

# BEING MORTAL

## Community Screening Toolkit

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## About the Film

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*Being Mortal* is a public television documentary, generously funded by the John and Wauna Harman Foundation, that explores the hopes of patients and families facing terminal illness and their relationships with the doctors who care for them. The film tells the story of a physician, Atul Gawande, who is learning to think about death and dying in the context of being a healer. By sharing stories from the perspective of the people and families he encounters, including his own, it sheds new light on how our system – so focused on a cure – often neglects the important conversations that need to happen so that a person’s true priorities can be known and honored at the end.

The stories in *Being Mortal* show us the value of shared decision-making in medicine at the end of life and illustrate the importance of thinking and planning ahead as we reflect on what matters most to us.

In February 2015, *Being Mortal* aired nationally on FRONTLINE. For more information about the film, visit <http://www.pbs.org/wgbh/pages/frontline/being-mortal/>. The film is adapted from Gawande’s 2014 nationally best selling book of the same name. You can find more information about the book at <http://atulgawande.com/book/being-mortal/>.

## About this Toolkit and Community Screenings

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The John and Wauna Harman Foundation and the California HealthCare Foundation are collaborating to support screenings of *Being Mortal* by organizations in communities throughout California over the summer and fall of 2015. This toolkit is intended to support the organizations in hosting successful events.

Inside you’ll find recommendations for engaging diverse audiences, event planning tips, a sample agenda, 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.

## Getting Started with Your *Being Mortal* Event

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### Project Goal

The aim of the *Being Mortal* screening series 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 care. The goal is to use the documentary 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 leave participants with the understanding they need to take concrete steps to identify and communicate their wishes for end-of-life care.

### Event Outcomes

The desired outcomes of the community screenings in support of this goal include:

- The film and discussion will spark dialog and reflection among broad audiences around end-of-life care and audience members will:
- have an increased interest in end-of-life care conversations and planning
- gain an increased awareness and understanding of advance planning resources
- come away with an plan for personal “next steps” related to discussing and sharing their end-of-life care wishes

## 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 *Being Mortal* with representatives from your target audience so that you can get their reactions to the film and ideas for structuring the event. They then are also likely to become 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. If you'd like to highlight the services you offer in end-of-life care planning (or those offered by an event partner), consider a brief presentation and Q&A format so the audience has an opportunity to ask about those services. 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.

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 17 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 15) 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 16) to help set the context for your event.

## Technical Preparation for the Event

Well ahead of your event, verify that your proposed venue has the equipment and facilities needed for a comfortable and successful screening and discussion. This includes details like the laptop, projector, and screen for playing the DVDs; mics and speakers; and whatever configuration of tables and chairs suits your event format.

There are three DVDs for this event. Before showing *Being Mortal*, you will play a short DVD by Secretary Diana Dooley of the CA Health and Human Services Agency welcoming the audience. Following *Being Mortal* and before the discussion or at the close of your event, you will show a third DVD featuring a special message from Atul Gawande. In this 2.5-minute piece taped just for these events, Dr. Gawande thanks people for coming and encourages them to bring these important conversations to their own families. (Refer to the **Event Checklist** on page 14.)

\*\*\*\*Ahead of time, test screen all three DVDs on the exact equipment you will be using the day of the event to catch any glitches. (This step is essential!)\*

The *Being Mortal* DVD has closed captioning (subtitles in English) for audience members who are hard of hearing. If you plan to use this feature, make sure your screen is placed high enough for the audience to see the subtitles.

## Administering the Participant Questionnaire

Administering the participant questionnaire to measure the impact of the film and discussion is an important part of the *Being Mortal* community screenings, as it will provide valuable data to help shape future end-of-life education efforts. It asks basic questions about beliefs, ideas, and intentions related to end-of-life care issues.

Here are some key details to keep in mind about the questionnaire:

- It will only be available in English
- It is a single document that includes:
  - Pre-event questions to be answered before the event begins.
  - Post-event questions to be answered at the end of the discussion.
- The post-event section concludes with a space at the end for the participants to write in their e-mail address, which the survey company will use for sending out a follow-up questionnaire 1-3 months later to measure any actions participants may have taken as a result of the event.

- The questionnaires are numbered for data entry purposes and will be mailed to you in hardcopy form before your event, based on a padded estimate of your anticipated audience size. (You will make arrangements for this in advance with Julie Boudreau, the project manager.)
- You will mail the completed questionnaires back to the survey company after each event. Pre-addressed and pre-stamped packaging will be provided for this purpose.

Some groups are using raffle prizes to encourage audience members to complete and turn in the participant questionnaire. This is of course optional, but an incentive like this can also motivate people to stay to the end of your event, so you may want to consider it as a possibility.

If language, literacy level, lack of access to e-mail, or other barriers may make it difficult for a significant portion of your audience to complete the event questionnaire or the follow-up e-mail questionnaire, talk this over with Julie Boudreau. Together you will determine whether your audience will be part of the official data collection process. If not, you will be given an abbreviated version of the questionnaire, which you may translate into other languages and which will not include the follow-up e-mail questionnaire. *To avoid confusion, you will use either the official or the abbreviated questionnaire at a given screening, but not both.*

Here are some suggestions to help make administering the questionnaire as easy as possible. (Also see the survey script below for other helpful details.):

- Assign one person to be in charge of administering the questionnaire.
- Have the questionnaire on the seats in the room in advance. As you greet people when they come in, encourage them to complete part one before the event begins. Make it clear that they are not to complete part two until the end of the event.
- Have someone posted to collect the questionnaires as people leave. This person can check to see that the e-mail address is legibly filled in.

### **Suggested Survey Script (for groups participating in the official survey)**

You should all have a **Participant Questionnaire**. Please raise your hand if you do not have one. We're asking that everyone in the audience please complete the questionnaire.

These questionnaires are an important part of our event, and were designed to help the event sponsors learn more about the usefulness of this film in helping people understand end-of-life issues.

You will be answering a few questions before the film, again after the discussion, and then once more via e-mail one to three months from now. Your answers will be confidential and will only be used by the sponsors to learn more about the

effectiveness of their work. Your e-mail address will not be used for any other purposes. We're very appreciative of your participation in this survey.

If you've not already done so, please take a moment now to complete the "Pre-Event Questionnaire." You may then set the survey aside.

At the end of the event, you will complete the second part, the "Post-Event Questionnaire." Please wait until you are instructed before filling out the second part of the survey.

## The After-Film Discussion

After viewing the film, the audience will participate in an interactive discussion (30-45 minutes) 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 17 that may be useful for this part of the event.

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

- *Being Mortal* closes on a moving note. Before diving too deep into the issues and planning, allow the audience a moment just after the film ends to reflect on the feelings that may have come up. One way to do this is to take 5-10 minutes for viewers to turn to the person next to them and share impressions.
- The **After-Film Discussion Prompts** on the following page provide sample questions for guiding your discussion.
- Have your team watch the film ahead of time, on their own, to process any feelings of their own before they help others do it. It’s also a good idea to meet at least once to walk through the discussion format.
- Consider using the “safe space” participant guidelines in the box below to help create the safety and trust needed for people to share their 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.



## AFTER-FILM DISCUSSION PROMPTS

Because time is limited and the goal of the after-film discussion is for participants to arrive at an action plan, you may want to ask some questions that help them identify personal actions that the film inspired them to consider.

Here are some ideas:

- Dr. Gawande explains that in his training as a surgeon, he has struggled with the fear of not being able to “fix” a problem for a patient, even when he knows the odds are not good. If you were Dr. Gawande’s patient, what would you like him to know about your hopes for how he would handle a difficult situation like this?
- Dr. Nayak’s patient, Bill, tells her that he is not afraid of dying, but he is afraid of the pain he might endure. What are your own worries or fears about facing an end-of-life situation like his?
- In one scene, Norma Bananeau gets very upset by the news that her cancer has taken a more aggressive turn because she has plans to take her family to Disneyland for Christmas. In a similar situation, how would you hope to make the most of the time you have left?
- The brain cancer doctor, Dr. Nayak, often works with patients who are not likely to survive their conditions. But even she feels the pressure to give them some hope. If you were her patient, what kind of conversation could you imagine having with her to help balance the need for hope with the desire to be realistic so that you can make the best use of the time you have left?
- In one scene, Jeff Shields and his grandson talk together about the fact that he is dying and his grandson has an opportunity to ask some difficult questions. How would you feel about taking time for a similar conversation with your loved ones at the end of life?
- Was there a particular part of the film that really hit home for you in thinking about what you want for yourself and your family around end-of-life decisions?
- Did the film give you any ideas about what you might want your doctor and those close to you to know about your end-of-life preferences? If so, what would you like them to know?
- 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?

- a. If so, who is it? Have you spoken to them about it?
  - b. If no, if there someone you would like to reach out to about this?
- What are two (or more) actions that you would be willing to take now in order to help yourself and those close to you communicate your wishes about end-of-life care?

For small groups without facilitators, consider handing out sheets of paper featuring two or three of these questions for the group to go over together.

If time allows, you may want to reconvene the full group after the small group discussions. This will allow people to ask any questions that may have come up in their group and can provide a sense of closure for your event.

One way to re-engage the audience as a full group once they've reconvened is to start by asking, "What was difficult and what was easy about the conversations you just had?"

## Follow-up Advance Care Planning Materials 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 community outreach department of your local hospice can direct you. The *Being Mortal* project manager, Julie Boudreau, can also assist you in finding local groups who are already doing this type of work. If one does not already exist, create a simple one-page list of these local resources and how people can access them, along with one or two good online resources. (See the list below for ideas.)

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.

Advance Directives are available in the “Being Mortal Community Screenings Event Tools” Dropbox folder. In addition, below is a list of organizations offering useful advance care planning materials online:

### **Coalition for Compassionate Care of California**

[coalitionccc.org](http://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](http://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/](http://theconversationproject.org/starter-kit/intro/)

### **Prepare for Your Care**

[prepareforyourcare.org](http://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](http://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](http://agingwithdignity.org)

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

## **Getting the Word Out**

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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.

The Dropbox “Being Mortal Community Screenings Event Tools” folder includes electronic files such as the event poster and sample event publicity copy and templates you may find useful. (The poster image and text cannot be edited except for the type-in fields at the bottom, but feel free to tailor the other publicity messages to your audience.)

Some publicity pointers to keep in mind include the following:

### **1. 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?”

### **2. 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.

### **3. Rely on more than one form of notification**

- Post the physical posters and flyers in high visibility areas.
- Create e-mail announcements and have other organizations forward them on to their e-mail 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.)

- In your electronic outreach, include a link to the [Being Mortal trailer](#) so people can see a preview. You may even want to embed it in your website or use it on Facebook.
- 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.

#### **4. Tap into local media**

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

#### **5. 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.

#### **6. 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 and record a short video to post\*
- 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.
- Share the best of the visual content with Atul Gawande, Frontline, and CHCF. Their Twitter “handles” are:  
 Frontline: @frontlinePBS  
 Atul Gawande: @Atul\_Gawande  
 CHCF: @CHCFnews

\* Always keep sensitivity in mind here, since dying is a sensitive topic and a camera could distract people or cause them to feel self-conscious.

## ***Being Mortal***

### **Community Screening Event Checklist** (For technical and survey logistics)

#### **Before the Event**

- ☐ Verify that the equipment needed for showing the film is available and functional in your chosen venue. This includes:
  - A DVD player
  - A screen large enough for all in your audience to clearly view the film
  - Sound amplification suitable for the venue
- ☐ Verify that you have all three DVDs needed for the event:
  - **Disc #1**- Welcome from Sec. Diana Dooley of the CA Health & Human Services Agency
  - **Disc #2**- FRONTLINE's *Being Mortal*
  - **Disc #3**- Atul Gawande's special comments taped for the community viewings
- ☐ Ahead of time, test screen all three DVDs on the exact equipment you will be using the day of the event.
- ☐ If you are using the closed captioning feature, test this ahead of time.
- ☐ Verify that you have enough participant questionnaires for the anticipated size of your audience. (These will be sent to you in advance.)

#### **Day of the Event**

##### ***AV Preparation***

- ☐ Have all three DVDs on site.
- ☐ Do a final equipment and sound check before the event begins.
- ☐ Cue up DVDs #1, #2, and #3 and verify that the system operator is clear about how to play them in sequence.

##### ***Survey administration***

- ☐ Give each audience member a questionnaire before the event begins.
- ☐ Provide clear questionnaire instructions to participants using the script provided.
- ☐ Collect all completed questionnaires at the end of the event.
- ☐ Verify that each questionnaire includes the participant's e-mail address.

#### **After the Event**

- ☐ At the end of the event, place the questionnaires in the pre-addressed and pre-stamped packaging provided and mail them to the survey company.  
*Note: If you host multiple showings, you will need to mail these after each event.*
- ☐ Complete the post-event evaluation for grantees. (*This only needs to be done once.*)

## ***Being Mortal* Community Screening**

### **Sample Event Agenda (2 hours)**

- Welcome/introduction to the film/time to complete the pre-event portion of the participant questionnaires (5 min.)
  - Screen the Introductory DVD from Diana Dooley (2.5 min.)
  - Screen the *Being Mortal* DVD (~60 minutes)
  - Pause to allow people to share their immediate reactions- can be done in pairs (5-10 min.)
  - Screen the DVD with follow-up message from Atul Gawande\* (2.5 min.)
  - After-film discussion 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.)
  - Collect participant questionnaires
  - Closing statement & Wrap-up (10 min.)
- \* An alternative time to show the DVD with Dr. Gawande's follow-up message is at the end of the event as part of the closing.

**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.

## ***Being Mortal* Community Screening**

### **Event Host Suggested Talking Points**

- Welcome and thank you for taking the time to come out and explore this important topic with us today. Our community has joined 40 other communities through out the state of California who are showing and discussing this important film. You are part of an important conversation that is happening statewide.
- *Being Mortal* first aired last February on national television. Since then the film's funder, the Harman Foundation, joined with the California HealthCare Foundation to provide funding to bring the film to communities like ours.
- Review of the agenda and invitation to take breaks as needed.
- Suggested Questionnaire Script (see page 6).
- Before we start the main film, we'll hear a brief message from California Health and Human Services Agency Secretary Diana Dooley. When Secretary Dooley learned of these community events, she asked if she could share a special welcome with us and here she is. (Play DVD #1)
- And now, *Being Mortal*. (Play DVD #2)
- Immediately after the film, a brief silent pause, 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.
- Following the sharing in pairs:  
Thank you. Now we'll hear a very brief message that Atul Gawande recorded especially for those of us who are attending these community screenings. (Play DVD #3)  
Note: An alternative time to show Dr. Gawande's closing remarks is at the wrap-up at the end of the event.
- 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. Please visit our resource table where you'll find additional materials you may find helpful. Please also take a moment to go back to the questionnaire that you began filling out at the beginning of this event and complete the Post-Event section.



# 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 legally 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: \_\_\_\_\_

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