ADVANCING PALLIATIVE CARE

25 Years

SUPPORTIVE CARE COALITION
2019 MISSION REPORT
We are a coalition of Catholic health ministries, informed by our faith and values, advancing excellence in palliative care.

**OUR MISSION**

**OUR VISION**

All persons living with or affected by serious illness will receive high quality, compassionate care that integrates their physical, spiritual, emotional, cultural, and relational dimensions.

**WE BELIEVE**

PALLIATIVE CARE IS A HALLMARK OF CATHOLIC HEALTHCARE THROUGH WHICH GOD’S HEALING LOVE IS REVEALED.
Message from the Board Chair and Executive Director

In 1994, a small group of visionaries came together to create a partnership unlike anything else in health care. These visionaries represented three Catholic health care systems with ministries in the Pacific Northwest where the “death with dignity” movement was gaining momentum. Not content to merely voice their opposition to death on demand, they committed to improving end-of-life and serious illness care in their hospitals, clinics, and hospices. They called their partnership, Supportive Care of the Dying: A Coalition for Compassionate Care. In 1999, they published a landmark study of their multi-system organizational assessment on the state of end-of-life care within Catholic health care ministries. While there were bright spots, the study revealed there was much work to be done.

With a growing membership of Catholic health care systems including the Catholic Health Association, the Coalition partnered with like-minded organizations on projects such as: Living and Healing During Life-Threatening Illness, the Philadelphia Community Model Project, St. Louis University's Life-Threatening Illness Services and Education Project, the CALL Care Project, and the Hospital-Based Spirituality Initiative: Creating Healing Environments. From 2001-2011, the percent of Catholic hospitals with palliative care programs went from 36.9% to 74%.

It was during this time the Coalition’s Board of Directors wisely discerned that it was time to change our focus from improving care of the dying and establishing palliative care programs to promoting excellence within Catholic palliative care. To reflect this change in focus, the Coalition was renamed the Supportive Care Coalition: Advancing Excellence in Palliative Care. By 2015, Coalition member systems Bon Secours Health and Providence Health and Services received Joint Commission Advanced Certification for Palliative Care. In 2016, member systems Bon Secours and OSF received the AHA Circle of Life Award and were followed by Providence St. Joseph Health in 2017. Clearly, our mission to promote excellence was well underway — yet there is still much work to be done.

For 25 years, the Coalition has:
- Advocated for palliative care specific legislation, policy, and payment models.
- Educated palliative care clinicians of all disciplines through our conferences, webinars, and sharing of leading practices.
- Integrated palliative care practice and Catholic teachings beyond the walls of our hospitals and clinics via resources for community clergy, parishes, parish nurses, and Catholic faith communities.
- Elevated spiritual care as essential to quality palliative care through our Spirituality Toolkit and participation in specialty chaplain certification.
- Activated engagement with the larger palliative care community through web-based resources to promote professional resilience and serve as a resource for up-to-date palliative care content.

Yet, according to data from the Center to Advance Palliative Care, there are 90 million Americans currently living with serious illness and this number is expected to double in the next 25 years. Of those 90 million, 6 million could currently benefit from palliative care. Barriers such as workforce shortages, inadequate staffing, and misunderstandings about palliative care by both providers and patients mean that many people who would benefit from the support of a palliative care team receive that support too late or not at all.

What three visionary organizations started together has become the collective, unified voice for excellence in palliative care in Catholic health care. Together we leverage our shared Catholic voice so that every person living with or affected by serious illness will receive timely, affordable, high-quality, and compassionate interdisciplinary palliative care no matter their age and no matter the stage of their illness.

On behalf of our Board of Directors and the Supportive Care Coalition staff we are grateful for your support and partnership as we enter our 25th year. We ask for your sustained commitment as we continue to transform the landscape of health care. And, together we look forward to a future where excellent palliative care is provided early, consistently, and everywhere it is needed.

May God continue to bless the work of our hands.

Bob Bergamini, MD
Chair, Board of Directors
Supportive Care Coalition

Denise Hess, MDiv, BCC-PCHAC
Executive Director
Supportive Care Coalition

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Our Members
Supportive Care Coalition members are located in 37 states and Washington, D.C.
The Supportive Care Coalition was founded in 1994 by three Catholic health organizations in the Pacific Northwest. From our beginnings, we have sought to lead the way in advancing excellence in palliative care through national advocacy, interprofessional education, spiritual care excellence, and the integration of Catholic teachings and ethical principles into palliative care practice.
EXCELLENCE CARE

2010
Fourth National Care Congress, "Recovering Our Traditions – Fourth National Congress on Palliative Care"

2012
The Coalition grew to 23 member organizations in 42 states
The first Mission Report was created

2013
Fifth National Palliative Care Congress "Leading Practices – Transforming Care," conjoined with the Catholic Health Association's Assembly
Spirituality in Goals of Care Project was launched
SCC became a member of the Patient Quality of Life Coalition (PQLC)

2014
SCC joined with the PQLC to participate in Lobby Day on Capitol Hill asking Congress to support the growing demand for palliative care through the Palliative Care & Hospice Education & Training Act (PCHETA)
SCC hosted first webinar

2015
SCC Ethics and Church Relations Committee created "Key Messages for Catholic Health Care Ministry Leaders" regarding palliative care

2016
SCC became an Inaugural sponsoring member of the National Academies of Sciences, Engineering and Medicine Roundtable on Quality Care for People with Serious Illness with Bob Bergamini as SCC's representative
SCC received the National Association of Catholic Chaplains Outstanding Colleague Award

2017
New SCC website was launched

2018
PCHETA H.R. 1676 passes House of Representatives

Denise Hess, MDiv, BCC-PCHAC Executive Director 2017-present

Tina Picchi, MA, BCC Executive Director 2009-2017
Then

The Supportive Care Coalition had 3 Founding Members

Catholic Hospitals Providing Palliative Care

Hospitals Reporting Palliative Care 2000

- 0%-40%
- 41%-60%
- 61%-80%
- 81%-100%
Since 2001 there has been a 152% increase in Catholic hospitals with palliative care programs.
According to a 2018 report from the Commonwealth Fund, people with serious illness continue to struggle to access quality palliative care.

People with serious illness report significant distress:

- **62%** feel anxious, confused, or helpless
- **48%** have emotional or psychological problems caused by their condition
- **32%** report feeling left out, lacking in companionship, or isolated from others

61% of people with serious illness reported at least one problem while receiving care, such as:

- understanding a medical bill or what their health insurance covered
The Supportive Care Coalition is committed to advancing palliative care in Catholic health care until palliative care is:

- Accessible
- Affordable
- Holistic
- Integrated
- High quality

For all people living with or affected by serious illness

53% report one or more dire financial consequences related to their care, such as:

- using up most or all their savings
- being unable to pay for necessities like food, heat, or housing
- borrowing money to get a loan or another mortgage

The Supportive Care Coalition is an endorsing organization for the newly published 4th edition of the National Consensus Project Guidelines for Quality Palliative Care. The Coalition joined more than 80 national organizations in endorsing the guidelines which include tools, resources, and practice examples to help with implementation across all settings of care, including community-based palliative care. The new eight domains of care are:

- Structure and process of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care
- Spiritual, religious and existential aspects of care
- Cultural aspects of care
- Care of the patient nearing the end of life
- Ethical and legal aspects of care

The Supportive Care Coalition is an inaugural sponsor of the National Academies of Sciences, Engineering, and Medicine Roundtable on Quality Care for People with Serious Illness. The Roundtable fosters ongoing dialogue about critical policy and research issues to accelerate and sustain progress in care for people with serious illness. This year marks the Coalition’s third year of participation with Dr. Bob Bergamini as the Coalition’s representative.

2018 Workshops:

- Implementing Quality Measures for Accountability in Community-Based Care for People with Serious Illness
- Integrating Health Care and Social Services for People with Serious Illness
- Pain and Symptom Management for People with Serious Illness in the Context of the Opioid Epidemic

With our partners at the Patient Quality of Life Coalition, the Supportive Care Coalition participated in the 5th Annual Lobby Day in support of the Palliative Care & Hospice Education & Training Act (PCHETA) in Washington, D.C. This year there were 23 participating organizations from 30 states, with 80 advocates, and 104 hill meetings resulting in 285 bipartisan co-sponsors for the bill. Supportive Care Coalition Members (from left) Denise Hess, Gregg VandeKieft, Lois Lane, Bob Bergamini, Sarah Hill, and Darren Henson (not pictured) visited multiple house and senate offices seeking additional co-sponsors for the bill.

The PCHETA bill passed in the House of Representatives on July 23, 2018.
The Supportive Care Coalition, with our partners at the Patient Quality of Life Coalition, took action to address the opioid epidemic while advocating for the needs of palliative and hospice care patients. In letters to Seema Verma, Administrator at the Department of Health and Human Services, Demetrios Kouzoukas, Principal Deputy Administrator and Director at the Center for Medicare, and Senators Lamar Alexander and Patty Murray of the Senate Health, Education, Labor & Pensions Committee, the Coalition raised our combined voices to advocate for pain medication access when and where it is needed most.

The Supportive Care Coalition continues to oppose the legalization of physician-assisted suicide (PAS) at the state, national, and organizational levels. This year the American Medical Association (AMA) considered changing their position on PAS. The Coalition and other like-minded organizations voiced our opposition to the AMA’s Council on Ethical & Judicial Affairs. The Council has reaffirmed their opposition to PAS and the issue will be re-addressed at future meetings of the AMA.
A CATHOLIC APPROACH TO PALLIATIVE CARE

With board members MC Sullivan, RN, JD, MTS and Darren Henson, PhD, STL, the Coalition developed and launched a new five-part video series titled: A Catholic Approach to Palliative Care.

This series is designed for Catholic clergy, laypersons, parish nurses, and others who are interested in learning more about palliative care from a Catholic perspective.

The series addresses questions such as:

**What is palliative care?**
When and how do I get it?
How does it align with Catholic teachings?

**What is advance care planning?**
How is it done?
What do Catholic teachings say about advance care planning?

How have changes in medicine affected the way we care for the seriously ill?
How might our faith compel us toward more holistic care?

How is baptism a call to fully embrace both our living and our dying?
How might our baptism prepare us for the journey with serious illness?

How does the Eucharist nourish us to live with serious illness?
How might faith communities welcome those with serious illness?

Each video is accompanied by a group discussion guide which includes resources for further study.

Please contact us for more information about viewing or using these videos with a faith group.
Pope Francis described palliative care as an “expression of our uniquely human need to take care of each other, particularly to care for persons who are suffering. Palliative care is a witness to the fact that the human person is always precious, even if old, even if sick. The human person, whatever his circumstances, is always good, for himself and for others, and is loved by God.” (Discourse of Pope Francis to the participants in the Plenary Assembly of the Pontifical Academy for Life, March 5, 2015).

Yet, the World Health Organization reports that only 14% of people who need palliative care worldwide receive it.

The Pontifical Academy for Life PAL-LIFE Project seeks to answer the call to address this need through convening experts to study and recommend ways to develop palliative care across the globe. In 2018, their first gathering was held in Rome and was followed by the first-ever gathering of the Academy in the US.

The US gathering included the issuance of the Joint Declaration on End-of-Life and Palliative Care endorsed by the Catholic and Methodist churches. The Joint Declaration was followed by the publication of the “White Paper for Global Palliative Care Advocacy: Recommendations from a PAL-LIFE Expert Advisory Group of the Pontifical Academy for Life” in the Journal of Palliative Medicine. Both of these documents and the ongoing work of the Academy promise to be a watershed moment for the development of palliative care in the US and around the globe.

SCC Board Members MC Sullivan, Sarah Hill, and Lois Lane were in attendance at several of the Academy’s gatherings.
2018 WEBINAR OFFERINGS

In Search of a Good Death: Living Well with Serious Illness
Steven Pantilat, MD, MHM, FAAHPM

The National Clergy Project on End-of-Life Care
Michael Balboni, PhD, ThM, MDiv

Interprofessional Case Presentation - Am I Helping My Patient Commit Assisted Suicide? A Patient's Request to Deactivate Her Cardiac Pacemaker
Virginia Boothe, MD and Rev. Amy Holtz, MDiv, BCC

Pain and Suffering
Janet Abrahm, MD, FACP, FAAHPM

Payer-Provider Partnerships and the Future of Palliative Care
Torrie Fields, MPH

Palliative Care Goes to Washington...and Your State Capitol
Gregg VandeKieft, MD, MA, FAAFP, FAAHPM

Interprofessional Case Presentation - Right Mind, Right Decisions: Caring for Palliative Care Patients with Mental Health Disorders
Angie Lee, MD and Rev. Tessie Mandeville, MDiv, BCC

The Current Status, Models, and Future of Outpatient Palliative Care
Michael Rabow, MD, FAAHPM

"EXCELLENT PRESENTATION WITH A WEALTH OF CLINICAL INFORMATION! ENGAGING, ARTICULATE, CONCRETE EXAMPLES. BEST I HAVE HEARD."
- WEBINAR PARTICIPANT
"THE WEBINAR ENCOURAGED ME TO BE MORE OPEN-MINDED AND OPEN-HEARTED, REALIZING THAT SOMETIMES THE MOST HEALING THING WE CAN PROVIDE TO ANOTHER IS COMPASSIONATE PRESENCE."

- WEBINAR PARTICIPANT

The Supportive Care Coalition has hosted 44 webinars with over 10,000 registrants since Fall 2014.

**Interprofessional Case Presentation - On His Own Terms:**
Outpatient Palliative Care for the Patient Who Is a “Fighter”
Francine Arneson, MD, Erin Gard, ACHP-MSW and Maren Dorn, RN, CHPN

**Palliative Care Pharmacy: 411 for the Interdisciplinary Team**
Kathryn A Walker, PharmD, BCPS, CPE and Mary Lynn McPherson, PharmD, MA, MDE, BCPS, CPE
The Coalition maintains an unwavering commitment to the integration of spiritual care as an essential component of quality palliative care. To that end, we seek to equip palliative care teams with tools and practices to enhance the spiritual care they provide. Visit our website to download the following resources:

- “Honoring the Spiritual Dimension of Palliative Care” guide
- “10 Stages of the Goals of Care Conversation” template
- Associate palliative care chaplain job description
- Senior palliative care chaplain job description
- Pocket card summary of the conversation guide
- “Spiritual Care: Essential to Palliative Care” Infographic

10 Stages and Tools for Goals of Care Conversations

Integrating Spirituality in Goals of Care Conversations

- Before the meeting, as a team, take a moment to center yourselves.
- Ask the patient/family: “What do we need to know about you as a person to give you the best care possible?”
- Be present, acknowledge, and validate expressions of suffering.
  - Welcome silence.
- Ask the patient/family: “Where do you find the strength to get through this?”
- Express gratitude to the patient/family. Honor their courage to have difficult conversations.
- Debrief as a team. Ask, “What did we learn about the patient/family, ourselves, and our team?”

Learn more at www.supportivecarecoalition.org

10 Stages of the Goals of Care Conversation

1. Planning the first encounter: determine cultural/spiritual background & designated decision makers
2. Team briefing and spiritual grounding
3. Introductions/deepen the conversation
4. Ask patient/family: what do they know?
5. Ask patient/family: what have they been told to expect?
6. Provide: medical review and prognosis
7. Be present to suffering
8. Offer options and medical recommendations
9. Summarize, express gratitude, plan next steps
10. Team debrief and document

11. Palliative care
12. Integrates spiritual care
13. With chaplains as specialists

For more information visit www.supportivecarecoalition.org
This year the Coalition continued to share best practices in spiritual care and palliative care through presentations at national conferences and palliative care educational events including (from top left):

- Francine Arneson at the Avera Palliative Care & Ethics Symposium
- Denise Hess at the Conference on Medicine & Religion
- Sarah Hill at the Catholic Health Association Annual Assembly
- Bob Sawicki at the OSF Supportive Care Conference
- Social Work Hospice & Palliative Care Network General Assembly
- Woody English at the Association of Professional Chaplains & National Association of Catholic Chaplains Annual Conference
In a 2014 survey, 61% of over 1200 palliative care professionals self-reported “high” levels of burnout including: emotional exhaustion, depersonalization, and a low sense of personal accomplishment at work. Given the individual and systemic elements of burnout, efforts to lessen its occurrence must include resources to address individual well-being and organizational flourishing.

We at the Coalition seek to do just that - improve professional flourishing, well-being, and overall resilience at both the personal and organizational level - by sparking new thoughts, encouraging new practices, and deepening our self-awareness. To that end we have created the “Cultivating Professional Resilience” weekly blog. Read the blog posts on your own and journal your responses. Or, better yet, use the blog posts as a team to spark reflection and dialogue.

“We can grow stronger at the broken places.” - Rachel Naomi Remen
THROUGH REFLECTION & ACTION

BLOG HIGHLIGHTS

What does healing mean to you?
A reflection on the difference between curing and healing

Overcoming the five dysfunctions of a team
A 5-part series to build better teams

What is a growth mindset?
An introduction to the latest mind-body research

What is self-compassion?
An introduction to the science and practice of being kind to ourselves

Good leaders make you feel safe
An exploration of the influence of workplace culture on well-being

Unbroken
A reflection on healing that comes through brokenness
The Board of Directors exemplifies their commitment to advance palliative care within their ministries and increase access to palliative care within all of Catholic health care.

(From top left)
- Colleen Scanlon receives the Catholic Health Association Sr. Concilia Moran Award
- MC Sullivan meets Pope Francis at the Pontifical Academy for Life
- The Board of Directors gathers for our fall meeting in Portland, OR
- Bob Bergamini speaks at the PCHETA Hill Day in Washington, D.C.
- Gregg VandeKieft receives the Hastings Center Cunniff-Dixon Physician Award