Changing the Way We Think about Living and Dying

GENERAL DISCUSSION GUIDE
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“There's nothing inherently medical about dying. It's much larger than medicine. It's purely human. Part of the mission is to keep all of this couched in humanity, not medical science, or social science, but really a full arc of humanity. Kindness, total openness, vulnerability, exchange.”

BJ MILLER, MD,
END GAME

End Game is about one thing we all share as human beings—the experience of death and dying. Many of us will be called on to be caregivers at some point in our lives, and many of us will be patients. As advances in medicine continue to develop, treatments and technology to sustain and extend our lives are allowing people to live longer with serious and chronic illness. And yet creating the space to talk about death and our values around end-of-life care is, more often than not, stressful and emotionally difficult. Fear of the unknown or of saying the wrong thing, or the belief that talking about it makes it happen, can prevent the topic from ever coming up until a health crisis occurs.
The filmmakers behind *End Game* have developed three resources:

- **General Discussion Guide** for community screenings with general audiences
- **A Clinician’s Guide for Screening *End Game*** for medical professionals in the palliative care field
- **Family Support & Discussion Guide** to support conversations on palliative care and end-of-life decisions within families

This Discussion Guide was created in partnership with the Florida Blue Foundation to support community discussions of *End Game*. Additional funding for *End Game*’s impact campaign is provided by the Cambia Health Foundation and the Stupski Foundation to support community discussions of the film. This resource reflects the work and vision of palliative caregivers and the intimacy we see take place between them, their patients, and their patients’ families at the University of California San Francisco (UCSF) Medical Center and at Zen Hospice Project. We hope that watching and discussing *End Game* will be an effective and meaningful step in changing the cultural paradigm and institutional practices around death and dying. We also hope this film will advance the understanding and use of palliative care.
“End Game urges viewers to think about our last days on Earth not as a heartbreaking tragedy but as an opportunity for true closure.”

THE NEW YORK TIMES

End Game weaves together three stories of visionary medical providers who practice on the edge of life and death, helping to change the way we think about both:

- The palliative care team at UCSF Medical Center, the most sophisticated acute care hospital in Northern California
- Zen Hospice Project, a unique mindful caregiving residential hospice
- BJ Miller, MD, a palliative care specialist who has worked with both UCSF and Zen Hospice Project

For many people the word “palliative” is unfamiliar and “hospice” is a code word for dying. This core group of caregivers in San Francisco see it differently. They are dedicated to relieving suffering and to changing the way we think about—and make choices about—how we live our lives as we near life’s end. Their commitment is vividly embodied in their interactions with terminally ill patients. These intimate and often highly charged emotional moments with caregivers, patients, and patients’ families and loved ones are at the heart of End Game.
MESSAGE FROM THE FILMMAKERS

We’ve discovered a subculture that we didn’t know existed, and that few people know about: people who devote their time and professional lives to relieving other people’s suffering. It’s the kind of suffering all of us will go through eventually, in one way or another.

Here is a group of people whose job it is to help us through this. They come out of medical and mindful caregiving specializations that are mere decades old. We wanted to learn who these caretakers were and where they came from.

At UCSF, we embedded ourselves with a team of palliative care doctors, nurses, social workers, and nondenominational chaplains, whose mission it is to help their seriously ill patients—and their families—make smart decisions about living and dying. We were honored to be present to film a family going through the last two weeks of the life of a much loved family member—a forty-four-year-old mother with an eight-year-old son. It was devastating, at moments almost unbearable, at times transcendent and sublime. The physical environment couldn’t have been more different than at Zen Hospice Project, but a similar spirit of loving care permeated even this institutional setting.

When we first approached Zen Hospice Project at their residential hospice, the Guest House, a primal reaction kicked in: dread. But entering this peaceful, lovely remodeled San Francisco Victorian home was anything but dreadful. Music was playing. Calm prevailed. The kitchen was preparing individual meals for current residents who had days to weeks or months to live, and knew it. They all seemed so taken care of by Zen Hospice Project’s mindful caregiving approach.

Many of these people didn’t start preparing early enough. People don’t like to think about end of life. It’s like putting away money for retirement when you can’t imagine retiring or even getting older.

We have a choice about how we leave this world. And to make the choice, we have to think and talk about it. That’s what we hope this movie will encourage and inspire.

- Rob Epstein and Jeffrey Friedman
Directors of End Game
WHAT IS PALLIATIVE CARE?

One priority for screening *End Game* in community settings is to inform audiences about the options available for palliative care, one of which is hospice. It is important that facilitators emphasize from the beginning the distinction between palliative care and hospice. Palliative care is quality-of-life care for people with serious and chronic illness, and hospice is a resource for people facing end-of-life decisions with a terminal prognosis of six months or fewer.

It is also important in any screening of *End Game* for audiences to begin the conversation with a shared understanding of terms used in the film. Depending upon your audience and setting, you may want to give an overview of the information included in this section or have it on hand as a reference. The glossary at the end of the Discussion Guide can also be a helpful tool.

DEFINITION

Palliative care is medical care focused on improving the quality of life for people with serious illnesses. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. It prevents or treats symptoms and side effects of disease and treatment, including emotional, social, practical, and spiritual needs that illnesses can bring up. When people feel better in these areas, their quality of life improves.

Palliative care can be given when the illness is diagnosed, alongside treatment meant to cure or treat the disease, during follow-up, and at the end of life. While receiving palliative care, people can remain under the care of their regular doctor and still receive treatment for their disease. Currently, to become a palliative care physician, a one-year clinical residency is required with physicians who specialize in palliative care from ten different medical specialties.

TEAM APPROACH

Palliative care is provided by an interdisciplinary team of clergy, social workers, physicians, nurses, volunteers, and caseworkers who provide emotional, psychological, and spiritual support as well as medical care for patients and their families. Age is not a factor in receiving palliative care, and palliative treatments are appropriate for any chronic or serious illness.

CURRENT APPROACH TO PALLIATIVE CARE ALONGSIDE ANY TREATMENT FOR YOUR ILLNESS

![Diagram showing the focus of care over time for palliative care, disease-focused treatments, hospice, bereavement, and death.](source: Dr. Steve Pantilat, UCSF)
WHAT IS HOSPICE CARE?

“We exist in a culture that is death-denying. We’re conditioned to avoid looking at our own mortality. Cultivating a relationship to death means contemplating all our losses, relationships that end as our kids age, changing jobs, losing the keys — how do you react. All offer openings—what are we resisting when we think about our own mortality?”

-ROY REMER, DIRECTOR OF EDUCATION AND TRAINING, ZEN HOSPICE PROJECT

DEFINITION

Hospice is one program under the umbrella of palliative care. It is designed to provide palliative care and emotional support to the terminally ill in a home or homelike setting so that quality of life is maintained and family members may be active participants in care.

Currently, the majority of at-home hospice or hospital costs are covered by the Medicare hospice benefit. However, residential hospice and long-term care may not be covered. Every year, 45% of Americans who die make use of hospice. Of those Americans who enroll in hospice, 15% graduate from hospice: they stabilize or get better. Hospice care does not necessarily mean the end of a life. Patients can transition out of a hospice facility and be cared for at their home or re-engage in treatment.

In End Game, we see an example of hospice care at Zen Hospice Project. Throughout the world there are many other models caring for and supporting individuals and families at this stage of their life.

HOSPICE CARE PROVIDES:

- Support for the patient and the family
- Relief to the patient from pain and symptoms
- Help for family members and loved ones who want to stay close to the dying patient
- Care in the home, in a hospital, residential hospice facility, or long-term facility with 24-hour nursing care
"If you're seriously ill, the best way to improve your odds is by thinking about your wishes in advance and telling your loved ones what you want. Find the time to let them know what's most important to you. Explain how you would like to live, be treated, and die, and even what you want done with your body after you die. Although these conversations are difficult and awkward, they're necessary. Without them, the care you receive won't be the care you want."³⁸

-STEVE PANTILAT, MD

**REASON 1:**

It is very important to discuss your values with family or loved ones and to write down your wishes about palliative care before a crisis occurs.

Dr. Pantilat’s recommendations are supported by a 2011 California Health Care Foundation survey:

- 67% of adults surveyed felt it was extremely important not to financially burden their families with their care
- 66% wanted to be comfortable and without pain
- 61% emphasized being at peace spiritually
- 60% did not want to burden their families with difficult decisions⁹

Yet despite these clear preferences, 56% of respondents had not communicated their wishes and 44% said the preferences of their deceased had not been followed even when they had communicated their wishes.¹⁰
REASON 2:

Palliative care improves the quality of life for individuals and families living with a serious chronic illness, but most people are not aware of what palliative care includes.

In 2010, The New England Journal of Medicine published a landmark study on palliative care. Led by Dr. Jennifer Temel at Massachusetts General Hospital, 151 newly diagnosed individuals with incurable lung cancer were divided into two groups. One group received palliative care alongside their chemotherapy, while the other got only chemotherapy. The study found that the patients who received palliative care with their curative treatments lived longer by almost three months. They had reduced pain and shortness of breath, relied less on antidepressants, led happier lives, and had a better quality of life. Families have also reported positive outcomes with palliative care during their bereavement.

REASON 3:

The United States will increasingly need trained palliative care medical professionals and facilities.

It is projected that the U.S. senior population on average will grow 49.5% by 2030. Twenty-five states will see increases greater than 50%. In other words, one in five Americans will be a senior citizen—twice today’s number. This will be one of the largest populations of senior citizens in our nation’s history, stretching our current health care system, particularly in end-of-life care and treatments, and testing our economy in unprecedented ways.

REASON 4:

Palliative care makes sense economically.

- The seriously ill constitute only 5-10% of patients, but account for more than half of the nation’s total health care costs.
- The 10% of Medicare beneficiaries with five or more co-morbid illnesses, or illnesses occurring at the same time, account for two-thirds of total Medicare spending.
- The 4% of the sickest Medicaid beneficiaries account for 48% of total program spending, while 76% of the national Medicaid budget goes to acute hospital services, which is the most expensive setting of care.
ROAD MAP FOR A SCREENING AND DISCUSSION

BEFORE SCREENING: FACILITATOR TIPS

○ RESEARCH AND PREPARATION:
Prepare yourself by viewing the film and reading the guide before your event.

○ READYING THE PHYSICAL SPACE:
Create a circle, if possible, to encourage dialogue, or use other strategies to engage the group in conversation.

○ INTRODUCTIONS AND GROUND RULES:
Introduce the intention of the conversation and set the general norms for fostering inclusive dialogue, respectful listening, and emotional support. These public conversations may be emotionally difficult and make participants feel vulnerable.

○ LISTEN TO WHAT YOUR AUDIENCE KNOWS:
Begin your screening event by asking the group what they know about palliative care. Use their responses as a jumping-off point to define terms and clarify any misunderstandings.

It is always helpful to know who is in the room and how familiar they are with the kinds of stories told in the film. We recommend starting End Game screenings by asking participants to raise their hands if:

• Your professional field is related to the film
• You are a layperson interested in learning more about palliative care
• Someone you know has recently died and was the beneficiary of palliative care and/or hospice care
• Another reason brought you here

AFTER SCREENING: ENGAGEMENT AND DISCUSSION STRATEGIES

○ TRANSITION TO DISCUSSION:
Bridget Sumser, LMSW, a clinical social worker with the Palliative Care Program at UCSF, has been part of several screenings of End Game and shared this insight about one of them: “When the film is over, everyone is crying. There is a moment where the audience is trying to shift from emotion to the thinking brain and this is hard. And in this particular screening, these were largely professionals working in this field.”

Sumser offered these recommendations:
1. Ask people to stand up, take a breath, and not to bypass their body’s response.
2. In a low-pressure, popcorn-style conversation, encourage each person to share a word or a feeling that came up for him or her during the screening.
3. Invite the group to share more of their feelings before moving on to their thoughts about the film.

○ ENGAGE WITH THOUGHT LEADERS:
End Game introduces us to the tremendous work happening at UCSF and at Zen Hospice Project. Thankfully, many institutions and leaders in palliative care generously share their scholarship and experience in the field through books, videos, journal articles, and film.

The “Engaging with Thought Leaders” section of this guide invites audiences to engage more deeply with the voices of leaders in the palliative care field through two of the central topics in End Game: “Using Patient-Centered Care” and “Open and Honest Conversations about Death and Dying.”

Each section includes:
• A question to begin discussion
• Compelling perspectives from clinicians and thought leaders to spark further engagement
• Discussion prompts inviting audiences to delve into conversation and reflection
OPENING QUESTION

When you hear the term “patient-centered care,” what does it mean to you? What do you think it includes?

- BRIDGET SUMSER, LMSW, UCSF ADULT PALLIATIVE CARE SERVICE

“Medicine is the business of keeping people alive. People are aware of and struggling with the reality that one quarter of Medicare funds are spent in the last year of life. That doesn’t leave anyone feeling good. For example, there might be a 96-year-old individual on a ventilator in the ICU because we didn’t talk about what was most important to her before her condition became critical. Now, when emotions are high, the conversation is acutely about death for the first time, even after ten years of illness. Most providers don’t have the tools or the time to talk to people about what is most important to them, relate these values to the medical choices available to them, and then communicate their options.”

- STEVE PANTILAT, MD

“Giving clear directions is a gift, an act of love. Your loved ones may have to make agonizing decisions at the worst, most highly charged emotional times. Not expressing your wishes will leave them guessing, and they could guess wrong... Clear directives help to avoid potential problems that could divide your loved ones... cause confusion and cause family disputes that can be gut-wrenching, costly, and divisive.

Doctors are trained to keep patients alive and emergency rooms and hospitals do everything to keep you going—unless you make it clear that you want something different. Without clear directives that state your preferences, you could be subjected to unnecessary pain, discomfort, and financial costs. Advance health care directives and a forceful advocate to speak on your behalf are the best ways to make sure that your wishes will be respected.”

- CONSIDER THESE STATISTICS FROM STANFORD UNIVERSITY:

- Approximately 80% of Americans would prefer to die at home, if possible.
- However, 60% of Americans die in acute care hospitals, 20% in nursing homes, and only 20% at home.
- Over 50% of Americans die in pain.
- Less than half of dying patients use hospice care, and even those patients are often referred to hospice only in the last three to four weeks of life.
- 30% of families lose most of their life savings while caring for a dying loved one.

- THE 2013 PEW RESEARCH CENTER “VIEWS ON END-OF-LIFE MEDICAL TREATMENTS” REPORT:

- 57% say they would tell their doctors to stop treatment if they had a disease with no hope of improvement and were suffering a great deal of pain.
- About half of this group (52%) say they would ask their doctors to stop treatment if they had an incurable disease and were totally dependent on someone else for their care.
- A third of adults (35%) would tell their doctors to do everything possible to keep them alive even in dire circumstances, such as having a disease with no hope of improvement and experiencing a great deal of pain.
DISCUSSION PROMPTS

• After watching *End Game* and reviewing these statistics, what does it mean to die on your own terms?
• What words or statistics were particularly troubling, illuminating, or confusing to you?
• What story do the statistics tell?
• In *End Game*, we see an exchange between Dr. Pantilat and Vaji, Mitra’s mother, that speaks to an important aspect of palliative care. Read the dialogue and discuss what this conversation reveals about patient-centered care:

  Dr. Pantilat: "The way we approach this is really trying to get back to Mitra. And if she was clear in her thinking, seeing herself in the bed, the way she is right now, what decision would she make about the treatment?"
  Vaji: "She didn’t like that. She wouldn’t like that."
  Dr. Pantilat: "She wouldn’t take the treatment, you think? But Hamid [Mitra’s husband] thinks she would."
OPENING QUESTION

If you were to describe your relationship with death in your life, what words come to mind? How would you explain your values and wishes about end-of-life care to your family or loved ones?

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**SHOSHANA UNGERLEIDER, MD**

Recalling an experience from her second year of medical internship:

“I wasn’t precisely sure what pronouncing a patient dead entailed. When I reached room 556, I entered to find a frail woman lying still on the bed. Mrs. Lee. She was surrounded by family members young and old, and, to my amazement, they were smiling, chatting, even laughing with one another. I mumbled a greeting, then crossed to the bed, where I proceeded shakily through the pronunciation checklist in my intern handbook.

One of Mrs. Lee’s daughters touched my hand. “This is my mother, she was a wonderful woman but had a long battle with Alzheimer’s, and it was time for her to go,” she said. “She just wanted to be comfortable in the end.”

The other family members nodded in agreement and went on talking about how much they had loved Grandma Lee’s custard buns and who would be getting her recipes. Mrs. Lee’s family and friends who had gathered around her to say goodbye moved me. Mrs. Lee had had the forethought to tell them how she wanted to pass, and they were by her side until the end. I had never before pondered the idea of a ‘good death,’ but that night I walked out of room 556 with a smile on my face, because, somehow, I had just witnessed one.”

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**BJ MILLER, MD**

“ ‘Friends with death’ may be pretty tough, but maybe what I more meant would have been to have some sort of relationship with this subject. It doesn’t need to be friendly at all. Just so that it’s less scary than this unknown thing in the closet that we never look at, never see, never touch... Because I don’t think that from where I sit, I’m not sure that we can know what it’s like to be dead from here... So, given that that’s not possible, next up would be: okay, if we can’t change that, well, maybe we can get used to it a little bit. So in terms of the ‘dead’ part, maybe our goal is to hold this idea of not knowing, holding the mystery.”

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**GEORGE KELLAR, EXECUTIVE DIRECTOR, ZEN HOSPICE PROJECT**

“Every month Zen Hospice Project brings people together from around the world for what we call our Open Death Conversations. People from all backgrounds attend our conversations, young, old, many people who have not had experience with death, some people who are facing their own end of life. We have no agenda other than to generate meaningful, energetic conversation free from judgment.”

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*I think the scary part is the unknown and the lack of control.*

- THEKLA HAMMOND, END GAME
DISCUSSION PROMPTS

Choose one or more of the perspectives included in this section that speaks to you and share why it is meaningful.

- Do you think there are stigmas and taboos around discussing death? Why?
- Is there such an experience as a “good death”?
- What resources or education would you want to have to prepare yourself for an open and honest conversation about how you want to die if facing a serious illness?
“By facing mortality, it seems to inform how you live. So, the secret is that facing death has a lot to do with living well.”

-B.J. MILLER, MD

End Game tells the stories of individuals, families, and health care professionals who model courage and compassion in the face of one of life’s most difficult experiences. Their stories are also a reminder to take the steps to ensure all our health care values and priorities are written down and communicated with physicians, family members, and other loved ones throughout our lives.

Consider these objectives in conversations about your own end-of-life care:

Advance Care Planning: Expressing and writing down our values around palliative and end-of-life care while healthy and not in crisis.

Goals of Care: Clarifying goals and identifying care and treatment that will help achieve these goals. As people get sicker, decisions about treatment are more immediate, and goals of care will guide treatment.

This section offers audiences resources on palliative and end-of-life care.
ADVANCE CARE PLANNING

**ADVANCE CARE DIRECTIVE:**
This legal document, called different things in different states and when used for different purposes, is used to provide family members and caregivers guidance on treatments in case of a future medical emergency. The directive can also be used to designate surrogates, or individuals who can speak for and make decisions for patients who are no longer able to do so themselves. All adults should have an advance directive and revisit their wishes over time. Be specific about what you want and don’t want. For example, I don’t want a feeding tube, but I do want pain medications.

Remember to give copies of your documents to everyone involved in your care along the way—family members, proxies, and health care providers. Don’t assume they will share this paperwork. You can change your decisions at any time, but be sure to tell everyone involved if you do. Copy, save, and share the new documents with your team.

**PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) FORM:**
This also has different names in different states, and while forms are state-specific, they cover the same information. Basically, POLST forms are formal physician’s orders worked out in advance with a patient or a patient’s advocate that detail the specific medical treatments a person wants, or does not want, during a medical emergency. POLST forms are appropriate for individuals with a serious illness or advanced frailty near the end of life. A POLST form does not replace an advance directive but they work together. It is important to complete both forms. Go to polst.org for more information.

CLARIFYING GOALS OF CARE

**GOLDEN QUESTIONS:**
Dr. Pantilat recommends spending time discussing and gaining clarity on what he calls the “golden questions” for individuals and families facing decisions on palliative or end-of-life care. The conversation and the emotions your answers elicit can help inform future decisions on the kinds of care most appropriate for your values and most helpful for you to achieve your goals.

“When you think about the future, what do you hope for?”

“When you think about what lies ahead, what worries you the most?”

**CHOOSING AND COMMUNICATING WITH YOUR SURROGATE:**
This will be the person who will speak on your behalf when you are unable to speak for yourself. Choosing your surrogate may be one of the most important decisions you make about palliative or end-of-life care. If you don’t choose a surrogate, or a committee (e.g., my three children), doctors will look to the family to make decisions. Your doctor cannot be your surrogate, nor can any person working for your doctor or in a care facility unless they are related to you by blood. Consider these criteria in selecting your surrogate:

- You can trust them to carry out your wishes.
- You know them well and have spoken to them about your preferences and goals.
- They will be available when needed.

**DISCUSS AND REFLECT ON YOUR QUALITY OF LIFE:**
Dr. Steve Pantilat suggests asking yourself these questions:

- What does quality of life mean to me?
- What gives me quality of life?
- What is the most important to have in my life in order to give it quality?
- What would make me think that I no longer have a good enough quality of life?

Write down your answers, and think about them as you define your own quality of life, particularly in relation to treatments for illness.

GOAL SETTING AND COMMUNICATION RESOURCES

**GO WISH**
An entertaining card game to help you find the words to talk about your values and what would be important to you if you were living with serious or chronic illness www.gowish.org

**DEATH OVER DINNER**
An interactive set of tools to help families and friends communicate their wishes about how they want to die www.deathoverdinner.org

**THE CONVERSATION PROJECT**
Tools to support discussion of end-of-life care www.theconversationproject.org
ADVANCE CARE DIRECTIVE
A general term that describes two kinds of legal documents, living wills and medical powers of attorney, which enable people to give instructions about future medical care should they become incapacitated or too ill to make medical decisions. Each state regulates the use of advance directives differently.

CAPACITY
In relation to end-of-life decision making, a patient has medical decision-making capacity if he or she can understand the medical problem and the risks and benefits of the available treatment options. The patient’s ability to understand other, unrelated concepts is not relevant. “Capacity” is frequently used interchangeably with “competency,” but the two concepts are different. Competency is a legal status imposed by the court.

DIGNITY
The Oxford English Dictionary defines “dignity” as the state or quality of being worthy of honor and respect. Dr. Pantilat asks, “But what does dignity mean in the context of serious illness? For some it means that life is sacred, and [that] they should maintain life for as long as possible even if it takes the assistance of machines and even if they can no longer speak or interact. For others, being connected to machines in the ICU and unable to engage with the world would be a complete loss of dignity.”

HEALTH CARE SURROGATE
A health care surrogate (HCS) is a person selected by a patient to advocate on his or her behalf. An HCS can be appointed by a doctor or nurse if there is no existing medical power of attorney and the doctor determines that the patient cannot make medical decisions. The surrogate may be a relative or friend, but there are hierarchies of consideration. A spouse would likely be appointed before an adult child, but the doctor also considers the ability of the person to make decisions, the kind of relationship, and the candidate surrogate’s level of concern. If there is no suitable relative or friend, the appointed health care surrogate may be unknown to the patient, someone from the hospital or an agency. In either case, the HCS will make decisions based on the patient’s “best interests,” but without an advance directive to guide them, they are likely to be affected by a personal bias or influenced by the philosophies of the institution for which they work.

HOSPICE
Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support tailored to an individual’s needs and wishes. Support is provided to the person’s loved ones as well.

LIVING WILL
A living will is a type of advance directive in which individuals document their wishes about medical treatment should they be at the end of life and unable to communicate. It may also be called a “directive to physicians,” “health care declaration,” or “medical directive.”

MEDICAL POWER OF ATTORNEY
Medical power of attorney is a legal document that authorizes someone selected by a patient to make decisions about their medical care should they be unable to communicate. This is a type of advance directive that may also be called a health care proxy, durable power of attorney for health care, or appointment of a health care agent. The agent only has this authority if it is determined by a doctor that a patient is incapable of making such decisions, or they are unable to communicate your wishes.
PALLIATIVE CARE
This field of medicine focuses on quality of life for patients and their families facing serious illness. Palliative care can be used at any time during the course of the illness, not just at the end of life. It is simply about comfort and living well at any stage.

PHYSICIAN-ASSISTED DEATH
As of 2018, seven states have passed legislation allowing mentally competent adults who have a terminal illness with a confirmed prognosis of six or fewer months to voluntarily request and receive prescription medicine to hasten the end of their lives. The legislation ensures that patients are the primary decision makers.

PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT FORM
POLST forms are formal physician’s orders worked out in advance with a patient or a patient’s advocate that detail the specific medical treatments a person wants, or does not want, during a medical emergency. POLST forms are appropriate for individuals with a serious illness or advanced frailty near the end of life. A POLST form does not replace an advance directive but they work together. It is important to complete both forms. Go to polst.org for more information.

POWER OF ATTORNEY
The general POA is a different document from the MPOA, and the courts do not automatically assume that someone with a medical POA would have any control over a patient’s finances.
REFERENCE INFORMATION FROM END GAME

- UCSF Palliative Care Unit
- BJ Miller, MD
- Shoshana Ungerleider, MD
- Zen Hospice Project

ORGANIZATIONS

- American Bar Association Advance Directive Toolkit
  www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html
  Resources to support advance planning for health care

- California Health Care Foundation: Community-Based Palliative Care
  www.chcf.org/resource-center/community-based-palliative-care
  Materials designed to assist organizations when planning, implementing, or enhancing their community-based palliative care services

- Center to Advance Palliative Care (CAPC) and National Palliative Care Research Center
  A 2015 state-by-state report card on access to palliative care in our nation’s hospitals

- Coalition for Compassionate Care of California
  www.coalitionccc.org/tools-resources/endgametoolkit
  A screening toolkit to support organizations hosting events for End Game

- Coalition to Transform Advanced Care
  www.TheCTAC.org
  A nonprofit, nonpartisan organization that advocates on behalf of individuals with serious illness

- The Conversation Project
  www.TheConversationProject.org
  Tools to support discussion of end-of-life care

- End Well
  www.endwellproject.org
  An interdisciplinary gathering of design, tech, health care, and activist communities working on human-centered innovations for the end-of-life experience

- Get Palliative Care
  www.getpalliativecare.org
  Articles, podcasts, videos, and webinars about palliative care

- Hospice Action Network
  www.hospiceactionnetwork.org
  An organization that advocates for policies that ensure the best for patients and families facing the end of life

- Mindful Caregiver Education
  www.zenhospice.org/mce

- Open Death Conversation
  www.zenhospice.org/odc
  Resources on workshops to facilitate and support conversations on death and end-of-life care

- Vital Talk
  www.vitaltalk.org
  A nonprofit organization that disseminates clinician and faculty development courses to improve communication between patient and clinicians

- Zen Hospice Project Blog
  www.zenhospice.org/blog
VIDEO

- BJ Miller’s TED Talk
  www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life

- Shoshana Ungerleider, MD
  www.shoshanaungerleider.com

- “Palliative Care: You Are a Bridge”
  www.youtube.com/watch?time_continue=100&v=lDHhg76lMhc

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OTHER RESOURCES USED IN END GAME DISCUSSION GUIDE

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  www.npr.org/programs/death/971107/death.html
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- The Pew Research Center, “Views on End-of-Life Medical Treatments”

- Pantilat, Steven Z., Life after the Diagnosis: Expert Advice on Living Well with Serious Illness for Patients and Caregivers

- Nutik Zitter, Jessica, MD, Extreme Measures: Finding a Better Path to the End of Life
2. These include Internal, OB-GYN, Family, Pediatrics, Emergency, Psychology, Neurology, Anesthesia Surgery, Physical/Rehabilitative medicine.
4. Including cancer, ALS, heart disease, Alzheimer’s, Parkinson’s. Adapted from public opinion survey conducted by ACS CAN and CAPC.
10. Ibid.
13. From an interview conducted with Bridget Sumser, April 11, 2018.
14. From an interview conducted with Bridget Sumser, April 11, 2018.
15. Pantilat, 227.
20. Excerpted from End Game.
“End Game urges viewers to think about our last days on Earth not as heartbreaking tragedy but as an opportunity for true closure.”

-THE NEW YORK TIMES
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