

## DAY ZERO

MACHINES EMITTING pinball-game sounds surrounded Max in the ICU, an antic video-arcade soundtrack to the lights and graphs flashing like one-armed bandits. Just to remind everybody that life's a crapshoot, Archie supposed. A metal halo screwed into his skull, Max lay so still his grandfather thought he must be sedated.

"Sleep well, Max," he called. "A good rest will set you up for tomorrow's flight."

No response, save perhaps for a shinier filminess to his eyes. Max had big green eyes; beautiful eyes, Archie thought, if too warm and trusting for *this* world. Of course, given the hissing ventilator that was breathing for him, he couldn't speak.

At his bedside, Kate moved the phone onto her own face.

"Thank goodness the day's finally here," Archie told her.

“You said it, Dad,” she answered, and went over the next morning’s arrangements: As soon as the doctors signed off on Max’s medical discharge, an ambulance would take them across the George Washington Bridge to the mediflight jet at Teterboro Airport. It was February, but no rain or snow was in the forecast, so with any luck they would land in Cincinnati by early afternoon and meet the ambulance that would take them to the renowned Joiner Center for Rehabilitation, Max’s home for the next whatever number of months. Until feeling returned to his limbs and he could breathe on his own, talk and eat, get up and walk out of there.

“Been a long road,” Archie noted.

“Tell me about it,” said Kate.

Rather than Day 36 of his grandson’s being in the hospital, Archie preferred to think of it as Day Zero. Seemed more optimistic to roll back the odometer.

Soon he was wishing them goodnight, ending FaceTime, helping Charlotte to bed and following after.

## DAY ONE

### Monday

The next morning, home from taking their younger grandson, Ricky, 12, to school, Archie set Charlotte up in front of HGTV with a jigsaw puzzle of willows weeping into a pond, and nestled her robotic cat, Tessie, next to her. *Home* being, temporarily, Kate's and Luther's house in Louisville.

Back in the day Charlotte had been a jigsaw terror, rapidly locking in a puzzle's edges and relentlessly filling it in. A 500-piecer? Good for a day. (Archie always pocketed a piece, that he might have the glory of completing it.) Now it was heartbreaking to have days pass without any two pieces being fitted together.

But his mind was on the jet: Had it left yet?

Poor Max, trapped in a hospital bed when he should be running around like any 13-year-old. Well, no, not Max the bookworm; that was Ricky the

athlete. But Max should either have his nose in a book or a guitar in his hands.

Such an extraordinary kid! A reader from the age of four and—even if he was nine before he learned how to tie his shoes—a musician of real promise: Piano lessons made his neighborhood teacher widen her eyes; referred to a local music school, he added the guitar and started singing folk songs. His *Stagger Lee*? Canonical.

And dripping with charm, if with no idea what charm might be; didn't cultivate it to the least degree. But also unrestrained by tact; of tact, no notion. His candor could hurt, except he never meant it to. "Grandpa, you have the squarest face I ever saw!" he'd say; impossible to take offense. "Gram, you're so *strange*!" And thoughtful, except when rampaging in one of his rare meltdowns. Never an inch did he concede to his Asperger's.

No one gave a thought to his funny little stoop, like an ancient scholar's—it rang no alarm bells in so bookish a family—until the November day Kate took him in for a physical and a DNA test. Max was 13½.

That's really what taking him to the doctor's was about, thought Archie: Puberty. Max's temper was becoming more volatile, and Kate was upset to find crusty little stains appearing on his sheets. When they started splotching his pillow, too, she lost it; just

too graphic for her. Like her mother, she liked things just so. Wanting *reasons* for Max being the way he was, off to Dr. Kitman—so good with high-functioning autistic children—they went.

His office was in a medical building off Eastern Parkway, a modern slab set into a hillside with a vista of bare trees. Dr. Kitman gave Max a thorough going over, recording his height and weight, checking his blood pressure and sugar, poking, prodding, listening, while Kate leaned back and watched.

“Mom, it’s embarrassing having you in here.”

“I’m your mother,” she reminded him.

After drawing a blood sample, for good measure Dr. Kitman handed Max a tube and asked him to fill it with spit. This he happily proceeded to do, topping it off in his droll and conscientious manner, beaming as he handed it back brimming. Max was all about DNA, after all; could even name the nucleotides.

“Very good,” said the doctor, corking it for shipment to the lab along with the blood.

Herself a test-taker extraordinaire, Kate was a big believer in tests. But Max’s was of a sort where no knack at multiple choice could help. When he got the results, Dr. Kitman asked her to bring him by again.

They went the next day. Kate paged through women's magazines of the sort she disdained while Max happily solved his Rubik's cube—he was pretty sensational at it—until the nurses, saying they'd look after him, called her into the doctor's office. They were very smiley that day, which scared her.

"Well, turns out we've found something it's just as well to know about," Dr. Kitman told her.

He handed her a sheet of bar graphs printed in shades of puce—his printer was low on color ink—and explained that Max had a rare genetic disease called *Neurofibromatosis*, probably, given the lack of family history, the result of a spontaneous mutation at conception.

He listed NF's symptoms, from intellectual disability to outbreaks of tumors on the skin and along the nerves, tumors benign but aggressive in their growth.

"Max doesn't have any of those," Kate pointed out.

"No external lesions—thank goodness, those who do tend to hide themselves away—and certainly his intelligence is unaffected, but what I want to do today is give him a CAT scan, see if there're any internal tumors."

– SAVE THE MAX MAN! –

So he sent them downstairs, where with surprising speed they rolled Max into and out of their machine and sent him on his way.

Kate drove straight to Graeter's Ice Cream; these procedures have their reprieves.

By the time they got home, Dr. Kitman and his radiologist had read the scans and seen the tumor squeezing Max's spinal cord. Already it had so crushed and separated neck vertebrae as to suggest he'd been decapitated; hence the stoop.

Surgery was imperative, Dr. Kitman told Kate, and meanwhile Max was to be super-careful—no backpacks, no riding his bike: A fall could *kill* him! His specialists suggested the hospital in New York and helped recruit the three best surgeons in the *world*. A date was chosen, too, December 16, a Tuesday. Then Kate postponed it, wanting to give Max a normal Christmas; fortunately, the surgeons were able to reschedule. Somehow reminded of the original lyric—*Have yourself a merry little Christmas/It may be your last*—Archie thought postponement a mistake.

The day the operation finally took place, Kate kept her Dad informed via terse text messages all morning and into the afternoon, until she FaceTimed in tears with the sickening news that surgery had been suspended and Max wheeled next door for an

emergency MRI because, even as the surgeons were painstakingly peeling layers of cells off the tumor, signals from his spinal cord had ceased.

The MRI would tell them whether they'd missed something or nicked a nerve, though they didn't think they had. Permit them to have a bite to eat, too.

Indeed, the MRI disclosing no surprises—sometimes, they told Kate, “spinal shock” just happens—Max's operation resumed and his surgeons patiently worked away until, the evening far advanced, they wearily declared it a success. This thing that had almost pinched the life out of the Max Man was *gone*. They left it to Nature to bring back nerve function in Her own sweet time, something they'd never seen Her fail to do in someone so young.

From start to finish the kid was under the knife 15 hours! Archie was never more beat in his life.

Poor Max woke up paraplegic—paralyzed below the neck.

In the weeks following, Kate startled Archie with news of additional surgeries—a more permanent refashioning of his tracheostomy, a GI-tract feeding tube.

All morning the only thing Archie could think was, *Are they in Cincinnati yet?*



AFTER LUNCH, the Christmas tune running through his head, Archie was sitting at Kate's desk staring at a blank screen, still balked at starting the little memoir of Paris his oldest friend wanted him to write, when FaceTime finally chimed.

"Bad news, Dad," Kate murmured, her eyes flicking aside. Paris flew out the window!

Max had gotten his medical discharge, she said, in fact was on a gurney in a corridor awaiting transfer to Teterboro when her health insurance company – through Beth, its hospital case manager – demanded that she pay, or agree to be billed for, a portion of the flight's cost!

"You mean you're still in New York?" Archie asked, bewildered.

"Uh-huh."

"How much do they want?"

"Six thousand dollars."

"*Six thousand dollars!*" roared Archie, feeling the rasp of sawblade on bone.

"Dad, we could just *pay* it, get him there *today* – "

"*Never!*" he said before the words were out of her mouth, his screen's corner box filled by a raging pit bull's square face. Only *him* standing between his grandson and the insurance company's greed? Fine

and dandy, he was up for it! Fighting for Max for weeks, he had more in him yet!

“But Dad —”

Why couldn’t she see the issue here? He hated having to spell it out.

“Kate, it’s not the *money*. I know how it looks, but it’s not *that*. It’s that they think they’ve *got* us! Us and everybody else in their clutches! Don’t you see, giving the insurance company whatever it asks for is just *wrong*?”

“They’ll fly Max *gratis* to Philadelphia Children’s Hospital, but because we chose Joiner in Cinci —”

“Kate, we’ve no business paying for what insurance should cover. It’s that simple. When you’ve got comprehensive coverage through Gaudens College?”

“It’s like a copay, Dad. We have copays. And remember last week Beth said they’ve already paid out more than a million dollars for Max?” She rubbed salt in the wound by repeating Beth’s assurance about how small a fraction of the air ambulance’s cost \$6,000 represented.

Didn’t she *get* it? Nothing infuriated Archie like the stranglehold insurance companies have on American healthcare: What should be every citizen’s *right* made a marketplace transaction! And letting the insurance company off the hook would amount

to an assault on the English language, on the meaning of words like *insurance* and *comprehensive*. It was a fight for right – not just for Max, but for every insurance company customer (*victim!*) everywhere.

The correct word for it? *Extortion*. Archie refused to be extorted! He might be David against Goliath, but that didn't mean he couldn't fight – and win!

So why not Philadelphia Children's Hospital? To Archie's mind, for two good reasons: First, it was a Shriners hospital, and he simply couldn't shake the association with drunken conventioners in fezzes. Wished he could, but when you see the doctors as clowns and the nurses as showgirls? Charlotte still spoke of the gaudiness (*read: vulgarity*) of the Shriners Circus they saw in the Sixties.

Then there was Luther's issue. Max's father's absurd job checking out and shelving books at the Louisville Free Public Library didn't give him Kate's luxury of taking a semester off without pay but with full benefits, including health insurance. No, in order for the self-styled polymath to help his son through rehab, Max had to be close enough to home that Luther could commute. Cincinnati was just two hours away. Get the kid to Cincy, Luther could put in library shifts and still be there every day. However grueling for *him*, better for *Max*. No, Philly was *out*.

“Joiner’s the place for Max, Kate,” Archie told her. “That’s what you decided, and you should stick to your guns.”

“But Dad, getting him to rehab *today* might be worth it. He’s had hardly any physical therapy.”

“Trying to make a point here, Kate, about not getting pushed around. But you and Luther do what you want. Forget about the principle of the thing.”

Seldom did he come down so hard on his kids (Kate’s brother was a bearded vegan academic in Washington State), but—as is natural to an English professor—Archie saw protecting the *language* as his special responsibility.

Cynical of the insurance company to target Kate and Luther when between them they didn’t have two nickels to rub together. But of course that was why: Those without money are the likeliest to put themselves through hell to find it. As any insurance company well knows.

Over time, Archie had learned that money says valid and revealing things about people, including that those without it (in *this* country?) are just begging to be taken. Lesson One: Don’t let it happen. Don’t let them do it to you. So if even his *daughter* was reaching for her pocketbook when the insurance company asked for it, he had to be strong.

“Beth’s helping us file an appeal —”

“Good!”

“—but meanwhile they won’t fly him anywhere. Except Philadelphia.”

“So we’re just supposed to *wait*? And you don’t think the appeal’s *rigged*, anywho?”

Losing color, Kate raised the phone to take in his grandson lying in that corridor and asked, “Want to talk to Max?”

She could be passive-aggressive like that, Archie reflected. Max’s eyes blazed as the ventilator wheezed and a portable array of lights and alarms kept up the casino atmosphere. Kate denied that her sweet child was angry, but Archie preferred to believe his own eyes: Max was *seething*. *Outraged*. His silent scream said, “*Get me out of here!*” The doctors said it didn’t matter because, howevermuch he suffered, he wouldn’t remember it later.

He glimpsed Luther, too, standing over him, looking every bit as resentful.

“No, that’s OK,” Archie said. “Tell him to hang in there.” Talking to Max in his present condition was like addressing someone undergoing torture on the rack. “Take him back to Intensive Care is my advice—and get on that appeal. Talk to you later.”

“Later, Dad.”

Archie poured himself a V8. Wine would have been nice, but it was time to go pick up Ricky. He

hoped Max knew he wasn't dependent on his parents alone to get better, on the loopy book-shelfer or the intellectual living inside her own head: He had *him*, too, *Archie*, on the job 24/7.

Tessie went "*Meow!*" as he went in to get Charlotte. Although Tessie's utterances seemed random, in fact she responded to flickers of shadow across her glass eyes. Her greeting made Charlotte look up from her puzzle—no pieces solved today—and smile.

And speak.

"What's that, my dear?"

"Was that Kate? Everything OK in New York? Have they left yet?"

"It's fine, just a silly last-minute glitch. Ready?"

He helped Charlotte into her folding wheelchair, got her down the temporary ramp, pushed her out to the car and strapped her in.

TURNED OUT, ON THEIR after-dinner FaceTime, that Kate consented to Max's being wheeled back to the ICU only when informed that the Joiner Institute had no bed for him, anyway.

"*What!*"

And even if a bed came open, she didn't want Joiner any more.

*"What the hell, Kate?"*

"Dr. Tennant says Joiner specializes in a different kind of spinal injury—more what you get in sports or accidents. Also, Max might be too small for some of their equipment."

Archie reeled. *"Now* he tells us? Where's this leave us, then?"

"Philadelphia Children's *very* good, he says. So does Eleuthra—says Philly's where she'd send *her* son." The nurse with the extravagant name was Kate's mainstay.

*"But Shriners, Kate: Those fezzes!"*

"Dad, *Luther* suggests Cincinnati Pediatric Institute. Smaller than Joiner, but it's CARF-approved."

*"What's that mean?"*

"He looked it up online: 'Commission on Accreditation of Rehabilitation Facilities'? By the way, Philly's *not* CARF-approved."

Sunlight broke through at last!

"Are you telling me," Archie said carefully, "the insurance company wants to fly Max to a facility that's not CARF-approved?"

*"But Philly has a wonderful reputation."*

“But no CARF approval! And *Cincinnati*: Luther could be there every day!”

Well, that settled it! Max would go to Cincinnati Pediatric just as soon as they sorted the air ambulance.

While Ricky did homework, Archie prepared his daily email update to family and friends. It was a chore, on top of all the others, but at least helped shield Kate from being bombarded with advice. Archie had no idea why anyone would think her (much less *himself*) in need of any, but how it flowed!

So he summarized the day’s drama, how Joiner had fallen through, but Cincinnati Pediatric was CARF-approved and they’d get Max there as soon as possible. Didn’t go into the money angle, though; no need to confuse anyone.

Even so, one of his little brothers actually called up, nine o’clock at night, to inform Archie that, for a big enough donation, Joiner would find Max that bed!

Archie loved how not only does everybody know everything, but—especially if they haven’t a *sou*—can tell you exactly how to spend your money.

He told his brother why Joiner wouldn’t do, and why Philadelphia Children’s was out of the question, too, before accidentally letting drop the insurance company’s demand for \$6,000.



– S A V E T H E M A X M A N ! –

His brother professed horror that Archie would hesitate!

“If you want Cincinnati, Archie, just write the check!” he said. “Can’t tell me it would break the bank *yada yada yada*, but Shriners hospitals are *excellent!* Some trade-group membership has no bearing *yada yada*. Where are Kate’s contingencies, anyway? Can’t wing it! Scoping out rehab for Uncle Jim, I formed Plans A, B, C and D, and a good thing, too, because *yada*—”

Archie had his work cut out to get him off the line so he could go to bed.

— S T E V E N K E Y M E Y E R S —

*Save The Max Man!*

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