



The Ins and Outs of Long-Term Care Planning

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June 3, 2016



Huntington's Disease
Society of America

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Presenter Disclosures

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What Will You Learn Today?

- What are the types of Long- Term Care
- What are the financial implications of each
- How to search for Long-Term Care
- How to make the transition to Long- Term Care

Types of Long- Term Care

- Home
- Assisted Living
- Nursing Home, Nursing Facility, Long-Term Care Facility

Long- Term Care at Home

Who are the Caregivers?

- Family
- Hired Caretakers



How will I pay for it?

- Private Pay
- Long-Term Care Insurance
- Medicaid
- Other County or State Waiver Programs....Maybe

Long-Term Care at Home

What should I ask myself?

- What is the home set up? Does it work?
 - Now? Long-Term? Until what point?
- Who are the caregivers going to be?
- If family, how many family members?

Long- Term Care at Home

What Should I ask myself?

- Is there respite care available?
- Do the level of care, availability of caregivers, and financial resources all match up?

Many say the ideal is to “age in place at home” but is it your ideal?

Assisted Living Facility

- **What is Assisted Living?**
 - Interim level of care-
 - Someone who can longer live on their own
 - Examples:
 - 24 supervision, Medication Assistance, Assistance with Bathing, Assistance with Meal Preparation.
 - Some are apartment style: Studios, one-bedrooms, two-bedrooms
 - Physician comes to the facility
 - Nurses and CNAs on site 24 hours

Many say you can age in place, beware this is not always true



Assisted Living Facility

- **How Will I Pay For It?**

- Private Pay
- Long- Term Care Insurance

Because the majority are private pay or LTC Insurance if you run out of fund you will have to move

- **Questions to ask yourself:**

- Can you afford this? And for how long?
- Are you ok with another move/transition?



Nursing Home

- What is a Nursing Home?
 - A facilities that provide 24 hour care and supervision.
 - They will have skilled nursing care.
 - Most will have rehab services (PT/OT/SLP)
 - Physician will come to the facility
 - There will be nurses and CNAs on-site 24 hours a day
 - Will have short-term and long-term options



Nursing Home

- **How will I pay for it?**
 - Private Pay
 - Long-Term Care Insurance
 - Medicaid
- **Other:**
 - Often older buildings (this is almost never an indication of the type of care)
 - Most people will have roommates



Nursing Home Admissions Criteria.....

- Clinical
 - Can the facility meet the applicants needs?
 - Does the applicant meet the Medicaid clinical requirement?
- Financial
 - What is the payment plan?
 - Private Pay vs. Medicaid
- Bed Availability
 - Is there an appropriate bed available?

What is the next step....

- Mr. Smith lives in multi-level with his wife and 2 children (ages 14 and 16). He is retired due to his HD and is home during the day by himself. His wife leaves lunch for him, though recently she has been concerned about him eating unsupervised. He has also had several falls on the stairs recently (thankfully, he has not had a major injury). His bedroom is upstairs. He needs assistance with showering, but so far has been ok using the bathroom on his own. He typically spends his day watching television. He used to go for walks, but got lost a few times. She knows that the current setup is not going to last much longer....

Financial Planning

- **What are my options for how I will pay for care?**
 - Private Pay
 - Long-Term Care Insurance
 - Medicaid



Medicare DOES NOT COVER Long-Term Care

Financial Planning

- **What should I know regardless of time-frame?**
 - Have a sense of how you think you are going to be able to pay
 - Understand the Medicaid rules for your state
 - If you have a Long-Term Care Insurance policy know it's rules.
 - Know how this will financially impact the rest of the family.
 - Is there a Financial Power of Attorney?

Genworth 2015 Cost of Long-Term Care Survey

These are the national averages for long-term care costs, according to the new Genworth 2015 Cost of Care Survey:

| TYPE OF SERVICE | MEDIAN RATE | % INCREASE OVER 2014 |
|--------------------------|---------------------------------|----------------------|
| Homemaker Services | \$20/hour | 2.63% |
| Home Health Aide | \$20/hour | 1.27% |
| Adult Day Care | \$69/day | 5.94% |
| Assisted Living Facility | \$43,200/year | 2.86% |
| Nursing Home | \$91,250/year (private room) | 4.17% |



Financial Planning Dependent on Time

- **5 or more years**
 - This is usually the most optimal time for estate planning
 - Start keeping financial records
- **1-4 years**
 - Keep records of bank statements and other financial accounts
 - Keep receipts and invoices of any expenses related to care
- **Less than a year**
 - Start collecting copies of any bank statements or financial accounts for the number of years Medicaid will look back at in your state.
 - Make sure you can access all necessary accounts



Financial Planning When You Have Run Out of Time

- Identify facility
 - Follow the facility application process
 - Inquire about Medicaid application requirements
 - Ask if there is a financial specialist you can speak to at the facility
- If applying for Medicaid or will be in the near future
 - Contact the state/county to answer general questions about Medicaid
 - Start to gather 5 years of financial history and other documents required for the application

Ms. Andrews is trying to find nursing home placement for her sister. Her sister receives about \$1800 in Social Security Disability Insurance. Up until about 6 months ago her sister was still in charge of her own finances, she only took over after she realized her sister had been spending recklessly. Her sister will need Medicaid to pay for placement, but their state requires 5 years worth of financial records.

How Do I know It is Time to Consider LTC

- **It is different for everyone but ask yourself:**
 - Does the set up of the home still work?
 - Are falls occurring?
 - Is it becoming too overwhelming?
 - What do the *doctors and care* professionals think?
 - Is there enough care for the person?
 - Do you know what your threshold is for someone to stay at home?

How Do You Choose the Type of LTC

- It's Personal!
- What should you consider?
 - Level of care needed
 - Finances
 - Transitions

The Search Process

- **What to do before I start looking**
 - Know what you are looking for
 - Have you financial information pulled together
 - Do you have all necessary legal documents?
 - POA, Advanced Directives, Etc...



The Search Process

- **How do I look?**
 - Identify a list of places to visit
 - Go on tours
 - Ask your community members

What Important Factors Should I Consider?

- Location
- Size of the Facility
- Knowledge of HD or willingness to learn about HD
- What are your personal deal breakers?
- What are the short-term and long term goals?



Sometimes flexibility is needed....

Mr. Mack lives in Virginia. He has had to be moved multiple times because facilities say they can long “meet his level of care.” His sister hopes that he can stay in the state and near his family. But they have yet to find a facility can meet his needs. However, a facility with an HD specialty unit 5 hours away is able to accept him and meet his needs. What should his sister do?

How to talk about HD during the Search Process

- To tell or not to tell?
 - Should you tell a facility about HD?
- Use your Doctors and Social Workers
- Use what other HD community supports you might have available
- Staff trainings
 - HDSA can do this!

Making the Transition

- How do I talk to my loved one about the transition?
- Should your loved one visit the facility ahead of time?

The Transition

- Get to know the staff and the managers
 - Don't forget the Certified Nursing Assistant (CNAs)
- Get to know the Social Worker
- Ask yourself what information have I provided to the staff? Is there anything else I should tell them about my loved one?
- Does the staff know who the contacts are and how to reach them?



The Transition and Expectations

- Who is going to visit? How often?
- Is there computer access?
- What is the phone access?
 - How often will you be able to call?

It is very important to set realistic expectations!

Other Expectations....

- Schedules
- Meals
- Staff/Resident Ratio
- Shower schedule
- Activities
- Private versus Semi-Private Rooms



Care Plans and Care Plan Meetings

- A care planning meeting is a regularly occurring meeting between the facility, the resident, and their caregiver.
 - This meeting is used to update families on a how person is doing and ensure that everyone still has the same goals.
- A care plan is a type of written documentation to show the treatment or care goals for an individual.
 - Ex. Mr. Smith has a care plan that shows he will only eat food that is pureed.

Problem Solving

- Use the Care Plans and Care Plan Meetings
- Work with the Social Worker
- Figure out what compromises are available
- Ask if they need additional education on HD
- Know when to involve the Ombudsman's office
- Use your HD doctors and Social Workers

Let's Hang Out!

- Mrs B's facility is concerned because she only wants to sit in her room and watch Television all day. They would like her to participate in more activities. When they speak with her husband he tells them she has always been an introverted person and often will not participate in group activities.
- How can the facility and Mrs. B and her husband compromise?

Medication, Medication, Medication

- Mr. Smith has episodes of aggression in the past. His HD Psychiatrist has worked with him for many years and it took her a long time to get his medications correct. Due to state regulations the facility would like to reduce some of his psychiatric medication. His family knows that when this has been tried in the past the results have not been positive?
- How do they work with the facility on this issue? Who else can they involve to help?

Something to Think About

- A gentleman that use to come to the local HD support group came one month after moving his wife to a long-term care facility. Prior to the move he had spent several years providing her 24 hour care with the assistance of an aid at home 8-10 hours a day. When asked how he was doing with the change he said:

“ I get to be just her husband again”

Special Thanks To:



MedStar Georgetown
University Hospital

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A Charles E. Smith Life Community



Questions?

Resources

- <http://hdsa.org>
- <http://hdsa.org/living-with-hd/long-term-care/>

HDSA National Office Help Line- 1-800-345-HDSA

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