Empowering Faith Communities through Palliative Care Education

Diane McCarthy, MA, BCC
Vincent Nguyen, DO, CMD
Our Purpose

- Prepare for one of the most profound events of life,
- Define Palliative Care and Advance Care Planning and how Church teaching supports both,
- Recognize the commonality between the profession of medicine and the ministry of healing,
- Discuss the Boston Initiative and the Whole Person Care Initiative of California.
What do all of us share in common?
# How Americans Die: A Century of Change

<table>
<thead>
<tr>
<th>Age at death</th>
<th>Top Causes</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>46 years</td>
<td>Infection</td>
<td>Not much</td>
</tr>
<tr>
<td>78 years</td>
<td>Accident</td>
<td>Days-to-weeks</td>
</tr>
<tr>
<td></td>
<td>Child birth</td>
<td>Weeks to years</td>
</tr>
<tr>
<td></td>
<td>Heart Disease</td>
<td>before death</td>
</tr>
<tr>
<td></td>
<td>Cancer</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stroke/Dementia</td>
<td></td>
</tr>
</tbody>
</table>
The Expectation
Trained to Fix

Unfixable problems: Chronic illness, frailty and debility of aging, and terminal illness.
Sudden Death

High

Function

Low

Time

Death
Organ Failure (COPD, CHF, Renal Disease)
Debility/Failure to Thrive (Dementia)
Catastrophic Event
(Stroke, TBI, Hip Fracture in Elderly)

Function

High

Low

Time

Death
If time is short, what do you want to accomplish?
Hope is not a plan

• When the plan is unclear, the default is to treat aggressively

• Family may be left with
  • Uncertainty and stress
  • Guilt and depression
  • Financial concerns
ILL-Preparation

https://youtu.be/-39QcDfatXM
I was ill and you cared for me

Mt 25:36
CATHOLIC SOCIAL TEACHING
The Care of the Vulnerable
The *Initiative for Palliative Care and Advance Care Planning*

Diane McCarthy, MA, BCC
Archdiocese of Boston
Parish Education Coordinator
Palliative Care & Advance Care Planning
A guide for our faith community

Archdiocese of Boston
Initiative for Palliative Care and Advance Care Planning
Why do we have this *Palliative Care/Advance Care Planning* initiative?

- Dignity of the human person made in the image and likeness of God
- Catholic social justice teaching – preference for the poor and marginalized
- Health care decision-making for Catholics includes knowing relevant Church teaching
- Desire to establish parish-based resource teams
The Archdiocese of Boston’s Initiative for Palliative Care and Advance Care Planning cordially invites you to attend

Training the Trainer:
Palliative Care and Advance Care Planning
Pastoral Center, Archdiocese of Boston
66 Brooks Drive, Braintree, MA 02184
Wednesday, October 17, 2018
10:00 AM – 2:00 PM
Registration will be from 9:15-9:45 a.m. Lunch will be provided.

MEETING DETAILS:
Join us at our annual workshop designed for parish/collaborative staff and volunteers who are interested in helping promote palliative care in their faith community. Speakers will discuss palliative care, the role of the trainer, pain management and advance care planning.

The program will include updated information, small group exercises and discussion.

Pastors and Administrators: Please feel free to post in parish—all are welcome!

IMPORTANT TO NOTE:
Your attendance at this workshop does NOT automatically commit you to be a trainer in your parish or collaborative, but it will qualify you to do so, if you are interested.
Why do we have this *Palliative Care/Advance Care Planning* initiative?

- Massachusetts 2012 ballot referendum on physician-assisted suicide - narrowly defeated 51% to 49%
- Current possible routes of legalization in MA:
  - Legislature – End of Life Options Act
  - Court case – physicians could not be tried for murder or manslaughter
  - Possible 2020 ballot referendum
Palliative care suffers from an identity problem. Seventy percent of Americans describe themselves as “not at all knowledgeable” about palliative care, and most health care professionals believe it is synonymous with end-of-life care.¹
Knowledge of Palliative Care among American Adults:
2018 Health Information National Trends Survey

Jinhai Huo, PhD, MD, MSPH\textsuperscript{1,*}, Young-Rock Hong, MPH\textsuperscript{1}, Reetu Grewal, MD\textsuperscript{2}, Sandhya Yadav, MHA\textsuperscript{1}, Isaac W. Heller, BS\textsuperscript{1}, Jiang Bian, PhD\textsuperscript{3}, Diana J. Wilkie, PhD, RN, FAAN\textsuperscript{4}

Abstract
Context
Palliative care will play an important role to alleviate disease suffering and improve quality of life for cancer patients and their family caregivers.

Objective
We examined the knowledge penetration of palliative care in a nationally representative sample of U.S. adults.

Conclusions
The proportion of adults who have knowledge of palliative care is low in the United States. Greater efforts are needed to promote palliative care and reduce the misconceptions of palliative care in the general population.
Presentation Outline
Part I – Palliative Care

• CAPC case study
• Why we have the initiative
• Define/describe palliative care – not identical to hospice
  • Physical, psychosocial, emotional and spiritual symptoms = Whole Person Care
  • Death is a normal process – countercultural thought
• Who is a candidate, when and how is it started
• Possible topics discussed in a palliative care planning meeting
Presentation Outline
Part II – Advance Care Planning and Church Teaching

• Define advance care planning
• Tools for use in advance care planning
• Sources of Church teaching on palliative care and advance care planning
• Review of specific ERDs
• Provide resources
But we’re Catholic, we have to do everything.”

ERD 57:

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.
“Use of pain medication is incompatible with my Catholic faith.”
CHA End-of-life guides

- Palliative and Hospice Care: Caring Even When We Cannot Cure
- Advance Directives: Expressing Your Health Care Wishes
- Teachings of the Catholic Church: Caring for People at the End of Life
Saturday, April 6, 2019
8am – 12:30pm at the Pastoral Center, Braintree

4th Annual Palliative Care Colloquium
*Moral Distress on Both Sides of the Bedrail: Always Wanting to Do “The Right Thing”*

*Featuring:*

- **Joseph D. Stern, MD**, a practicing neurosurgeon in the largest neurosurgical group practice in the country, Carolina Neurosurgery and Spine Associates, and is author of the memoir: “Grief as My Guide: A Brother’s Loss through a Doctor’s Eyes.”

- **Mary K. Buss, MD, MPH** currently practices both as a medical oncologist and a palliative medicine specialist at Beth Israel Deaconess Medical Center where she built and now directs the outpatient palliative care clinic.

- **Fran Hauck, M. Ed, LCSW** is a Pastoral Associate at Holy Name Parish in West Roxbury with extensive ministerial experience working in bereavement and other relevant topics, including caring of the seriously ill and dying. Fran also does chaplaincy at Brigham & Women’s Hospital.

An informative session which concludes with the celebration of Holy Mass with Fr. J. Bryan Hehir

Archdiocese of Boston
Initiative for Palliative Care and Advance Care Planning
Parish Presentation Statistics

- June 2017- April 2019
- 23 months
- Presentations in 56 out of 284 parishes (19.7%)
- Attendance: 1,187 out of 1.9 M Catholics, 218,600 of whom attend Mass (2018 statistics) (<1%)
- Average attendance = 21
- Range of 2 – 60 people per presentation
Other presentations

- Theological Institute - 2
- Diaconate post-ordination formation
- Fall River Diocese – 2 parishes
- Springfield Diocese Clergy Day (in conjunction with St. John Paul II Foundation)
- Long-term care facilities - 4
Blessings

• Call re: hospice going against Catholic faith
• Widow’s relief
• Sister’s relief
Challenges

• How many people want to go to heaven?

• How many people want to go today?
Opportunity

“We prepare for everything we consider important in life. Preparation makes a wonderful experience possible.”

Matthew Kelly, Rediscover Lent
Whole Person Care Initiative
The OC Diocese Experience

Dr. Vincent Nguyen, DO
Program Director
HOAG CARES
Whole Person Care Initiative
- Purpose -

1. Strengthen and improve the availability of WPC and palliative care in Catholic health systems and hospitals;
2. Develop and implement WPC programs in dioceses and parishes.
• Whole Person Care Video
Whole Person Care Initiative

Community Education

Five Wishes

CARE, PREPARE, AND CONNECT

Love, wanted, and worthy through the end of life’s journey
WHOLE PERSON CARE CONFERENCE 2018
OCTOBER 25 FROM 7:30 A.M. - 4:30 P.M.

Join Healthcare and Faith Leaders as they discuss the Whole Person Care Initiative being rolled out across California.

WHAT:
The Whole Person Care Initiative is a new comprehensive approach to caring for the sick and dying spearheaded by Catholic healthcare, the Catholic Church, community healthcare providers, and public health leaders. This effort seeks to reframe how our healthcare system addresses death and dying and lays out a vision for a network of care that addresses both the physical and spiritual dimensions of care. This day-long summit is open to professional care providers, community health leaders, parish volunteers, and clergy.

WHERE:
CHRIST CATHEDRAL CAMPUS
13280 Chapman Ave.
Garden Grove, CA 92840

REGISTRATION:
wholepersoncare.eventbrite.com
Cost of Attendance: $30/person
Includes light breakfast and lunch

CONTACT:
For questions or sponsorship information, kindly contact Esther Ramirez eramirez@rcbo.org or call (714) 282-3105

Presenting Sponsor
Irvin’s Cottages

Dr. Ira Byock, MD, FAAHPM
Dr. Byock is founder and chief medical officer of the Institute for Human Caring at Providence St. Joseph Health, based in Torrance, Calif. The institute measures, monitors and improves person-centered care and engages diverse communities in goal-aligned, person-centered models of care. Dr. Byock’s books include Dying Well, The Four Things That Matter Most, and The Best Care Possible.

Dr. Magory Anderson
Dr. Magory Anderson founded the Sacred Dying Foundation in 1996. She is trained and skilled in comparative religions and theology. She is the author of the books Sacred Dying: Creating Rituals for Embracing the End of Life and Attending the Dying, as well as numerous articles and chapters on end of life and palliative care.

The Most Reverend Kevin W. Vann, JCD, DD
Bishop Kevin Vann is a member of the USCCB Committee on Migration, as well as the Committee on Catholic Education, the Committee on Canonical Affairs & Church Governance, the Task Force on Health Care and the Subcommittee on Health care Issues.

Conference Includes:
• Screening of End Game and panel discussion
• Choice of workshop:
  - Companioning the Long Suffering - Palliative Care for the Soul by Sr. Eileen McNerney
  - A Catholic Perspective on End-of-Life Care by Dr. Vincent Nguyen & Mark Jablonski
• Opportunity to connect with organizations

Educational Credits are offered when attending this conference. Further details can be found on the back of this flyer.
<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th># of Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>7/10/18</td>
<td>St. Cecilia (Tustin)</td>
<td>100</td>
</tr>
<tr>
<td>7/17/18</td>
<td>St. Cecilia (Tustin)</td>
<td>160</td>
</tr>
<tr>
<td>10/11/18</td>
<td>Our Lady of Mount Carmel Church (Newport Beach)</td>
<td>75</td>
</tr>
<tr>
<td>10/20/18</td>
<td>St. Edward the Confessor Church (Dana Point)</td>
<td>190</td>
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<tr>
<td>10/30/18</td>
<td>St. Bonaventure (HB)</td>
<td>40</td>
</tr>
<tr>
<td>1/18/19</td>
<td>Christ Our Savior (Santa Ana)</td>
<td>59</td>
</tr>
<tr>
<td>2/13/19</td>
<td>Mission Basilica (San Juan Capistrano)</td>
<td>17</td>
</tr>
<tr>
<td>2/27/19</td>
<td>St. Joseph (Placentia)</td>
<td>100</td>
</tr>
<tr>
<td>4/12/19</td>
<td>Christ Cathedral Parish (Garden Grove)</td>
<td>4</td>
</tr>
<tr>
<td>4/27/19</td>
<td>St. John the Baptist (Costa Mesa)</td>
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<td></td>
<td><strong>Total as of 4/4/19</strong></td>
<td><strong>741</strong></td>
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**Community End Game Screenings**

<table>
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<tr>
<th>Date</th>
<th>Location</th>
<th># of Attendees</th>
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</thead>
<tbody>
<tr>
<td>9/18/18</td>
<td>Oasis Senior Center (Corona Del Mar)</td>
<td>18</td>
</tr>
<tr>
<td>9/26/18</td>
<td>Chapman University (Orange)</td>
<td>40</td>
</tr>
<tr>
<td>9/27/18</td>
<td>O'Connor Mortuary (Laguna Hills)</td>
<td>26</td>
</tr>
<tr>
<td>10/10/18</td>
<td>Cerritos Senior Center (Cerritos)</td>
<td>33</td>
</tr>
<tr>
<td>2/17/19</td>
<td>End of Life Panel (Saddleback College)</td>
<td>50</td>
</tr>
<tr>
<td>3/27/19</td>
<td>St. Joseph Health (Anaheim)</td>
<td>17</td>
</tr>
<tr>
<td>4/3/19</td>
<td>Amici Group (Irvine)</td>
<td>31</td>
</tr>
<tr>
<td>4/16/19</td>
<td>Fullerton Senior Center (Fullerton)</td>
<td></td>
</tr>
<tr>
<td>5/30/19</td>
<td>UCI Medical School (Students) <em>date tbd</em></td>
<td></td>
</tr>
<tr>
<td>6/18/19</td>
<td>Saddleback Memorial Hospital (Laguna Hills) <em>tentative</em></td>
<td></td>
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<tr>
<td>7/22/19</td>
<td>Norman P. Murray Community &amp; Senior Center (Mission Viejo)</td>
<td></td>
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<tr>
<td></td>
<td><strong>Total as of 4/4/19</strong></td>
<td><strong>215</strong></td>
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**Advance Care Planning Workshops**

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th># of Attendees</th>
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</thead>
<tbody>
<tr>
<td>7/11/18</td>
<td>Newport Plaza Atria</td>
<td>10</td>
</tr>
<tr>
<td>7/26/18</td>
<td>San Clemente Villas by the Sea</td>
<td>25</td>
</tr>
<tr>
<td>9/23/18</td>
<td>United Methodist Church of Yorba Linda</td>
<td>26</td>
</tr>
<tr>
<td>11/14/18</td>
<td>Fullerton Senior Center—Important Choices for Living and Dying</td>
<td>20</td>
</tr>
<tr>
<td>12/7/18</td>
<td>POLST Inservice for Healthcare Partners (Arcadia)</td>
<td>35</td>
</tr>
<tr>
<td>1/10/19</td>
<td>United Methodist Church of Orange</td>
<td>34</td>
</tr>
<tr>
<td>1/16/19</td>
<td>End Game Webinar (Alzheimer’s OC)</td>
<td>-</td>
</tr>
<tr>
<td>3/19/19</td>
<td>ACP/POLST - OHEA Nurses</td>
<td>10</td>
</tr>
<tr>
<td>3/21/19</td>
<td>Federal Occupational Health (Laguna Niguel)</td>
<td>60</td>
</tr>
<tr>
<td>4/9/19</td>
<td>POLST Webinar (Alzheimer’s OC)</td>
<td></td>
</tr>
<tr>
<td>4/16/19</td>
<td>Chatteron and Associates (Anaheim) - 10am</td>
<td></td>
</tr>
<tr>
<td>4/16/19</td>
<td>Chatteron and Associates (Anaheim) - 6pm</td>
<td></td>
</tr>
<tr>
<td>4/17/19</td>
<td>Chatteron and Associates (Anaheim) - 10am</td>
<td></td>
</tr>
<tr>
<td>4/17/19</td>
<td>Chatteron and Associates (Anaheim) - 6pm</td>
<td></td>
</tr>
<tr>
<td>5/23/19</td>
<td>Oasis Senior Center (Corona Del Mar)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Total as of 4/4/19</strong></td>
<td><strong>220</strong></td>
</tr>
</tbody>
</table>

**“Being Mortal” screening & Conversation Café**

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th># of Attendees</th>
</tr>
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<tbody>
<tr>
<td>10/14/18</td>
<td>United Methodist Church of Yorba Linda</td>
<td>25</td>
</tr>
<tr>
<td>10/16/18</td>
<td>Health Care Center (Seal Beach)</td>
<td>20</td>
</tr>
<tr>
<td>11/29/18</td>
<td>St. Boniface (Anaheim) * Spanish Event*</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td><strong>Total as of 4/4/19</strong></td>
<td><strong>115</strong></td>
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</tbody>
</table>

**Other ACP/POLST educational opportunities**

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Location</th>
<th># of Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>8/8/18</td>
<td>Faith Community Nursing Summit</td>
<td>Fullerton EV Free Church</td>
<td>97</td>
</tr>
<tr>
<td>8/25/18</td>
<td>Diocese Presentation: Whole Person Care</td>
<td>Christ Cathedral Campus</td>
<td>75</td>
</tr>
<tr>
<td>10/6/18</td>
<td>Death is Inevitable: Conversations on Living and Dying Well</td>
<td>Chapman University</td>
<td>400</td>
</tr>
<tr>
<td>10/25/18</td>
<td>Whole Person Care Conference</td>
<td>Christ Cathedral Campus</td>
<td>270</td>
</tr>
<tr>
<td>2/20/19</td>
<td>OC POLST Stakeholders’ Meeting</td>
<td>Town and Country Manor</td>
<td>55</td>
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<tr>
<td>5/31/19</td>
<td>Hospice Volunteer Managers Association Annual Meeting</td>
<td>TBD</td>
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<tr>
<td></td>
<td><strong>Total as of 4/4/19</strong></td>
<td></td>
<td><strong>897</strong></td>
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## Program Recap

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Attendance</th>
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</thead>
<tbody>
<tr>
<td>6/6/18</td>
<td>St. Timothy</td>
<td>30</td>
</tr>
<tr>
<td>6/10/18</td>
<td>St. Joachim</td>
<td>26</td>
</tr>
<tr>
<td>6/13/18</td>
<td>OLQA</td>
<td>50</td>
</tr>
<tr>
<td>6/20/18</td>
<td>Blessed Sacrament</td>
<td>60</td>
</tr>
<tr>
<td>6/27/18</td>
<td>St. Irenaeus</td>
<td>98</td>
</tr>
<tr>
<td>7/10/18</td>
<td>St. Cecilia</td>
<td>100</td>
</tr>
<tr>
<td>7/17/18</td>
<td>St. Cecilia</td>
<td>160</td>
</tr>
</tbody>
</table>

Total attendance at 7 events: 524

Surveys completed: 95
How did you hear about this program?

- Parish Announcement: 64
- Friend/Relative: 11
- OC Catholic Newspaper: 9
- Facebook: 7
- Website: 1
Why did you attend?

- Want to be prepared 42
- Understand options for loved ones 18
- Understand Church’s teachings 15
- Social / Community Engagement 6
- Work related 2
Palliative Care

Relief from symptoms and stress of a serious illness

End-of-Life Care

Hospice Care

Prognosis ≤ 6 months and Curative treatments are exhausted
Palliative Care Visit

- Understanding
- Fears & Worries
- Coping & Support
- Symptom management

- Advance care planning
- Dying
### Advance Care Planning Removes DISTRESS

<table>
<thead>
<tr>
<th>Decrease in depression and anxiety</th>
<th>Less aggressive care with better quality of life (QOL) (6.4 \text{ vs } 4.6)</th>
<th>Longer hospice with better QOL (6.9 \text{ vs } 5.6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease rate of CPR (0.8% \text{ vs. } 6.7%)</td>
<td>Reduce ICU admission (4.1% \text{ vs. } 12.4%)</td>
<td>Better QOL with improved caregiver outcomes</td>
</tr>
</tbody>
</table>

Palliative care is associated with BETTER QUALITY OF LIFE and OVERALL SURVIVAL when compared to Standard oncology treatment + early palliative care.

Standard oncology treatment vs. Standard oncology treatment + early palliative care:
- Happier, more functional and less pain.
- Median survival 8.9 vs. 11.6 months.

**Palliative care** is an expression of the proper human attitude of taking care of one another, especially those who suffer.

It **bears witness** that the human person is always precious, even if marked by age and sickness.

— **POPE FRANCIS** —
Living Life as Well and as Fully as Possible…

The Gift of Palliative and Hospice Care
Preservation of Life and Health
(Ordinary and Proportionate)

Cardio Pulmonary Resuscitation (CPR)

Artificial Nutrition