



Questions to ask when looking for a long term care facility



Huntington's Disease Society of America

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Anthony J. Lechich, MD and Rebecca Ferrini, MD

Dr. Lechich is Chief Medical Officer
Terence Cardinal Cooke Health Care Center in New York, NY
Archcare.org

Dr. Ferrini is Medical Director of Edgemor DP SNF, Santee California
2009 American Medical Director's Association Medical Director of the Year.

Both are members of HDSA Long Term Care workgroup to explore ways to improve
long term care services for advanced H.D.

Presenter Disclosures

Anthony J. Lechich, MD and
Rebecca Ferrini, MD

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**No relationships to disclose
or list**



Huntington's Disease
Society of America

When do we think about long term care?

- Disease is in middle or later stages
- Needs for assistance (dressing, cooking, bathing, toileting, incontinence) become greater and there is no one at home who can do it.
- Swallowing difficulties reduce nutrition; weight loss, feeding is difficult
- Need for supervision or controlled environment-more falls, dangerous behavior.
- Refusal of help.
- Caregivers are exhausted

Long Term Care is available in the home, in the nursing home and in many sites “in between.”

But finding the right care is difficult and each option has benefits and drawbacks.

What works best for you and your situation depends on

Would you rather have a great place that is far from your home or a worse place you can visit often?

Is safety more important to you or autonomy?

- What is available in your area,
- Income and assets and eligibility for services,
- The abilities, needs and preferences of the individual

What are care needs now and in the future?

- Supervision
- Feeding
- Bathing
- Incontinence care
- Locked placement? Wandering/elopement?
- Providing medications
- Short term or long term?

Aligning Expectations

- There is a confusing web of services available, but each has its own eligibility requirements, paperwork and rules. They are not that integrated.
- Almost everyone needs help to navigate these programs and find something that works the best for them.
- All choices have good and bad points



NURSING HOMES: FINDING AND CHOOSING ONE

Choose a nursing home that is nearby, “good” and “knows about Huntington’s Disease.”

- Nursing Home Compare lists all certified nursing homes by zip code. www.medicare.gov/NHcompare--
- **[HDSA has a comprehensive guide to choosing long term care](#)**
- To access the Family guide Series to LTC go to www.hdsa.org, click on Living with HD and then publications. Scroll down to caregiving. Click on Long Term Care
- Ask in specialist office or others affected to recommend (or steer you away from) one.
- A great guide to long term care services and choosing a nursing home is <http://www.medicare.gov/Publications/Pubs/pdf/02174.pdf>

NURSING HOME COMPARE

Medicare.gov - Nursing Home Compare - Search Criteria - Windows Internet Explorer

http://www.medicare.gov/NHCompare/Include/DataSection/Questions/ProximitySearch.asp

File Edit View Favorites Tools Help

Home Manage Your Health Medicare Basics Resource Locator Help & Support

Nursing Home Compare

<< [Back to NHC Home](#)

Step 1: Enter Search Criteria

Choose one option and enter your search criteria. Then fill in the required fields for each option. After you enter your search criteria, click on "Continue" to proceed with your search.

Choose one option and enter your search criteria

- Find a Nursing Home by entering some or all of the **Name**
- Find a Nursing Home within a certain distance of a **ZIP Code**
- Find a Nursing Home within a certain distance of a **City**
- Find a Nursing Home within a **State**
- Find a Nursing Home within a **County**

Choose one option and enter your search criteria

¹**Note:** CA, FL, NY, OH, TX have a large number of nursing homes. To make your search easier, we split these states in half geographically (e.g., Northern California & Southern California). If you are not sure which area you need to search, you can [view a list of counties](#) belonging to each area in these states.

Back
Forward
Save Background As...
Set as Background
Copy Background
Select All
Paste
Create Shortcut
Add to Favorites...
View Source
Encoding
Print...
Print Preview...
Refresh
Export to Microsoft Excel
Properties

What's New

In early 2012, the Centers for Medicare & Medicaid Services (CMS) will begin to display new quality measures based on MDS 3.0 nursing home resident assessments. These new quality measures will replace the quality measures that currently appear on Nursing Home Compare. CMS will not calculate a 5 Star Overall Rating or a 5 Star Quality Measures Rating based on these data until late 2012.

Learn More

Click on each link to get the following information:

- [File a Complaint with your State](#)
- [Your Rights as a Nursing Home Resident](#)
- Learn important information about each nursing home
 - [Five-Star Quality Rating](#)

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Internet 100%

MyMedicare

You can save these providers to a personalized favorites list from the My Providers tab of your MyMedicare.gov account.

[Sign up for MyMedicare.gov](#) to learn more. Already a Member? [Log in to your MyMedicare.gov account.](#)

Refine Your Results:

- [Nursing Homes within a Continuing Care Retirement Community](#)
- [Nursing Homes within a hospital](#)
- [Nursing Homes with Resident and Family Councils](#)

Show Information [View Nursing Home Locations on a Map](#) [What is this?](#)

Choose up to 3 nursing homes to Sort Table By:

Nursing Home Name and General Information ▲	Overall Rating [What is this?]	Health Inspections [What is this?]	Nursing Home Staffing [What is this?]	Quality Measures [What is this?]	Program Participation	Number of Certified Beds [What is this?]	Type of Ownership
<input type="checkbox"/> EDGEWOOD HOSPITAL 655 PARK CENTER DRIVE SANTEE, CA 92071 (619) 596-5500 <i>Located in a Hospital</i> Resident & Family Councils Mapping & Directions	★★★★★ 5 out of 5 stars	★★★★★ 5 out of 5 stars	★★★★★ 5 out of 5 stars	★★★★ 4 out of 5 stars	Medicare and Medicaid	192	Government - City/county

Choose up to 3 nursing homes to



What is a “five star facility”?

Star ratings are from:

- Health Inspections—”survey” by the government
 - Staffing—how many caregivers and nurses are there
 - Quality Measures—bedsores, falls, restraints, etc.
-
- The Five Star Quality Rating System is not a substitute for visiting the nursing home. It helps compare facilities to each other and gives you questions to ask.
 - Compares within a state, not between states.
 - Currently data is from January to September 2010—out of date?

Staffing is an important aspect of quality

Strengths:

- Tells you if the facility has enough staff to provide care.
- Adjusted for the Population: The ratings consider differences in how sick the nursing home residents are in each nursing home, since that will make a difference in how many staff are needed.

Limits:

- Self-Reported: The staffing data are self-reported by the nursing home, rather than collected and reported by an independent agency.
- Snap-Shot in Time: Staffing data are reported just once a year and reflect staffing over a 2 week period of time.
- Doesn't say how good the staff are, just how many there are.

Quality Measures use numbers to measure quality.

Strengths:

- Many measures on things that are important.
- National Measures: Same ones used in all homes in USA

Limits:

- Self-Reported Data:
- Doesn't take into account different populations
- Can be used as a reason not to take those with Huntington's Disease
- Limited to a few aspects of care.

TIP: Talk to the nursing home staff about quality measures and ask them to explain ones that seem off. Ask what else they are doing to improve the care they give their residents. Think about the things that are most important to you and ask about them, especially if there are no quality measures that focus on your main concerns.

Health Inspection results are an “outsiders view”

- Survey looks at all major aspects of care in a nursing home (about 180 different items).
- Focused on regulations more than on the experience of the residents.
- Variation between states—compare within a state not between states.

2012 everything turns upside down.

- This year, the Centers for Medicare & Medicaid Services (CMS) will begin to display new quality measures based on MDS 3.0 nursing home resident assessments.
- CMS will not calculate a 5 Star Overall Rating or a 5 Star Quality Measures Rating based on these data until late 2012.



Let's go and see.

WHAT TO ASK AND LOOK FOR ON A VISIT

Milieu

- Ask: what kinds of patients do you have here?
- Ask: What activities do you offer?
- Ask: What is your experience with Huntington's Disease? If not much, then ask "What about brain injury?"
- Observe:
 - Are there younger residents?
 - What are residents doing?
 - Do residents look happy?

Eating

- Ask: what are your thoughts about G-tubes?
- Observe: staff feeding a patient
- Ask: Can you get food 24/7?
- Observe: Does the food smell and look appetizing?

Safety

- Ask: When do you use physical restraints?
- Ask: How do you prevent falls and reduce the chance of injury when falls happen?
- Observe: Take a look at the beds and mats for the floor.
- Ask: What are your smoking policies?
- Ask: How secure is the facility?

Staffing

- Ask: How many patients to each staff on days, evenings and night shift?
- Observe: posted hours per patient day
- Ask: are staff consistent? What happens if more staff are needed?
- Observe: Are staff making eye contact with you, smiling, speaking kindly to the residents—do staff look happy?
- Talk to a direct care staff member and ask her about her job and what she likes about it.

Equipment: Broda and Care Foam Chairs



Expertise and consultation

- Ask: Which neurologist, psychiatrist and hospitals do they use? Are they satisfied with the help they receive?
- Ask: How does the doctoring work—are residents seen by their own MD or by SNF MDs?
- Observe the population—are younger people there? Men? Does the nursing home seem to attract different “kinds” of people of various ages and disabilities?
- Ask: What experience do they have with neurological disorders and brain injury?

Check it out

- Clean, odor free
- Is there a family council? Can you talk to another family?
- What is facility experience with Huntington's Disease
- How often does the doctor come to see the patients?

Is everyone in agreement?

- Individuals maintain autonomy unless these rights are removed from the courts.
- If an individual is impaired, but agrees with a good plan, then there is no problem.
- If an individual is impaired and does not agree with the plan, this is a problem.

Do you need conservatorship?

- Multiple types remove rights and give family or officials control over medications, admission or financial decisions.
- Usually needed if placement in a locked facility
- Solves some problems, but not others—not practical to force many things even if you have the “right” to.
- A durable power of attorney for health care or informal surrogate decision-makers may be enough.

Money matters

- You need INSURANCE
 - Medicaid. #1 funder of LTC. Must apply, have limited assets/poor
 - Medicare: over 65 or disabled two years. Apply. Pays for brief, “skilled” care after hospital.
 - Private insurance—generally pays little for long term care
- You need INCOME
 - SSI/SSDI —can provide income allowing board and care or assisted living.

SSDI

- After 2 years of SSDI, get [Medicare](#) coverage
- Requires earned credits for taxable work.
- Disability benefits are payable to:
 - blind or disabled workers
 - [their children](#)
 - [widow\(er\)s](#)
 - [adults disabled since childhood](#)
- Monthly disability benefit based on the Social Security earnings record of the insured worker.

SSI

- Benefits are not based on prior work history.
- Usually automatically eligible for [Medicaid](#).
- SSI benefits are payable to: over 65, disabled
- Eligibility requirements:
 - have limited [income](#) and [resources](#) meet the living arrangement requirements
 - a U.S. citizen or national, or in one of certain categories of aliens.
- Monthly payment varies

• http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/245/~/-/difference-between-social-security-disability-and-ssi-disability

What services are in your area?

- **Administration on Aging (AoA)** lists long term care services in each state: Visit www.aoa.gov or call 1-202-619-0724.
- **Centers for Medicare & Medicaid Services (CMS)** has free booklets. Call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.
- **Eldercare Locator** is a nationwide toll-free service to find local services. Visit www.eldercare.gov or call 1-800-677-1116

BECAUSE SO MANY RESOURCES ARE NEEDED, THESE PATIENTS ARE YOUNG, THEY FALL, THEY TAKE A LONG TIME TO FEED, THEY NEED A HIGHER STAFFING LEVEL, AND THEY HAVE DIFFICULT BEHAVIORAL PROBLEMS (SMOKING, VIOLENCE, SUICIDAL).

TOO RISKY AND TOO EXPENSIVE

**PLACING H.D. PATIENTS IN
NURSING HOMES IS HARD.**

Why can't I find a nursing home for B?



What's the problem?

- Wants to walk but falls at least twice a week and usually is bruised.
- Wears skimpy tank tops, refuses normal shoes
- Takes two antipsychotic medications and a benzodiazepine.
- Hugs and kisses everyone, even if they don't like it.
- Screams when thwarted, may hit.
- Loves activities, but has to leave after 5 minutes, returns, leaves—cannot focus.
- Calls her family incessantly—they are exhausted.

Who is this a problem for?

- Nursing homes care for very sick people with low reimbursement, untrained and low levels of staffing, and strict state and federal regulations governing care that are designed for elderly.

Nursing homes don't want

- Medicaid
- Younger patients
- Those who take too long to feed
- High risk residents who might fall, hit, choke, take antipsychotic medications.
- “difficult families”

Expected issues for H.D.

- Diet/nutrition
- Behavioral management
- Safety
- Expert consultation
- Management of medical conditions
- Psycho-social-spiritual concerns
- End of life concerns
- Physical, occupational speech rehabilitation therapies
- Risk sharing
- Supporting caregivers

Getting a nursing home to choose you!

- Present yourself as flexible, knowledgeable about both H.D and the concerns of the nursing home and not likely to sue.
- Be prepared to educate them about HD.
- Offer your assistance—e.g. “I will come and feed every lunch”
- Suggest a respite stay.

Aligning Expectations

- Nursing homes cannot work miracles—they assign each resident to a caregiver who is often caring for 6-12 other residents at the same time.
- The average resident in a California nursing home gets about 3-4 hours of care in every 24 hours. , it is much less in other states.
- Nursing homes have gravity, hard floors, sharp edges and don't miraculously fix behavior problems.

Adjusting and Aligning Expectations

Caring for H.D, especially in the later stages, is all about adjusting your expectations and often about giving up a need for control.

Remember

All
treatment
for HD is
palliative

- focus on:
 - maximizing autonomy and self-determination
 - Reducing, but not curing symptoms
 - enhancing quality of life
 - preserving function,
 - promoting safety.

Options to stay at home a little longer or try an intermediate step.

SECOND THOUGHTS ABOUT NURSING HOME?

Want to stay at home?

- Services are available, often funded by Medi-Caid, to keep people in their own homes
 - in house support services
 - Home visits from doctors
 - Skilled home care services including therapy, wound care
 - Hospice
 - Respite care
- You can find these services through Area Agency on Aging, Social workers at hospitals and doctors' offices.
- Most providers not too familiar with Huntington's Disease.

Alternatives to Nursing Homes

Continuing Care Retirement Communities (CCRCs)

- CCRCs offer multiple levels of housing or care, depending on need.
- You pay a fee, and move from one level to the next as your condition and needs change—all the way to a nursing home.
- Usually a large payment to start and then monthly fees.
- Find out if a CCRC is accredited and get advice on selecting this type of community from the Commission on Accreditation of Rehabilitation Facilities and the Continuing Care Accreditation Commission (CARF-CCAC) by calling 1-202-587-5001 or www.carf.org and check Nursing Home Compare.

Board and Care/Group Homes

- Share a room
- Group living in the community
- Help with some activities of daily living like bathing, dressing or using the bathroom.
- Not all take wheelchairs, not all offer much help with medications, some exclude those with “dementia.”
- Not paid for by Medicare or Medicaid.
- The monthly charge is usually a percentage of your income –SSI/SSDI (a sliding scale) that covers the cost of rent, meals, and other basic shared services.

Assisted Living Facilities provide food and recreation and some services, for a fee.

- Own room or apartment within a building
- Provides meals, recreational activities, some health care.
- A little more supervision
- Help with ADLs AND can provide medications, appointments or meal preparation—all for a fee.
- Highly variable about costs and benefits, Need to check it out and make sure it is right for you.

Alternatives to Nursing Homes: PACE or Waivers

Program for All Inclusive Care for the Elderly (PACE)

- Program for those with Medi-care and Medi-Cal, age 55 and up, who are eligible for nursing home, but prefer to stay home with services.
- PACE manages all of the medical, social, and long-term care services for frail people to remain in their homes and to maintain their quality of life.
- To find out if there is a PACE program in your area, visit: www.cms.hhs.gov/PACE.

Home and Community-Based Waiver Programs

- Program for those eligible for Medicaid funded SNF, but who choose to stay in community.
- Offers help like homemaker services, personal care, and respite care.

More Options for those who need care

Hospice Care

- Requires MD certification of prognosis of less than 6 months to live
- Benefit provided with Medicaid and Medicare.
- Many services to provide comfort and support through a team of experts
- Care provided in home, hospice facilities or nursing homes.

Respite Care:

- A short admission to nursing home or hospice for caregiver relief.
- Medicare covers 5 days for those on hospice.
- A chance to find out how a loved one will do in a facility.

CONTACT US WITH QUESTIONS



alechich@archcare.org

Anthony J. Lechich, MD
Terence Cardinal Cooke Health
Care Center
1249 5th Ave.
New York, NY 10029

Rebecca.ferrini@sdcounty.ca.gov

Edgemoor Distinct Part SNF
655 Park Center Drive
Santee, California 92071
619-596-6351

RESOURCES

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