

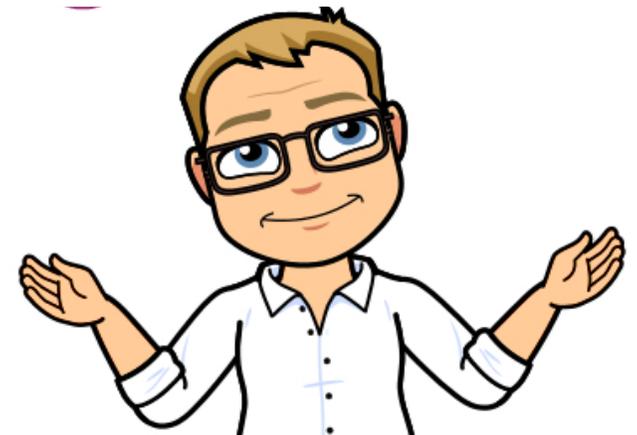
Storytelling in Action

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Disclosures

- I am a thoracic medical oncologist
- A palliative care physician
- A father and a husband and a friend.
- I am a storyteller. Story is important to me.
- In retrospect it may appear that I had a grand plan. I disclose that I did not.



Outline

- 55-word short stories
- Obituaries
- Minutes Matter
- 6-word short stories
- Best Case/Worst Case, <https://www.youtube.com/watch?v=FnS3K44sbu0>
- Vivid Vignettes
- 5 Defining Moments
- It's Okay to Talk about Dying
- Organ Donation Podcast
- The Condemned

55-word Short Stories

- A challenge – “sitting with suffering” conduct a prolonged visit with a patient
- Write a 55 word Short story
- Thanks to Marcia Childress PhD

...55-word Short Stories...

Dying.

So sudden.

Why *her*? Why not *me*?

The doc's here. I hear him speak, but it's all just noise. All I think about is her.

Weeping, I lean over to show my love and kiss her goodbye.

She whispers to me, "Don't be sad. We've been married for 62 years.

We'll always be together."

By: Paul Anderson

...55-word Short Stories...

I thought it was a headache. They said its cancer. Nothing to be done. Waiting. So many people in and out. Lots of people without answers. Lots of questions I can't ask. Im in my own world. No family, just one friend. I hope she cares. My whole lifetime lost in this little hospital room.

By: Angie Appel

...55-word Short Stories...

I am Andy's wife, and every time I talk about him it feels like the past tense. He had a brilliant mind. He was kind and considerate. He was a videographer. He would never forget the right word. He's back to me now, but I wonder when will be the next time I lose him.

By: Emily Yu

Obituary

Matthew...passed away on Monday... Always the pragmatist, he decided his last days would best be spent on the farm amongst family and friends -- many of whom he forced to take long leaves of absence from their jobs and coerced to travel long distances. He is grateful that nobody let him win any card or board game during his demise.

His life was unfortunately, but not unfairly, short. Though, his time lacked length, he was compensated with concentrated intensity, happiness, and curiosity. Of course, he wishes he had a more nights with a certain beautiful woman in his arms, more time to delve into novels, more time for globe trotting and camping trips.

Had a greater allotment of time been granted, he would not have been a great man. Cold, lonely greatness where history or culture remember his name would not have been his path. Instead, a life filled with companionship, warmth, and kindness -- a life of a mediocre man -- would have sufficed. He would have loved to see where his career as a physician would lead and he is disappointed that he would not be able to touch the lives of his patients. His only regret is never getting a chance to read the *His Dark Materials* and *Wrinkle in Time* books to his children. He is glad he is not leaving behind fatherless children, but thinks he would have done hilarious character voices.

Obituary

Lastly, he had always hoped to be a simple man and apologizes by being maddeningly complex. He hopes that when all the right's and all the wrong's are tallied, that the balance clearly favored good.

In lieu of flowers, cards or donations, he asks that his memorial is simply found in the enjoyment of a beer at the end of a long day, love of company around a campfire, and in dance moves with lots of finger pointing and elbows.

When Minutes Matter

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The day I realized I had bucket lists all wrong was a sunny, warm, Wisconsin summer day. It started with a bike commute through the University of Wisconsin campus along the shores of Lake Mendota en route to a home visit. I first met Keith and his family in the hospital for a palliative care consultation. Keith, who had lower motor neuron disease, had been admitted with hypercar-

end-of-life care, including stopping positive pressure ventilation. They all cried and felt a sense of control that had previously been absent as they set their minds to planning one final party during which Keith would stop his BIPAP.

In a moment alone together before I left, Keith told me, using 3 breaths, "Minutes matter; it's exhausting."

Imagine what it must feel like to have all your minutes matter? When there "is no time for anything inessential," as Oliver Sacks said in the NY Times (2/19/15). You cannot know exactly when the end will come but you know it's soon and there aren't that many minutes left. You're in life's 2-minute drill. Would any of us spend time doing the inessential - watching TV, sleeping, taking a long shower?...

While the idea that one would develop a list of aspirational activities and goals to finish before dying is compelling, the reality is that most dying people don't spend their time daydreaming about parachuting or scuba diving or eating cronuts. Those who have prognostic awareness are focused on a different set of activities and frequently their goals include the antithesis of a bucket list - a time to be content and at peace in quiet. I had this all wrong until I met Keith...

My thinking has evolved and now I understand the value of fighting for a moment of normal, for a minute that doesn't matter. Perhaps we clinicians should give occasional recommendations to live as if you do not have cancer for an hour or a day or a weekend. I've hand written a prescription for "a cancer-free weekend." We could be more like a coach giving permission to call a time out, during life's 2-minute drill, for moment of normal amidst the noise of a life at its end...

6 word short stories

- Hemingway. “For sale: baby shoes. Never worn.”

Six Word Stories

She'll go swinging into the light.
Well, mom's never been a fighter

Tortured soul hated being here today

Try Me... or die... HAAA You

"Aiye, Aiye, Aiye, Aiye;" She Commands

Diarrhea: Goals of care not clear.
He's been fighting, but not angry.
First opioids were up the butt

I can't, I'm taking a poop

I'm continuing to float, nothing's changed.

Candy a day keeps Palliative away

Save sinful bites for the weekend

Got one ^{of} 'dem Macular Puckers

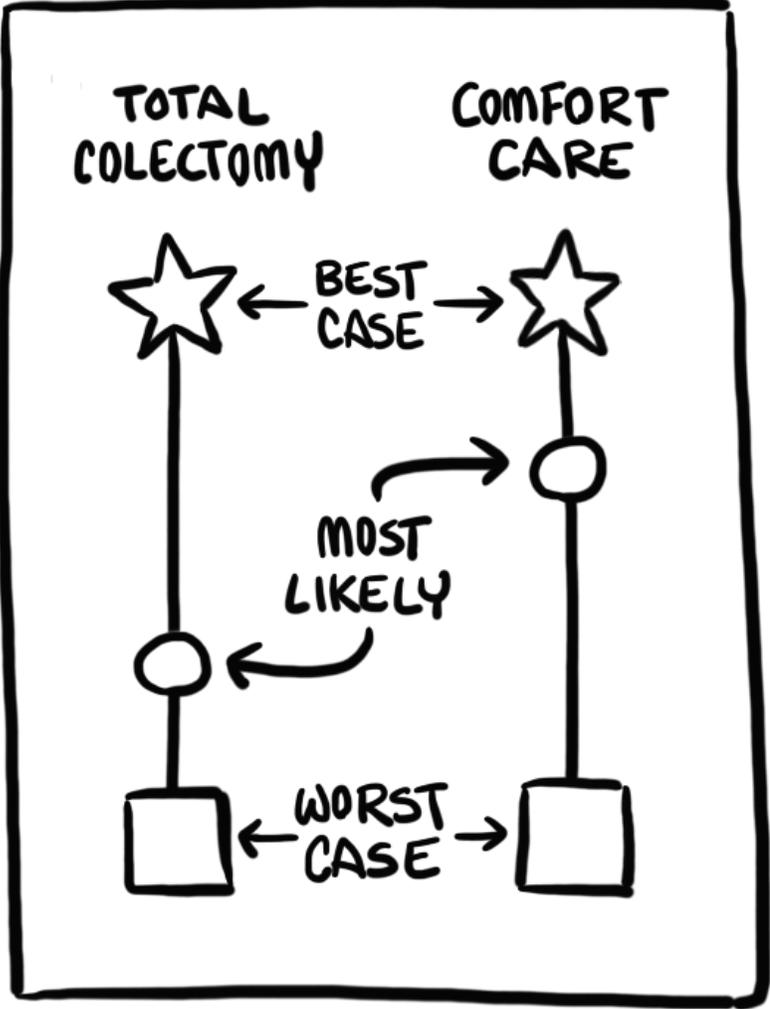
I am a walking hardware store.

YOU CAN BUY JESUS ON AMAZON.

- She'll go swinging into the light.
- Well, mom's never been a fighter.
- You can buy Jesus on Amazon.
- "Got one of 'dem macular puckers"
- "Aiye, Aiye, Aiye, Aiye:" she commands.

BEST CASE / WORST CASE

<https://www.youtube.com/watch?v=FnS3K44sbu0>



Vivid Vignettes

- Refer to the patient using the vivid vignette in discussions with colleagues and in the ID or summary section of progress notes.
- This helps you and your colleagues to see the patient more vividly as a person, and to see your interactions with the patient as part of an evolving story, one in which you may become an important character.
- Use reflections, for example, a patient beams at the thought of returning to his artwork and you say, “You’d love to be known as the artist, not the addict.”
- “What matters to you?”, “What brings you joy?”
- “What gets in the way of you attaining your goals?”
- “What are you known for?”
- “Our team will meet frequently to discuss how to help you. I want to make sure everybody knows who I am talking about when I bring up your name. I’m thinking of introducing you as follows. What do you think?”

Vivid Vignettes Structure

- **Included the patient's own words**
 - "Self described goofball"
- **Values / Hopes / Aspirations**
 - "who looked forward to watching the 1st presidential debate"
- **Barrier / Challenge**
 - Described by his daughter as having a rough life
- **Professional**
 - "Masters in education, and loved her work with the state of WI"
- **Hobbies / Interests**
 - who loved sewing and embroidery
- **Families / Social**
 - Devoted mother, grandmother
- **Personality Description**
 - who was "just like Don Draper without the scotch"

Vivid Vignette Examples

- Chef and world traveler with a vivid personality, whose eyelid stayed sharp for palliative sedation.
- XX is a XX year-old college professor, piano mentor, and family man who is determined to continue teaching while undergoing treatment and despite the symptoms he feels from his newly diagnosed lung cancer.

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Episode details



Annie Marsh

Published on 12-03-2021

Dr. Annie Marsh, director of pediatric palliative care

00:00



37:16





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Title: It's Okay to Talk about Dying

This story starts with Lisa.

Title Priority: Honesty. I don't want people to accidentally read this book so honesty in the title will let A) people find it who want to find it and B) keep safe those who would rather not find it.

... It's Okay to Talk about Dying...

People are like living jigsaw puzzles. With every new thing we do or learn—crossing the monkey bars, making a friend, learning to tie your shoe, singing your favorite song—we create a new puzzle piece to add to our collection. There are pieces for all your memories, and they are yours forever...

As you grow up, the world gives you more experiences—more puzzle pieces—and you add them all in as you create your own unique puzzle picture. There are pieces for things we like, like how to roast a marshmallow, kick a soccer ball and run through the sprinkler without getting wet.

... It's Okay to Talk about Dying...

Everyone is born. It's the first part of life. A big part of life is living, every day. Some days are exciting. Some days are boring. Some are loud. Some are quiet. A life is made up of lots and lots of days. Most people live a good long time until they grow very old. They have lives full of family and friends and work and play and a thousand thousand other things.

Every life is different, and all lives are important.

... It's Okay to Talk about Dying...

Everything that is alive will also die. That's another important part of life.

Flowers are born. They grow towards the sun, open their petals, show their bright colors, and release their smells. They give pollen to bees to make honey. Then, as a flower dies, its petals wilt and fall to the ground. That's how a flower lives its life.

People grow up, go to school, and make their life. They are creating their puzzle picture. And then, often after they have grown quite old, they get a serious sickness. This may make them be unable to do some of the fun things they did before. They may have to take more naps. And, one day, because of the sickness, they die. It's usually not scary or a surprise.

Often the people who die are people we only know a little bit. But a few times in your life, the person who dies is someone special to you, someone you love and who loves you.

Organ Donation

- Organ recovery prior to donation, Moments of silence

Carissa



Heather



The Condemned

- People who have to face a *crazy* death complete with an powerful Presidential antagonist, an insurgency, cleaners, the A.N.T., and a girl who saves the world.

6 Word Short Story of your own