

Wiley, on the right, at his first concert about three weeks before

## It's later than you think

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Eight years ago, during the same month, I had twin boys and co-founded Cloudability. About three months ago Cloudability was acquired. About three weeks ago we lost one of our boys.

When I got the call I was sitting in a conference room with 12 people at our Portland office talking about PTO policies. Minutes earlier, I had admitted to the group that in the last 8 years I'd not taken more than a contiguous week off.

My wife and I have an agreement that when one of us calls, the other answers. So when the phone rang I stood up and walked to the conference room door immediately.

I was still walking through the door when I answered with "Hey, what's up?"

Her reply was icy and immediate: "J.R., Wiley is dead."

- "What?" I responded incredulously.
- "Wiley has died." she reiterated.
- "What?! No." I yelled out, "No!"
- "I'm so sorry, I have to call 911."

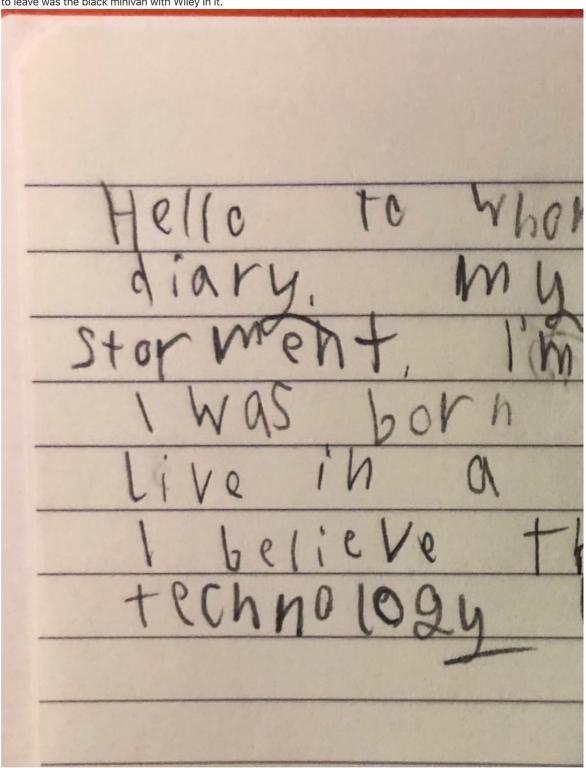
That was the entire conversation. The next thing I know I'm sprinting out the front door of the office with my car keys in hand, running ferociously across the street and muttering "oh Fuck. oh Fuck." Half way down the block I realize I don't have the opener to my parking garage. Running back into the lobby, I all but shout "Someone drive me! Somebody drive me!" Thankfully, a helpful colleague did.

By the time I got home twelve minutes later, our cul-de-sac was packed with emergency vehicles. I sprinted through our open front door and ran straight towards the bedroom that the boys share. One of a half-dozen police officers there stepped in front of me blocking the way. When a child dies suddenly, it becomes a potential crime scene.

It was 2.5 painful hours before I could see my boy. After an hour of waiting in shock out front, I told the armed police officers guarding the doors that I couldn't wait any longer. They allowed me to go out to the deck facing the kids room to peer through the sliding glass window. He lay in his bed, covers neatly on, looking peacefully asleep. I put my hand on the glass and lost it.

When the medical examiner finally finished his work, we were allowed in the room. An eerie calm came over me. I laid down next to him in the bed that he loved, held his hand and kept repeating, "What happened, buddy? What happened?"

body bag as he was wheeled down our driveway. Then all the cars drove away. The last one to leave was the black minivan with Wiley in it.



A journal of Wiley's we found the day after he died.

Wiley was obsessed with starting a business. One day it was a smoothie stand, the next it would be a gallery, then a VR headset company, then a 'coder', then a spaceship building company. In each of these scenarios he was the boss. His brother (and sometimes us) were invited to work for—not with— him and were each assigned jobs. In the gallery scenario, Wiley informed Oliver that he would be manning the cash register.

Around 5 years old, Wiley decided he was going to get married as an adult. By 6 he had identified the girl, holding her hand at recess on the first day of kindergarten. Over the next two years as we moved from Portland to London to Hawaii, he kept in touch with her by handwritten letter. Not long before we moved back to Portland, the two agreed (by letter) to marry. She beat him to the punch and asked him. He accepted. Happily, he got to see her twice after we moved back to Portland in June.

form crushed me. The first said: "Occupation: Never worked" and the next: "Marital Status: Never married". He wanted so badly to do both of those things. I feel both fortunate and guilty to have had success in each.

Over the last three weeks I have come up with an endless stream of things I regret. They tend to fall into two categories: things I wish I had done differently and things I'm sad not to see him do. My wife is constantly reminding me of all the things he did do: Wiley went to 10 countries, drove a car on a farm road in Hawaii, hiked in Greece, snorkeled in Fiji, wore a suit to a fantastic British prep school every day for two years, got rescued from a shark on a jet ski, kissed multiple girls, got good enough at chess to beat me twice in a row, wrote short stories and drew comics obsessively.

And then he died in his bed overnight. The evening before was normal. Wiley was healthy and engaged. We had friends with kids over for dinner. We all jumped on the giant trampoline that had been the first purchase for the house we had bought just a few weeks ago.

That evening Wiley got be bossy with the other kids (other than his mother, he was one of the most opinionated people I know) and started telling everyone they were playing the game wrong. I pulled him aside. I was stern with him. Too stern in hindsight. And I made him cry. It's one of the last interactions we had and I've beaten myself up for it a dozen times. I can still see the tears rolling down his face and the protestations of "But you're not listening to me. No one listens to me".

A few hours later, things had calmed down. We ordered take out and Wiley ate his favorite meal: rice with yellow dahl. Then we put the kids to bed. I had a very sweet interaction with Wiley at bedtime and apologized for making him cry. We had a good snuggle and I went to bed myself.

About 15 minutes later, I was laying in bed and through the darkened room saw his half naked form—always impossibly tall and lean for his age— walking up the stairs to our bedroom.

"Papa, I can't sleep."

There was loud music playing outside from a neighbor's party and it was keeping him awake. I walked him back to his room and shut all the windows. He said that was better. We had another quick snuggle and a sweet exchange. Then I went to bed for good.

Around 5:40am, the next morning I woke up for a series of back to back meetings. I did a Peloton ride, took an analyst call from my home office, one with a colleague on the drive to work, then the rest at the office. None seem that important now. I left that morning without saying goodbye or checking on the boys.

Late that morning, Jessica had thought Wiley was simply sleeping in. He loved to sleep, he loved his bed, and it had been a big week of late bedtimes and fun daytime activities with visiting friends. Eventually she got the sense it had been too long and went in to check on him.

He was cold. The Medical Examiner later estimated he had been dead for at least 8-10 hours by the time she found him, indicating he passed early in the night.

Last year, Wiley was diagnosed with a typically mild form of epilepsy called Benign Rolandic Epilepsy that is most common in boys between 8-13. It's called 'benign' because it typically resolves on its own by the teenage years. Wiley's was light: we only saw a single confirmed seizure occur. It happened about 9 months ago while we were visiting Portland from the UK.

All of the multiple pediatricians and neurologists with whom we discussed his condition said there was little to be concerned about. He had the "best" type of epilepsy and we should let it run his course. None mentioned what ultimately killed him. SUDEP is shorthand for Sudden Unexplained Death of Epilepsy. It's rare enough that there is a philosophical debate in the neurology community about whether to proactively tell parents about it.

SUDEP is generally seen to be unpredictable, unpreventable, and irreversible once it starts. It can be tied to a seizure but many times the brain just shuts down. Statistically, it was highly unlikely to hit our son: 1 out of 4,500 children with epilepsy are affected. Sometimes you end up the statistic.

Many have asked what they can do to help. Hug your kids. Don't work too late. A lot of the things you are likely spending your time on you'll regret once you no longer have the time. I'm guessing you have 1:1 meetings on the books with a lot of people you work with. Do you have them regularly scheduled with your kids? If there's any lesson to take away from this, it's to remind others (and myself) not to miss out on the things that matter.

I haven't gone back to work yet. So, if you've emailed or messaged me, it's likely I haven't replied. When I do go back, I may end up declaring an email bankruptcy.

of Kahlil Gibran who said, "Work is love made visible." To me, that line is a testament to how much we gain, grow and offer through the work we do. But that work needs to have a balance that I have rarely lived. It's a balance that lets us offer our gifts to the world but not at the cost of self and family.

While I sat writing this post, my living son, Oliver, came in to ask for screen time. Instead of saying the usual 'no', I stopped writing and asked if I could play with him. He was happily surprised by my answer and we connected in a way I would have formerly missed out on. Small things matter. One silver lining from this tragedy is the improving relationship I have with him.

Our family has gone from having two units of two (the parents and the twins) to now being a triangle of three. That's a big adjustment for a family that has always been four. Oliver's brilliant reply when we discussed the shape of our new family: "But Papa, the triangle is the strongest shape." By some sad and beautiful irony, Oliver has met three sets of 8-year-old twins in our new neighborhood since Wiley passed.

I've learned to stop waiting to do the things the kids ask for. When we sold the business I gave each of the boys a \$100 dollar bill. They decided to pool their money to buy a tent for camping. But we didn't make it happen before Wiley died. Another regret. So, after the first round of family visits after his death, I took Jessica and Oliver to REI to get gear and we left town quickly to camp near Mt. St. Helens.

Somehow, we got to the wilderness without enough cash to cover the campground fee and had a slight panic. Jessica then realized that Wiley's \$100 bill was still in his seat pocket. He got to spend his money on camping after all. Collectively, the family said a big, "Thanks, buddy" out-loud to him. It was one of many bittersweet moments we will experience for the rest of our lives. Each happy time brings with it the sadness that he doesn't get to experience it.

One of Wiley's happy times was listening to music and dancing. Damn, could that kid dance. He loved the Oregon Country Fair and the year before we left for London, we listened to a band there play a version of "Enjoy yourself (It's later than you think)". The words stuck with me that day three years ago and painfully so now:

"You work and work for years and years, you're always on the go

You never take a minute off, too busy makin' dough

Someday, you say, you'll have your fun, when you're a millionaire

Imagine all the fun you'll have in your old rockin' chair

Enjoy yourself, it's later than you think

Enjoy yourself, while you're still in the pink

The years go by, as quickly as a wink

Enjoy yourself, enjoy yourself, it's later than you think"

As my wife writes in her beautiful post (she's always more eloquent than I am), All That Remains, "Please ask us about our son's life and his death. We heal in small bits while talking about it."

Out of these ashes have come many new and restored connections. Thank you for being one of mine. And I hope from this tragedy you consider how you prioritize your own time.

Published By

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2,634 comments

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Now

Immediately after reading this, I left my home office and went into my 8-year old son's bedroom where he was resting (he has a cold) and hugged him tight. I didn't wanna let go, and I'm so thankful he's healthy and safe. Thanks for sharing this and reminding me of how lucky I am as a father.

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