Advocating for your Loved One seeking quality of care and quality of life

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A Webinar for ALOA

Adult Lutherans Organized for Action

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My friend Judith. . . .

 One of 1.3 million people in a nursing home in the United States





Focus of Webinar

Overview of long term care system Options and definitions

Finding a Nursing Home

Considerations and Steps to Take

Promoting Quality of Care and Quality of Life

Resources

Overview of LTC System

Lots of Options available for those who need long term care

Senior Housing (with and without services)

Home Care

Assisted Living (small group homes and large homes) - ALFs

Nursing Homes - NHs

SubAcute Care

Hospice Care – end of life and palliative care

Retirement Communities (services are co-located)

Community Care Retirement Communities – CCRCs

Nursing Homes

Licensed by each state to provide nursing home care

 must comply with regulations based on Nursing Home Reform Act

 Serve medically fragile people who need nursing care and help with activities of daily living (must have RN)
 all ages, short term and long term

Most Provide Rehabilitation and Long Term Care

Other relevant terms

Certified – Nursing Homes funded by Medicare and Medicaid must be "certified" by the Centers for Medicaid and Medicare (CMS)

SFF – Special Focus Facility

a nursing home identified by the Federal Government as having serious compliance problems over an extended period of time and needing increased oversight; 3 in each state

Other relevant terms

Person Centered Care (sometimes called person directed care or individualized care)

- The facility focuses on the individual resident instead of on the organization (i.e., implements practices that promote quality of life dining with a buffet so residents have more choice; promoting resident involvement in decision making; importance of individualized care planning)
- The Pioneer Network has led this movement in the US and nursing homes join the Pioneers to enhance their ability to promote quality of life and care. Examples include the Eden Alternative and Green Houses.

Ombudsman

Swedish for advocate

- Liaison
- Educator
- Link to the Community
- Citizen Representative

Long Term Care Ombudsmen are mandated by Federal & State Law for those in NH, ALF and in 13 states those receiving home care.......

1) Identify, investigate and resolve complaints from any source on behalf of a resident in a nursing home or assisted living

2) Represent the interests of residents before governmental agencies and seek remedies to protect the health, safety, welfare and rights of residents

Ombudsmen do:

Individual Advocacy

Systems Advocacy

Ombudsmen can provide info to help in the selection of a facility, answer questions about long term care, and work to resolve grievances in a facility with the permission of the resident. Ombudsmen also have legal authority to address policies and practices that impact long term care.

Finding a Nursing Home

Considerations:

- Type of facility to meet resident needs
 - Location
- Preferences of person needing care
- Cost any resources to pay for care?
- Quality of Care AND Quality of Life

Placement, may be hard but may be necessary Goal: minimize transfer trauma

Engage your loved one as much as possible in:

- visiting options
 - -identifying her preferences
 - -choosing items to take

My Mom: type of care needed? Large Assisted Living, Small Group Home, Hospice

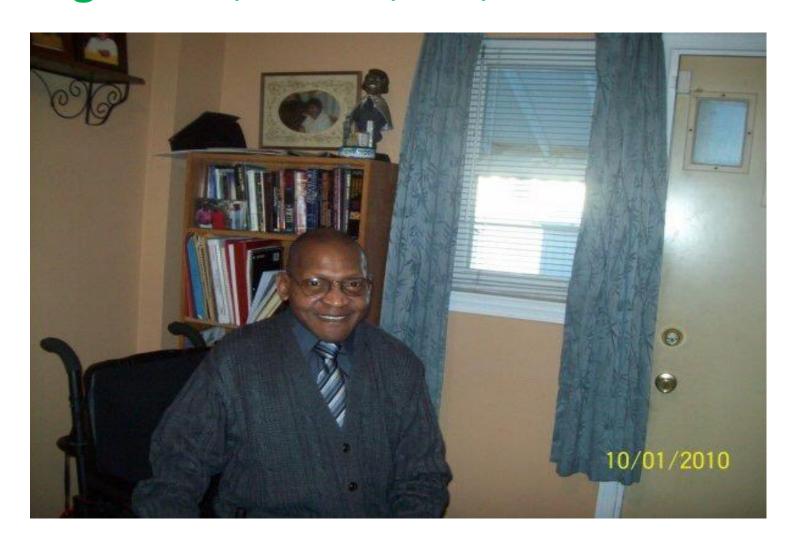


Fred's mom, type of care needed? Assisted Living, Nursing Home (4X), Hospice





Home and Community Based Care Nursing Home, Rehab, NH, Home with services



Type of care needed

Rehabilitation?

On-going long term care? Respite Care?

Memory care? End of life care?

Expertise in a particular disease?

Location

Visits from family and friends results in

- higher quality of life
 - improved care
 - access to spiritual care (pastors, deacons, etc.)

Access to other needed services

- dialysis? Specific doctors? Etc.

Preferences of the Resident, ESSENTIAL TO QUALITY OF LIFE

Include the resident in as many aspects of choosing a facility as possible.

Ask clearly, "what nursing home would you prefer?" " What would improve the experience for you?"

Remember, the resident may have certain preferences that you would never have considered.

Consider personal history of the resident, her preferences, choices and life style in the past.

What is important to residents. . .

- Being treated with dignity and respect as a unique individual
- Relationships
 through
 -Quality of life and quality of care
 -Staffing -Training
 -Engagement

Cost of Care is paid for by:

- Long Term Care Insurance (check the policy)
- Medicare (related to medical need, often for rehabilitation)
- Medicaid (related to income level, often for extended stays after the resident's personal income reaches a certain level)
- Insurance
- Private Pay Other???

Quality of Care AND Quality of Life

Quality of Care: Inspection Reports (also called Survey Reports), reputation of facility, 5 star rating system by CMS, staffing levels, staff turnover and training. Rehabilitation capacity.

For profit vs. non profit

Quality of Life: Food, activities, staffing levels, consistent assignment – staffing is done systematically to strengthen the relationships of certified nursing assistants with the resident, person centered care, opportunity to make decisions

NH Compare Resource

- •Look at Nursing Home Compare (CMS Website listing every NH in the United States and ranks them; checklist for choosing a facility)
- •Focus on inspection reports and staffing, SFF facilities and why facility ranked low or high

Nursing Home Compare,



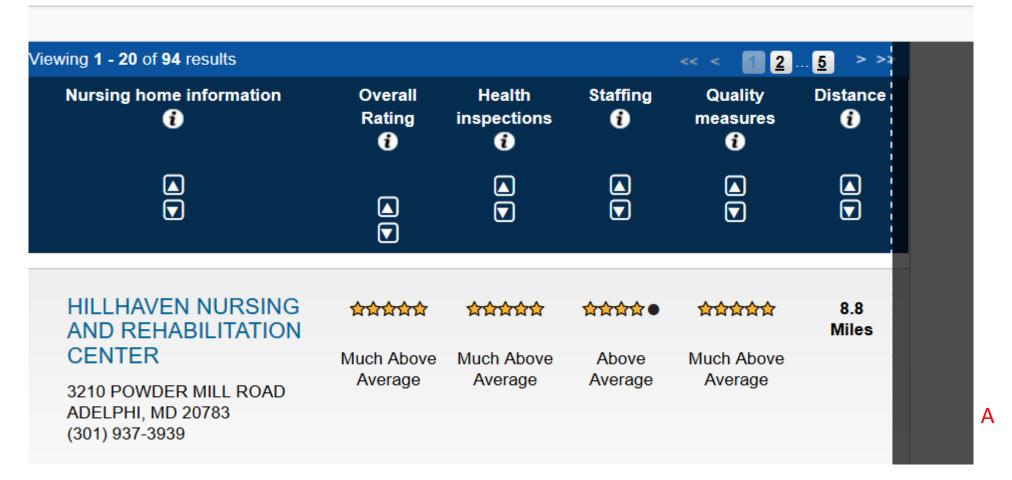


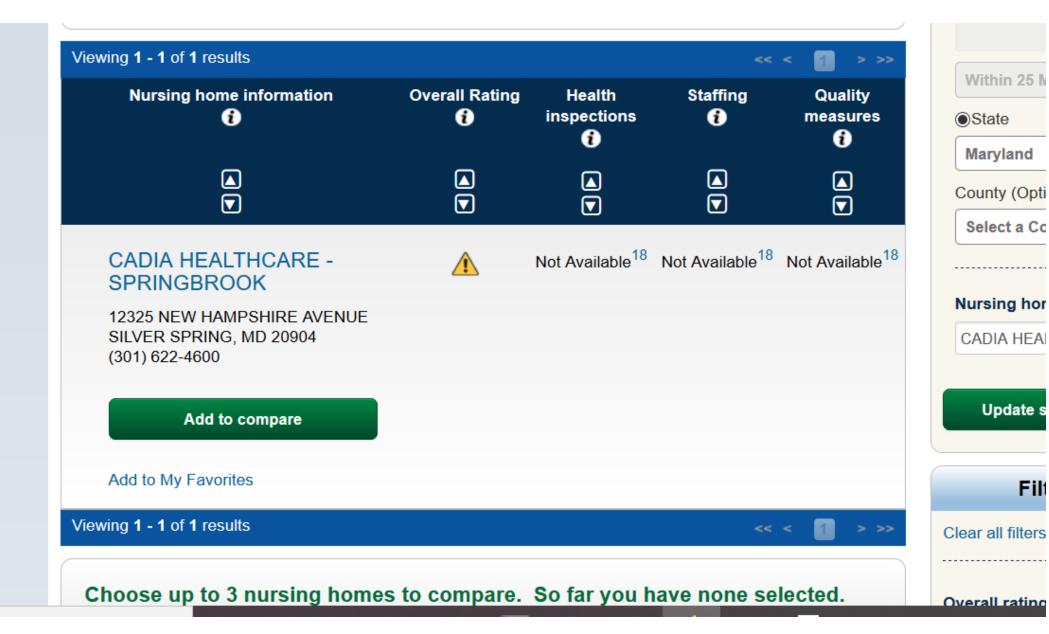
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Medicare Nursing Ho

https://www.medicare.gov/nursinghomecompare/results.html#loc=20784&lat=38.9477341&lng=-76.8807437

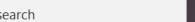




Filt

General information	Health inspections	Fire safety inspections	Staffing	Quality of resident care	Penalties		
	CARROLL LUTHERAN VILLAGE		AUGSBURG LUTHERAN HOME		THE LUTHERAN VILLAGE AT MILLER'S GRANT		
Learn more about the overall star ratings	Overall rating ①: ☆☆ ● ● ● Below Average 200 ST. LUKE'S CIRCLE WESTMINSTER, MD 21157 (410) 848-0225		Abov 6811 CAMPFIELD BALTIMORE, MD	Overall rating ①: ☆☆☆● Above Average 6811 CAMPFIELD ROAD BALTIMORE, MD 21207 (410) 486-4573		Overall rating ①: ☆☆☆☆ Much Above Average 9000 FATHERS LEGACY ELLICOTT CITY, MD 21042 (410) 696-6700	
Learn why these characteristics and services are important Health inspection	Add to my Favorites Map and Directions		Add to my Favor Map and Direction	Add to my Favorites Map and Directions		Add to my Favorites Map and Directions	
rating 1	☆☆ ● ● ● Below Average			☆☆☆☆● Above Average		☆☆☆☆☆ Much Above Average	
Staffing rating 1	AA ● ● ● Below Average		☆ ● ● ● ¹² Much Below Average		会会会会 Much Above Average		
Quality measures rating 🚺	☆☆☆◆ Above Average			全体合 Much Above Average		☆☆☆ ● ● Average	
Number of certified beds 🚺			131		12		

The health inspection star rating is based on each active provider's current health inspection survey and the 2 prior surveys, as well as findings from the most recent 3 years of complaints information and inspection revisits. AUGSBURG LUTHERAN HOME Health Inspection rating Above Average Date of most recent health inspection 06/21/2019 View full report > Total number of health citations 10 15.1 Average number of health citations in Maryland 8.2 Average number of health citations in the U.S. 05/08/2019 Date(s) of complaint inspection(s) between 10/1/2018 - 9/30/2019 View full report Number of complaints in the past 3 years that resulted in a citation Number of times in the past 3 years a facility-reported issue resulted in a citation View all health inspection, complaint, and facility-reported issue details View all health inspection details ## 0 ≓ŧ w ΧI N



















This is an important decision, get input from others:

- Hospital Discharge Planner
- Long Term Care Ombudsman
- Local Alzheimer's Association Chapter
- Faith leaders
- Friends and Family with recent experiences

Steps to Finding a Nursing Home based on considerations

- Identify preferred location
- Talk with trusted persons about their experiences
- Get assistance from hospital discharge planner who will identify specific facilities
- Narrow down to 2 to 4 facilities
- Visit if possible Use your senses, ask questions ask @ level of staffing, training, turnover, person centered care
- Discuss with the resident
- Make decision and figure out transportation to facility

Moving to a Nursing Home

Determine transport to NH

Determine what to bring for first days of stay

If possible, go during the day on a weekday

Prepare for paperwork

Note: No longer need to sign arbitration agreement as a condition of being admitted

Keep paperwork in a safe place

"I'm in a safe nest."
I can figure it out."



Consistent schedule

Close to family and friends

Interaction with others

Individualized room

Once your loved one is in a nursing home...

Learn as much as you can about Nursing Home Care and Issues

Residents have rights (established in 1987)

Facilities are licensed and monitored by regulatory agencies "inspection" (often called survey) every 9 to 15 months

Care is to be "individualized", based on the needs of the resident person centered

Some facilities embrace "culture change", resident centered care

Nursing Home Reform Law

- The federal Nursing Home Reform Law, passed in 1987, is part of the Social Security Act.
- It protects each nursing home resident and requires that nursing homes "provide service and activities to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident in accordance with a written plan of care."
- What this means is that **each** resident's individualized needs are to be discovered and addressed.

Describing your loved one, paint a picture

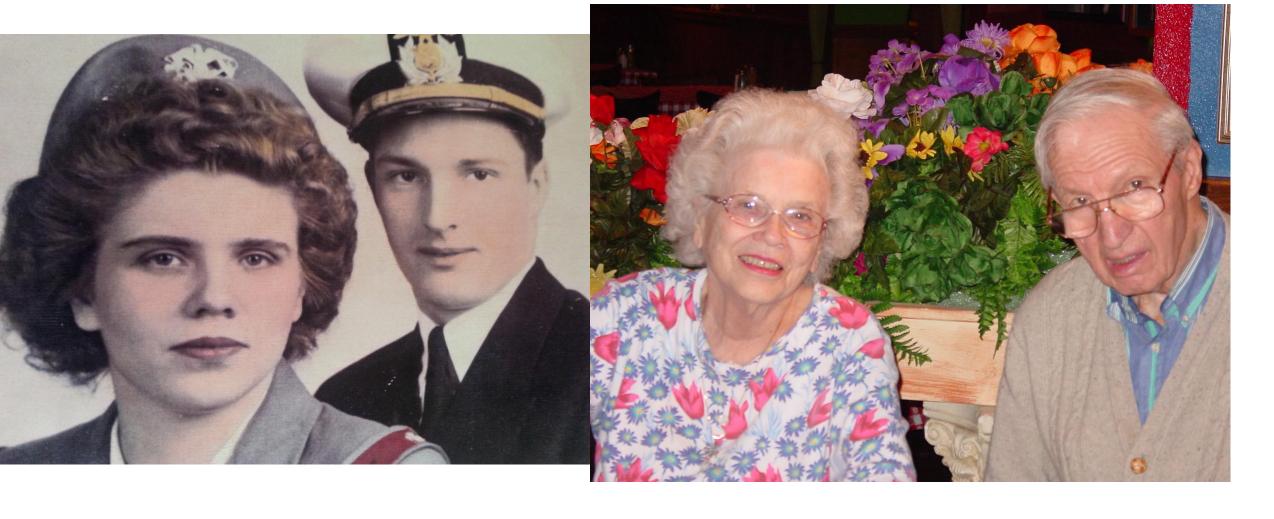
In application process
In assessmen - In decor



In day to day interactions with staff

"My mom is a unique person, with a rich history and a fun loving personality. A woman of faith and simple love of food, family and flowers."

(Better yet: Encourage your loved one to speak for herself.)



Use pictures to illustrate your love ones personality and history

Visit

Visit at different times in the week and during the day

Encourage others to visit, including those who provide spiritual comfort

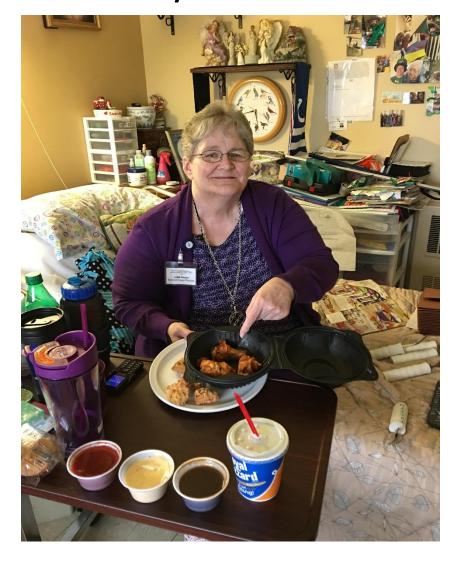
Participate in activities with your loved one

Initiate activities your loved one might enjoy

Quality of Life



Quality of Life





Personalize room

Resident has the right to decorate room, bring items from home

favorite recliner, blanket, pictures, clothes, small refrigerator, etc. that will help the person be more comfortable. Particularly important for people with memory loss.

Develop Relationships....

- Identify nursing home staff who are involved in loved one's care and help them understand your loved one's situation i.e., "My mom has been in the hospital and is confused; but the doctor thinks that she will improve and be able to participate in the activities here." "My mom is a night owl! She loves to read and will watch movies over and over again!" "Every evening, my mom reads a hymn and sings it for her night time devotions. She loves music."
- Identify who to contact if there is a medical concern (oftentimes the charge nurse or the Director of Nursing)
- Identify who to contact if there are other concerns
- Express gratitude for small and large actions that provide comfort, good care, and friendly engagement

Participate in life of loved one. . .IF she wants you to

- Care Planning!!!!
 - Family and Resident Councils
 - Family Events
 - Other

"I'm in a safe nest.

I can figure it out."

Consistent schedule
Close to family and friends
Interaction with others
Individualized room

Addressing Problems. . ..

Before they occur:

Ask the facility who to go to with concerns Learn the facility grievance policy

When they occur:

Report abuse immediately

Bring to the attention of appropriate staff

Ask for a meeting, or a care planning session

Set follow up

Hints for problem resolution. . . .

- Write down notes about the problem including:
 what shift, who was involved, what happened, how often,
 and the impact on the resident
- Seek input from the ombudsman if unsure what to do (remember everything you discuss is confidential)
- Articulate the problem(s) in a calm voice
- Ask clearly "What can be done to address this problem."
- Set follow up time frame
- Express appreciation for staff person's involvement

More Hints. . .Goal: see situation from resident perspective

- Look at what occurred based on the resident. Be a detective! i.e., is an infection the cause of resident behaviors and mood change? Is the resident not wanting to shower because it is painful to experience a shower? Is the resident frightened because a staff person looks like a childhood abuser?
- Make every effort to settle family differences so that the facility is not having to work with multiple family members and multiple opinions.

 i.e., DON'T limit access to a family member just because other family members don't like him. If the resident once enjoyed the person's company, most likely the resident will want to see the person now.
- Learn what regulations and rights apply to the situation

Goal: Problem resolution Quality of life and care for loved one

"The filling station used to be full service. But now it is self serve and I can't find the pump." Questions to ask: Is my loved one typically living in an environment that is caring, respectful and engaging as well as meeting her physical needs? Are my loved one's needs beyond the capacity of the facility?

Problem resolution not working?

- Talk with the administrator of facility or person designated by facility to address complaints
- Contact the ombudsman for guidance and/or assistance
- Contact the regulatory (licensing agency)
 can be anonymous or name used

Consider Options

WRAP UP

- Have the conversation before long term care is needed for your loved ones and yourself
- Visit friends, family members and church members in a nursing home.
 40% of residents have no regular visitors, family or friends
 Consider a nursing home ministry in your congregation
 cards, activities, devotions, video broadcasts, visits