

Chrysalis: Transforming the End-Of-Life Experience



CENTRAL
BAPTIST
Village

Loretta Downs, MA, CSA
Founder, Chrysalis End Of Life
Inspirations

Carlo Salvador, AIA, LEED, AP
Principal, Keganivo Group

Dawn Mondschein, LCSW, LNHA
Executive Director, Central
Baptist Village





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

End of
Life
Inspiration



Supporting the End of Life



My mother, Anna Piazza Schenk, and I, in her “home”





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 SL1, 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/>



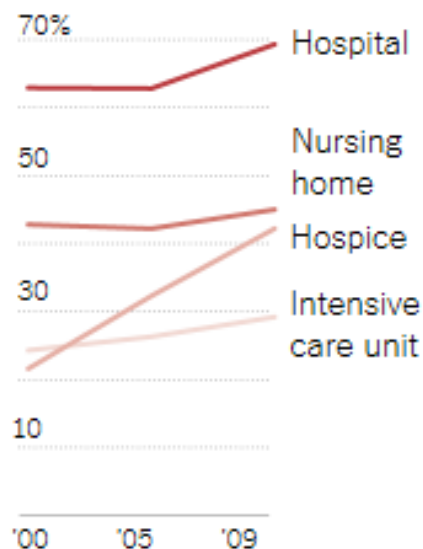
Care at Life's End

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**

Place of care

Percentage receiving treatment in last days**

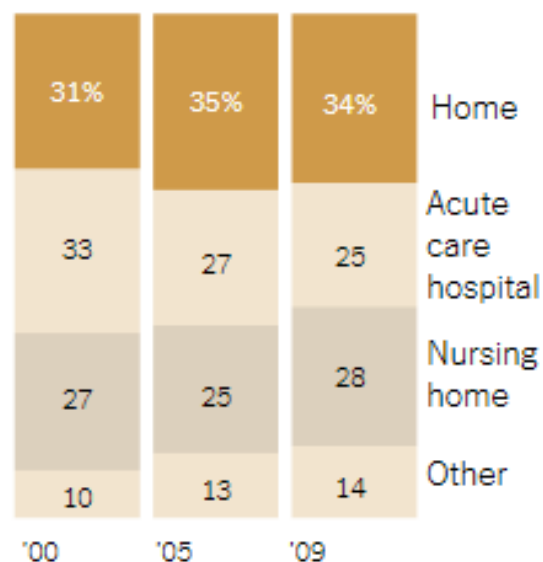


Transfers

Among facilities and home, average number in last 90 days



Place of death



*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

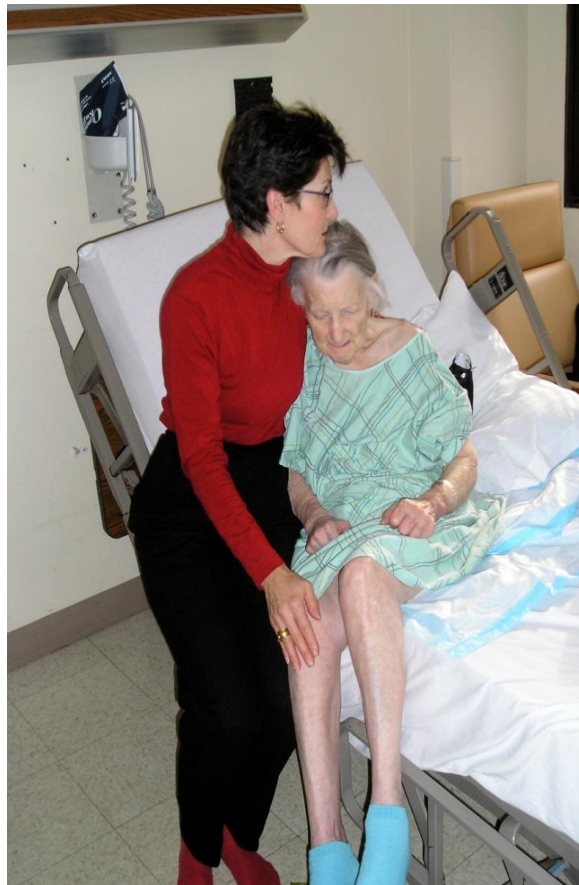
“Reported care experiences are typically worse in the nursing home setting, according to the latest results of a survey by the Centers for Medicare & Medicaid Services.”

Source:

<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., Clarridge, B.R., Casey, V., Welsh, L.C., Wetle, T., Shield, R., Mor, V. (2004). Family perspectives on end-of-life care in the last place of care. *Journal of the American Medical Association*, 291(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:

CENTRAL
VALLEY



I love you



CENTRAL
CRISIS
Village



Thank you



CENTRAL
CALIFORNIA
Village



I'm sorry.



CENTRAL
CRISIS
Village



I forgive you



CENTRAL
CRISIS
Village



Goodbye






In the Chrysalis Room With Anna

<https://www.youtube.com/watch?v=hJEfgNJwahM&feature=youtu.be>

CENTRAL
VILLAGE





“LIFE GIVES US TWO GREAT
GIFTS,
LOVE AND DEATH.
MOSTLY, THEY ARE PASSED
ON UNOPENED.”

—RUMI





Carlo Salvador, AIA, LEED® AP
Principal, Keganivo Group



KEGANIVO
GROUP
ARCHITECTURE - CONSULTING



Designing for Hospice



Central
Valley



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



Blue Skies of Texas designed by Perkins Eastman

- 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





Childers Place designed by Perkins Eastman



Resident Focus



Childers Place designed by Perkins Eastman

- 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



Childers Place designed by Perkins Eastman

- 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





Childers Place designed by Perkins Eastman

PERKINS
EASTMAN





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



Wilson Hospice, designed by Perkins + Will

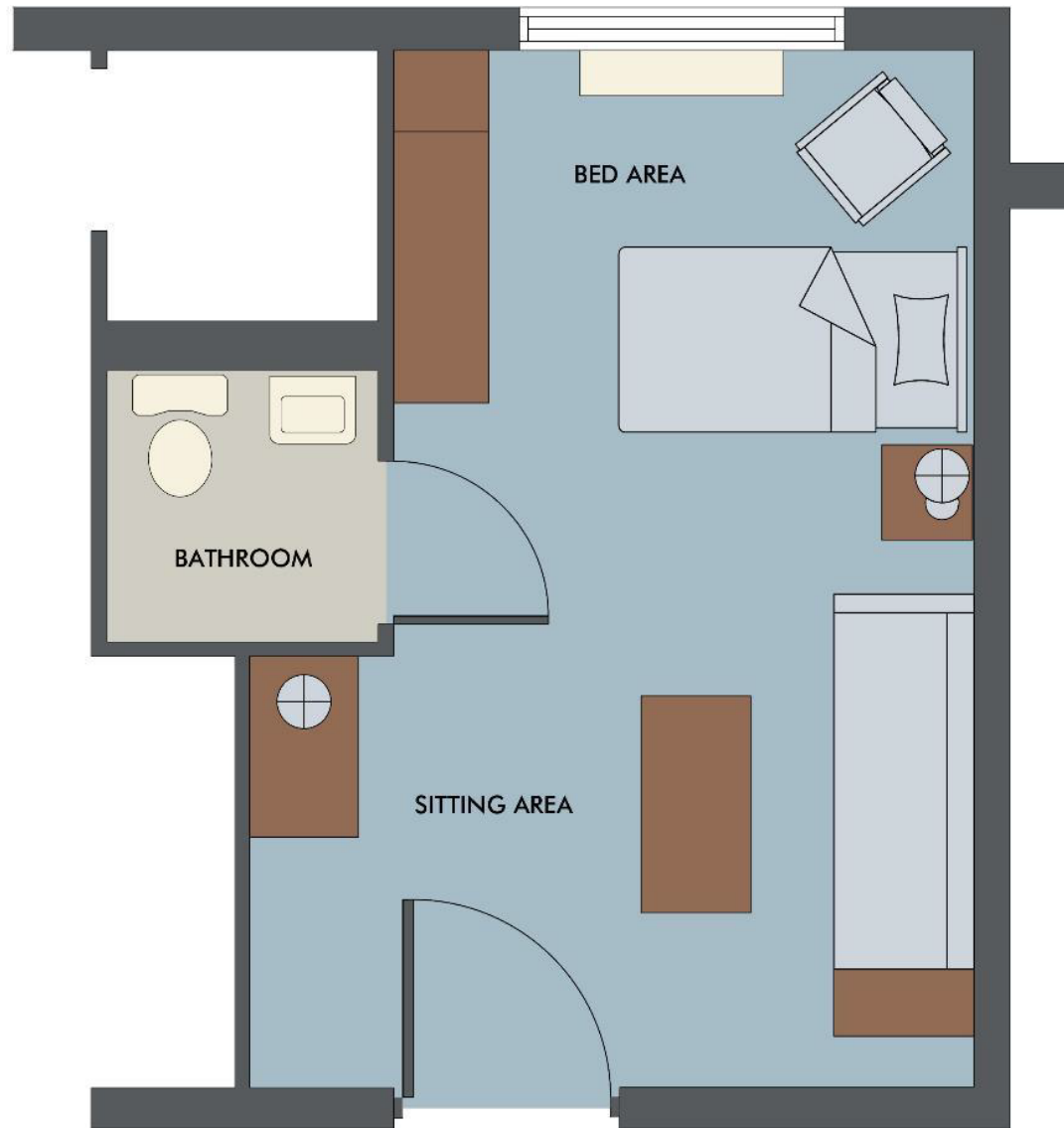
Perkins + Will



Case Study: Central Baptist Village









Serene artwork

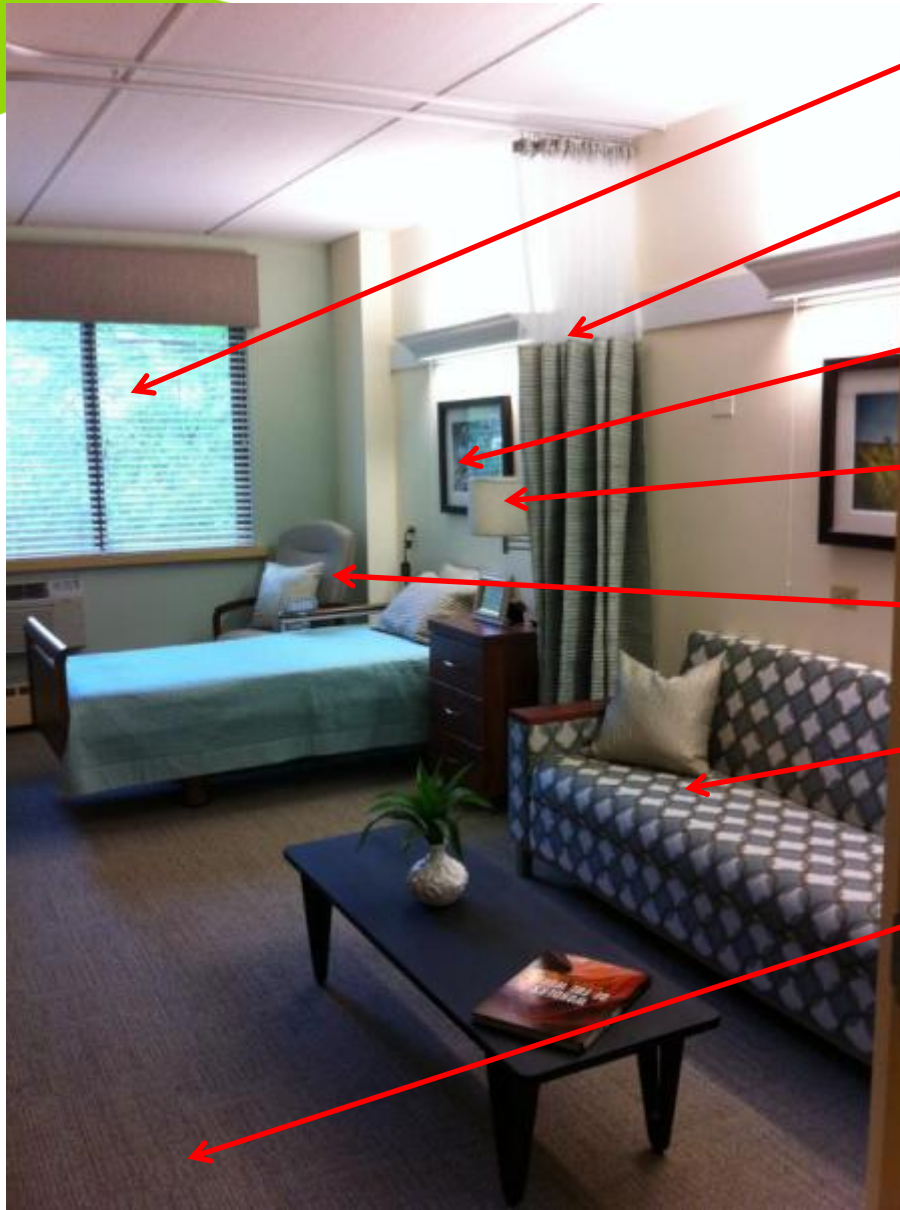
Accent lighting to provide various lighting levels in the room

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

St. Vincent
Village



Transforming the EOL Experience

Philosophy

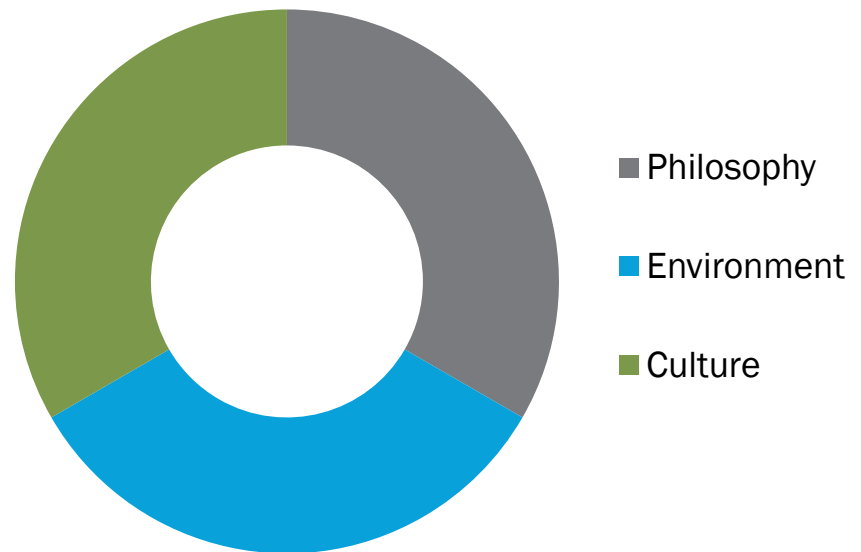
Chrysalis EOL Inspirations
Loretta Downs

Environment

In-patient Hospice Tours
Perkins Eastman Designers

Cultural Shift

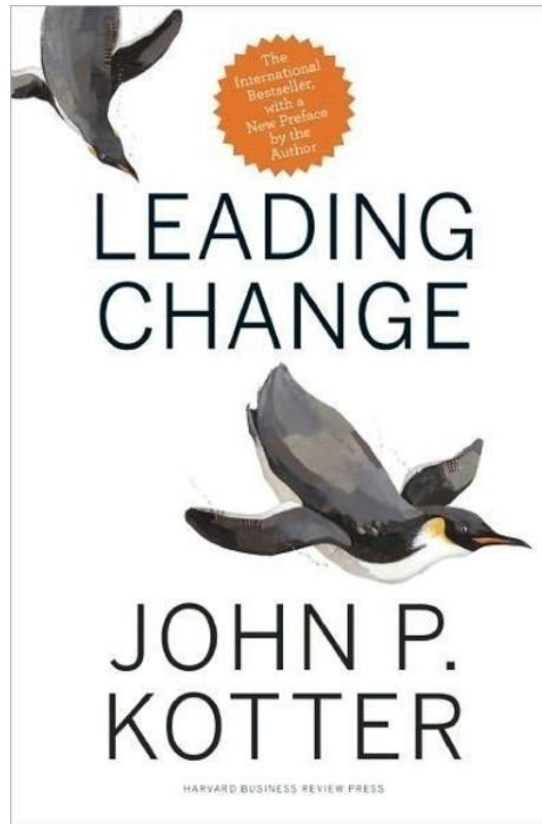
Culture Change Strategy
John P. Kotter



Central
Values



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

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





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 CHRYSLIS ROOM

(kris-l-is)

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 CHRYSLIS 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

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

Central
Florida
College



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.”

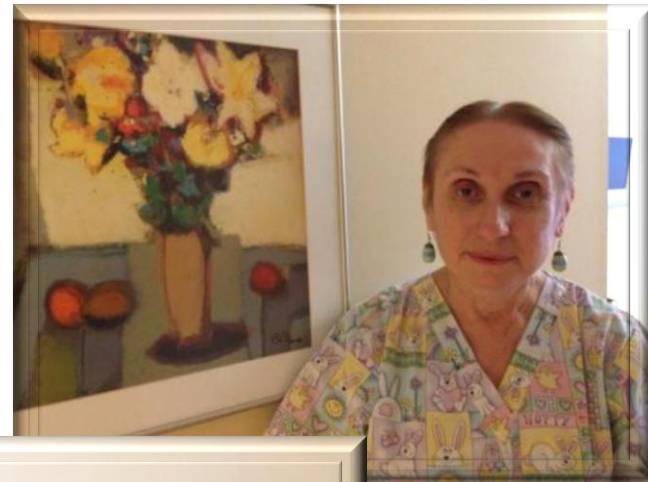
“The most important thing is to make sure my Resident is clean and comfortable. I want everything to look and feel peaceful for the family.”





“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”

CENTRA
Village



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.”

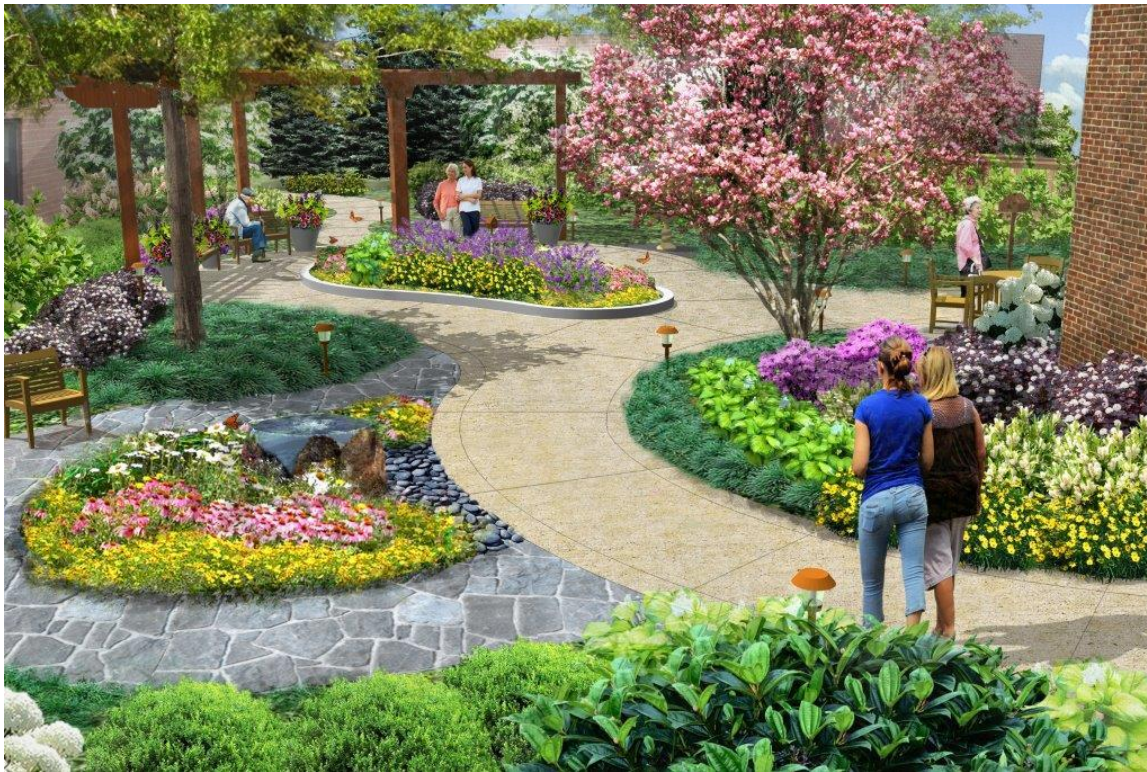


Generating Wins - Celebrate Success!



Consolidating gains & producing more change

Memory Garden





CHRYSTAL
KIMBLE
KIMBLE



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.”

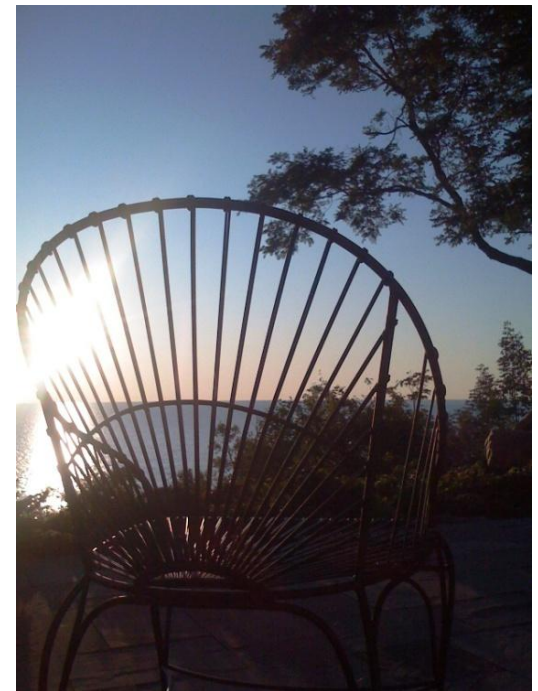


Family Testimonials

“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”

Center
Village





***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?

