



END GAME

Event Planning Toolkit

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END GAME: About the Film

Filmed and edited in intimate vérité style, *END GAME* follows visionary medical practitioners who are working on the cutting edge of life and death – and dedicated to changing our thinking about both.

Directed, produced, and edited by Academy Award® winners Rob Epstein and Jeffrey Friedman.

Credits:

Directors	Rob Epstein & Jeffrey Friedman
Producers	Rob Epstein, Jeffrey Friedman, Rebekah Fergusson William Hirsch
Cinematographers	Rob Epstein & Rebekah Fergusson
Editors	Jeffrey Friedman & Rob Epstein
Executive Producers	Jason Spingarn-Koff, Zana Lawrence, Lisa Nishimura Shoshana Ungerleider, Steven Ungerleider, David Ulich
Co-Executive Producer	Jim Mittelberger
Assistant Editor	Cyrus Tabar

About this Toolkit and Community Screenings

This Toolkit is fashioned after one developed by the John and Wauna Harman Foundation and the California Health Care Foundation in their collaboration to support screenings of *Being Mortal* by organizations in communities throughout California. This toolkit is intended to support organizations in hosting successful events around the showing of *END GAME*.

Inside you'll find recommendations for engaging audiences, event planning tips, a sample agenda, discussion prompts, and other recommendations. Ultimately, you know best what will be most appropriate within your community and for the audiences you wish to reach, so feel free to pick and choose the resources inside that are most useful to you.

Netflix®, the owner of *END GAME*, is making the film available for FREE to community organizations for use in public screenings. **Netflix® has expressly forbidden community organizations from charging money for screenings of *END GAME*.**

END GAME: Project Goal & Event Outcomes

Project Goal

The aim of END GAME screenings is to engage a wide and diverse range of communities – multi-ethnic and cultural, in rural, suburban and urban settings —in conversations about end-of-life and end-of-life care. We hope that you will use this film as a tool to educate participants about the issues they might face as they near the end of their lives and to prompt them to consider and talk about the kind of care they would like to receive. Ultimately, we hope these screenings will help participants understand the importance of taking concrete steps to identify and communicate their wishes for end-of-life care so that they receive the care they need and no less, and the care they want and no more.

We believe that as a tool, this film can start a conversation or begin a relationship with an individual or group that might eventually lead to advance care planning. Please understand that behavior change and/or action is the result of a process that can begin with use of a tool like this, but will not end there. You may find that it requires multiple engagements with the same individual or group before they are ready to make a plan.

Don't be too goal (next steps) oriented.

Event Outcomes

The desired outcomes of a community screening in support of this goal may include:

- Increased knowledge of the complex emotional terrain surrounding serious illness and end-of-life.
- Dialog and reflection around end-of-life care.
- Increased interest in end-of-life care conversations and planning.
- Increased awareness and understanding of advance planning resources.
- A plan for personal “next steps” related to discussing and sharing end-of-life care wishes.

***END GAME*: Event Planning**

Community Partners

A great way to ensure you are reaching the desired audiences for your event is to partner with local organizations and leaders who are known and trusted by that community and who have experience working with them. Consider the following as a start: community centers, faith-based organizations, culture-based organizations, healthcare centers, hospitals, senior service agencies, caregiver support organizations, and colleges.

Including these groups in the planning process from the very start will not only help to broaden your reach, it can also help to ensure you are designing an event that is appropriate, relevant and respectful of this new audience. You will also be building important relationships for future collaborations.

Consider hosting a pre-screening of *END GAME* with representatives from your target audience so that you can get their reactions to the film, ideas for structuring the event, and engage them as champions for the event. In addition, explore options for community venues that are familiar and accessible to your desired audience.

Event Format Suggestions

Consider your audience and your desired outcomes as you choose a format for your event.

It may take a series of engagements with an audience to get to a desired outcome. You might want to plan a follow-up event in the weeks following a screening (allowing your audience to absorb what they have seen and heard) to delve deeper into the subject.

If you think it will be helpful to present perspectives and experiences that represent the communities you're engaging – or simply to localize the story — consider inviting a few speakers from the community to briefly share their stories. Be sure to hear the stories ahead of time to assure that they are on point.

A small group format for the after-film discussion is another option, and can allow for greater individual participation.

If you want this discussion to be facilitated, medical social workers, hospice chaplains, and palliative care staff often have the skills and experience to facilitate and may be willing to volunteer.

If it works better to have unfacilitated discussion, you can give people an opportunity

to break out into small groups to talk about a personal action plan and then rejoin the large group to have professionals answer any questions that came up about the next steps they can take.

The Advance Care Planning Checklist on page 18 may be useful for this part of the event.

Whatever format you decide on, try to keep your agenda as simple as possible. We've created a Sample Agenda (see page 9) for your convenience. Feel free to use it if it feels appropriate, or simply refer to it for ideas.

We've also provided sample Event Host Suggested Talking Points (see page 10) to help set the context for your event.

Technical Preparation for the Event

Well ahead of your event please visit this website to make arrangements to use the film:
<http://endgame-documentary.com/host/>

You will be asked to complete a form. The team will respond with more information about the technical details of hosting a screening in your community.

PLEASE DO THIS EARLY IN YOUR PLANNING PROCESS, so that you have plenty of time to make sure that the technical aspects of the event are in order.

You will need to verify that your proposed venue has the equipment and facilities needed for a comfortable and successful screening and discussion. This may include details like the laptop, projector, and screen; mics and speakers; and whatever configuration of tables and chairs suits your event format.

****Ahead of time, test the equipment you will be using the day of the event to catch any glitches. (This step is essential!)****

END GAME: Getting the Word Out

There are many ways to spread the word about your event. In general, using a combination of methods is the best way to reach a large number of people.

Some publicity pointers to keep in mind include the following:

The most effective outreach grows out of relationships - start there.

Simply asking community partners, “Where do your clients usually get their information about community events?” is a good place to start.

Ask each community partner you connect with, “Can you think of other community groups who might be interested in this topic?”

Take advantage of existing networks to help with publicity.

In addition to your partners’ networks and their recommendations above, see if local organizations like senior centers, hospices, caregiver resource centers, etc. would be willing to post your flyers and promote your event.

Check with established community networks such as interfaith councils to see if they would be willing to help spread the word.

Attend any relevant community events where you might be able to network and share your flyers.

Rely on more than one form of notification

Post the physical posters and flyers in high visibility areas.

Create email announcements and have other organizations forward them on to their email lists two weeks before the event. Ask them to also send a reminder a few days before the event.

If appropriate for your audience, post on Facebook, Twitter, Instagram or other relevant social sites. Consider setting up an “event” in Facebook and inviting members of your community to forward the event information to friends. (Be sure to enable the features that allow this.)

If you have a blog, write a brief post about why you are holding this event. If possible, include a personal or local story that helps potential audiences make the connection between their own lives and the event’s focus.

Tap into local media

Create a media notice to send to daily newspapers, free weeklies, radio stations, etc. used by your target audiences. Find out how to be added to the community calendar section.

Invite local journalists and elected officials to attend the event. Journalists are much more likely to respond if you provide a tie-in to a recent local issue or story such as a new end-of-life care program or service, statistics on local end-of-life care outcomes or trends, or some other “hook” with local relevance.

Keep your message simple

Include “The 5 Ws”: Who, What, Why, When, Where

Create 4-5 simple messages about the event and use them consistently in a variety of materials.

Maintain the momentum with publicity during and after your event

Particularly if you plan to have multiple events or to offer other ways for people to stay engaged after your event, you may want to do post-event publicity.

If you use social media, consider designating someone to take photos or record a short video to post. Remember that this is a sensitive issue, so a camera might be distracting for your audience. Also, always get a release to use someone’s image.

Interview attendees: why did you come, what did you think of the film/discussion?
After the event, add the visual content you captured to your Facebook page, Instagram, etc.

Netflix® has expressly forbidden community organizations from charging money for screenings of *END GAME*.

END GAME: Event Checklist

Before the Event

Connect with <http://endgame-documentary.com/host/> to request a showing.

- Engage community partners to plan and publicize your event.
- Create and distribute promotional materials.
- Verify that what you will need to show the film is available and functional in your chosen venue. This includes:
 - Equipment appropriate for showing the film
 - A screen large enough for all in your audience to clearly view the film
 - Sound amplification suitable for the venue
- Ahead of time, test screen the film on the exact equipment you will be using the day of the event.
- Verify that you have enough participant handouts for the anticipated size of your audience.

Day of the Event

- Do a final equipment and sound check before the event begins.
- Cue up the film.

***END GAME*: Sample Event Agenda**

(1 ½ hours)

- Welcome/introduction to the film/thank your host/introduce yourself (5 min.)
- Screen *END GAME* movie (40 minutes)
- Pause to allow people to share their immediate reactions or sit quietly with their emotions (5-10 min.)
- After-film discussion, possibly leading to action plan (30 min.)
(This can be a panel with Q & A, a full group discussion, small group discussion, or other format, depending on what you deem best for your event.)
- Closing statement & Wrap-up (10 min.)

A note about breaks: At film screenings followed by discussion, people are inclined to leave if there is a break after the film. For that reason, we recommend that you not offer a break, but move directly from the screening into the after-film activity. If you do this, at the beginning of the event be sure to invite people to get up whenever they want to get refreshments, use the restroom, stretch their legs, etc.

***END GAME*: Event Host Suggested Talking Points**

- Welcome and thank you for taking the time to come out and explore this important topic with us today.
- We understand that end-of-life is a difficult topic and we are committed to giving you the time, space, and support that you may need to find this useful.
- *END GAME* was filmed in San Francisco in both the hospital and hospice setting. It was designed to show a range of situations, options, and approaches.
- There is no “right” decision about end-of-life care. We only seek to help you understand and communicate the right decision for you so that you get the care that you need and no less, and the care that you want and no more.
- Review the agenda and invitation to take breaks as needed.
- And now, *END GAME*. (Play film)
- Immediately after the film, pause briefly, then:
Please take a few minutes to turn to the person next to you and share a few thoughts and feelings about a moment or person that struck you in the film. Please take turns so that you each have two or three minutes to talk. Or if you’d like to remain quiet, please do so and absorb what you just saw.
- Does anyone have anything that they would like to share about the film or your experience watching it?
- You can utilize the After-Film Discussion Prompts here, if desired.
- Closing comments following the after-film discussion:
Thank you for the valuable discussion we just had and for putting thought into your own action plan. It’s important to us that you carry these conversations into your homes or other places where you gather with loved ones, and that you feel you have all the resources you need to continue your own end-of-life care planning.
- Remember that your wishes for care cannot be carried out unless you make your loved ones and care providers aware of them.
- Please visit our resource table where you’ll find additional materials you may find helpful.
- If you are planning a follow-up event, talk about that now.

END GAME: After-Film Discussion

After viewing the film, you may ask the audience to participate in an interactive discussion (30-45 minutes) about their thoughts and feelings about what they saw, the implications for their own lives, and possibly leading to the development of a personal “action plan” that specifies two or more concrete steps they plan to take toward clarifying and communicating their end-of-life care wishes. Actions could include things like choosing one’s healthcare agent and having a conversation about care wishes, making a list of questions to ask the doctor, completing an advance directive, or other related goals.

See the Advance Care Planning Checklist on page 18 that may be useful for this part of the event.

The following suggestions may be helpful in planning the after-film discussion:

- *END GAME* shows strong and moving imagery. Before jumping into discussion and planning, give the audience a few minutes to digest and reflect on what they have just seen. This can be accomplished by allowing 5 minutes of quiet time, during which audience members can just sit with the material, or quietly talk to those around them.
- The After-Film Discussion Prompts on pages 13 - 15 provide sample themes, quotes, and questions for guiding your discussion.
- Have your team, including your site hosts, watch the film ahead of time, to process any feelings of their own before they help others do it. You may want to discuss any feelings when you have your pre-event walk-through meeting or telephone call.
- Consider using the “safe space” participant guidelines in the box on page 12 to help create the safety and trust needed for people to share their feelings or experiences.
- Seek guidance on cultural considerations for structuring the discussion, as different communities represented in your audience may vary in their comfort and customs around discussing personal topics in a public setting.

Sample “Safe Space” Agreements for Group Discussions

- **One mic:** One person speaks at a time.
- **Keep it in the room:** These experiences are personal; what is discussed in the room is confidential and will not leave the room.
- **“I” statements:** Speak from your own experience as much as possible.
- **No wrong answers:** Questions are geared toward reflection and sharing - your perspectives and experiences are always correct!
- **Share what you can:** Share as much or as little as you are comfortable with.
- **Share the stage:** If you are a quieter person, we encourage you to feel welcome sharing your thoughts here. If you speak a lot, step back so that others have a chance to share.

END GAME: After-Film Discussion Prompts

The aim of END GAME screenings is to engage a wide and diverse range of communities – multi-ethnic and cultural, in rural, suburban and urban settings —in conversations about end-of-life and end-of-life care. We hope that you will use this film as a tool to educate participants about the issues they might face as they near the end of their lives and to prompt them to consider and talk about the kind of care they would like to receive. Ultimately, we hope these screenings will help participants understand the importance of taking concrete steps to identify and communicate their wishes for end-of-life care so that they receive the care they need and no less, and the care they want and no more.

Based on the film, we have identified a few themes, quotes, and questions that can be used after an *END GAME* screening to trigger productive discussion among the participants. These are merely suggestions – feel free to guide the discussion in whatever way works best for your audience.

THEMES TO EXPLORE:

FAMILY DYNAMICS – When dealing with serious illness or end-of-life, emotions and complex family dynamics can be intensified and bubble to the surface in unexpected ways.

DECISION MAKING – Understanding our own values and wishes as they relate serious illness and end-of-life can help inform and facilitate the decisions that need to be made for ourselves and others.

CHOOSING AN AGENT – A healthcare agent or health decision surrogate makes decisions for you when you are not able. Is there someone in your life who knows what matters most to you in making the kinds of decisions we saw the patients and families in the film having to make?

MAKING A PLAN - A personal “action plan” specifies concrete steps toward clarifying and communicating end-of-life care wishes.

DISABILITY - People can grapple with disability at different times during their lives. For some the disability that comes at the end-of-life is the first time they have to deal with limitations.

HUMANITY – The philosophical thought process of being human. The quality of being humane. Kindness. Benevolence.

QUALITY OF LIFE – A patient’s perception of quality of life. The ability to enjoy normal life activities.

END GAME: After-Film Discussion Prompts (continued)

QUOTES TO DISCUSS

"It took me several years before I stopped comparing my new body to the old body, but when I did stop comparing, when this became the whole me, not me missing stuff, I stopped suffering. My identity had accommodated the facts of my life." BJ Miller, MD

Dr. Miller gave Thekla the assignment to *"make friends with death."* She told him she failed the assignment.

"There is nothing inherently medical about dying. It's much larger than medicine. It's purely human." BJ Miller, MD

The nurse asked Hamid, Mitra's husband, *"How are you doing?"* and he replied, *"The way she wanted me to be. Happy, and to do the right thing. That's what she wants me to do."*

"It's healthy people who think about how they want to die and sick people who think about how they want to live." Steve Pantilat, MD

QUESTIONS TO CONSIDER

When sharing her situation, Pat, the lady in hospice with uterine cancer, said, *"I feel better more than I feel bad. I'm here now with someone who can watch the symptoms with me, and understand what's right or wrong with it, and give me medication and monitor it, so I don't have to do it all by myself."* **Why do you think this was important to her? Would that be important to you?**

Mitra's husband, Hamid, and her mother, Vaji, don't agree on Mitra's situation. Hamid believes that Mitra still has a chance to fight and that they should fight. Vaji believes that there is no hope. She implores Hamid to *"Ask her, she can answer."* He responds, *"And if she cannot talk?"* to which Vaji says, *"Then you have to decide."* **How do you feel about the way that they dealt with their opposing views about what Mitra would want?**

Mitra's mother, Vaji, told the chaplain that she equates hospice with death and asks the chaplain not to bring hospice up with Mitra. Kym, the patient who was a nurse, says that in her experience, people went into the hospital to die, and she didn't want that to be the way it went for her. Kym's husband says they are not ready for hospice because that's the end. **What are your own thoughts about what hospice is and what it means?**

END GAME: After-Film Discussion Prompts (continued)

Pat's nurse explains the potential benefits and costs (or harms) of chemotherapy. She explains how the chemotherapy will make Pat feel. Pat seems surprised by what she is hearing. The nurse asks Pat to think about if it's the kind of time that she wants. **If you were a patient, would you want your caregivers to be so blunt?**

Some people describe an advance directive as a gift that a person can give to their loved ones. **Why do you think people say that? Does that ring true to you?**

How might a better understanding of a person's end-of-life wishes provide patients and/or family with a more peaceful end? In what way(s)?

How important is independence and self-sufficiency in your life? How might that change as you grow older?

Did the film give you any ideas about what you might want your doctor/care team and those close to you to know about your end-of-life preferences? If so, what would you like them to know?

Was there a particular part of the film that really hit home for you in thinking about what you want – or don't want -- for yourself and your family?

What do you think will be important to you when you are dying (e.g. – physical comfort, no pain, family members present, etc.)?

Do you have a preference regarding how your end-of-life might be?

Where would you prefer to die?

Have you communicated your end-of-life preferences to your loved ones and care team?

How did you feel about the scene in the film where the researcher is asking Mitra's family about whether or not they would want to have an autopsy done or donate her body for research? Would you want your family to have to make that decision for you?

END GAME: Follow-up Advance Care Planning Resources for Participants

As you plan your event, do an inventory of the available Advance Care Planning services and resources in your community. If you are not sure where to start, the CCCC webpage has a list of local coalitions (<http://coalitionccc.org/who-we-are/local-coalitions/>). Find the one in your area and reach out to them for assistance. If there is not a local coalition in your area, you can research resources online and create a simple one-page list of these local resources and how people can access them, along with one or two good online resources.

You can make up participant packets ahead of time that include your resource list, the Advance Care Planning Checklist at the end of this toolkit, an advance directive, and a few other materials of your choice. In addition, a resource table at the event can serve as a way to share follow-up materials. Whichever method you choose, bear in mind that too many documents and choices can easily confuse people, so decide ahead of time which materials you'd like to focus on and keep it simple.

On the page 17 is a list of a few organizations offering useful advance care planning materials, including Advance Directives, online. This is not an exhaustive list. There are many resources online that deal with many different aspects of advance care planning and end-of-life decisions. Find and use the one(s) that is/are right you're your audience.

Coalition for Compassionate Care of California

coalitionccc.org

Resources include advance directive forms, guides for starting an Advance Care Planning conversation, instructions for choosing a healthcare agent, instructions for healthcare agents, Physician Orders for Life-Sustaining Treatment (POLST) forms, and more.

The Conversation Project

theconversationproject.org

Features *The Conversation Starter Kit*, aimed at helping people overcome barriers to planning and to start talking to family and loved ones. Available in English, Spanish, French, and Mandarin. theconversationproject.org/starter-kit/intro/

Prepare for Your Care

prepareforyourcare.org

A web site designed to empower people to make decisions, talk with providers and get medical care that is right for them. Prepare for Your Care walks people through basic steps in Advance Care Planning and provides prompts and videos to help them get started.

Caring Connections

caringinfo.org

A program of the National Hospice and Palliative Care Organization providing free resources to help people make decisions about end-of-life care before a crisis. There are links to Advance Directives for all 50 states.

Aging with Dignity and Five Wishes

agingwithdignity.org

Provides practical information, advice and legal tools for Advance Care Planning, including the popular “Five Wishes” Advance Directive.

Consumer Reports (Advance Care Planning)

consumerhealthchoices.org/wp-content/uploads/2017/04/CarePlanningCCCC-ER.pdf

Free, downloadable patient ACP booklet available in English and Spanish.

National Institute on Aging

nia.nih.gov/health/caregiving/advance-care-planning

General material, definitions and explanations for Advance care Planning. Printable Wallet Card. Links to other resources.

What Matters Most?

Advance Care Planning Checklist



**There are many steps you can take
to keep the conversation going!**

- Make a list of the three most important things you want those close to you to know about your wishes for end-of-life care.
- Think about who you would want to make your medical care decisions for you if you could not speak for yourself.
- Plan when and where you might want to talk to that person and others close to you about your wishes.
- Make a list of questions you'd like to ask your doctor.
- Fill out an Advance Directive form to record your wishes and appoint the person (agent) who will speak for you if you can't speak for yourself.
- Make copies of your Advance Directive and give them to your agent, your doctor, and anyone else you would like to know your wishes.
- If you already have an Advance Directive, review it to make sure it fits with your current wishes.
- Talk with those close to you about their wishes.

Other steps you'd like to take:
