



End-of-LifeTool Kit

Il of us as have two experiences in common birth and death. One is greeted with joy and celebration; the other is often accompanied by a wide range of emotions such as fear, relief, sorrow, joy, grief, and loss. In the process of dying, and in death itself, cultural practices and rituals play a key role in the individual's and family's experience of end-of-life. Understanding how death and dying have come to be expressed in culturally-specific traditions and diverse art forms offers remarkable insight into endof-life situations, allowing healthcare professionals to develop essential cultural competencies and increased empathy.

This End-of-Life Toolkit is a set of resources that accompanies an

eLearning course entitled "Heritage to Health: Harnessing the Power of the Arts for End-of-Life Care." The Toolkit provides resources on death and dying, geared to both health professionals and the public. It contains links to textbooks, stories, poems, cultural perspectives on death and dying, as well as compelling video clips, examples of various art forms, and "how to" information for creating various types of memorials when an individual passes away. The Toolkit expands the opportunities for healthcare providers to enhance their skills in end-of-life care through the use of the Arts. It focuses on ways to create a culturally sensitive yet individualized environment for those at the end-of-life, using the Arts as a clinical tool for supporting patients' beliefs, traditions, and customs in a meaningful way.

### **Background of the Heritage to Health Series**

The Heritage to Health series of eLearning courses is designed to build cultural competence in healthcare through the use of the Arts. Each course is about 1 hour in length, and uses artists, folklorists, tradition bearers, poets, and storytellers to showcase the therapeutic and important role that the Arts can play in healthcare practice. To access each of these courses, click on the link below:

<u>Course #1: Concepts of Culturally Sensitive Care</u> <u>Course #2: Welcoming Patients to Your Practice</u> <u>Course #3: Harnessing the Power of the Arts in End-of-Life Care</u>

### Harnessing the Power of the Arts Videos

The videos below will expand your understanding of cultural aspects of death and dying. These resources showcase the Arts as a clinical tool for supporting patients' beliefs, traditions, and customs in a meaningful way. You can use them to create an individualized environment for those at the end-of-life.



Evocation to the Yorùbá God of Death and Rebirth with Michael Manswell



Perspectives with Keith Bear & Mary Louise Defender Wilson



Sadness and Beauty in Death with Luana Morales and Tara Rynders



Bharatanatyam Dance with Malini Srinivasan



# **Cultural Aspects of Death and Dying**

#### ABCD Cultural Assessment Model

Developed by Dr. Marjorie Kagawa-Singer and Dr. Leslie Blackhall, this model is a cultural assessment mnemonic approach to assess the degree of cultural adherence to help avoid stereotyping and decrease the risk of miscommunication (Kagawa-Singer & Backhall, 2001.) Learn more...

#### **Special Cultural Consideration**

Customs and rituals about death vary dramatically from culture to culture. <u>Here we showcase 15 examples of</u> <u>different cultures, highlighting a few</u> <u>key points from each.</u>

For more detailed information, go to <u>ethnomed.org</u>

## **Podcasts**

#### **<u>Grief Dialogues Podcasts</u>**

A podcast about death, grief, and the art it creates.

#### E1D (Everyone Dies) (every1dies.org)

Created by a retired nurse practitioner working in hospice and palliative care for 43 years, this is a resource for public education about issues related to serious illness, dying, death, and bereavement.

## **Barriers to Communication** Video for Patients

This video from End-of-Life Choice New York, provides information and guidance for older adult immigrants and their families about how to navigate the medical system while honoring cultural values, beliefs, and traditions.

End-of-Life Choices New York is the leading nonprofit organization in New York working to improve end-of-life care and expand life options. Learn more here...



Your Health, Your Values: A Conversation About Honoring Your Family's Wishes for Care

# **Expressive Art Forms**

# Troubled Times - Turning to the Arts

In this article, Dr. Peña reminds us that art can comfort us, art can help us understand and express our own emotions, and art can give us hope. <u>Learn more...</u>

#### **Creating Memorial Altars**

Harness the power of the arts to honor your loved one.

<u>Creating a Home Altar</u>, from the book *Giving a Voice to Sorrow*, *Artful Responses to Death and Mourning* by Ilana Harlow and Steve Zeitlin Death and loss sever our real time connection with someone we love, but memorial quilts restructure that pathway to connection through a beautiful, tactile, intensely personal object.

Lori Mason

#### **Creating Memorial Prayer Flags**

"Creating Prayer Flags for a Memorial Celebration" is an essay written by Jennifer Mathews, M.A., that details what prayer flags are, what you need to create them, tips for the gathering or service, and ideas for the prayer flags after they are made. Learn more...

#### **Memorial Quilts**

<u>Making a Memorial Quilt</u> by Sheryl Mullane-Corvid and Kathleen Doyle from the book *Giving a Voice to Sorrow: Artful Responses to Death and Mourning* by Ilana Harlow and Steve Zeitlin.



Memorial Quilt created by William Rhodes



# Music

## The Healing Tradition of the Harp

The harp has been revered as a healing instrument for thousands of years and by many cultures.

The characteristics that make the harp unique for healing include:

- The instrument's archetypal significance as an ancient, spiritual healing instrument.
- Its wide pitch range which can vibrate the entire body.
- Its varied and soothing palette of tone colors.
- The ethereal effect created through the harp's unique glissando technique.
- The tension-then-release associated with the emotional expression of plucking its strings, as Pythagoras suggested when he saw the strings as symbols of the nervous system.

(Excerpted from the Spring '96 Harp Therapy Journal)



Fabien Maman, French composer and musician, says in the Summer '98 Harp Therapy Journal, "When natural acoustic instruments are played, their sound resonates with the corresponding element and organ in the body. Stringed instruments, for example, correspond to the energy of the heart, small intestine, pericardium, and Triple Warmer meridians. The fundamental note played on an acoustic instrument nurtures the physical body, while the overtones resonate in the subtle bodies... The plucked harp strings spread the sound — it surrounds the listener. The harp vibrates through the wood and the listener. It is a very feminine instrument and touches the heart... Other stringed instruments are more directional and restricted in their range."

- ▶ <u>Harp for Healing</u>
- ► The harp's power to soothe & heal
- ► The goodness of Harp Therapy

The harp, with its many strings, consistently generates a profound response in the listener. ... There are many effective instruments, but the harp seems to be the epitome of a healing instrument.

Laurie Riley founder of the Music for Healing and Transition Program

The Drumming of Traditional Ashanti Healing Ceremonies

#### **Decorated Caskets**

"Daughters Craft a Coffin for

**Their Father"** told by Peggy King-Jorde from the book *Giving a Voice to Sorrow: Personal Responses to Death and Mourning* by Ilana Harlow and Steve Zeitlin. Learn more...

### 23 Funeral Casket Decoration Ideas and Inspiration – Titan Casket

<u>Texas man makes custom caskets</u> <u>for Uvalde school shooting victims</u> <u>- Good Morning America</u>

# **Expressive Art Forms**



Coffin painted by Pieper Bloomquist

#### **Making a Memorial Toolkit**

This Memorial making toolkit is by folklorist Kay Turner for a project that City Lore is sponsoring called NAMING THE LOST MEMORIALS. Made from simple resources, a grassroots memorial is a common gesture of mourning and remembrance that can carry deep meaning and resolve. Learn more...

### **Remembering a Life Coloring Page**

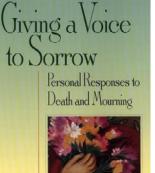
<u>Remembering A Life coloring pages</u>, are peaceful images which provide a safe space to reflect on a loved one who has died. This relaxing activity requires no artistic skill, little instruction, and few materials.

download a pdf here...



# End-of-LifeTool Kit

# Books



Steve Zeitlin and Ilana Harlow

Giving a Voice to Sorrow: Personal Responses to Death and Mourning by Ilana Harlow and Steve Zeitlin



The Spirit Ambulance: Choreographing the End of Life in Thailand by Scott Stonington

# RICHARD HOLLOWAY Waiting for the Last Bus Reflections on Life and Death

The Sunday Times bestseller

Waiting for the Last Bus: Reflections on Life and Death by Richard Holloway



The Wild Edge of Sorrow Ritual: of Renewal and the Sacred Work of Grief

> FRANCIS WELLER Foreword by MICHAEL LERNER

The Wild Edge of Sorrow: Rituals of Renewal and the Sacred Work of Grief by Francis Weller

# Poems

- Do Not Stand at my Grave and Weep, Poet Mary Elizabeth Frye
- Epitaph, Poet Merrit Malloy
- Symphony in P-Flat, from "My Song for Him Who Never Sang to Me", Poet Merritt Malloy
- Where I'm From, Poet George Ella Lyon

#### **Additional Websites**

<u>Transforming adversity, loss, and mortality</u> <u>COVID Grief Network</u>

### **Featured Artists**

#### Mic

Mandan/Hidatsa Storyteller Three Affiliated Tribes Reservation, ND website

#### **Regi Carpenter** Storyteller, Artist Ithaca, NY

Ithaca, NY <u>website</u>

**Keith Bear** 

**Rev. Cynthia Carter-Perrilliat, MPA** Faith & Health Advocate, Vocalist, Minister, Activist Alameda, NY website

#### Ofelia Esparza

Alter Maker, National Heritage Award Winner Los Angeles, CA website

#### Rosanna Esparza Alter Maker Los Angeles, CA <u>website</u>

Soren Glassing Artist, Buddhist Chaplain New York-Presbyterian Hospital New York, NY website

Annie Lanzillotto Performance Artist/Storyteller Yonkers, NY website

# Michael Manswell

Trinidadian carnival & J'ouvert artist, Yoruba Priest Brooklyn, NY <u>website</u>

#### Luana Morales

Ancestral Healing Arts Practitioner and Death Doula Hyde Park, NY <u>website</u>

#### William Rhodes

Memorial Quilter, Artist San Francisco, CA <u>website</u>

#### Tara Rynders,

RN-BC, MFA, BSN, BA Dancer Denver, CO <u>website</u>

Malani Srinivasan Teaching Artist City Lore Sunnyside, NY website

#### Mary Louise Defender Wilson National Heritage Award

Winner Dakotah/Hidatsa Storyteller Standing Rock Indian Reservation, ND website

Generous support of this End-of-Life Toolkit was provided by the National Endowment for the Arts and the Robert Wood Johnson Foundation.





The views expressed in this Toolkit do not necessarily reflect the views of the National Endowment for the Arts or the Robert Wood Johnson Foundation.