



DISCUSSION GUIDE

Exit Music

Documentary film

Directed by Cameron Mullenneaux

Exit Music is a rare invitation into the world of a young artist dying of cystic fibrosis as he and his family navigate the ominous, sacred, and unmapped journey at the end of life.

FILM SYNOPSIS

Artist-musician Ethan Rice was born with cystic fibrosis, an incurable genetic illness that eventually leads to respiratory failure. Equal parts comedy and heartache, *Exit Music* is the last year, last breath, and final creative act of Ethan Rice as he awaits the inevitable.

With stunning access, the film closely follows Ethan's final months, weeks, days, and hours and is witness to death's transformative influence on a family. Home video footage traces the bond between Ethan and his father Ed, a Vietnam veteran with Post Traumatic Stress Disorder who withdrew from the world to become a stay-at-home dad. Ed immersed Ethan in a world of art, creativity, and imagination and documented it all on camera, a hobby that provided relief from the fear of his son's ominous prognosis and his own painful past.

Interweaving home movies with Ethan's original music and animation, his story is an unflinching meditation on loss and invites the viewer to experience Ethan's transition from reality to memory. In a culture that often looks away from death, Ethan's story is a reminder that dying is a profound and universal cornerstone of the human experience.

WHAT IS CYSTIC FIBROSIS?

Imagine your body is like a big, complicated plumbing system. In people with cystic fibrosis (CF), there's a problem with the pipes: they get clogged up with thick, sticky mucus. This happens in places like the lungs, where it makes it hard to breathe, and the digestive system, where it makes it tough to get nutrients from food.

Normally, our body makes mucus to keep things moist and protect organs, but in CF, the mucus is much thicker and stickier than it should be. This causes two main problems:

1. **In the lungs:** The thick mucus gets stuck in the airways, causing infections, coughing, and trouble breathing.
2. **In the digestive system:** The mucus blocks enzymes from getting to the stomach, which means people with CF can't digest food properly and may have trouble getting the nutrients they need.

It's a genetic condition, so people are born with it. There's no cure, but with treatments and care, people can manage the symptoms and live longer, healthier lives.

NOTE ABOUT DISCUSSION GUIDE

We've compiled a series of questions to help individuals and groups to discuss and reflect on end of life issues. Not all questions are applicable to every viewer, so we hope you will use this guide as inspiration to curate the appropriate experience for your group. Please keep in mind the sensitivity of these deeply personal issues. Some individuals may not feel comfortable responding in a group setting. Consider using some of the questions as journal prompts. We've offered a lot of options and hope you will pick and choose the discussion direction that works for you.

PRE-SCREENING PERSONAL REFLECTIONS

Before watching the film, reflect on these questions:

1. When you imagine what the "end of life" looks like, what is the first word or image that pops into your head?
2. What issues do you expect to see in a film about terminal illness?
3. Do any current events or media headlines come to mind about the topic of end of life or terminal illness?
4. Do you have any fear or resistance going into this film?

POST-SCREENING PERSONAL REFLECTIONS

After watching the film, consider these questions:

1. How do you feel after watching the film?
2. Did anything surprise you about the film?
3. Does the film make you think differently about your relationship to death and mortality?
4. How can individuals, families, and/or healthcare professionals better prepare themselves, loved ones, and patients for the end of life?
5. Is there anything about Ethan's story that you can relate to in your own life?
6. Why do you think death is often a difficult topic for people to talk about?
7. How might our collective fear about death impact the way we care for people who are ill or dying?
8. How do you think different cultures or religions view death? Can you think of any rituals or customs that help people cope with loss?
9. What does it mean to "live well" or to "die well"? How do you think the way a person lives their life influences their death?

QUESTIONS ABOUT THE FILM AND STORY

1. What role do you think humor plays in facing suffering? Can you describe an instance where Ethan reacted to a difficult circumstance with humor? Any examples from your own life?
2. Ethan talks about how he's not going to be able to reach all the milestones people his age expect to experience: travelling, buying a house, getting married, etc. He says "I'm watching life wiz past me and there's nothing I can do about it. I constantly have to find a short term goal..." Share your ideas about the power of setting short term goals?
3. In one scene, Ethan is in a hospital bed scrolling through Facebook seeing pictures of his friends apple picking. He says he isn't invited to do things anymore because he's a nuisance to have around with all his medical equipment and needs. Loneliness is a universal human emotion, but how do you think Ethan's illness impacts his friends?
4. What does Ethan's doctor mean when she says "a natural death for Ethan would've been two decades ago?"
5. You see two sides of Ed, the fun-loving father and the scared and overwhelmed caregiver. What did you learn about caregiving that you didn't know before?
6. Can you discuss your observations of Ed and the analogy of "fighting the disease like a war."
7. Seeing Ethan at a concert, what do you think went into making that happen?
8. Ethan has a huge epiphany after Dr. McVeigh says, "You have to think, is there a point when this technology is no longer serving you? There's this line that's crossed where is it helping you live or is it prolonging your dying?" What do you think is going through Ethan's mind?
9. When the doctors came over to the Rice house to mediate a conversation between Ethan and his family, Ed was visibly shaken and said, "The question I have to ask Ethan is if he wants as many rescue methods as we can do by hand meaning mouth to mouth resuscitation and CPR." Knowing Ethan doesn't want to be hooked up on machines and doesn't want life-preserving interventions, why do you think Ed said this?
10. Ethan's mom Edith had a subtle presence in the film, what do you learn about her and what do you see as her influence on the family
11. Why do you think Ed was drawn to documenting Ethan on camera?

QUESTIONS FOR STUDENTS/PROFESSIONALS IN HEALTHCARE

Personal Beliefs and Professional Responsibility

1. How do your personal beliefs about death and dying influence your approach to end-of-life care?
2. How do you navigate potential conflicts between your values and the needs of your patients?
3. Should healthcare professionals be required to reflect on their own beliefs and biases regarding death in order to provide more effective care? If so, how can this be done respectfully?

Communication and Decision Making

1. How do you initiate conversations with patients and families about end-of-life care, especially when there is resistance or fear surrounding the subject?
2. How do you balance the need for clear, honest communication with the desire to maintain hope in terminally ill patients and their families?
3. What is your role in ensuring that patients' advance directives (living wills, DNR orders) are respected, and how do you handle situations where family members disagree with them?

Palliative Care vs. Curative Care

1. How do you determine when curative treatments should no longer be pursued in favor of palliative care?
2. In your experience, what are the barriers to integrating palliative care early in a patient's illness, and how can these barriers be overcome?
3. How do you manage the transition for patients and families from aggressive treatment to comfort-focused care without creating feelings of abandonment?

The Role of Hospice Care

1. How do you assess when hospice care becomes appropriate for a patient, and how do you ensure that patients and families understand the benefits of hospice services?
2. In your experience, what are some misconceptions that patients and families may have about hospice care? How can these be addressed effectively?
3. What are the most significant challenges you face when transitioning a patient to hospice care, and how can you better support families during this time?

Grief and Bereavement Support

1. What role do you see for healthcare providers in supporting the grieving process for families, both during the patient's life and after their death?
2. How do you approach your own emotions when you form close bonds with terminally ill patients or their families? How can healthcare providers avoid burnout while remaining empathetic and compassionate?
3. What can be done to improve the integration of grief counseling and bereavement support within the healthcare system?

Classroom Activities or Project Assignments

1. **Research and Reflection:** Break out into small groups and divide up the following topics:
 - a. Research the difference between “palliative sedation” and “physician aid in dying” and share your findings with the group.
 - b. Research “health care proxy” and “living will” and discuss them with the class.
 - c. Research the medicalization of death and dying and how that might impact our cultural attitudes towards death and the grieving process.
 - d. What constitutes a good death?
2. **Debate:** Hold a class debate on a controversial issue related to end-of-life care, such as physician-assisted suicide or the use of life support. Assign students to different sides of the debate and have them research and present their arguments.
3. **Guest Speaker:** If possible, invite a healthcare professional or a hospice worker to speak with students about their experiences with death and end-of-life care, and open up a Q&A session for students to ask questions.
4. **Art and Creative Expression:** As a class, come up with several themes of the film. Then, choose a theme to inspire an art project using any creative art form (drawing, watercolor, music, poetry, photography, etc). Write an artist statement to go along with the project.
5. **Interview a friend or relative:** Choose a friend or relative and interview them about death and dying. You can ask personal questions about their own end of life wishes, spiritual beliefs, and personal experiences with loss and grief. Come up with interview questions and write an essay about what you learn.

RESOURCES

Workbook and conversation starter kit

Initiate end of life discussions with family members, friends, and patients:
www.theconversationsproject.org

Personal reflections and memoirs

"When Breath Becomes Air" by Paul Kalanithi

This memoir is by a neurosurgeon who was diagnosed with terminal cancer. He reflects on life, death, and the intersection of medicine and human experience.

"The Year of Magical Thinking" by Joan Didion

This memoir explores Didion's experience with the sudden death of her husband and the prolonged illness of her daughter. It's a raw and poetic exploration of grief and loss.

"Tuesdays with Morrie" by Mitch Albom

A beloved classic, this book recounts the author's conversations with his old professor, Morrie Schwartz, as he approaches the end of his life due to ALS. It's a touching exploration of life, death, and the lessons we learn along the way.

"The Denial of Death" by Ernest Becker

This book dives into how humans are often in denial about death and how this denial shapes much of our behavior. It's a deep and sometimes difficult read but incredibly thought-provoking.

"On Death and Dying" by Elisabeth Kübler-Ross

This classic work introduces the five stages of grief (denial, anger, bargaining, depression, and acceptance) and explores the emotional processes that people go through when faced with terminal illness.

"Being Mortal: Medicine and What Matters in the End" by Atul Gawande

Gawande, a surgeon, examines how modern medicine deals with aging and dying. He discusses the challenges of end-of-life care and advocates for more humane and compassionate approaches to death.

"The Five Invitations: Discovering What Death Can Teach Us About Living Fully" by Frank Ostaseski

This book is written by a co-founder of the Zen Hospice Project. It presents five guiding principles that help you live more fully by understanding death.

Children's books

"The Fall of Freddy the Leaf" by Leo Buscaglia

This book uses the story of a leaf to explain the natural cycle of life and death. It's simple yet profound and is often recommended for younger children.

"When a Pet Dies" by Fred Rogers

Written by the beloved Mr. Rogers, this book offers comfort and clarity for children dealing with the loss of a pet, but its message can apply to many types of loss.

Coping with Grief

"The Grief Recovery Handbook" by John W. James and Russell Friedman

This is a step-by-step guide to help people who are grieving. It gives practical tools and a structured way to process grief.

"Grief Is Love: Living with Loss" by Marisa Renee Lee

A blend of personal experience and practical advice, this book offers comfort to those experiencing the profound pain of losing someone.

Movies

End Game: Explores the process of death and dying by following individuals as they navigate their final days, particularly highlighting the approach of the Zen Hospice Project which aims to provide a more holistic and humane experience around death. Directed by *Rob Epstein and Jeffrey Friedman*.

How To Die in Oregon: Documents stories of terminally ill Oregonians utilizing legal physician-assisted suicide, their loved ones, doctors involved, and passage of a similar law in Washington. Explores perspectives around this ethically complex issue. Directed by *Peter Richardson*

A Lion in the House: Five families struggle with the ups and downs of cancer treatment over the course of six years. Five families struggle with the ups and downs of cancer treatment over the course of six years. Directed by Steven Bognar and Julia Reichert.

Organizations and Institutions in Palliative Care

The Palliative Care Institute (USA) – Offers training and education for healthcare providers on palliative care practices.

The World Health Organization (WHO) – The WHO has done extensive work on defining and promoting palliative care globally.

The National Hospice and Palliative Care Organization (NHPCO) – An advocacy group in the U.S. that works to expand access to hospice and palliative care services.

GLOSSARY OF TERMS

Palliative Care: Palliative care is a specialized form of medical care focused on providing relief from the symptoms, pain, and stress of serious illness, regardless of the patient's age or stage of the illness. It aims to improve the quality of life for both the patient and their family, and it can be provided alongside curative treatments. It addresses physical, emotional, social, and spiritual needs.

Hospice Care: Hospice care is a type of palliative care specifically for patients who are nearing the end of life, typically when they are no longer seeking curative treatments for a terminal illness. Hospice focuses on providing comfort, pain management, emotional support, and helping families with the emotional challenges of dying. It is often provided in the home or in a hospice facility, and it emphasizes quality of life rather than prolonging life.

Palliative Sedation: Palliative sedation is the use of medication to induce a state of deep sedation or unconsciousness in a terminally ill patient who is experiencing intolerable suffering that cannot be relieved by other means. The goal is to alleviate extreme pain, agitation, or distress in the final stages of life. It is typically used when a patient is near death and suffering from intractable symptoms like severe pain or breathlessness.

Physician Aid in Dying: Physician aid in dying refers to a practice in which a physician provides a terminally ill patient with the means (typically a prescription for a lethal dose of medication) to end their own life. This is distinct from euthanasia, where the physician directly administers the lethal medication. Physician aid in dying is legal in some U.S. states and other countries, but it is subject to strict regulations and only available to patients who meet certain criteria, such as having a terminal illness with a prognosis of six months or less to live.

Prognosis: Prognosis refers to the likely course or outcome of a disease, including the chances of recovery, remission, or death. In medical contexts, it involves an estimate of how long a patient might live or how an illness may progress. A prognosis can be based on factors like the type of disease, the patient's age, overall health, and response to treatment.

Right to Die: The "right to die" refers to the belief or legal stance that individuals should have the autonomy to choose to end their own life, particularly in cases of terminal illness or severe suffering. This concept is tied to the debate over physician-assisted suicide, euthanasia, and the legal ability to refuse life-sustaining treatment. The right to die is a controversial topic and is governed by different laws in various regions and countries.

Respiratory Failure: Respiratory failure is a medical condition in which the lungs are unable to adequately exchange gases (oxygen and carbon dioxide) to maintain normal blood oxygen levels or remove carbon dioxide. It often requires immediate medical intervention, such as oxygen therapy or mechanical ventilation, to support breathing.

Health Care Power of Attorney (HCPA): A Health Care Power of Attorney (sometimes called a Medical Power of Attorney or Durable Power of Attorney for Health Care) is a legal document that allows an individual (the principal) to appoint someone (the agent) to make healthcare decisions on their behalf in the event they are unable to do so due to illness, injury, or incapacity. This can include decisions about medical treatments, life support, and end-of-life care.

Oxymizer: An **Oxymizer** is a type of oxygen-conserving device that allows patients to use less oxygen while still receiving the necessary amount. It is typically used for people with chronic respiratory conditions like COPD. The Oxymizer system works by delivering oxygen in a more efficient way, reducing the amount of oxygen wasted with each breath, which can make oxygen therapy more affordable and effective.

Post-Traumatic Stress Disorder (PTSD): a mental health condition that can develop after someone experiences or witnesses a traumatic event. This can include events like combat, natural disasters, accidents, assaults, or any situation that causes intense fear, helplessness, or horror. Symptoms of PTSD can include:

- **Intrusive thoughts:** Flashbacks, nightmares, or unwanted memories related to the trauma.
- **Avoidance:** Steering clear of places, people, or activities that remind the person of the traumatic event.
- **Negative changes in mood or thinking:** This might include feeling numb, detached from others, or having difficulty remembering parts of the trauma.
- **Hyperarousal:** Being easily startled, feeling tense, having trouble sleeping, or being irritable or angry.

Stop-motion animation: a filmmaking technique where objects or characters are photographed one frame at a time, with slight movements made between each shot. When played back at normal speed, the images appear to be in motion. The technique has been around for over a century and has influenced both short films and feature-length movies. It's especially popular for its tactile, handmade feel, which digital animation sometimes can't replicate.

ABOUT THE FILMMAKER

Cameron Mullenneaux

Exit Music, Director

Cameron Mullenneaux is an Emmy-nominated nonfiction filmmaker whose work captures the emotional undercurrents of the human experience. Her directorial debut Exit Music, a co-production of ITVS, premiered at Hot Docs International Film Festival, broadcast on PBS in 2019, and is now streaming on Amazon. She directed and produced Angelique, a short film nominated for a News and Doc Emmy and acquired by Conde Nast/Glamour. Cameron is a fellow of SFFILM's FilmHouse artist residency and served as a creative producer for Masterclass and senior story editor for OMGYES. She holds an MFA in documentary film production from Wake Forest University and a BA in death and dying studies from Warren Wilson College.

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