

## Approaching End of Life Across the Continuum of Care



Pioneer Network Conference, August 4, 2015

The Power to Redefine Aging.  
 

---

---

---

---

---



---

---

---

## Objectives

- The learner will define 3 common domains of well-being important to residents, families and staff at the end of life
- The learner will list ways to assess what each person considers important at the end of his or her life.
- The learner will list and compare approaches for anticipating and meeting the needs of residents and families at end of life.

The Power to Redefine Aging.  
 

---

---

---

---

---

---

---

---

## Hebrew SeniorLife

- Who are we?
- Multi sites and services
- Continuing Care Retirement Community (CCRC) on Dedham campus and within greater system

The Power to Redefine Aging.  
 

---

---

---

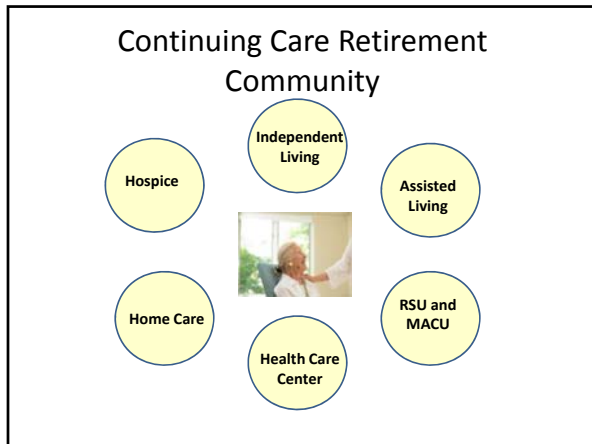
---

---

---

---

---



---

---

---

---

---

---

---

---

### What is End of Life?

- Days, months, years?  
End of life care is 'providing comfort care and holistic care to dying patients and families in a time frame of days to weeks when they are actively dying'?

OR:

A discreet time period when the person is aware of the end of life, but not limited to a medically determined period of time?

- Who defines the term 'end of life'?

The Power to Redefine Aging.  
 Hebrew SeniorLife | HARVARD MEDICAL SCHOOL AFFILIATE

---

---

---

---

---

---

---

---

### End of life choices

- The goals of care (for example, whether to use certain medicines during the last days of life)
- Where you want to spend your final days
- Which treatments for end-of-life care you wish to receive
- What type of care you wish to receive

The Power to Redefine Aging.  
 Hebrew SeniorLife | HARVARD MEDICAL SCHOOL AFFILIATE

---

---

---

---

---

---

---

---

## Defining a Good Death

“There is no one definition of a good death...quality end-of-life care is a dynamic process that is negotiated and renegotiated among family and residents...a process moderated by individual values, knowledge and preferences”

Steinhauser, 2001



---

---

---

---

---

---

---

---

## Defining a Good Death

- Freedom from pain
- Clear decision-making/wishes followed
- Completion
  - Saying goodbye to important others
  - Being at peace with God
  - Resolving unfinished business
  - Prayer
  - Discussing personal fears about dying
  - Having a chance to talk about the meaning of death



---

---

---

---

---

---

---

---

## Domains of well-being

- Physical well-being and symptoms:
  - Functional ability
  - Strength and fatigue
  - Sleep and rest
  - Nausea
  - Appetite
  - Constipation
  - Pain



---

---

---

---

---

---

---

---

### Domains of well-being

- Psychosocial well-being
  - Anxiety
  - Depression
  - Enjoyment/leisure
  - Pain distress
  - Happiness/fear
  - Financial burden
  - Roles and relationships
  - affection

The Power to Redefine Aging.  


---

---

---

---

---

---

---

---

### Domains of well-being

- Spiritual well-being:
  - Love and Belonging
  - Forgiveness and Reconciliation
  - Trust
  - Hope
  - Meaning
  - Gratitude
  - Identity

\* From HSL's Spiritual Assessment Tool

The Power to Redefine Aging.  


---

---

---

---

---


---

---

---

### Guiding EOL Wishes- Making Choices

- Who decides?
- Principle of autonomy
- Documents that address advance directives
  - MOLST, POLST...
  - 5 Wishes
- Knowing each person
- Art of communication

The Power to Redefine Aging.  


---

---

---

---

---

---

---

---

### Choices about Physical Comfort

- What amount of pain do you consider acceptable?
- If we need to make a choice between drowsiness and comfort, what do you prefer?
- Does physical touch soothe you? Or would you rather not be touched?
- Does music help ease the physical pain?
- What has helped you to feel better in the past?



---

---

---

---

---

---

---

---

### Choices about Emotional Comfort

- Would you prefer to participate in your usual activities for as long as possible, even if doing so may cause physical discomfort?
- Are there tasks you need to complete?
- Who do you want with you during this time?



---

---

---

---

---

---

---

---

### Spiritual Choices

- Who do you want to be with at this time?
- Is there anyone you want to forgive or reconcile with?
- Who would you like to say goodbye to?
- What will help you feel at peace?
- Would you like any religious rituals? Prayer?
- Would you like to talk about dying? About what is happening to you?
- Is there anyone you would like to express gratitude to?



---

---

---

---

---

---

---

---



## End of life Thoughts in Independent Living

Interview with Executive Director

Chaplain/Rabbi:

- Transitioning from home to 'independent housing within a CCRC'
- Communal living- loss of privacy
- Loss of autonomy
- Frailty and isolation
- Losing a spouse or life partner
- Losing loved ones and friends
- Preparing for last stage of life



---

---

---

---

---

---

---

---

## End of Life Thoughts Across All CCRC Settings

- Assessing readiness to discuss end of life concerns "Meeting the person where they are"
- Providing space to discuss loss and grief
- Educating about options and choices available
- Challenge of balancing living fully and well and also planning for end of life
- Self-care



---

---

---

---

---

---

---

---

## Hebrew SeniorLife Mission

In the spirit of the Fifth Commandment, as illuminated by the traditions of the Jewish people, our mission is to honor our elders, by respecting and promoting their independence, spiritual vigor, dignity and choice, and by recognizing that they are a resource to be cherished. As part of our mission, we accept special responsibility for the frailest and neediest members of our community who are most dependent on our care. Everything we do flows from these tenets and is further inspired by the duty of *tikkun olam*-to heal the world.



---

---

---

---

---

---

---

---

### End of Life 'Care' in IL setting

- Support group: "Conversations about Loss and Grief"
- Advance Care Planning informational meetings
- Community groups led by Rabbi from our hospice




---

---

---

---

---

---

---

---

### Opportunities for Healing

#### Mi Sheberach Prayer for Healing מִי שְׁבֵרַח

Healing of the spirit and healing of the body רְפוּאָת הַנְּפֹשׁ וְרְפוּאָת הַגּוּף

Mi shebeirach avoteinu      *May the one who blessed our forefathers*  
 M'kor hab'racha l'imoteinu      *Source of blessing for our foremothers*  
 May the source of strength,  
 Who blessed the ones before us,  
 Help us find the courage to make our lives a blessing,  
 and let us say, Amen.

Mi shebeirach imoteinu      *May the One who blessed our foremothers*  
 M'kor habrachah l'avoteinu      *Source of blessing for our forefathers*  
 Bless those in need of healing with r'fuah sh'leimah, complete healing  
 The renewal of body, the renewal of spirit,  
 And let us say, Amen

~ Words and music by Debbie Friedman




---

---

---

---

---

---

---

---

### End of life 'Care' in the Health Care Setting (Long term care)

- Admission process
- Susan Mitchell work "Advance Dementia: A Guide for Families"
- Environment of care
- Palliative care team/approach




---

---

---

---

---

---

---

---



## Palliative Care and Culture Change

- Culture change is the transformation of older adult care based on person-centered values and practices where the voice of elders and those working with them is considered and respected
- Palliative care is an approach that improves quality of life of residents and their families facing life-limiting illness through the prevention and relief of suffering, physical, psychosocial and spiritual in nature



---

---

---

---

---

---

---

---

## Palliative Care Principles

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends to neither hasten or postpone death
- Offers a support system that people live as actively as possible until death
- Uses a team approach to address the needs of residents, families, and staff
- Resident and family-centered care
- Based on resident's values, beliefs, preferences and goals
- Communication skills



---

---

---

---

---

---

---

---

“Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice”

Coalition for Compassionate Care of California and the California Culture Change Coalition, 2010



---

---

---

---

---

---

---

---

## Macro Response

- New position: Collaborative Care Advisor
- Transitions between locations
- AL/IL Life Enhancement Coordinator
- IL/HCC link with retired mental health providers group




---

---

---

---

---

---

---

---

Rav Nachman said to Rav, "Dying was as gentle as lifting a hair out of milk." (Talmud Mo'ed Katan 28a)

*"Dying should be gentle.... [people] should not die for the wrong reasons: from loneliness, boredom, or uselessness; for lack of food because the money of their youth will not suffice for the needs of their old age; because of reliance on medications when love and care will suffice...; for lack of good teeth because of inaccessible dental care; because no one asked them to dance or to play with their babies; or to advise them on their troubled love lives; because someone did not hug them or kiss them or touch them enough; because no one asked them 'What are you good at doing?';...because no one asked them to share their life stories...; because they were told too many times, 'Let me do this for you'..... (source unknown)*




---

---

---

---

---

---

---

---

*You Matter Because You Are.  
You Matter to the Last Moment of your Life.  
(Cicely Saunders)*

Heather Dexter, LICSW  
Roslindale Long-Term Care  
617-363-8405  
[heatherdexter@hsl.harvard.edu](mailto:heatherdexter@hsl.harvard.edu)

Anne Mahler, Clinical Nurse Specialist,  
Professional Development  
781-234-9347  
[annemahler@hsl.harvard.edu](mailto:annemahler@hsl.harvard.edu)

Susan Moser, Chaplain  
Culture Change Coach  
617-363-8799  
[susanmoser@hsl.harvard.edu](mailto:susanmoser@hsl.harvard.edu)




---

---

---

---

---

---

---

---