

***EXTREME MEASURES:  
FINDING A BETTER PATH TO THE END OF LIFE***

DISCUSSION GUIDE

## WELCOME

*Extreme Measures: Finding A Better Path to the End of Life* is a powerful tool for changing the way we die. Individuals and organizations across the globe have used the book to take a step back and ask: When death comes, what do we really want for ourselves, our loved ones, and our patients?

It is our hope that this Discussion Guide will be of use for navigating the book, helping users reflect on its key questions, and taking the next steps to prepare for the final stage of life.

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For more information about the film, or to learn more about inviting Dr. Zitter to host an event or workshop for your community, please reach out to Dr. Zitter's team at [info@jessicazitter.com](mailto:info@jessicazitter.com).

## **INTRODUCING *EXTREME MEASURES***

*Extreme Measures* charts Dr. Zitter's two-decade journey through intensive care units across the country. Over this time, she was dismayed to see how the dying are treated in our current medical culture, where mechanization and protocol override patient-centered care. The resulting moral distress led her to the burgeoning Palliative Care movement, which focuses on the overall wellbeing of the patient, rather than just the disease.

*Extreme Measures* shares the stories of patients, families, and healthcare providers on the frontlines of this issue. It offers an insider's perspective on a public health crisis that will touch us all. Bringing the reader into a world that most will only enter during crisis, the book offers guidance to help us navigate this rocky terrain. Thus prepared, we are equipped to live the best lives we can-- right up until our last moments.

### **INVITING DR. ZITTER**

Organizations across the country have invited Dr. Zitter to share more about her book and lead guided discussions about a new kind of heroism in medicine. Learn more about inviting Dr. Zitter to your event, as well as her other offerings, [here](#).

Dr. Zitter offers personal guidance by video conference for your book group. Book purchases and a fee apply. Please email [events@jessicazitter.com](mailto:events@jessicazitter.com) for more information.

### **ORDERING BOOKS**

*Extreme Measures* can be purchased anywhere that books are sold. And if you choose the audiobook, you'll hear Dr. Zitter reading it herself.

For events and organizations wishing to purchase more than 25 copies, we recommend contacting [800-CEO-Read](#).

## DISCUSSION TOPICS

*Extreme Measures* offers many opportunities for reflection. The following sections highlight twelve of the many themes that the book touches upon.

In each section, you will find:

- Stories from the book indicated by page numbers with a short summary
- A set of suggested discussion questions
- Insights from Dr. Zitter on the topic

We encourage you to use these as a springboard for further exploration.

And we commend you for engaging with these important topics!

## **1/ WHAT WE WANT FROM OUR DOCTORS**

### **“HE’S A FIGHTER” - PAGE 138-142**

#### **QUESTIONS FOR DISCUSSION**

- Why do you think Walter’s doctor was giving him treatments that he knew weren’t helping?
- When you begin to die, what kind of doctor would you choose? What attitude would you want your doctor to have about your condition and treatment?
- Why do you think Walter’s wife was so uncomfortable talking to the oncologist?

#### **FROM DR. ZITTER**

In this story we see Walter’s wife struggling with a decision. Does she heed her husband’s instruction to keep fighting at all costs, or does she choose to switch course? Does she give up the hope for a miracle cure, and acknowledge that her beloved husband is dying? Tragically, the person that she has trusted to guide her seems to be on autopilot.

This is an all-too-common scenario, where doctors default to protocolized, aggressive treatments, even after those treatments stop helping. Why is this? Studies show that we doctors generally do not possess good 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. And patients, data tells us, do like us better if we give good news rather than bad. And when we aren’t willing to face death, we are more susceptible to believing that an elite fighting unit will deliver us from the inevitable.

You will be more likely to get the truth if you ask for it directly. It helps to say that you understand that the doctor doesn’t have a crystal ball, but that you would still like to know what she is thinking, based on her experience.

#### **OTHER STORIES ON THIS TOPIC**

- Trapped By Their Own Words (page 131-137)
- The Big Three (page 84-86)
- Where Did Everybody Go? (page 100-102)

## **2/ THE END-OF-LIFE CONVEYOR BELT**

### **“PLUGGING IN” - PAGE 81-84**

#### **QUESTIONS FOR DISCUSSION**

- Have you had a friend or relative die attached to machines in an ICU or ventilator facility? How did that affect you?
- Is the possibility of living permanently connected to a breathing machine an acceptable risk to you?
- Have you talked to your family and loved ones about your preferences?

#### **FROM DR. ZITTER**

In this passage, I discuss the often-automatic process by which many people become permanently attached to machines. It can seem to the family to be the logical next step, as they may not know there is a possibility that the patient's condition will not improve. We know that when physicians communicate more clearly about prognosis, patients and families tend to choose less technologic and machine interventions.

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 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.

#### **OTHER STORIES ON THIS TOPIC**

- I Want You To Do Everything (page 87-94)

### **3/ PLANNING FOR THE INEVITABLE... OR NOT**

#### **“MY FRIEND SUSAN” - PAGE 170-171**

##### **QUESTIONS FOR DISCUSSION**

- Have you observed families, your own or others', dealing with the death of a loved one? Was this process healthy and productive, or painful and divisive?
- Are there any issues in your family that could interfere with an effective decision-making process for a dying loved one?
- What might you do now to mitigate or avoid potential problems that might arise?

##### **FROM DR. ZITTER**

In moments of profound grief and stress, discord is more of a risk. And so it pays to plan ahead. My friend Susan turned a potentially complicated situation into one that drew her family closer together. Planning makes all the difference, and there's no time better than the present.

##### **OTHER STORIES ON THIS TOPIC**

- Avoidance and Denial (page 202-204)
- My Own Death (page 274-278)

## **4/ UNDERSTANDING MEDICAL CULTURE**

### **“BLOWING THE WHISTLE” - PAGE 213-215**

#### **QUESTIONS FOR DISCUSSION**

- Were you surprised by the way my colleague was treated in this story? Did it give you further insight into some of the interactions you may have had with physicians in the past?
- Knowing this culture, if you or a loved one were in the ICU, what might you ask of your doctor?

#### **FROM DR. ZITTER**

Medical training and culture can be harsh when it comes to going off protocol. But personal preferences must be taken into consideration-- especially with the dying. Unfortunately, as this story illustrates, there are many reasons that a physician might not feel comfortable discussing the possibility of withdrawing or withholding medical treatments with their patients. While the onus should not be on the patient and family to initiate honest conversations about prognosis, sometimes it won't happen unless the family initiates it.

My hope is that this story might give you a better sense of how physicians are trained and acculturated, even as it empowers you to insist on getting the information you need and deserve.

#### **OTHER STORIES ON THIS TOPIC**

- ICU Culture (page 215-217)
- Linda (page 75-77)
- Please Just Deal with His Pain (page 103-105)

## 5/ THE ROLE OF A SURROGATE

### “FAMILY DYSFUNCTION” - PAGE 186-187

#### QUESTIONS FOR DISCUSSION

- Have you ever served as a surrogate decision-maker for a dying person? If so, how was your experience?
- Have you thought about who would be your surrogate, should you need one?
- Is this someone you chose by default (ie. spouse, child), or through a careful process of considering their actual qualifications (ie. knowledge of your preferences, as well as their ability to function in this crucial role)?

#### FROM DR. ZITTER

Being a surrogate for a seriously ill or dying patient is a critical job. 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.

As we have seen, forces within medical culture often place a patient on the end-of-life conveyor belt unless there is an active opting-out. Moreover, family dynamics might also prevent a surrogate from keeping the patient's preferences at the center of consideration. I recommend that you choose a surrogate who can stand firm in the middle of a storm, and make sure that she or he knows what is most important to you.

#### OTHER STORIES ON THIS TOPIC

- Overpowering Optimism (page 124-128)

## **6/ DEALING WITH UNCERTAINTY**

### **“TIME TRIALS” - PAGE 244-247**

#### **QUESTIONS FOR DISCUSSION**

- Have you ever had a doctor express uncertainty about your, or someone else’s medical condition? How did it make you feel about that doctor?
- What is a strategy that you have used in your life to deal with the anxiety of uncertainty?

#### **FROM DR. ZITTER**

Uncertainty is rife in medicine, but doctors generally aren’t comfortable acknowledging it. Admitting it can make a physician feel insecure. But the risk is that without that acknowledgement--and a plan-- patients may be led down the wrong path.

In this story, I had just begun to care for a medically complex patient. His case was murky--he might have recovered completely, or gone on to die. This type of uncertainty can be a trap of sorts. The decision to continue a full-court press approach may make sense in the early stages, but it can become very difficult to change that plan once initiated. In this way, even as the prognosis becomes more dire, the course has been set.

Time trials can be a skillful way to respond to an uncertain scenario, as I describe in the book. With a little more time, we often get more clarity, and this can make all the difference.

Knowing that your physician might be struggling with a host of unknowable factors, you can bring this issue to the fore by inviting her to share whatever uncertainty she might be facing.

## **7/ MAINTAINING YOUR SPIRIT AND DIGNITY**

### **“GOALS OF HAIR” - PAGE 256-257**

#### **QUESTIONS FOR DISCUSSION**

- What seemingly trivial thing would actually be important to you if you were lying sick and dying in bed? Have you told this to your loved ones?
- Think of someone important to you. Can you come up with one or two conditions you think would be unacceptable to this person, yet could easily occur on their deathbed?

#### **FROM DR. ZITTER**

The smallest attempt to restore someone’s dignity can be the biggest gift. I have seen families create a beautiful and dignified space for their dying loved one, even in the fluorescent glow of the ICU. It is of course easier to achieve this at home, with its familiar sights and smells. For the dying, it is well worth attending to the details.

#### **OTHER STORIES ON THIS TOPIC**

- A Tiny Flight of Pureed Food (page 254-256)

## **8/ THE ROLE OF RACE, CULTURE, AND RELIGION**

### **“MISS MABLE” - PAGE 151-153**

#### **QUESTIONS FOR DISCUSSION**

- Have you ever felt that your doctor didn't understand you, due to differences in culture, race, or religion?
- When it comes to your culture and background, what elements would you most want your clinician and healthcare team to understand?
- When you think of your dying process, what practices from your culture and background would be most important for you to have incorporated into your care plan?

#### **FROM DR. ZITTER**

We all come from different cultures and backgrounds, and these factors can come into play at this vulnerable time of life, whether in the form of distrust of the patient, misunderstandings, disrespect or implicit bias of the healthcare team, or a lack of communication altogether. While the healthcare workforce is becoming increasingly diverse, with more women physicians and more physicians of color, we still have a long way to go.

It is critical that we do our best as healthcare teams to try and understand how it would feel to receive care from people who do not look or sound like you. And to do our best to behave sensitively and respectfully. It is also very helpful for patients and families to advocate for themselves and their needs.

#### **OTHER STORIES ON THIS TOPIC**

- Roland Dreux (page 163-169)

## **9/ ENVISIONING YOUR FINAL HOURS**

### **“MARCIA GREEN” - PAGE 279-288**

#### **QUESTIONS FOR DISCUSSION**

- Have you ever thought that you couldn't handle the truth, but then surprised yourself by your resilience?
- Write about a time you got everything you wanted and nothing you expected.

#### **FROM DR. ZITTER**

This case is a shining example of how patients and families are far more resilient than any of us, clinicians and patients, believe. And this fear can hold us all back from facing the stark truth--that we will all someday die. However, when we can muster the courage to face reality, we are all better prepared to manage whatever is coming our way. And losing that opportunity is, in my view, an avoidable tragedy.

We couldn't save Marcia's life. But we did save her humanity. And all of us were the better for it.

#### **OTHER STORIES ON THIS TOPIC**

- My Own Death (page 274-278)

## MOVING FORWARD

Ideally, we would all be prepared to reach these often-difficult decisions after deep reflection with our loved ones and ample communication with our providers. In reality, that opportunity is available to us only when we plan ahead.

This section shares some of the next steps you and your family can take, as well as a variety of resources available to help you.

### 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 in the eye of the beholder. It's 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 all around. 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, like breathing machines, dialysis, or a feeding tube?
- How important is it that you are able to communicate? To eat on your own? To wash your own face?

#### **2/ Make Sure You've Done Your Homework**

In order to ensure that these carefully thought out and very personal preferences are honored, it is critical that some preparation be done. This should include communicating with those you love about this difficult subject. 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 harried moments of chaos and anxiety.

Simultaneously, you need to document these preferences, and pick a person whom you trust to ensure they are presented to the healthcare team and 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**

When dying is a possibility, 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. And yet when patients do learn the truth, they tend to make vastly 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**

There are so many incredible people and organizations out there transforming our culture around death and dying.

Patients and families can become powerful advocates in our healthcare system. 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.

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@jessiczitter.com](mailto:events@jessiczitter.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@jessiczitter.com](mailto:info@jessiczitter.com).

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