

# e-Patients as Communications Ambassadors: **A Guide for Creating and Maintaining an Effective e-Patient Communication Plan**



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## Contents

I.	Introduction .....	2
II.	Our e-Patient Ambassadors.....	4
III.	Building an e-Patient Communication Team.....	6
IV.	Creating an e-Patient Communication Campaign .....	7
V.	Engaging e-Patient Ambassadors/Lessons Learned from e-Patients.....	9
VI.	Managing e-Patient Engagement/Lessons Learned .....	14
VII.	Sample Campaign Tools/Resources .....	15
	A. Observances Calendar	
	B. CCCC Resources	
	C. Palliative Care News	
	D. Twitter Cheat Sheet	
	E. Social Media Samples	
	F. Sample Research	
	G. Sample Stories	

## I. INTRODUCTION

This Guide is designed by the Coalition for Compassionate Care of California and our e-Patient Ambassadors to help organizations interested in working with engaged patients, their family members and caregivers on a communications campaign. The suggestions, tools and tips contained in this resource are based on the activities and lessons learned from our e-Patient Palliative Care Ambassadors project, a patient-driven palliative care outreach project funded by a Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI).

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers and clinicians with the evidence needed to make better-informed health and health-care decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work.

The Coalition for Compassionate Care of California promotes high-quality, compassionate care for all who are seriously ill or nearing the end of life. CCCC is a collaboration of thought-leaders in healthcare systems, providers, government agencies, and individuals. Through advocacy, education, and resource development, we're working to ensure that organizations and communities have the information, knowledge, and tools to create the future of palliative care.

One of the key priorities of CCCC is to improve patient access to palliative care. Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients, and their families, with relief from the symptoms and stress of a serious illness.

Engaged patients, also known as “e-Patients,” are individuals who are equipped, enabled, empowered and engaged in their health and health-care decisions, allowing health care to be an equal partnership between e-Patients and the health professionals and health systems that support them.

E-Patients, as well as their family members and caregivers, have a unique, person-centered perspective which can make them a valuable and effective voice for communicating to both consumers and health care providers regarding medical topics such as palliative care. In our prior work with e-Patients, they told us they felt that current communication on palliative care often reflects health care providers’ perspective, rather than the authentic patient voice.

The goals of the e-Patient Palliative Care Ambassadors project were to:

- Recruit and train a small team of "e-Patient Ambassadors" to work together to craft and disseminate information about palliative care, advance care planning and person-centered health care to a nationwide audience through the use of social media and their existing networks within disease specific advocacy organizations and communities.
- Guide and assist the Ambassadors in promoting palliative care information and research to a broad audience of providers and consumers.
- Create and disseminate a toolkit of best practices to help all patients and advocacy organizations share information about palliative care, advance care planning and person-centered services.

The project is part of a portfolio of projects approved for PCORI funding to develop a skilled community of patients and other stakeholders from across the entire health-care enterprise and to involve them meaningfully in every aspect of PCORI's work and dissemination of PCORI-funded research.

## II. OUR e-PATIENT AMBASSADORS



### **Grace Cordovano, PhD BCPa**

*West Caldwell, NJ*

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Significant gaps exist between cancer patients and their doctors – gaps in communication, information, empathy and understanding. To address these gaps and support patients during their cancer journey, Dr.

Cordovano founded Enlightening Results, a private, personalized patient advocacy service which specializes in the cancer arena. She is a champion for palliative care, and wants to see it be incorporated earlier in cancer treatment planning paradigms. Dr. Cordovano is a member of the Alliance of Professional Health Advocates (APHA), the Society for Participatory Medicine (SPM), Health 2.0 NYC, and an ambassador for Citizen Health.



### **Sharon Hall**

*Cumming, GA*

[sharonhall419@yahoo.com](mailto:sharonhall419@yahoo.com) | [dementianeeds.blogspot.com](http://dementianeeds.blogspot.com) | Twitter: @srhall419

Sharon retired from a long career in the corporate world in 2014 to care for her mother full time. When Sharon’s husband was subsequently diagnosed with frontotemporal degeneration and she couldn’t find the

resources or support she needed to best care for him, she had to create her own resources. Helping those recently diagnosed with early onset dementia and their caregivers has become a mission that is particularly close to Sharon’s heart. Sharon firmly believes that the palliative care services her husband has received since his diagnosis have lessened her stress and enhanced her husband’s life. She has shared her experiences as a care partner speaker at the NIH 2017 Research Summit on Dementia Care and Services, as well as at national caregiver conferences. She also facilitates a local support group and an online chat for care partners, and produces a monthly podcast with a dementia expert to give families much needed information.



### **Mary Millard**

*Prairieville, LA*

[mary51802@gmail.com](mailto:mary51802@gmail.com) | [www.marymillard.org](http://www.marymillard.org) | Twitter: @HAISurvivor

Mary lives with chronic *Pseudomonas Aeruginosa*, a bacterium she acquired during a lifesaving hospital procedure. *Pseudomonas* is considered a “superbug” and resistant to antibiotics. She is on lifetime antibiotics to keep the bacteria out of her bloodstream and contained on

the biofilm of her aortic graft and valve replacement. She is passionate about palliative care – it has helped Mary endure 98 x-rays, 20 CT scans, 14 ECHOs, heart failure due to the septic shock, and 6 rehospitalizations so far. She has also seen palliative care help her husband and others who are close to her. Mary lives in Louisiana with her husband, a dog and two cats.



**Michelle (Shelly) Reinhart**

*Rancho Cucamonga, CA*

[shellytap@yahoo.com](mailto:shellytap@yahoo.com) | Twitter: @Reinhart\_shelly

Shelly’s experience as caregiver for her brother during his battle with cancer – during which palliative care services were never offered – activated her as a palliative care champion. For months, she questioned daily whether she was doing the right thing for her brother. She wonders now what his life and death would have been like if he and their family had access to palliative care services when they needed them. Shelly became a volunteer with the American Cancer Society Cancer Action Network (ACS-CAN) in 2009. She volunteers at Relay for Life events and has held numerous lead positions within the organization. Shelly has attended ACS-CAN State Lobby Day in Sacramento for many years, as well as National Lobby Day in Washington, DC, for the last 3 years. She uses her story to convince policy makers to pass beneficial legislation.



**Selene Seltzer**

*Ashland, OR*

livingwell@seleneseltzer.com | [www.seleneseltzer.com](http://www.seleneseltzer.com) | Twitter: @SeleneSeltzer

As a dually board-certified Clinical Healthcare Chaplain who has experienced two cancer events, chronic illness, and severe injury, as well as caring for family members through their illness and dying processes, Selene has a deep understanding of the unique challenges and opportunities that people with serious, chronic, life-limiting illness or injury face. She is specially attuned to psycho-social-spiritual needs and their potential impact on individuals, their care partners, and healthcare teams. Selene’s mission is to educate, encourage and empower members of her community to explore ‘how to live fully when we realize we are going to die.’

### III. BUILDING AN e-PATIENT COMMUNICATION TEAM

The following are some suggestions for building your e-Patient communication team.

#### 1. Build Your e-Patient Team

- Determine possible funding/resources for program and program participation
- Solicit potential e-Patient Ambassador team members through research, referrals and direct outreach
- Clarify basic expectations for team member involvement/commitment
- Determine candidates' willingness/ability to participate
- Finalize team selection and welcome team

#### 2. Understand Your e-Patient Team

- Gather basic information about each team member
- Identify team members' individual areas of expertise/strengths
- Identify education needs and resource needs of each team member

#### 3. Teambuilding/Education

- Have team members share their stories to raise awareness within the team
- Create opportunities for team to communicate with one another
- Access education/information needed
- Provide education/support

## IV. CREATING A COMMUNICATIONS CAMPAIGN

Each communications campaign is unique, but the following provides a basic framework for developing a campaign around e-Patients Ambassadors and palliative care.

### 1. Build Campaign Foundation

- Clarify campaign goal/key messages
- Identify potential target audiences for campaign
- Identify primary communication vehicles for team (i.e., social media, community engagement)
- Determine roles/priorities of team and team members
- Create a simple communications campaign strategy
- Gather basic informational/educational resources about palliative care
- Gather and record baseline data needed to track progress of campaign

### 2. Create Messaging

- Develop key messaging/elevator speeches
- Identify research studies, reports and educational resources to share
- Identify events/commemorative dates which can be tied-in to messaging
- Identify/prioritize communications channels (email, Twitter, Facebook, etc.) for each team member
- Create/ develop sample messaging for social media channels
- Develop simple graphics to accompany social media posts
- Create simple overarching communications plan for group and individual plans for e-Patient Ambassadors
- Create editorial calendar with dates for key messaging, research and event tie-ins, etc.
- Create list of primary hashtags for message dissemination for social media. Register any new hashtags with Symplur.

### 3. Launch Campaign

- Post/communicate messaging through appropriate channels and following campaign calendar/plan
- Incorporate research/data into messaging
- Incorporate current news/events into messaging
- Incorporate e-Patients' own stories into messaging
- Each e-Patient Ambassador communicates campaign-specific messaging and individually-focused messaging
- Gather examples of response to messaging

- Encourage e-Patient ambassadors to engage in responsible conversation that may stem from any messaging

#### **4. Build Audiences/Expand Networks**

- Identify and connect with important individual influencers within palliative care
- Identify/connect with related organizational influencers
- Tag/Follow/Retweet Influencers

#### **5. Refine Messaging**

- Collect data from each team members' experiences
- Meet as a team to address input and experiences
- Gather/evaluate data from outreach/campaign
- Bring team together to discuss experiences/successes/roadblocks
- Adjust campaign based on evaluation/input/feedback
- Define next steps

#### **6. Campaign Conclusion**

- Collect final data from each team members' experiences
- Meet as a team to address input and experiences
- Gather/evaluate final data from outreach/campaign
- Bring team together to discuss experiences/successes/roadblocks
- Record lessons learned and potential refinements for future efforts

## V. ENGAGING e-PATIENT AMBASSADORS | LESSONS LEARNED

The following are the shared thoughts of the e-Patient ambassadors regarding their experience as e-Patient ambassadors for palliative care, as well as tips and lessons-learned for others who might follow in their footsteps.

### On what motivated them to become e-Patient Ambassadors for Palliative Care...

**Experience** – Personal experience – either with having received palliative care or seeing missed opportunities where palliative care might have improved someone’s quality of life if it had been made available – and the desire to make a difference by sharing that experience with others, is what motivated most of our e-Patient ambassadors to participate in an effort to raise awareness about palliative care.

*“As a patient advocate specializing in the oncology space, as well as the primary care partner to two disabled adults, I was gravely concerned about the lack of awareness about palliative care in general patient community. Doctors simply weren’t mentioning it, even when it was clear that a person may be approaching end-of-life. Speaking from personal and professional experiences in the northern NJ/NYC area, both patients and health care organizations have significant unmet needs with respect to incorporating palliative care as an extension of the care team.” ~Grace*

*“I saw this project as an opportunity to effect change and provide information through social media. I chose to focus my social media outreach efforts through the Twitter platform with the goal of enhancing the understanding of Palliative Care and its benefits, to increase awareness and acceptance of PC as well as drive demand for Palliative Care services. I wanted to reach non-Hospice and Palliative Medical professionals who may not understand the essence and benefits of Palliative Care; to inform the general public, persons with serious illness, and their caregivers what PC resources are and how they may benefit them. “ ~Selene*

*"I was motivated to become an ambassador due to first-hand experience in not receiving palliative care because I was told it is 'just for the dying.' After learning more about palliative care, I realized what it truly was and I wanted to educate people on its true meaning." ~ Mary*

*"I have felt for some time that the dementia community, especially young onset dementia, needed to involve palliative care from time of diagnosis. This project gave me the opportunity to educate the dementia community on palliative care." ~ Sharon*

*"The first time I heard about palliative care was after my brother Jeff's death from inoperable Stage IV colorectal cancer. Palliative care made so much sense to me. I thought it was a new kind of care. I got angry when I realized that it had been around for years. Jeff was actually seen at a facility with one of the highest rated palliative care programs in the area. It was never offered to him because he was only 30 years old." ~ Shelly*

### **On the support they found most valuable...**

**Support from the Team** – Whether it was in-person or via telephone, email or social media, the e-Patient Ambassadors found connecting with each other was of great value. It helped to maintain continuity in the work, and allowed them to amplify each others' work and messaging.

*"Connecting with four other incredibly amazing Ambassadors was inspirational, educational, and self-motivating." ~ Grace*

**Immersion at CCCC’s Annual Summit** – The Ambassadors had an opportunity to come together at CCCC’s 2019 Annual Palliative Care Summit where they participated in educational sessions presented by national leaders in the field, participated in educational and interactive sessions with the healthcare provider attendees, and had private meeting time to get to know each other, learn about the project, brainstorm and share ideas.

*“The conference was superb in being a good launch pad for our mission. It also made all of us as Ambassadors talk and get to know each other, and that helped us feel more comfortable asking questions.” ~ Mary*

*“Being able to learn about the different ways that palliative care can provide benefit and healing across different diseases was eye-opening.” ~ Grace*

**Help Connecting with Social Media Leaders** - One of the most helpful resources was a list of palliative care-related social media hashtags along with the names and Twitter handles of several prominent palliative care, hospice, and end-of-life care thought- leaders to follow.

**Information to Share** – Receiving sample talking points, copies of current news articles related to palliative care, a calendar of commemorative events like National Health Care Decisions Day, and information on PCORI-funded research provided inspiration for the e-Patient Ambassador’s social media posts.

*“The emails with information and research were very helpful. It was nice to be able to show studies to combine with personal details.” ~ Shelly*

**Education** – Educational materials and free access to online education was valuable in expanding the e-Patient Ambassadors’ knowledge base.

**Advance Care Planning Tools** – Access to existing resources on palliative care and advance care planning, including sample advance directive forms, FAQs, informational brochures and conversation tools such as health care decision aids provided reference materials for e-Patient Ambassadors to use in their social media interactions.

*"I used info contained in CCCC's Decision Aids as a resource + educational material to highlight decisions within the ACP process to explain the complex topics of life-sustaining treatments and using consumer-friendly language with evidence-based information." ~ Selene*

## Communication Strategies/Tips for the Ambassadors

### Grace recommends:

- Set clear expectations as to what the end goal for the e-Patient ambassador is and for generally along the way.
- Maintain continuous communications with your Ambassadors, at minimum via email or calls. It is essential to building comradery as well as to share best practices and/or concerns.
- Provide regular feedback on any deliverables, both positive and negative.

### Mary recommends:

- Persistence and repetition of the subject. Not all social media is effective. Twitter is by far the most effective however. LinkedIn and Facebook are not, in my experience.

### Selene recommends:

- When dealing with those holding misperceptions or ignorance about Palliative Care and its benefits, it's imperative to find common ground. Whether it's the general public, persons with recent diagnoses, their caregivers, or non-HPM clinicians, I believe "Quality of Life" is this common ground. Thus, amplifying the Palliative Care message of enhancing Quality of Life is key.
- Assist people with recent and longstanding diagnoses find the support and information they needed by amplifying illness-specific Twitter chat groups through the use of the hashtags and disease descriptors.

**Sharon recommends:**

- Create webinars and handouts to talk about the value of palliative early in disease that can be used when you speak.
- Have info on your organization's website about palliative care and finding it near you.

**Shelly recommends:**

- Be very clear with expectations. Knowing our end game before we begin is helpful.

## VI. MANAGING e-PATIENT ENGAGEMENT | LESSONS LEARNED

This award built on the tremendous success of the Coalition for Compassionate Care of California's (CCCC) previous work with e-Patients, which demonstrated the feasibility of engaging seriously ill patients as advocates and ambassadors to increase consumer awareness of palliative care through social media. Prior e-Patients with whom we have worked told us they felt that communication on palliative care too often reflects the voice of providers, rather than the authentic patient voice.

Our work on this project demonstrated that those who are dealing with serious illness – both the patient as well as the family caregiver – are uniquely qualified and effective ambassadors for palliative care. This approach infuses an authentic patient voice into communication and empowers patients and caregivers with the information needed to ask for palliative care and/or understand their treatment options when faced with a health crisis.

In our capacity as project managers, CCCC has learned the following lessons:

- **It is important to pay e-Patient Ambassadors.**  
As part of our e-Patient Ambassadors project, we felt it was important that our five e-Patient Ambassadors receive financial stipends in recognition and appreciation of their expertise and for the extensive time commitment expected for the project. Our selection criteria indicated that the e-Patients should be “palliative care eligible” or caregivers, and we were sensitive to the fact that our e-Patient Ambassadors would likely be coping with a serious illness and may have already limited energy levels and/or negatively impacted financial situations.
- **It is always more difficult than you think it will be to convene.**  
Engaging e-Patient Ambassadors who could be patients, caregivers, or both, and who hailed from across the United States, offered a rich variation in experiences, but it also presented logistical challenges related to different time zones and availability for group calls and meetings. Use of Doodle polls at least two weeks in advance of potential meetings was helpful in scheduling and planning.

## VII. ADDENDUM | SAMPLE CAMPAIGN TOOLS/RESOURCES

- A. Observances Calendar
- B. CCCC Resources
- C. Palliative Care News
- D. Twitter Cheat Sheet
- E. Social Media Samples
- F. Sample Research
- G. Sample Stories

## SAMPLE RESOURCES: Health Care Observances Calendar

### 2019 Events/Observances

#### SEPTEMBER

September 8	<p><b>National Grandparents Day</b> Organized by Generations United; <a href="http://www.grandparents.org">www.grandparents.org</a></p>
September 10	<p><b>World Suicide Prevention Day</b> International Association for Suicide Prevention; <a href="http://www.iasp.info/wspd2019/">www.iasp.info/wspd2019/</a></p>
September 8-14	<p><b>National Suicide Prevention Week</b> American Association of Suicidology; <a href="http://www.suicidology.org/about-aas/national-suicide-prevention-week">www.suicidology.org/about-aas/national-suicide-prevention-week</a></p>
September 25	<p><b>National Women's Health &amp; Fitness Day</b> Health Information Resource Center; <a href="http://www.fitnessday.com/">http://www.fitnessday.com/</a></p>
Month of Sept	<p><b>Healthy Aging Month</b> Purpose: To encourage local level Healthy Aging events that promote taking personal responsibility for one's health. Organized by Healthy Aging® <a href="http://www.healthyaging.net">www.healthyaging.net</a></p>
Month of Sept	<p><b>Childhood Cancer Awareness Month</b> Organized by American Childhood Cancer Organization National Office <a href="http://www.acco.org/childhood-cancer-awareness-month">www.acco.org/childhood-cancer-awareness-month</a></p>
Month of Sept	<p><b>National Sickle Cell Awareness Month</b> Organized by NHLBI Center for Health Information <a href="http://www.nhlbi.nih.gov/health/educational/sickle-cell-awareness">www.nhlbi.nih.gov/health/educational/sickle-cell-awareness</a></p>
Month of Sept	<p><b>Leukemia, Lymphoma and Myeloma Awareness Month</b> Organized by the Leukemia &amp; Lymphoma Society; <a href="http://www.lls.org">www.lls.org</a></p>
Month of Sept	<p><b>National Ovarian Cancer Month</b> Organized by National Ovarian Cancer Coalition; <a href="http://www.ovarian.org">www.ovarian.org</a></p>
Month of Sept	<p><b>National Prostate Cancer Awareness Month</b> Organized by ZERO - The End of Prostate Cancer; <a href="http://zerocancer.org">http://zerocancer.org</a></p>
Month of Sept	<p><b>Ovarian Cancer Awareness Month</b> National Ovarian Cancer Coalition; <a href="http://www.ovarian.org">www.ovarian.org</a></p>
Month of Sept	<p><b>Pain Awareness Month</b> American Chronic Pain Association; <a href="http://www.ovarian.org/">http://www.ovarian.org/</a></p>

## **SAMPLE RESOURCES: Available on <https://coalitionccc.org/>**

### **Basic information about Palliative Care**

**Webpage:** <https://coalitionccc.org/tools-resources/palliative-care/>

**Video: *Palliative Care is Good Medicine***

*Brief video with seniors and ePatients discussing palliative care*

- Link: <https://youtu.be/ov32igbP2ZE>

### **Pediatric Palliative Care**

**Webpage:** <https://coalitionccc.org/what-we-do/pediatric-palliative-care/>

### **ePatient Ambassadors**

**Webpage:** <https://coalitionccc.org/what-we-do/e-patient-ambassadors/>

**Meet our Ambassadors:** <https://coalitionccc.org/e-patient-ambassadors/>

### **Reports/Articles**

**Snapshots of Palliative Care Practices (2015)**

*Snapshots of Palliative Care Practices was compiled as part of a session on palliative care capacity, need, and resources at the Coalition for Compassionate Care of California Annual Summit in April 2015. Participants were asked to share examples of their approaches to working with patients, working with providers, and measuring the impact of their services.*

- [https://coalitionccc.org/wp-content/uploads/2013/12/snapshots\\_pc\\_practices\\_2015.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2013/12/snapshots_pc_practices_2015.pdf?x90552)

**Value Snapshots Fact Sheets**

- Value Snapshots for Advance Care Planning (PDF) (2015)
- Value Snapshots for Home-Based Palliative Care (PDF) (2015)
- Value Snapshots for Hospice Care (PDF) (2015)
- Value Snapshots for Inpatient Palliative Care (PDF) (2015)
- Value Snapshots for Palliative Care Clinics (PDF) (2015)

### **Making the Case for Palliative Care/Research**

**20 References To Help You “Make The Case” For Palliative Care**

Link: <https://coalitionccc.org/tools-resources/palliative-care/make-the-case-for-palliative-care/>

**Finding Common Ground: Quality & Fiscal Incentive Alignment for Community-Based Palliative Care (2013)**

- <https://coalitionccc.org/wp-content/uploads/2014/01/CBPC-business-case-Aug-2013.pdf?x90552>

**Intensity of Care & High Costs at End-of-Life & Impacts of Advance Care Planning, Hospice and Palliative Care (2012)**

- <https://coalitionccc.org/wp-content/uploads/2014/01/Intensity-cost-PC-ACPapr20121.pdf?x90552>

## Decision-Making Tools/Advance Care Planning

### Adult Decision Aids

Handouts which explain the complex topics of life-sustaining treatments, using consumer-friendly language with evidence-based information. Topics include: artificial hydration, cardiopulmonary resuscitation (CPR), mechanical ventilation (ventilator), and tube feeding (artificial nutrition).

- <https://coalitionccc.org/tools-resources/decision-guides/>

### Conversation Guide

This guide offers suggestions on how to raise the issue of advance care planning, responses to concerns your loved one might express and questions to ask.

- Link: [https://coalitionccc.org/wp-content/uploads/2013/12/CCCC\\_ACP\\_Conversation-Guide\\_June2014.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2013/12/CCCC_ACP_Conversation-Guide_June2014.pdf?x90552)

### Finding Your Way: Medical Decisions When They Count Most

- English: <https://coalitionccc.org/wp-content/uploads/2014/02/Finding-Your-Way-English.pdf?x90552>
- Spanish: <https://coalitionccc.org/wp-content/uploads/2014/01/Finding-Your-Way-Spanish.pdf?x90552>

### Thinking Ahead

This advance directive booklet created by CCCC contains words, symbols and pictures that facilitate discussion and decision-making regarding values, goals and treatment preferences at the end of life.

- Link: <https://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>

### Advance Health Care Directives FAQ

Frequently asked questions and answers regarding advance health care directives.

- Link: [https://coalitionccc.org/wp-content/uploads/2014/10/AHCD\\_Frequently\\_Asked\\_Questions.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2014/10/AHCD_Frequently_Asked_Questions.pdf?x90552)

### Choosing a Healthcare Agent

This simple guide helps you determine what to consider when you are selecting a healthcare agent to make decisions you would if you were able.

- English: [https://coalitionccc.org/wp-content/uploads/2014/10/Choosing\\_an\\_Agent.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2014/10/Choosing_an_Agent.pdf?x90552)
- Spanish: [https://coalitionccc.org/wp-content/uploads/2016/01/Choosing\\_An\\_Agent\\_Spanish.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2016/01/Choosing_An_Agent_Spanish.pdf?x90552)

### Help For Healthcare Agents

Making medical decisions for your loved one can be a challenge. This easy-to-read companion piece is here to help you serve as a healthcare agent.

- English: [https://coalitionccc.org/wp-content/uploads/2014/10/Help\\_for\\_Healthcare\\_Agents.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2014/10/Help_for_Healthcare_Agents.pdf?x90552)
- Spanish: [https://coalitionccc.org/wp-content/uploads/2016/01/Help\\_for\\_Healthcare\\_Agents\\_Spanish.pdf?x90552](https://coalitionccc.org/wp-content/uploads/2016/01/Help_for_Healthcare_Agents_Spanish.pdf?x90552)
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## Physician Orders for Life Sustaining Treatment (POLST)

Website with information on California's Physician Orders for Life Sustaining Treatment California forms, FAQs, consumer information

- <https://capolst.org/>

## **SAMPLE RESOURCES:** Palliative Care News and Information

### **Palliative Care Blogs/Newsletters**

#### **AAHPM Smart Brief/Blog**

*Newsletter of the American Academy of Hospice and Palliative Medicine*

- Newsletter: <http://aahpm.org/publications/smartbrief>
- Online blog: <http://aahpmblog.org/>

#### **Pallimed**

*Hospice and Palliative Medicine blog edited by Christian Sinclair, MD, FAAHPM*

Online blog: <https://www.pallimed.org/>; ([Sign up](#))

Twitter: @Pallimed

#### **GeriPal**

*A geriatrics and palliative medicine blog*

Online Blog: <https://www.geripal.org/>

Podcast: <https://www.geripal.org/p/geripal-podcast.html>

Facebook: <http://www.facebook.com/GeriPal>

Twitter: @GeriPalBlog

#### **Get Palliative Care**

*Blog of the Center to Advance Palliative Care (CAPC)*

Online blog: <https://getpalliativecare.org/blog/>

Podcasts: <https://getpalliativecare.org/podcasts/>

#### **National Hospice & Palliative Care Organization (NHPCO)**

Website: <https://www.nhpc.org/>

Twitter: @NHPCO\_news

#### **Palliative Care Doctors**

Online blog: <http://palliativedoctors.org/>

#### **Palliative Care in Practice**

*Blog of the Center to Advance Palliative Care*

Online blog: <https://www.capc.org/blog/>

#### **Palliative Care Success**

*A commentary on how palliative care programs and physicians can play a role in the improvement of advanced illness management in the US.*

Online blog: <http://palliativemedicine.blogspot.com/>

#### **Palliative Care Network**

Online blog: <https://palliativecarenetwork.com/blog/>

## Resources for Patients & Families

### Center to Advance Palliative Care (CAPC)

*Website has articles and stories, information on palliative care and how to access it, provider directory, patient stories, videos, podcasts, webinars, etc.*

- Get Palliative Care website: <https://getpalliativecare.org/>
- Handouts for patients and families: <https://getpalliativecare.org/handouts-for-patients-and-families/>
- Quiz: Is Palliative Care Right for You?: <https://getpalliativecare.org/rightforyou/>
- How to find palliative care: <https://getpalliativecare.org/how-to-find-palliative-care/>

### GeriPal Blog

*GeriPal focuses on palliative care for older individuals. This blog keeps in mind the special needs of geriatric patients — and their providers. Resources include news, podcasts, article library, interviews with medical professionals, and information on the latest research.*

- Online Blog: <https://www.geripal.org/>
- Podcast: <https://www.geripal.org/p/geripal-podcast.html>

### Palliative Doctors

*Basic information on palliative care and the palliative care team. Includes information on questions to ask your doctor, how to develop a care plan, and patient stories.*

- Online blog: <http://palliativedoctors.org/>

## SAMPLE RESOURCES: Twitter Cheat Sheet for Palliative Care Advocates

HASHTAGS			
#	For Tweets related to:	#	For Tweets related to:
#EOL	End of life	#palliative	Palliative care
#EoLc	End of life care	#pallonc	Palliative care in oncology
#HPM	Hospice and palliative medicine	#pedPC	Pediatric palliative care
#HPMglobal	HPM around the world	#POLST	POLST
#NHDD	Natl Healthcare Decisions Day		

ORGANIZATIONS TO FOLLOW	
Organization Name	Twitter Handle
American Academy of Hospice & Palliative Medicine	@AHHPM
Chinese American Coalition for Compassionate Care	@CAforCC
Coalition to Advance Palliative Care	@CAPC AND @CAPCpalliative
Coalition for Compassionate Care	@CoalitionCCC
EndWell	@endwellSF
GeriPal (blog)	@GeriPalBlog
Hospice & Palliative Medicine Chat	@hpmchat
Hospice & Palliative Medicine Journal Club	@hpmJC
National Hospice and Palliative Care Organization	@NHPCO_news
New York MOLST	@NYMOLST
Pallimed (blog)	@Pallimed
Patient Care Quality Network	@PCQN_Team
POLST (National)	@NationalPOLST

INDIVIDUALS TO FOLLOW	
Individual/Organization	Twitter Handle
Pat Bomba, New York MOLST	@PatBombaMD
Kathy Brandt	@kathy_brandt
Ira Byock, MD	@IraByock
Betty Ferrell, PhD, ELNEC	@BettyFerrellPhD
Michael Fratkin, Resolution Care	@MichaelDFratkin
Atul Gawande, MD Author	@atul_gawande
Judy Thomas, Coalition for Compassionate Care	@JudyThomasJD
Diane Meier, Center to Adv Palliative Care	@DianeEMeier
Thaddeus Pope	@ThaddeusPope
Christian Sinclair, Pallimed	@ctsinclair
Shoshana Ungerleider, MD	@ShoshUMD
Amy Vandenbroucke, National POLST	@AmyVDB1
Charles von Gunten, Journal of Palliative Medicine	@CvonGunten
Eric Widera, MD, GeriPal	@EWidera

## **SAMPLE RESOURCES: Palliative Care on Social Media**

### **Overview of Palliative Care**

*Palliative care is good medicine. Palliative care is specialized medical care for people who have serious or chronic illness. Often delivered by a team of doctors, nurses and other specialists, palliative care is an extra layer of supportive care which focuses on relieving the symptoms, pain and stress of a serious illness. Palliative care can be provided at the same time as curative treatment, and is appropriate at any age and at any stage of serious illness.*

#### **Palliative Care Is**

- Specialized medical care for people with serious illnesses
- Relieves symptoms, pain, and stress of a serious illness—whatever the diagnosis
- Improves quality of life for both the patient and the family
- Provided by a team of doctors, nurses and other specialists who provide an extra layer of support
- Appropriate at any age and at any stage in a serious illness along with curative treatment

#### **Patient Benefits**

- Puts the patient's goals and wishes first
- Improves quality of life
- Relieves suffering by identifying and treating physical, psychosocial and spiritual pain
- Helps patients and families better understand treatment plans and options
- Supports the patient and family
- Reduces unnecessary hospital visits

#### **Utilization & Cost Benefits**

- Fewer ER visits
- Fewer hospital admissions/readmissions
- Fewer number of days in hospital ICU
- Improved efficiency/reduced costs

## Sample Tweets

*Tip: Keep your Tweets under 280 characters.*

Did you know that you can get #PalliativeCare while still receiving curative treatment? It's true. Palliative care provides an extra layer of support for anyone with a serious illness, regardless of age, stage or prognosis. Learn more. (<https://bit.ly/2Xcs58R>)

#PalliativeCare focuses on relieving a patient's physical, emotional and psychosocial pain and suffering. It can significantly improve the quality of life of people dealing with serious or chronic illness. Learn more. (<https://bit.ly/2Xcs58R>)

People often misunderstand #PalliativeCare. You don't have to give up other treatments and anyone with a serious or chronic illness, regardless of age, stage or prognosis, may be eligible.

#PalliativeCare can help relieve the physical and emotional pain and symptoms from cancer treatment. Learn how #PalliativeCare can help you or your family. (<https://bit.ly/2Xcs58R>)

If you are suffering from pain or unpleasant side effects from medical treatment, #PalliativeCare might be able to help improve your quality of life. Get the extra support you need. (<https://bit.ly/2Xcs58R>)

Serious illness can bring physical and emotional pain to patients and their families, but #PalliativeCare can help. Learn more. (<https://bit.ly/2Xcs58R>)

Who can benefit from #PalliativeCare? Anyone with a serious or chronic illness, including those with cancer, Alzheimer's disease, multiple sclerosis, heart disease and more. Learn more. (<https://bit.ly/2Xcs58R>)

Did you know that Medicaid and many insurance plans will cover palliative care? Ask your health care team to connect you with a case manager or someone at your hospital or clinic to learn about payment options.

#PalliativeCare is more than just help with pain and symptom management. It can include care coordination, advanced care planning and emotional and spiritual support for the patient and family members.

When a child is seriously ill, it affects the entire family; #PalliativeCare can help support everyone. #pedpc

You don't have to be in a hospital to get #PalliativeCare – it can be provided in a clinic or at home.

#PalliativeCare can begin at any stage of a serious illness, and be provided alongside other treatments.

#PalliativeCare is about living the best life you can – even if you are seriously ill. Ask your healthcare provider how it can help you and your family (<http://go.usa.gov/3eA3e>)

#pedpc is supportive care for children with serious illness and their families. (<http://go.usa.gov/3eA3e>)

## Sample Facebook Posts

5 Quick Facts about Palliative Care (1) The focus is on improving quality of life; (2) It can be given alongside curative treatment; (3) It provides an extra layer of support for anyone with a serious illness; (4) It is covered by most health insurance; (5) It's not about giving up – it's about getting the extra support needed. (<https://bit.ly/2Xcs58R>)

Pediatric palliative care can provide support to children who live with serious illnesses. It aims to maximize quality of life for the child, parents, and siblings. Care is based on the unique needs of each family, and a vast range of subspecialists offer customized support. <http://go.usa.gov/3eA3e>

When a family member has a serious illness, everyone in the family is affected. Palliative care can be there to support everyone in the family from early diagnosis through treatment.

What can you do to ensure someone with a serious illness has the care, comfort, and support she/he needs? Find out what palliative care can offer.

Palliative care is different from hospice care. It can start at any time, any age, any stage of illness. And, it can be provided alongside other treatments. Learn more!

All caregivers and families of individuals with serious illnesses deserve support. Find out more about palliative care and how it can help. (<https://bit.ly/2Xcs58R>)

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Learn more. (<https://bit.ly/2Xcs58R>)

Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Myth Buster! Some people think palliative care is just for people who are near the end of life. Wrong! Palliative care can provide pain and symptom support at any stage of a person's illness, and can be delivered by a team of specialists along with curative treatments.

Need extra support to deal with pain and symptoms from a serious illness? Don't be afraid to ask your healthcare team about Palliative Care. Support can be provided to patients of any age, and at any stage of serious illness.

## **SAMPLE RESOURCES: Palliative Care Research/Papers**

### **Research-Based Quotes/References**

#### **Awareness of Palliative Care:**

**A national survey of 800 US adults conducted in 2011 by the Center to Advance Palliative Care found that 70% were “not at all knowledgeable” about palliative care.**

*Am J Hosp Palliat Care. Awareness and Misperceptions of Hospice and Palliative Care: A Population-Based Survey Study; 2018 Mar ([Link](#))*

**Despite the documented benefits of palliative and hospice care on improving patients' quality of life, these services remain underutilized. Multiple factors limit the utilization of these services, including patients' and caregivers' lack of knowledge and misperceptions.**

*Am J Hosp Palliat Care. Awareness and Misperceptions of Hospice and Palliative Care: A Population-Based Survey Study; 2018 Mar ([Link](#))*

#### **Benefits of Palliative Care:**

**Combining standard care with palliative care for patients with malignancy leads to better outcomes, including symptom management, quality of life, and reduced burden on caregivers. For some, early palliative care is even associated with longer and better-quality life, reduced intensive care, and more appropriate hospice referral.**

*Temel, JS, Greer, JA, Muzikansky, A et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010; 363: 733–742*

**Patients who received palliative care along with standard treatment for advanced cancer reported having a better quality of life and mood than patients who did not receive early palliative care, according to the results of a randomized clinical trial.**

*Randomized trial of early integrated palliative and oncology care; Joseph A. Greer, et al; Journal of Clinical Oncology 2016 34:26\_suppl, 104-104  
[https://ascopubs.org/doi/abs/10.1200/jco.2016.34.26\\_suppl.104](https://ascopubs.org/doi/abs/10.1200/jco.2016.34.26_suppl.104)*

## **SAMPLE RESOURCES: Stories**

### **Telling Your Story**

#### **Articles about the Importance of Story Telling:**

##### **Storytelling Helps Hospital Staff Learn About The Person, Not Just The Patient**

<https://www.npr.org/2019/06/03/729191879/patient-biographies-may-help-health-care-providers-relate>

##### **Bill Novelli: Advocacy Through Storytelling**

[https://www.thectac.org/2019/02/bill-novelli-advocacy-through-storytelling/?utm\\_source=Member+Alert&utm\\_campaign=09f241cc94-EMAIL\\_CAMPAIGN\\_2019\\_02\\_12\\_02\\_46&utm\\_medium=email&utm\\_term=0\\_e1d9f6f769-09f241cc94-150820285](https://www.thectac.org/2019/02/bill-novelli-advocacy-through-storytelling/?utm_source=Member+Alert&utm_campaign=09f241cc94-EMAIL_CAMPAIGN_2019_02_12_02_46&utm_medium=email&utm_term=0_e1d9f6f769-09f241cc94-150820285)

##### **3 keys to sharing your story**

<https://www.youtube.com/watch?v=5nNEDRPctQw>

##### **Why Sharing Your Personal Story Can Offer Real Health**

**Benefits** [http://www.oprah.com/health\\_wellness/why-sharing-your-personal-story-can-offer-real-health-benefits](http://www.oprah.com/health_wellness/why-sharing-your-personal-story-can-offer-real-health-benefits)

#### **Video Stories:**

##### **Patient Ambassador Video Introductions:**

- **Grace Cordovano** (June 5, 2019) <https://youtu.be/3FYfiSJ1Ud8> (1:28)
- **Sharon Hall** (June 5, 2019): <https://youtu.be/tSD0JJoChlo> (2:16)
- **Mary Millard** (June 5, 2019) <https://youtu.be/9Sd53yIhTJ4> (0:44)
- **Shelly Reinhart** (June 5, 2019) <https://youtu.be/yoaEi8pGw80> (2:24)
- **Selene Seltzer** (June 5, 2019) <https://youtu.be/glbrxvIQpbg> (2:29)

**What is Palliative Care/Palliative Care Makes Good Sense** video with MarlaJan Wexler and Charlie Blotner: <https://youtu.be/ov32igbP2ZE> (1:51)

**Patient Julie G. shares the importance of palliative care in her life:** <https://youtu.be/ROOCTZThQmM> (1:20)

**Meet e-Patient Dave** (Dave deBronkart) on TEDx Stage

[https://www.ted.com/talks/dave\\_debronkart\\_meet\\_e\\_patient\\_dave?language=en](https://www.ted.com/talks/dave_debronkart_meet_e_patient_dave?language=en) (16:24)

**Debbie's Palliative Care Story** (2014) <https://youtu.be/8HZM0pL3a8E> (2:33)