



*HDSA National Convention
June 27, 2015*

Long Term Care: When is it time to Consider?

Cheryl Lenheiser, LCSW
Licensed Clinical Social Worker
South Central Region



Huntington's Disease
Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2015 HDSA Convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenter Disclosures

Cheryl Lenheiser

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
or list



When to Think about Long Term Care

Long Term Care can seem like an overwhelming option to many patients and families. What options are available? When is it the right time to start looking for long term care and how can my family afford to get help?

What is Long Term Care?

- Long Term Care (LTC) is a term used to refer to a variety of services which help meet both the medical and non-medical needs of a person who is disabled or has a chronic illness. (wikipedi.com)
- A combination of medical, nursing, custodial, social, and community services designed to help people who have disabilities or chronic care needs. Services may be provided in the person's home, in the community, in assisted living facilities or in nursing homes. (caregiver.com)

Signs Care is Needed:

- Spoiled food that doesn't get thrown away
- Missing important appointments
- Unexplained scraps and/or bruising
- Forgetfulness
- Uncertainty or confusion when performing a once familiar task
- Difficulty with walking, balance and mobility
- Trouble getting up from a seated position
- Strong smell of urine in the house
- Noticeable decline in grooming and personal hygiene
- Un-kept or dirty house / living space
- Extreme clutter in the house

- Dirty laundry piled up
- Stacks of unopened mail or an overflowing mailbox
- Late payment notices, bounced checks and calls from bill collectors, thank you notes from charities or crisp unread magazines
- Poor diet or unexplained weight loss
- Loss of interest in hobbies and activities
- Plants that are dying, dead or simply disappear
- Pets that appear neglected

- Extreme mood swings
- Medication Issues
 - Forgets to take
 - Takes wrong dosage
 - Refuses medication

(www.aging.com, 2014)

Additional Signs:

- Anxiety
- Aggression
- Isolation
- Caregiver Stress

(caregiver.org)

Emotional Responses

- The decision to incorporate care, in or out of the home, is complex
- Emotions can run high
 - possible increase in anxiety or aggression
- Denial
 - The unrealistic hope that a problem is not really happening and will go away by itself
 - Loss of awareness versus denial

Loss of Independence – a major role in our society

Caregiving & Caregiver Stress

- More than 15 million Americans devote time and energy to caring for a loved one with a chronic illness. (caregiving.com)
- Sometimes the cost of caregiving becomes too high as the caregivers find themselves unable to bear the burden of providing long term care without suffering from stress and illness themselves.
- The psychological cost of caregiving has been likened to the effects of post-traumatic stress disorder. (New York Times, February 2013)

Caregivers may experience symptoms such as:

intrusive thoughts, disabling anxiety, hyper-vigilance,
avoidance behaviors

Caregivers experience:

isolation, sleep deprivation, anger, resentment and GUILT

What Happens When My Loved One Needs More Help?

- Deciding on care is never easy: caregiver guilt and grief play a role
- “Lose Twice” – lose family member to the disease and then again when they pass
- Separation Anxiety for both the loved one and the caregiver
- Loss of traditional roles in the family

Steps Involved

- Plan ahead
 - Research options, visit facilities, explore finances to pay for help
- Communicate with all involved
 - Counseling, Support Groups, Connect with Others
 - “Seek out help – medication can be a powerful tool when appropriate but no pill can provide the supportive connection and warmth of another person.” (A Place for Mom, 3/11/2013)

Pay attention to Health

Regular Exercise and a Healthy Diet for both parties

Realize you are HUMAN and can only do so much before taxing your own health

Types Of Care

- Telephonic Call Assurance
 - Automatic or live telephone system / regularly set calls to confirm medication taken
 - Emergency Response Systems / press a button for a fall
- Companions / Caregivers / Private Duty
 - Assistance with housekeeping, shopping, meals, driving, and provide social interaction.
 - Does Not include medical care or dispensing of medication
- Respite Care (in-home or at a facility)
 - Short term care while the primary caregiver is away
 - Some facilities have beds available for Respite Care
 - Some agencies will contract for in-home Respite Care

- Home Health Care / Visiting Nurses
 - Registered Nurse (RN) who comes to the home to provide medical care, rehabilitation or hospice care
 - Must be ordered by a physician
 - Short term only (2-6 weeks)
- Skilled Nursing Placement (following a hospitalization)
 - Must be ordered by a physician
 - Short term
 - Medicare coverage / Private Insurance contracts
- Retirement Communities
 - Typically age requirements of 65 or older
 - Must be Independent in Daily Living except for meals and laundry

- Assisted Living
 - Can increase care as needs increase
 - Meals, housekeeping, laundry and some personal care
 - Socialization and community activities
- Nursing Home / Long Term Care Facility
 - Full-time medical care
 - Full range of care and activities
 - Considered Custodial Care
- Continuum Care Facilities
 - Facilities / Communities that offer multiple levels of care
 - Range of care from Independent to full nursing care

- Hospice Care
 - Requires a physician order
 - Must be “terminally ill” and approximately in the last six months of the disease process
 - Available at home or in a care facility

Questions & Discussion

Resources:

www.hdsa.org

A Physician's Guide to the Management of Huntington's Disease

www.wikipedia.org

www.caregiver.com

www.caregiver.org

www.aging.com

www.longtermcare.gov

Cheryl Lenheiser, LCSW
Licensed Clinical Social Worker
South Central Region
Huntington's Disease Society of America
214-952-2378
clenheiser@hdsa.org