

EAT YOUR CATFISH

A FILM BY ADAM ISENBURG, NOAH AMIR ARJOMAND, SENEM TÜZEN



POV

DISCUSSION GUIDE



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Film Summary



Paralyzed by late-stage ALS and reliant on round-the-clock care, Kathryn Arjomand clings to mordant wit as she yearns to witness her daughter's wedding. Drawn from 930 hours of footage shot from her fixed point of view, *Eat Your Catfish* delivers a brutally frank and darkly humorous portrait of a family teetering on the brink as they grapple with the daily demands of disability and in-home caregiving.

Using This Guide

This guide is an invitation to dialogue. It is based on a belief in the power of human connection and designed for people who want to use *Eat Your Catfish* to engage family, friends, classmates, colleagues, and communities. In contrast to initiatives that foster debates in which participants try to convince others that they are right, this document envisions conversations undertaken in a spirit of openness in which people try to understand one another and expand their thinking by sharing viewpoints and listening actively.

The discussion prompts are intentionally crafted to help a wide range of audiences think more deeply about the issues in the film. Rather than attempting to address them all, choose one or two that best meet your needs and interests. And be sure to leave time to consider taking action. Planning next steps can help people leave the room feeling energized and optimistic, even in instances when conversations have been difficult.

For more detailed event planning and facilitation tips, visit <https://communitynetwork.amdoc.org/>.

Tools for the Facilitator

Eat Your Catfish is a film about death, dying, care, loss, and family dynamics. We encourage you to take your time, regroup, and listen to your body and your needs. We also encourage you to take great care of your participants and those in the audience. Invite them to take care of themselves, to step out if they need a break, and to remember that we never know how much loss folks are carrying with them throughout their days. Be gentle, be kind, and move as slowly as necessary.



Participants

Kathryn Arjomand, the protagonist, is in the advanced stages of ALS. She is married to Saïd and is mother to Noah and Minou.

Noah Arjomand, Kathryn and Saïd's son. Living with his parents in their New York apartment, he is the principal caregiver for his mother. He is also the initiator and co-director of the film.

Saïd Amir Arjomand, Kathryn's husband.

Minou, Kathryn and Saïd's daughter. The film follows the approach and experience of her wedding.

Technology, Kathryn depends on a ventilator to breathe and eye-gaze technology to communicate. A camera mounted on the back of her wheelchair centers her perspective in the film.

Key Issues

Eat Your Catfish is an excellent tool for outreach and will be of special interest to people who want to explore the following topics:

- Death and dying
- ALS and quality of life
- Care
- Cultural taboos
- Family life
- First-person film
- Film as a tool for social change
- Agency and consent/ethics
- Love

Background Information

The Taboo of Death and Dying

Death and dying are everywhere and nowhere—if we're lucky enough, that is, to be unaffected by war, say, or famine or life-limiting illness. News stories of crime victims, footage of wildfires, movies of missions impossible fill our screens in often spectacular and sentimental ways. Yet the realities of death and dying, of the pain, messiness, and monotony of a slow or even a sudden decline, are rarely shown. Likewise, they are rarely spoken of.

“The denial of death,” according to Ernest Becker’s 1973 Pulitzer Prize-winning bestseller of that name, stems from fear. Fear fuels our actions and lavish attempts to evade the truth of our own mortality. For Philippe Ariès, this state of denial marks a longer historical journey. From medieval to modern times, death shifted from being familiar to becoming forbidden. Until the eighteenth century, death was a shared event: an individual died at home, surrounded by family, neighbors, and children. After that, death became increasingly private, mannered, and mournful.

And in contemporary times, convention rules. It has become normal to segregate the dying into hospitals, to regulate the excesses of grief, and to hide the body in decline. There are various causes assigned to this enduring taboo. In *Western Attitudes Toward Death from the Middle Ages to the Present*, Ariès blamed the distinctly North American emphasis on the “preservation of happiness” in the early twentieth century for the modern state of denial. More recently, palliative care professionals have come to see the social and clinical imperative to prolong life as wholly unhelpful and responsible for how ill-prepared, how lacking in death literacy, people are when it comes to end-of-life decisions.

Sources:

Sarah Russell et al. *End of Life Care for People with Dementia: A Person-Centred Approach*. London: Jessica Kingsley Publishers, 2017.

Film and Life-Limiting Illness

Mainstream cinema has provided us with moving tales of terminal illness, but these rarely go beyond stereotypical or sanitized content. Whether it's Bette Davis in *Dark Victory* (1939), Ali MacGraw in *Love Story* (1970), Michael Keaton in *My Life* (1993), Sofia Vassilieva in *My Sister's Keeper* (2009), 50 Cent in *All Things Fall Apart* (2011), or James Norton in *Nowhere Special* (2020), those approaching death on screen are characterized by bravery, goodness, beauty, stoicism, and self-sacrifice if not self-improvement. There are exceptions: fiction films that offer much more honest, much more bodily and unsentimental accounts of decrepitude, such as *Hilary and Jackie* (1998) but especially *Wit* (2001) and *The Death of Mister Lazarescu* (2005). However, these are predominantly about women and white lives.

With documentary film we gain much greater insight into real dying. Notable examples like *Near Death* (1989), *Dying at Grace* (2003), and *Silverlake Life: The View from Here* (1993) get us up close to the truth of the experience. The first two are made by the esteemed documentarians Frederick Wiseman and Allan King, respectively, and are observational films set in hospitals. They're cut from hours and hours of footage recorded in palliative care wards. The latter is different. It is a video-diary that follows the everyday activities of a long-term gay couple, Tom Joslin and Mark Massi, who are both dying from AIDS. Most significantly—and groundbreakingly at the time—it was directed by Joslin himself, who dies on screen, along with his good friend Peter Friedman. Following the film's release, Friedman, in an interview with the Los Angeles Times, said, "Silverlake Life "involves two things this society tries to keep out of view—death and homosexuality. I really don't know what can be done about that resistance except to fight it by being honest."

The AIDS crisis provided the urgency behind *Silverlake Life* and technology enabled its intimacy. Shot on a handheld camcorder, a technique increasingly used in the 1990s, it follows the protagonists in their day-to-day lives. Film technology plays a similar role in *Eat Your Catfish*. The camera, most frequently mounted on the back of Kathryn's wheelchair, gives us access to the most personal of spaces and experiences, thereby defying the taboos and conventions surrounding illness and dying. It also ensures that Kathryn's perspective and experience are privileged and that this is her story, sometimes even told in her own, albeit computer-generated, words.

ALS and End-of-Life Care

Amyotrophic lateral sclerosis is a degenerative nerve disease. In the United States it is also known as Lou Gehrig's disease—after the baseball player who brought it to public attention when he was diagnosed with the disease in the late 1930s. It is a form of MND or motor neurone disease. Approximately 5,000 new patients are diagnosed with ALS every year in the United States and the mean survival rate is two to five years. It is a progressive disease. Symptoms get worse, but there is no fixed pattern or timeframe for their development. As yet, there is no cure for ALS. However, as Kathryn tells us in the film, opting for mechanical ventilation means that she could, in effect, go on indefinitely. This, she suggests with typical wit, is both its pro and its con. Subsequently, the emphasis shifts to the quality of life in this deferral of death, something that Kathryn alludes to at various moments.

English nurse and writer Cicely Saunders, founder of the modern hospice movement, spoke of helping patients live well until they die—a mission that underlies the ethos of palliative care worldwide and the mission of the ALS Association. That goal is achieved much more easily when attitudes toward illness and dying stop being shaped by taboo, silence, stereotype, and fear. Integral, therefore, to the outreach goals of the end-of-life community is enabling honest conversations about illness and death. Noah has said that his hope for the film is that it “succeeds in making life with and around ALS relatable and our shortcomings understandable without shying away from hard realities.”

Sources:

The ALS Association. als.org/.

“Amyotrophic Lateral Sclerosis.” Centers for Disease Control and Prevention. cdc.gov/als/What-is-ALS.html.

“Paralyzed by Late-stage ALS, Kathryn Clings to a Mordant Wit in ‘Eat Your Catfish’ on POV—July 24 at 10 pm.” WOUB Public Media, July 18, 2023. woub.org/2023/07/18/paralyzed-by-late-stage-als-kathryn-clings-to-a-mordant-wit-in-eat-your-catfish-on-pov-july-24-at-10-pm/.

Care

While we increasingly hear, see, and read stories about individuals' experiences of serious, life-limiting, or terminal illness—whether through movies, television documentaries, newspaper columns, first person films, or online vlogs—caregiving often remains invisible. When it is shown, the carers are often unnamed, interchangeable and peripheral. In *Eat Your Catfish*, though Kathryn's carers are still peripheral, we spend a great deal of time watching them do their jobs. We learn a few of their names, and we glimpse some nurses' close relationships with her and her family.

We also see Noah and Saïd struggling to respond to Kathryn's physical needs and emotional frustrations. Kathryn's care is an enormous part of her and her husband and son's lives, and the film must be understood in relation to the round-the-clock attention, or labor, that an advanced ALS patient requires. It must also be understood in relation to the mechanics and resourcing of the social care system. Kathryn is very fortunate to benefit both from a loving and dedicated family and from the constant support of a care agency that provides a stream of mostly familiar nurses. This won't be everyone's experience. Though research remains limited, clear discrepancies in access, treatment, and outcomes exist for minority groups. So, as a 2020 journal article on racial disparities in such care put it, "The story about race and palliative and hospice care in the United States is very much the same story of racism in health care." It is also worth remembering that, according to the World Health Organization, only 10% of people in the world who need palliative care receive it.

Care is the delivery to an individual of essential support or services that are needed due to illness, disadvantage, or disability. Care is also an expression of attention and affection: it conjures a sense of our deliberate and personalized connection with another individual's needs. In a short film about living with advanced ALS/MND, Andrew Burchall complains that carers “don't have any status at all”—unlike god-like surgeons or other medical doctors—yet their care is critical on an everyday level. *Eat Your Catfish* draws our attention to different kinds of care. For example, it contrasts Noah's patience with his mother and his and his father's exasperation with her. The direct-care workforce in the United States is huge, but caregiving is a job with long hours, job insecurity, and low wages. Figures for 2021 suggested that 40% of caregivers in the United States live in poverty or close to it.

Sources:

Mohsen Bazargan and Shahrzad Bazargan-Hejazi. “Disparities in Palliative and Hospice Care and Completion of Advance Care Planning and Directives Among Non-Hispanic Blacks: A Scoping Review of Recent Literature.” *The American journal of Hospice and Palliative care* 38, No. 6 (December 2020): 688–718. [ncbi.nlm.nih.gov/pmc/articles/PMC8083078/#bibr282-1049909120966585](https://pubmed.ncbi.nlm.nih.gov/PMC8083078/#bibr282-1049909120966585).

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Kimberly S. Johnson. “Racial and Ethnic Disparities in Palliative Care.” *Journal of Palliative Medicine* 16, No. 11 (November 2013): 1329–34. [www.ncbi.nlm.nih.gov/pmc/articles/PMC3822363/](https://pubmed.ncbi.nlm.nih.gov/PMC3822363/).

Kezia Scales and Lina Stepick. “Understanding the Direct Care Workforce.” PHI Policy Research. www.phinational.org/policy-research/key-facts-faq/.

Donna Wakefield et al. “Why Does Palliative Care Need to Consider Access and Care for LGBTQ People?” *Palliative Medicine* 35, No. 10 (2021): 1730–32. journals.sagepub.com/doi/full/10.1177/02692163211055011.

“WHO Takes Steps to Address Glaring Shortage of Quality Palliative Care Services.” World Health Organization, October 5, 2021. who.int/news/item/05-10-2021-who-takes-steps-to-address-glaring-shortage-of-quality-palliative-care-services.

DISCUSSION PROMPTS

The discussion prompts, which follow specific chapters of the film, are an invitation to dialogue. Please select discussion questions that are relevant to your community.

Starting The Conversation

Illness and dying are hard to talk about, and despite this film's warmth and humor, it is not an easy watch. This will be even more true for certain people, such as bereaved participants who have had similar experiences. It is important to give people time to reflect on the film and to gather themselves for a discussion. Creating a safe and relaxed space for this discussion is very important.

Some broad and icebreaking first questions could include:

- **What other films have you watched about illness and dying? In what ways is this film similar or different?**
- **If you were going to tell a friend about this film, what would you say? How would you describe the main message(s) of the film?**
- **Describe a moment or scene in the film that you found particularly disturbing or moving. What was it about that scene that was especially affecting?**
- **Did anything in the film surprise you? Was anything familiar?**
- **If you could ask anyone in the film a single question, whom would you ask and what would you want to know?**

Living with ALS/Life-limiting illness

- The film lays bare the pain and strain of ALS and of caring for a loved one at home. Kathryn reckons with her own agency and the frustrations and joys of continuing to participate in family life. *Eat Your Catfish* is a great film for generating conversations about palliative care and for increasing what Lisa Graham-Wisener has termed “death literacy,” defined as “the practical know-how [about dying that]... directly shapes the decisions we make about the care we receive as well as our ability to care for others.” What did you learn from the film about Kathryn and her life before and with ALS?
- What did you learn about ALS?
- What do Kathryn and the film teach us about quality of life? How does Kathryn want to live and die?
- Does the film provide insight into any other participants’ feelings about her condition? If so, who and what are their feelings? How did you feel in response?
- Has the film affected your attitude toward your own health and mortality? If so, how?

Care

- Thinking about the end of life requires thinking about care. Although medical interventions receive the greatest attention, status, and remuneration, it is care that shapes the last stages of someone's life: what kinds of care are shown in the film?
- Think of a few different examples of caregiving, or moments of care, being provided in the film. What are they characterized by? What does good or bad caregiving look like?
- What does the film teach us about care and caring?
- How did the film make you feel about the healthcare system?

Agency, Consent and First-person Filmmaking

- *Eat Your Catfish* is about Kathryn's experience of ALS and her relationships with her family. It works hard to tell the story from her perspective, to ensure her agency as far as possible. In what ways is *Eat Your Catfish* Kathryn's film?
- Through what means are her experiences and feelings centered in the film? Did this guarantee her ownership or authorship of the film?
- Think of different scenes from the film. How are Kathryn's wishes foregrounded? How are they compromised or forgotten?

Using Film for Social Change

- Film is a particularly powerful medium because of the way in which it immerses us so completely in others' experiences. Not only can it make us feel what others are feeling, but it can even compel us to act upon that feeling, to make us do something about the injustice or problem that has been exposed or, at least, to stop supporting its continuation through our silence or complacency. Do you think you'd have had a different response to Kathryn's story if you read about it in a newspaper article? Why is that?
- In what ways does technology play an important role in the management of Kathryn's condition? How does technology play an important role in the film?
- Senem Tüzen and Adam Isenberg had to edit down 930 hours of footage that Noah had generated into this 74-minute film. How do you feel about the amount of editing done? Can what you're seeing still be considered true, or objective, if so much is left out?
- Do you think this film can alter people's views on life-limiting conditions? What do you think is the most important ingredient for this?

Human Flaws and Family

- *Eat Your Catfish* is very honest about family dynamics and human failings, especially under duress. What were the key scenes about family in the film?
- Some may say that the film is above all else about love. Kathryn certainly suggests as much—her perseverance and choice to live on are about her love for her children. How does the film illustrate or define love?
- What kinds of emotions are expressed by family members? Jot down a list of the different emotions attached to the different participants. What do you notice about the dynamic of feelings in relation to one another?
- When Minou is trying on her wedding dress with her mother and her mother's best friend, Kathryn says, "Saïd is deeply concerned about the overrepresentation of Jewish interests at the wedding." Following gentle laughter, Minou says, "Well, he doesn't have to be worried. I'm more worried about the overrepresentation of sociologists." This feels typical of the film's, and the family's, sharp humor, but it also does a nice job of softening fraught subjects like Iranian-Jewish relations. What did you appreciate, or not, about the Arjomands as a modern American family?

CLOSING QUESTION/ ACTIVITY

OPTIONAL

At the end of your discussion, to help people synthesize what they've experienced and move the focus from dialogue to action steps, you may want to choose one of these:

What do you think is the main legacy of the film?

What do you think are the benefits of watching this film?

Did it change any of your views or attitudes?

TAKING ACTION

The most obvious action to be taken in response to the film is to use it to open up conversations about death and dying with loved ones. Such conversations can be an invaluable stepping stone toward ensuring that our wishes are known, understood, and fulfilled and that we live as well as possible until the end. Use the film to seize the moment.

Visit someone you know who can't get out much because of a life-limiting condition.

Become a buddy to or befriend someone in a hospice or palliative-care ward.

Set up a death café (see Resources) in your neighborhood or city.

If you're already part of a palliative-care organization or movement, connect with others to build a compassionate community and earn compassionate community or compassionate city status (see Resources).

Resources

ALS Association: www.als.org/
The preeminent organization fighting ALS on all fronts, including treatment, research, support, and social advocacy. The organization’s website is full of information about the disease and about support available via chapters throughout the United States.

Death Café: deathcafe.com/
Death cafés aim “to increase awareness of death with a view to helping people make the most of their (finite) lives.” They do this by setting up public discussion groups. These cafés are informal and characterized by their comfortable settings, absence of agendas, and availability of tea and cake.


End Well: endwellproject.org/
End Well is a nonprofit that works to transform how the world thinks about, talks about, and plans for the end of life.

Life:Moving—Using Film to Change Understandings of Dying: lifemoving.org/ This research-based and hospice-located project produced six short films by terminally ill participants. Shared with a wide range of audiences around the world—from medical

students, to nurses, to filmmakers, to community groups—they offer a diverse range of individuals and experiences. Two of the films are by ALS/MND sufferers. The project has now been turned into a clinical and creative training resource available on the site.

Public Health and Palliative Care International: phpci.org/ This association is an international forum for the exchange of information on research and good practice in the fields of public health and palliative care. It is also an informational hub for networking and becoming a compassionate community or compassionate city.

Credits & Acknowledgments



Michele Aaron is professor of film and television studies at Warwick University in the United Kingdom and director-curator of the Screening Rights Film Festival, where *Eat Your Catfish* screened in 2022. Among other publications, she's written an award-winning [book](#) and [essay](#) on death, dying, and the moving image and she specializes in the ethics of film and television. In 2017, she produced a series of short films made by participants affected by terminal illness as part of the [Life:Moving](#) project.

THANKS TO THOSE WHO REVIEWED THIS GUIDE

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