

# ***BEING MORTAL***

## **Community Screening & Discussion Toolkit**

# **TABLE OF CONTENTS**

<b>ABOUT THE DOCUMENTARY</b>	<b>2</b>
<b>ABOUT THIS TOOLKIT AND COMMUNITY SCREENINGS</b>	<b>2</b>
<b>PLANNING THE EVENT</b>	<b>4 - 9</b>
<b>GETTING THE WORD OUT BEFORE THE EVENT</b>	<b>10</b>
<b>KEEP THE CONVERSATION GOING</b>	<b>10</b>
<b>“WHAT MATTERS MOST?” ADVANCE CARE PLANNING CHECKLIST</b>	<b>11</b>

# ABOUT THE DOCUMENTARY

---

*Being Mortal* is a FRONTLINE public television documentary that explores the hopes of patients and families facing terminal illness and their relationships with the doctors who care for them. The documentary tells the story of 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 both physicians and the people and families he encounters, including his own, the documentary sheds new light on how our system – so often focused on a cure – 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 to us most. The stories further reveal the human side of physicians, whose own vulnerabilities, fears, and lack of training may impede timely and open discussions with patients.

*Being Mortal* aired nationally on February 15, 2015. For more information about the documentary, visit <http://www.pbs.org/wgbh/frontline/film/being-mortal/>. The documentary is adapted from Gawande’s 2014 nationally bestselling book of the same name. For more information on the book, visit <http://atulgawande.com/book/being-mortal/>

# ABOUT THIS TOOLKIT AND COMMUNITY SCREENINGS

---

Welcome and congratulations for bringing this important film for your community. This toolkit contains detailed information to help you host a successful community event with the goal of bringing together lay community members *and* clinicians to watch and discuss the documentary, advance care planning, and what matters most at the end of life. Ultimately, you know what will work best for your community, so this resource is intended to serve as a guide and offer suggestions.

The aim of a *Being Mortal* event should be to raise awareness of the importance of having conversations about end-of-life care and advance care planning and should include a wide range of individuals including clinicians who provide care. As an event organizer, you should make it a goal to ensure that a wide range of community members attend your event to watch the film and take part in the post-program discussion. Consider using the event to:

- support dialogue between medical and general audiences so both can hear from one another and discuss the issues;
- encourage, prepare, and train medical professionals to bring up these issues with their patients (more effectively);
- inspire general audiences to bring this topic up with their doctors and loved ones and to take the next steps in developing their end-of-life wishes.

The documentary and discussion will spark dialogue and reflection around end-of-life care, encouraging audience members to:

- gain an increased awareness and understanding of advance care planning resources;
- understand that being proactive about end-of-life conversations and planning is an important part of medical care and will affect their future and their family’s future;
- share what matters most to them at the end of life.

# PLANNING THE EVENT

---

## GETTING STARTED

- Set the date and time, allowing at least two hours for the event, and secure a suitable venue.
- View the documentary to assist in identifying your target audience and planning the audience discussion.
- Consider the benefit of collaborating with a community partner to plan, publicize, and host your event.
- Create promotional plans to engage your target audience, including laypeople and clinicians, utilizing your knowledge of your community.
- Prepare advance care planning resources for attendees.
- Prepare for your post-screening discussion
- Consider providing your audience with a survey to assess the impact of your event.

**Public Screening Rights:** The Frontline/PBS limited public screening rights restrict you from charging a fee or requiring a donation for your event. In addition to being precluded from charging an audience to attend, you may not distribute the program in any other way, including open cable, satellite, etc. (See sticker on the back of the DVD.)

## AUDIENCE

Think broadly about your audience. This event provides the opportunity to teach by engaging other communities and organizations. If you generally work with a community audience, consider adding another dimension to your event by inviting clinicians who may not feel that they all have tools necessary to start these conversations, such as:

- Medical professionals, particularly those who work in specialty areas such as oncology, cardiology or dementia, and others who work with the elderly;
- College and graduate students in related fields (medicine, nursing, social work, religious studies, counseling);
- Non-medical professionals who work with families facing end-of-life decisions, such as clergy, elder care attorneys or caregiving experts.

Consider your objectives and audience before finalizing your format. For example:

- *Additional Perspectives:* If you are trying to engage specific audiences who are not well-represented in the film, consider organizing your discussion to include a panel that features voices from those communities to ensure their perspectives are present, especially low-income and other underserved communities. Also consider language barriers.
- *Expert Facilitation:* You may want to ensure you have an experienced facilitator and/or someone who can respond to specific questions related to end-of-life care.
- *Large or Small Group Discussions:* Depending on the size of your audience, group conversations can offer both medical and non-medical audiences a space to share their fears and concerns around starting these conversations and open up opportunities for them to hear from each other about the challenges, desire, and need for these conversations.

# PLANNING THE EVENT...continued

Consider reaching out to groups in your community that can help broaden the reach beyond your usual audiences such as:

- faith-based and culture-based organizations,
- civic groups/clubs and community centers,
- human resource departments of local companies/large employers,
- local YMCAs, Rotary clubs, Kiwanis, libraries, PTAs,
- campus groups and schools of medicine, social work, nursing, gerontology, social work, and other relevant fields,
- medical providers (physicians, hospice, palliative care providers, oncology, etc.),
- caregiving institutions (domestic workers, home health aides, physical therapists, etc.),
- service providers (bereavement, mental health, Alzheimer's, disability, family wellness, etc.),
- neighborhood and other volunteer groups,
- service providers (family wellness, child day care centers, legal aid, etc.), and
- community advocacy organizations (affordable housing/evictions, elder-abuse, mental health, etc.).

## VENUE AND TECHNICAL NEEDS

When choosing a venue for your event, be sure your location is:

- large enough to comfortably host your anticipated audience (remember that the documentary will deal with many difficult situations so choose a venue that is appealing and comfortable),
- equipped with a functioning DVD player, large screen, and adequate sound system,
- spacious enough for both a general discussion and the option for small group conversations,
- adequate for handicapped accessibility and easy parking,
- user-friendly, with space for you and other organizations to share information, provide refreshments, etc.,
- one with adequate restroom facilities, and
- accessible a few days prior to the event to test the equipment.

## SAMPLE AGENDA

Plan to allocate at least two hours for the event plus any time you need for set-up and clean-up.

- **Welcome (5 mins):** Share the outline for the day, including the discussion afterward and the importance of participants completing surveys, if you provide them.
- **Screening (~60 mins):** Show the *Being Mortal* DVD.
- **Reactions (5-10 mins):** Pause to allow people to share their immediate reactions with those around them. Be mindful that an intermission of any significance may produce the unwanted result of your audience leaving before participating in the discussion or completing the survey.
- **Discussion (30-45 mins):** This can be a facilitated full group discussion, a panel with Q&A and discussion, small facilitated group discussions or other format, depending on what you deem best for your audience.
- **Surveys (5-10 mins):** Toward the end of the discussion, hand out surveys and allow time to fill out. Make sure your audience knows that these are anonymous.
- **Closing (5-10 mins):** Collect surveys. Share information about your organization's resources and others in the community and wrap-up.

# PLANNING THE EVENT...continued

## EVENT FORMAT IDEAS

**Q&A and Speakers:** If you'd like to highlight the end-of-life care planning services offered by you or your community partner/s, 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 are engaging – or simply to localize the story – consider inviting a few speakers from the community to briefly share their stories.

**Group Discussions:** A small group format for the discussion can sometimes encourage greater individual participation. If you want the 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 an open 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.

**Panel Discussions:** A panel with a facilitated group discussion may enable you to draw clinicians to the event as “experts.” Be careful, however, that this does not create a lopsided discussion dynamic; having a mixed panel of lay people who are willing to share their end-of-life experiences with loved ones and “experts” may help to diffuse this risk.

## EVENT HOST SUGGESTED TALKING POINTS

Here is a suggested script that will help you organize your remarks to your audience:

Welcome and thank you for taking the time to come out and explore this important topic with us today. Our community has joined hundreds of communities across the nation who have shown and discussed *Being Mortal*.

- *Being Mortal* first aired on PBS in 2015 and has been viewed by thousands of people in hundreds of communities across the country.
- We hope that by the end of today's event, you will be encouraged to think about your own wishes at the end of life and to “take action” to begin creating documents and having conversations with your doctor and your loved ones about what those wishes are. We'll be providing you with some resources to help with that process.
- We will also have time to have your questions answered by those who know about end-of-life care options.
- Let's take a few minutes to introduce our hosts and go over the agenda for the day [note: be sure to mention any resources you have available.]
- At the end of the program we will ask you to complete a short questionnaire. Your answers will be completely confidential. We're very appreciative of your participation in this survey.
- And now, *Being Mortal*. (Play DVD)
- Immediately after the documentary, a brief silent pause, then:  
Please take a few minutes to turn to the person next to you and share some thoughts and feelings about a moment or person that struck you in the documentary. You can also write them down if you are more comfortable doing so.

Begin the post-documentary discussion in whatever format you have developed (see detailed suggestions in the post-documentary section below). Encourage participants to use the discussion and resources to begin forming their own “action plan” with regards to advance care planning.

# PLANNING THE EVENT...continued

## Suggested remarks following the post-documentary discussion:

Thank you for the valuable discussion we just had and for putting thought into your 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. Now please be sure to fill out the survey and turn in before you go. [Note: You may want to station people near the doors to collect the questionnaires in closed box so people are certain about the anonymity of their responses.]

## DETAILS ABOUT THE POST-DOCUMENTARY DISCUSSION

After viewing *Being Mortal*, an essential component of the event will be an interactive discussion (30-45 minutes). The discussion will allow you to answer questions, share stories, and provide advance care planning resources. These discussions will ideally encourage participants to take two or more concrete steps toward clarifying and communicating their end-of-life care wishes.

Actions could include steps such as:

- choosing one's healthcare agent,
- having a conversation about care wishes,
- making a list of questions to ask the doctor,
- completing an advance directive, or
- beginning this conversation with aging loved one.

*Being Mortal* is a moving documentary that addresses very personal, challenging questions. Consider these ideas in the planning of your post-documentary discussion:

- Before diving too deeply into the issues and planning, allow the audience a moment just after the documentary 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, or ask each participant to write a sentence or two about his or her immediate response to the documentary.
- You may want to start with something light and easy to respond to such as, "Which story do remember the most or could you connect with and why?"
- Ensure that the discussion is facilitated in such a way that creates the safety and trust needed for people to share their experiences.
- Consider keeping Kleenex on hand, as many of the themes raised can bring up emotions.
- 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.
- Use the discussion prompts below as possible discussion starters.

## CONSIDERATIONS FOR FACILITATING GROUP DISCUSSIONS

**One at a time:** One person speaks.

**Consider privacy:** These experiences are personal; assure the audience that 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.

# PLANNING THE EVENT...continued

**Share what you can:** Share as much or as little as you are comfortable with.

**Make space for others:** 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.

## POST-DOCUMENTARY DISCUSSION PROMPTS

The goal of the discussion is for participants to arrive at an action plan for their own advance care planning. But before they can do that, they will benefit from a conversation that helps them to connect the dots between the story, the issues, and their own feelings and experience.

**Help audience members connect to the story** by asking them to walk in the shoes of certain characters. What would they do? The discussion prompts in the guide can help.

### **Ask audiences what barriers they have experienced:**

- In bringing the conversation up with their doctor/their patient/their family.
- In taking other steps in their planning, such as developing advance directives or identifying a primary decisionmaker.

These questions are designed to help identify ideas for personal action and to open up the discussion.

- 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 communicate with you if he had determined that he could no longer “cure” you? If you are a clinician, how do you balance your training to “cure” a patient while still providing hope, even when a cure is no longer possible?
- 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 what the end-of-life situation might be like? If you are a clinician, what tools do you need to help address patient concerns about pain at the end of life?
- 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. Are there activities or plans you have that you are counting on completing in your lifetime?
- 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 balance hope with reality so that you can make the best use of the time you have left? As a clinician, what role does “hope” play in your discussions with patients who are facing end-of-life decisions?
- In one scene, Jeff Shields and his grandson talk about the fact that he is dying and his grandson has an opportunity to ask some difficult questions. How would you feel about having a similar conversation with your loved ones at the end of life? Would that conversation with an adult be different than the one you’d have with a young person?

# PLANNING THE EVENT...continued

- Was there a particular part of the documentary that really hit home for you in thinking about what you want for yourself and your family around end-of-life decisions?
- What ideas did the documentary give you about what you might want your doctor and those close to you to know about your end-of-life preferences? Thinking about the answer to this question is the first step in taking action to document your wishes.
- 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 documentary having to make?
  - a. If so, who is it? Have you spoken to him or her about it?
  - b. If no, is 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?
- If you are a medical professional, what is difficult for you about starting the conversation about end-of-life treatment options with patients with a possibly terminal diagnosis and what would you like your patients to know?
- As a patient or potential patient, what do you expect from healthcare professionals – physicians, nurses and social workers? What would you like them to know about these conversations?

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?"

## PREPARE 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. Create a handout of these local resources, as well as national resources, and encourage participants to use them in their personal planning. HFA has a list of national resources on their website.

Make up simple participant packets ahead of time that include:

- A list of local and national advance care planning resources.
- The Advance Care Planning Checklist ("What Matters Most?") at the end of this toolkit.
- State-specific or local advance directive forms.
- Information about the range of services provided by your organization and your partners.

A resource table at the event can be another way for your organization and others to share 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.

# GETTING THE WORD OUT BEFORE THE EVENT

---

Work with your community partner and other groups to determine the best ways to reach your target audience. Consider posters, press releases, PSAs, radio spots, invitations, text and images for social media postings, and event flyers.

Create four to five simple messages about the event that will resonate with your community and use them consistently in your materials. Some other tips:

- Start with your networks and partners; the most effective outreach grows out of relationships.
- Explore other publicity opportunities through like-minded organizations, such as senior centers and hospitals.
- Create e-mail announcements and ask other groups and partners to share with their mailing lists to promote the event.
- Set up an “event” on Facebook and invite members of your network to forward information to friends.
- Contact local media to be added to community calendars or even be featured on a local radio or TV show prior to the event.
- In addition to event information, consider finding clinicians and others who would share their own stories of end-of-life planning with the media and potential audiences to underscore why they should attend.
- In your social media outreach, include a link to the *Being Mortal* trailer so people can see a preview. You can also embed the trailer on your website or Facebook page and share it with local television stations.
- Journalists are much more likely to cover the event if you provide a tie-in to a recent local issue or story such as a new end-of-life care initiative, program or service, statistics on local end-of-life care outcomes or trends, or some other “hook” with local relevance.

# KEEP THE CONVERSATION GOING

---

Maintain the momentum with publicity during and after your event, particularly if you plan to have multiple events, and offer ways for people to stay engaged after your event.

- 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 documentary/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 @Atul\_Gawande and Frontline @frontlinePBS

Pay attention to the “champions” in your audience who might emerge at your event who can help you continue these conversations in your community.

\* Always keep sensitivity in mind here, because end-of-life discussions are a personal and sensitive topic and a camera could distract people or cause them to feel self-conscious. Ask permission of attendees before using their photograph publicly.

If you have any questions, please feel free to email HFA at [screening@hospicefoundation.org](mailto:screening@hospicefoundation.org).

# 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:

---

---

---