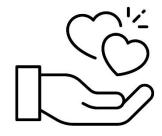
Caregiving is also fulfilling:

91% say they feel grateful for the opportunity to help a loved one.



Caregiving can be a Positive Experience





Gratitude



Forgiveness



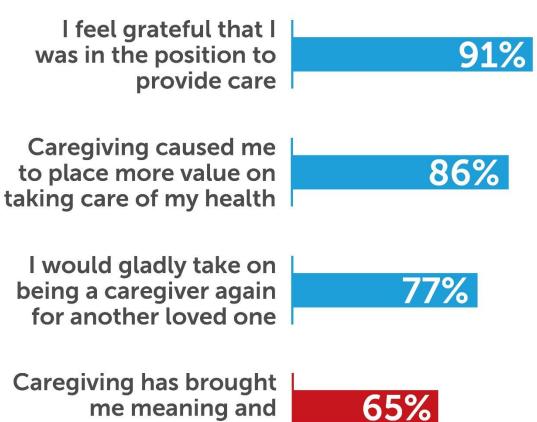
Empathy





Caregiving Gives Back to Caregivers

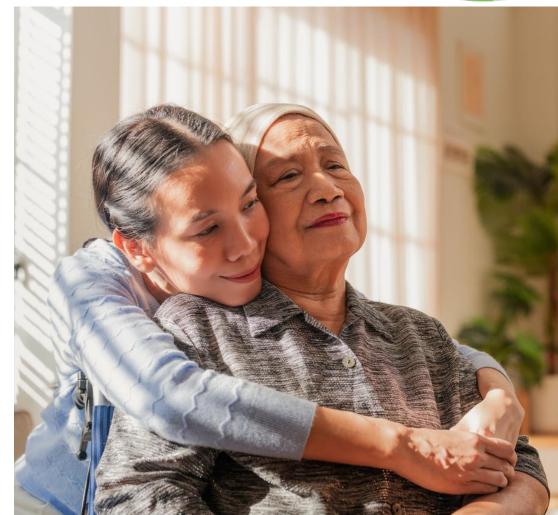




purpose to my life

care inc. To care all ways.

To care always.







Important to take a moment to reflect about your situation

- Where am I in my journey?
- Who am I caring for?
- Where am I providing care?
- How much caregiving do I do?
- What are my top 3 emotions that describe how I feel about caregiving?

Your Journey



I'm No Expert

Lessons From a Caregiver Linda Levin,



Lesson 1: Grace

We each do what we can, what we are capable of, what we have capacity for.

Let go of expectations.

Lesson 2: Acceptance

Ask for help

Accept Help



Lesson 3: Presence

You don't have to be creative to make or find joy.

Lesson 4: Authenticity

- Be straight with them.
- Meeting them where they are.
- Understand what is important to them, not

The Little Boy and the Old Man By Shel Silverstein

Said the little old man, "I do too."

The little boy whispered, "I wet my pants."

"I do that too, " laughed the old man.

Said the little boy, "I often cry."

The old man nodded. "So do I."

"But worst of all," said the boy, "it seems grown-ups don't pay attention to me."

And he felt the warmth of a wrinkled old hand.

"I know what you mean," said the

Lesson 5: Respect

- Roles are NOT reversed; the child DOES NOT become the parent.
- Honor them and respect them as the adult they are and provide care with love and dignity.

Lesson 6: Mindfulness

- •Do things with intent and awareness.
- Remember
 what we are
 there to do, for
 who and why.





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Navigating the Network

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Owner, Almost Home Day Care and Assisted Living

Mauri Mizrahi,

CEO, River Garden











Home Sweet Home Options As We Age

Kathryn Murphy RN, MSN, CMC
Comfort Keepers Jacksonville
President/Owner
Aging Life Care Consultant



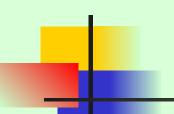


Statistically Speaking

- Every day until 2030, 10,000 baby boomers will turn 65
- An estimated 7 out of 10 people will require long term care in their lifetime
- A woman's life expectancy that is 65 y/o today is 86.6
- A man's life expectancy that is 65 today is 84.3
- By 2030, there will be a billion people on Earth that are over 65 y/o

Sources:

<u>Social Security Administration - Life Expectancy Calculator</u> - Site accessed 07/18/24 <u>Caring for an Aging America: Meeting the health care needs of older adults.</u> -Site accessed 07/08/24 Alliance

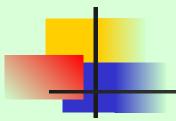


Key Questions To Determine Care Needs



- Is your loved one struggling with daily tasks?
- Has there been a memory decline?
- Have there been falls or instability?
- Do they seem isolated or depressed?
 - → If yes to even one, it may be time to explore care options.





Understanding In-Home Care

<u>Definition</u>: Care in a person's home (or residence) to support independence and safety

<u>Goal</u>: Support physical, emotional, mental and social wellbeing



What Is In-Home Care?

Companionship Services

- Companionship
- Incidental transportation
- Meal preparation
- Errand services
- Grocery shopping
- Grooming
- Live-in services
- 24-hour care
- Respite relief or relief for family

Personal Care Services

- Bathing, grooming, hygiene
- Mobility assistance
- Transferring and positioning
- Toileting and incontinence
- Feeding and special diet or meal preparation
- Medication reminders
- Alzheimer's/Dementia Care

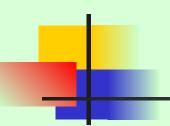
RN/LPN Services

- Assessment
- Medication Management



Providers of Home Care

- Licensed Home Health Agencies
 - Medicare Certified Agencies
 - Non-Medicare Certified Agencies
 - Personal Care Agencies
- Nurse Registries (placement/referral services)
- Hospices (profit or nonprofit)
- Homemaker/Companion/Sitter Services
- Independent Caregivers







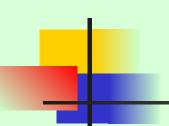
Family, Friends & Neighbors

- Sometimes Inconvenient
- Aggravating and Stressful
- Decreased Independence
- Difficult To Match Schedules
- Two Income Families Many Responsibilities





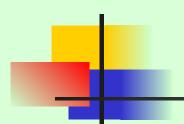
- Enjoys significant savings in housing costs
- Assists in family chores/contributes to the family environment
- Enhances social interaction
- Decreases the feeling of social isolation
- May cause restrictions and tension on family members







- Companion and Homemaker Agencies Provide Non-Medical Care
- Home Health Agencies Provide a Wide Range of Personal Care Services
- Nurse Registries/Independent Caregivers



Employee versus Independent Contractor



Be certain the caregiver is an "employee" of a licensed home health company and not an "independent contractor" if you want peace of mind when caring for a loved one.

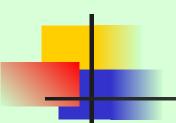






- No Background Checks
- No Workman's Compensation
- No Bonding
- No Liability Insurance?
- No Supervision
- No Agency Back-up

You may be subject to pay FICA and FUTA taxes

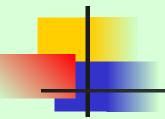


Client Protections with Caregivers Who Are **Employees**



- Yes General liability insurance
- Yes Professional liability insurance
- **Yes** Worker's Compensation insurance
- **Yes** Unemployment insurance
- Yes Fidelity Bond
- Yes Supervision





Client Protections (continued)

- Background screening
- Drug and alcohol testing
- Work and personal references
- Auto and driving history
- Supervision and training
- Back up plan



Independent Living Centers

Living Independently Within A Structured Setting

- Apartment like setting designed for seniors
- No medical staff around the clock
- Group social activities provided
- Services <u>may</u> include cleaning and meals
- Transportation <u>may</u> be provided in groups and travel in vans to common places (Wal-Mart, Publix)
- Often home care services are obtained by the resident or their family member





- Medicare very limited
- Medicaid limited services
- County and state programs
- Veterans Administration
- Long Term Care Insurance
- Private pay



Summary

- We are living longer
- Medical expenses continue to climb
- Continue to educate yourself on options
- Proper planning with professionals is a must
- Stay healthy to minimize the need





Caring for someone you love is one of the most important roles you will ever have.

Remember, you don't have to do it alone.



Navigating the Network Options in Care

Jamie Glavich, Certified Dementia Practitioner Assisted Living CORE Trainer, Alzheimer's Trainer



Variety of Care Settings - Adult Day Care, Assisted Living

- How do you manage all day? Why do you continue?
- 3 reasons why caregivers provide care
 - 5 65% want to keep family member at home
 - 48% provide care because they are geographically close
 - 38% provide care because of their perceived obligation as spouse or partner
- When is it time to place?
- What can I do to keep my family member home as long as possible?



Variety of Caregiving Settings

Combining resources and partnerships can help prevent premature placing into a higher level of care

- Home
- Adult Day Care
- Assisted Living
- Nursing Home
- Hospital



Challenges of Caregiving – Setting a path

- No two people experience aging in the same way
- Finances drive care options
- Medical issues—disease process—also drives care options
- Family dynamics



Care Options – Family and Friends

- These are usually unpaid volunteers that may have very active lifestyles of their own
- May not have a clear understanding of the care needed due to non-exposure on a daily a basis
- If you are going to rely on family and friends–keep a calendar
- Keep track of who committed to what



Adult Day Care Services

- Typically operates Monday through Friday
- Social model or a medical model
- Socialization
- Exercise
- Variety of therapies such as music and art



Adult Day Care Provides

- Abilities and Disabilities change from day to day
 - Partnership with day care professional that will assist with referrals and care
- Day cares provide meals and snacks
- Supervision by professional and trained staff
- Guidance through the day



Adult Day Care

- Private Pay \$50-125 per day
- Medicaid
- Alzheimer's Disease Initiative
- Some long-term care insurance policies
- Guide Program

 –under Medicare respite program



When 24-hour Care is Needed-Assisted Living

- Next transition would be to an ALF
- Variety of care philosophies, models, and price ranges
- We all follow the same regulations under Florida's Agency for Health Care Administration
- Each ALF decides the level of care they which to provide under regulations
- ALFs can be 2 beds up to 300 beds
- Variety—apartment style, country club, hotel like and residential home style
 in neighborhoods
- Go walk through



Searching for the Right ALF

- If you are searching for someone with dementia (Alzheimer's) will the ALF care for them and is there a separate area?
- How long will the ALF keep someone? What would require a discharge?
- What about incontinence care?
- How much care, attention, and supervision does the ALF provide?
- Do they have health care providers that come in to see residents?
- How do they handle nutrition (food service)?
- Does the ALF offer hospice services when needed?
- Some ALFs do respite care

Searching for an ALF

- Paying for the ALF
- Private pay -\$3000-\$12,000 a month
- Long Term Care Medicaid
- Veteran's Aid and Attendance as supplementing cost
- Regulations allow aging in place
- Nursing home is not an ALF and has different regulations and paying sources



Hospice Care

- Can be in your home, ALF, nursing home or hospital
- It is more than end of life care—not just 3-6 months life expectancy
- Quality of life—helping the caregiver
- About intervention
- Palliative option
- Full hospice care
- Holistic approach in the last phase of life



Survival Tips

- Keep your sense of humor and patience
- Take care of you
- Get enough rest and eat right
- Drink water
- Make time to do what is FUN to you--daily
- Be flexible and be ready to steer elsewhere
- Find out what re-energizes you
- It is okay to start planning now
- Turning discussion to nursing home information



Nursing Home Option

- Many resources can be brought into ALF
- NH needed when person needs 24-hour supervision and care from a nurse
- When funding ALF is challenging—NHs get Medicaid approval more quickly than ALFs for people needing care and assistance
- NHs are for short and long-term rehabilitation covered under Medicare

Navigating The Network

Mauri Mizrahi

Chief Executive Officer

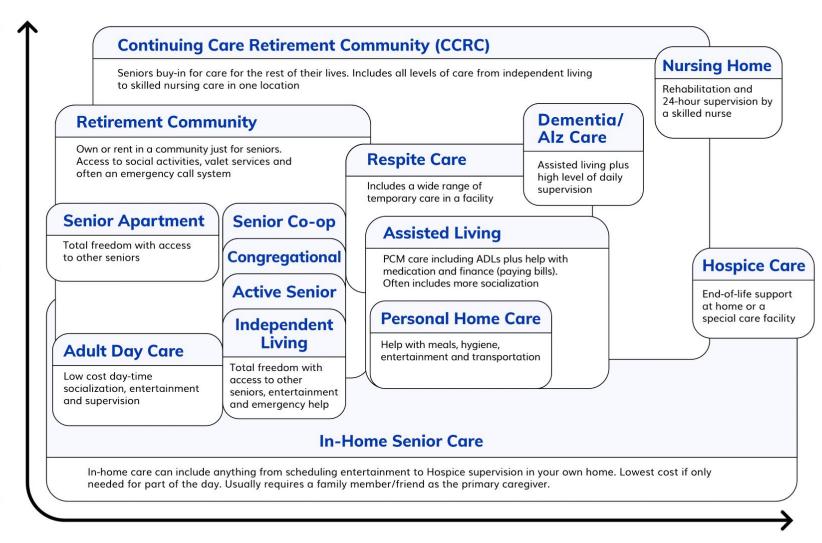
River Garden Senior Services



Confusing landscape with varying costs and levels of care

The Senior Living Spectrum

This graph shows how different types of senior care overlap and the relationship between the level of care and the cost.

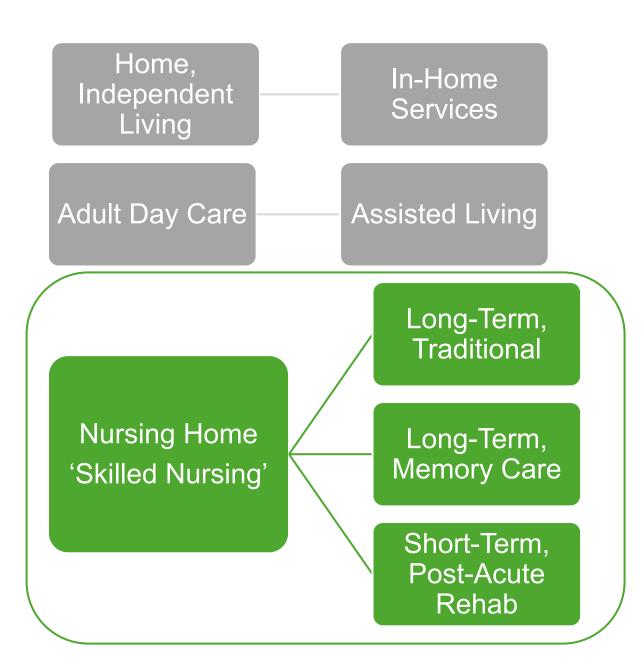


HIGH

COST

LOW

ntinu



A well-integrated continuum of care including skilled nursing, can improve and encourage independence and quality of life

Basic Facts

- Nursing home, skilled nursing facility terms are used interchangeably sometimes
- •24-hour licensed staff onsite: RNs, LPNs or CNAs
- Provides higher level of personal and medical care
- Private or shared rooms
- •Full-service, with scheduled meals and snacks
- Highly regulated

'Nursing Home'

- Long-term residence
- Custodial care
- Goal is to focus on wellness and life enrichment activities
- Private pay, long-term insurance or Medicaid
- If needed, skilled nursing services are available and may be eligible for Medicare reimbursements

'Post-Acute Rehab'

- Short-term residence
- Supportive environment to recover, regain independence and participate in social activities
- Goal is to return to residential living in the community
- Generally, Medicare pays

Beds Licensed as 'Skilled Nursing'

Choosing A Nursing Home Why?

- •Higher level of care, 24/7
- Clinical complexities
- Advanced medication administration (oxygen, injections, etc.)
- •Transfers, mechanical lifts (or bedridden)
- Wound care
- Assistance for eating, toileting, etc. (ADLs)

Short-Term, Post-Acute Rehab Why?

- Intensive rehabilitative therapy
- Specialized care services for chronic or specific conditions
- •24/7 care, assistance and support
- •Safety!



Learn More Online

- Facebook
- Instagram
- Website
- LinkedIn





Come & See

River Garden Ice Cream Social for Caregivers and Families

Sunday, September 14

1:30PM
Thank You
Mauri Mizrahi



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How Can I Pay for Care and What Are My Options?

Megan Wall

Managing Attorney, St. Johns Legal Aid

Carrie Ann Petesch

SHINE Advocate, ElderSource

C. H. "Bubba" Schlader

VA and Long-term Care Benefits Specialist









Medicaid Eligibility in Paying for Long-term Care

Megan Wall, Managing Attorney St. Johns Legal Aid

About St. Johns County Legal Aid

The mission of Jacksonville Area Legal Aid is to provide high quality legal assistance to low income and special needs groups - to empower them to accomplish energetic and affirmative advocacy, all to alleviate the circumstances, incidents and causes of poverty and discrimination.





Nursing Home --- long term care ---Medicaid Eligibility rules were written decades ago when the world was a very different place, especially healthcare coverage!



Homestead!

Homestead!

Homestead!



Do you have the "intent to return to your home?" and the only answer is ... YES!



Transfers are permitted between spouses (but few others, so be careful)!

Look back is **5** years for transfers.



Community Spouse, the spouse in the house, can have an extra \$157,920 in addition to home (and contents), car, burial funds, retirement and Social Security income, as well as have a Spousal Support Order Absent Dissolution (for all of the marital income of both spouses).





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Navigating Medicare

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Medicare Support for Caregivers

This publication has been created or produced by the State of Florida with financial assistance, in whole or in part, through funds from the Administration for Community Living.

Anne Chansler, Director of Elder Opportunities,

Michelle Branham, Secretary, Department of Elder Affairs









SHINE - Serving Health Insurance Needs of Elders

A program of ElderSource, funded by the Florida Dept. of Elder Affairs offering:

Free, confidential, unbiased counseling on Medicare benefits.

What Medicare Covers for Caregiver Support

(Original Medicare & Medicare Advantage)

Medicare does not pay for ongoing, full-time caregiving or custodial care.

However, it does cover certain services, training, and resources that can help people in a caregiving role.

1. Caregiver Training (When Part of Covered Services)

- Covered under Part A (hospital insurance) or Part B (medical insurance) when:
 - Ordered by a doctor
 - Provided by a Medicare-approved healthcare professional
 - Related to the patient's medically necessary care plan (e.g., wound care, medical equipment use, therapy exercises)

Caregiver training is included as part of home health care services and is not billed separately.

Medicare Home Health Care Coverage





2. Respite Care (Hospice Benefit)

- Covered by Part A only if the patient is in a Medicare-covered hospice program.
- Allows a caregiver to take a short break while the patient is cared for in a Medicare-approved facility.
- Usually covered for **up to 5 consecutive days at a time**.
- Can be used multiple times as needed during hospice care.
 - Medicare Hospice Care & Respite Coverage

3. Home Health Services

- If the patient qualifies for Medicare-covered home health care:
 - Skilled nursing
 - Physical, occupational, or speech therapy
 - Caregiver instruction for medical tasks
- Does NOT cover 24/7 home care, meal prep, housekeeping, or personal care if that's the only care needed.
 - Medicare Home Health Benefits





4. Counseling & Social Services

- Hospice benefit may include grief and loss counseling for the patient and family members.
- Medical social services can help connect caregivers to:
 - Support groups
 - Community programs
 - Long-term care planning resources
 - Medicare Hospice Counseling Services

5. Medicare Advantage (Part C) Extras

- Some plans may offer caregiver-friendly benefits beyond Original Medicare, such as:
 - Adult day health services
 - Transportation to medical appointments
 - Limited home modifications (grab bars, ramps)
 - Additional respite care
 - Over-the-counter allowances for supplies
 - Medicare Advantage Plan Coverage







Tips for Caregivers:

- Always ask the provider or plan if a service is covered and what documentation is required.
- Veterans' Benefits
- Long- term care insurance
- Medicaid Long term care (LTC)
- ElderSource offers Caregiver support and resources:

(888)-242-4464 or MyElderSource.org







Carroll H Schlader, End-of-Life & ElderCare Financial Planner

Certified in Long-Term Care
Dept of Veterans Affairs Accredited Advisor
Security-Credentialed Affiliate, Dept of Veterans Affairs
Medicaid and Medicaid Waiver Planner
Long-Term Care Insurance Licensed

Government benefits preplanning and crisis planning

End-of-Life and Estate Planning

Risk Management: LTC Insurance planning

Veterans Advocacy

Member: American Institute of CPAs / National Care Planning Council

What is Long Term Care / Extended Care?

Non-professional custodial care

provided to an individual

who has a chronic need for help

with the 6 things one does when they get up in the morning:

transferring

ambulating

toileting

bathing

dressing

eating

Supervision due to cognitive impairment

Cost of Extended Care In Northeast Florida



Home Care Aide (avg 44 hours /week): \$5,700 per month / \$68,400 per year

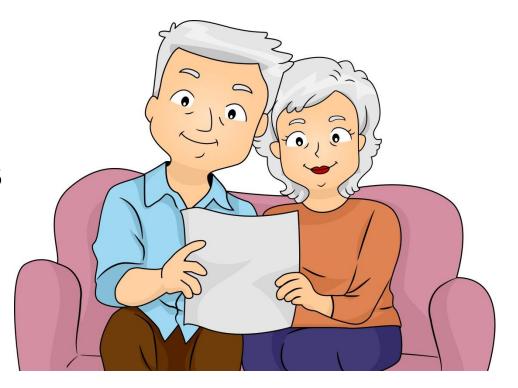
Assisted Living (1 BR Apt - Room & Board): \$5,700 per month / \$68,400 per year

Nursing Home Residency (Semi-private): \$9,660 per month / \$115,920 per year

Planning Strategies for Extended Care

X- Not Medicare or Health Insurance

- Self pay
- Long-term Care Ins.
- VA Disability Benefits
- ABD Medicaid
- Children / OthersPay



Long-Term Care Insurance

Sharing and Reducing Risk with an insurance company.

- CMS says if you live to age 65, you have a 70% risk in your lifetime.

Policies are underwritten, similar to life insurance.

- The younger and the healthier, the lower the premium.
- Average issue age is 56. Maximum age for most carriers is 79.
- Health issues can render one uninsurable

Most polices are purchased for home care and include assisted living and nursing home

Purposes:

- 1. allow insured to remain in the community without risking the emotional and physical wellbeing of those who will provide the care (spouse and/or children manage vs provide care)
- 2. preserve the retirement plan
- 3. insures the financial viability of the surviving spouse

Long-Term Care Insurance Triggering Benefits

Require assistance with 2 or more activities of daily living Or....

Require supervision due to cognitive impairment





Veterans Health Care System

Hospitals --- Clinics --- Pharmacies

Any Veteran with honorable discharge can enroll

Priority:

- Service-connected disabled
- Service in any combat zone
- Financial need based on net income

Other Services:

- VA doctor prescribed custodial home care
- Low prescription drug co-pays
- Family caregiver support stipends
- HISA Grants for home handicap remodeling



Disability Benefit Programs Administered by Dept of VA



- I. Service-connected Disability
 - A. Disability Compensation
 - B. Dependency & Indemnity Comp (DIC)
- II. Non-service-connected LTC benefit
 - A. Disability Pension plus A&A Allowance
 - B. Survivor Pension plus A&A Allowance

DISABILITY COMPENSATION The Service Connected Disability Benefit

Some "Heads-Ups" for seniors:

- 100% rated disabled in need of aid and attendance:
 - + \$936 allowance per month
- DIC recipient in need of aid and attendance:
 - + \$409 allowance per month
- Terminated DIC can be reinstated
- Vietnam War, Gulf War, and Post 9-11 War veterans who served in the theatres of war and their survivors: LEARN about PRESUMPTIVE ILLNESSES



Presumptive Illnesses

Illnesses/Diseases Recognized by the VA as Connected to Agent Orange Herbicide Exposure

- AL Amyloidosis
- Bladder Cancer
- Chronic B-cell Leukemias
- Diabetes Mellitus Type 2
- Hypertensioin (High Blood Pressure)
- Hodgkin's Disease
- Hypothyroidism
- Ischemic Heart Disease ex. Congestive Heart Failure Coronary Artery Disease

- Monoclonal Gammopathy of Undetermined Significance
- Soft Tissue Sarcomas
- Multiple Myeloma
- Non-Hodgkin's Lymphoma
- Parkinsonism
- Parkinson's Disease
- Porphyria Cutanea Tarda
- Prostate Cancer
- Respiratory Cancers

Location: Gulf and Post 9-11 Areas Toxin: Burn Pits Toxins



Presumptive Illnesses

Illnesses/Diseases Recognized by the VA as Connected to Burn Pit Toxin Exposure

Cancers:

- * Brain cancer
- * Gastrointestinal cancer- any type
- * Glioblastoma
- * Head cancer of any type
- * Kidney cancer
- * Lymphoma of any type
- * Melanoma
- * Neck cancer of any type
- * Pancreatic cancer
- * Reproductive cancer of any type
- * Respiratory cancer of any type
- Urethral cancers

Illnesses:

- * **Asthma** diagnosed after service
- * Chronic bronchitis
- * Chronic obstructive pulmonary disease (COPD)
- * Chronic rhinitis
- * Chronic sinusitis
- * Constrictive bronchiolitis or obliterative bronchiolitis
- * Emphysema
- * Granulomatous disease
- * Interstitial lung disease (ILD)
- * Pleuritis
- * Pulmonary fibrosis
- * Sarcoidosis



1. "Aid and Attendance Pension"Is aNeeds Based Benefit

#1 Aid & Attendance Required:

#2 Financial:

Income: Income equal to or less than the cost of care Countable assets must be below \$159,000

How much will VA pay?



"Aid and Attendance Pension" 2025 Rate Table

Category	MAXIMUM Annual	MAXIMUM Monthly
Married Veteran	\$ 33,546	\$ 2,795
Single Veteran	\$ 28,298	\$ 2,358
Surviving Spouse	\$ 18,186	\$ 1,515
Disabled Spouse	\$ 22,215	\$ 1,851

A&A Pension Eligibility Requirements

Age 65+

Active Duty: 1 day during wartime era -- 90 days overall

Better than dishonorable discharge

World War II: December 7, 1941 through December 31, 1946

Korean War: June 27, 1950 through January 31, 1955

Vietnam War: August 5, 1964 through May 7, 1975

(Start date is November 1, 1955 for veterans who served "in-country")

Gulf War: August 2, 1990, through a date yet to be determined



Veteran must have proof of above: Separation (Discharge) papers: Form DD-214

Surviving Spouse of a Veteran A & A Pension Requirements

- (1) Married to wartime Veteran at his/her death
- (2) Married to wartime Veteran for 1 year or more
- (3) Has not remarried
- (4) Veteran served 90 consecutive days ACTIVE DUTY
- (5) Veteran served 1 of the 90 days in a war-time period
- (6) Veteran was honorably discharged
- (7) No age requirement for surviving spouse

Same aid & attendance requirements as veteran Surviving Spouse Document Requirements:

- 1- Veteran's Separation/Discharge Papers
- 2- Death Certificate must show cause of death
- 3- Marriage Certificate



Caregiver Panel Discussion

Kristin Moore

Legend Senior Living, Moderator

Cheryl Jefferson Marc Dickerson Necole Daniels







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To care always.

































Time for Laughter Yoga!

Amanda Jones









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