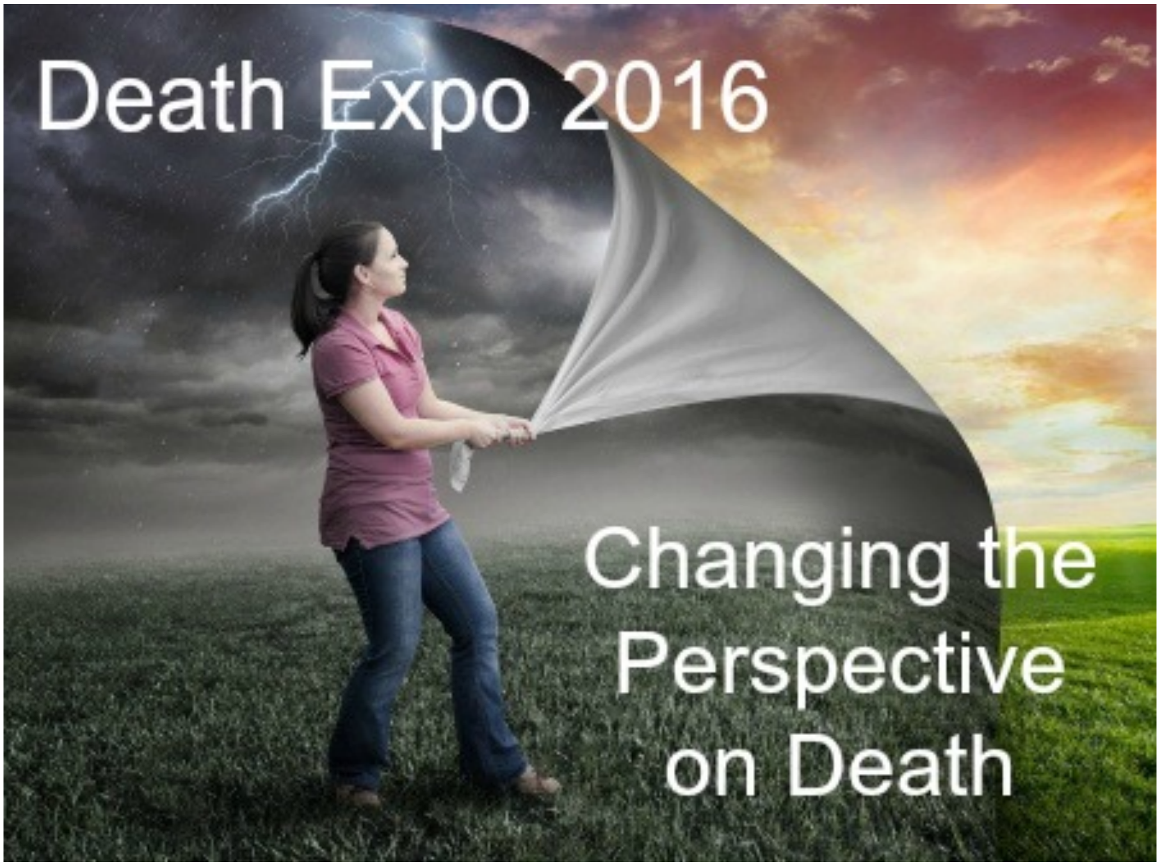

DEATH EXPO 2016
Resource Guide

Karen Wyatt MD

In this guide you'll find additional resources to complement each of the 12 presentations from Death Expo 2016.

Enjoy listening to the recordings of the presentations as you browse these resources!

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Presentation 1: Through the Camera Lens: Right, before I die with Andrew George

Introduction by Andrew George

I often question, as I recall personal events that once seemed important but that have faded from memory, my ability to have perspective. Sometimes, I take this to the extreme, and wonder what I will value in my final moments.

Where does one learn perspective? Is it taught by family and friends? Or in school or other communities? Does life guide us, as we invariably and increasingly witness evidence of our mortality, toward deeper and wiser perspective?

This appears clear – so much depends on the extent to which we observe, and how we process, death. This is no easy task in Western society, which encourages plausible denial of death. I'm not sure this has afforded us perspective on what matters, truly matters, during our limited time. I believe it takes real courage to accept that everything we see as so vital and integral to our lives will vanish.

Some of us will have the fortitude to go beyond the fear of our mortality and confront this unknown journey bravely. These portraits convey my admiration of 20 such individuals who face a premature or impending death and do so with acceptance and peace.

I spent the last two years taking these photographs. Accompanying them are excerpts from interviews and handwritten letters where I asked everyone to express what they were feeling. Some were more comfortable speaking, others in writing. There are passages of distilled insights and others with a more descriptive narrative - I value one way as much as I do the other. In a few instances, I cleaned up grammar for clarity but aside from that, you are reading their words as I heard and understood them.

The men and women who so generously shared with me their stories and personal beliefs are profoundly different and yet very much the same. From their diverse backgrounds and situations, among the least relevant facts were their former professions and the condition or disease to which they were succumbing, so I chose not to include that.

These testimonies of uniquely forged strength in facing death – and making sense of life with such brutal honesty – are something from which I believe we can all take inspiration, hopefully using it to enrich our own lives. Most of these wonderful people have passed, but I hope you will now remember them with me and treasure their perspective and wisdom.
A.G.
Los Angeles
Spring 2014

Presentation 2: Improving Medical Training Through Palliative Care Education with Shoshana Ungerleider, MD

Description of Palliative Care Education Program:

Our innovative, comprehensive resident palliative care education program includes:

1. A required two-week palliative care education block in both first and second years led by a dedicated palliative care educator tailored to resident's unique skills and needs.

- The mandatory first year curriculum includes didactic palliative medicine through a combination of online references, one-on-one lecture/discussions, and case-based self study focusing on prognosis, advanced care planning and symptom management.
- Residents choose a topic for more in-depth literature review and informal presentation at the end of the two week period.
- Residents are exposed to the clinical practice of palliative medicine by shadowing a chaplain, a social worker, and members of the inpatient palliative care team as they care for hospital patients with advanced illness.

2. Communications skills are taught in conjunction with the Health Psychology fellowship program at CPMC.

- Each resident has simulated patient experiences within a palliative care context. Feedback from this encounter and self-identified goals for growth are then used to create an individualized one on one learning experience where residents are taught and practice using specific communication skills.
- A second simulated patient encounter then offers an opportunity to practice leading a goals of care conversation, and again the resident receives direct feedback on their communication skills.

3. Throughout all three years, resident wellness is supported by access to local providers for physical and mental health, acupuncture, massage, gym memberships, and readings on physician wellness.

4. A series of noon conferences supplement classroom and hands-on learning for residents delivered by CPMC physicians from a variety of

disciplines connected to palliative care and advanced communications skills.

5. A quarterly lecture series was initiated in early 2015, bringing in experts in palliative care to engage in conversation with the community. Click for more information.

6. We are collecting data to evaluate the success of the program in the following areas:

- Increasing residents' knowledge about the technical aspects of palliative care;
- Resident skill in communication about goals of care and end-of-life treatments;
- Resident attitudes towards, and interest in, humanistic elements of care;
- Resident well-being and self-care.

Frequently Asked Questions About Palliative Care

From the Center to Advance Palliative Care

1. How do I know if palliative care is right for me?

Palliative care may be right for you if you are experiencing pain, stress and other symptoms due to a serious illness. Serious illnesses include but are not limited to: cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's, AIDS, amyotrophic lateral sclerosis (ALS) and multiple sclerosis. Palliative care is appropriate at any stage of a serious illness and you can get it along with treatment meant to cure you.

2. What does palliative care do?

- Pain and symptom control: Your palliative care team will identify your sources of pain and discomfort. These may include problems with breathing, fatigue, depression, insomnia, or bowel or bladder. Then the team will provide treatments that can offer relief. These might include medication, along with massage therapy or relaxation techniques.
- Communication and coordination: Palliative care teams are extremely good communicators. They put great importance on communication between you, your family and your doctors in order to ensure that your needs are fully met. These include establishing goals for your care, help with decision-making and coordination of care.
- Emotional support: Palliative care focuses on the entire person, not just the illness. The team members caring for you will address any social, psychological, emotional or spiritual needs you may have.
- Family/caregiver support: Caregivers bear a great deal of stress too, so the palliative care team supports them as well. This focused attention helps ease some of the strain and can help you with your decision making.

3. What can I expect?

You can expect to have more control over your care and a comfortable and supportive atmosphere that reduces anxiety and stress. Your plan of care is reviewed each day by the palliative care team and discussed with you to make sure your needs and wishes are being met and that your treatments are in line with your goals. You can also expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care addresses the whole person. It helps you carry on with your daily life. It improves your ability to go through medical treatments. And it helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life.

4. Will my insurance cover palliative care?

Most insurance plans cover all or part of the palliative care treatment you receive, just as with other hospital and medical services. This is also true of Medicare and Medicaid. If costs concern you, a social worker or financial consultant from the palliative care team can help you with payment options.

5. Do I have to give up my own doctor?

The palliative care team provides an extra layer of support and works in partnership with your primary doctor. Your primary doctor will continue to direct your care and play an active role in your treatment.

6. Can I have curative treatment together with palliative care?

Absolutely. Your treatment choices are up to you. You can get palliative care at the same time as treatment meant to cure you.

7. Who else, besides the patient, can benefit?

Everyone involved! Patients as well as family caregivers are the special focus of palliative care. Your doctors and nurses benefit too, because they know they are meeting your needs by providing care and treatment that reduces your suffering and improves your quality of life.

8. Where do I get palliative care?

Palliative care can be available in a number of places. These include hospitals, outpatient clinics, long-term-care facilities, hospices or home.

9. Who provides palliative care?

Usually a team of specialists, including palliative care doctors, nurses and social workers, provide this type of care. Massage therapists, pharmacists, nutritionists and others might also be part of the team. Generally, each hospital has its own type of team.

10. Can I get palliative care if I am at home?

After discharge from the hospital, you, your doctor and the palliative care team can discuss outpatient palliative care. Some hospitals also offer outpatient palliative care even if you have not been in the hospital. Check with your doctor.

11. What is the difference between hospice and palliative care?
Palliative care is for anyone with a serious illness. You can have it at any age and any stage of an illness, and you can have it along with curative treatment. It is not dependent on prognosis.
Hospice is an important Medicare benefit that provides palliative care for terminally ill patients who may have only months to live. People who receive hospice are also no longer receiving curative treatment for their underlying disease.

12. How do I get palliative care?
Ask for it! Start by talking with your doctor or nurse.

Presentation 3: Navigate the Uncomfortable By Preparing Long Before the Need Arises with Alison Anthoine, JD

Understanding Advance Directives

From the National Hospice and Palliative Care Organization

What are advance directives?

"Advance directives" are legal documents that allow you to plan and make your own end-of- life wishes known in the event that you are unable to communicate. Advance directives consist of (1) a living will and (2) a medical (healthcare) power of attorney. A living will describes your wishes regarding medical care. With a medical power of attorney you can appoint a person to make healthcare decisions for you in case you are unable to speak for yourself.

What is a living will?

A living will is an advance directive that guides your family and healthcare team through the medical treatment you wish to receive if you are unable to communicate your wishes. According to your state's living will law, this document is considered legal as soon as you sign it and a witness signs it, if that's required. A living will goes into effect when you are no longer able to make your own decisions.

What is a medical power of attorney?

A medical power of attorney is the advance directive that allows you to select a person you trust to make decisions about your medical care if you are temporarily or permanently unable to communicate and make decisions for yourself. This includes not only decisions at the end of your life, but also in other medical situations. This document is also known as a "healthcare proxy," "appointment of healthcare agent" or "durable power of attorney for healthcare." This document goes into effect when your physician declares that you are unable to make your own medical decisions. The person you select can also be known as a healthcare agent, surrogate, attorney-in-fact or healthcare proxy.

Who should I select to be my medical power of attorney?

You should select someone you trust, such as a close family member or good friend who understands your wishes and feels comfortable making healthcare decisions for you. You should have ongoing conversations with this person to talk about your wishes at the end of life. Make sure your medical power of attorney feels comfortable and confident about the type of medical care you want to receive.

Most state laws prevent your doctor or any professional caregiver from being assigned as your healthcare agent. You can also select a second agent as an alternate in case your first healthcare agent is unwilling or unable to serve.

What do I need to know about end-of-life decisions to prepare my advance directive?

Learn about life-sustaining treatments

Life-sustaining treatments are specific medical procedures that support the body and keep a person alive when the body is not able to function on its own. Making the decision about whether or not to have life-sustaining treatments can be a difficult decision depending on your situation.

You might want to accept life-sustaining treatments if they will help to restore normal functions and improve your condition. However, if you are faced with a serious life- limiting condition, you may not want to prolong your life with life-sustaining treatment. The most common end-of-life medical decisions that you, family members or an appointed healthcare agent must make involve:

- Cardiopulmonary Resuscitation (CPR)
- Do Not Resuscitate Order (DNR)
- Do Not Intubate Order (DNI)
- Artificial Nutrition and Hydration

What is cardiopulmonary resuscitation (CPR)?

Cardiopulmonary resuscitation (CPR) is a group of procedures used when your heart stops (cardiac arrest) or breathing stops (respiratory arrest). For cardiac arrest the treatment may include chest compressions, electrical stimulation or use of medication to support or restore the heart's ability to function. For respiratory arrest treatment may include insertion of a tube through your mouth or nose into the trachea (wind pipe that connects the throat to the lungs) to artificially support or restore your breathing function. The tube placed in your body is connected to a mechanical ventilator.

What are advance directives?

A Do Not Resuscitate (DNR) order is a written physician's order that prevents the healthcare team from initiating CPR. The physician writes and signs a DNR at your request or at the request of your family or appointed healthcare agent if you do not want to receive CPR in the event of cardiac or respiratory arrest. The DNR order must be signed by a doctor otherwise, it cannot be honored. DNR orders:

- Can be cancelled at any time by letting the doctor who signed the DNR know that you have changed your decision.

- Remain in effect if you transfer from one healthcare facility to another. However, consult the arrival facility's policy to make sure. Also, the DNR may not be honored if you are discharged from the facility to your home if your state does not have an out-of-hospital DNR policy.
- May not be honored during surgery but this is something very important to discuss with your surgeon and anesthesiologist before surgery so your wishes are honored.
- Should be posted in the home if that is where you are being cared for.

If there is no DNR order, the healthcare team will respond to the emergency and perform CPR. The team will not have time to consult a living will, the family, the patient's healthcare agent or the patient's doctors if they are not present.

What is a Do Not Intubate (DNI) order?

When you request a DNR order, your physician may ask if you also wish to have a "do-not-intubate" order. Intubation is the placement of a tube into the nose or mouth in order to have it enter your windpipe (trachea) to help you breathe when you cannot breathe adequately yourself. Intubation might prevent a heart attack or respiratory arrest.

Refusal of intubation does not mean refusal of other techniques of resuscitation. If you do not want mechanical ventilation (breathing), you must discuss intubation because it may be included as part of a DNR order. Even if you have completed a DNR order that does not mean that you have refused to be intubated. If you do not want life mechanically sustained, you must discuss your decision about intubation with your doctor.

What is artificial nutrition and hydration?

Artificial nutrition and hydration are treatm t allow a person to receive nutrition (food) and hydration (fluid) when they are no longer able to take them by mouth. This treatment can be given to a person who cannot eat or drink enough to sustain life. When someone with a serious or life-limiting illness is no longer able to eat or drink, it usually means that the body is beginning to stop functioning as a result of the illness.

How can I prepare my advance directive?

You can fill out a living will and medical power of attorney form without a lawyer. The National Hospice and Palliative Care Organization, your state hospice organization, local hospitals, public health departments, state bar associations or state aging offices provide state-specific forms and instructions. It is very important that you use advance directive forms specifically created for your state so that they are legal. Read the forms carefully and make sure you follow legal requirements determined by your state. You may need to have a witness signature and get the forms notarized (signed by a notary public.)

Keep your completed advance directive in an easily accessible place and give photocopies to your primary medical power of attorney and your secondary, alternate agent. This document stays in effect unless you cancel it or decide to complete a new one with changes.

Can healthcare professionals refuse to honor my advance directive?

Some healthcare professionals may choose to ignore what is written in your living will if they believe that what is written is against your best interest or for moral or religious reasons. In some cases there may be a misunderstanding of the law, medical ethics or professional responsibilities. It is important for you to know if your doctor will honor your request. Bring your completed living will to your next healthcare appointment and ask your doctor if he or she has questions or concerns.

Who would decide about my medical care if I did not complete an advance directive?

If you are unable to make decisions, healthcare professionals must consult your family members. Some states have decision-making laws to identify individuals who may make decisions on your behalf when you do not have an advance directive, such as your spouse, parents or adult children.

Does my advance directive include my wishes about organ donation, cremation or burial?

Some states may include your wishes about whether you want to be an organ donor as part of the advance directive. If it is not included, you can still write down your decision about organ donation. However, you should fill out a specific form for that purpose.

You should also let your loved ones know if you wish to be buried or cremated.

www.CaringInfo.org

Guidelines for a Healthcare Proxy – Karen Wyatt MD

What is a “healthcare proxy?

A proxy is a person who makes healthcare decisions for someone else, particularly when they are unable to speak for themselves. Other names for this position include *healthcare agent*, *durable medical power of attorney,* or *durable power of attorney for healthcare* (depending on the state or province where you live.)

Responsibilities of a healthcare proxy:

- Learn the end-of-life preferences of the person you have agreed to represent
- Keep a copy of the advance directive forms for the person you are advocating for
- Know the person you represent well enough to have familiarity with the types of choices he or she might make in a crisis situation
- Engage with medical personnel to find out the options available for the patient
- Ask questions to make sure you understand the medical condition of the patient
- Be strong enough to advocate for the wishes of the patient even if others do not agree

Steps for healthcare proxy to follow:

1. Get comfortable talking and thinking about the end-of-life
2. Have an in-depth conversation with the person you are representing about their hopes, wishes and expectations for the end-of-life; ask questions to make sure you understand thoroughly and take notes if needed
3. When a medical crisis occurs, be available to talk with doctors and get a complete understanding of the situation, the prognosis, and any tests or procedures being recommended.
4. Make the best decision you can based on what you know about the patient.
5. If you’re not sure what the patient would choose, then choose what is in the best interest of the patient.
6. Communicate with the patient’s family members about the decisions you have made and the reasons for them.

Presentation 4: Celebrants: Providing Modern and Meaningful Ceremonies for Life's Transitions" with Charlotte Eulette

Celebrant Foundation & Institute Ritual and Ceremony
Primary Source for References and Research

The ritual observance of rites of passage and seasonal changes has ancient and widespread roots, and over the centuries has grown to encompass the practices of myriad religions and philosophies both living and dead, civic and political events, and personal milestones. As society worldwide, especially Western society grows increasingly more pluralistic and secular, many individuals, families, and organizations are seeking ways to mark important junctures in a manner that respects the variety of diverse points of view and beliefs, while allowing the beauty and relevance of the ceremony to shine forth.

The Celebrant Foundation & Institute, believes that everyone should have access to ceremonies and rituals that have the most meaning to them, and was the first organization in the United States to provide training in this discipline through a direct lineage from the International College of Celebrancy in Australia, the birthplace of the modern celebrancy movement. As the practice of modern celebrancy grows, so does the interest in investigating the impact that personal, religious, and secular rituals have on our inner and outer experiences, as well as on society at large. While early scholarship, chronicled by Arnold Van Gennep, Ronald L. Grimes and Mircea Eliade, focused on age-old and universal practices, modern academics and contemporary authors are viewing ritual and ceremony with fresh eyes, documenting the changing cultural landscape.

We are a species through which the desire to mark threshold crossings is strong, and through which ceremonies flow in an unending stream. From ancient celebrations of the Winter Solstice to entering a monastery, from crowning a monarch to welcoming a child into the tribe, from Japanese tea ceremonies to Victorian mourning practices, and on to contemporary events as varied as celebrating 50th wedding anniversaries and the dedication of the 9/11 memorial, we know that ritual is one of the defining characteristics of being human.

The Celebrant Foundation and Institute honors all threshold crossings on the human journey, and is proud of its rigorous training programs and emphasis on continued learning opportunities. The sources we have gathered here range through peer-reviewed journal articles and classic texts to popular blogs and contemporary concepts. This places ceremony and ritual into historical and sociological contexts while offering you a broader and deeper view of the role of ritual in your own life. Whether you are a perspective client, a potential or current student, a practicing celebrant or a rite-of-passage enthusiast, we trust that you will find something of interest in the web-links and resources listed below.

By Carole Wallencheck, CF&I Ceremony Research Developer

On-going research projects

- Pew Research Center's Religion & Public Life Project http://www.pewforum.org/
- Pluralism Project at Harvard University http://www.pluralism.org/
- University of Oxford Institute of Cognitive and Evolutionary Anthropology - Ritual, Community, and Conflict Project http://www.icea.ox.ac.uk/research/ritual/

Surveys on Religious and Secular Affiliations in the United States

- ARIS (American Religious Identification Survey) – General American Population, 2008 – conducted by Trinity College, Hartford, CT. http://commons.trincoll.edu/aris/files/2011/08/ARIS_Report_2008.pdf
- ARIS (American Religious Identification Survey) – American College Students, 2013 – Conducted by Trinity College, Hartford, CT http://commons.trincoll.edu/aris/files/2013/10/ARIS-2013_Students-Oct-01-final-draft.pdf
- Pew Forum on Religion & Public Life / U.S. Religious Landscape Survey (done in 2007) http://religions.pewforum.org/reports

Blogs

- Threshold Ceremonies – Barbara Parker - http://canmoreceremonies.ca/ceremony-years-2/
- Sweetgrass Ceremonies - Kristine Bentz –
  Weddings and Unions - http://weddings.sweetgrassceremonies.com/
  Memorials and Natural Departures - http://memorials.sweetgrassceremonies.com/

- Inclusive Ceremonies – Cristina Kollett - http://inclusiveceremonies.com/blog/

Suggested Reading

- *The Art of Ritual: A Guide to Creating and Performing your Own Rituals for Growth and Change* - Renee Beck and Sydney Barbara Metrick
- *Deeply Into the Bone: Re-inventing Rites of Passage* - Ronald L. Grimes
- *From Beginning to End: The Rituals of Our Lives* - Robert Fulghum
- *Hero with a Thousand Faces* – Joseph Campbell
- *Rites and Symbols of Initiation: The Mysteries of Birth and Rebirth* - Mircea Eliade; translated from the French by Willard R. Trask
- *The Rites of Passage* - Arnold van Gennep; translated by Monika B. Vizedom and Gabrielle L. Caffe
- *Ritual: Power, Healing and Community* - Malidoma Patrice Some
- *Ritual Theory, Ritual Practice* - Catherine Bell
- *The Water of Life: Initiation and the Tempering of the Soul* - Michael Meade

Written and researched by Celebrant, Carole Wallencheck. Feel free to reach out to Carole at naturecelebrant@hotmail.com with any comments and ideas. Thank you.

###

Presentation 5: Urban Death Project: A Sustainable After-Death Alternative with Katrina Spade

Frequently Asked Questions About Recomposition

What is the project's mission?

Our mission is to create a meaningful, equitable, and ecological alternative for the care of the deceased.

To do so, we're creating a holistic new model that is:

- Ecological: providing a disposition system wholly based on the natural cycles - a way to grow new life after death and celebrate our place in the natural world.
- Transparent: being clear with our services and pricing, providing an income-relative fee structure, and cultivating a culture of giving.
- Meaningful: acknowledging that death is an important part of life and supporting the grieving as they participate in all aspects of death care.

At the heart of this model is a new system of disposition called Recomposition, which gently transforms bodies into soil. It is replicable, straightforward, and elegant, removing the manufactured barriers between death and the natural processes of renewal. Environmentally, it is a vast improvement over the industry standard.

In our redesign of the funeral paradigm, these Recomposition systems are housed in community spaces that support the grieving as they return the deceased to the earth. Gardens are nourished from the soil created on-site, as the cycles of life are woven into the urban fabric and become part of the public consciousness.

What is the problem the project is hoping to solve?

Current funerary practices have come to us almost accidentally—part historical convention and part funeral industry mandate—and they are environmentally atrocious. Each year, 2.6 million people die in the U.S, and most are buried in a cemetery or cremated, impacting land use and contributing to climate change. Wasteful, toxic, and polluting, these options undervalue the potential of our bodies and place an enormous strain on the environment.

When left to the status quo, the last thing that most of us will do on this earth is poison it.

The current funeral system also fails to provide people with the support they need in times of grief. This $20 billion (U.S.) industry depends on the sale of needless consumables to vulnerable people, often turning what should be a meaningful event into a time of consumer confusion. Families struggling to make ends meet are often pushed into debt, and bodies go unclaimed when families cannot afford to bury or cremate them.

How is recomposition different from the status quo?
The funeral industry is a broken system. Many aren't prepared to choose how to dispose of a loved one's body during their time of grief, and so they are pushed to choose the most costly and invasive option. The approach of this project is a bold departure from this status quo – never before have humans been "recomposed". Our work is inspired by the natural burial movement, a rural option that is respectful of both the human body and the earth. This project changes the way that we think about our bodies after death, to view them as part of the solution to our environmental crisis.

The Urban Death Project is a manifesto for a new model of death care. We believe that humans deserve better than a system that relies on the sale of needless consumables to vulnerable people. Our goal is to banish practices that bewilder and dis-empower, and create a non-profit model that is transparent and meaningful.

Why would I want my body to decompose?
Unless we are cremated or mummified, our bodies will decompose after we die. Being embalmed and placed in a casket and a concrete grave liner will delay the process, but only for a few weeks or months. We like the idea of facilitating the decomposition, so that our bodies can be part of the earth as soon as possible. We also like the idea that we can be productive and help solve our environmental crisis - even after we die.

What are the benefits of compost?
The earth is covered in a living, breathing skin. Our soil supports the living planet and all of the food that we grow, filters and recycles our water and waste, and acts as a carbon sink. It's a beautiful substance, and it can take hundreds of years to renew. Compost - organic matter that has been decomposed and recycled as a fertilizer - supports and improves the soil, as

well as reducing the need for the petroleum-based chemical fertilizers, pesticides, and additives that can do more harm than good. Composting is a way to take dead organic materials and give them new life. The process of composting is also a great reminder that we are all very much part of the working cycles of nature.

Is it safe to compost bodies?

Composting creates heat, which kills common viruses and bacteria. Research into mortality composting of livestock has found that the temperature inside the compost reaches 140 degrees Fahrenheit, which is high enough to kill off pathogens. Farmers are using mortality composting in order to safely dispose of their dead livestock, as well as to control odor and runoff. The Urban Death Project is fine-tuning this process to be appropriate and meaningful for humans in an urban setting.

How does religion fit into all this?

The Urban Death Project fills a niche, providing an alternative method for the disposal of the dead designed for the density of the city and envisioned on a neighborhood scale, and it was initially designed for the millions of people for whom traditional religion is not a guiding force. That said, the architecture of the Urban Death Project will include space for those of any faith to gather, pray, and mourn.

It is important to note that the Urban Death Project is not simply a system for turning our bodies into soil-building material. It is also a space for the contemplation of our place in the natural world, and a ritual to help us say goodbye to our loved ones by connecting us with the cycles of nature. Quite simply, for many, this option will be deeply spiritual – an ecological, productive, and beautiful thing to do with our physical bodies after we have died.

What about natural burial?

Natural burial, where bodies are buried (unembalmed and often without a casket) in a natural setting is a lovely alternative to the conventional. However, natural burial is a decidedly rural option - the Urban Death Project is meant to be an alternative for the disposal of our dead in cities.

What about the bones?

Research into mortality composting has shown that bones can be fully composted, although they do take longer than the flesh to decompose. We are currently working to determine the exact amount of time it will take to turn a human body into nutrient-rich, soil-building material.

How will you overcome the stigma of "dead bodies in my yard'?

In the end, we leave behind our bodies. And what happens to them makes most of us squeamish. But the truth is that without decomposition – the process by which organic material is broken down to support new growth – we would not exist at all. The bodies we leave behind aren't just shells of our former selves, rather, they are full of potential – nitrogen, water, calcium and phosphorus – the building blocks of nutrient rich soil.

We will overcome the stigma of "dead bodies in our yards" through education. Dead bodies are all around us, in cemeteries and mausoleums.

We believe that given the chance, people will embrace the idea of compost that has been created from the bodies of our neighbors. The idea of being folded back into the urban community where we have lived, and of helping to heal the earth by doing so, is very powerful.

Some parallels can be drawn from the home composting movement. Just a few decades ago, most people would have been squeamish to have food decomposing in a container on their kitchen counter. Today, municipalities run composting facilities, and it is a point of pride for many that their food scraps are being turned back into soil. San Francisco and Seattle already require home food scrap composting; New York is proposing the same beginning in 2016.

More and more, urban dwellers desire a deeper connection with the cycles of nature, and to be part of the solution to our environmental dilemma. The rise in popularity of urban farming, permaculture, and the use of city infrastructure to produce food and energy (such as rooftop gardens, aquaculture, urban green space and solar power) are examples of this. The Urban Death Project goes hand in hand with these movements. Through education, including a careful explanation of the chemical processes happening inside the core, the feelings of squeamishness will change into something more bold and beautiful, an embrace of our part in the grand cycle of life and death, growth and decay.

How does this project reduce greenhouse gas emissions?

- A fundamentally aerobic process, composting does not produce methane, a potent greenhouse gas. Methane is produced by anaerobic processes, such as the putrefaction of an embalmed corpse in a sealed concrete vault six feet under.
- Compost significantly reduces agricultural energy demand, in part because the application of compost results in a reduced need for GHG producing petroleum-based chemical fertilizer, pesticides, herbicides, and additives. The UDP will partner with community gardens and local farms, so that compost produced directly offsets the use of chemical fertilizers and additives.
- Fewer greenhouse gasses will be produced by the manufacture of embalming fluids, vaults and coffins, as more and more people choose to have their bodies composted.
- Fewer trees will be cut down to make caskets.
- Less arable land will be used for cemeteries, allowing crops to be grown closer to urban centers, reducing the need for fossil fuel powered transport of food.

Will compost created by the Urban Death Project system be used to grow food?
No. The compost that is made from the bodies of the deceased will be used to grow trees, flowers, and memorial gardens, not food crops.

What about toxic pharmaceuticals within the bodies - how will you protect our groundwater from those?
One of the chief things we'll be testing in the prototype we're building at Washington State University is what happens to pharmaceuticals in the recomposition process. We've already started testing to understand what happens to the mercury in amalgam dental fillings.

What about pacemakers and metal in the body - what will happen to it?
Once a body has been recomposed and has transformed from human into a coarse compost, we will screen for non-organics like gold teeth and titanium hips. Pacemakers will be removed before the process (like they are before a cremation.)

What's the environmental footprint in building this facility? Refrigerated units need electricity? coal fired? Hydro? Solar?

We haven't yet calculated, but we will definitely be designing it to the highest environmental standards. And, whenever we can, we will use the "waste" heat created by the process to warm the space. Finally, there is good potential for re-purposing old infrastructure to use as Recomposition Centers - old churches, warehouses, etc. So there won't always be a need for a buildings.

www.UrbanDeathProject.org

Presentation 6: Final Passages: Reawakening the Sacred at the End of Life with Jerrigrace Lyons

Frequently Asked Questions About Home Funerals

From the National Home Funeral Alliance

What exactly is a home funeral?

A home funeral happens when a loved one is cared for at home or in prepared space after death, giving family and friends time to gather and participate in:

- keeping the body cool with noninvasive techniques, such as ice
- filing the death certificate and obtaining transport and burial permits
- transporting the deceased to the place of burial or cremation
- facilitating the final disposition, such as digging the grave in a natural burial
- preparing the body for burial or cremation by bathing, dressing and laying out for visitation
- hiring professionals for specific products or services
- planning and carrying out after-death rituals or ceremonies

Are home funerals legal?

Yes. In every state and province, it is legal for families to bring or keep their loved one home until time of disposition. In ten states, a funeral director may need to be involved in some capacity, but this does not hinder the ability to have a home funeral.

Are home funerals safe?

Yes. Dead bodies do not pose an increased health risk any more than when they were alive. With appropriate hygiene and cooling techniques, it is perfectly safe to keep a loved one home for several days. Embalming itself poses more than an eight times greater risk to embalmers of contracting leukemia than the general population. In fact, bodies with infectious diseases are not usually candidates for embalming and are simply kept cool in a professional setting if not at home.

What does a home funeral cost? The average professionally-directed funeral now costs $8,343, without casket, vault, cremation or burial costs included. A home funeral costs the price of ice, if used, copies of the death certificate as desired, gas to transport the body, and a rigid container, such as a cardboard box or pine casket, usually totaling under $200. Burial and cremation costs would be added at whatever the going rate is in your cemetery or facility.

What are the benefits of home funerals?
The many significant benefits are environmental, financial, therapeutic, and spiritual. Families who choose to care for their own report a sense of completion, a feeling of having done their best for those they love, and a stronger connection to their friends and family and community. Having something meaningful to do to help others through a crisis or sorrowful time is usually empowering for all involved.

What are the top reasons families choose home funeral care?
Top reasons for electing to conduct care of the deceased include, in no particular order:

- to take the time to be truly present
- to avoid outsourcing the responsibilities they choose to assume themselves
- to avoid professionalizing a family rite of passage
- to make meaning of the death
- to begin healing the family and community
- to take environmental responsibility by foregoing invasive and toxic procedures
- to make the funeral affordable
- to find spiritual connection
- to participate more fully in their own lives and in their family life

What is the difference between a Death Doula and a Death Midwife?
As the movement grows, people have created many terms to explain what death workers do. We have surveyed and researched the terms, and have adopted these words to help clarify what a Death Midwife, Death Doula, home funeral guide, transition guide, and many more terms mean when people identify themselves in all or parts of this work.

How did the NHFA come into being?
A group of home funeral guides from all over the US gathered to form an organization to support home funerals and those who guided families through them. An annual (now biennial) conference was established, attracting people involved after-death care from all walks of life. The NHFA is the leading body of home after-death care support and education in the country since 2010.

Who owns the dead?
In the language of the law, the family member who has the most direct link in the next-of-kin chain has legal custody and control of the body. If unwilling or unable to assume that responsibility, members along the chain as spelled out by state law are imbued with the authority until someone is able to act.

The fact that most families choose to relinquish that partial responsibility by signing a contract with a professional that transfers physical custody does not negate the family's right to decide what ultimately happens to that body. Funeral directors have no medico-legal authority. The only service they are licensed to perform that a family member cannot is embalming.

Some states require that refrigeration and/or disposition occur within a certain time frame, which usually apply when being handled by a funeral firm, but home funeral families choose in most states how the body is handled, preserved, transported, and disposed of on their own timetable. Even in cases of autopsy (where the ME's right supersedes the family's temporarily) and organ donation, the decision remains with the next-of-kin after the process is complete, including having the body brought home.

What, other than legal requirements, impede families from exercising their right to care for their own dead?
Because the funeral industry is a tight-knit community, often crematories, cemeteries, and newspapers refuse to accept bodies or information directly from the family by policy or business practice. Even when families have the right to this according to law, they are still being obstructed from handling the entire process without being forced to hire an intermediary.

Some hospitals and hospices also require removal by a professional without regard for policy compliance with the law. Care facilities and hospitals often have limits on how long a body can be housed, forcing the family to hire a funeral director to file the death certificate quickly, especially on holidays and weekends when the local offices are not open, in order to obtain the transport permit needed to remove the body to the home.
The process is becoming more, not less, cumbersome for families with the implementation of state Electronic Death Registration Systems, or ERDS. Funeral directors have a direct link to Vital Statistics software, as do town or city clerks, though they are infrequently well-trained. Some states empower

doctors and even state police to file death certificates but few have proved willing.

If a body is not embalmed, what must a family do to care for it? When should the body be buried?

This is a more complex question than it sounds. Care of the deceased changes depending on whether it was an anticipated death or unanticipated, under what conditions the person died, under what regional weather conditions the period will be subject to, and whether there will be travel involved.

Unembalmed bodies (according to the CDC, CID, WHO and PANO) are not dangerous nor are they more infectious than they were in life. Simple methods of cooling the body such as using dry ice, Techni-ice, an a/c unit, or opening a window in cool weather are more than sufficient. Even without these methods, most bodies can be kept for up to 3 days in a 65 degree room. Bathing the body with simple soap and water to remove the usual surface bacteria will dispense with concerns about smell. The body is then dressed if desired or wrapped in a shroud or blanket, sheet, or quilt.

Removal for final disposition — either burial or cremation — is at the discretion of the family, either themselves or by hiring that service. Some states require that a funeral director file the death certificate or witness a burial, but in most states the family can file any necessary paperwork and make any other additional arrangements themselves, such as calling Social Security or filing obituaries. There is no time limit in most states for burial or cremation unless cause of death requires it, and only a handful of states have mandatory waiting periods before cremation.

What do home funeral guides charge for?

Home funeral guides are allowed by law to charge ONLY for educational services. This may include general instruction, presentations, demonstrations, phone consulting, and other means of imparting information.

Home funeral guides MAY NOT charge for hands-on body care of any kind. Home funeral guides who charge for consulting time spent with the family during a death AND sell anything to them, such as a casket, shroud, ice, or item needed for the physical care of the deceased are bound by the FTC’s

Funeral Rule to provide a General Price List and are bound by the Rule's protocol and processes.

Home funeral guides and community groups who convene to be available to families during the funeral period do so as volunteers. The fact that they may have a website or promotional materials does not imply business transactions. They are also not responsible for reporting to any agency or office what home funerals occur with or without their involvement.

"Home funeral guides are not currently certified by any third party organization. They are trained not to do the work of preparing the body, providing transportation, filing the paperwork, or anything a professional is licensed to do, but to assist the family with information about all of these things and more. Home funeral guides are trained to know the law, know when bodies need additional attention, assist in finding local resources, and a myriad of other skills and educational services. They make sure things are done properly, safely, and legally; but more importantly, they are there as back-up support to family members and friends who may want to care for their own but are not confident about how. Any money changing hands is for educational services only. Any hands-on work is strictly voluntary at the request of the family."
—From the NHFA publication *How Funeral Directors Can Support Home Funeral Families*

www.HomeFuneralAlliance.org

Presentation 7: The Heart of Grieving with Michelle Peticolas

Dia De Los Muertos, Or 'Day Of The Dead,' Helps Families Cope With Grief Through Sugar Skulls, Food, And Drinks

By Lizette Borreli

MedicalDaily.com

You've most likely heard of it but probably don't know much about it. The Mexican holiday *Día de los Muertos* (Day of the Dead) is commonly known for its colorful, grinning sugar skulls — a symbol of the dead — seen in art and fashion. But the two-day holiday, which falls on Nov. 1-2, is more than that. Over the course of two days, friends and family congregate in cemeteries to remember, pray for, and celebrate the deceased with food and drinks. While it may seem strange to celebrate death, the festivities can actually help some people deal with the effects of grief.

1. DAY OF THE DEAD: THE ORIGINS

The Day of the Dead goes back to thousands of years before the Spanish conquest, when various ethnic groups in the region, including Aztecs, Mayans, and Toltecs, commemorated the deceased at different times of the year. They'd dedicate certain months to honoring the death of children, while other months were designated to honor adults.

The celebrations are based on the indigenous Mexican beliefs that the soul is eternal and can therefore travel back and forth between this world and the afterlife. They believed the departed would return during the festivities, which were full of music and dancing rather than mourning, to receive gifts.

2. THE SUGAR SKULL: A DEPARTED SOUL

Skulls typically depict a dark and macabre atmosphere. But on the Day of the Dead, the skull — called La Catrina — symbolizes the departed souls as well as the ability to "laugh at death itself," Kriss A. Kevorkian, a thanatologist and self-proclaimed "deaducator" in the field of end-of-life care for over 20 years, told *Medical Daily*.

The colorful, whimsical skulls were first introduced in the early 1900s by Mexican artist Jose Guadalupe Posada, who would use them in his art, which served as political and cultural critiques of the upper classes during the 35-year reign of Porfirio Diaz. Since Posada's death, however, his skulls have become associated with the Day of the Dead. Children and their parents often visit fairs where they can buy skulls made of candy — hence the term "sugar skull" — and subsequently give them to friends and family as gifts.

Traditionally, the names of the deceased are written on the skulls' foreheads before being placed on the ofrenda, or altar, in the family's home. A photo of the person who died accompanies the skull, along with Cempazuchitl — a marigold flower native to Mexico — candles, food, beverages, and clothes. This collection of items is often a combination of the dead's favorite things and are given as gifts.

Tracee Dunblazier, a spiritual empath and certified grief counselor based in Los Angeles, Calif., celebrates Day of the Dead every year. She sees the holiday as recognition that "our loved ones exist on another "plane" and says we have "access to them when the spiritual veil is thin around the fall equinox." For those who grieve, then, the Day of the Dead offers a way to mourn by creating a new frame of thought around death. It allows us to relate to those who are no longer physically with us.

3. THE CEMETERY: A PLACE OF CELEBRATION, NOT MOURNING

Families start preparing for the return of their loved ones weeks before the Day of the Dead. At home, families set up a table top exclusively used for the altar, or they build one from a stack of crates, and lastly, drape cloth over it to arrange the *ofrendas* (offerings), including Cempazuchitl, candles, incense, photos of the deceased, pan de muerto, sugar skulls, among many others. The deceased are believed to absorb the aroma and the energy of the foods to nourish and replenish their spirits.

The ceremony is different from typical funerals or memorial services in the United States. Prior to the celebration, the gravesites of the deceased are cleaned and adorned with marigold flowers and candles, along with toys for the deceased children, and bottles of liquor for the deceased adults. On Day of the Dead, well after dark, people visit the cemetery where their loved ones are buried. Visitors sit on blankets next to the tombs to eat the favorite food of their loved ones throughout the night.

These ceremonies allow people to establish and celebrate the connection between the living and the dead. After all, as Kevorkian, says, death is a part of life. "The celebration acknowledges the physical loss of a loved one, but the relationship doesn't have to be severed as other cultures seem to insist upon through sayings such as, 'Get over it' or 'She was old,' which only causes more difficulty for the person in grief," she said.

4. A NEW WAY OF MOURNING?

The morbid and daunting view of cemeteries in the U.S. has changed, and it's not only because of traditions like Day of the Dead. A relatively new phenomenon called graving has emerged; it involves visiting grave sites — either for fun or to find information. Some people, for example, are interested in finding the graves of 1950s Hollywood stars while others are genealogical gravers, who try to complete their family tree with the help of information from headstones.

Gravers obtain this information from FindAGrave.com , a database of more than 138 million burial records. Gravers simply enter the deceased's name, biographical details, and burial location. Cemetery, date of birth and death, and even "claim to fame" are also available search filters on the database. And users can leave comments and virtual flowers, or upload portraits or headstone photos.

Russell Friedman, executive director of The Grief Recovery Institute Educational Foundation in Sherman Oaks, Calif., believes visiting these graves can have a positive effect on people and, to a much lesser degree, a negative one. "A visit to the grave can help us look at the relationship in a way that helps us discover some of the things that we wish had been 'different, better, or more,'" he told *Medical Daily* in an email.

But awareness of these situations doesn't equate to an understanding of what happened, Friedman said — after all, there are multiple sides to every issue. For this reason, opening a dialogue with loved ones can help us connect the dots, especially if we have revelations while visiting the grave.

Graving may go against the norm, but it also provides a 21st century approach to how we should look at death — and cemeteries, for that matter. Those who cannot bring themselves to physically visit a gravesite, for example, can do so online with Find a Grave, and it'll be on their own terms. While this may not be a tradition like Day of the Dead, it is an alternative option to commemorate the dead.

As humans, we're conditioned to fear death because it is seen as our destiny, but what if we were to view death as a celebration, like Day of the Dead?

The holiday fuses the realities of life and death, encouraging families of the deceased to embrace the passing of a loved one with music, food and drinks. It provides meaning to human existence and gives those who celebrate it an answer to what happens next — therefore, in a way, it's life after death. Despite its name, Day of the Dead is truly a celebration of life.

Presentation 8: Holistic Nursing, Integrative Nurse Coaching at the End of Life with Barbara Dossey, RN

Holistic Nursing Q & A

Barbara Dossey, RN

Can you give a working description of holistic nursing?
Holistic nursing embraces all nursing practices that strive to heal the whole person. The central task of a holistic nurse is to practice healing from the deep understanding that each person is more than the sum of individual parts-that we each live in a dynamic and busy world and are influenced by both our internal and external environments. Holistic nurses draw upon nursing theories and practical expertise-and the guidance of their intuition-as they become therapeutic partners with patients.

Holistic nursing requires that nurses integrate self-care/self-responsibility in their lives in order to help facilitate healing and caring for others. In turn this self- care/self-responsibility leads nurses to a greater awareness of the interconnectedness of all individuals and their relationships to the human and global community.

How does the human spirit impact our physiology?
Emotions, love, attitudes, meaning, and purpose are parts of the human spirit that can literally leave "tracks" in the body. Scientific physiologic data on the mind's modulation of the autonomic nervous system explain how the human spirit is transduced to the cellular level. Biochemical changes occur in the endocrine, immune, and neuropeptide systems in relation to one's emotions, attitudes, and thoughts. These biochemical changes are "tracks of the spirit in the body." For example, if you trace anatomic locations from the limbic system down the nerve pathways and into the extremities and organs, the physiologic changes in the brain correlate with emotions, attitudes, and thoughts. Likewise, these neurotransmitters carry impressions back to the brain, sketching the dimensions of one's spirituality.

What is the difference between “doing” and “being” therapies?
"Doing" therapies involve medications, surgery, and procedures; "being" therapies involve states of consciousness and inner awareness (meditation, contemplation, and directed or non-directed prayer).

What are you describing when you speak of “transpersonal human caring transactions”?

The human caring process is an interplay of nurse, client, family, and the individual uniqueness of all involved. This creates a dynamic event of caring. The human caring process also has a transpersonal dimension, in which the nurse affects and is affected by the patient. Both are fully present in the moment and feel a sort of union with each other. The experience becomes part of the life history of both. This coming together can be done in a distant, mechanical manner in which the nurse or client responds without acknowledging the other or recognizing each other's potentials. Or it can be done humanely, as when the nurse and client come together with a presence of caring that involves actions and choices made by both.

How can nurses facilitate the spiritual dimensions when counseling patients?

In this age of change, people are seeking to create new perceptions for their lives and to find wholeness and spirituality. They need guidance in their transformation. In order to deal with the spiritual dimension more effectively, nurses should be aware of the following complex factors that shape their own world views and influence their ability to help patients with spiritual issues.

- **Basic attitudes:** Nurses hold belief systems about illness, aging, and suffering.
- **Pluralism:** Nurses and clients each have a vast array of beliefs, values, meaning, and purpose.
- **Fear:** Nurses may be confused about their own beliefs and values, lack confidence in their ability to handle situations, and feel concern about invading their client's privacy.
- **Awareness of own spiritual quest:** Nurses may contemplate meaning, purpose, hope, and presence of love in their own lives.
- **Confusion:** Nurses may experience conflict between religious and spiritual concepts.

Barbara Dossey, RN
www.dosseydossey.com

INTEGRAL PERSPECTIVE, HEALING, AND CHANGE

Barbara Dossey, PhD, RN, AHN-BC, FAAN HWNC-BC
Director, International Nurse Coach Association (INCA) www. inursecoach.com
Co-Director, Nightingale Initiative for Global Health (NIGH) www.NIGHvision.net

Integral Perspective: An integral perspective is a comprehensive way to organize multiple phenomenon of human experience related to *four perspectives of reality.*

UL—Individual interior (personal/ intentional) **UR**—Individual exterior (physiology/behavioral)
LL—Collective interior (shared/ cultural) **LR**—Collective exterior (systems/structures)

Quadrants and Change Approach Summary: To create the conditions for change to be sustained requires an exploration of the individual's inner space of interiority (UL), the outer space of actions, goals and timelines (UR); the shared space of relationships (LL); and the outer space of systems/structures (LR). To leave any quadrant exploration out leaves a client with many insights and actions without a way to understand, integrate, and sustain the desired change.

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Presentation 9: The Chrysalis™ Room: Transforming Death in the Nursing Home with Loretta Downs

Creating Sacred Space: How Hospice Improves Quality of Death in Nursing Homes

by Loretta Downs

To provide a high quality of life for those frail elderly and chronically sick individuals who live in long-term care, we must consider providing them with a high quality of death as a means to ensure their autonomy, personhood, dignity, and a peaceful transition. Nearly 25% of older adults die in long-term care (Munn et al, 2008) and that number is expected to rise to 40% by 2020 with the swell of the baby boom (Forbes- Thompson & Gessert, 2005). Nursing homes are focused on rehabilitation and restoration, which often results in death-denying behavior and motivates the transfer of dying residents to hospitals for treatment. Thus, as many as 30% of hospital deaths involve persons transferred from long-term care facilities who die within three days of hospital admission (Sloane et al, 2003). Medicare expenditures on acute care hospitalizations for beneficiaries who die reach 30% of the total annual budget. Because the preferential care of hospice is holistic comfort care, providers address physical comfort of the patient and the emotional needs of the caregivers so hospitalizations at end of life are avoided and expenditures significantly reduced (Miller, et al. 2004).

Studies of quality of death have illuminated significant themes and practices that improve the end-of-life experience. The most frequently cited are advance care planning, communication across the care continuum, pain management, dignity, the role of the family, and being there, (Munn & Zimmerman, 2006). While the number of nursing home residents receiving hospice care is growing, their length of stay is shrinking, which indicates inadequate palliative care, postponed end-of-life diagnoses (Bercovitz et al, 2004) and reduced quality of death.

Finally, the work of dying is intimate and spiritual as well as medical, making returning the sacred to the act of dying (Anderson, 2001) a reminder of the philosophy on which hospice was founded. Along with the deeply personal work of transitioning out of the body, the loved ones who support the dying person are coping with their own tasks of letting go, healing, reconciliation, grief and loss. These powerful processes occur more easily and deeply in a private space.

Components of a High Quality Death

In order to provide residents with a good death, we must understand the components that facilitate it. Commonly sited components of a good death are the following: family support, (Munn et al, 2008), outcomes that are consistent with desires (Reynolds et al, 2002) as chosen in documented advance care plans (Teno et al, 2007), with a named decision-maker (Munn et al, 2007), emotional as well as physical support and comfort is provided (Teno et al, 2004), psycho-social and spiritual needs are addressed (Ersek, 2003), personal hygiene is addressed, physician acceptance of death (Keay et al, 2003), and knowledge of the person (Munn et al, 2007), implementation of palliative care and hospice (Welch et al, 2008), being cared for by compassionate caregivers (Munn et al, 2007) who respect the dignity of the person (Munn et al, 2007) and who receive ongoing training in end-of-life care (Rice et al, 2004), an indication of preparedness to die and the appearance of peacefulness (Munn et al, 2007).

Every person should have access to what he and she defines is a *good death,* though that may be "one of ten thousand doors for men to take their exits" (Nuland, 1993, p.xvii). McCullough says it is "an expected, supported, well-attended death in a location of choice" (2008, p. 196). For Webb,

> "Those deaths that seem good often have these things in common: excessive treatment—treatment that extends the process of dying longer than a patient wants it extended—is not given; pain and other disquieting or humiliating symptoms are managed aggressively and well; the dying person is granted as much decision- making power as he or she wants; emotional issues are addressed; and the patient, his family, and his friends get all the psychological, spiritual, and physical help they need." (Webb, 1997, p. 28-9).

The following conceptual model was developed from research for an extensive survey of family members' experience with dying comparing quality of death in the last place of care:

> "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 et al, 2004).

Munn et al (2008) identified five themes in the end-of-life experience in long- term care. Their first theme described the components of a good death in long-term care as:

> "one of comfort, dignity, and closure. Within this theme there were sub-themes of physical symptom management (e.g., 'being kept

> comfortable’), circumstances of death (e.g., ‘short in duration, not hanging on,’ ‘not hooked up to machines,’ acceptance of death and giving permission to die), spirituality (‘God here I am. Go ahead and do what you need to do.’), dignity (attentiveness to issues of incontinence), and lack of family burden (e.g., relieving family burden was a motivation for initially moving into long-term care).”

Within these descriptions are clearly identifiable components that collectively result in an image of the elements of a high quality of death to which nursing homes, as a primary location of death, must aspire to for their residents. The provision of these elements is secured by integrating palliative care and hospice care into the resident’s plan of care early enough to benefit the care recipient and the care givers.

Preparation

Although advance care planning is frequently cited as contributing to high quality of death (Lopez 2007), nursing home staff is not adequately trained in advance care planning (Hanson 2002), families are unaware of the need for planning, residents are not given the time to learn about the value of advance directives, many residents have dementia and cannot complete advance directives, and in some cases advance directives are not honored (Munn et al, 2007).

Palliative Care

Hospice does a better job of providing pain control than does the nursing home (Trotta 2007), but the nursing home staff must collaborate and facilitate medication protocol. Untreated chronic pain is present in 45 to 83% of nursing home residents (Erseck 2003) yet palliative care and hospice is not prescribed adequately or in a timely manner. Even when offered, nursing home staff often manages palliation poorly. (Erseck 2003) (Lopez 2007) (Munn & Zimmerman 2006) (Munn et al 2007) (Reynolds 2007) (Trotta 2007). Alleviation of residents’ pain is confounded by high rates of dementia in nursing home residents who are unable to make accurate reports of pain and staff issues such as inadequate skills, poor training and high turnover (Erseck 2003) contribute to insufficient pain assessment. Persons in institutional residential communities and assisted living facilities were more likely to be able to speak and write during the last month of life than nursing home residents (Sloane et al, 2003). Thus, resident experience of untreated chronic pain in the last three months of life may be as high as 86% (Lopez 2007).

Hospice Improves Quality of Death

Although hospice service use in nursing homes has increased nine fold between 1991-1992 and 1999-2000, the 2004 National Nursing Home

Survey (Bercovitz et al, 2004) found only 2.4% of current residents receiving hospice care. The objectives of hospice care seek to identify and document goals of care, manage symptoms and pain, attend to psycho-spiritual needs, prevent suffering, and address issues of grief and bereavement for both the patient and the caregivers (Ersek and Wilson, 2003).

While loved ones often fear or deny the death of the person for whom they care, they do know that death will arrive eventually. Yet one of the most secure obstacles to admission to hospice care is the denial of death by caregivers, which underlies the reluctance to identify individuals as dying (Parker-Olive, 2002). This denial prevents the necessary preparation that facilitates high quality of death and often results in suffering and sudden, unexpected death (Miller et al, 2004). Another imbedded obstacle is the unwillingness of physicians to identifying the resident as dying (Rice et al, 2004) thus preventing admission to hospice and the consequent change in plan of care from aggressive treatment to palliative care and hospice.

The holistic approach of hospice care provides a dimension of care that is essential to high quality of death (Trotta 2007). By inviting the services of hospice, everyone involved is made aware of the value of limited time and the need to prepare for death. By accepting hospice care, the person becomes the center of care rather than the disease. Hospice is able to manage symptoms that accompany end of life, such as pain and apnea, more effectively than the nursing home which is subject to regulations and directives that aim to restore and rehabilitate the resident (Forbes-Thompson and Gessert, 2005) and not to support the dying process.

With hospice caring for a resident, the process of anticipatory grief begins and the process of letting go is encouraged by the mere presence of the supportive activities provided by hospice caregivers. The hospice staff is vigilant as death nears, recognizing the signs of imminent death, increasing symptom management and alerting loved ones.

Family Support

One study analyzed family members as an average of 61 years of age; two-thirds were adult children; 19% were other family members such as nieces, nephews and grandchildren; fully 50% worked full-time (Munn et al, 2007) proving that caregiving is a cross-generational experience with widespread implications. Families are the most frequent source of reporting on the death experience of their loved one. It is the family who will carry the experience of their loved one’s death through their own life, learning from it.

Many individuals become surrogate responders for loved ones who have lost the capacity to speak for themselves, a role that is often performed with no guidance from the care recipient either directly or by written advance healthcare directives. The inability of residents to communicate their wishes for end-of-life care often results in family conflicts over medical decisions, can exacerbate sibling rivalry and may foster death denial which then manifests in aggressive medical treatment being given to the resident receiving care (Lopez 2007).

Staff

Residents often consider staff to be family, and staff members often consider themselves as family. However, high turnover caused by poor salaries, high stress, low status, paperwork burdens and unresolved grief issues adversely affect quality of life and death for nursing home residents (Ersek 2003). Despite the constant presence of paid caregivers and an increasing presence of hospice personnel in nursing homes, more than half of the dying experience death with no one present (Sloane et al, 2003). The value of being there (Munn and Zimmerman, 2006) for the dying includes staff, who are often unavailable to be present for more time than is allowed to accomplishes the required daily tasks of their jobs under the constraints of the facility regulations. Staff become attached to residents and wish to be there for them through death, which facilitates their grief, which is so often unrecognized.

Creating Sacred Space

Demand for different levels of care in response to the many elderly experiencing the slow declining ability to function fully has given rise to the growth of residential community and assisted living facilities. These are also becoming a location of death where nearly one-third of residents remain until they die (Sloane et al, 2003).

Traditional design in nursing homes requires residents to share a room with at least one other person. As death becomes imminent and loved ones wish to gather, there is a need for privacy, which is difficult to find (Forbes-Thompson 2005). This is the time to gather the supporters and provide private space to facilitate the need of family and staff for "being there" with the person who is dying (Munn and Zimmerman, 2006).

A private room in the dementia unit at The Vermont Veteran's home has improved quality of death for the residents, families and staff (Simard 2007). By providing privacy and comfort for the person who is dying and for those supporting her or him, we are supporting the transformational process of dying as something personal and valuable. We thus experience the ritual of vigil and create a sacred space for dying.

Conclusion

In the United States, death occurs for most people in hospitals and nursing homes, which are mandated to provide life-saving, death-delaying treatments, resulting in prolonged dying. The consequences of this practice and its denial of dying are that many die alone, in pain and with no control over their end-of-life experience.

For nursing homes, these consequences result in a high incidence of residents who do not receive hospice care although they are eligible for it. Low rates of advance directive completion often complicate identifying those residents at risk for death. High rates of untreated chronic pain have been recognized in nursing home residents at end-of- life. High turnover in staff, low salaries and inadequate training in end-of-life care result in poor care of dying residents. Not only residents, but family members and loved ones are often unprepared for death even when it is expected.

New policies are needed that direct nursing homes to assess end-of-life conditions earlier and provide appropriate palliative care and hospice care for residents. Pain management must become the highest priority. Families need to be made a part of the planning process from resident admission through the dying process. Advance care planning should become an automatic and frequently reviewed experience for nursing home residents and their caregivers. Education about hospice care needs to be available to staff, families and residents on a continuous basis. Increasing salaries, job value, training in end-of-life care skills, and providing bereavement services will improve staff turnover and quality of care for the dying. Changes must be fostered in the culture that move dying out of the realm of medical failure and into its rightful place as a natural, universal experience of transition. We must recognize the need of loved ones, staff and other residents to be thee for the dying. To do this, we need to provide a special place, a sacred space, where loved ones can be present for the dying and the dying can die with dignity and in peace.

www.endoflifeinspirations.com

Presentation 10: Transforming the After-Death Experience for Loved Ones with Amy Cunningham

How to Choose a Funeral Home
from Funeral Consumers Alliance

Perhaps your loved one is nearing death and you must find a funeral home quickly. Or you have decided to pick a funeral home for yourself long before it's needed, to spare your family the ordeal of making this decision while grieving and pressed for time.

If you have used a funeral home in the past, don't automatically assume it's the best choice. Without comparing prices and services, you can't tell whether their fees are reasonable, or you've been overcharged generation after generation.

Use this step-by-step guide to help you find the best funeral home for you and your family. By learning how to choose wisely, you could save hundreds or even thousands of dollars, and improve your overall satisfaction with the services you receive.

1. **Consult your family and decide on a budget**

Have you and your family discussed a budget, and decided on an amount that's affordable for you—that you're willing and able to spend without hardship? Shopping for a funeral should be like making any major purchase—you know what you can afford before you start shopping. Don't make the mistake of buying a funeral the way many people do—accepting the funeral home's price then scrambling to find the money.

Ask your family some specific questions. Do they have preferences about the type of final arrangement? If you are planning for a loved one, did he or she leave any written instructions? Have arrangements at a certain funeral home already been prepaid, perhaps years ago? Be sure to look for any documents that will help in the decision-making process before going forward.

2. **Learn about your funeral rights**

Next, review your rights as a funeral consumer. Briefly, the Federal Trade Commission's Funeral Rule affirms your right to:

- Get price information over the telephone
- Receive a written, itemized price list when you visit
- Buy only the goods and services you want
- Choose not to have embalming
- Use an alternative container instead of a casket for cremation

- Provide the funeral home with a casket or urn bought elsewhere without incurring additional fees
- Receive a written statement after you decide what you want, but before you pay

3. **Weigh your priorities**

Ask yourself: How important is a convenient location? Do you prefer proximity to your home, place of worship, or cemetery? Is price a critical factor? How flexible is your budget? If you or your family used a funeral firm in the past, how satisfied were you? Do you have special religious or cultural requirements? If you want a viewing or service, will you need a large facility with ample parking, high-tech video screens, or handicap-accessibility? Or is simplicity your first priority?

If both price and location are important, remember that most funeral homes will travel 20 to 30 miles to pick up the deceased without any extra charges. If the funeral home will not be a gathering space for family, why choose the place closest to your home? Which is better—saving $1,000 or 15 minutes of driving time?

4. **Choose the type of arrangement**

- You might donate your body to a medical school for research, which in some cases incurs no charge for survivors
- Other very economical choices are “direct cremation” or “direct burial” with no embalming or visitation
- You could consider a funeral service held at home
- Green, or natural burial, in a shroud or simple box, can be very affordable and ecologically friendly
- Perhaps you prefer a traditional earth burial with embalming, visitation and an elaborate funeral service

Whatever you decide, write down your wishes in detail. The arrangement choice is the biggest factor in helping you determine the best, and most reasonably-priced, funeral home for your needs.

5. **Get a list and compare prices**

First, check with your local Funeral Consumers Alliance to see if they have a survey of prices in your area. If so, check the range of costs for your chosen arrangement, and pick out some affordable funeral homes. You may find a huge price difference for the same option, so doing a cost comparison might save you several thousand dollars. Often those specializing in cremation offer the lowest prices for that service, but not always—be sure to double check.

If you can’t find a price survey, look online or in the phone book for funeral home listings. Call five or six and get their prices for your chosen arrangement; perhaps ask about casket and urn prices as well. If a particular funeral director seems uncooperative, cross him off your list. Do the costs fit within your budget? If not, you may have to consider a more affordable type of arrangement, look beyond your immediate area for lower prices, or eliminate extra expenses like embalming or visitation.

6. **Narrow your choices**

Keeping in mind your personal priorities, do further research. Visit the funeral homes' websites. Ask your family, friends and colleagues for their experiences with any of your choices. You could also check online customer review sites, or ask your local Funeral Consumers Alliance if they have received any complaints about any of them. Then focus your attention on two or three of the most promising choices.

7. **Visit several funeral homes**

Make an appointment to visit those funeral homes if possible. Bring a list of questions and a friend or family member less emotionally invested in the funeral than you are. Ask the funeral home for their General Price List and have the director review it with you. You might want to see an array of urns or caskets, ask about their billing policy, or meet the staff. Do you like the facility? Does the funeral director seem helpful and trustworthy, and answer questions willingly? Is he or she sensitive to your values and cultural or religious needs? Don't select a funeral provider unless you feel completely comfortable with the director and the premises.

8. **Get quotes**

At each funeral home, discuss your specific arrangement choices and ask for an itemized statement. It will list the goods and services you have chosen, the price of each item, and total cost. Do not sign anything yet. Take a copy of each statement home to review more carefully, then compare and discuss them with your family.

9. **Make a decision**

When you have thoroughly evaluated information from several funeral homes, choose the one you like best. If the funeral is imminent, call the funeral home to begin the arrangements. At this point, you could fill out the funeral home's pre-need planning form and pay a deposit if required. But remember, never sign a contract for more than you or your family can afford to pay!

If you are prearranging your own funeral, do not be tempted to pay for it yet. Many states have inadequate safeguards to protect consumers' prepayment funds, and your money could be at risk. Read FCA's article "Should You Prepay Your Funeral" for further guidance.

10. **Put your wishes in writing**

If you are planning a funeral in advance of need, be sure to tell your loved ones about your decisions. Write down your specific instructions and funeral home choice. Give copies of your instructions to your family members or close friends, lawyer, and/or spiritual advisor. Do not put your written plans only in your Will or safe deposit box—they might not be found and read until too late—after your funeral is over.

Supporting Someone Who is Grieving

From the National Hospice and Palliative Care Organization

Often people feel unsure about how to help someone who is grieving after a death. What most people need after a loss is comfort and caring from family and friends. Listening, running errands or simply being present are a few examples of how you might support a grieving person

The following are possible ways you might be of help during this stressful time:

Listen

Listening is the greatest gift you can give someone who is grieving. Ask them to tell you about the person who died. Encourage them to talk about their relationship and their memories. Respond to emotions as they arise, try to be comfortable with tears, and take time to listen.

Accept all feelings

Expressing emotions is a natural and necessary part of the grief process. Do not pass judgment on how "well" the grieving person is or is not coping. Everyone grieves in their own way, and in their own time.

Offer hope

Many people who are grieving have difficulty imagining they will ever be happy again. Believing in your friend or relative's ability to get through this time will strengthen them. In time, with your support, they will rediscover their own inner strengths.

Respect individual needs

Someone who is grieving may want to spend time alone. The person may decline offers to visit or may not return phone calls. These are signals that the person may need to withdraw for a while; it is important to respect their need for privacy.

Understand and accept cultural and religious perspectives about death that may be different from your own

It is important to understand that the way someone experiences loss may be shaped by cultural, religious and family traditions. Many cultures and religions have specific rituals when a person dies. Interfering with, restricting or judging these practices may complicate the grief process.

Avoid clichés

It is common to feel helpless when you care about the person who is grieving. Although you may be tempted to say something you think might be helpful, it is better to err on the side of listening. Avoid clichés such as: "At least he didn't suffer," "I know how you feel," "God won't give you more than you can handle." It is best to be honest and say "I don't know what to say " or "I'm so sorry."

Make specific offers of help

Instead of saying "please call me if I can help," it is best to offer to help with a specific chore such as caring for a child, preparing a meal, running errands, doing housework, helping with yard work, or shopping. For example, suggest "I'll bring dinner on Thursday, how many people will be there?" If Thursday doesn't work, ask what night will. Specific offers of help are less stressful to the grieving person, as the person does not have to spend time thinking of a response to an open ended question such as "What can I do to help you?"

Help the person ease back into activities

When they seem ready, help the person renew interest in past activities and hobbies or discover new interests. An example is, "Would you like to go to the museum on Saturday to see the new exhibit?" The person may not feel ready to do what you asked, so understand if your offer is declined and ask again after some time has passed.

Remember to check on your friend or relative as time passes and months go by

Periodic check-ins can be helpful throughout the first two years after the death. Stay in touch by writing a note, calling, stopping by to visit, or perhaps bringing flowers.

Be sensitive to holidays and special days

For someone grieving a death, certain days may be more difficult and can magnify the sense of loss. Anniversaries and birthdays can be especially hard. Some people find it helpful to be with family and friends, others may wish to avoid traditions and try something different. Extend an invitation to someone who might otherwise spend time alone during a holiday or special day, and recognize they may or may not accept your offer.

If you think your friend or family member needs more help than you can offer, talk to him or her about contacting a local hospice. Hospices throughout the country offer grief support to anyone in the community who has had a loss through death, not just to those who were cared for by hospice. Hospice has bereavement professionals that specialize in grief and loss and can offer further suggestions or sources of support. Hospice can also provide guidance or resources on how to support others who are grieving. To find a hospice in your area, or for more information, visit www.caringinfo.org or call 800-658-8898.

Presentation 12: MORTALLS: The Death-Positive Conversation Game
with Jim and Jess Erskine

Can Playing an End-of-Life Conversation Game Motivate People to Engage in Advance Care Planning?

Van Scoy LJ1, Green MJ2, Reading JM3, Scott AM4, Chuang CH5, Levi BH6.
Author information

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Abstract
BACKGROUND:
Advance care planning (ACP) involves several behaviors that individuals undertake to prepare for future medical care should they lose decision-making capacity. The goal of this study was to assess whether playing a conversation game could motivate participants to engage in ACP.
METHODS:
Sixty-eight English-speaking, adult volunteers (n = 17 games) from communities around Hershey, Pennsylvania, and Lexington, Kentucky, played a conversation card game about end-of-life issues. Readiness to engage in 4 ACP behaviors was measured by a validated questionnaire (based on the transtheoretical model) immediately before and 3 months postgame and a semistructured phone interview. These behaviors were (1) completing a living will; (2) completing a health-care proxy; (3) discussing end-of-life wishes with loved ones; and (4) discussing quality versus quantity of life with loved ones.
RESULTS:
Participants' (n = 68) mean age was 51.3 years (standard deviation = 0.7, range: 22-88); 94% of the participants were caucasian and 67% were female. Seventy-eight percent of the participants engaged in ACP behaviors within 3 months of playing the game (eg, updating documents, discussing end-of-life issues). Furthermore, 73% of the participants progressed in stage of change (ie, readiness) to perform at least 1 of the 4 behaviors. Scores on measures of decisional balance and processes of change increased significantly by 3 months postintervention.
CONCLUSION:
This pilot study found that individuals who played a conversation game had high rates of performing ACP behaviors within 3 months. These findings

suggest that using a game format may be a useful way to motivate people to perform important ACP behaviors.

Thanks for joining Death Expo!

If you have enjoyed these presentations you might also like End-of-Life University—an ongoing online series with 2 interviews each month about end-of-life issues.

Go to http://eepurl.com/ExfLL to register.

You can also listen to the weekly End-of-Life University podcast from Dr. Karen Wyatt.

Go to http://eolupodcast.com to check it out.