

EXTREMIS
DISCUSSION GUIDE

DR. JESSICA ZITTER

EXTREMIS DISCUSSION GUIDE, 2019

WELCOME

Extremis is a powerful tool for both personal reflection and cultural transformation. Organizations across the globe have used the film as a tool to invite audiences of all kinds to take a step back and ask: What do we really want for ourselves, our loved ones, and our patients when death comes?

It is our hope that this Discussion Guide will be of use to both individuals and organizations for navigating the film, as well as taking the next steps to prepare for critical care situations.

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For more information about the film, or to learn more about inviting Dr. Zitter to host an event or workshop based on this and other narrative tools for your community, please feel free to reach out to Dr. Zitter's team at info@jessicazitter.com.

INTRODUCING *EXTREMIS*

Extremis offers a front row seat to the ICU.

Conceived by Dr. Zitter as a catalyst for changing the current paradigm of medical care for the dying, *Extremis* was initially released in September of 2016, becoming the first original short documentary to be acquired by Netflix. Since its release, *Extremis* has garnered interest internationally. During the first week alone, the *Extremis* trailer was viewed by over 5.7 million people worldwide. It has since been translated into 90 languages.

Directed by Emmy and Academy Award-nominated filmmaker Dan Krauss, this verité documentary explores the harrowing decisions facing patients, families and physicians in urgent end-of-life cases. As it follows Dr. Jessica Zitter and her team through the intensive care unit of a public hospital in Oakland, California, this 24-minute film provides a uniquely intimate look at the intersection of science, faith, and humanity.

Set in a public hospital in Oakland, California, it highlights the discrepancies in healthcare delivery for underrepresented communities, particularly African Americans and the economically underprivileged. The film also touches on the role that religion plays in decision making at the end of life.

Drawing its power from the true stories of ordinary people, it invites the viewer to grapple with the complexities of urgent medical decision-making in serious illness. Ultimately, we witness both the beauty of saving life and the beauty of a good death.

AWARDS & NOMINATIONS

Extremis has received or been nominated for:

- Academy Awards - Nominated for Best Documentary Short, 2017
- Emmy Awards - Nominated for Outstanding Editing, 2017
- Emmy Awards - Nominated for Outstanding Short Documentary, 2017
- Tribeca Film Festival - Winner of Best Documentary Short, 2016
- San Francisco International Film Festival - Winner of the Golden Gate Award for Bay Area Documentary Short, 2016
- International Documentary Award (IDA) - Nominated for Best Short, 2016
- Cinema Eye Honors Awards - Nominated for Outstanding Achievement in Nonfiction Short Filmmaking, 2016

INVITING DR. ZITTER TO YOUR SCREENING

Organizations across the country have invited Dr. Zitter to introduce the film and follow the screening with a guided discussion and Q & A.

Dr. Zitter offers guided workshops using *Extremis* and other narrative tools to empower patients, families, healthcare providers, and organizations to transform the way we care for the dying.

Learn more about inviting Dr. Zitter to your event, as well as her other offerings, [here](#).

NETFLIX AGREEMENTS

Netflix generously allows the film to be screened for free for education purposes through an existing Netflix account. [Learn more about their policy here](#).

HOW TO USE THIS GUIDE

In each section, you will find:

- A prompt related to the content of the film
- A set of suggested discussion questions
- Insights from Dr. Zitter on the topic, including her own reflections on the film.

We encourage you to use these as a springboard for further exploration. It is our hope that these discussion topics serve only as a guide to helping you facilitate a meaningful and engaged discussion around the film for your community.

If you would like to share feedback on this discussion guide, please write to info@jessicazitter.com. We welcome your suggestions.

DISCUSSION QUESTIONS

1/ THE END-OF-LIFE CONVEYOR BELT

In the film, we learn that Gordon and Donna had discussed Donna's aversion to breathing machines long prior to her hospitalization. Nonetheless, Donna still ends up on a breathing machine during her intensive care.

QUESTIONS FOR DISCUSSION

- Why do you think Donna ends up on a breathing machine?
- What did you notice about the flow of communication regarding Donna's preferences, prognosis, and treatment options?
- How would you have felt about this outcome in your own healthcare?
- What would have had to have been done differently to ensure her preferences were both known and followed?

FROM DR. ZITTER

I am a great believer in saving lives with medical technology. It's why I have loved working in the Intensive Care Unit. But when these powerful tools and technologies are used on the dying without any discussion about the benefits or the burdens of such treatments, and without acknowledging the reality of impending death, then we have a situation that is not centered around the patient's preferences. I call this the "end-of-life conveyor belt," which results from our modern medical drive to use machines and technologies to "save the day." It's such a powerful, automatic, and fast-moving conveyor belt that it's hard not to get carried away on it, right up until the end.

Why does this happen? There is a tremendous communication barrier that often exists between the doctor and the patient and family. Studies show that we doctors do not have much in the way of communication skills, and thus often do a poor job at transmitting the seriousness of a patient's condition. In addition, doctors have a very hard time breaking bad news. So, we instead focus on the next treatment we can apply to the failing organ system, even if we don't really think it will help. We want to keep trying, keep hoping, keep offering new options. It makes us feel more caring, more kind, more successful. But in so doing, we risk becoming technicians, guided by protocol, rather than the caring professionals that we want to be.

2/ KNOWING WHAT YOU WANT

Following the decisions made in the film, Selena lived, semi-conscious and often in pain, on machines for almost six months until she died. Since we did not know what Selena's preferences were, we could not know whether this outcome was acceptable to her or not.

QUESTIONS FOR DISCUSSION

- Why do you think Selena ends up living on machines until her death?
- What did you notice about the communication regarding Selena's prognosis and treatment options?
- Would this outcome be acceptable to you?
- What would have had to be done differently to provide for an alternate outcome?

FROM DR. ZITTER

People's preferences are unique, as they should be. For one person, living attached to machines would never be acceptable, while for another, it would be preferable to death. For one person, anything less than full emotional and cognitive functioning feels essential, while for another it might be acceptable to live without all of those faculties if they were able to still enjoy the company of their family. And importantly, these preferences can change over time, and with the advent of worsening disease.

I wish that Selena had given her daughter, and her doctors, a sense of her preferences in this circumstance. If I knew for sure that she would have found the last 6 months of her life acceptable, I would have felt a lot less conflicted by our efforts to keep her alive.

I cannot stress enough the importance of all families having conversations about these preferences in advance. This allows everyone - the patient, her surrogates, and the healthcare team - to be comfortable in knowing that we are truly honoring a patient's wishes.

I will admit something else here: when I watch the film, one of the places that I cringe is when I hear myself say: "She won't have a meaningful recovery." What I wish I had said is that she wouldn't have a functional recovery, that she won't be able to have much mental awareness, live independently, or physically care for herself going forward. But it was not my place to make a judgment about whether living as she did for 6 months wouldn't be meaningful to her.

3/ LIFE-PROLONGING TECHNOLOGY

If Donna had agreed to be placed permanently on a breathing machine with a surgical tracheostomy, she would have stayed alive longer, weeks, maybe even months. But having watched her father and sister die from the same disease on ventilators, she was absolutely clear that she didn't want that for herself.

QUESTIONS FOR DISCUSSION

- Under what conditions would you be willing to undergo efforts by the medical team to prolong your life at all costs?
- The latter might include breathing machines, dialysis, feeding tubes, and living in a healthcare facility. Consider for yourself:
 - Would it be crucial that you are eventually able to feed yourself again?
 - To recognize your family again?
 - To be able to speak again?
 - To eventually manage your own personal hygiene?

FROM DR. ZITTER

There is no right or wrong here. Again, this is a very personal matter, and I will underline the importance of taking the time and doing the important work of thinking these issues through for yourself, and then, importantly, transferring that information to your loved ones and healthcare team.

Related to this topic, although it does not appear in the film, is the rising interest in medical aid in dying. This is of course something to think about very seriously, and one that both your loved ones and healthcare team should know your opinions and preferences regarding.

4/ PALLIATIVE CARE

Even though Selena's daughter directed us to keep her alive at all costs, she benefited from ongoing Palliative Care intervention to address her symptoms. Likewise, Donna and her family benefited from our interventions of enhancing communication as well as keeping her physically and emotionally cared for all the way until the end.

Although people often assume that Palliative Care is only for dying patients, these services can also be helpful to any patients with serious suffering. They can be delivered either instead of or alongside high-tech life prolongation.

QUESTIONS FOR DISCUSSION

- What is your understanding and perspective on Palliative Care?
- What conditions would inspire you to request it?
- Have you witnessed a case where a patient benefited from Palliative Care services? Or perhaps one where you wish they had been used?

FROM DR. ZITTER

A lot of people are unaware of the differences between Hospice Care and Palliative Care, which is not only for dying patients.

I see Palliative Care as “wrapping an extra layer of care” around the patient and family by enhancing communication and understanding about what is happening and what the options are, as well as bringing a unique expertise relating to the management of suffering.

If you are finding that you are confused about what is happening, aren't getting the communication you would like from your healthcare team, feel that things are happening without your knowledge or understanding, suspect that you aren't being told the full truth, or are suffering from ongoing and inadequately treated symptoms, I recommend you request a Palliative Care consultation from the treating team.

Hospice is a subset of Palliative Care. It is for patients who are considered to be 6 months away from death, and is most often administered in the patient's home. Hospice services are available to those patients who have decided to cease disease-oriented treatments like chemotherapy, which by this point are often found to cause more harm than benefit.

5/ FAMILY CONFLICT

In moments of crisis and high stress, conflict can be a normal response. In the film, we see moments where both of the main families have episodes of conflict between family members.

QUESTIONS FOR DISCUSSION

- In your family, has conflict or disagreement ever impacted the experience of a dying loved one?
- What are some strategies you used or could imagine using to resolve it?
- What would be some resources you could draw on?

FROM DR. ZITTER

Serious illness can often bring out unresolved past conflict and raw emotions in families. While not surprising, this can put a vulnerable patient at significant risk. Most of the time, these conflicts arise from the stress and sadness of the situation, but financial issues, sibling rivalry, and guilt can all play roles.

Most of the conflicts that arise might have been avoided with advance planning, whether care-related, financial, or medical. It is human nature to deny our mortality, and so it makes sense that these details often haven't been attended to. But I have borne personal witness to the suffering that results in these situations and I encourage all of you to "lean in" to the work that needs to be done.

6/ COMMUNICATING WITH YOUR FAMILY

Gordon and Donna knew exactly what Donna's disease trajectory would bring, having watched other family members with the genetic condition progress through respiratory failure and eventually die on a ventilator. She had repeatedly told Gordon that she didn't want to be put on machines, and that clarity helped her to die the way she wanted.

QUESTIONS FOR DISCUSSION

- Have you spoken with your family about your preferences around dying?
- Have you discussed each member's preferences for how they would want to live until the very end?
- If you have had these conversations, what did you learn from them?
- If you haven't had these conversations, what have you noticed as the obstacles to starting them, and what steps could you take to move in that direction?

FROM DR. ZITTER

Having the clarity of Donna's preferences allowed me to care for her in the way that she wanted. As you see in the film, I tried every which way to communicate with her when she was on the ventilator, but was unable to. I depended on the information that she had given, repeatedly over time, to her brother.

I cannot encourage you enough to reflect on your preferences and values, and then communicate them to your loved ones and physician over the entire course of your adult life. Our preferences will likely change over time, so it is important to maintain ongoing communication. That clarity helps us all--patient, loved one, and doctor alike--to rest in the comfort that we will do the right thing at this critical time.

7/ COMMUNICATING WITH YOUR HEALTHCARE TEAM

“That’s the first time I’ve heard that,” says Selena’s brother, when Dr. Zitter states that Selena will not likely wake up again. Data show that less than half of advanced terminal cancer patients understand their terminal prognoses (*Palliative Medicine*, May 2017). We can juxtapose this with Selena’s daughter, who does not seem to want to hear Dr. Zitter’s poor prognosis for her mother, stating that Dr. Zitter is “dwindling the optimism.”

QUESTIONS FOR DISCUSSION

- How did you feel about the communication between Dr. Zitter and the families?
- Are you the kind of person who prefers to “stay positive” and would prefer to hear only good news? Or would you rather hear what the doctors are really thinking, both positive and negative?
- What are the pros and cons of each?

FROM DR. ZITTER

The failure of information transfer between healthcare team and patient can be attributed to two main factors:

- 1) The healthcare team isn’t telling it like it is
- 2) The patients and/or family doesn’t want to hear bad news.

It is now widely accepted that physicians are not adequately trained or compensated to tackle the difficult work of breaking bad news. Yet data overwhelmingly shows us that patients who have more knowledge are able to make better choices for themselves. We doctors must do better. Medical education is changing slowly. But in the meantime, you will be more likely to get the truth that you need if you ask your doctor directly for her sense of the prognosis.

Even when physicians are trained and willing to do this, it can be very difficult for us. Data shows that patients and families like doctors better who bring good news rather than bad. That has been true in my experience, and I struggle between my desire for my patients to like me and my desire to tell them the truth as I see it. It is always easier for me to do this if the family or patient is open, even asking, for the truth.

8/ ROLE OF THE SURROGATE

In the film, we see two different “surrogate decision makers,” Donna’s brother Gordon, and Selena’s daughter Tama. The surrogate is ideally chosen by the patient in advance of incapacitation. This person is responsible for making medical decisions for you if you are no longer able to speak for yourself. You should take great care when selecting this person, as it is a serious emotional responsibility.

QUESTIONS FOR DISCUSSION

- How did it feel watching Gordon and Tama make decisions on behalf of their loved ones?
- How would you feel if you were in that position, or if someone had to play that role for you?
- What would you want them to know?
- Who would you choose as your surrogate if you were unable to speak for yourself?
- If you are someone’s surrogate, what would you know from that person?

FROM DR. ZITTER

Although it is always best to learn about the patient’s preferences and values directly from her own mouth, sometimes we have to settle for second best if the patient can no longer speak to us.

The job of the surrogate decision maker is to make decisions as the patient’s representative, in a process called *substituted judgment*. In an ideal world, that would mean that the patient would have directly communicated her choices, in the event of a variety of different possible outcomes, for the kind of medical treatments she will receive. Or the surrogate would have a sufficiently robust knowledge of the patient’s preferences that he could speak knowledgeably about what she would want, even if that particular outcome had never been discussed.

9/ DEALING WITH UNCERTAINTY

As we see in the film, Drs. Zitter and Bhargava disagree on when to break bad news to Donna and her family. Surrogates also struggle with uncertainty, as seen with discussions involving Selena's brothers.

QUESTIONS FOR DISCUSSION

- What did you notice about the different approaches to dealing with uncertainty presented in the film?
- Do they wait until they have done everything possible to be 100% certain she is dying, or do they let the family know what they are thinking even without "perfect certainty?"
- Would you rather that your doctor wait to achieve perfect certainty before sharing news, or would you prefer to be informed about her thinking along the way?
- Have you been in situation where you had to balance uncertainty in your decision making process? What did you learn?

FROM DR. ZITTER

There's no perfect certainty until death. Uncertainty provides us all, doctor and patient alike, with a way to avoid difficult conversations. Some doctors feel justified in withholding their experienced opinions about prognosis if they have even the slightest uncertainty about how long the patient has to live.

The problem is that we are frankly never 100% certain that someone will die until he actually does. And so too often patients and families don't end up learning what their doctors think until it's too late, or the suffering has gone on too long. And patients and families, for their part, often welcome a reprieve from the truth as well.

We know that patients and their families like doctors who give good news better than those who bring bad news. And everyone wants to be liked, even your doctor. So if you want to hear what your doctor actually considers the patient's trajectory, you might need to encourage her by saying that you understand there is no crystal ball, but you would still like to know what she's thinking. Remember, you can't plan for a good death if you don't know that you are dying.

10/ TREATMENT CHOICES

Donna chose to be extubated, and she had a good death. Selena's daughter chose to keep her attached to machines until she died several months later. Some people have felt that the two main stories in the film send the message that patients with serious illness are going to be better off if they withhold or withdraw life-prolonging treatment, but it's never that simple.

QUESTIONS FOR DISCUSSION

- What did you notice about the different approaches to the use of life-prolonging treatments?
- What are your personal feelings about the use of life-prolonging treatments in serious or terminal illness?
- What would you want for yourself in such a situation?

FROM DR. ZITTER

It is hard to represent all perspectives in a 24 minute documentary, and filmmaker Dan Krauss did a wonderful job of bringing out some of the important issues in these two cases that he was able to observe. But I deeply believe that the best medical decisions made for patients at the end of life are those which hold true to their preferences and values, whatever they may be.

Medical technology is not the problem. With it, I have saved countless lives. And I have prolonged some patients' lives on it so that, even though they are living in a ventilator facility attached to machines, they are able to live in a way that is acceptable to them. The problem with medical technology only arises when it is used by default, without reflection and discussion about what the patient would want.

11/ ROLE OF RELIGION & SPIRITUALITY

In the film, Selena's family members express strong belief in God and the possibility of miracles. The family ultimately decides to keep Selena alive on machines until her death, in the event that God will work a miracle and change the course of her medical condition.

QUESTIONS FOR DISCUSSION

- How do you relate to this family's decision-making process?
- How do you see the role of religion or spirituality in healthcare?
- Does your religion hold a view on the cessation of life-prolonging treatment?
- How do you relate to the perspective that withdrawing support could connote "giving up hope" or not trusting in God?
- If you are a person of faith, do you feel God has any particular expectations of doctors and loved ones when the patient is dying?

FROM DR. ZITTER

Many of my patients are people of faith. And most people, whether religious or not, want to maintain hope as they contend with serious illness. Often, they express their hope, and their faith in God, by stating that they are waiting for a miracle.

I am Jewish, and I too believe that there is a higher power present in the world. And I have come to see that there are many different kinds of miracles that we can hope for: the miracle of someone's pain being controlled; the miracle of a relationship reconciled before death; the miracle of a few days at home with family. And I've also experienced the importance of praying with families of faith as their healthcare provider. Where I used to leave the room when people started to pray, now I stay and support them, even join their circle. It is healing and strengthening not only for them, but for me as well.

Where I used to shy away about talking about hope and miracles, now I embrace that conversation, realizing that if I can help my patients and their families find hope and appreciation in the things that we are able to do to improve a patient's life, I can drastically change the course of it.

12/ RACIAL INEQUITIES IN HEALTHCARE

Extremis was filmed at Highland Hospital, a public hospital in Oakland, California, which serves a predominantly African American population. There is rising concern as well as increasing amounts of data that attest to the fact that African American patients receive care and die very differently than white patients. Data shows they are more likely to die attached to machines in institutions, less likely to die at home, and that there may be a preference among African American patients for an increased level of aggressive care.

QUESTIONS FOR DISCUSSION

- How do you interpret this data? Do you believe there is a true difference in preference, or is something else at play?
- What is your perspective or experience of racial inequities in healthcare? If you are African American or a person of color, what has been your experience receiving healthcare? What did you notice about communicating with your healthcare team?
- How could healthcare professionals better care for African American patients?

FROM DR. ZITTER

I have spent my career caring for mostly African American patients in the inner cities of Newark, New Jersey and Oakland, California. I have always been aware of injustices in our system, but over the past few years the disparities that exist in end-of-life medical care have become glaringly obvious. The data are clear: African Americans die very differently. They don't benefit from helpful services like Hospice, in nearly the numbers that white people do. They suffer more pain. They are less likely to be home with their loved ones, where most people state that they would want to be.

I have become painfully aware that I am a part of the system that perpetuates this reality. In my own practice, I've noticed that in cases where I have to discuss poor prognosis or the possibility of withdrawing life-prolonging machinery, I am less likely to push forward in difficult conversations with African American patients and families. I worry that my recommendations might be construed as an intentional withholding of care. Given our country's history, this is uncomfortable cultural terrain, filled with potential missteps. But I know that by being quicker to withdraw from those conversations, I am increasing their vulnerability. As a result, those patients become more subject to the end-of-life conveyor belt, rather than the full spectrum of palliative or hospice care options available to them.

MOVING FORWARD

It is best to plan ahead regarding your preferences for end-of-life medical care. This section shares some of the next steps you and your family can take, as well as some resources to get you started.

NEXT STEPS FOR YOU & YOUR FAMILY

1/ Think about what is really important.

What if cure is not an option? How might you live the best possible life right up until the very end? Dying well is very personal. What would you want around you? And who? For Stephanie, one of my patients, it meant good wine, puzzles, and having her family close. My father-in-law wanted his hand held, and knowing that, we organized shifts so that someone was always holding his hand in his final days.

Here are some questions to ask yourself about your final days:

- Where do you want to be?
- Who do you want to have at your side?
- What do you want to tell them before you go?
- How do you feel about being on life support? This might include breathing machines, dialysis, a feeding tube, and other life-prolonging treatments.
- How important is it that you are able to perform certain tasks? To eat on your own? To wash your own face? To communicate with your loved ones? To give a hug?

2/ Make Sure You've Done Your Homework

In order to ensure that your preferences are honored, preparation is critical. This should include communicating with your loved ones. I know many people who believe that talking to their parents about death is cruel. And if the parent initiates this conversation, they might protest, "You're not going to die!" or plug their ears. I've seen this happen in my own family! But to be sure preferences are honored, they must first be shared. Ideally this is a process conducted over years of reflection, rather than decisions made in moments of chaos and anxiety.

You also need to document these preferences, and pick a person you trust to ensure they are carried out. Tools to document include:

- An Advance Directive, which allows you to legally identify the person you'd like to make decisions for you if you are unable to do so yourself. It also allows you to provide general guidance on your attitude toward the use of life-prolonging technologies in the event that you have a serious illness or injury.

- A Physician Order for Life Sustaining Treatment (POLST) is another important tool that you might find helpful. It is an official doctor's order that indicates exactly which technologies would and would not be acceptable to you. The difference between this and an Advance Directive is that the POLST, being a physician order, legally obligates any first medical responder (EMT, Paramedic, ER physician) to carry out your wishes.

3/ Don't Chase Fantasies

Be open to hearing the truth from your doctor. Ask yourself whether you want to know what your doctor is really thinking. If so, be sure to state explicitly that you want to know her view of the prognosis, even if she isn't 100% certain. If doctors don't feel you can handle or want the truth, they will be less likely to tell you. Patients who imply that they only want positive news are likely to get just that.

When patients do learn the truth, they tend to make very different choices than would be made for them by default.

4/ Demand a Seat at the Table

The patient is the expert on the patient. And when the patient can't speak for herself, the loved ones are the experts. Be sure to step into your role and remember that the healthcare team needs your input to create the best plan of care. Even if they aren't acting like it.

5/ Get Support for Yourself and Your Loved Ones

It is important that you get both the emotional as well as the logistical support that you need at this key time of life.

If you are not getting clear information about your prognosis and treatment options, or if you are not getting relief from symptoms from your regular doctor, ask for a Palliative Care consultation. Palliative Care professionals are trained in communication skills that can help clarify the conversation and unite all parties around a shared set of goals. They are also experts in the management of suffering, be it physical, emotional, or spiritual.

ADDITIONAL RESOURCES

These resources are designed to provide an insider's perspective on healthcare, and to help you navigate this often difficult terrain. You can find some suggestions for these on our [Patient and Family Resources page](#).

Physicians and healthcare providers have a unique opportunity to advocate from within the system. These resources are designed to shine a light on how we

currently care for patients at the end of life, and offer a new paradigm for providing care. Explore some of these on our [Healthcare Provider Resources page](#).

LEARN MORE ABOUT DR. ZITTER'S WORK

If you'd like to learn more about Dr. Zitter and her perspective on end-of-life care, we recommend the following resources.

[*Extreme Measures: Finding a Better Path to the End of Life*](#) charts Dr. Zitter's journey through the world of medicine, from single-minded lifesaver to patient-centered caregiver. The final chapter and extensive appendices provide a practical guide and resources for readers seeking more autonomy during this important time of life.

On the [articles page of our website](#), you will find Dr. Zitter's writing and opinion pieces on how we can transform the culture around end-of-life care for the New York Times, TIME Magazine, The Atlantic, and The Huffington Post, and other publications.

To learn more about Dr. Zitter's upcoming speaking events for a variety of audiences, or the possibility of having her come speak for your community, explore the [events page of our website](#). You can also reach out to our Events Coordinator directly at events@jessicazitter.com.

To keep your finger on the pulse of the movement to improve end-of-life care, you can follow Dr. Zitter on social media, where she is active on [Facebook](#), [Twitter](#), and [LinkedIn](#).

We welcome your questions of all kinds at info@jessicazitter.com.

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