



The Unreliable
Ultimate
Playlist
of a Sometimes
Dying
Deaf Girl



BAILEY ANNE VINCENT

This is a work of nonfiction. Nonetheless, some names, identifying details and personal characteristics of the individuals involved have been changed.

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For my Grace and my Grumby. I am forever yours.

*This book in part due to the donations and encouragement of Nancy King and
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Album 1

Contents

Chapter 1: The Chapter Where I Write a Book I Shouldn't Write	1
Chapter 2: The Chapter Where I Say Poop On 18 Separate Occasions (Or More Commonly Known as, 'The Chapter Brought to You By Cocaine')	39
Chapter 3: The Chapter With That Sentence From Page 8	94

1

The Chapter Where I Write a Book I Shouldn't Write

If I were to write a book, I wouldn't know where to begin.

I've written books before, of course. Ones that weren't published. Ones littered with fiction fruition and focused fantasy far beyond the scope of my every day. This is not that.

I've thought about writing this for a long time. Too long, even.

"I don't even know where to begin," I said to my best friend Hepburn nearly two years ago, while cloistered in a tiny West Virginia town on our annual hideaway New Year tradition. "There is nothing less motivating than writing a book about myself." Instead of going out and partying for the novice year, she and our small friend group (my partner and his makeshift brother Jonathan) pick an isolated town we've never been to, rent a place to stay for

a long weekend, and hideout together. We like to approach the New Year as if it's the zombie apocalypse, and the older we get, the more it feels like one. We discover local coffee shops and stores we've never been. We drink a lot of red wine. And we argue about everything and nothing long after my kids have gone to sleep.

“What if you broke it up by body parts?” she suggested, as we perused a retroactively rustic book store together, just a few blocks from our tiny Airbnb, “One chapter on head, one chapter on the heart, and onward.”

If this book were the way I want it to be, this would be when I'd cue “Down in the Valley” by The Head and the Heart as the underlying score; a footnote to the reality that was then, in the now.

If this book were what I want it to be, I would score every page.

“People who write books about their life when they've only been alive for three decades are asinine,” I explained to her, long after she'd stopped listening and moved on to Atul Gawande and James Patterson. “Or they're narcissists.”

“Well you're definitely the latter.”

I don't actually know if this is what Hepburn replied, of course, because I have a terribly unreliable memory, peppered with anesthesia stupors and Fentanyl apathies... but one could easily assume.

Perhaps it should go without saying but: I am a very untrustworthy

narrator.

I remember very little of my life after so many surgeries and sedations. I paint my own perspective like a Frida Kahlo quote, etched on forearm in kind. And I reflect backwards only when it serves me best.

Still, since you're reading this currently and haven't stopped at the first page, one could assume you're okay with taking a small leap of faith that the truth therein is (mostly sort of) true, and that the blanks we fill in together are what (mostly sort of) happened.

In this case, and in the case of any moment Hepburn appears in this book, one can rightly assume “you're a narcissist” is definitely something she would have said, when or if given the chance. And... she's right.

So let's continue.

I don't know how to begin this book.

In order to write about oneself and one's experiences, one would assume there is a certain amount of implicit “liking” involved. And the fact of the matter is: I don't always like myself.

But if I were to write a book (which at this point, I'm fairly certain I'm doing), I'd want to write it like a movie. If writing about love is like dancing about architecture (while making *Playing By Heart* references for the two percent of the population who understands), then writing about writing is like dancing about music.

That analogy didn't make sense to me either, but the point is: I love producing. It's what I love about being Artistic Director of my professional dance company... and choreographing... and creating in any form.

And if this book were a movie, it would definitely not open with an existential crisis like this one. Or a West Virginia town I've only been to once. Or even a bookstore with my best friend who can sort of be a dick (in a good way) the majority of the time.

No, it would definitely open with something far more cinematic. Something like... a closed eye.

As the camera slowly retracts, my eye would flutter upwards (it has to be my eye because I'm a narcissist, as previously established), and then we would realize I am, in fact, on an operating table (which, in truth, is where I've spent a majority of my life), and I'm waking up from the afore mentioned anesthetized amnesias, about to become the most defective storyteller you've ever known.

Some of you are here only for the guts and gore, so naturally we have to open in a hospital. My being surgical sashimi is a primary draw for many. I get this. Marketing is important. But what you don't realize is that- Eternal Sunshine clichés aside and Requiems for my dreaming notwithstanding- I think in song. I'm also profoundly Deaf (more on that later).

Perhaps the best or only way to actually produce these pages is to tell them through the soundtrack of my funeral.

Even if you can't hear the music... it doesn't mean it isn't playing.

Song #1: "This Is the Day" by The The

I created a playlist for the funeral I haven't had.

This song is not the most truist on the list (I'll reserve that for, "You Can't Always Get What You Want", as someone respectfully raised on The Big Chill), but it is a quality opener.

It is lively, though I'm presumably no longer alive. It imparts a sort of "the world is so much larger than even we know" sense of wonderment to unite. And it incites notions of fanciful dance parties in the kitchen in our skivvies. (Nothing says, "I am both intrinsically deep and impetuously adorable" than a pantless dance scene.)

If we were The Breakfast Club, this would be when we come of age.

If we were a romantic dramedy, this would be when we turn up the music and forget our PG13, easily resolved troubles, even if for a moment.

If we are a funeral playlist and our protagonist just died, this would be when we look back and smile, knowing all the pain and punishment was somehow worth it.

But was it? That is what we are here to discuss.

First, we have to cover why you're reading this to begin with, even if it's about not knowing how to begin it. If you are reading because you believe (due to some preconceived knowledge of my poor health or work as an advocate) that I am in fact worth reading about ... you are sorely mistaken.

For even though I am sorely and poorly a majority of the time, it has sadly done little to make me a better person. Certainly not in the sense that I am now more inspiring with how I overcome, or more reflective and refined in the ways with which I warrior.

I might go so far as to say that if you use words like "inspiring" or "warrior" in your daily vernacular, you're going to regret reading this book entirely. I am none of those things. Instead, I like to use all the words you shouldn't use, especially before your children go to bed.

Words like fuck.

If you don't like reading that word, turn away now. I don't overuse it. It's a beautiful word best saved for when it truly means something. But believe me, it will be needed.

I am not a warrior. I am not an overcomer. I am not an inspirer or blessingser (despite the former being tattooed on my spine, and the latter being made up entirely). I am none of the "ers" and all of the airs that we err to the side of.

I put on constantly. I worry more about my pores than I do about my pancreas. I stress about dirty dishes instead of doxycycline.

And I don't always have the right words at the right time. But I do, as you already know, have a playlist for my funeral, because I'm organized when it comes to composing my decomposition.

The day my life surely changed was not the day my health first began to decline. Or the day I realized my body could be used as the entry point for another against my will. Or the day I didn't walk down the aisle for the second time after not having walked down it the first time.

No, it was the day I peed on a stick and realized I would never be just a Me again.

Let's talk about that day... because... Holy fuck did it change everything.

See? It's needed.

This may be a little early in our meeting process to shove my all-consuming love of my children in your face, but if you're going to get to know me, you need to get to know them.

The truth of the matter is: I am more loyal to my daughters than any other human being on earth. More than my husband. More than my friends. More than myself. Is that wrong and ill-advised by many a relationship guide and self-care self-help anthology? Yes. Is it the truth? Also yes.

I used to pretend I figured out the "balance" of being a selfless lover and sacrificial sister and soul-seeking self... but I have not. (Also, don't you hate when people say lover?)

I love my children in the suffocating sort of way that leaves you awake all hours of the night, worrying about what to do if robot ninjas attack and you are their lone defense against digitized dystopia. I love them in sickness and in health, and in all the unhealthy manners that mothers pretend to not love their kids. I love them in the way that doesn't really care how much they accomplish in this life or which university they go to, because I'll love them forever and ever so long as they're Democrats.

Becoming a mother was nothing like what I expected.

Becoming a parent (if we are to express this in a non-binary, anti-sexist sort of way, as explained two sentences ago) is nothing like what I expected.

And – and this is possibly the most important thing I'll say in this

entire book- biology has absolutely nothing to do with it.

If you showed up on my doorstep and handed me a child today, I would feel exactly the same as I do now. As I did then. As I wish to feel again.

Oh, how I wish to know it again. To adopt. To have my uterus intact. To have not lost our one chance at getting lost again. But I don't want to talk about any of that yet. What I want to talk about is the irrefutable fact that every word written here has been underwritten by the soul-crushing chaos of my petulant, exhausting, and sometimes-insane kids, even though you won't see them here at all.

Loving them hurts.

I didn't have to create them to know that. Loving is easily the most painful thing I have ever experienced and ever will experience in my lifetime (and I've had multiple organs removed).

It doesn't hurt in the physical sense- although my eldest was delivered without medication and epidural, and the failed attempts at breast-feeding still make me want to clutch swollen, bloody sausage-nipples - but in every other way.

In the morning, I wake up and hurt because I wonder if the coral reefs will still be dying when they're grown and gone.

At night, I wonder how to protect them from the dying and the growing and the gone.

Every day, in every way, I am filled with infection. My lungs are infected by pseudomonas and varying colony warfare. My sinuses- surgically overhauled again just three weeks before writing this- overrun from mold specimens and aspergilluses (aspergillusi?) But inside, deep within my chest, I am inhabited with the worst sickness around: loving in a world that hurts more.

You never know who someone truly is until you see who they become on their worst day as a parent. I've seen a great many changed. I've seen a great many fail. There is no winning when it comes to raising another human (who you can't direct or defend beyond daydreams and daring)... but there is failing.

The only way to fail is to never try at all. To not let yourself feel the pain. To not admit that this hurt- this hivering hush that befalls each night- is meant to be your compass forever more. It is mine. It was mine. And even then, when I first became a Momma instead of a Me, I had no idea the hurt that lay ahead.

My health has always been unfortunate. I had progressive hearing loss temporarily cushioned with hearing aids and tepid self-advocacy. I had a nervous stomach which left me in the bathroom for hours at a time. I had cold after cold, and walking pneumonia after walking pneumonia, but never really knew why.

And even if I cared to know, the all-consuming pain of parenting quickly took over. My decline felt like a John Green novel: slowly and all at once.

It's important you understand my love for my daughters before you continue on because, although I will share a great many things that shaped and sculpted that which surrounds us... I will share very little about them.

Maybe, one day, they will.

Even though the following chapters will explain the pieces that fell to pieces since, the one part I will never explain is who they are. Who I hope they become. Who I believe them to be.

That must be earned.

Before I knew what I now know, I knew only one thing: they are the most painful purpose I've ever known.

Today I woke up and tried to ignore the pain.

The pain started forty-eight hours before, and was so bad I became mean. Pain has a way of doing that sometimes. I never let the mean come out... but I can feel her there, simmering beneath the surface.

Every time my daughter bounces on the bed, it swells like boiling water. Every time the cat jumps haphazardly on my torso, it throttles to my throat. The meanness comes with the pain, and the pain is made of mean. And it's within me, always... even when I don't show it.

The pain is from my pancreas, or so my doctors think.

The first time I felt it to this magnitude I was in New York City for work. I had flown in earlier that morning to meet with my soon-to-be future dance partner, a beautiful Adonis of a man who both intimidated and electrified me. I didn't know we'd soon become the perfect mix of work husband and stage love. Different enough from one another that we balance in battus, but similar enough that he could toss me in the air without need for words.

At that time, I barely knew him, and was nervous to create on crunched time.

Then the pain came. It was growing for weeks within my lower back. I thought it was faulty architecture, as usual. Perhaps it was that old tailbone injury from falling down a flight of stairs at fourteen. We didn't know until the X-ray years later that I had

actually fractured two vertebrae and ravaged an arabesque forever.

This was likely that, I thought. And so I kept going. As we walked next door for Thai tea and appetizers, ready to discuss this beautiful project with a composing collaborator... I realized something was brewing beyond the tea.

Before I knew it, I blacked out entirely on the hallway floor on the way to the bathroom. When I came to, I was halfway between the open Ladies' Room and side passage; out of sight of composer and friend, but knocked-out in a New York City restaurant, none the less.

Perhaps it should be stated, however briefly, that even though this is a book of a sick person... I am a sick person who doesn't believe in fainting. I own nary a fainting couch nor daisy designation, and have only weaved and wobbled in the past from heart issues and humidity when no one's looking. If you like books about people dramatically crumpling to the floor... search elsewhere. Except for now.

By the time I sat up, locked the door, and wearily smacked my face to attention, I'd already decided this couldn't be happening and I would be fine. The men in the other room were mere strangers, and I was soon to be sleeping on the couch of one; building choreography over the course of a weekend I'd long looked forward to.

My dance partner first contacted me to collaborate when I was (ironically) sitting in a hospital bed, a week into a GI related stay.

I had just had a surgery of some sort (I should probably research which surgery for the sake of this chapter?), and, upon receipt of his email, immediately said yes.

“Am I insane for saying yes to something that starts in a month, while I'm literally in the hospital?”

“Yes”, my husband said, which I ignored.

Now, here I was shaking and sweating on the floor of Thai-fusion bar, wondering if perhaps he was right all along.

The details of what happened next aren't really important, since the point of this chapter was not to rehash the past, but describe the present. The pain I presently feel. Either way, it got worse before it got better.

I threw up on the floor which, again, might not seem particularly shocking to someone reading a sick book about a sick person but... considering my stomach has been surgically altered so I biologically cannot throw up... it was pretty shocking.

I felt like I could barely walk the subway stairs or hold my suitcase on the way back to his apartment. By midnight that night, I wandered into the living room (where my soon-to-be future dance husband was graciously sleeping so I could have the bed) to say, “I might need to go to the hospital”... and then ran to the bathroom to throw up again. (I was making a great first impression.)

I didn't go to the hospital. But days later when my husband drove

to the city and eventually drove me home, it was the first place we went. Although my local ER is not the best (perhaps why they shipped me to my specialist-hospital two hours away, mid-stay), they figured out my liver levels were elevated, my eyeballs basting yellow, and somewhere between my liver and pancreas likely to blame. (The day I was discharged from this double-down stay, I drove directly to an inaugural rehearsal of my dance company's season and finished out the day.)

If this chapter is looking and feeling like a crazy person wrote it, then you're correct (my husband already said so). And, in the case of the pain, if it looks and feels like pancreatitis... it's sort of correct. But not quite.

It's a biliary back up (despite no longer having a gallbladder) and, wow, is it the meanest of mysteries. There is a surgery to fix it, of course. It's maybe in my future. For now, there is the pain and there is me, and we are frequently one in the same.

From the first time this happened to the countless times since, the pain has never truly gone away. It fades and gives... but at any given moment or month, it's rearing to return.

Today I woke up and tried to ignore the pain.

I had almost forgotten how bad it can be, after months of dulcet delays and naïve notions it was finally over. Every time it arrives, I search for the easiest way to blame myself.

In New York, I had eaten exactly one banana and one protein bar

upon landing, before leaving the airport. I sipped a coffee in the Uber on the way to the studio, and snacked a few simple bites of bagel and schmear while rehearsing straightaway.

As you'll soon find, all of my greatest memories and worst mindsets are peppered with one of two things: meals and music. I can remember exactly what I was eating at any given moment no matter how many years back, and exactly what I intended to listen to.

If you're thinking, 'But wait, didn't she already mention that she was Deaf somewhere on Page 4 and just left it there without any explanation?' Yes, yes I did, and yes, yes I am.

For now, the details of this book will be highly specific when it comes to food, falsettos and art that fuels, and more or less useless when it comes to medical jargon and pharmaceutical juggernauts.

I fainted... but that's not the focus. I threw up... but we aren't producing one of those frat-comedies where we unnecessarily show the character vomiting, just so we can wince away. We don't need surplus details in order to know the pain is pressing and present and projected through the page as we speak; swelling up my back as I write like a familiar heartache known too well.

Despite my predilection for food happenings and snack superstitions, nothing connects. Nothing I ate that morning (or any thereafter) have ever been the cause. Not clearly, anyways.

It just happens.

The pain happens and I wait. I wait for the next time. I wait for the now. I wait for the moment when it finally goes away. Just like the fractured vertebrae decades before, I never know when something inside of me is broken, ready to show itself.

I barely knew my dance partner, but I trusted him. I barely knew the broken parts, but I felt them. Just because the cause isn't clear or the case isn't cut and dry, doesn't mean the pain isn't just as painful as if it were.

it's within me, always... even when I don't show it.

I have two dreams that have haunted me for as long as I can remember.

The first has to do with snakes, my least favorite of subjects. I wish I was one of those girls who coolly coils with reptiles, and doesn't wear a helmet on the back of a motorcycle, or even goes on a motorcycle, and doesn't look at hot air balloons like floating flaming death traps... but I'm not.

I am so scared of snakes that even if they're in cartoon or Pixar form, I look away.

In my dreams (or, more aptly, nightmares), snakes are always super smart. They're extra fast and extra aggressive and they can out wit and out chase me in ways you couldn't imagine (but, seemingly, I can).

It's a general rule of mime to not trust things with either too few appendages or too many... but really, I hate the way they move. Big fat sluggish snakes don't freak me out as much the smaller ones.

if I were to look back on my life (which seems a begrudging obligation as to the very nature of this book), I might remember the time a boyfriend gallantly protected me from snakes with his bare hands.

The bare hands were actually a rock thrown aggressively at their heads in a river, while I frantically attempted to ascend from water nearby. There were two of them. They got within inches of me. And yes, I still feel guilty because I love and revere all creatures

(even the creepy ones).

Still, though this seems like a savior story with a happy ending, it's actually one of my least favorite. The gallant boyfriend later became a nightmare all his own; my early instinct of protector leading to need to be protected.

The second dream is far more common in cultivation: It involves my daughters and I trapped in a car that has run off the road into expanding water. I have to figure out how to get them both unhooked from unforgiving seatbelts to escape the descent.

We are yet to reach the surface.

Instead, I wake up drowning in sweat, panicked as to how to keep them both from drowning. You could say that parts of my life have felt like these dreams combined. Avoiding snakes which shift and move, while wondering how to save a ship that won't stop sinking.

If this were a movie, "Why" by Annie Lennox would cue, specifically the part where she says, "Why can't you see this boat is sinking?"; ideal for dream successions. But my life is not this, nor a Filter video, filling with water while we sing, "Could everyone agree that no one should be left alone?"

The only place I am guaranteed to be alone is in my dreams, and yet... they come. Drowning deaths. Vexed vipers. Moving metaphors for what should be or could have been or is yet to happen. And I don't know how to stop it.

In my dreams, I am not always Deaf either. Sometimes I can hear and respond, sometimes I can't. Sometimes I use sign language, sometimes English.

"Are you Deaf when you're dreaming?" people have asked before. Or, "Do you dream in sign?"

They also ask things like, "Can you drive if you're Deaf?" or "How do you dance to music?" One of the biggest curiosities of the abled world seems to be "What is it like to be Deaf?" and I don't have an easy riposte.

Deafness is almost like living inside my two dreams: always a bit underwater, looking for fast moving things from the corner of my eyes.

As I dance, I take in a myriad of motions; constantly cataloguing, creating cranial cartography. I use mirrors, periphery, mirrors again. If I'm bent over in combés, I use side-eye to access. Footsteps, feeling, mirrors once more.

"Do you feel the music?" others ask, and in a way, yes. But it's more than that. As I hit play (on a song I've already mastered), the button sets a domino of events inside.

First, the internal timepiece, ticking to the measure of muscle memory. If the sound stopped, it would keep ticking, ticking, ticking, until I tell it otherwise.

Next, the feeling and vibrato in the room... under foot... in my skull. Then, the knowing of the lyrics, the layers, the lexicon of

opus learned beforehand. I study the performers. I watch their hands and form; the way their foot taps with an instrument. I observe the videos, feel the varying versions, and memorize the libretti again and again and again. Until, finally, my muscles know it better than I.

The metronome begins, and I keep track inside: some singing, some feeling, some counting; never one over the other. Do I hear the music? No, not anymore. That has long since passed. But do I listen to it? Maybe more than you do.

Being Deaf feels like feeling everything while everyone assumes you're feeling nothing.

I feel your body language across a room long before you perceive it yourself. I know when my husband is getting irritated by the trigger of an eyebrow, the hint of his jaw. I know the flexion in someone's face and what it means: if they're speaking too loudly, breathing too much. I know the tension in a brow or what the shape of your chin implies to accent. But, most of all, I know what your body says when you don't want it to speak at all.

Some people become aware of a Deaf person in the room and kindly adjust to face; movements placid, loquacious clear. Others (maybe more of them than you'd like to know) make no adjustment at all: moving their face more, finding shadows, covering beard with hand.

There is an unspoken agreement in the speaking world that the majority of us operate within: "If I can understand you, you

can understand me". And, even if we learn someone cannot participate equally, if our communication needs are met, we mind the matter no longer.

But that's not how it works for someone who's Deaf... especially a hearing-passing person like me.

Sometimes I wish I wasn't hearing-passing; some Type B version of Daphne from *Switched at Birth*. Able to warrant "Ooohs" and "Aaaahs" for my many talents and trickery.

"I would never even know you were deaf!" they say, or: "But you don't sound deaf at all!"

And the thing that most are surprised to know is: this isn't actually a compliment to a Deaf person... or even the goal. Telling a Deaf person how they sound isn't something we generally care about.

You know....

Because we can't hear.

No one should write a book about themselves at thirty.

I have never left the country, despite it being the singular item on my non-existent bucket list (let's save that for another chapter). I've never truly published a novel (this doesn't count), though I've written many. I've never taken a lover, or fought for my country, or marched for injustice, or rationed toilet paper to reasonable amounts. I've never seen *Back to the Future*.

(Again, don't you hate when people say lover?)

I read books about people who've survived wars... created cures... pas de borreé'd through history like Mata Hari or Elizabeth I.

I am one of the Hystericals... or at least I hope to be. The sick breed of burning that wants to be the Strong Female Lead, yet best serves as Manic Pixie Sidekick instead. They have done things. They are worth books. All I have done is survive the war inside myself, which could only best be described as being an adult human. Nothing more, nothing less.

Growing up, I used to think the scars I created for myself marked me as special. That if I loved harder, burned brighter, churned more wildly than those before me, I was a unique. I wanted to be of the Hystericals. I wanted heartbreaks and fevers and furies worth novels. I was... well, okay, so I was a teenager.

Raising a teenager now is much like witnessing the same. Every crush is as if no other crush existed before. Every feeling deeper, yearning longer. And everything that my teenager knows- no

matter what has been said or how wrong she is- is only of her knowing.

I know nothing, of course (I'm an adult human) ... but sometimes I wonder, maybe she's right?

Maybe everything we feel when we first start feeling is all we are meant to feel, but most of us become numb to calloused cynicism and curated calm. Maybe the numbness- the one I'll explain later, and currently feel forever from hip to hip- is just a symptom of spending too long here. Growing older, not wiser. Hardening, not opening.

This book is not a book of adventure and heroics and memoir mosaics. This book is the mistake of someone who's made far too many mistakes, but doesn't mind writing them down as memories.

I wish I had been a bigger part of history. I've lived through September 11th, 2001. I've lived through the War on Terror. I've lived through Paris Hilton calling other women bitch. And, now as I write this, I'm living (hopefully) through the corona virus pandemic. But I didn't participate in them. Not really. Those are not my future histrionic hysterics for sharing, they are just a part of my proximal past.

How can you write about your life when you haven't had much of one? When your past isn't even that far passed? You can't. Only an ego would seek to do so, and mine (though alive, thriving and very well fed) is uncomfortable at best.

Still, here I am... writing.

The war of my lifetime is drawn on my skin. A scrapbook of scalpels and surgical stamps. I will write the map soon enough. But what you don't see are the losses that don't exist. The loving Papa my daughters didn't always have. The infant of possibility stopped from creation. The candle forever burning through gaslight.

If it feels like I'm writing myself the villain, perhaps I am. Jason Robert Brown wrote himself the Jamie in *The Last Five Years* as a way to atone for his own sins; pledging misgivings through song. An unending apology, on or off the stage.

Maybe this is that. As I've already said, I'm not a trustworthy narrator. However, as you may have already noticed... you have no one else to trust.

Even the Hysterical rebels of history aren't who you think they are. Or were. Coco Chanel a Nazi sympathizer. Elizabeth I an image-obsessed conceit, vain and vulnerable at best. Even my own Frida Kahlo was a calamitous communist, returning again and again to the man with the flame, handing gasoline over herself (but holy hell do I still love her for it).

There is no such thing as the women you want to read about.

They doesn't exist here. I am not she.

She is not brave in the face of pain, or calm in the palms of surgeons. She doesn't brazenly stand up to an abuser. She doesn't

take lovers, or lose gracefully, or even love Love all the time. (That's the last time I'm saying lover.)

There is only one part of my history in which I am not the greatest villain. In which I, and the Jamie inside me, quite quietly take the backseat.

And that's the part I'm writing about now.

I am only going to write about this once.

And I want to get it over with sooner than later.

The last thing I want is for he to cast a shadow over the duration of these pages, though he already does and will. That would be giving him too much power and... frankly, that's the only currency understood.

You don't know whom I'm talking about or why. You can't prove who countersigned these pages with the pressing of a fist. You don't know who's fingertips laced across my neck. And you don't have to.

This could be anyone. Imagine your own history instead. Whatever you need to get through. All you need to know is that he will never fully know it is he that I am writing about, because he will never see himself for who he is.

He is sick. He sees what others see as fake news. Everyone is jealous... bitter... out to bring the better man down, and (even when she lied and says she's in love with him), boy did she deserve a Better Man.

But this isn't time for our playlist. No song befits this portion of life; no tempo true to those who've lived it.

He did it again too... long after me. The other women found me later. Validated experiences. Confirmed what we knew to be true but long were lit to think otherwise. And, even now, I light myself

worst of all.

The shadow is always there. Here, right now, living inside this book.

It's there when someone questions a small fact I know to be true (something as innocuous as who wrote that Pearl Jam song), and I find myself spewing and sputtering, overreacting to the largest degree. My truths become mirages; infernos flickering in and out while I scramble, desperate to prove what no one else cares to know.

Believe me. Believe me. Believe me.

It's there when someone raises their voice, and I wonder how soon until a fist goes passed my face and through the wall millimeters away.

That's not abuse, he said, no longer deserving quotation marks to words. That's not abuse.

It's there when I remember how I should remember how it could have been worse. He loved to say this.

I was lucky to have him. He made sure it never got worse. Not like his parents before us. Not like worst cases that truly were worst cases. Why didn't I appreciate it could have always been worse? That a hole in the wall or a broken piece of furniture or a burst blood vessel was not worthy of all this?

It's there when someone blocks a doorframe, accidental or in jest. I feel the feeling of a toddler in my arms; squishy thighs in the perfect nook between waistline and hip. The parts of me made perfectly to hold the parts of her.

I remember the feeling of keys in hand; Always in hand. Trying to open the door, and being stopped. Blocked. Prevented. It was harmless enough. It wasn't a slap across the face or shove to the floor. He didn't do those things, not really. And so, you see, it could always have been worse.

It's there when I realize the right to leave a building when you're feeling unsafe is a right we all deserve... but one I did not have. Not then. Maybe not now. Those seconds weren't mine for the taking. They were his for the taking, always.

It's there when I remember the car racing alongside my heart. An infant child strapped safely in the back. My voice, screaming- always screaming- to stop. The more I cried, the faster he drove. And he waited, always waiting, until I could taste the tenor of death in my throat before stopping.

Maybe if I hadn't raised my voice at all? Maybe if I hadn't expected more, asked for it. Maybe if I hadn't pointed out what wasn't normal, felt wrong. Maybe if he wasn't always right.

This chapter tells you the only real thing I've ever overcome in my life: not knowing how to keep your children safe when it is your only purpose on earth.

It'll be worse if you leave, he said... so certain. This is going to be harder.

And he was right. Always right. The only thing scarier than being in it, was trying to get out of it.

I know the feeling of seeing a light-switch flip behind someone's eyes. Being pregnant with a hand against esophagus. Knowing even if the bruises are inward ... or the fear of gun upon hip innocent... It still counts. Doesn't it? I can count them. The cons. The lies. The dogs kicked until cowered; pissing themselves when he walked through the door. The prolific, fat tears poured down cheeks, until I, a coward, cowered to make them better. Make him better. Why couldn't I make it better?

The shadow is always there. It's here, right now, living inside this book. Living inside me. But I don't feel it as strongly as I once did. Don't fill every door frame with the lines of his frame.

I am writing this now, so that it doesn't haunt 'til the end. Though, in some small way, it always will.

I am here, and you are there, and that was then, and this is now. This could be anyone. Imagine your own history instead. Whatever you need to get through.

Believe me. Believe me. Believe me.

“Dear Daughters,

I was reading a book today and it said the following sentence:
“Scar tissue is usually stronger than the tissue it replaces, but it does not stretch.”

Most mornings, you witness Momma doing a singular thing: trying to dance.

I stretch and weave and sew new pieces through strength and stamina, until the barres that once held me now become me. I try and I fail. Again and again and again.

“My back hurts,” I say almost every single day, or “I just can’t figure this out.” No matter how I push and pull, attempting to find a balance within, it never gives like I need. My scar tissue is obdurate and has no interest in the places meant to mend and mold.

This life is going to stretch you, Dear Daughters. It’s going to push you to your brink. Sometimes, you’re going to want to quit. Not a single morning of my life spent dancing hasn’t also been a morning I’ve considered quitting.

Oh, how easy it would be! The sweet relief. To lose the parts of me that pain. To forget what I must forgive. To no longer be faced

with what I cannot do- day in and day out- reflected on and on.

I was not meant to do this. My body neither forgives, nor forgets.
I am interlaced with a cement of scars, and some you cannot see.
Some skipped the surgeon's scalpel altogether. They are shrapnels
of worry instead, said from mirror to me.

No one believes in me less than me, and you might find this to be
true one day too. I see the wrong. I see the weak. I see everything
I want to be but cannot. But, that's the thing: just because you
cannot doesn't mean you can't.

Do what pushes you. Do what scares you. Do what moves you to
move. Failing is the only part of living that makes you appreciate
the living, so find time for it a little bit each day.

You're going to be stretched by this life, ladybugs... so let it make
you stronger.

Yours,

Momma"

2

The Chapter Where I Say Poop On 18 Separate Occasions (Or More Commonly Known as, 'The Chapter Brought to You By Cocaine')

The time has come to talk about poop.

I probably should wait until we know each other better, but waiting this long feels like new territory since it's one of my favorite subjects.

It's my daughter's favorite subject too. Any time she's sad or worried about the world, she looks at me optimistically and says: "Tell me about your most embarrassing butt surgeries, Momma," and that's enough for giggles galore.

I have had a lot of embarrassing butt surgeries. And I don't talk about them. I prefer to write all medical happenstance as if a filtered, blurred slow motion shot of one of Cameron Crowe's leading ladies in a film: looking back, laughing. Winking, all knowingly. A dichotomous mixture of complicated, curious and candy-coated.

I do not have embarrassing medical stories, because if I did, I couldn't be the lead. Or get my slow motion scene. Or even dance sexily across the forefront of your mind. No, there is no place for me to be both sensually "female" and strikingly flawed (but not in the human way, just in the male gaze, misogynistic 8mm sort of way).

Here, there, and everywhere, I must be broken, but not too broken.

Blood is okay, as long as it's not coming from the lining of my uterus (don't worry, it doesn't do that anymore). Poop is okay as long as I joke about it in the "Everyone Poops" manner, preferably illustrated as a James Herriot. Mucus is okay if you're one of the many men who message me online, asking to buy videos of my coughing it up (there is a distinct fetishist subset for this, and yes, I do wonder how much money I could actually make).

As long as I stick to the lady-like rules of how to be desirable while being destructively, devastatingly, and at times disastrous levels of sick (which, in case you were wondering, is disgusting), then I'm playing the game correctly.

But if I were to really talk to you about what it means to be ill- what it does to the human body and the byproducts it creates- this

might be a different story.

Don't worry: this isn't that story. This is the one which contrarian-counter-argues everything I say I'm not going to say, and lulls you into a false sense of reality where you know I'm lying but keep reading anyways. Somewhere inside, you also want the guts, gore, and glory. Somewhere inside, we all want to watch someone else bleed.

For now, I'll share a few sordid details about what sexual, sensual, desirable bodies do when also degrading slowly inside from genetics and poor luck... but not too much. Too much is to real, and we've only just begun.

But we can talk about poop because it's basically always the time to talk about poop.

"My butt is so burned alive from acid- I'm just straight pooping bile and acid right now – that it literally feels like someone poured vinegar all over my...."

I'll stop the sentence there for now. A radio edit for my mother's sake. But this was the text I sent my best friend Hepburn this morning at 2:31 PM. (Yes, any time poop is mentioned thrice in succession, Hepburn – like Peter Pan's fairies or mother Mary in the mirror – will appear. Also, yes, 2:31 PM should really be reconsidered for morning.)

"It hurts to sit," I elucidated beyond her need for imagination, "And it's making me scared to go to the bathroom or eat because..."

you know. That leads to pooping.”

Everything worth doing in this life leads to pooping.

Being scared to eat is even less ideal when you’ve had to “starve your pancreas out” over the last three days, as I have done. It helped the pain, but not the sanity. (If writing about poop by Chapter 2 of this book doesn’t show that things are dissolving faster than a Senna tablet, than nothing does. Poo-puns for days.)

My poo used to be different. It used to be a lot worse. People with Cystic Fibrosis (or a variant of Cystic Fibrosis like I have) have a long history of poop problems, but most people think we just cough a lot. It’s both.

Having my colon removed was one of the best decisions I’ve ever made. It had already prolapsed purposefully, which came the same week I performed professionally with BalletNext in New York.

At the time, Hepburn and I had rented a tiny apartment for the week, and hustled to and from the stage for nightly performances. She is fluent in American Sign Language, and was interpreting aspects of the performance, including a poem by Robert Frost. It was everything a proper City debut should be. Odorous pointe shoes in bag... blisters on both feet... utter exhaustion... and an adrenaline high like you can’t imagine.

The critics from the show were relatively tame, even though they have a history of not being so. One said I had “fluid lyricism” and that my choreography- named after my youngest - was the best

part of the night. Another said I had poor technique and they didn’t understand aspects of the show.

I didn’t really care. (Just kidding. I’ve obsessed over the technique comment every day since. Who do you think I am... someone with self-esteem?) I tried to only care about what we were creating. The one thing I should have cared more about, however, was the fact my digestive system had all but shut down. (Butt shut down.)

“Can you tell my stomach is bloated?” I would ask Hepburn in the dressing room, using sign language so other professionals were spared that which I’m so willingly exposing you.

“No,” she would say, “But I can eat your peanut-butter filled pretzels for you if that would help?” (Again, not fact, but likely something she’d say.)

I’d wait until the costume mistresses and stage managers had left the dressing room and then frantically run to the restroom (a stall located in ear shot of everything and everyone).

“Guard me!” I’d say, “Wave your hand under the stall if someone comes in.” And she would. But it didn’t matter really because I couldn’t go. I was fueling myself moderately for intensive, nightly performances, yet it went nowhere. System shut down.

It might be important to add that most colo-challenged citizens such as myself take daily laxatives. I was popping softeners and chugging magnesium citrate like Courvoisier. The only thing that would consistently happen was filling toilet bowls with blood, and

that's never anyone's goal. (Filling toilet bowls with blood is still a favorite pastime of mine, though back then it happened with a lot more frequency.)

"It's like Game of Thrones when I'm on the throne," I pun to doctors, since elevator pitch-quips are a perk of the job. (You have to have at least four at the ready for any new resident. A favorite includes: "I have a drug tolerance like Keith Richards", which works less and less the less frequently baby-faced anesthesiologists learn their classic rock. Posers).

Anyways, I couldn't poop. And, when or if I did, it was blood. Back to the story.

The day I got home from this most-professional debut, shit hit the fan. (But not really. Because that would be the desired effect.)

The irony of pushing my body to the max while performing with my idols - only to literally dislodge internal organs as a final finale - was not lost on me. I arrived home on a Sunday. I used the rest room right before bed. And immediately knew something was wrong.

The steps that followed were complicated in nature and not worth a lot of concern. The shitty synopsis includes a massive surgery to fix lapsed rectal-regions and sew them to my sacrum bone. (We also took out an equally lapsed uterus, but we can discuss that in the vagina chapter. Should we have a vagina chapter?)

Unfortunately, the recta-repair was beyond repair. Countless

partial obstructions, tears downstairs, and near nightly enemas later... And we took the damn thing out (my colon, that is). And (it begs repeating)... it was one of the best decisions I've ever made.

If you want to know what it's like living in a body that reads like a Wikipedia nightmare, you finally picked the right book. Everything the internet says you shouldn't see, is everything I see and saw. Blood. Mucus. Oil. You get it. Still, it was worth it. I no longer use enemas or prescription laxatives. I no longer cry or push organs out from the inside. And I no longer feel completely stuck with how stuck my digestive tract can be.

It still isn't "normal" and probably never will be. There is no such thing for me. I cry from pure acid or bile (or text Hepburn instead). I increase digestive enzymes depending on the lack of nutrients I'm absorbing. And I still bloody bleed, annoying as that is.

If I've learned anything from having a defunct, paralyzed, mucous-riddled colon (and, now, a missing large intestine) it is: you can function like a WebMD Most Wanted... and still live your life.

If I stopped every time my pancreas created ghost-white poop in the morning... I would never start.

If I stayed home every time I saw blood or bile or bright greenery ... I'd never leave.

If I let the weird symptoms I Google determine how I define myself on the daily... I'd do nothing at all on any given day.

We don't know when the end will be (or if our end will even work), but I hope it's good when we get there.

And I hope Cameron Crowe directs.

You haven't met my husband yet.

And if you did, I can't guarantee you'd like him.

He doesn't move his face a lot when he speaks, which isn't the easiest for a Deaf person. I've spent the majority of our relationship saying, "Are you mad at me?" or "What are you thinking?" And (after surely knowing it was something like What is dark matter and why can't we see it?, or Why must three percent of the ice in Antarctica be made from penguin urine?, or Why does everyone hate JJ Abrams when he actually makes large-franchise movies enjoyable for people like my wife who only cry when Adam Driver cries and feels for no one else?) I receive a "nothing" in return.

We lived across the street from my eldest sister a few years ago, around the corner from my parents, and she would ask "Is JL upset with me?" - he would drive by frozen from focus, never seeing her waves or sweet smiles- and I would say: "That's just his face."

He falls asleep almost instantaneously at night, while I lay awake; a sea of sweat and knowing that koala fingerprints are so similar to humans, they've been accidentally accused at crime scenes before. One moment he's talking, the next he's doing that subtle twitch

thing everyone does as they drift off, not a worry or concern on his mind. (I hate him.)

He takes everything out of his pockets and leaves it on the table next to his bed, as if the mounting Kilimanjaro of dimes and receipts is going to eradicate itself.

He takes dirty dishes out of the sink and puts them next to the sink without cleaning them, then leaves them there until I find grey hair in my part line and wonder if I can be a sexy silver-fox one day and then choose otherwise.

He gets wayward wizard catfish-whisker eyebrows and doesn't notice them (though I do wonder if they help with his vibrissal sensing as well?), while I examine every pore and nose-hair and nuance of my facial structure to ensure my humanity isn't too visible.

He once wrote me the following sentence in an email: "So I will say, unequivocally, that I miss seeing your beautiful, soft, all-while-being-slightly-agape mouth-breathing face in the morning."

We have a script, you see. I say, "I'm not being passive-aggressive... I'm being aggressive-aggressive!" while contemplating murder due to the Grey Gardens level of trash in his car, or the Howard Hugh's laundry pile in the corner, and he says Well, he says nothing. (He swallows his rage; preferring channeled internal ulcers instead.)

But even though I worry about all the ways we weigh on one

another, he is the first thing I think about when I wake up in the morning (How did he sleep? Ugh, I hate him. What did he dream? He doesn't dream. Does he want to have coffee with me?) and the last thing I ponder at night.

I worry about him all the time. I worry about his health and how many vitamins he's taking. I worry about the dangers of the world and how to protect him (motorcycles seem a bad idea. So are helicopters. And again with those damn hot air balloons). I worry and then I wonder: Why do we love?

I signed up for this. I asked for this pain, this psychosis. I chose to go insane over someone who drives me insane, because I can't stand to think of a universe in which he isn't happy in some small way (even if his face doesn't show it). I willingly participated in every single decision and Do and would do every don't again if I got the chance.

And, it's often for the little things that no one thinks to know.

He lets our daughter paint his nails and gel his hair, even though Kinky Boots is not his thing (but it's my thing, so if he'd just embrace his Brendon Urie a little bit more?)

He never pees in front of me (even though we are seven years in and he's carried my catheter bag in hospital more than once) and always cleans hair out of the clogged drain because it makes me gag.

He hands me a coffee with too much creamer, or a microwaveable

enchilada meal at night, without my even asking.

He winces and becomes silent if he accidentally runs over a spot of road kill on the highway, despite being long since dead.

The first words he ever messaged me were: "I will actually admit that I was hoping you were going to still be around," and the last ones were: "I'm bringing a Chick-Fil-A lemonade back to you."

He once wrote me the following sentence in an email: "So I will say, unequivocally, that I miss seeing your beautiful, soft, all-while-being-slightly-agape mouth-breathing face in the morning."

We met at the most inopportune time you could imagine. I was a single mother of two girls, recently-heartbroken-from and slightly-still-entangled-with my first and only fall since freeing myself years prior. I hadn't really known love; not the adult kind. And I did love. He was Deaf and brilliant and funny and the pain in my chest after he broke up with me (twice) was crushing despite my charades otherwise.

If you're thinking, "Should we really bring up ex-lovers in the first chapter we've met your husband?", you definitely don't know us. (There's that word again. I told you I lie.)

I had a life before he, and he before I. I was under no misgivings that, when we finally fused ours together, I was some unique flower of few (although I really do wish he'd stop bringing up the one he spoke fluent Spanish with).

I've never been a jealous person. I've always thought: "If you want me, you want me. If you don't, you don't." And, since I've been queer for as long as I can remember (is that too big of a bomb to drop haphazardly on Page 48?), I am not exclusively drawn to one soul or another.

My husband doesn't always find this easy, by the way, though I'm discussing it candidly now. I have told every partner I've ever been with (and there have been very few and far between, so definitely underestimate that with which I speak) that I am drawn to women as much as men. I remember telling my mother this at fourteen. I even told the one we won't speak about any more. Back then I called it bi, but it meant something different.

It was their mannerisms. Their expression. Whether they winced at road kill when overtaking by accident.

I've always been this way, though I don't talk about it much. I don't talk about it because... well, it's really no one's business (except yours, because you're reading this). It's a part of me just like any other part, and you have to know me to know me.

"If you want me, you want me. If you don't, you don't."

I don't want to be any more identified for who I love then for how I hear (which is not at all). I ended up in a monogamous relationship with a hetero normative male purely because he is who I ended up with, not because I am either hetero, nor normative. I am, and have never been, either of the above.

But I pass for it. Just like I pass for hearing. And truthful. And all other sorts of things you're learning now not to rely. And even though my partner and I are fundamentally different, and my jealousy bone is not the strongest, we both lived lives before architecting our own.

He was turning thirty at that time. His closet full of skeletons. His heart encompassed by ghosts. We have a haunted love. One that is consistently trespassed and forged through former fights from another. That is what happens when you make mistakes and choose wrong and the wrong person chooses you before you get the righter one.

My daughters and I talk about the spectrum of love and life all the time. They know that people identify as a great number of things, and it's not who we love but how we build a life with them that matters.

This is mine.

If I hadn't gone through the unspeakables of my past (which we spoke about before but won't speak about again)... I wouldn't know what I really have. I think about the women who left my now-love. Do they think they dodged a bullet or did the right thing? Do they think empathetically towards the sorrows of the next? Maybe they did dodge a bullet. Maybe they just didn't know what they had.

But it's not about the paper. I've had paper prestige in the past and it left a hand-sized hole in my wall. This love came with files

and files of fallacies: debts and dreams gone wrong and daring
optimism turned dark with dread. In the end, it is all the little “it’s”
I so easily forget.

It’s the scar along the lower left side of his jaw.

It’s the song he sings the girls at night when they can’t sleep.

It’s the way they look at him while he’s looking at them.

It is a haunting worth having, again and again and again.

Song #2: “It’ll Be Better” by Francis and the Lights

**If this were a movie, this would be the part where we
show you something you don’t want to see.**

My life has been filled with things not worth seeing, yet they’re
etched in mind forever. Whether the time my hands swelled up
three times their normal size after six failed IV dextrose attempts,
burning like gasoline ... or infected incisions gone wrong... or
coughing up mucus again and again for waiting techs... or lying
naked while heart monitors are placed on exposed flesh.

After an epidural failed to fade, I ended up sick. I made such a
mess of myself that nurses had to strip me bare and roll me over,
while I yelled at my partner to leave the room. I still remember
Hepburn’s eyes filling with tears when I told her this later, probably
because it was one of few times I cried on description. (I still shiver
thinking about it now.)

Anyone who has ever been in an ICU knows it is a lot like my
favorite place on earth -a well-lit stage- in the worst way. Lights
won’t dim. Flimsy curtains and glass panes make doors. And
cameras rest in corners high atop, even when catheters are placed.

“Could someone be watching right now?” I remember asking, as
two kind nurses coached me through yet another wide leg cath
con, angled directly towards lens and frame.

“Yes, but no one will be,” they said kindly, “And the screen is very very small.”

The medical system is nothing if not another person asking you to spread your legs while you softly whisper no. It is humiliating, it is invasive, it is traumatizing... and anyone who tells otherwise has never actually been sick. But it is also healing. And hopeful. And filled with humans who have saved my life more than once. Not everything in life is just one thing.

Sometimes, I wish it were. I've never sat topless on a beach in Barbados, but a room of strangers has seen my breasts fully exposed.

The world is full of people who've had a couple of surgeries before but take years to psychologically heal from them. Or who have never slept more than a few nights inpatient. Or who haven't been sick for decades. Or who think a couple scars counts as many.

This is the part where I show you something you don't want to see because... this is the part where you realize who I really am. Or can be.

I am not always nice. I am not always compassionate. I am not always inspirational. In fact, sometimes, I'm just resentful.

I am resentful of those with family members who fly to them during treatments. I am resentful of those who haven't driven themselves to their own portacath surgery before (it was just a replacement, so it wasn't that big of a deal), and then sleep it off in the front seat of their best friend's car. I am resentful of those who

have remission. I am resentful of those who have memories before they got sick. I am resentful of those with healthcare, or housing, or income that allows respite from work during tough times. I am resentful of those who don't actually get what it's like to do this for this long in this way, and never will, because they only see their own experience instead.

If you are cringing at these sentences, don't worry... so am I. They are the worst sides of me.

The only thing I hate more than those who don't understand how good they have it (even while enduring their personal worst) is those who compare themselves to someone else. And, here I am. Being my personal worst, when I should be the best at this by now.

My type of care can't be counted down with bells and blessings. And though I pretend this doesn't consume parts of my life and person, it does and has... I don't want it to consume anyone else.

I can't blame another for not always doing the “right” thing at my specific “right” time, when even I don't like me that much these days.

It's hard to pray for someone who doesn't get permanently better.

It's hard to believe in something you can't cut out or chemicalize away.

It's hard to see how hard it is if I don't show you...

And that's no one's fault but mine.

This is a letter for someone I'll never meet.

“I’m writing to you because we’ve never spoken before. You’ll never meet me – even though I am made of you- and you’ll never know I wrote this because you are no longer here. You never were.

You’re gone because of me. Because I never got the chance to grow you. To greet you. To go from grape to pear to pineapple to person.

I still remember how your sisters smelled when they were young. The suede feeling from cradled hair. The achiness of forearms bounced and bobbed until sobs become stifles. Motherhood creates muscles that not everyone knows about: the angle of a hip to prop; biceps numb from sharp right angles.

Your sisters each got a song when they were born, coordinating to whatever Dave Matthews Band album arrived that season. “American Baby” for the eldest, “Baby Blue” for the youngest. My Dad gave all five of us a song too: “Little Princess” by Elton John for me. I wished I had “Tiny Dancer” like my eldest sister, because... that’s what sisters do. We want what we can’t have and we have what we can’t want.

I wish you knew what sisters were like, and all the secret rules they inscribe. How someone must always get the front seat, even if “shotgun” isn’t called. How someone must stay awake an hour later than another, though birth order shouldn’t determine. How someone must be the keeper of all the other’s secrets, though white

lies are a currency that keeps until middle-age.

Where would you fit in? Would you not tell your mother about the tattoo without approval, even though you sat hand-in-hand beside your sister, sipping Slurpees in panicked provision? Would you not know the taste of a Hookahs from visiting her in college, or what she really said to the bully on the playground in your defense? Would you not know the deep desperation of wanting to be exactly like someone who wants exactly nothing to do with you?

The unrequited love of a sister is a hurt most heavenly... How would it feel for you?

I see your name everywhere. In businesses and brands. On Page 20 of this book. A daydream in my mind, drawn across every moving van or Billboard to pass.

Would I yell your name as I yell theirs? Angry at opposition. Defiant from disregard. Changing syllables and tones until I've all but destroyed it. Motherhood creates dialects that not everyone knows about... a way of looking and phrasing; singular words stretched to sentences. There are two ways to say a name... Which way would I say yours?

Your Dad doesn't have a song. Not in the way that my family gives them. But he and I share one. One about choosing. One meant for first dances (though your sisters interrupted ours). What would yours be?

A certain song comes to mind these days: "Downtown" by Majical

Cloudz. It's one I keep playing again and again, hoping it swallows me whole. It's the perfect song for dancing, dreading, dreaming.

"There's one thing I'll do," it says, "If it ever goes wrong, I'll write you into all of my songs."

It went wrong... And still, you're in the marrow of every mistake I make. The dances, the dreading, the dreaming. You're here, now. "And if suddenly I die I hope they will say, that he was obsessed and it was okay."

I'm going crazy for you... but that's how it's supposed to be. I wouldn't have it any other way. You deserve that much; that little.

I'm going crazy at never having met you. "Is it really this fun when you're on my mind?"

Your dad would have been the best dad to you. He has been for mine most of the time. He would be for another. He wanted that for the one that mattered most, though kept away until loving meant hurting.

Have you ever known someone so selfless, they would rather give up than ground another from truths they needn't know? That's a giving that few know. That's who you would know. Who he is. How lucky you'd be.

But... you aren't. You don't exist because of me. My body failed you, as it fails most things. My body failed us, as it fails most things. My body failed.

“Is it really this cool to be in your life?”

I’ll never know. But still... I know. I know how happy you would have been. How much we would have loved you. How he would have been as your dad. How I would have been as your mom. How they would have been as your sisters; you a sibling to them. It’s a hurt most heavenly. There is no one to blame but me... but that seems like a fair trade, doesn’t it?

I should never forgive the loss because it needs to be felt. You deserve that much; that little.

We want what we can’t have and we have what we can’t want.

And what I wanted was you.

Yours,

Momma”

My feeding tube is bleeding.

It has been doing this every night for a week. It begins dripping when I lay to go to sleep, normally after eating a large meal. Ironically, it does not bleed during hour-long ballet barre sessions, or tepid attempts at core work on my living room floor. That I would understand. Instead, no matter my movement or modality, food (in particular, my larger dinnertime meal) seems to bring the mayhem.

I should probably explain that I’m stuck at home right now (or “safe at home” as the jargon police prescribe) along with the rest of the world.

I’m sure anyone who is living through the Covid-19 epidemic is not going to want an ambush of this term when least expected (I want this to be a safe space, after all), but in case anyone finds this in a time capsule two hundred years in the future, it’s important to establish context of when this is being written. The synopsis is: Humans wanted too much; stretched too far. We caught a rouge virus. We quarantined society until we found a cure for the virus. Hundreds of thousands of people died.

It is essentially the plot of every Young Adult dystopian novella my teenager is currently reading, and too many things will be and have been written about it already.

I don’t want to write about it. There is no way to say something that hasn’t already been said before, better.

If this were a movie, this would be the part when you realize I'm secretly writing this from my bunker of a home (lake house with a loft), while yelling at my delightfully-spoiled thirteen-year-old that, "No, eating peanut-butter pancakes on your papasan chair while not seeing the neighborhood kids for two weeks does not qualify as Ann Frank levels of suffering."

I could write about this all day... perhaps because I have nothing else to do all day.

We are positioned inside our forty-five by twenty-five foot rental home, with sisters who share a bedroom yet don't have a bedroom door to slam, and one bathroom. Frankly, I feel like I've been preparing for this for years. Whether when I was a single mother and lived in our tiny apartment where we painted a wall Frida (Kahlo) freedom-red, or the decade or more of homeschooling together... I have never known life alone.

Every novel I've ever written (including this one) had children screaming in the background. Every paycheck I've ever earned had an infant in a stroller or a pre-teen doing math nearby. If you ever want to do shit alone (showers, sleeping, or taking one)... don't have children.

I adapted quickly though. Multitasking is my mainstream and fusing our lives together has brought more joy than pain (this chapter notwithstanding). At this exact moment, my ten-year-old has already interrupted four separate times, and I have said the sentence "I can't even get through one sentence!" four more than

that.

This is what my life looks like most days of the week. Before the pandemic. Hopefully after the pandemic. And onward.

Most of us are sick of reading about it. I'm sick of writing about it. And the senseless loss of life is too great to name or number or attempt to frame into prose that does it any justice. My fractured phrasings hold no place here, and only seem to add insult to insurmountable injury.

"The single greatest threat to your life within your lifetime is out there right now," my Dad said to me the other day (he's great with pep talks), "You have to be careful."

He's right. As someone who's extremely high-risk due to pre-existing conditions and poor health (est. 1986), this time in history is particularly terrifying. I don't want to write about the fear though. Not yet. I want this book to be a safe space... even for me.

Of course, I can't get the following sentence out of my mind: I don't want to die alone. (I haven't done anything in my life alone... Why start now?)

This has been a worry of mine for decades prior to this endemic end game, and it has only gotten worse. While before it felt a neurotic knowing exacerbated by CF exacerbations, now it's a reclusive, required reality happening (as I write this), globally, upwards of eight thousand times per day

While writing this sentence, someone is dying alone.

While reading this sentence, someone else may be dying alone.

There is nothing I can write here that hasn't been written... but it's hard to pretend it's not happening. Do I pretend it's not happening? Do I let this book be a vortex for anyone hiding from the outside world? Maybe that's what we need right now. I don't know.

I know I have a bleeding feeding tube, and a doctor to email, and a cup of coffee to drink (the three are not mutually exclusive but the latter might be influencing the former more than I'd like to admit). I know I don't want to die alone. These are the things that I know.

And If I had to create a bloody montage for this movie we aren't actually making, I would say the following scenes must be included: The time I coughed up so much blood that it filled three red Solo cups and left residual Pollock on our wall for years thereafter, or the time I was in a professional modern dance company in DC and had to secretly mop Black Swan drippage post pas-de-deux.

Blood and I are familiar with one another.

In fact, I could write about this all day... perhaps because I have nothing else to do all day.

But, instead, I'm going to change the subject.

"My favorite type of stories are the ones with a push and pull."

My husband said this this morning, while talking to our eldest daughter about creative writing. She is preparing to take an online, week-long class that focuses on fantasy world-building and character development, and I sipped my lukewarm coffee while watching them talk.

"The best writers establish whether the main character is being pulled towards something- their final goal or motivation- or pushed even if they don't want to," he continued, "And I find that the books that establish the distinction are my favorite."

I prefer my coffee scalding hot.

"I know," she said in reply, because that's all our teenager says any more.

"Why don't you like reading fantasy novels?" my husband asked, turning his attention towards me, "Is it because you think it's the lesser form of book or something?"

"No," I replied glibly (an appropriate amount of glibness is always necessary in the morning), "I think I just wasn't exposed to it growing up. Any time I was – like the entire Animorphs series or Harry Potter- I devoured it. But now I just love reading about people. I love going down the research rabbit hole of real humans and their experiences."

"That just means you're old," he said in response.

And that's true. The older I get, the more I find the former flame

of Psychology and Sociology majors burning uselessly inside of me, ready to binge on antiquated truth and biography.

Is that what this is? This book most undeserving of such a title. I am not a writer who has established the push or pull of our central character, because she is me, and she is still often a mystery.

Falling into a routine while enclosed at home- the four of us in four by fours of wooden flooring and sallow A-frame- has been easier said than done. Or rather, a lot of saying, and a lot less doing. Today is technically a Saturday and that means a weekend as a family. But since it's been nearly three weeks without leaving our property, Saturdays become Fridays and Fridays become no-days and on and on.

"I think I'm not listening to myself, honestly," I said to someone online, just minutes ago, while discussing whether to establish a schedule at home or do what feels right.

If there is one thing I do know about our central character at this point in time, it's that she passionately and patently doesn't know what feels right. She thought that staying with someone who killed stray cats with BB guns and once beat another bloody because he spilled powdered doughnuts at a frat party was right (weirdly, she tried to cancel that first date because she wasn't feeling well, and now wishes her health had intruded for once in the right way). She thought that leaving college with a 4.0 grade point average and ongoing Dean's List status was right, since she was too sick from pregnancy (and increasing unexpected decline) to focus. She thought that Hillary Clinton would win, and bleaching her hair

blonde would look natural, and that Robin Williams would live forever.

Most days, I approach truths like coffee: ingesting even when it hurts; burning my tongue and making parts go numb forever. Truths taste a certain way; a roast of regret and remorse, though I've made a habit of pretending I don't regret things.

Regretting means my daughters wouldn't exist. Regretting means my Later Love wouldn't have happened. Regretting means remembering... and that's a push and pull I don't always want to feel.

Instead of relaxing into life without regimen or routine, I've found myself overthinking every twist, turn and corner (and there are twenty-three distinctive corners in this house, to be exact. We counted).

"You need to find a way to just be with yourself," I dictate to my eldest daughter on a frequent basis, "To not do all the time. To just be still."

Normally she argues about how this makes her anxious. "Holding still and forcing myself to calm down just brings all my nervous thoughts to the surface," she'll say, but lately she just says: "I know."

So why can't I take my own advice? Why can't I be in the way I hope others can be? In all twenty-three corners of this house, there is no one I'd rather be with less than me.

On a good day (so a Monday or a Friday), I would do everything right that a sick person is supposed to do. This means I'd wake up and unplug myself from a feeding tube extension cord: delivering overnight supplemental nutrition to my calorically defective intestines. I would rinse my nose with sinus antibiotics and interchanging salines; settling down for nebulized medications (Duoneb, Pulmozyme, and Hypersal) for hours at a time.

Sometimes my jaw hurts from clenching the mouth-piece too tightly with my teeth. I want to do other things with my hands: reading, writing, making; anything but the mind-rot that medications can feel.

Maybe I would eat something healthy while taking five to six Creon enzymes to help my body digest. An Activia yogurt or a banana with peanut butter or a misbegotten egg and cheese. Later that day, I'd do other treatments too: lung clearance, more nebulizers, rolling out my muscles, popping pills, repeat. But this is not that day and, honestly, it very rarely is.

Most days, I do the best I can and lately (with increasing frequency) it's just not good enough. So, on a bad day... a day like today... I would do nothing but regret how much I regret nothing.

I woke up and crawled to the couch with a handful of blankets and pillows, glaring through slatted eyes, eager to become invisible. My children were not fooled by this invisibilia, and began immediately downloading before my modem had dialed up. The husband was listening to NPR Invisibilia and staring out over the water through

the window. I like the idea of sitting with him in silence while he does this; zero access to the sounds and segment, but every access to the rare but real revelation that he may, occasionally, relax.

“What is your biggest regret?” I ask him, deeply on topic and totally off base at the same time.

“You know what it is”... he says, shifting in posture.

I do know what it is. I was hoping he would say something different. I can't tell you what it is, sadly, despite the slight nod in this book, because it's for he and I to know and only us. One day she will read this and maybe she will know too. One day, she might know the truth.

But for now, even on the slowest of mornings, the truth tastes bitter and burnt like usual.

If Hepburn was your best friend, you would text her photos of your poop.

This is what I did on Thursday at 11:54 AM. I prefaced it first with a: “Want to see my poop lately?”

“Yes I want to see your poop,” she replied instantaneously, “Duh.”

So I did. And she saw. “I feel like this should be in textbooks describing what the large intestine does,” she said in response, after admiring the pure liquid-oil-sludge. (For anthropomorphizing reference, imagine the Hexxus, the entity of destruction villain from Fern Gully: The Last Rainforest.)

This is the type of best friend that Hepburn would be to you.

She is also the type of best friend who would pretend her name is really Meriam, and that she’s secretly a world-famous professional ballerina on a night out with friends. To be more specific, a night out with friends in which one of you is married to one of the friends, and days after the love of your life died unexpectedly from a brain aneurism.

His death felt about as unexpected as that sentence in this book.

There was no warning. One moment Hepburn was talking to him on the phone (he lived continents away in England), and the next... there is a text reading: “George is dead.”

“Your George?” I replied, while driving home from an

appointment of some kind with my Mom. I rode shotgun and thought maybe she’d mistaken herself, typing the wrong words.

By the time I was dropped off and ran into our hundred-and-thirty-year-old home at the time, I found her balled on the couch, sobbing uncontrollably.

George was a healthy twenty-three-year old one moment and no longer existed the next.

We were used to friends dying of course, since we knew many a Cystic Fibrosis sufferer then. If someone passed, we would take a shot of strong alcohol in their honor, knowing it wouldn’t be long before the next had come to pass. But George... well, there are chapters worth what George could and should have been.

But that is hers to write.

I’ll just describe what happened after. I tried to say all the right things in the wrong way. We called up Jonathan an hour and half away (the makeshift brother and obviative missing-quarter to our cluster from Page 1), who rushed down to join us. Eventually, we focused on forcing Hepburn to eat and drink things, or do basic physical functions like blink and breathe. It took time.

But once we fast forwarded through the worst of the grief (but none of it at all, since it is of her and with her forever and always), we decided to get blindingly drunk and pretend we weren’t ourselves at all.

She and I took on the roles of Mariam and Veronica, respectively, and ventured out for a night on the town (something that, considering I have two children and a shoddy liver, happened very rarely, if at all). I lent her my wash-off tanning mousse to paint herself a person who lounges on afghans and sips Rum Runners through plastic straws while baby sea turtles cry, and added my most vacuum-suctioned dress to seal the deal.

We had the boys- the one I love and the one I'm married to- drop us at a bar downtown, and head to another destination for incidental interference should it arise.

"Pretend you don't know us," I said excitedly, while limping along in heels more suffocating than our midnight mourning, "And then we have to meet as if we've never met before."

The first terminus was innocent enough. In no time at all we met two men who turned out to be the sweetest, most sincere nerd-friends that truly loved their girlfriends back home.

"No matter where we go," she whispered later, "We always find the good-guys."

I can't recall if I pretended to be hearing or if we continued the preferred lingo of our friendship: American Sign Language. I do remember pretending to be famous, successful dancers who had never had their hearts broken, and certainly not by a ballooning blood vessel in the brain.

The second destination led us to a booth with collegiate basketball

players that both thought we were college age as well (we were not, and possibly never have been), and that we'd want to join them in their hotel room later to smoke the pot.

We did not smoke the pot.

"Those two are such a cute couple," someone remarked to Hepburn hours later, while motioning across the room to a presumed couple, awkwardly standing around waiting for their real-life wife and life-long best friend to drop the charade and pretend to know them again.

"Oh them?" she said, grabbing her refill of red wine... "Yeah they are... Aren't they?"

Pretending to be someone else didn't work as well as we'd hoped. Our alter egos didn't know the cure for devastating grief nor uncomfortable shoe-wear, and later that night, when walking downtown in bare feet and blisters, we wondered if our remorse could wash off as easily as the fake tans we'd so foolishly applied.

Looking back on it now, so many years long gone, I can't help but realize we eventually became our fantasized selves. I would find myself dancing with role models in New York, Seattle and beyond; earning free Gaynor Mindens and truffle-laced ice cream like a neurotic rock star I didn't know I could be. She would travel beside and beyond me; fouting through projects and performances while casually earning her doctorate.

Yet, perhaps the biggest staple in our friendship that you need

to know is not the fiction or surrealism shared along the way...
It's the poop-pics at 11:54 AM and small deaths to former selves
incurred on couches when least expected.

If Hepburn was your best friend, she wouldn't be the same after
she lost George either... but she'd still be yours.

And that is a fantasy too great to imagine.

If we were to have a fight, it would go like this.

First, I would deflect and defend, because there is nothing I hate
more than being to blame.

I have guilt issues that rival no one else. I feel guilty when a nurse
comes in my hospital room to help with a bed pan, because I
should somehow play hostess and make her feel more comfortable.
(First step: lose the bed pan.) I feel guilty when I see someone's face
go from happy and hopeful to sad, and then replay the slow-mo
disappointment-drop again and again in my head like a Deaf-girl
directed, maudlin, Llewyn Davis medley. I feel guilty about how
guilty I feel when other people say I shouldn't feel guilty.

If my partner is working on a project which I can't actually help
with (so, like, ninety-five percent of what he works on, including
opening Gatorade bottles or anything involving wood), I stand
nearby doing nothing. I loiter because I feel too guilty to relax, but
not enough to actually help. (That's generally the area with which I
reside most of my life.)

My partner fights in one of two ways: He either stings with
Cancer-born ferocity, or goes completely silent for hours at a time.

The silence, it goes without saying, is deafening... even for me.
It brings on a sort of unintentional Tourette effect which forces
me to fill the void with anything I can find: accusation, projection,
pejorative. (They're the typical trifecta but sometimes I range into,
"Don't twist my words" catch phrasing too.)

The final phase in having a fight with me is my complete and utter loss of hope and belief (two words that almost mean the same thing but somehow feel different).

If you (as the reader) feel like this is a trap of some sort... you're probably right. My husband believes so too. He says, "This feels like a trap," more than anyone on earth, second only to: "Why do you only speak in hyperbole?"

"Are you airing our dirty laundry right now?" he asks, as I ask him for common things we say during fights.

"I must say certain things again and again," I urge, turning to my eldest for evidence instead. Surely she will rat her mother out.

"No," she says quickly in retort, "That's more my thing."

"Well, quick, let's keep talking about it because it feels like we are about to have a fight... and then we'll know!"

I'm ignored.

I am not, for the record, airing dirty laundry... because is it even considered dirty laundry if he doesn't throw it in the hamper on occasion instead of draping it over the footboard of the bed?

I digress: If you were to fight with me, I would bring up everything you've ever done before and hold it against you. Every sentence like a scar shorn deeply across my chest (which, suffice it to say, is already fairly shorn with scars), rather than admit my own wrong

doing. Always fake-forgiving, never full-forgetting.

But don't worry, because I do the same thing to myself... only worse. I remember every single sentence I shouldn't have said. I replay every altercation with grander result. I resolve issues internally which haven't been resolved, and live in the Worst Case forevermore.

I have actually had the Worst Case more than once in this life, which creates a type of person who doesn't just forget... they fear the Other Shoe in every waking moment.

Happiness, to me, is a sign that we are just due for something bad to happen again.

But am I really this pessimistic? Would you really want to fight me? Yes and no. I constantly remind myself how lucky I am, and the blessings to be counted. I'm perpetually curating new perspectives and climbing to fresh vantage points. I know how the Worst Case feels so... I surely should appreciate what happens between, right?

Sometimes I wonder if the Forced Perspective is just my way of dealing with guilt (always with the guilt) which arises from constant awareness of the Other Shoe.

When will it hit? When is the next best worst? How much will we have to fight next time?

Maybe I don't know how to be happy any more...

I just know how to know it's not as bad as it could be.

I don't like truffles on my ice cream.

I know this because I once had truffles on my ice cream, and that's all I need to know in order to know this.

The mushroom-covered dessert occurred during a truffle-laced multiple course meal with a patron of the arts somewhere in Manhattan. We, as ballerinas of the arts, had to attend said dinner with said patron of the arts, because it was our unspoken job to please him with pleasantries (and eat all the truffle pasta) so his money might support shows and rehearsals in the future. And it did.

He had billions and was just one of many I've had to Smile And Nod for in the line of work that is dance. Dancers aren't supposed to talk about this unspoken job (so I won't, because tacky), but it very much is real regardless of what you've read.

I have a weird relationship with money, to be honest (just like I have a weird relationship with wealthy donors that smack bare ass when changing in dressing rooms). Money and I aren't always friends.

Life can feel like two extremes: the professional and polished, and the progressively penniless... with very little between.

If someone lists the more posh aspects of living (like I'm about to do), it sounds as if that someone is bragging. To be clear: I am not. For those I have worked, danced, and engaged with over the years,

none of the following are even note-worthy, unusual, or worth mentioning. They would not write a chapter about any of the above or that which is to follow. It is simply their life.

For me, however, it is both and none at all.

Hepburn and I have experienced a myriad of moments in contrast to our many blue-collar ones in the last couple years alone: eleven-course meals with the rich and famed... sitting on the floor of private town cars...VIP club rooms within the VIP club rooms... doors within doors... Alice diving deeper and deeper and deeper.

I've gone to see a go-see and then gone to see another. I've witnessed the bejeweled treasure trove of a pointe shoe fitting room for the fittest of the fit; styles and satin for the taking. Cocaine at the after party after the after party. That's just how this goes, and I already knew it from my other lifetime. A decade ago, while working as a lifestyle and fashion journalist, I experienced much of the same. More cocaine with the CEO of companies (I did not partake, but yeah... cocaine is surprisingly still a thing?) Swag upon swag upon swag.

At a conference in Miami – not too far from where I originally grew up- I corralled beautiful products into gift bags by day, lounged by the pool in afternoon, and watched friends hand out condoms to strangers on the Floridian streets by night. (They were sponsored by the condom brand, of course. It totally made sense.)

But none of it really makes sense, does it? At any given moment, I am divided into equal parts: the constant marketing mensch who

lives for brands and packaging and chemistry and creation, and the frugal freak who purges most of her possessions in one sweep.

The former is someone who thinks there is nothing weird about wearing a Kardashian-brand dress (sent to her while working the press line at their event) only to be literally bounced from the bathroom by their bodyguard because she foolishly attempted to pee at the same time as they.

See how I'm bragging? Except I'm not. The truly cool things won't be repeated here, because the truly cool things had nothing to do with D level fame or designer hand bags or dalliances by night. The coolest moments are the ones you don't see from the outside.

The time in Las Vegas that I spotted a shy looking guy across the room wearing giant hearing aids, walked up and introduced myself. We chatted for most of the night- sumptuous dinners and sinful side events – while wishing we could dip out altogether. Or the beautiful Deaf friend I bonded with in South Florida, who later rented a summer home with me for a week-long, sign-language filled stay with friends. Or the nerdy asides with nerdy-new-acquaintances to the side of impromptu dance floors on third stories of multi-million town homes in the city.

“You can't miss the after party,” my partner said, after a string of dance performances ended, and the rock and roll was set to begin.

“It's not the after party,” I said, “It's the after party after the after party, and I'd rather just be with my people.”

My husband and his two childhood bests- Jonathan and Matt- had driven to see the final show, and Hepburn and I wanted to celebrate how we know best.

“Can't we just go to a pub and hang out?” I asked, truly wanting to forgo living room turn tables and Vodka shooters and sides of (always, inevitably) cocaine.

“I wouldn't want you to miss this,” my husband encouraged, and so we went. He forgot that sometimes the frivolous fanfare is well worth missing.

“Are you going to go out and greet everyone after the show?”

This is another question I've been asked many a time. It is tradition for ballerinas to throw off their costumes and tights, mop their sweat, and change to a low cut dress, before entering the lobby to see those who came to see them. It's a way of saying thank you... and, that's important. But, I've always felt weird about it? Even after shows with my own company.

As my beautiful deserving dancers dash to celebrate, my Stage Manager teases me for hanging back and hiding out instead. I'd rather clean with the crew. Dry mop the stage. Avoid the praise and patronage, for whatever reason. This is selfish, in many respects, and I realize that.

“What am I supposed to do?” I ask Hepburn, rhetorically, for the hundredth time, “Go out and let people compliment me and say how great it all was, while feeling weird because I'm just collecting

praise?”

No one is going to tell me to my face if I didn't do that well. No one is going to say, “Good job but you were a little sloppy in your developpé, and you could stand to stop pandering to the audience for a change.” No one except Hepburn, Jonathan, my partner, and my older sister (older sisters are always good for those sorts of things). They are the people.

I know that patronage and pandering and praise is a part of the job... but it's the part that makes me feel the weirdest, because I can always do better. I am not more deserving than someone else. It's a matter of luck, privilege and perspective that has gotten me there in the first place.

My favorite after party after the after party was when the four of us went to varying pubs on the East Side, and shot perennial shit with one another, no turn-tables necessary.

I'm fortunate to have lived a life of extremes, of course. To experience Mick Jagger mayhems of the upper echelon, but return to quiet Target trips and lakeside lazing with my girls. My eldest attends beauty campaign shoots with me in Brooklyn one moment, and cleans-her-dang-room the next.

I don't know why I rage so hard against the consumerist machine and social hierarchy hashtags, but I don't think it will ever change.

The other side of me is alive and well. It's the side that wore a five-dollar Walmart dress to her Good Morning America interview

in Las Vegas because it made her feel powerful. Or that never stopped feeling slimy when interviewing Next Top Models or designers or Tim Gunns because we are all the same and “what really makes them so special?” (even though Tim really is the sweetest, so definitely special). Or the side that just doesn't like shaved truffles on vanilla ice cream, because cookie dough is better.

I've known social climbers in my lifetime (heck, I was deeply entwined with one) and it is not a way to be. There are beautiful humans at the top who see life is so much bigger than the top... and there are those who think it's all there is.

It isn't.

It's nice and sometimes it tastes good... but it isn't.

Living within this paradox is painful at times, truly. I would skip meals and pay for cut-rate coffees with dimes while dancing on the Upper West, worried I wouldn't be able to afford my subway fare from the studio later. Even though I participate in the praise, I am actually scrubbing for pennies on the side.

My husband is a Special Education teacher (soon to be without a job at the time I write this) and I am a chronically ill adult who can't work consistently enough to make progress before the next hospitalization arises. The cost of managing the medicine is a chapter in of itself... or the medical bankruptcy I had to file... or more. But let's save that (despite the obvious lack of savings), because the only thing more disappointing than the unreliability of my body is how much it costs to keep it alive. I derive a great deal of power and pleasure from saving instead, as if I'm actually

contributing. I hunt for the best deal as if I'm foraging for berries (and, sometimes, the quality goes a little more Christopher McCandless than I'd like to admit).

Life has given me a number of things with which I can't refute. Praise I don't always deserve. Privilege I don't always want. Polarizing perspectives and prosperous propaganda when all I really want are pubs.

It's easy to reject the royalties of this profession, because I know what they look, feel, and felt like. But for those who've never had truffles on their ice cream before... it's an entirely different story.

It doesn't matter whether you pay with dimes or with dance... not everyone wants to Smile And Nod for dinner...

Sometimes... hunger just tastes better.

"Dear Daughters,

If you become a parent one day, you need to prepare yourself to give a lot of cares to what you care very little.

Last night, I had to pretend to care about how close your cushions were together while watching a movie on the floor as a family. The youngest of you believed they should be farther apart, and the eldest no longer cared. The eldest did care the night before, mind you ("She said her mattress couldn't be near mine during movie night... now mine can't be near hers"), but chose to be impassive later.

At the time this occurred, I was attempting to read the first sentence of book number two of the Harry Potter series- The Chamber of Secrets- loud for all to hear. I never made it further than "Privet Drive" before bickering began.

Earlier that day, you fought about the following: who made the larger mess on the stairs and who was going to clean it up, who deserved to do the most of the dishes because both claimed they had done their share already, and who said what in a certain tone that made the other believe they were worthless and unloved and that now you hate each other.

Sometimes, raising siblings is like watching a mini microcosm of the world: Everyone vying for the best resources, time, and

attention, and no one willing to learn to speak the same language at the same time. If someone makes you feel badly even once, you make it your life's mission to make them feel as badly the next night.

The only thing most of us care about in life is us. That's just a fact. Like your Papa and I's favorite Trampled By Turtles song says: "We come into the world alone, and we go out of the world alone... But in between, there's you and me."

My largest fear isn't going out of the world alone... but leaving you two alone within it. I've said it before and I'll say it again (in as many Dear Daughters letters as it takes): This is it. You are it. You are all the other has in this world... so your floor cushions might as well be closer than apart.

After you fought yesterday, we watched another Pixar movie with another microscopic morality plug and you had tears in your eyes by the end. As the credits rolled and a new Brandi Carlile song played, you marveled at the mastery of lyrics and how much they match our lives.

It's much like the other Carlile song we love so much: "Wherever is your heart, I'll call home."

Do you remember the time I left a road map for all the ways to love? I was going in the hospital for some time, and worried how you would do without me. So, I made a game. I wrote different songs for different days of the week and hid them all around the house on tiny scraps of paper.

I had hoped you would search and seek together, and blast sounds as loud as can be (as we so often like to do), feeling connected indefinitely. To me. To each other. To this ultimate of playlists.

And you did... sort of. But by the time I got home, you had already lost interest in the auditory treasure hunt and forgotten the scraps completely. "Wherever Is Your Heart" stayed stuck to the bottom of a jar of peanut butter in the pantry for at least two months thereafter; deserted and alone.

Don't do this to each other. Be there... even when you don't want to share, or search, or seek. Even when you speak in conflicting ways. Even when your cushions come to cataclysmically close.

We come into the world alone and we go out of the world alone...

But in between, there's you and you.

Yours,
Momma"

3

The Chapter With That Sentence From Page 8

It is probably time we talk about that sentence on Page 8.

I slipped it right by you. It was the sentence where I said: “The day I realized my body could be used as the entry point for another against my will.”

You’ve read about this before, of course. Not from me... but from almost every female who has ever existed as a female on this planet. Not everyone wants to share this sort of information, so maybe they don’t say it directly... but it is shared by most of us nonetheless.

If you name a woman with whom you know and trust, she has

likely had some sort of experience in her body with which she did not give full permission, nor feel entirely comfortable. Our bodies are not ours, you see... At least mine has rarely been.

My body has been my boyfriend’s before, on cold tile floors; even when I said the word “no.”

I pushed at his shoulders and told him to stop, but he was too drunk to remember. He continued, bleary beleaguered, as if I’d never spoken at all. Had I spoken at all?

He cried a little the next day when we talked, and didn’t deny it, but didn’t remember clearly either. If only one of you remembers, does it really make a memory at all?

My body remembers a lot of things. It remembers thighs grabbed by strangers in crowded venues and dance events. It remembers knees held by passengers who didn’t know the knee enough to touch it. It remembers hands and hips tightly squeezed by friends I thought would never squeeze them.

Muscle memory is a funny thing. It carries us through dance shows while kicked into autopilot; adrenaline overtaken. It shivers at the smell of antiseptic, or the knowing that no one knows more about my body than me, though no one has less say in it. It feels the feelings I pretended not to feel, long after I’ve felt them.

I don’t write this chapter to say: “Look at me! I’ve lived a dramatic life. I am an overcomer of illness, and deafness, and a really vaguely-creepy story about her ex, and even shoddy boyfriends and

bad decisions. Aren't I exciting?"

No. I write this to prove the point that... well, it *isn't* that noteworthy. What I'm writing is what most women could write, if given the chance, because most of us have experienced some level simply as a side effect of being Woman. It's not that rare, and it's not exciting.

The fact of the matter is: I have given my heart to very few people in my lifetime, and two out of four of them took from my body in ways that didn't want to be given. This isn't shocking or climatic or the part in the movie when we realize why I'm so broken and damaged after all... it's just... sort of normal.

For most of us, this is sort of normal.

My muscles remember when to point my left foot, or inhale on the third count, or press my shoulders down to execute a turn. My muscles remember when to look away at the brunt force of a needle, or exhale to adjust a catheter, or breathe deep to process a fresh concern. My muscles remember me, sometimes, when even I have forgotten.

I don't write this chapter to say I am different. Or special. Or more broken and bruised than the next. No.

I write this because I'm not. Because you're not. Because all of us, on some level, are not.

I write this because.... No.

Song #3: "Carried Me With You" by Brandi Carlile

This song made my eldest daughter cry.

It hit her on a Tuesday night (although it very well might have been Monday with how the days blend together more and more), as she lay on the floor watching yet another movie for family movie night.

The Governor says that we must stay home unless we have a note of compliance suggesting otherwise.

The virus is spreading every day as I write this, and is expected to only get worse before it gets better. That is how living in my body feels sometimes too: worse before better. Worse before worse. I am told to listen to it and respect it and stay still when it needs (my body, that is). Just like this virus. Just like parenting.

We stay. We sit. We listen. And we watch movies that make my eldest daughter cry, because she's thirteen (a week from fourteen) and the only thing she does more than say the words "I know" is cry.

The first night we watched *Onward*, in which Chris Pratt voiced the eldest brother. The next night was *The Delivery Man*, in which Vince Vaughn played Chris Pratt's best friend. Then we watched *The Internship* featuring Vince Vaughn with Owen Wilson, then *Shanghai*

Noon because Owen Wilson and Jackie Chan, then *Shanghai Knights* because Jackie Chan and some guy credited as Charlie Chaplin but we were really running out of options and we IMDB'd him to *The Illusionist* the next day so we could move on from the Shanghais.

Anyways, despite the veritable mix of Kevin Bacon-ing movie watching (which clearly is also half the point of my writing this book), the production of my living room is often more dramatic than anything I could dream or dance.

“The lyrics make me think of Papa because we call him our lighthouse,” my eldest said, while slow-mo-tear treading to the final credits of the film.

“Like a lighthouse in a storm, you were always guiding me” it says, and (although Brandi Carlile really lyricizes our family like no other, including my third favorite ‘The Mother’ which says: “The first things that she took from me were selfishness and sleep, she broke a thousand heirlooms I was never meant to keep, She filled my life with color, canceled plans, and trashed my car, but none of that was ever who we are”)... she is right.

For as far back as I can remember, my girls have called my partner a lighthouse, even giving lighthouse-themed coffee-table books and regalia that he (a heartless Northerner growing up on dog sleds and snow) had very little exposure. As a South Floridian myself, before this moving middle-ground of Blue Ridge mountains and Sound, I have known many a lighthouse, Miami lightning storm, and scarred back to manatee.

Sometimes it feels we have nothing in common at all.

“How has Papa been your lighthouse?” I ask, stoking the emotional flame perpetually burning (since she doesn't have proper *Dawson's Creek* soundtrack as our generation did).

(More on that: She thinks *Riverdale*, which I am yet to let her watch, is the same, but let's be honest: It's boobs and blood and blonds, and there is nary a loquacious Pacey “I'm afraid because you're the single most important being to ever grace my existence” saying to be found. If our home is going to be filled with hormones and heartbreak, it might as well have a better vocabulary.)

“Because when I go through hard times or have gone through them in the past – which is a lot – Papa is always the one who brings me back,” she says, after a long drawn breath and minimal contemplation.

“Do you know what lachrymose and mawkish mean?” I ask her.

“No.”

“I have just proven my point to whomever is reading this.”

Within a few hours, she was crying again, but this time for completely different reasons. This time it was because she had fought with her sister and stormed down to the couch, and I told her she could not sleep on the couch, and she said some mean things, and then she cried.

Our daughters sleep in an exposed loft without a bedroom door so the day-bed downstairs becomes the hottest piece of protest property around.

“You can’t sleep down here,” I said, which she knew I would say, but still made me say anyway because that’s what kids do.

She explained the varying ways in which her sister was being a jerk, and I explained the varying ways in which she still needed to sleep upstairs and that they’d both be in trouble if they said another word, and she got mean, and I said Parenting Things which she knew I would say, but still made me say anyway because that’s what kids do.

“What’s she doing now?” I asked my husband, because he can hear, and thus takes the brunt of auditory opus most of the time.

“Crying,” he replied, though I already knew the answer.

Every time our eldest gets teen-mean, she eventually cries, which I take as a win (evidence she still has a soul even though teenagers don’t often have those). But I also have a new tactic which might be unexpected for someone who’s (rightfully) crying at the decisions they’ve made and the words they chose to say... I hug her.

Hugging someone who just spewed vitriol in your general direction might seem contradictory at first (and believe me, it’s not easy), but even when she’s in the midst of venomous venting, a hug can quickly shift the mood.

“You’d be so surprised what hugging someone can do, even when they’re in the middle of yelling at you,” I marveled the other day, “It’s so hard to do in the moment, but it shifts things every time.”

Maybe every angry adult just really needs more touch and treatment. Maybe this book is becoming the Care Bear bible of a liberal snowflake. Maybe being in the midst of a global, contagious pandemic is not the time for me to wonder about more hugs for all at all?

“We are stuck at home right now, right?” I pitched to my husband weeks prior, when we assumed the quarantine would number a couple weeks only, “Now is the perfect time to try this science experiment. What if every time our child is hateful, we don’t counter with anger... We counter with love? And if our love screws her up, it’s okay because we have another kid!”

(In the least, it would annoy her, right?)

“You’re the soul who understands,” Brandi Carlile says, “The scars that made me who I am”... and, sometimes, parenting feels like a soundtrack of scars. He’s the lighthouse and I’m the sand tread upon and broken into more pieces than she can count (I’m also the martyr it would seem). Sand is partially made from parrotfish poop which really is fairly poetic at this point given my predilection for poop so... maybe it really is all connected. Or, like I said, maybe we have nothing in common at all.

The virus is spreading every day as I write this and is expected to only get worse before it gets better... but some things are definitely

unexpectedly better.

Our soundtrack of scars has Carlie at the forefront, but it also has “Feels Like Home” by Bonnie Raitt, and “I Will Do the Breathing” by Matt the Electrician, and “The Luckiest” by Ben Folds. Better yet, it has “Smile” by Mikky Ekko, which says: “So smile, the worst is yet to come, We’ll be lucky if we ever see the sun, Got nowhere to go, we could be here for a while, But the future is forgiven so smile.”

We are on episode two of *Dawson’s Creek* and so far it’s going well.

Dancing in this body is a complicated process.

It begins with ignoring pain that’s inevitably there. It starts along my back, most often on the left-hand side. I feel it when I open my eyes in the morning and when I close them at night. I feel it when I take medications, or use heating pads, or apply IcyHot. I feel it at all times because I feel it at all times.

My favorite thing to do is lay down, pulling limbs and length in moving stretches. Gradually warming and adjusting like a prone Tin Man, stiffening with age. I don’t think about what makes my body different because to do so would make my body different... or at least let my mind know the matter matters. And it doesn’t. I don’t want it too. So I lie to myself instead.

But if I were to take note- a careful calculation and invisible inventory- it would feel like this.

My back is where my stem cell treatment occurred: tubes inserted aggressively on either side so that fat could be sucked and ravaged from end to end. I was wide awake despite the sedatives and remember every millisecond; thorax throbbing with bruises and pain days later. I was game to do this experimental gamble because I was sick of being sick; willing to clap for fairies we can’t see.

My lung function was at twenty-six percent back then, and oxygen tanks totaled many. I still don’t know, in looking back, if it was the stem cells that truly worked (the ones harvested from me and mixed with magic and mystery before reinsertion), or the

fundoplication and heart medications in months before and after. The chicken and egg blur and mix until the only message received is “something worked” and that’s all that’s known.

But inside the scars remain. You would see where needles entered ribs and back, from one and then the other. You would see the extended recovery process of the upper curve of my stomach being wrapped around my esophagus, plus hernial repair. You would see the implantable cardioverter-defibrillator buried beneath chest muscle; breast tissue and fat too minimal to shove under skin alone.

What helped, we might ask? Which one really made the difference, boosted Pulmonary Function, and gave another chance at life... another turn at dancing? I don’t know. All I can describe is how it felt, how it feels, and what got me from here to there. And here there are scars and there there was pain. And now I am a little bit better.

Across from the pacemaker and defibrillator is their neighbor portacath. It is far less-worse than its provincial friends, though the first one hurt more than the second. By the second surgery, I knew what I was getting into. Pain becomes less potent when our mind knows what to map.

Down the road we find the densely populated city of scars that is my stomach. Here we had a gastric pacemaker surgery and congruent pyloroplasty... my first PEG tube surgery for supplemental calories overnight... my first J tube surgery that occurred because my stomach stopped working properly and my eventual GJ fails (more than I could count in a matter of weeks)

became too great.... The second J tube surgery that happened two weeks after the first, because the first was too close to my lungs and the lack of expansion and ability for lung clearance led to a month of IV Bactrim... and the second G tube surgery that happened a year after the first one was taken out, because my altered and adapted innards cannot properly release air, and the pain was problematic.

My double feeding tubes have settled now and proven worthy beyond belief. Every time I think I could go without one or have it removed, a new infection or blockage builds, and I rely on one once again. Maybe one day they’ll go. For now, they’ve given more than they’ve taken, although they do take away.

They take away when I dance. They take away because I can’t comfortably stretch or strengthen my back while laying on my stomach. I cannot reach retroactively; turning and twisting my torso actively or otherwise. It hurts to arch my back or expand in full; a literal straight jacket of scar tissue no matter how I push or pry. I wish I could rip it sometimes; shred and shorn, until pliable weightlessness becomes mine. But it isn’t possible. I am stiff and still and stifled, and no stretch has warranted otherwise.

Beyond the middle of me comes other mistakes. The hip-wide scar of numbness, rivaling that of C-sections, which took the concept of conception to rejection. I knew I couldn’t have a baby; not with this body, this frame. But I wanted to lose the Maybe at thirty-one.

If I feel an itch at night, I cannot scratch it. My fingertips feel the touch of abdomen and my brain feels the feeling unpleasant, but

my stomach feels neither fingers nor relief, and the itch just goes on itching.

Dancing in this body is a constant reminder of what it has endured and how far it has to go. From the scars in my skull to the ones deep inside, it's hard to hide the hurts when they're numbered many.

I ask it to move and it begs me to remember.

I ask it to pretend and play along, and it tells me it can't forget.

There is no day off.

Dancing or standing still, I feel it at all times because I feel it all the time.

There are two balloons on the marley, but there is no party.

The marley is the type of flooring we have in our home right now- a small strip of dance-friendly material taped over hardwood to provide a slip-free surface. I own my own dance company so we were able to use some of the scraps of unused flooring and apply it to our living room. This has turned out to be the scrappiest decision we could have made, because (now while sheltered-in-place due to viral eviscerations) we have a landing pad for dancing.

I tend to the marley daily like one would a fine friend. I dry mop him and Swiffer and protect him at all costs ("Take your shoes off! Don't track on the marley!") Even though he's just the forgotten piece- and the better parts are wound gently in rolls, awaiting their next show and stage- he has been good to us.

We spend time together nearly every day. Morning roll-outs and tepidly-timed stretch sessions with the type of playlist best left for early dawn rising and bleary eyed oblivion. It's hard to get my body moving most days, and requires a languid warm before the official warm has even commenced.

I prefer classical before anything else- "Reversing" by Takenobu and "The Consolations of Philosophy" by Max Richter- before softer sounds like James Taylor, Father John Misty, or Frightened Rabbit. I prefer a lot of things... but this morning held none of them.

There are two balloons on the marley now, but there is no party to be found.

They look like lost souls, honestly – pastel pink and eggshell white- which is sort of how I feel too. If this scene were a movie, you'd see the tragic end to a wedding reception with too much Lizzo requested, or a baby shower where someone smiled along while crumbling inside because they'll never have their own.

Classical would probably fit this scene too, instead of the angry yells inevitably emitted upstairs, or the tearful-teenage-tyrant playlist of Taylor Swift and The Script which Alexa so amiably provides.

I would choose Alexandra Streliski, or even Andrew Bird.

The balloons were thrown from the overhead loft during my daughter's latest spiral; a term we use loosely around here because they happen so frequently for as long as we can remember. At first, we tried everything one could ever try. The books, the therapists, the tactics and time. Everyone has a suggestion in situations like these.

"Maybe if she just had a better schedule," they say... so we pack it with activities and antecedents until she spirals because she has too much to do.

"Maybe if you just keep her busy with a really nice peer group." So we move and adjust and surround with that special sort of youth-group friend until she spirals because social situations make

her feel panicky and like she might throw up.

"Maybe if you give her calm moments to meditate, or medicate, or measure through reading and relaxation." So we do the collective Yoga, and attend the talk therapy, and buy the amusing journals, and muse on the ways we can mold our minds... until she spirals because being still with herself makes her anxious and angry.

We talk all the time about how to better pass the time. We talk about talking. We feel everything, and then talk about those feelings, and then dance out the feelings, and feel the feelings in as many environments as possible, and then feel how it feels to feel the feelings.

She loves people and is very outgoing. She loves quiet time to read. She loves creating and doing. She thrives on the outside... but on the inside, in the photos you can't see framed on walls or earnest posts omitted from Instagrams, she also feels like a popped balloon. And that's okay, because sometimes so do I.

The balloons shine distinctly, as I look at them now. They're not floating anymore; laying within an arm's reach of one another. Sometimes I wish she was still in an arm's reach; that I could scoop her up as I did when she was a baby, and remind her that underwear isn't a suitable outfit for the grocery store.

The party is over here and there is always a mess to clean up. This mess wasn't ours in the making. It comes from a shroud of memories and morphed moments which amass in her mind, triggering outwards when we least expect it.

And I sit, covered in shrapnel and sound, saying all the things I'm supposed to say. Sometimes I say the things I shouldn't. No one sees this, you see. No one knows this from the outside looking in. And that's okay. No one needs too.

We all have this side on the inside, and we all need a parent who will pick up the balloons once we've thrown them, and remind us we can float again, soon enough.

"Is it okay if I share a bit about your spirals in the chapter today?" I asked her, after she'd calmed down from a long shower and two-hours of strained silence. "It might help someone else who deals with anxiety too."

"Yeah," she said.

There is always a suggestion for how I could be doing better from someone who hasn't fully done it before. Or maybe they have, and I'm just bad at this. I know all the tips anyways, before they've even said them. I know what it is to love someone who doesn't yet know how to love themselves. I know what it is to not love myself for how I'm loving, and wishing someone else did.

I remember being her age and wondering why it didn't matter more. Why didn't my pain matter more? Why didn't someone just stop what they were doing and hug me? And they don't. As we grow and shape and learn, we realize: they don't.

Can I be that for her... for both of them? Can I be that even

when the silence is vociferous and the rain of objects overhead feel weightless and crushing at once?

If I knew the answer, I'd tell you. I'd promise I'm always going to do this right. That even when no one else can stand the suffering, I will show up and say the right things, and soften the world around them. That I will be the body hurled before bullets which will inevitably be thrown their way because that is what living *is* and there is no guarantee to the contrary. They will get hurt. They have been hurt. And now, the hurt has nowhere to go but down onto the marley below.

The only thing that's ever worked is staying. Sitting still, being the sounding board, seeing through the shrapnel, and staying. Sometimes I'm sick of that being the test. The push and pull and fury, just to see if I will walk away. I won't walk away. I don't walk away. But she still thinks I will in some way, just as others have done before.

It's hard to sit and stay when it hurts this bad... but it would hurt worse to leave.

So I pick up the balloons before they float away.

And I change to the next song on the playlist.

It's 11:17 PM and I'm feeling manic.

I'm feeling manic because I decided to feel manic.

"I think I'm going to get super manic tonight and pound through more of my book," I said to my husband at about 10:30 PM, while ominously making myself a cup of coffee. "I just need to feel like I achieved something big today. Even if I have to stay up all night and pull an all-nighter... I need to do something and do it to completion."

I have completed very little this day. This is in part because my children are insane, and I don't feel well (a running theme, if you hadn't noticed), and everything I tried to do failed. But, it's also because I am sheltered-in-place right now with no consistence scheduled or societal demand, so "what the fuck does it even matter if I stay up late and sleep in... Let's do something different!!!" (That's what I yelled earlier when explaining the manufactured mania, while brandishing both middle fingers in the air.)

(It's okay. My kids are asleep.)

My schedule has always been amiss from my partner's, even from the beginning. He goes to bed early and easy, and I stay awake for hours (even without the coffee), but could sleep-in for days. While he is brewing and brushing and doing responsible adult deeds by 8 AM, I've just started to fall into whatever limited langaring my body allows. Most nights, I don't truly sleep until I should be

waking... although, it's getting better, I swear.

I didn't know, when I first met him, how different we'd truly be. I didn't know how difficult we'd sometimes have it. Or how something like sleeping could divide and diminish. Honestly, all I knew was that he seemed pretty hot while walking down the hallway of the deaf and blind residential school where we first met.

If this was a movie, this would be our Meet Cute. And, to be frank, it was actually pretty damn cute. He was returning to campus for the day to visit some of his former students, and I was working as a Teacher's Assistant in the multiple disability classroom.

The job basically consisted of waking up at 5-something AM (I've already established that's not a strong skillset of mine), clocking in not long after, going into the girls dormitory and gently trying to wake some of my favorite Deaf and blind teenagers who did not want to wake. A lot of the time I said things like, "I don't get paid enough to do this," or "I am not trained to be a nurse", when dealing with the more aggressive behavioral issues which arose from special needs.

"You're very good at this job," someone once said in kindness (and possible mistruth) during an acutely grueling day, "Because you're always so positive."

I remember that because I clung to it with white-nailed fingers for the months of attempt that followed. I wanted to be good at it. I loved the students and the institution (despite my below-breath bitching towards minimum wage or over-my-head medical curve

balls)... but I just wasn't. I wasn't good enough for the job, and – within a few months' time- I left.

I had a good reason of course. My lungs were becoming worse and worse, and after many blue-fingered incidents from low oxygen and long hours on my feet, I tossed in the towel and went back to writing. My Mom was relieved because she had to wake up earlier than I did in order to intercept time with the girls before school.

I thought the job would be ideal because my hard-of-hearing youngest was a student there already, and my eldest had previously been a hearing peer for other Deaf students. The school, in many ways, had been home to us (before our literal home became school through homeschooling) and delving further seemed a natural fit.

It was not. Not for me, anyways... though working in my preferred language was. Looking back, it's hard to remember a happier time than when I was completely voice-off for days on end, communicating with hands and body alone.

My husband didn't even know I could speak until three-dates in, when I shocked by sounding off out of nowhere on a car ride back from hanging out with friends. He didn't need to know I could talk because I needed to know if he would meet halfway in the future.

"I can't read someone's lips for the rest of my life," I remember telling friends then, while rolling my eyes about every hearing guy we'd ever known, "It's so much easier to date Deaf."

And... it really is. And was. The Deaf man I loved before opened

my eyes to a great number of positives, and it was hard to imagine ever going back. (Ironically, my sister told me he is now married to a hearing woman, so I guess we all find our match in the end.)

But love doesn't care much about language, or background, or culture... It only cared how sexily he walked down that hallway eight years ago, and it was sexy.

"It was sort of love at first sight," I argue with him now, though I know he doesn't believe in that sort of thing.

"I don't believe in that sort of thing," he says in return.

"Well, it was definitely love at first spark," I push, "Or spark at first sight. Or love at first lust."

It was something. And even though I didn't talk to him and he barely knew sign, a resident Occupational Therapist standing nearby went so far as to interpret my invitation to come join us at Cross Country practice later that day.

"It really was false marketing," he now says, having thought I was someone who runs for reasons other than apocalyptic meltdown.

"I faked it well enough on our first date though, right?" I'll counter, referencing the actual first-date which came a week later. I thought it was a potential friend hangout and he thought it was a first-date date. "We went hiking and I hid my wheezing well!"

"You know it was a first date," he would say right now if reading

this. “You brought a second outfit to change into after the hike.”

He took me to a Deaf owned restaurant, in which I spent the better portion of the evening gleefully signing with the wait staff while he waited, weary, wishing he knew more sign. But I knew, then and forevermore, that he was different from The Other Hearing Guys. I knew he was someone who would surprise me with sign-language saturated dining experiences after shaky hikes in the mountains, all before he even knew I could speak.

Our Meet Cute was cute. After the first runaround (literally, since we helped guide blind students through fields and fauna after school), I disappeared without saying goodbye. My girls had to be picked up from my parents.

Maybe it’s ironic that our first meeting memorialized this major motivation in life, which he quickly learned when asking co-workers why I ran away before the stroke of midnight. Motherhood isn’t always the cutest companion to Meet Cutes... but he found me on Facebook regardless, and shot a message early the next day.

Tonight, we sat side by side watching *The Social Network* with the kids, and it made me question everything all over again.

“Don’t you just want to de-active your account like me when you see what an asshole he is?” I ask.

“My account is basically your account anyways,” he resounds right away, “What’s yours is mine, right?”

We watched *Aloha* last week because, as already mentioned, I love anything Cameron Crow (clichés abound), and since Emma Stone was in that, we watched *Magic in the Moonlight* the next (even though we shouldn’t anymore because Woody Allen is a bit of an asshole), which led to *Now You See Me* thanks to magic (we decided to consider magic an actual character in this case), which became *Now You See Me 2* (my youngest felt should have just been called *Now You Don’t*), and ended on *The Social Network* because of Eisenberg.

I love finding connections between ordinary things and chasing them. But back when we first met, the connection seemed too far to last. He lived almost two hours away, and we started dating slowly and somewhat secretly.

I didn’t want my girls to have anyone in their lives who wasn’t ready to stay there forever, and he didn’t know how many skeletons were still in my closet. (The worst skeleton is the one we won’t mention in this book any more, but it should go without saying that not a day goes by I don’t pinch myself we survived. And the other skeleton is my literal one. It is always F-ing things up.)

I remember listening to “Alone” By Trampled With Turtles on the drive back from his place, where he lived with our now best friend Jonathan. I’ve mentioned Jonathan on a grand total of four pages so far, with no real explanation as to who he is or why he matters, but we will eventually get to that.

Then, however, the playlist of our lives was numbered to just a few

critical songs.

Ryan Adams (even though we shouldn't listen to him anymore because he's a bit of an asshole), and Jeff Buckley ("Last Goodbye" is of course on the funeral playlist), and Ray LaMontagne. "You Are The Best Thing" is one of ours, and so is "Skinny Love" by Bon Iver. Our first dance at our wedding was to "I Choose You" by Sara Bareilles, but let's talk about the wedding another time.

Maybe we can talk about the wedding when we talk about the funeral that hasn't happened. Or the mania that had to happen but isn't over. Or the Meet Cute long after the momentum has faded.

Maybe then you'll understand why "what's yours is mine" isn't true after all. He will never fully be mine, nor I fully his... but all I've ever wanted is to be Yours to someone.

I talk about my body in a very specific way.

You may have noticed. I say surgeries and pseudomonas with Seussian sways. I blur past the details and drudgery of Doxy and disease. I go completely Kanye with inferences of immune systems and Ursodiol.

brag in cold blood (my blood) and don't feel a lot of shame about it. I list missing organs like one would flair from the Fridays-esque restaurant in *Office Space*. I chipperly chirp chief triumphs like a Daft Punk song (better, faster, stronger). I brag about some of the best-worst moments of my life... for better and mostly worse.

I think it's because I think if I can handle being unwell "well", then I'm somehow worth more.

"Suck it up and drive on," is a popular phrase in my family, and one I've revered for years.

As a kid, I felt tough when the gym teacher marveled at a lack of tears after splitting my knee open on the playground during recess. As a young mother, I felt I had more rights to my own knowing of pain during childbirth without drugs or epidural with my first, versus my medicated second.

"I know pain," I've said to doctors who assume I don't, "I've had a baby *naturally*."

I don't know if doctors assume I don't, but know as a woman, it's

likely already been established ahead of me. As the proud owner of a vagina and one set of non-boobs (I haven't said the word vagina since Page 42!), I am automatically assumed idiopathic. (Again, *Should we have a vagina chapter?*)

I am not. I never have been. Almost everything I've felt or said has been solidified later, but the need to validate what I'm feeling goes back farther (dating to furtive fights in my former relationship). You spend long enough being told you're not feeling what you think you're feeling, and you begin to get really intense about your rights to feelings.

"What you're describing to me is a feeling," I say to my daughters all the time when they argue, "And I can't argue that because only you know if that's what you're feeling."

People I know and love have said unforgiveable things before fully knowing what was wrong... and it's hard to let that go. To know that others could be so cruel. To know that we can be so cruel to ourselves before a cure has come. And there is no cure, of course... but there is a label, and no one leverages much loving learnedness without one. I

've never cared what label I had so long as I received treatment and some semblance of quality of life. And we've fixed things and found things and life has carried on. There is no mystery here; just medicine. But it's interesting how others treat another before that tag is placed. And.. it's hard to forget.

I don't recall ever feeling that way about someone else. Doubting

or dredging or darning as we go. Perhaps I know that science is fallible. That solutions take time. That nothing is black or white here; it's all just grey matter.

We prove and disprove and make discoveries constantly. What we thought and felt fifty years ago isn't what we think or feel now. I don't think or feel the same from year to year, and I certainly don't expect others to. But, I do get frustrated with those who think the worst case scenario is the only worst even when it's someone else's best.

I'm not immune to rolling eyes at someone else's concept of weakened immunity, or wondering why we wax and wane at waning issues. If you don't know how bad it can really be, you don't know, right? I didn't know.

I used to ring the alarm too often, too quick. Every new symptom or fresh decline felt ominous and original because to me, it was. Now, I am calmer. I know what to expect and what really warrants wails (and I am not someone who wails in pain).

Who brags about how bad their health has been in the past as a way of showing how badass they hope to be in the future?

Me (if you've been reading this)... and it's not how I want to be either. Still, sometimes the only way to synthesize the saturations of my skin is to make it into a sport.

I handled my second G-tube surgery the worst, waking up to a gallbladder attack that left me doubled over in pain, unable to

control reactions. I remember Jonathan vividly then, rubbing my back and trying to keep me calm. By the end of the day, they took me back for a second surgery. The clogged organ needed evicting at 1 AM.

It was such an eerie feeling. Seeing an absentee hospital; abandoned hallways and empty prep stations. I asked my surgeon if he'd had enough coffee to make it through the night. After, as my body was in "waking up from surgery mode," my husband was falling asleep on a hospital bench nearby.

I remember Jonathan in many moments despite not mentioning him fully. I remember looking up at him after my ICD surgery, a couple of weeks into an ICU stay, and holding his hand while wailing in pain. (And I am not someone who wails in pain.)

It was a rare nine on the pain scale. I don't know why, since the surgery was relatively low key in the scheme of stitches since. Perhaps because the machine was placed so deep beneath muscle, and my muscle would not retract upon waking? Pain meds did little, and it wasn't until the relaxers kicked in that I found relief.

It was insatiable that pain... and there have been others. Sometimes I've had long-standing epidurals that make the waking easier. Or maybe there is enough Dillauded to dent. Most of the time, I am calm and complacent. (And I am not someone who wails in pain.)

Sometimes (mostly with pancreas, pleurisy or positional coughing) it's a hungry burn that won't relent. I wish I could skip coughing

fits like most humans can. Or that my body could just heal or had a lifetime off from doing so.. Or that my operations mark an end of some sort; roll credits.

So, I brag instead. I brag when it hurts and I brag when it doesn't.

"Did I handle that well?" I ask my partner, normally right upon waking, "Was I a badass?"

"I really wish you wouldn't ask me that," he's prone to say, "It's a weird thing to focus on."

Even smaller incidents felt medal-worthy in moments. I remember the time I had a hefty dose of potential skin-cancer removed from my left-side jaw, and the dermatologist said, "I considered sending you to a plastic surgeon for this," but I went anyways. I wasn't worried about the scar, and, even though she was, you can't see it at all against the lines of my face.

That was so easy then, so simple. I didn't know how many times I'd have to hold still when my brain told me to bolt. How many stoma alterations and feeding tube switches; arms pinned by sides, cannula on. How many deep-nerve needles and spinal taps in time; bent over balking.

It's a super power, really, it has to be said. Going into OR after OR, nary a lorazepam in sight, portacath locked and ready, fully lucid. I'm awake as they lay drapes over torso, sterilizing skin with iodine ideations. I transfer over amicably, from stretcher to slab, serenading anesthesiologists with smiles.

It is the thing that I can do to make the unknowns better. It is the thing that I can do.

I think if I can handle being unwell “well”, then I’m somehow worth more.

I’m not.

(But I’m not someone who wails in pain.)

“Dear Daughters,

Sometimes things in life just don’t work. Sadly, you’ve already learned this at a very young, but maybe it’s best you know now.

You can’t make someone love you who doesn’t. You can’t make someone change who won’t. And you can’t be responsible for anyone’s decisions or reactions other than your own. (Unless you have kids. And then you’ll be writing Dear Daughters in their thirties).

Sometimes I think about medicine and how peculiar it is. How we place our life in the hands of someone with hands of their own; hands that make mistakes, get tired, feel grumpy. Hands that forget to grab their car keys as they run out the door. Those hands are not any less human than yours or mine... but we give them all the power in the world. Even the power to tell us who we are.

Medicine is lined with mistakes. The very first hand ever X-rayed, in fact, was the wife of Wilhelm Röntgen, and she later died of radiation sarcoma. She died by proxy to his experiment. He won the Nobel Peace Prize.

Our hands communicate everything. How gently we reach for someone... how we speak in languages unspoken... how we push and pull like the protagonist in this story. What will push and pull

you one day? No prize is worth poisoning another. No degree is worth debt you can't repay. No dance is determined by how perfectly you execute alone.

You are going to make mistakes. You do now. But how you react matters more than the result you intend. Own your mistakes. Face your flaws. Highlight your hinderances. They are the only way you're going to learn, gain or grow as you go.

If we did everything right all the time, we'd never appreciate what it's like to not be wrong. Be wrong. There is bravery in it. But don't be wrong if it harms or hurts someone else. Hands are just hands. No one has the power to know more about you than you.

“What you're describing to me is a feeling, and I can't argue that because only you know if that's what you're feeling.”

Put more into the world than you take away, dear ones, and, if you takeaway anything, remember that there is no such thing as mistakes in a world that holds you.

Yours,

Momma”