

Chrysalis: Transforming the End-Of-Life Experience



CENTRAL
BAPTIST
Village

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Inspirations

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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



A monarch butterfly is shown resting on a leaf. The word "SUPPORTING" is written vertically on the leaf. The slide has a decorative leaf graphic in the top-left and bottom-right corners.

**My mother, Anna Piazza Schenk,
and I, in her "home"**



A person is seated in a wheelchair, being pushed by another person in a hallway. The slide has a decorative leaf graphic in the top-left and bottom-right corners.

Demand For Nursing Homes


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 'elder orphans' of the Baby Boom Generation By Carina Storrs, Special to CNN Updated 4:22 PM ET, Mon May 18, 2015
<http://www.cnn.com/2015/05/18/health/elder-orphans/>



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.

A national study of the location of death for older persons with dementia
 Mitchell SL, Teno JM, Miller SC, Mor V. J Am Geriatr Soc. 2005 Feb;53(2):299-305. Erratum in: J Am Geriatr Soc. 2005 Apr;53(4):741.

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.

Source: Stanford School of Medicine Palliative Care, <https://palliative.stanford.edu/home-hospice-home-care-of-the-dying/patient/where-do-americans-die/>

Care at Life's End

At their last days, when patients are no longer able to be attended at home, hospice, nursing homes and hospitals are typical of Medicare and Medicaid coverage. (1) In addition, most die in all ambulatory care settings at home.

Among Medicare beneficiaries over 65 who die*

Place of care	Percentage receiving treatment in last month**
Hospital	2
Nursing home	2
Hospice	1
Intensive care unit	1

Transfers	Among facilities and home	Average number in last 51**
Hospital	27%	33
Nursing home	27%	27
Hospice	13%	18

Place of death	Percentage
Home	20%
Acute care hospital	39%
Nursing home	25%
Other	14%

*Excludes Medicare Advantage members. **Patients may get care in more than one place. Those receiving hospice care may also receive care in a skilled nursing facility.

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:
<http://seniorhousingnews.com/2014/08/17/nursing-homes-rank-as-worst-setting-for-end-of-life-care/>

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."

Teno, J.M., Cleverley, B.A., Casey, V., Wehn, L.C., Wells, T., Rabold, S., Mor, V. (2004). Family perspectives on end-of-life care in the last place of care. *Journal of the American Geriatrics Society*, 52(1), 88-93.

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 CHRYSALIS ROOM—CREATING SACRED SPACE


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

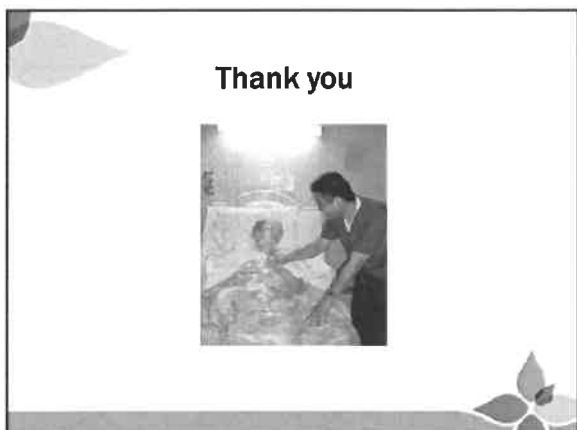


•The Four Things

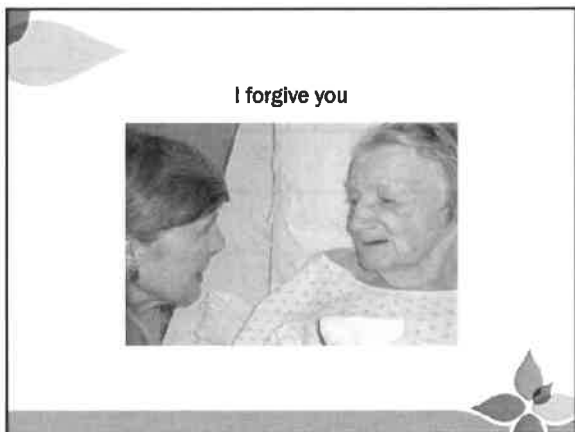
....we need to say before we say goodbye:

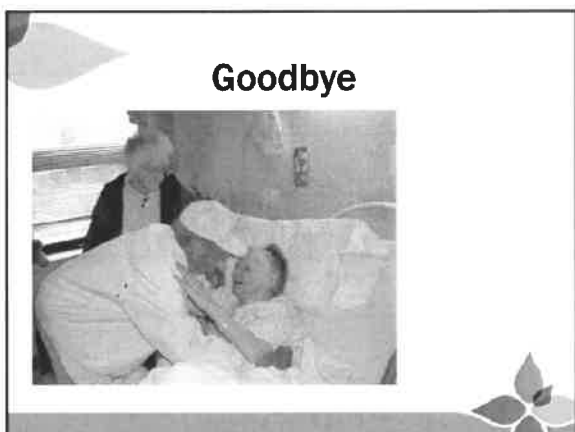


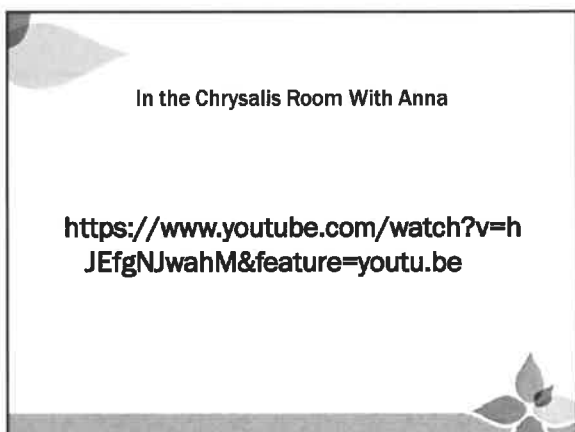


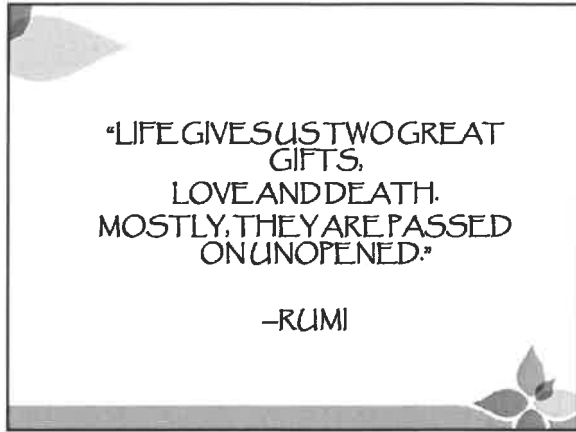


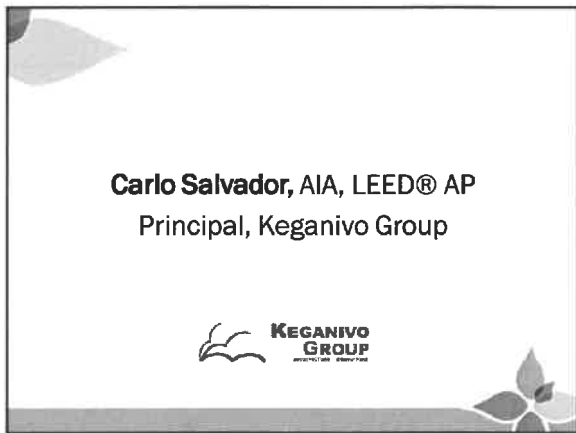
















Biophilia - love of life or living systems




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





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

Childrens Place designed by Perkins Eastman

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

Childrens Place designed by Perkins Eastman



Childer's Place designed by Perkins Eastman



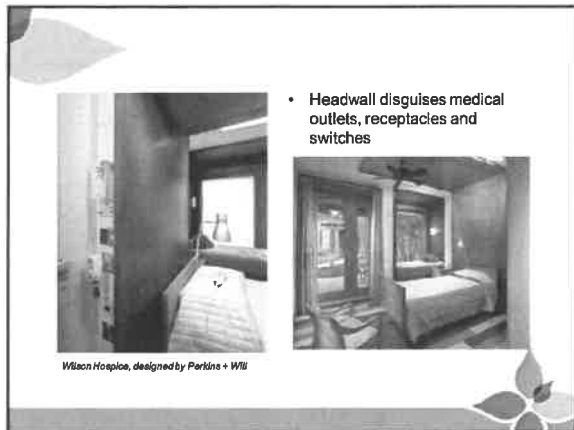
Type A - Walk Out Sun Porch

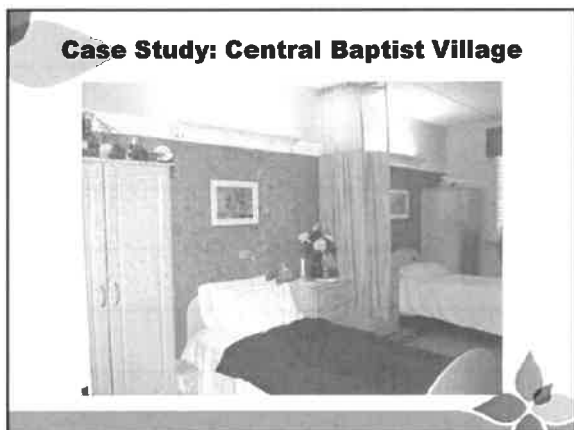
Type B - Bay Window

Childer's Place designed by Perkins Eastman



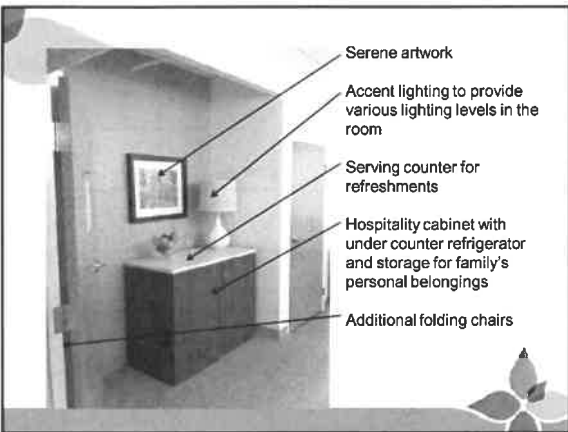
Blue Skies of Texas designed by Perkins Eastman

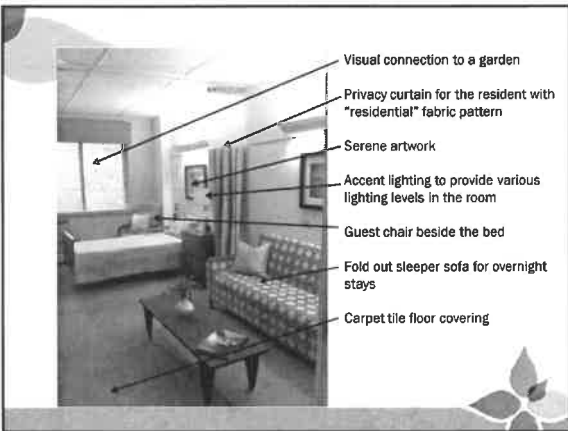


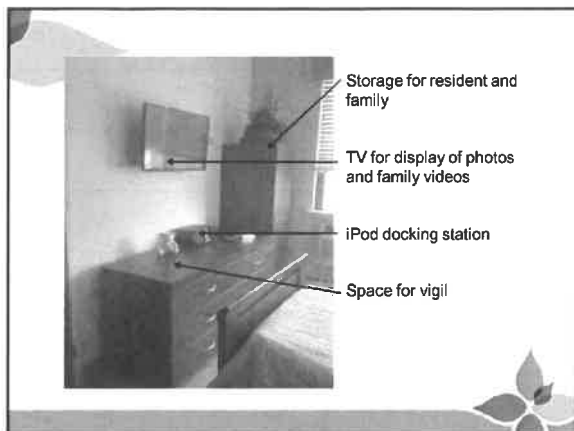













Budget

- **\$4,900 bed**
 - Residential styling
 - Hidden castors
 - 36"x82" mattress
- **\$1,800 soft treatments**
 - New cubicle curtain (re-use existing track hardware)
 - New cornice
- **\$8,400 KI Furniture**
 - Footwall
 - Bedside table
 - Sleeper sofa
 - Bedside chair and footrest
 - Hospitality cabinet
- **\$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

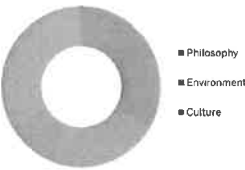
Census

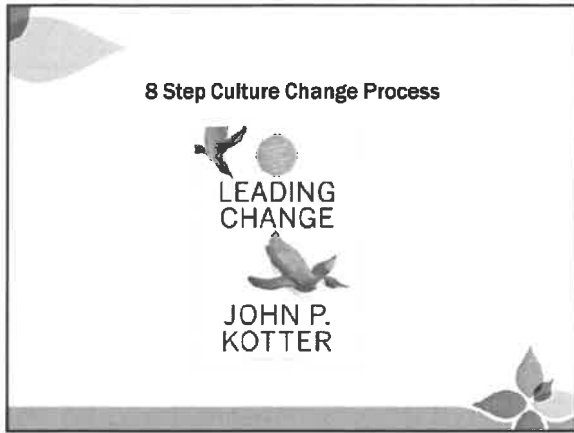
Transforming the EOL Experience

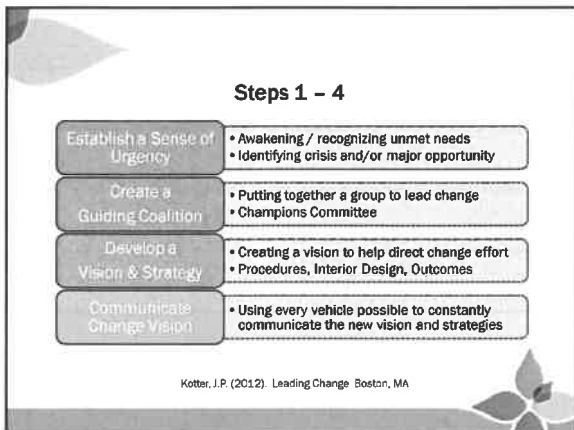
Philosophy
Chrysalis EOL Inspirations
Loretta Downs

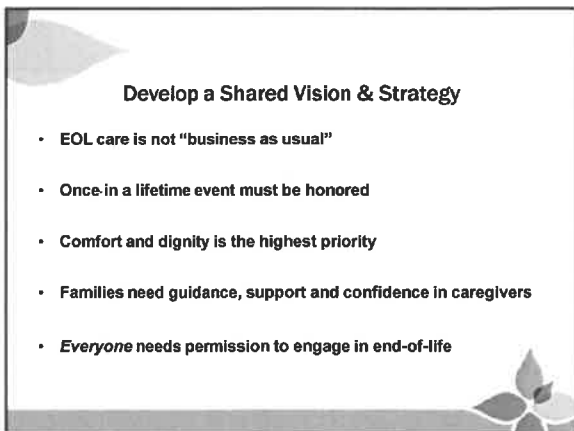
Environment
In-patient Hospice Tours
Perkins Eastman Designers

Cultural Shift
Culture Change Strategy
John P. Kotter









Communicate the Change Vision

COMING SOON...
CHRYSALEIS ROOM
(7/6/16)

A journey to the light
 of change is what it is
 called the chrysalis room
 is to day

Our Chrysalis Room, inspired by the life cycle of the butterfly,
 is specially designed to support residents and their loved ones during the
 end of life journey.

The first coming special includes:

- Dedicated quiet hallway leading to the room of choice
- Dedicated hallway storage for residents and loved ones
- Dedicated care for extended support worker & family presence
- 24 hour dedicated personal care
- Dedicated dining table and chairs for residents
- Staff will support in making the hallway ready when the family
- Bed and table set
- Personal care
- Personal care for others
- Personal care for others

Take your steps in a special part of life, a special place
 that is yours to enjoy and meant to be shared with loved
 ones and staff for all

Lanette Conner

Grand Opening & Dedication
 Introducing CB's very own
CHRYSALEIS ROOM

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

JOIN US TO CELEBRATE THE GRAND OPENING AND DEDICATION OF
 THE NEW CHRYSALEIS ROOM WITH YOUR FRIENDS AND
 FAMILY ON A SPECIAL AFTERNOON AT THE NOURISHMENT CENTER.

**All steps, meals are included in a special
 DEDICATION CELEBRATION!**

10-11 AM Wednesday, June 17
TIME 1:30 p.m.
10-11:30 AM The Pavilion - Room 116B

Steps 5 - 8

Empowering Broad Based Action	<ul style="list-style-type: none"> • Getting rid of obstacles, policies that undermine changes • Encourage risk taking, make mistakes!
Generating Short Term Wins	<ul style="list-style-type: none"> • Create those wins, celebrate success • Visibly recognize & reward people who make wins possible
Consolidating gains & more change	<ul style="list-style-type: none"> • Use increased credibility to promote more change • Reinvigorate the process with new projects & themes
Anchoring New Culture	<ul style="list-style-type: none"> • Articulate the connections between new behaviors and organizational success • Develop means to ensure leadership & succession

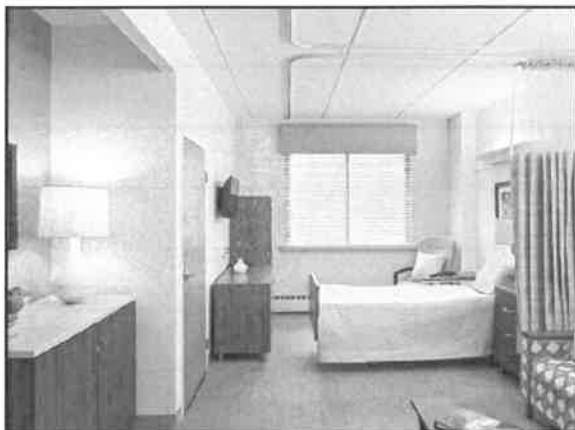
Kotter, J.P. (2012). *Leading Change*. Boston, MA

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





Empowering Broad Based Action

"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

Generating Wins: Feedback & Recognition



"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 you 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?

