Changing the Way Families Think about Living and Dying Members

FAMILY SUPPORT AND DISCUSSION GUIDE

SOMETIMES THE ONLY CHOICE IS HOW YOU FACE IT.
3 INTRODUCTION
4 About the Film
5 Where to Start: Exploring Your Role
6 USING THE FAMILY GUIDE WHEN SCREENING END GAME
7 Planning for end-of-life care before an illness occurs
8 An entry point to talk with family when facing end-of-life care decisions and care preferences
9 Saying goodbye
9 For grieving families seeking comfort through listening to the stories of others
10 For individuals supporting families during end-of-life care
11 CLOSING REFLECTION
"There’s no right or wrong answer here. You know, some families, some patients in this situation will say, 'I want to be home. I want to be with my family. I want to figure out how to get good caregiving at home, I don’t want more treatment,' and it’s a very legitimate decision. And there are other people in this situation who will say, 'If there’s a medicine that might make my symptoms a little better, might help me live a few more weeks, I would like to give it a try.'"

STEVE PANTILAT, 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 family 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 also allowing people to live longer with serious and chronic illness. And yet creating the space to talk about death with family and loved ones and sharing our values around end-of-life care are, 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.

This Family Guide for *End Game* was created to further 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 a supportive and helpful tool for your family.

We are grateful to the Florida Blue Foundation for supporting community discussions of *End Game*. We are also grateful to the Cambia Health Foundation and the Stupski Foundation for their support of *End Game*’s impact campaign.
**About the Film**

*End Game*, a forty-minute observational documentary film by the Academy Award-winning team Rob Epstein & Jeffrey Friedman, 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. These medical providers are:

- The palliative care team at [UCSF Medical Center](https://www.ucsf.edu/), the most sophisticated acute care hospital in Northern California
- [Zen Hospice Project](https://www.zenhospice.org/), a unique mindful caregiving residential hospice
- [BJ Miller](https://www.bjmillermd.com/), 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 code 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 their terminally ill patients. These intimate and often highly charged emotional moments with caregivers, patients, patients’ families, and loved ones are at the heart of *End Game*. 
End Game reveals the very intimate experience of individuals and families as they navigate end-of-life decisions and care with the support of palliative care teams in a hospital setting and in a residential hospice facility.

Bridget Sumser, a UCSF clinical social worker who cared for Mitra, described the high level of trust in their relationship:

The palliative care service at UCSF was able to work with and support Mitra and her family for eighteen months before the scenes you see in End Game. During this time, the team assisted with symptom management and emotional support as Mitra and her family lived with constant change. We explored activities central to Mitra’s sense of self, including her role as a mother and wife, what a good-enough day looks like, how to talk to family about how Mitra’s illness was evolving (including their son and other young family members), how to take care of oneself as a caregiver, how to manage the demands of a household and work life when being at the hospital demands most attention. We also relished small things: the opportunity to connect with one another (family members and providers) on a daily basis, the power of gratitude and humor, the sensory experiences of sunlight, favorite foods, and visitors. Our time together allowed us to consider and hold the most existential elements of being human and being alive, as well as the everyday experiences that create our lives.1

WHERE TO START: EXPLORING YOUR ROLE

"Until end of last breathing, I want to be with my baby, and I can take care of her either here or at home. I don’t care."

- VAJI, MITRA’S MOTHER, END GAME

RESOURCES TO EXPLORE CAREGIVING

Family Caregiver Alliance is an organization and website with tip sheets and a “family care navigator” with links to services, programs, and resources for caregivers by state.

Losing a Puzzle Piece is a website and blog that supports sibling caregivers. It was created by two sisters who lost their older sister to cancer at the age of thirty-nine.

National Alliance for Caregiving is an organization and website covering it all: caregiving advocacy, research, resources, and news.

Stupid Cancer is an advocacy and support organization that provides a voice for young adults with cancer as well as their caregivers, and promotes awareness of age-appropriate resources.

Working Daughter, a blog offering support and information to caregivers, focuses on caring for aging parents but speaks to the challenges of all types of caregivers. The blog addresses balancing caregiving while managing work and the rest of your life.2
"Palliative care goes much further than physical care. It is a holistic approach that improves the quality of life for patients and their families by addressing the psychosocial, legal, and spiritual problems associated with life-threatening illness."

- OPEN SOCIETY FOUNDATION

This guide includes discussion and resources to help you learn more about:

- Planning for end-of-life care before an illness occurs
- Talking with family when facing end-of-life care decisions
- Saying goodbye
- Seeking support for grief
- Supporting families during end-of-life care
PLANNING FOR END-OF-LIFE CARE
BEFORE AN ILLNESS OCCURS

“We exist in a culture that is death-denying. We’re conditioned to avoid looking at our own mortality. But death is a natural part of life; we all die. We can try to stop or slow it, but to avoid it is impossible. If we can accept for all of us that we’ll all die and death is part of life, the question then is how do we want to live until we die?”

- ROY REMER, ZEN HOSPICE PROJECT

In our culture, death is a taboo topic. Discomfort, lack of language, or a fear that talking about it will make it happen, among other reasons, keeps us from discussing end-of-life medical care and death until they start to happen. It’s incredibly helpful to everyone involved to find a way to discuss your values regarding life and medical care before you or someone you love faces these decisions, especially in a time of great stress and hardship.

Watching End Game together provides an opportunity for this discussion.

Creating a record of your wishes in the form of an advance directive or physician orders for life-sustaining treatment (POLST) will help ensure that your values and desires are honored.

ADVANCE CARE DIRECTIVES

Advance directives are legal documents that designate a medical decision maker for you and inform loved ones and care providers of your wishes if you get sick or injured, or otherwise can’t make medical decisions for yourself. Creating an advance directive does not lock you into decisions. If you are able to make your own decisions, you can change your mind at any time, and hospitals are not required to honor them if the circumstances do not make sense. Advance directives do, however, offer a helpful guideline to follow.

RESOURCES TO HELP PLAN FOR END-OF-LIFE CARE

The Conversation Project is a nonprofit organization with a mission to improve end-of-life care for every American through conversations with our loved ones about our wishes. A free Conversation Starter Kit in multiple languages is available through their website. This project is funded in part by the Cambia Health Foundation.

PrepareForYourCare.org is a free resource for creating an advance directive. Videos on the website offer examples of why advance planning matters, and ideas for conversations. Steve Pantilat, MD, who is featured in End Game, was on the advisory board for this project.

MyDirectives.Com walks individuals through creating an advance care plan, then stores the information for sharing with providers and others.

Physician orders for life-sustaining treatment (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, and it is important to complete both forms. POLSTs look different in different states. Visit www.POLST.org for your state’s form.
The Family Guide for End Game aims both to inform audiences and to correct misinformation about palliative care and hospice. Throughout the film, we hear differing opinions about hospice, ranging from an understanding and acceptance of the support and care it offers to patients and family members, to strong resistance and equating hospice with giving up or imminent death.

**PALLIATIVE CARE AND HOSPICE**

It is critical to understand that all hospice care is palliative care, but not all palliative care is hospice. Palliative care is quality-of-life care for people with serious and chronic illness. Or as Dr. Pantilat explains, “To live as well as possible for as long as possible.” Hospice is a resource for people facing end-of-life decisions with a terminal prognosis of six or fewer months. Palliative care can be given when the illness is diagnosed, throughout treatment, during follow-up, and at the end of life. While receiving palliative care, people can remain under the care of their regular doctor and continue receiving treatment for their disease.

Hospice is not a place; rather, it is a program that provides care wherever patients live. The goal of hospice is to improve the quality of life for patients and their families by addressing their physical, emotional, psychological, and spiritual needs. You do not have to choose between palliative care and hospice. You can have both.3

“To have received the proper training we wanted [as caregivers of our sister], it likely would have required more time enrolled in hospice. Sadly, our story is not unique and many patients (35%) are enrolled in hospice less than 7 days, and many more for less than 30 days (62%), according to data from the Medicare and Medicaid services.”4

-Jessica and Shane, Losing a Puzzle Piece

“Just so you know, I had some conversation with her [Mitra] and her mother [Vaji] exactly about that, and her mother came outside the room afterwards with me and said basically, ‘Hospice means death. Do not talk about it with her.’”

- DENAH JOSEPH, CHAPLAIN, END GAME

“At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.”

- NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

More often than not, we read of families wishing they had accessed hospice support earlier, at least at the time of diagnosis. Research has shown that hospice patients live longer and have an improved quality of life during hospice.5 As you look into hospice, keep in mind the four levels of care available to you:

- **Routine care:** Provided in the comfort of your home wherever you may live—assisted living, a nursing home, or your own residence. A hospice nurse will coordinate all your care needs and medications with your primary physician.
- **Respite care:** Short-term care as a relief to caregivers who provide day-to-day support, respite care is usually provided at a nursing facility.
- **Continuous care:** Provided for short periods in your home when skilled nursing care is required to manage symptoms.
- **General inpatient care:** Provided for short-term stay in a residential hospice care center, nursing facility, or hospital when twenty-four-hour care is needed.

**RESOURCES FOR FURTHER LEARNING ABOUT PALLIATIVE CARE AND HOSPICE**

End Well is a multidisciplinary community bringing together design, technology, health, policy, and activist communities to reimagine end-of-life care and the experience of dying.

Get Palliative Care is an online resource with articles, podcasts, videos, and webinars aimed at informing individuals and their families about palliative care.

Hospice Action Network advocates for policies that ensure the best care for patients and families facing the end of life.

National Hospice and Palliative Care Organization is the largest nonprofit membership organization representing palliative and hospice programs.
SAYING GOODBYE

"Making friends with death may be pretty tough, but maybe ... to have some sort of relationship with it. 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."

- BJ MILLER, MD, IN END GAME

Acknowledging the feelings and seeking help from hospice staff or outside support systems can be difficult. Saying goodbye may be done in a variety of compassionate ways, including sitting quietly and holding hands, lying close together, or writing a letter saying what you need to say. Many families, even secular ones, seek the guidance and comfort of faith leaders or spiritual communities when coping with dying. A palliative-care approach encourages patient-centered religious choices and practices. Tears and feelings of loss are a normal and natural way of saying goodbye.6

The film End Game offers several moments and entry points to begin a conversation with a loved one or another supportive person. These conversations help with feelings that arise around the reality of illness and impending death.

RESOURCES TO BUILD AWARENESS AND HELP ENGAGE PEOPLE IN CONVERSATIONS ABOUT DEATH

Death Cafe is a website that connects people who want to talk about death with one another and offers tools to structure and facilitate conversations.

Death Over Dinner is a website that guides people through organizing a select group for conversation about death.

FOR GRIEVING FAMILIES SEEKING COMFORT THROUGH LISTENING TO THE STORIES OF OTHERS

"Grief ain't easy, but it can be poignant and gorgeous."

- BJ MILLER, MD, IN END GAME

The grief process happens differently for each person and each support system, and resources are needed at different times for different reasons. There are no clear stages, no order, and no right or wrong way to experience grief and loss.

End Game offers an opportunity for families to listen and reflect, and quite possibly find comfort through the stories and experiences of others.

RESOURCES TO HELP THOSE COPING WITH LOSS AND GRIEF

Grief.com provides all you may need to know about grief.

ModernLoss.com is a website offering candid conversations about grief through personal essays and other resources.

Open to Hope is an organization that seeks to give voice to grief and recovery, with resources such as articles and a radio show. The website has a section about hope after loss of a sibling.

The Compassionate Friends is an organization focused on grieving the loss of a child or young person. The website has a section on sibling grief, with links to brochures. The organization refers to siblings as "forgotten mourners."
“On a personal level, End Game is an opportunity to show people in my life what I do all day, the environment I’m in all day. This is my life, nobody in my family understands what I do all day.”

- BRIDGET SUMSER, LMSW, MEMBER OF THE UCSF PALLIATIVE CARE TEAM
ON WHAT IT WAS LIKE FOR HER TO SEE THIS FILM

For people who support families during end-of-life care, such as clergy, friends, or staff members in palliative and hospice care settings, it is important to pay attention to your own emotional needs and well-being.

RESOURCES TO FURTHER YOUR EDUCATION

www.endgame-documentary.com/resources
A Professional Development resource is available to help you use End Game in building skills around “Clarifying Myths and Misconceptions About Palliative Care,” “Patient-Centered Care,” “Connected Communication,” and “Self-Care in a Palliative Care Setting.”

Mindful Caregiving Education: Training resources are available from Zen Hospice Project for clinicians and volunteers who provide care in palliative care and hospice settings.

End Game can be part of your self-care and demonstrate your work to those who care for you. It is a reminder that you are not alone in your work.
Watch one of the final scenes in *End Game*—an exchange between Mitra’s husband, Hamid; her mother, Vaji; and Andrew Lai, MD—and hear the full spectrum of emotions from the family and the clinicians.

Consider the following scene in light of your own family’s discussions. We hope the stories in *End Game* will be a resource for you and your family.

<table>
<thead>
<tr>
<th>Name</th>
<th>Statement</th>
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</thead>
<tbody>
<tr>
<td>Andrew Lai, MD</td>
<td>We all want to make sure she doesn’t suffer, but at the same time we wanted to clarify what happens when she dies, and we’re going to be very blunt about that. When her time comes, when she does die, we’re going to continue to treat her well during that time, but we’d really strongly recommend allowing her to just naturally die on her own, and not attempt CPR, not try to put in a breathing tube, those kind of things.</td>
</tr>
<tr>
<td>Vaji (Mitra’s mother)</td>
<td>Naturally.</td>
</tr>
<tr>
<td>Hamid (Mitra’s husband)</td>
<td>It’s hard, but...</td>
</tr>
<tr>
<td>Andrew Lai, MD</td>
<td>It’s hard. And again, we hope nothing is going to happen anytime soon. We don’t anticipate that, but I think this was just another good, natural time to think about it.</td>
</tr>
<tr>
<td>Hamid</td>
<td>And I appreciate everybody’s help. Unfortunately, all these good things... still, Mitra is leaving us. And we believe in it now. I mean, I still believe in miracle[s], to be honest with you. This last medicine, I hope it works. I don’t want to let her go.</td>
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2. We would like to thank Losing a Puzzle Piece for recommending many of the resources in this guide.

3. From the Denver Hospice Patient and Family Guide. www.thedenverhospice.org, p. 5


6. Adapted from the Denver Hospice Patient and Family Guide. www.thedenverhospice.org
“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
End Game discussion guides were created in partnership with the Florida Blue Foundation to support community discussions of End Game. Additional support for End Game’s impact campaign is provided by Cambia Health Foundation and The Stupski Foundation Fund.