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OF *THE BEAK OF THE FINCH*

HIS
BROTHER'S
KEEPER



A STORY FROM THE
EDGE OF MEDICINE

JONATHAN
WEINER

His

BROTHER'S KEEPER

A Story From The Edge of Medicine

Jonathan Weiner

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If you would like to know what men really are, the time to learn comes when they stand in danger or in doubt. For then at last words of truth are drawn from the depths of the heart, and the mask is torn off, reality remains.

LUCRETIUS,
The Way Things Are

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I have followed the story of the Heywood brothers since the first months of 1999, when Jamie transformed himself from a mechanical engineer into a genetic engineer and began his race to save Stephen. In this book, where I reconstruct what was spoken in the past or quote someone else's reconstruction, I put the passage in italics.

The Key in the Door

For every birth a death.

LUCRETIUS

Portents

When they were boys, Jamie and Stephen Heywood loved to arm wrestle. They made it a ritual: first the right arm, then the left, then, if there was time, a wrestling match on the rug. Their rules of engagement were so complicated and so long unspoken that no one else ever learned the game. Even Jamie's best friend Duncan Moss did not know how to play. Duncan would take one step across the line on the rug. Then he would see the look on Jamie's face.

What? What did I do?

He did not know the rules.

The Heywoods lived in an old house on Mill Street in Newtonville, Massachusetts, a suburb of Boston. All three of the Heywood boys, Jamie, then Stephen, and then the youngest, Ben, were athletic dreamers, inventors of many rituals and adventures. The house on Mill Street is a block from a patch of woods and a pond. The brothers played football there in a corner field by the house of a neighbor they called Aunt Betsy. Late at night when it rained hard, Jamie and Stephen snuck out with boogie boards. They hopped a fence to the creek, which got roaring in a good storm. Through the dark and the rain they rode the rapids out of Bullough's Pond.

Their parents, Peggy and John Heywood, are well known in Newtonville. They love traditions, too. Each of them has served terms as Senior Warden of Grace Church, in Newton Corner. When their boys were young, they went back every summer to the dairy farm in South Dakota where Peggy had grown up. She had won a full scholarship to Radcliffe, in Cambridge, which is where she met John. Peggy worked as a therapist; she kept her practice small and devoted herself to the family.

Every seven years, they spent a year in England, where John was born and raised. John Heywood is a professor of mechanical engineering at the Massachusetts Institute of Technology, and an international authority on internal combustion engines. He is the son of a British coal engineer who turned to solar power early on, back when only the cranks were interested in what he had to say—back when a maverick who worried about coal smoke, soot, and acid, and praised the power of the sun, was like a bolt from the future. John Heywood consults about energy efficiency for Ford in Detroit, Ferrari in Italy, Toyota in Japan. When he is at home, he runs MIT's Sloan Automotive Laboratory, to which he commutes from Mill Street on a bicycle.

Each summer in July or August, Peggy's side of the family gathered from across the country for a reunion at the beach town of Duck, near Kitty Hawk, in the Outer Banks of North Carolina. A few of the children on the beach were always honorary Heywoods, as Aunt Betsy was an honorary aunt. John

and Peggy, Jamie, Stephen, and Ben each brought friends. The boys swam, sailed, surfed, and raced on the cold shining track the waves made for them. Every summer on one of their last days at Duck they played a game of basketball at the beach, wickedly violent games that routinely sent one of their cousins to the hospital.

As Jamie and Stephen got older, they kept arm wrestling, ritually. In their late teens and early twenties, when the two and a half years between them no longer mattered, they were perfectly matched. But Jamie became a mechanical engineer, like their father and his father in England. Jamie was intelligent and driven, and spent his days and nights working at a desk. Stephen became a carpenter, a hands-on man like their mother's father and brother in South Dakota. Stephen was intelligent, too, but he mistrusted desks and ambitions. He spent a few years swinging a hammer on a framing crew, and his right arm became unbeatable.

Late in July of 1997, when Jamie was thirty and Stephen was twenty-eight, they arm wrestled in the beach house their parents had rented that summer at Duck. Jamie was five feet, eleven and three-quarter inches tall, and he weighed one hundred and sixty-five pounds; Stephen was six-foot-three, two-twenty. Jamie was keeping himself in shape, but Stephen was building his first house that year, and his right bicep and tricep were very well-defined. In arm wrestling, there is always a moment when the winner knows he has won and the loser knows he has lost. The brothers were both surprised when they realized that for the first time in five years, Jamie would force Stephen's right arm down to the table.

Jamie whooped. *I beat my carpenter brother. I'm the man! I'm the man!*

Stephen won the next bout, which they fought, as always, left-handed. That shut up Jamie.

Neither of them suspected that anything was wrong.

That year a team of scientists and veterinarians in Scotland announced the birth of a strange lamb, the identical twin of its mother. The news hung above the year like a comet. All around the world, the arrival of the lamb was received as a portent, like an earthquake, a fire, an eruption, a millennial battle won or lost. Something was out of whack in the order of the world and would have to be put right, if it could ever be put right—or else turned to advantage, transformed into acts of healing as novel as the conception of that cloned lamb.

That was also the year the world's front pages carried the story of the death of Jeanne Louise Calment, from Arles, France. She helped inspire people to hope that in the new millennium, human beings might live as long as Methuselah. Jeanne Louise Calment was 122 years old. She remembered Vincent van Gogh.

Those who loved science and those who mistrusted it felt an almost supernatural touch of hope and dread that year, as if all our human rituals were about to change forever. Some scientists and doctors dreamed of a new, regenerative medicine. Soon, maybe as soon as the turn of the millennium, they might be able to control the forces of generation and regeneration that bring us all into being and maintain our bodies as long as we are here, powers that had labored unseen on the face of the earth since the first quickening of life. Lucretius invokes those powers at the start of *The Way Things Are*,

his epic poem in praise of what we now call science, composed in Rome before what we now call the first millennium. “Mother of Love!” Lucretius begins, calling on the goddess Venus, “to whom all living creatures owe their birth.” Mother of Love, for whom “the artful earth sends up sweet flowers. Mother of Love, who made “the first rise of things,” who created “the seeds of all things,” the goddess who makes the birds and beasts seek their own kind in the spring, and so renews the world.

“O Mother of Love, help me write my verses!” the poet pleads, opening the story of science with a prayer.

Now miracles seemed possible, likely, imminent: the curing of the incurable, the repair of the irreparable, the saving of lives that in any other generation would have been given up for lost. But the cures might come or they might never come. They might come that year or not for another hundred years; and nobody knew. So when a man, woman, or child contracted a disease—one of the innumerable diseases that were still fatal and incurable—the doctor, the patient, the patient’s family and friends all wondered if they were forced to accept defeat or if they could fight and win.

Under the sign of the comet, a certain kind of medical story entered the news more and more often. Families in need of miracles were moved to acts of extraordinary courage. Here and there a man or a woman, like a hero in an ancient legend, ran to the edge of medicine and a little over the edge, racing into the science of the future, storming the walls and setting them on fire. These people committed acts of selfishness and great selflessness, of self-interest and the purest altruism. They were trying to save one life, and they were trying to save the world.

I am a science writer. I spent the last years of the twentieth century looking over the shoulders of biologists who watched evolution in action. I went to the Galápagos Islands, also called Darwin’s Islands. The beaks of their finches and mockingbirds helped lead Darwin to his theory of evolution by natural selection, and his followers can now see Darwin’s process at work in real time as it sculpts and resculpts the beaks of his finches. I also visited many of the molecular biologists whose laboratories are now, for better and for worse, our new Galápagos.

Being a science writer means being a perpetual student, and those trips gave me some of the greatest lessons of my life. I will never forget the moment when one of Darwin’s mockingbirds perched at the top of my spiral notebook, as bold as a bird in the Garden of Eden, to watch my pen point squiggle on the page. In the laboratories, mutant fruit flies also landed on my notebook, which was a less glamorous experience. But out in the field or inside the laboratories, I thought I had come as close as anyone could ever come to the process that Darwin discovered at the heart of life.

By 1997, I knew that this work was coming closer to home than the Galápagos or the islands and archipelagoes of the world’s universities. That year Darwin’s process was a matter of human experiment and experience. This is what we seemed to see everywhere at the edge of medicine—evolution, the potential for evolutionary change, the genetic engineering of human beings. So I decided to tell a story that would take me out of the field and the lab, and into human experience.

To write about medicine has always been to confront the whole human experience. “Medicine takes you there,” as the director of a famous research hospital told me later, when I met him in the university cafeteria and he heard what I was doing on campus. “Medicine *demands* that you are there

This is more true in our time than in any since Hippocrates, as the field of medicine moves toward its new power over first and last things, over birth and death, beginnings and endings. Beginnings and endings have always been the times to learn what people really are. Around a birth or a death there are moments when you seem to see the entire span of a human life, and sometimes even the span of the species—the whole story, beginning, middle, and end, from first to last.

And now even more than before, when the edge of medicine may change human nature forever.

I followed many stories at the turn of the millennium, but one of them came closest to home for me. It was the story of two brothers, an engineer and a carpenter: a brilliant young mechanical engineer who turned himself almost overnight into a genetic engineer in his race to save the carpenter. For a little while I became an honorary Heywood, too, or wanted to be one.

The Heywoods' story taught me many things about the nature of healing in the new millennium. It also taught me about what has not changed since the time of the ancients and may never change as long as there are human beings—about what Lucretius calls “the ever-living wound of love.”

The Heywoods mean the whole story to me now, an allegory from the edge of medicine. A story to make us ask ourselves questions that we have to ask and do not want to ask. How much of life can we engineer? Are there any lines we cannot or should not cross?

What would you do to save your brother's life?

The Family Artist

In snapshots from one of their first summers on the farm in South Dakota, Jamie sits in his uncle's old go-cart, making it *go*. Stephen squints off into the sky, holding a butterfly net. As a child, Stephen was always wandering off with that butterfly net and getting lost. He ran ahead at the Statue of Liberty and the National Air and Space Museum and got lost. Once on a family camping trip in the Scottish moors he wandered right out over the horizon. He had to be rescued by Heywood search parties.

Stephen was the biggest reader of the three brothers, and he might have been the most intellectual, but he did not like the pretentiousness of intellectuals. He thought about them and studied them in a sort of askance way, but he was determinedly not one of them. Even lovable and unpretentious academics like his father worked on an abstract plane that floated somewhere above the way things are. It is still a joke today with the Heywood boys that their father never worked on the family cars.

“I did change the oil once or twice,” John says.

“The author of *Internal Combustion Engine Fundamentals* has never worked on a car except to change the oil,” says Jamie.

“Nobody does,” says John. “People who know the theory don't know the practice. I don't know practice. If I bring my car in, I make it a *practice* not to tell them my diagnosis, because I'm so very often wrong.”

John Heywood is wiry, with a graying, auburn, close-clipped British mustache. His right eye angles toward his nose, but his left eye has a level and candid gaze. In the magnifying lenses of his glasses, his wandering eye used to terrify the boys' friends when they were small. He works sixty-hour weeks at the lab. Peggy is just as wiry, and in spite of the sophistications of life around Boston you can see at a glance the farmer's hardworking daughter. Neither John nor Peggy is tall, and from early on their sons towered over them.

Jamie and Stephen both loved to read the kind of science-fiction novel in which a boy growing up on a farm or a suburban planet discovers that he is destiny's child, born to save the galaxy. One of their favorite books, *Ender's Game* by Orson Scott Card, begins when Ender Wiggin, a small, brilliant boy of six, is yanked from his family to be raised in a space station. Ender and his friends in space believe they are just playing training games, computerized war games. In reality they are blasting real enemy starships, slaughtering the Buggers and saving the human race.

Jamie would not even take Orson Scott Card's books into the bathroom. That would have been sacrilegious. ~~But when Stephen was reading a paperback he liked, he tore it down the spine and gave Jamie the part he had already read.~~

In London, during John's first sabbatical leave from MIT, he did some consulting work in Coventry and drove back to his family in a loaned Jaguar. Until that point the Heywoods had never owned anything better than a secondhand Ford. They were all seduced by the experience. They drove around London with the Jag's sunroof open, blaring the old hymn that John Heywood loved to sing in his tolerable baritone in church choirs: *Bring me my Arrows of Desire...Bring me my Chariot of Fire.*

John and Peggy sent Jamie to one of the better schools in London. Stephen and Ben ended up in local state school instead, where Stephen machined a hammer out of steel. He wrote a funny essay about the contrast between the students. Jamie's friends were all diplomat's sons, spoke forty languages, and walked as if they already ruled the world. Stephen's friends were all in gold chains and looked like pimps.

In his teens, Jamie tinkered with bigger and better engines and the software of the Heywoods' first IBM computer. At night in the woods behind the house on Mill Street he and a half-dozen of his friends held epic battles of laser tag. Some of them remember now that Jamie took those battles much more seriously than Stephen, or anyone else in the game. One of Jamie's friends at Newton North High School called him King of the Geeks. Stephen felt comfortable with all kinds of people, and he ran with many crowds: the toughs, the Beautiful Ones, the artists, the actors. The Heywoods' cousins called Stephen the Male Model. He was the best-looking of all the cousins, and there were a lot of them. Girls followed him.

This is a first son's dream: *I am going to be just like my father.* A second son says, *I will be different.* The first son says, *I am going to be just like Dad but better—cosmically better—and save the world.*

Both Jamie and later Ben went through their father's department at MIT and graduated with degrees in mechanical engineering. But like many middle sons, Stephen rejected his father's line of work and went looking for one of his own. He went to Colgate, where he experimented with writing, painting, and what he later decided was more than his share of illegal substances. He wandered after college, too, tooling across the country on a customized Harley-Davidson in a brown leather motorcycle jacket and brown leather boots, a diamond in one ear. With his girlfriend, Stephanie—the had been together on and off since they were sixteen—Stephen backpacked in the Rocky Mountains. Wherever he lived, he picked up odd jobs painting and carpentering.

Stephen was now as sturdy as he was tall, with thick black hair, a clear, steady gaze, and a strong square, cleft chin. He wore T-shirts and khakis and a three-day stubble.

Jamie's forehead was higher and his cleft chin tapered to a point. He had the kind of bright pale face that signals health as much as good color. His high-wattage shine, along with his intensity, and his remarkably regular features, made him look like a man from the future. He became something of a clotheshorse. He liked expensive Eastern-establishment suits. Sometimes he dressed like the young Turks and techno-prophets: black Italian jackets with dark shirts and dark silk ties that set off his pale face and had their own mystic and expensive sheen.

Stephen was happy to be a twentysomething in the generation that called itself X, for expectations unknown. He was ironic, he was laconic, and he did not mind saying he was lazy. He enjoyed being a slacker.

“I’ve been sponging off my parents for years,” he used to say. “I’m totally a Gen Xer.”

“Stephen totally defines it,” said Jamie.

But the Heywood brothers stayed close. They were all exceptionally talented, and they had an old-fashioned style of family pride. When Ben graduated from high school, Stephen sent him a small check and a scrawled note:

What, a letter from Steve? This is for graduation, and also to tell you that I’m proud of you. You have managed to do a heck of a lot better than either James or I did in school, and I respect that. I also think that you have gotten what you deserve by getting into MIT. You should continue to do what you have done in the past, as I think you have something that 1 & 2 may be missing. Always remember, be a Heywood.

Eventually Stephen and his girlfriend landed in an apartment in San Francisco. Stephen put up a few notes on bulletin boards in hardware stores and found part-time jobs painting garages and building decks. After six months, he and Stephanie broke up.

By Alamo Square Park, there is a row of Victorians, the famous Painted Ladies, one of the only rows of fine old houses that survived the great San Francisco earthquake and fire of 1906. Stephen used to sit in the park and study the Painted Ladies. One day an eccentric architect, Mark Little, saw a card of Stephen’s in a hardware store. The architect built and restored fine houses with something like Victorian high style. He hired Stephen, first part-time, then full-time, and became his mentor; and eventually Stephen decided to restore a house on his own.

In 1996, he found a dilapidated cottage in the Crescent Park neighborhood of Palo Alto, which is just south of San Francisco. Stephen studied the neighborhood from his Harley. Palo Alto reminded him of Newtonville: palm trees instead of maples, but the same professional people, the same engineers, psychotherapists, professors on bicycles. He thought he understood real estate in Palo Alto and the cottage was just what he was looking for. It was tiny, and it was a wreck, a junker, but it was surrounded by homes that were worth easily half a million, a million, and more.

Stephen was broke. His credit card debt was \$15,000. But the other Heywoods helped. His brother Ben had just split up with his girlfriend, too—his fiancée. Ben quit his job at a bioengineering company, cashed in his stock options, and went partners on the cottage with Stephen. John and Peggy put up most of the down payment—calling it an investment. The brothers bought their Heartbreak Hotel for \$325,000, which approached what their parents’ house was worth back in Newtonville.

After the signing, Stephen rode straight to the cottage on his Harley. He and Ben had gotten the place on a low bid because they had waived their right to an inspection. The owner was an old woman who had let it rot around her and then abandoned it. The tiny lot was overgrown with tall weeds, the stucco was mottled and crumbling, the asphalt roof leaked, the walls were stained, the halls were

packed with junk, and half the wiring was dead. Stephen had to bushwhack to the front door, crawl through the junk in the hallways on his hands and knees, and plug one of the feed wires into the meter before he could turn on a light.

The brothers camped out in the place and hired half a dozen college dropouts and Ivy Leaguers and loose ends to share it and work with them. Stephen learned to draw blueprints, to pour foundations, to flirt with the planning lady at City Hall. He bought a black Ford pickup truck. He and Ben and their crew knocked down so many walls that they had to move out. After a year or two there was nothing much left of the cottage. Of the original frame, Stephen had saved only one beam, and whatever relics he had preserved were all shining, polished, varnished, and standing in new places. When the city inspector came by to see the work in progress, he crossed his arms, shook his head, annoyed and amused. *I thought this was supposed to be a renovation job.*

Stephen loved the project, right down to the blueprints. One of his cousins, David Searls, visited Palo Alto in the middle of the construction work. He remembers Stephen standing over a set of complicated plans. "It just struck me that it might have been a work of art to him," he says. "It was sort of that pose." The pose of the artist lost in his labors.

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