CHRYSALIS:

TRANSFORMING THE END-OF-LIFE EXPERIENCE

Loretta S. Downs, MA, CSA

www.endoflifeinspirations.com

Dawn Z. Mondschein, LCSW, LNHA

Supporting the End of Life

"The field of bioethics has, since its earliest days, debated end-of-life issues; yet American society more broadly remains ill equipped for the experience of dying…*The challenge for bioethics is to create a framework for teaching an aging population to prepare for death and to support one another through the dying process.*"

--Lydia Dugdale, "The Art of Dying Well," *Hastings Center Report* 40, no. 6 (2010): 22-24

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

A Social Revolution

In my own adulthood, the culture of birth changed. It wasn't doctors who first tossed out the stirrups and ushered in fathers and video cameras and "birthing rooms." It was parents who said, birth is not just a medical experience, it's a human experience. Now we are finally saying that dying, too, is not just a medical experience, it is also a deeply human experience.

--Ellen Goodman, Founder The Conversation Project

Source: NY Times 7/1/15, http://opinionator.blogs.nytimes.com/2015/07/01/how-to-talk-about-dying/?_r=0

What would happen if we include quality of death in our standards for our quality of life?

"Nearly 25% of older adults die in long-term care and that number is expected to rise to 40% by 2020 with the swell of the baby boom."

Sources: Munn, J.C., Dobbs, D., Meier, A., Williams, C.S., Biola, H., Zimmerman, S. (2008). The end-of-life experience in long-term care: Five themes identified from focus groups with residents, family members, and staff. *The Gerontologist,* 48(4), 485-494.V

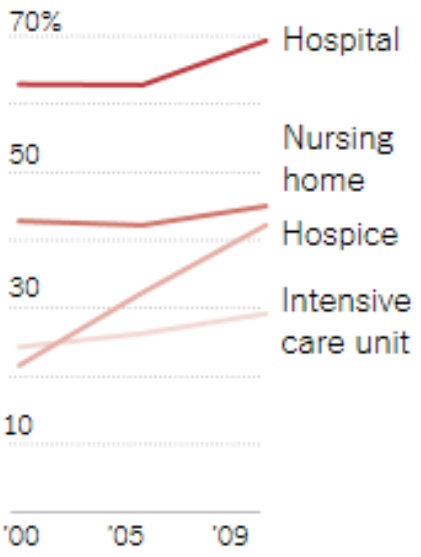
Forbes-Thompson, S., Gessert, C.E. (2005). End of life in nursing homes: Connections between structure, process, and outcomes. *Journal of Palliative Medicine,* 8(3), 545-555.

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.

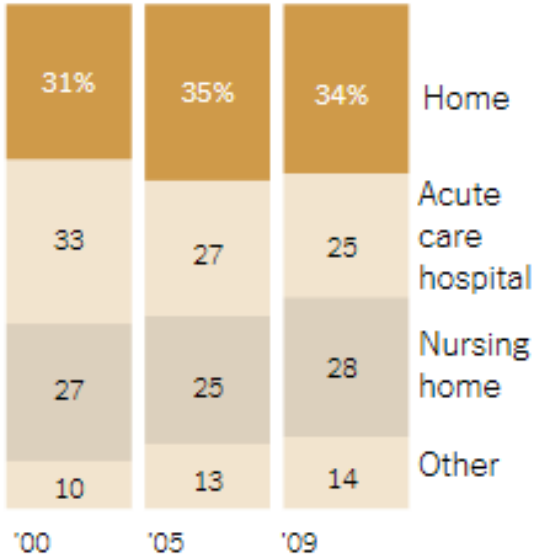
*Among Medicare beneficiaries over 65 who died**

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/

Family Attitudes as Obstacles

- "You're my baby sister. I don't want you to ever die."
  - --My sister when asked to be my Power of Attorney for Healthcare. I did not choose her.

- "He always got better. We thought he'd get better this time."
  - --a daughter, about her father who died 6 days into hospice care

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.

Length of Stay in Hospice Care

- **180+ days 11.5%**
- **90 - 179 days 9.2%**
- **30 - 89 days 18.0%**
- **15 – 29 days 12.7%**
- **8 – 14 days 14.3%**
- **< 7 days 34.5%**

- Median LOS for 2013 was 18.5 days

- Source: National Hospice and Palliative Care Organization 2104 Facts and Figures Hospice Care in America

Components of High-quality end-of-life care

"…results 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.

The Need For Keeping Vigil in a Comfortable, Private Space

The environment in which an experience occurs,

effects the quality of that experience.

The Call for Sacred Space

- "Dying is a spiritual process with medical implications."

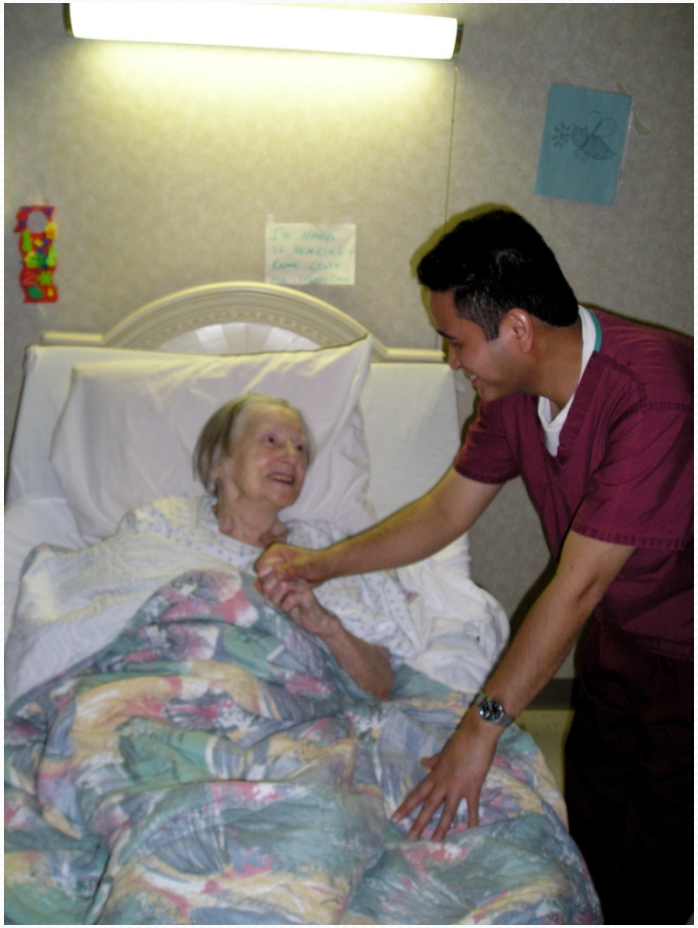
- --Gwendolyn London, PhD, Duke University School of Divinity

The Four Things

...we need to say before we say goodbye

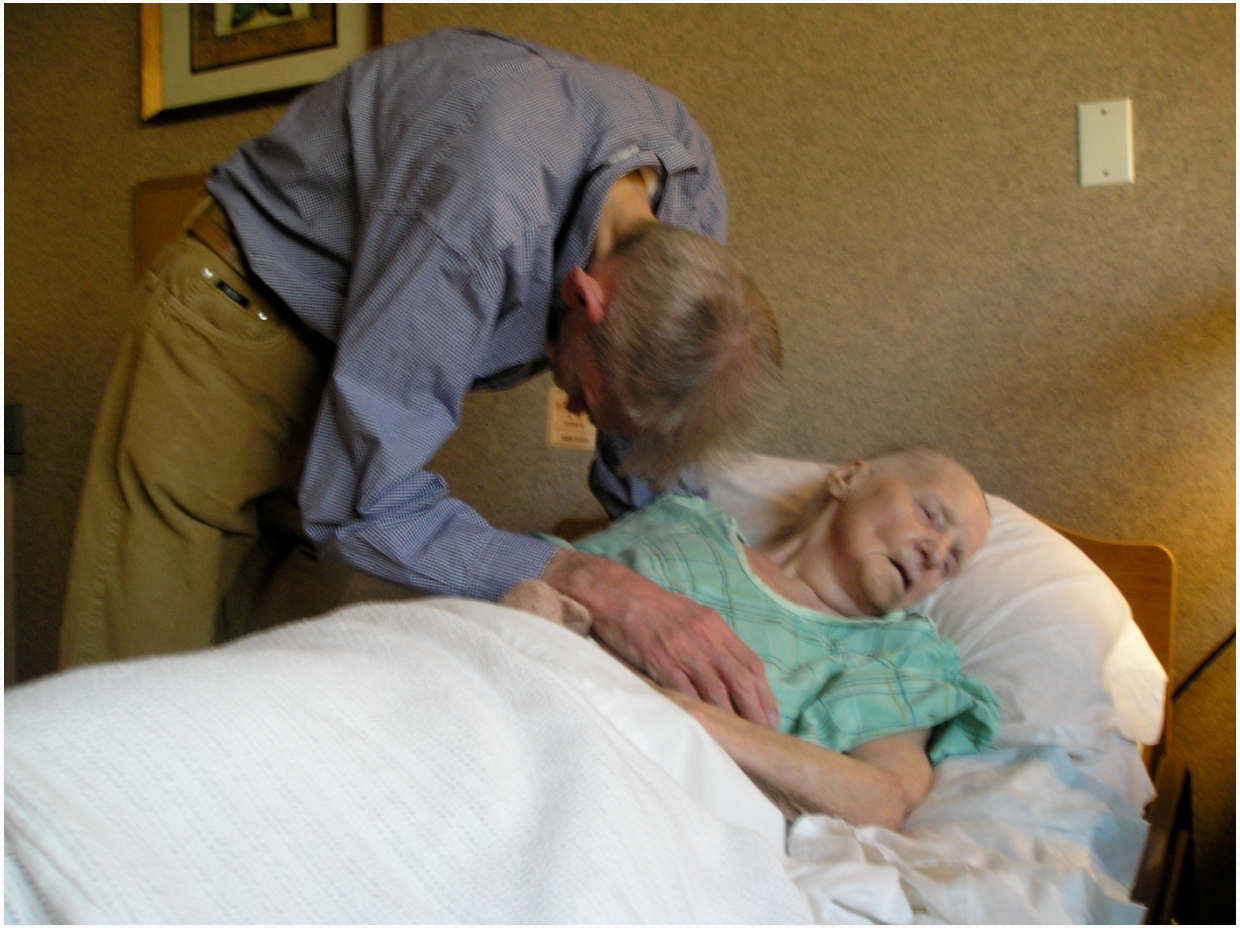
by Dr. Ira Byock

Thank you



I love you

I’m sorry.



I forgive you

Goodbye

CREATING SACRED SPACE

- Sacred spaces have common elements.
- They are protected and safe from danger.
- They are quiet, serene, contemplative places.
- They have soft lighting.
- They are spacious yet we can be close to each other and in privacy.

SACRED SPACES

- They are symbols of the human search for meaning in life
- They invite people to be there.
- They are comforting.
- Emotions are evoked within them.
- Sacred spaces facilitate personal transformation.

In the Chrysalis Room With Anna

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

Lead By Example

Like the Monarch butterfly, each of us has a chrysalis stage of transformation at the end of our life. Let us treat the end of life the way we do the beginning of it:

Prepare for it.

Support it.

Create sacred space for dying.

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

--RUMI

Case Study: Central Baptist Village

250 unit non-profit CCRC
Norridge, Illinois
Independent – Assisted – Skilled Nursing – Memory Care

Project Rationale

Unmet needs of Residents and loved ones

Natural extension of mission

Opportunity to excel & differentiate

Census

Project Goal

Enhance the comfort of
our residents and their loved ones
and honor the end of life
experience for all.

Transforming the EOL Experience

Philosophy

Loretta Downs

EOL Inspirations

Environment

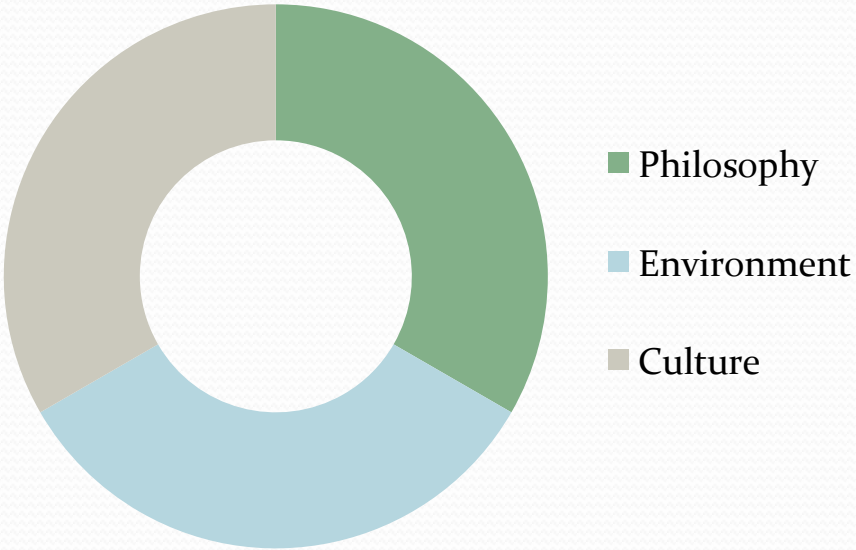
Perkins Eastman

In-patient Hospice Tours

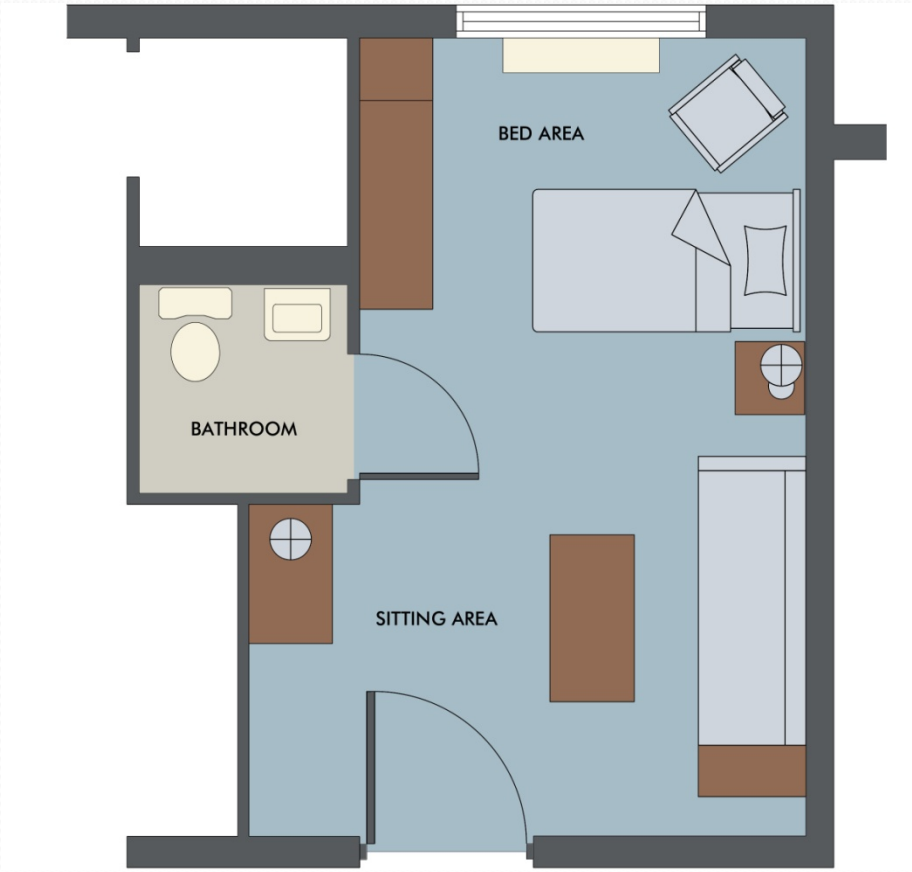
Cultural Shift

Champions Committee

Culture Change Strategy



Environmental Design


BED AREA
BATHROOM
SITTING AREA


WONDERS OF THE WORLD

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

Visual connection to a garden

Privacy curtain for the resident with “residential” fabric pattern

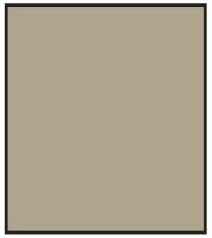
Serene artwork

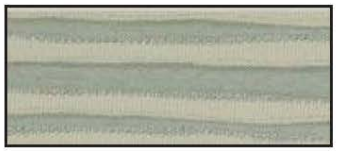
Accent lighting to provide various lighting levels in the room

Guest chair beside the bed

Fold out sleeper sofa for overnight stays

Carpet tile floor covering





Operational & Financial Considerations

Operational Considerations

Location

Residential
Peaceful
Underutilized space
Licensure

Operational Considerations

Procedures

Formal and informal practices

Staffing

Room change

Duration

Additional needs

Natural evolution

Financial Considerations

An organization's reputation is the most valuable asset of all.

Financial Considerations

Revenue Impact

Dependent upon occupancy rate

No bed loss

Return on Investment

HUGE Marketing ROI

PR Currency

Financial Considerations

Project Cost

$16,000 capital expense

Operational Cost

Minimal daily operating expenses

Range of Alternatives

Budget

- $8,400 KI Furniture
  - Footwall
  - Bedside table
  - Sleeper sofa
  - Bedside chair and footrest
  - Hospitality cabinet
- 4,900 bed
  - Residential styling
  - Hidden castors
  - 36”x82” mattress

Budget

- $1,800 soft treatments
  - New cubicle curtain (re-use existing track hardware)
  - New cornice
- $675 artwork

Total = $15,775

Cultural Transformation

8 Step Change Process

1. Establish a sense of urgency
2. Create a guiding coalition
3. Develop a vision & strategy
4. Communicate the change vision

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

Shared Vision

- 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

COMING SOON…

CBV's very first

CHRYSALIS 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

CHRYSALIS 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**

8 Step Change Process

5. Empower broad-based action
6. Generate short-term wins
7. Consolidate gains and produce more change
8. Anchor new approaches in the culture

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

Keys to Culture Change

- Staff input and ownership
- Clear vision and goal
- Over communication and program awareness
- Ongoing feedback

Celebrate Success!

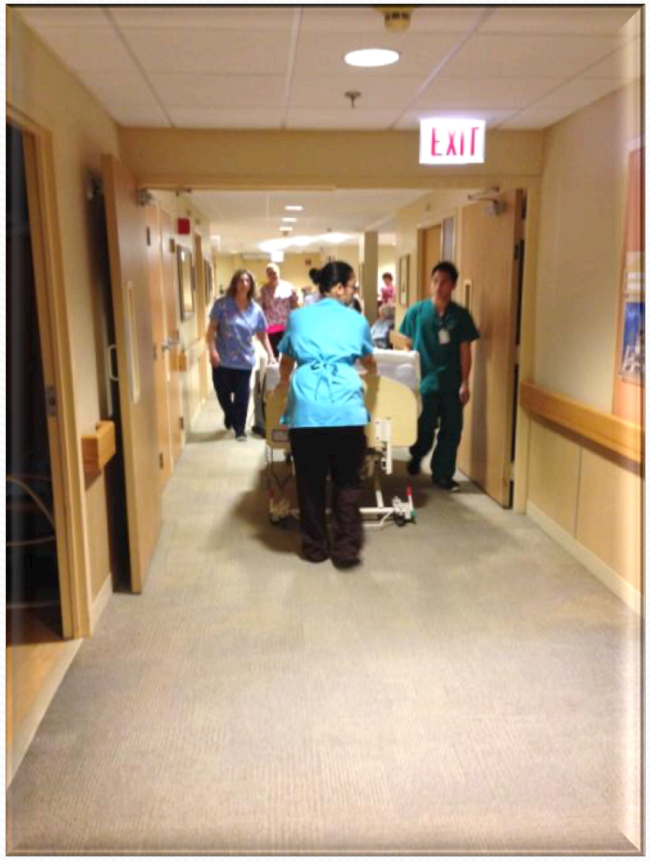
Program in Motion

- Room change request
- “Sacred Journey” to the Chrysalis Room
- Primary caregivers attend to Resident & loved ones
- Culinary delivers refreshments to the nourishment center

Program in Motion

- Visitors, Resident 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

Sacred Journey




WONDERS OF THE WORLD

Engaged Staff

"I pray for them. I spend time just holding their hand."

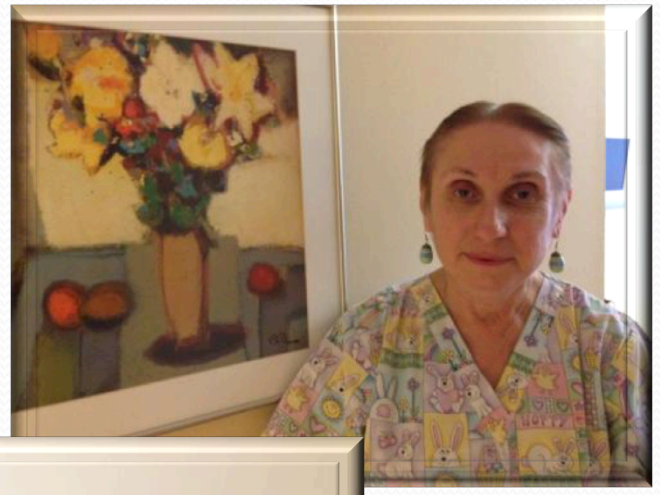
"I tell them how much I loved them."

"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."

Engaged Staff

"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'"



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 thresholds of life.

thresholdchoir.org

Final Rituals

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

"She went peacefully & her comfort was unbelievable…"

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

"…she needed and deserved this"

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"

Family Testimonials

"It's a wonderful service. It allowed me to spend the night with my mother – I would have never been able to do that in her other room."

Family Testimonials

"The room was so peaceful and quiet and out of the way. It felt really private, our own little world."

Family Testimonials

"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."

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.

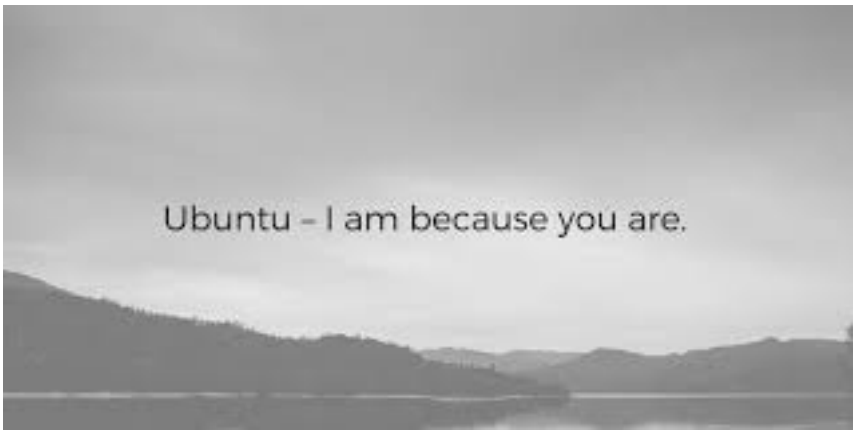
~ Loretta Downs

2015 Pioneer Network Conference
Chicago, Illinois

The Heart of Dementia

Sonya Barsness
Karen Stobbe

Servus is an Eastern European greeting
that comes from the Latin word servus,
which means servant.
It is thought that the greeting is
intended to mean
"I am your servant" or
"I am at your service".
Servus!
- Sonya and Karen are from Eastern European descent



Ubuntu *(uu-BOON-tuu)*

Archbishop Desmond Tutu, the South African human rights activist, once explained Ubuntu like this: "One of the sayings in our country is Ubuntu – the essence of being human. Ubuntu speaks particularly about the fact that you can't exist as a human being in isolation. It speaks about our interconnectedness. You can't be human all by yourself, and when you have this quality – Ubuntu – you are known for your generosity. We think of ourselves far too frequently as just individuals, separated from one another, whereas you are connected and what you do affects the whole World. When you do well, it spreads out; it is for the whole of humanity.

Nelson Mandela understood the ties that bind the human spirit. The word – Ubuntu – that describes his greatest gift: his recognition that we are all bound together in ways that can be invisible to the eye; that there is a oneness to humanity; that we achieve ourselves by sharing ourselves with others, and caring for those around us.

Christine Bryden, a person living with dementia, says in her book "Dancing with Dementia", "Truly we must include all people with dementia when we say 'ubuntu'- we are together in our great humanity. Like Mandela we people with dementia can transform a personal tragedy into a triumph. We need no longer be the forgotten ones who have forgotten to remember."

http://blog.ted.com/further-reading-on-ubuntu/
https://en.wikipedia.org/wiki/Ubuntu_%28philosophy%29

Reframing Behaviors into Actions & Reactions

In dementia care, the word "behavior" has become synonymous with bad things that our elders or residents do. We need to change our mindset and see these "behaviors" as purposeful actions or intentional (and normally appropriate) reactions to an action.

First lets think about our core needs as human beings and how those unmet needs may be communicated in an action or reaction to you.

Core Needs of Human Beings

Dr. Tom Kitwood suggested that people with dementia, like all people, have six psychological needs: attachment, love, comfort, identity, inclusion and occupation; and that as we care for people with dementia, we should strive to fulfill those needs everyday.

As we care for persons with dementia (or anyone for that matter), we need to consider finding ways to fulfill these needs everyday.

1. **Attachment** – We need to feel attached to another person or to a group. We want to feel *connected* to someone or something

2. **Love** – Everybody needs it. To love someone; to be loved and accepted; to love an activity, a food, a person, to love God and to feel self-love/self-respect.

3. **Comfort** – We all need to feel comfort. We need to be warm, dry and clean; to have a full stomach and not be thirsty; to have quiet when we want it; to have a sense of tenderness, closeness and bonding with others.

4. **Identity** – We need to have others know *who I am* or *who I was.* We want to be individual, to be special, to have our own identity. We want our individuality to be recognized in our food preferences, our clothing, our activities and recreation.

5. **Inclusion** – We want to feel we are a part of something; to belong to a group; to be a member; to not feel left out.

6. **Occupation** – We want to be occupied. To have something to do, to help others, to occupy us with 'work' that has meaning and purpose.

What if we approached everyone with these ideas in mind?

What would you do?

If someone walked in your own room without knocking...

If someone that you do not remember ever meeting before joins you in the bathroom and starts taking off your clothes…

If someone starts pushing your wheelchair without asking you or telling you where you are going…

If someone tells you that you live here now, but you know deep in your heart and mind that you live on a farm in Iowa…

If someone did any of these actions to you, how would you react?

We are the ones who need to change OUR actions.

Their REACTIONS are completely appropriate and accurate
AND NORMAL.

-adapted from *Dementia Reconsidered* by Tom Kitwood

Treat people as if they were what they ought to be,
and help them become what they are capable of being.
--Goethe

Never doubt that a small group of committed people can change the world.
Indeed, it is the only thing that ever has. -- Margaret Mead

All growth is a leap in the dark,a spontaneous unpremeditated act
without the benefit of experience. - Henry Miller

When you least feel like it, do something for someone else.
You forget about your own situation.
It gives you a purpose, as opposed being sorrowful and lonely. ~ Dana Reeve

Resources

CMS Hand in Hand Training Toolkit
Download for free at: http://www.cms-handinhandtoolkit.info/
Order DVD hard copies:
http://www.ntis.gov/search/product.aspx?ABBR=AVA21573DVD8

Ted Talks

Julian Treasure	www.ted.com/talks/julian_treasure_5_ways_to_listen_better
Brene Brow	www.ted.com/talks/brene_brown_on_vulnerability
Joan Halifax	www.ted.com/talks/joan_halifax
Daniel Goleman	www.ted.com/talks/daniel_goleman_on_compassion

Websites
CMS Partnership to Improve Dementia Care

- https://www.nhqualitycampaign.org/dementiaCare.aspx
- There are tons of resources on the Advancing Excellence website related to reducing anti-psychotics, including assessment tools, policies, etc.

Care Fit for VIPS http://www.carefitforvips.co.uk/

- An excellent website that provides resources, assessment tools, and a general guidance for developing a person-centered dementia program.
- Based on the VIPS framework of person-centered dementia care developed by Dr. Dawn Brooker.

In The Moment: Creative Ideas for Training Staff : Karen's website
http://www.in-themoment.com/index.asp

Books on Person-Centered Dementia Care
Bell, Virginia and Troxel, David, *The Best Friends Approach to Alzheimer's Care*
Brooker, Dawn. *Person-centered Dementia Care: Making Services Better.*
Fazio, Sam and Seman, Dorothy. *Rethinking Alzheimer's Care*.
Kitwood, Tom, *Dementia Reconsidered: the Person Comes First*.
Power, G. Allen, *Dementia Beyond Drugs*. and *Dementia Beyond Disease.*
Taylor, Richard, Alzheimer's From the Inside Out
Farrell, David; Brady, Cathy; & Frank, Barbara. *Meeting the Leadership Challenge in Long-Term Care.* Baltimore, MD: Health Professions Press.
Logan, Dave; King, John; & Fischer-Wright, Halee. *Tribal Leadership: Leveraging Natural Groups to Build a Thriving Organization*. NY, NY: Harper-Collins.

"Dementia Care: The Quality Chasm"
http://www.ccal.org/national-dementia-initiative/white-paper/

Central Baptist Village Threshold Choir . . .

Threshold Choir was founded by a woman named Kate Munger. She is a retired music teacher from California, and a composer.

She started the choir after spending an afternoon with a dying friend. He was in a coma, and he became extremely agitated. So she decided sing to him. As she sang, she noticed the singing calmed him, and brought her comfort as well.

So she bought a computer, and began composing songs for bedside. Many of her composer friends joined her. In 1999, she started her 1st choir in California with 15 women. Now Threshold is international with over 120 choirs & 1000 singers. Most of the choirs are composed of women only, however there are choirs which include men. There is no audition – the only requirements are: you enjoy singing & can carry a tune!

Our singers' backgrounds are varied – some are on staff or in the Family Council at CBV. One of our singers is a resident & one's daughter is a nurse at CBV. Some have extensive musical background, and some just enjoy singing. Each of us comes to this work for her own reason, but we have joined together to provide this gift of music – for recipients & their families. And as Kate Munger discovered that day she sang to her friend, we also benefit from the gift. Music is good for everyone.

As CBV Threshold Singers, we also complete volunteer training, where we learn about the different types of residents CBV serves - their needs, and the needs of their families, and how we fit in with the other team members there.

We learn songs by listening, singing them over & over. Since we sing A Cappella at bedside, we memorize the songs we sing. Most are short & easy to remember.

We sing in small groups – 3 to 6 singers. We bring stools to be able to assemble around the recipient's bed, and to sing at their level. In addition to the Threshold songs available to us, we will also take requests - spiritual songs, patriotic songs, songs in Polish & Japanese, songs from musicals, oldies, holiday songs. We will encourage the resident & family to sing or hum with us. Since our first sing in July of 2013, we have sung at over 390 bedsides.

Our recipients may not remember the songs, or even that we sang them, but the feelings they experience during a bedside sing do linger.

The songs we sing at bedside are chosen to give comfort - to the recipient & the family.

Sometimes we see & feel the effects of our songs - a smile, a tear; one resident loves to direct us as we sing. Sometimes, however, the effects are unknown – a mystery. When we approach a bedside, we can only offer this prayer, “Understanding the suffering is beyond us. Understanding the healing is too. But, in this moment, we are here. Use us.”

To learn more about Threshold Choir, visit www.thresholdchoir.org.

Hospital Newspaper – November 2009
Consultants Corner
Chrysalis Room: Creating Sacred Space for the Dying

By Loretta S. Downs, MA

Death is a spiritual experience that now occurs for 75 percent of us in a healthcare institution rather than in the comfort of our own homes. Like birth, modern medical practice has taken death into venues where skilled medical care is close at hand.

This is understandable. The science of medicine and the technology that supports it, along with modern chemistry have delayed death and increased the human lifespan to almost 80 years--twice what it was just a century ago. We now survive mortal bodily injury and we recover from diseases and conditions that used to kill us quickly. We so often return from the edge of death that is it no wonder that we won't accept death until it has come and gone.

This denial of death has resulted in a median length of stay in hospice care that is now only 20 days, with hospice providers grieving the growing numbers of patients who die the day they are admitted. This is not long enough to address the needs of the dying or those who care for them. Consequently, our loved ones often leave us suddenly--even after long battles with chronic illness--with everyone unprepared.

We have to do better.

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. We have an innate desire to be there when a loved one dies. 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. So how can we not talk about the quality of death as we so fervently talk about the quality of life?

For the last 25 years I have shared the end-of-life experience with friends, family, hospice patients and nursing home residents along with the loved ones and professionals who attend them through death. They taught me the importance of keeping vigil, the value of just being there, the privilege of being present for the dying. No one can *be there* if we are not willing to acknowledge the dying process and the imminence of death, and provide the private space to support it, to share it, to experience it—to keep sacred vigil on sacred ground.

Stage of Transformation

That is the purpose of a Chrysalis Room, which I named for the stage of stillness in which a caterpillar transforms into a butterfly. My mother died in the first Chrysalis Room. She was a 93-year old hospice patient. She lived in a nursing home for six years, the Fairmont Care Center in Chicago, whose compassionate administration agreed with my request to provide a Chrysalis Room for its residents.

When I was told that my mother was dying, I began to prepare. The message was sent out so that family members could choose to come and sit vigil with her, or create a vigil wherever they were. Comfort was the order prescribed for her care, with the goal of supporting her and her family through her death. We did this in a space that accommodated our needs for privacy, peace, and community, aware that every minute shared would be remembered.

The Chrysalis Room was far away from the noisy nursing station and even though a hospital bed was in the center of it, it felt like a home. The room is light and spacious enough for many people to fill its soft armchairs and sofa. Snacks and beverages were brought in. We played healing music CDs. We were bathed in soft, soothing light from table and floor lamps. A bed was set up for me; folding chairs waited for other loved ones. We gathered around her, accepting her imminent death, with our presence supporting her through it.

Nurses and aides came to do their tender work. I could sense their silent prayers as they softly laid a hand on my mother's, or swept a wisp of hair back from her forehead, or gently slipped an ice chip between her lips. We held each other and some would weep in my arms over missing their own mother or father's death.

Mother's grandchildren and great-grandchildren came and filled the room with youthful energy. We sat on her bed and talked about how much she meant to us--and told stories about her life while we memorized the feel of her linen skin and the silk of her fine hair. Friends brought offerings of food and flowers and their presence. We laughed and cried for eight days of living in the Chrysalis Room, with my mother dying in the center of it.

Last Moments

The sun was just rising when I awoke and went to her side. She opened her eyes and looked straight into mine and I knew she was leaving me. Through a waterfall of tears I said, "I know you have to leave now. I love you. Thank you." I moved to get in bed next to her but she frowned, stopping me. I sat close against the bed, put one arm around her and held her hand in the other as she closed her eyes and left me, as peacefully as I could ever have hoped for.

Merely moments later my sister arrived, then my best of friends and the hospice aide who was working on her own birthday. Together we bathed and dressed my mother in the light of the new day with the dignity and honor worthy of a queen. Residents and staff came to say goodbye and covered her with the petals from flowers in vases around the room. We felt that we were participating in something truly divine.

It is time that we regard the process of dying in the way we have come to regard the process of giving birth. We prepare for birth. We offer choices. We teach classes on how to give birth. We train midwives and doulas to provide non-medical support. We share birth with those we love so no one is born alone. We address the physical pain. We cherish the experience despite the necessary unpleasantness that comes with it. We design comfortable birthing rooms that feel like home in the hospitals where birth occurs.

Final Gifts

The final gifts of quiet, private vigil—reminiscence, reconciliation, and unconditional love—are opened when we attend to the dying with the hope of providing a good death. Although it is a common description, I don't know if there is such a thing as a *good* death. But I do know that a *supported* death is a good way to die. Death teaches us what is most important in life. It teaches us about time, about love and forgiveness, about letting go and healing, about starting over again, and about leaving. Those of us who have the privilege of supporting the death of a loved one, even in spirit from miles away, have less fear of death as a result.

The end of life is a part of life that we all must experience with our loved ones before we ourselves die. We can make that experience a positive one for everyone involved. Let's honor death the way we honor birth. Let's create a private, sacred space in the places where we die, and let no one die alone, as no one is born alone.

Loretta Downs founded Chrysalis End of Life Inspirations: www.EndOfLifeInspirations.com

Pioneer National Conference August 3, 2015

THE CHRYSALIS™ ROOM: TRANSFORMING
THE END-OF-LIFE EXPERIENCE

Loretta S. Downs, MA, CSA
www.endoflifeinspirations.com
Dawn Z. Mondschein, LCSW, LNHA
Central Baptist Village, Norridge IL

WEB RESOURCES:

www.nhdd National Healthcare Decisions Day website. Use April 16th to provide education and awareness events in your community. The website is a library of resources for Advance Healthcare Planning, for organizations and individuals.
Lead by example: have *the conversation* with *your* loved one and complete your own advance healthcare directives. This intimate conversation builds understanding, empathy, and skill for serving those you care for, and it brings you closer to your loved ones.

http://theconversationproject.org The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. Find a Conversation Starter Tool Kit for talking with family and doctors.

http://www.geripal.org A Geriatrics and Palliative Care blog with essential information for increasing quality of life and death in long term care.

https://www.youtube.com/watch?v=axcjfmcqh4o Watch a video of Loretta Downs' inspiring and uplifting presentation on the end-of-life issues we all face, "Oh, Just Bury Me in the Backyard!"

https://www.youtube.com/watch?v=hJEfgNJwahM&feature=youtu.be View the slide show of "Anna in the Chrysalis Room" on You Tube.

https://www.youtube.com/watch?v=VRkr09ZMI3w Watch a FRONTLINE interview with Dr. Atul Gawande on "Aging, Dying and Being Mortal.

http://www.ted.com/talks/atul_gawande_how_do_we_heal_medicine?language=en A TED talk by Dr. Atul Gawande, "How Do We Heal Medicine?"

http://www.sacreddying.org/about/ The Sacred Dying Foundation. The Sacred Dying Philosophy is concerned with bringing spirituality, through presence and ritual, into the physical act of dying. Sacred Dying facilitates the creation of a setting where death is experienced with honor, respect, and sacredness. This can be as simple as being present with a loved member of your family and as complicated as transforming the vision of our entire society.

http://www.peacehealth.org/shared-pages/Pages/_no-one-dies-alone-default.aspx?from=/sacred-heart-riverbend/services/end-of-life-care Build a "No One Dies Alone" program in your community

http://imcw.org/Talks/TalkDetail/TalkID/384 "Compassionate Caregiving" is a presentation by Susan Akers, RN. Each one of us has the potential to become a compassionate caregiver for those individuals who are experiencing suffering. This talk will explore suffering, the avoidance of suffering, and the natural compassion that arises when we face our own suffering. This talk will also emphasize the value of mindfulness practices in the awakening of this natural capacity for compassion.

BOOKS:

Being Mortal, Medicine and What Matters Most in the End, by Dr. Atul Gawande, the NYTimes best seller on aging, illness and dying in America.

The Conversation, A Revolutionary Plan for End-of-Life Care, by Dr. Angelo Volandes

Dying Well, and The Four Things, by Dr. Ira Byock

Sacred Dying, by Megoray Anderson.

AWARDS AND PRESS:

"Chrysalis Rooms Lend Families Support." Life Matters Media, 5/11/2014, http://www.lifemattersmedia.org/2014/05/families-receive-support-chrysalis-rooms/

Awarded Mather Lifeways Institute on Aging 2014 Promising Practices Award http://www.matherlifewaysinstituteonaging.com/wp-content/uploads/2015/03/Innovation-at-Work_PromisingPracticeWinners.pdf

"CCRC Transforms End-of-Life Care with Innovative Space." Senior Housing News, 6/8/15, http://innovation.seniorhousingnews.com/ccrc-transforms-end-of-life-care-with-innovative-space/

CONTACT:

Loretta S. Downs
1658 N. Milwaukee Avenue
Suite 514
Chicago, Illinois 60647
773-343-8208
www.endoflifeinspirations.com

Dawn Z. Mondschein
Central Baptist Village
4747 N. Canfield Avenue
Norridge, IL 60706
708-583-8500
www.cbvillage.org