Chrysalis: Transforming the End-Of-Life Experience

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Learning Objectives

Learn how to integrate quality of death into quality of life and transform the entire care environment for residents, staff and loved ones.

Identify design elements that create a “sacred space” that supports end-of-life care in senior living settings.

Review a case study of a successful implementation of a Chrysalis Room and Memory Garden within an Illinois CCRC.

Share best practices and future innovations supporting end-of-life care.
Loretta S. Downs, MA, CSA
www.endoflifeinspirations.com
Supporting the End of Life
My mother, Anna Piazza Schenk, and I, in her “home”
Nearly one-quarter of Americans 65 and older could become "elder orphans" with no family to help care for them.

Approximately one-third of Americans 45 to 63 years of age are single.

71% of Americans over 75 live alone.

It is estimated that by 2030 about 5.3 million seniors will be living in nursing homes, which include hospital, rehabilitation and hospice facilities. That is up from about 1.3 million Americans in 2012.
The Dementia Effect on End of Life Care

The majority of older Americans whose underlying cause of death is attributable to dementia on their death certificate die in nursing homes.

Where do Americans die?

Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.

Despite this, 60% of Americans die in acute care hospitals, **20% in nursing homes** and only 20% at home.

A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life.

However, not every patient will want to die at home. Dying at home is not favored in certain cultures (due to cultural taboos) and some patients may wish not to die at home, out of concern that they might be a burden on the family.

Care at Life’s End

In their last days, older patients are increasingly likely to be shuttled among hospitals, nursing homes and hospices in pursuit of Medicare and Medicaid coverage. Ultimately, most die in an institution, rather than at home.

Among Medicare beneficiaries over 65 who died*

<table>
<thead>
<tr>
<th>Place of care</th>
<th>Percentage receiving treatment in last days**</th>
<th>Transfers</th>
<th>Place of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>70%</td>
<td>3</td>
<td>31% Home</td>
</tr>
<tr>
<td>Nursing home</td>
<td>50%</td>
<td>2</td>
<td>35% Acute care hospital</td>
</tr>
<tr>
<td>Hospice</td>
<td>30%</td>
<td>1</td>
<td>27% Nursing home</td>
</tr>
<tr>
<td>Intensive care unit</td>
<td>10%</td>
<td></td>
<td>28% Other</td>
</tr>
</tbody>
</table>

*Excludes Medicare Advantage members. **Patients may get care in more than one place. Those receiving hospice care may get it anywhere, not just in a stand-alone hospice.

Source: Journal of the American Medical Association
Nursing Homes Rank as Worst Setting For End-of-Life Care

“Reported care experiences are typically worse in the nursing home setting, according to the latest results of a survey by the Centers for Medicare & Medicaid Services.”

Source:
What would happen if we include quality of death in our standards for quality of life?
Components of High-quality end-of-life care

“...result when health care professionals (1) ensure desired physical comfort and emotional support, (2) promote shared decision making, (3) treat the dying person with respect, (4) provide information and emotional support to family members, and (5) coordinate care across settings.”

Actions that result in a High Quality Death

- Staff training on the natural dying process
- Lead by example: complete your own advance directives and hold community education events: www.nhdd.org
- Person-centered discussion to determine goals of care and quality of life at every stage of life
- POLST form
- Acknowledge turning points and adjust goals of care
- Provide person-centered palliative care
- Admission to hospice care
- Provide Sacred Space for keeping vigil with the dying
Length of Stay in Hospice Care

- 180+ days: 10.3%
- 90 - 179 days: 8.7%
- 30 - 89 days: 17.8%
- 15 – 29 days: 12.9%
- 8 – 14 days: 14.5%
- < 7 days: 35.5%

Median LOS for 2014 was 17.4 days

Source: National Hospice and Palliative Care Organization
2015 Facts and Figures Hospice Care in America
We use Hospice as a last resort, when it is a last reward.

Hospice improves quality of death. This in turn, improves the quality of all of our lives.
The environment in which an experience occurs, effects the quality of that experience.
The Call for Sacred Space For Keeping Vigil

“Dying is a spiritual process with medical implications.”

—Gwendolyn London, PhD, Duke University School of Divinity
The Four Things

....we need to say before we say goodbye:
I love you
Thank you
I’m sorry.
I forgive you
Goodbye
In the Chrysalis Room With Anna

https://www.youtube.com/watch?v=hJEfgNJwahM&feature=youtu.be
“LIFE GIVES US TWO GREAT GIFTS,
LOVE AND DEATH.
MOSTLY, THEY ARE PASSED ON UNOPENED.”

—RUMI
Carlo Salvador, AIA, LEED® AP
Principal, Keganivo Group
Designing for Hospice
Biophilia - love of life or living systems

Biophilia is defined as the inherent need of humans to interact and affiliate with the natural world to achieve and maintain optimum health and well-being.

Edward O. Wilson 1984
Harvard Biologist
Connection to Nature

- Access to outdoor spaces and gardens
- Creates Physical Well-being
- Promotes Positive Interactions
- Reduces Stress and Mental Fatigue
- Helps Heal
Design with Family in Mind

- Welcoming reception area with 24 hour service
- Family and friends should have access to a living room to allow for refreshments, TV watching, and a place to simply get away.
- Shower facilities for visitors
- Space for family counseling

Blue Skies of Texas designed by Perkins Eastman
Childers Place designed by Perkins Eastman
Resident Focus

- Single bedrooms with ensuite bathrooms
- Connection to the outdoors with the ability to roll the bed outside
- Allow for personal items to be displayed, with rails or shelving
- Easy access to the nurse call system
- Larger beds for family or friends to sit with the resident
Resident Focus

• Acoustics are very important to both aid in hearing and ensure privacy

• Minimize noise by using carpet on the floor, acoustic ceiling treatments, upholstered furniture and window treatments
Type A - Walk Out Sun Porch

Type B - Bay Window

Childers Place designed by Perkins Eastman
Blue Skies of Texas designed by Perkins Eastman
• Headwall disguises medical outlets, receptacles and switches
Case Study: Central Baptist Village
Serene artwork

Accent lighting to provide various lighting levels in the room

Serving counter for refreshments

Hospitality cabinet with under counter refrigerator and storage for family’s personal belongings

Additional folding chairs
Visual connection to a garden
Privacy curtain for the resident with “residential” fabric pattern
Serene artwork
Accent lighting to provide various lighting levels in the room
Guest chair beside the bed
Fold out sleeper sofa for overnight stays
Carpet tile floor covering
Storage for resident and family

TV for display of photos and family videos

iPod docking station

Space for vigil
Budget

- $4,900 bed
  - Residential styling
  - Hidden castors
  - 36”x82” mattress

- $8,400 KI Furniture
  - Footwall
  - Bedside table
  - Sleeper sofa
  - Bedside chair and footrest
  - Hospitality cabinet

- $1,800 soft treatments
  - New cubicle curtain (re-use existing track hardware)
  - New cornice

- $675 artwork
Dawn Mondschein, LCSW, LNHA
Executive Director, Central Baptist Village
Case Study: Central Baptist Village

250 unit non-profit CCRC

Independent – Assisted – Skilled Nursing – Memory Care
Project Rationale

Unmet needs of residents and loved ones

Natural extension of mission – if not us, who?

Opportunity to excel & differentiate

Census
Transforming the EOL Experience

Philosophy
Chrysalis EOL Inspirations
Loretta Downs

Environment
In-patient Hospice Tours
Perkins Eastman Designers

Cultural Shift
Culture Change Strategy
John P. Kotter
8 Step Culture Change Process
Steps 1 – 4

**Establish a Sense of Urgency**
- Awakening / recognizing unmet needs
- Identifying crisis and/or major opportunity

**Create a Guiding Coalition**
- Putting together a group to lead change
- Champions Committee

**Develop a Vision & Strategy**
- Creating a vision to help direct change effort
- Procedures, Interior Design, Outcomes

**Communicate Change Vision**
- Using every vehicle possible to constantly communicate the new vision and strategies

Develop a Shared Vision & Strategy

• EOL care is not “business as usual”

• Once in a lifetime event must be honored

• Comfort and dignity is the highest priority

• Families need guidance, support and confidence in caregivers

• *Everyone* needs permission to engage in end-of-life
Communicate the Change Vision

COMING SOON...

CBV's very first
CHRYSLASIS ROOM
(kris-l-iss)

A chrysalis is the stage of stillness in which a caterpillar transforms into a butterfly.

Our Chrysalis Room, located on the first floor of the Pavilion, is specially designed to support residents and families during the end of life transition.

This new sacred space includes:
- Comfortable décor featuring soothing colors and nature inspired artwork
- Eastern view featuring filtered light and overlooking the patio, pond, trees and evergreens
- Specialized bed for enhanced Resident comfort & flexible positioning
- Flat screen television and music system
- Countertop to display personal photographs and memorabilia
- Chair with ottoman at bedside and additional folding chairs for visitors
- Sofa and coffee table
- Refreshment station
- Internet access for visitors
- Sleeper sofa for families to rest or spend the night

"Like birth, death is a natural part of life, a sacred transition that is meant to occur and meant to be shared with those who love and care for us."

Loretta Downs

Grand Opening & Dedication
Introducing CBV's very first
CHRYSLASIS ROOM

A sacred space for Residents and Families during the end of life transition

Chrysalis is a stage of stillness in which a caterpillar transforms into a butterfly.

Join us to experience this sacred space and learn about how we at Central Baptist Village can help residents and families enjoy a graceful, peaceful, and sacred transition.

All employees are invited to a special DEDICATION CEREMONY:

WHEN: Wednesday, June 12
TIME: 2:30 p.m.
WHERE: The Pavilion ~ Room 3148
Steps 5 - 8

**Empowering Broad Based Action**
- Getting rid of obstacles, policies that undermine changes
- Encourage risk taking, make mistakes!

**Generating Short Term Wins**
- Create those wins, celebrate success
- Visibly recognize & reward people who make wins possible

**Consolidating gains & more change**
- Use increased credibility to promote more change
- Reinvigorate the process with new projects & themes

**Anchoring New Culture**
- Articulate the connections between new behaviors and organizational success
- Develop means to ensure leadership & succession

Empowering Broad Based Action

• Nurses & Social Workers initiate room change request

• “Sacred Journey” to the Chrysalis Room

• Primary caregivers attend to resident & loved ones

• Culinary delivers refreshments to the nourishment center
Empowering Broad Based Action: Sacred Journey
“I pray for them. I spend time just holding their hand.”

“I tell them how much I loved them.”

“The most important thing is to make sure my Resident is clean and comfortable. I want everything to look and feel peaceful for the family.”
“I sing to my Residents. Whatever songs I know they liked. This way they know they’re not alone.”

“I let them know it’s okay to go. I’ll encourage them…’Go ahead, your husband is waiting for you to make him the BEST Sunday dinner in the world’”
Empowering Broad Based Action

- Visitors, peers & staff support family and loved ones
- Community members extend support to the resident, family & each other
- Threshold Singers pay a visit…or two
- We wait in peace and comfort
Threshold Singers

Threshold Choir is a network of *a cappella* choirs of primarily women's voices: a community whose mission is to sing for and with those at the threshold of life.

[thresholdchoir.org](http://thresholdchoir.org)
“She went peacefully & her comfort was unbelievable...”

“[staff] got me through the toughest time in my life”

“...she needed and deserved this”
Generating Wins: Feedback & Recognition

“The caregivers were amazing. They took care of mom and they spent lots of time comforting me all through the night.”

“We will never forget your kindness.”
Generating Wins - Celebrate Success!
Consolidating gains & producing more change

Memory Garden
Memory Garden Escort & Cultural Reinforcement
Outcomes & Benefits: Staff Testimonials

“The room is like a stage that let’s us do our job just right”

“It helps us let-go of our Residents; helps us grieve”

“The room changes family expectations - it takes the pressure off the nursing staff to help the Resident get better again.”
Staff Testimonials

“This room stops the suffering. It heals.”

“Most of all, it puts the family at ease seeing their loved one comfortable and tended to with compassion.”

“The families finally get a glimpse of the bond we have with their loved ones.”
Family Testimonials

“Definitely helped bring about closure a lot faster by being there”

“To be able to witness the dying process this way was very enlightening – it’s not as frightening as we once thought”

“It was a good bonding experience for our entire family”
Keys to Culture Change

• Staff input and ownership
• Clear vision and goal
• Over communication and program awareness
• Ongoing feedback
Organizational Benefits

• Renewed sense of purpose

• Staff empowerment

• Visible commitment to mission

• Leaves a “lasting impression”
It is in being with dying that we learn how to die, and the death experience of a loved one stays with the survivors for the rest of their lives.

~ Loretta Downs
Group Discussion Questions

1. Describe your idea of the ideal setting for end-of-life

2. What are the obstacles or challenges your community faces in providing a high quality of death?

3. What does your community currently do and what are some new, innovative ways to support end-of-life?