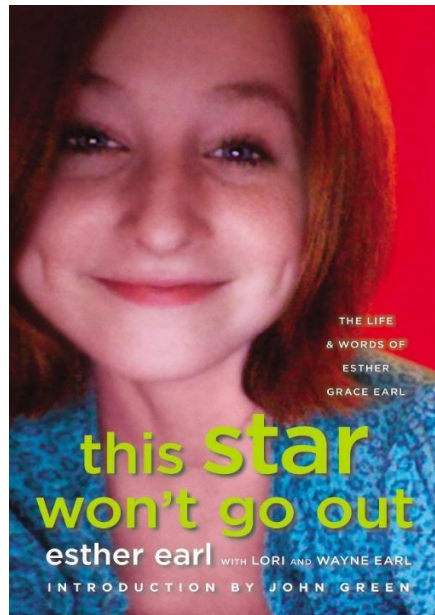




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DISCUSSION & ACTIVITY GUIDE

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BACKGROUND

"I'm not always amazing, and I'm not always awesome, and I'm not always strong, and I'm not always brave, and you guys should know that, you know? I mean, I'm not always this perfect person. I get pissed...I do stupid things. I get angsty. I cry. I hate my cancer. I judge people. I yell at my parents." – Esther Earl

Esther Earl is diagnosed with thyroid cancer when she's just twelve years old. In the next four years she becomes an internet sensation, one of the major inspirations for John Green's novel *The Fault in Our Stars*, helps to win \$250,000 for the Harry Potter Alliance charity, and inspires countless other small, enormous moments of love, just because of her openness and character.

This Star Won't Go Out is Esther's life in her own words. The book is a collection of Esther's journals, letters, poems and pictures, alongside transcriptions of her vlogs, blogs and tweets. Although this is Esther's life as told by her, authorship is shared with others who shared her life during this time—author John Green, her parents Lori and Wayne Earl, and her attending physician Dr. Jessica Smith each contribute an introduction to the book. Interspersed with Esther's own words throughout the text are snippets from various online communities that she was involved with, especially **Catitude** and **CaringBridge**. The book concludes with some examples of Esther's fiction work, a glimpse into what might have been if her life had continued.

Over the course of the book, readers are invited on an extremely personal journey with Esther, including, but not ending with, the moments around her death. It is an intimate and at times bracing account of Esther's experiences, so readers and teachers should be aware of any sensitivity, particularly with students who may have lost someone to cancer or a similar illness. Esther's pages themselves are for the most part frank and upbeat. Although she doesn't shy away from her cancer, or from describing any of the medical procedures that she undertakes, they are not the defining moments of her life. Esther constantly asks herself if she can be better, or do more, knowing that she may only have a short time in which to do it, and that question underpins most of her words and actions. Other perspectives are given too, from friends and family. The narration of her **CaringBridge** page (a site which facilitates communication between families and their "caring communities") is primarily by Lori and Wayne. Although their narrative is mostly about Esther's journey, through their words we are given an insight into their struggles as parents and as a family as well, and into their relationship with their dying daughter. Each portion of the text is color-coded, making it much easier to follow the various narratives.

Watching some or all of the additional Youtube videos (links included at the end of these notes) is recommended. Although these three videos are transcribed in the book, watching them will remind readers of the reality of Esther as a person and not just as a "character," allowing them to consider the issues in the book with greater complexity and a deeper understanding.



DISCUSSION GUIDE

Narrators

Esther Earl—Esther Earl is very much the narrator of her own life and her own story. This collection of her writing is raw, unedited and personal. She welcomes anyone who is interested to share her thoughts. ***This Star Won't Go Out*** is a collection of Esther's memories, as well as the memories of those who were lucky enough to know her.

- How does Esther describe herself?
- How is Esther described by others in the book?
- How does Esther describe her cancer? What is her attitude towards being sick? How does it change in various parts of the book?
- How does Esther's description of herself change? Start by looking at her "All About Me" poster (29) and the "Interview with the Class" (33) and see if you can find more examples of answers to these questions.
- Do you get a sense of Esther as a real person, or is she just a "character" in a book?
- **Activity:** Watch some of Esther's vlogs (links included at the end of the notes). Consider how they change your view of her. How is your reading of the book enhanced by hearing her speak? What complexities do you notice about her that you didn't notice initially in your reading of the text? Read the corresponding transcript of the vlog that you watch. What do you notice about the vlog that you don't notice in the transcript?

Along with Esther herself, ***This Star Won't Go Out*** is told by a number of people who shared her life. They are:

John Green—Author John Green talks candidly in several of his vlogs (links following notes) about his friendship with Esther. While the idea for *The Fault in Our Stars* began some years earlier, during his work as a chaplain, his friendship with Esther influenced the book a great deal, and the book is dedicated to her. In his introduction, John talks a lot about their friendship, as well as her contributions to his online following, the Nerdfighters. He captures the reality of Esther when he remembers the time he spent with her and other members of ***Catitude*** in Boston:

"...she was fully with us, as alive as any of us, as capable of love and joy and anger and grief...She had such an improbable capacity for empathy. And most of all, she was a person, complete and complex." – John Green (8)

Lori & Wayne Earl—As her parents, Lori and Wayne played significant roles in Esther's journey. Each of them has quite a different narrative style, Lori's being more observational while Wayne's is more reflective. One of the most impressive things about their relationship with Esther is how openly they discuss her disease and treatment, and how readily they accept her determination to accomplish great things regardless. They, too, welcome people into their home and on their journey, enabling much of what Esther herself is able to achieve. Wayne Earl gives an excellent TedX talk (link following notes) about living life to the fullest. Lori and Wayne write an introduction to the book, and also share some of the narrative, especially in the ***CaringBridge*** portions of the text. There is a great deal of pride in their narrative voices, and they encourage Esther's writing throughout her life:

"Like many people her age, keeping a journal helped her navigate the passage from childhood to young adulthood." – Lori & Wayne Earl

Dr. Jessica Smith—Although Dr. Smith is obviously present through a large part of the journey that is chronicled in these pages, she is not mentioned in the book as much as some of the other narrators. Despite



this, she offers a thoughtful introduction that serves not only as an example of Esther’s impact on all of those around her, but also offers a more factual perspective on the medical world that readers are about to enter. Dr. Smith talks about Esther’s response to her treatment and her ability to take ownership over the decisions surrounding her health:

“Early in our relationship, Esther stood out as a quirky and highly intelligent caffeine-drinking teenager who was wise beyond her years. She always listened quietly but attentively to our discussions, and her questions were not only smart but medically astute. Even when she was thirteen, Esther was able to respectfully challenge medical decision-making and provide thought-provoking inquiries.” – Dr. Jessica Smith (42)

Catitude—**Catitude** is the name given (by themselves) to a group of friends participating in regular Skype chats. Becoming a community and support network in themselves, **Catitude** was born from a shared love of Harry Potter, Nerdfighters and a unique and immediate bond between its members. Many of Esther’s **Catitude** friends offer quotes and thoughts within the **Catitude** pages, and there are transcripts of Twitter sessions and copies of letters and pages from a shared journal between **Catitude** penpals. Their friendship serves as a wonderful exploration of positive online relationships, as well as a testament to the strength of community and friendship.

Others—Other friends also offer short memories of Esther as a part of the book. For purposes of classroom discussions, students may find it useful to fill out the table below as they read.

	FRIENDS	MEDICAL	FAMILY
NAME			
PAGE			
RELATIONSHIP			
NARRATIVE STYLE			

Narrative Style

Esther’s story is told not only by a number of narrators, but in a number of narrative styles. **This Star Won’t Go Out** collects journals, photographs, drawings, fiction, letters, poetry and transcripts of online interactions as a way of painting a complete portrait of Esther.

Through their studies of **This Star Won’t Go Out**, students can expect to cover a range of reading and communication skills. The varying structures within the text, as well as the potential for comparisons with other forms of communication (online, print and digital) allow students to explore this book, across a wide range of reading levels and learning styles.

- What are the various forms of communication that Esther uses, both in the book and outside of it?
- What is the benefit of each of these styles? What are the drawbacks?
- Does she use some forms more frequently than others with particular people in her life? Why do you think this is?
- Do the other narrators use a different style? Is this out of necessity or preference?
- How does their narrative style impact the telling of Esther’s story?
- Style vs. Voice: Lori Earl describes her narrative role as “the pragmatic one” (257).



- Although Lori and Wayne Earl use the same narrative techniques (journal entries and updates), their voices are very different. Discuss how this occurs and how it impacts the narrative.

Activity: Think of a moment in your life that you'd like to write about. Write it using two of the following styles: diary entry, comic strip, blog, vlog, or poem. Answer the following questions:

- Who is your audience for each piece? How are they different and why?
- Are there specific parts that you edited or deleted based on the format?
- How does this change the story? How might it change the understanding of the reader?
- What is the difference between these styles of writing and standard fiction?
- Compare Esther's personal narration with her fictionalized account of a scenario on pages 407-409. How is her story different when it is written as fiction?

Themes

Being an inspiration

"We have a habit of imagining the dying as fundamentally other from the well. We hold them up as heroes and imagine they have reserves of strength forbidden to the rest of us. We tell ourselves that we will be inspired through the stories of their suffering—we will learn to be grateful for every day, or learn to be more empathetic, or whatever. These responses, while certainly well-intentioned, ultimately dehumanize the dying: Esther was uncommon not because she was sick but because she was Esther, and she did not exist so that the rest of us could learn Important Lessons about Life." – John Green (8-9)

Discuss this quote in relation to *This Star Won't Go Out*:

- What does Esther inspire because of who she is, and not because of what she is going through? Try to find examples among the people that she is close to, as well as considering her impact on those who come to know her through the book.
- What are the dangers or difficulties involved with being idolized? How can this change people? How does Esther control and maintain her privacy?
- What inspires Esther? What inspires you?

On Death and Living

"When we think of death, we often imagine it as happening in degrees: We think of a sick person becoming less and less alive until finally they are gone. But even in her final days, Esther was wholly alive, as alive as anyone else, and so even though everyone who loved her understood she was dying, her death was still a terrible shock to me. She did not leave slowly, but all at once, because even when she could not get out of bed, she found ways to be fully alive: to play with her friends, to crack jokes, to love and to be loved. And then she was gone, all at once." – John Green (10)

It is impossible to read *This Star Won't Go Out* without thinking about death. Towards the end of the text, Esther's last moments are observed closely by her family, and readers are offered a very intimate view of Esther in the moments just before she passes away.

- How do you feel reading the scene in which Esther dies?
- Discuss the way that this has been included in the text. How do you feel about the details that are shared with the reader?



- Do you feel that this scene is too upsetting or personal to share with an audience? Why do you think it has been included in this way?
- How does Esther feel about dying? How does she write about it in other parts of the book?
- How does her death impact the people around her?

The other side of this theme, of course, is Esther’s determination to be fully alive and present in every moment.

“At the end of our life, author Jack Kornfield says, the most important question is not how hard we worked or how much we accomplished. It’s ‘Did I Love Well?’ And Esther loved well.” – Andrew Slack (280)

- How does Esther make the most of her life?
- What evidence can you find that Esther loved well?
- Why is this so important?

Community

*“I have other friends who have said they are envious of the total openness and uninhibited love that exists between all of us, Catitude, as friends. I guess that’s a pretty great thing to be a part of.”
– Teryn Gray (211)*

Esther is involved in a number of communities, both online and in the physical world. There are her closer family and social networks, as well as the more structured online communities that she belongs to.

Communities are important as places where we can feel safe and secure, and where we receive support from our loved ones. Esther has this relationship with many people, but especially with those in her family community.

- Look at Esther’s writing style in her letters to her parents. At one point she tells her mother that “it seems a bit like I’m talking to my diary, not to you!” (51)
 - How do you think Esther’s experiences have shaped her relationship with her parents?
 - How has it shaped her relationships with her brothers and sisters?
 - Who else might be included in this very intimate “community”?

Community also refers to the wider communities that Esther is a part of, from **Catitude**, **Nerdfighters** and the **Harry Potter Alliance**, and to the communities that formed as a result of knowing Esther—her followers online, for example.

- Make a list of all of the communities that Esther was a part of. Decide whether the relationships are personal or impersonal.
- Discuss how being a part of a community helped her, not only in terms of being sick, but in other ways as well.
- Make a list of communities that you’re a part of, and write a reflection on how your life has been shaped by your involvement with them.
 - Are there some that are more important to you than others?
 - What do you feel you gain from being part of a community?
 - What do you feel you contribute to the community?



- As a class, discuss why community is so important.
 - How does it change individuals?
 - How does it change the world?
- Make a list of different communities in the United States that are specifically designed to help people with cancer.
 - What are their different functions?
 - As well as physical support, what other types of support can you find?
 - Why is this sense of community so important to people who have cancer and their families?

Making a Difference

“She helped us see our potential, our life, what we could contribute...our awesomeness, right? Some relationships are bad for you, you want to get out of there as soon as you can, and others are good. You like them, you like them to stay that way. And others change us, and we’re never the same. We walk away and we say, ‘Something happened to me, I am different...’” – Wayne Earl (349)

Esther is determined to make a difference somehow.

- How does she do this before and after her death?
- Who helps her achieve this?
- How limited is her reach?

Online vs IRL

“The Internet was one of the only places Esther could go and not be treated as Cancer Girl. Looking back, I am extremely grateful that I had that time to get to know Esther, the real Esther, free from the constraints that are inevitably put on a relationship when something like cancer is thrown into the mix.” – Lindsay Ballantyne (198)

Much of Esther’s time in the last four years of her life was spent online or on her computer, and by reading her story we can see the impact that this had on her life, her words and her friendships, as well as the ways that she used her online presence to make a difference in the world.

On pages 199-200, Esther tells her **Catitude** friends for the first time about her cancer.

- Why has she not told them before this?
- How is she worried that they’ll react?
- How do they actually react?
- How does sharing this news change their relationship?
- Do you think it was a good decision or a bad decision to tell her friends?

Many people disagree about the issue of how “real” friendships made online can be. Esther’s online friends truly prove their worth by travelling to see her and supporting her extensively throughout their friendship.

- Discuss the idea that friends made online are less real/more real/the same as friends made face to face.
- Do these friendships go beyond the internet?
- What are some concerns associated with internet friendships? How do Esther and her friends make fun of these concerns?
- How does Esther initially become friends with the members of **Catitude**? How do we see their friendships grow and develop over the course of the book?
- How are they different to friendships you have experienced in real life?



- Look at the language that Esther uses on her blog and on Twitter. Find examples of the shortening that usually takes place in tweets or texts (eg. IRL = in real life, DFTBA = don't forget to be awesome).
 - What other examples can you think of that aren't in the book? ○ What are some of the issues associated with "textspeak"?
 - What are some of the benefits?



ADDITIONAL ACTIVITIES

- Write a journal entry before reading the book. Write another one immediately after finishing.
- Put both away for a week and then take them out and reread them, comparing your attitudes to the book before reading it and after. What other things have changed during this time?
- Make a vlog. It can be in any style, but the Nerdfighter site or Esther's YouTube channel might provide some inspiration. Collect the class vlogs and post them to the class blog or website.
- At the end of the text we discover that Esther has used an online site to send an email to her future self. Although future Esther isn't around to read it, her family includes this letter in the book. Students should go to futureme.org and write their own letter to their future self. What would they tell themselves in six months? A year? Ten years? (A partner exercise to this would be to write a letter to their past self—see the site dearme.org for inspiration.)
- Do a comparison study with John Green's book *The Fault in Our Stars*. Look at questions such as:
 - Can you see moments that may have been inspired by his friendship with Esther?
 - Why do you think the book is dedicated to her?
 - How is this fictionalized account of cancer accurate, based on your understanding from *This Star Won't Go Out*?
 - What parts of *The Fault in Our Stars* do you feel are less believable or further from the truth because they're fiction?



ADDITIONAL RESOURCES

Esther Earl Vlogs transcribed in *This Star Won't Go Out*:

- “insert some sort of relevant title/thankful video” (224-227)
<http://www.youtube.com/watch?v=HFTSsEQIO2s>
- “Nothing More Than Feelings” (312-313)
<http://www.youtube.com/watch?v=fa3XHeMtY3s>
- “re: Esther Day” (389) <http://www.youtube.com/watch?v=PXURnZ92cGM>

Further Viewing:

- “Rest In Awesome – John Green Memorial Vlog”
<http://www.youtube.com/watch?v=Mj96HM9kDTQ>
- “With Esther – John Green Vlog”
<http://www.youtube.com/watch?v=7DKrs3IngoE>
- “Dying is Inevitable: Living is Not” Wayne Earl talks at TedX Youth
<http://www.youtube.com/watch?v=Dqqh5KhYhGMU>

Websites:

- Caring Bridge <http://www.caringbridge.org/visit/estherearl>
- Dear Me <http://www.dearme.org>
- Earl Family Youtube channel
<http://www.youtube.com/user/wayneandloriearl>
- Future Me <http://www.futureme.org>
- Harry Potter Alliance <http://thehpalliance.org>
- This Star Won't Go Out: Esther's Story <http://tswgo.org/esthers-story.html>

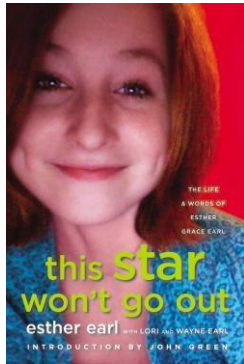
Further Reading:

- Betts, A.J., *Zac and Mia*
- Davidson, Jessica, *Everything Left Unsaid*
- Downham, Jenny, *Before I Die*
- Green, John, *The Fault in Our Stars*
- Sparks, Nicholas, *The Notebook*
- Wunder, Wendy, *The Probability of Miracles*



ABOUT THE BOOK

A memoir told through the journals, letters, and stories of young cancer patient Esther Earl.



In full color and illustrated with art and photographs, this is a collection of the journals, fiction, letters, and sketches of the late Esther Grace Earl, who passed away in 2010 at the age of 16. Essays by family and friends help to tell Esther's story along with an introduction by award-winning author John Green who dedicated his #1 bestselling novel *The Fault in Our Stars* to her.

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Author Bios:

Wayne and Lori Earl are the parents of the late Esther Earl and founders of the non-profit organization This Star Won't Go Out (tswgo.org), whose mission it is to financially assist families struggling through the journey of a child living with cancer. Together Wayne and Lori have created a financial and emotional support system for more than 50 families struggling with childhood cancer, giving out nearly \$100,000, from purchases of TSWGO bracelets, through donations given individually, at LeakyCon, and Project for Awesome; and by fabulous fundraisers planned and implemented by individuals and groups. TSWGO also funds occasional projects that fit their mission statement, such as sponsoring events for children with cancer, giving financial support to pediatric cancer research, and other related projects.

Visit Wayne and Lori at www.tswgo.org
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