HMOs and the Breakdown of Medical Trust



George Anders
author of Merchants of Debt

# HEALTH AGAINST WEALTH

HMOs and the Breakdown of Medical Trust

GEORGE ANDERS

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### HEALTH AGAINST WEALTH

#### BOOKS BY GEORGE ANDERS

Merchants of Debt: KKR and the Mortgaging of American Business

Health Against Wealth: HMOs and the Breakdown of Medical Trust

# FOR MY PARENTS, AND FOR BETSY

## Preface

Every November my wife and I participate in a small American ritual: we sit down at the kitchen table, surround ourselves with insurance-company brochures, and choose a health plan. In the first few years of our marriage, we made our decision quickly, almost frivolously. We were in our early 30s and healthy; our medical needs were minimal. We dabbled in HMOs, PPOs, MedSpend plans, and fee-for-service coverage, picking plans mostly on the basis of what piqued my curiosity as a staff writer at the *Wall Street Journal*. I even was without insurance for nine months in 1989–90, because we were tardy in filling out the forms. At that stage in life, health insurance didn't seem to matter much.

The past two years have been very different. Some of the people closest to us have confronted a difficult childbirth, an unexpected bout with cancer, a losing battle with diabetes. We have seen first-hand what happens when the medical/insurance system fails; we also have seen the life-saving power of the right doctor at the right time. As a result, our most recent kitchen-table sessions have been a lot longer. We have explored a series of "What if . . . ?" questions we had never asked before. "What if we become parents? What if our child has special needs? What if we have an emergency at night? What if we need to see a top specialist?"

Millions of other Americans find themselves in the same situation. New health plans offering some form of "managed care" beckon to workers and retirees alike. These plans are frequently known as health maintenance organizations (HMOs) or preferred provider organizations (PPOs). Not only are such plans cheaper than traditional

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insurance, they offer reduced paperwork and assurances that they can guard members against overtreatment. The advantages sound irresistible. But the choice isn't that simple. Managed-care plans save money by limiting patients' choices and by installing overseers who restrain what doctors can do. These restrictions can lead to painful breakdowns in medical care just when patients need help the most.

This book is meant for anyone who has tried to make sensible choices in the fast-changing world of medical insurance. There are no automatic answers that will be best for everyone. Within our own household, in fact, we are split: I'm willing to gamble that I can make managed care work; my wife is not, especially as she anticipates motherhood. But for everyone considering these choices, it helps tremendously to know how the game is played and where the greatest dangers lie. The middle chapters of the book talk about what managed care does well — and what it does badly — in treating major diseases. The final chapter offers some remedies to make the system work in patients' interests.

This book also is meant for people who make their living in health care: doctors, nurses, hospital administrators, and employees in allied fields. For most of the years after World War II, health care was a booming industry with almost unlimited resources for the effort to fight disease. Now the cost-minded dictates of managed care have drastically transformed the health-care market, and many providers find the new rules alarming and bewildering. The early chapters of this book explain why this transformation occurred; Chapters 12 and 13 spell out the factors that will determine what forces prevail in the continuing struggle over the future of American medicine.

Finally, this book is written for people with the power to change how we pay for medical care: legislators, regulators, investigative reporters, and ordinary citizens. When I started writing about health care for the *Wall Street Journal* in 1993, America was consumed by the idea that a single, sweeping national health plan could correct all the flaws in our medical system. That idea never was realized; the Clinton health plan and its offshoots collapsed in the summer of 1994. But as I worked on this book, the health-care debate moved to the states. By one estimate some 400 bills pertaining to managed care were introduced in state legislatures in early 1996. Some of those bills may be flawed, but many of them point the way toward a better health-care system, one that is both cost-effective and compassionate.

PREFACE

Each chapter of this book is meant to contribute to the discussion about creating such a system.

People in the HMO industry may view this book as a tough critique of their work. My mission was never to be hostile but always to be forthright. Over the next five years managed care undeniably will become the dominant form of American health insurance, if it isn't already. For all the theoretical appeal of managed care, however, there are too many instances in which lofty principles have been compromised or ignored on the way to the exam room or the patient's bedside. To avoid more such mistakes, we must identify the worst problem areas and start focusing on them. The cautionary examples in this book are meant as a first step.

Hundreds of people interrupted their lives to talk candidly with me about what managed care has meant to them. The bravest of all were the patients and their families, particularly Lamona Adams, Edmund Popiden, Stephen Bosworth, and Terry Lusignan. Doctors across the United States added their insights, hopes, and frustrations. Among HMO executives, Hyman Kahn, Joe Gerstein, Bill Popik, and Malik Hasan were thoughtful advocates for managed care, even in the face of difficult questions. Some HMO officials chose not to comment; their silence should not be interpreted as having any negative implications.

At the *Journal*, managing editor Paul Steiger encouraged me several years ago to learn about the intersecting worlds of medicine and money — and then cleared the way for me to write this book. Ron Winslow, Mike Waldholz, and Jerry Bishop taught me a lot about the subtleties of medical reporting. Colleagues, including Laura Johannes, Laurie McGinley, Hilary Stout, Elyse Tanouye, and Rhonda Rundle, freely shared ideas and sources. Neil Ulman, Dennis Kneale, Dan Hertzberg, Barney Calame, and Alan Murray also helped make this book happen.

Many outside readers and advisers helped me with quick feedback and wise advice. Edward and Joan Anders, Jack Corcoran, Ira Wilson, M.D., and Deborah Shlian, M.D., reviewed innumerable drafts of chapters. Each of them nudged me to explain things better while sharpening my thinking about what managed care does well and poorly. Tina Erickson opened doors in rural Tennessee. Nina Youngstrom, Adam Lilienfeld, and Mary Agnes Carey performed crucial

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research. Tom Petzinger, Arnie Milstein, M.D., Chuck Stevens, Jerome Kassirer, M.D., David Golub, Martin Kessler, Jeff Taylor, David Hilzenrath, David Schiman, and Nanci Schiman all provided helpful ideas.

At Houghton Mifflin, Steve Fraser proved once again to be a terrific editor. Lenora Todaro, Peg Anderson, and Glenn Kaye guided a bulky manuscript with skill and good cheer. My agent, Kim Witherspoon, and her colleague, Maria Massie, handled every negotiation well and honorably.

Once again my wife, Elizabeth Corcoran, was a special partner in completing the book. She was the first reader of every draft. She also was a selfless colleague, interrupting her own work at the *Washington Post* to help research a chapter in Tennessee, just when my deadline crunch seemed most overwhelming. Her support was a wonderful blessing.

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# A Baby's Struggle

HIS WASN'T THE WAY Lamona Adams wanted to spend the night. Resting her infant son on her shoulder, she paced to the edge of her garage and peered into the darkness, looking for the first sign of the headlights of her husband's car. It was 4:35 A.M. on a chilly March morning. All the other houses on Fireleaf Way were dark and still. Families in Fairburn, Georgia, were enjoying a few more hours of sleep before Saturday began. In a few hours the streets and lawns would be filled with the typical sights of an American suburb on a weekend: children bicycling, Rollerblading, or playing catch; parents going shopping or driving into Atlanta.

But Lamona Adams was already wide awake and very worried about her six-month-old son. What had started the day before as a moderate fever was steadily worsening. She had skipped work on Friday and taken the boy to the doctor, who recommended giving him Tylenol every four hours. That had helped for a while. By nighttime the Tylenol wasn't subduing his fever anymore. At 3:30 A.M., Lamona had awakened to find her son, James III, feeling unusually hot, panting and moaning. His temperature: 104 degrees Fahrenheit.

Alarmed, Lamona called her health plan's after-hours hotline at 3:50, asking what to do next. That was standard procedure for her; like millions of other Americans, she belonged to a "managed-care" plan, which required members to have most medical treatment approved in advance and to use only the most cost-effective doctors and hospitals if they wanted their bills covered. Only if a grave emergency arose were those restrictions waived.

It took a few minutes for Lamona's health plan, Kaiser Permanente,

to log in the baby's symptoms and relay information from an operator to a nurse, from the nurse to a doctor, and then back to the nurse again. But by 4:05, word had come back: take the baby to the emergency room of Scottish Rite Children's Medical Center.

"That's the only hospital I can send you to," the hotline nurse added.

"How do we get there?" Lamona asked. She and her husband had moved to Georgia just a few months earlier and were still learning their way around.

"I don't know," the nurse replied. "I'm not good with directions." Rather than guess, the nurse passed along the hospital's phone number and suggested that Lamona call for directions herself.

For the next 20 minutes, Lamona hurried to get ready. She phoned her husband, James Jr., who was working as a night security guard, and implored him to come home at once. She called Scottish Rite and got directions. She told her sister, who was staying with her, to remove the baby from the cool bath that had been started moments earlier. The two women dried the infant and got him dressed. Around 4:25, Lamona slipped her baby into his shoes, grabbed his blanket, and scrambled downstairs to the garage. A few minutes later, she saw the first flicker of her husband's headlights. As her husband arrived, Lamona jumped into the back seat of their Plymouth Acclaim, holding the baby.

Her husband asked for directions, and she gave them. They had to drive three miles to reach Interstate 85 just south of Atlanta, then travel north on I-85 for more than 30 miles — past downtown Atlanta and on to the northern outskirts of the city. After that a junction, west six more miles on I-285, and about another mile on local streets.

"That's way up north!" James said. "I know," Lamona replied. "But that's the hospital that they told us to go to." With the streets deserted, James picked out a favorite shortcut that got them onto I-85 a little faster than usual. A former army sergeant who had served in Saudi Arabia as part of Operation Desert Storm, he was accustomed to making cool decisions in a crisis. As James started the long northward journey on I-85, Lamona urged him to drive faster. The speedometer nudged up to 75 m.p.h., then 80. James might have driven even faster, but it started to rain. What began as a drizzle quickly turned into a hard, torrential downpour. The small Plymouth slid across lanes, barely under control, then hydroplaned briefly on one of the curves.

Afraid that he might crash the car, James had no choice but to slow down.

About 20 miles into their drive, the Adamses passed the skyscrapers of downtown Atlanta. A few miles off the highway was the Egleston Children's Division of Emory University Hospital, a renowned pediatric center that could handle almost any crisis. Nearby were two more of Atlanta's leading hospitals: Georgia Baptist and Grady Memorial. Without permission to use any of those institutions, the Adamses kept driving. They had 22 more miles to travel. In the back seat of the car, Lamona kept looking into her baby's eyes, trying to reassure herself about his illness while making the baby aware that his mother was very close. For the first two thirds of the drive, the boy blinked back at her. As the car continued north, his eyes fell shut.

"Budé!" his mother snapped, calling her child briskly by a favorite nickname. "Budé!" The boy's eyes opened again. Lamona leaned forward and told her husband, "James, hurry!" The father accelerated as much as he dared, and he began to grow nervous too. A few minutes later he realized he had shot past the junction for I-285, the road leading toward Scottish Rite.

"I don't care, just go, go, go!" Lamona replied. They spotted a large blue "H" road sign, directing them to a closer hospital. As they neared the exit, the boy's eyes closed again. A few moments later his heart stopped. At 5:29 A.M. the parents pulled into the parking lot of Kennestone Hospital at Windy Hill. Lamona bolted out of the car holding her son and ran into the emergency room, crying, "Help my baby! Help my baby!"

A nurse grabbed the infant and gave two breaths of mouth-to-mouth resuscitation. A pediatric "crash cart" was wheeled into the area, stocked with emergency equipment designed to save a baby's life. Nurses and doctors began a whirlwind of rescue measures — inserting breathing tubes into baby James, beginning cardiopulmonary resuscitation and administering two doses of epinephrine, a powerful hormone and heart stimulant. As they started to work on the inert baby, his head lifted, then thudded against the emergency-room cot.

When she heard that thud, Lamona Adams screamed. She fell to her knees and, by her own account, became hysterical. Hospital employees took her arms and escorted her to the hospital's nearby chapel. A nurse came in and tried to soothe her. A few moments later her husband arrived, with grim news. "It doesn't look good," he said. "They've got

all these tubes in him." Unable to move, Lamona stood in the chapel, praying, again and again, "Don't take my baby, God."

After nearly 20 minutes of resuscitation efforts, Kennestone's nurses reported the first sign of a renewed pulse. By 6 A.M. the baby's heartbeat was steady enough that CPR could stop. But blood tests showed that he was still profoundly sick, with carbon dioxide levels far above normal. Even more ominously, the original cause of his fever remained undiagnosed. Doctors administered antibiotics in the hope that they would help; they learned a day later that his body was ravaged by a potentially fatal infection: meningococcemia.

At 7 A.M. Kennestone's doctors decided to transfer the Adams baby to Scottish Rite, the hospital he originally was headed for, which could do far more for gravely ill children. This time, at last, an ambulance carried the boy. At Scottish Rite swarms of specialists clustered at the boy's bedside around the clock for days. Neurologists, surgeons, infectious-disease experts, and others tried to assess the damage. It was clear that antibiotics were subduing his fever and that the hospital could keep the infant alive for at least a few days. But the doctors' early assessments were full of foreboding. Meningococcemia had already caused vast, perhaps devastating, damage to little James. He was immobile and unresponsive. The blood flow in his hands and feet had essentially ceased.

One of the doctors, James Jose, began talking with the parents about whether it might be appropriate to withdraw life support at some stage. The crucial question, he said, was how badly the boy's brain had been damaged. Could he still see? Would he ever be able to move? To speak? To read? Even if his brain had withstood the double trauma of meningococcemia and heart stoppage, further crises lay ahead. Little James's skin had begun to turn black at his extremities, as blood cells and tissue died. It was clear that if he did survive, his ruined hands and feet would have to be amputated.

"We all understand that a tragic outcome is definitely in the future," Dr. Jose wrote in the boy's medical chart on March 31, 1993. "The parents are quite brave, intelligent and articulate issues well. But the best, or most acceptable, course isn't yet clear." The parents decided to wait a week to see if the boy's condition would improve at all. If not, they said, they would agree to withhold life support, let the boy die quickly, and be buried intact, without any surgery.

April 6 was the Adamses' self-imposed deadline. Early that morning they got an excited phone call from Dr. Jose: "He's following the bear!" As part of a routine neurological test, Dr. Jose had passed the boy's teddy bear back and forth in front of his eyes. For the first time, James's eyes tracked the stuffed animal and seemed to recognize it. His vision and at least part of his higher mental capacities were saved.

For the Adamses and their doctors, the next step was clear. Within an hour the boy was wheeled into a pediatric surgery unit, where he would undergo amputations to ward off further gangrene. From this point onward doctors would do everything they could to help the boy—though he would have to live with the catastrophic loss of both his hands and both his feet. The baby's medical chart, written in aloof clinical language, tried to mask the horror of what needed to be done. "Under general anesthesia, the patient's extremities were prepped and draped in the usual fashion," wrote Steven Cohen, a pediatric plastic surgeon at Scottish Rite. "The procedure took place very rapidly, beginning first at the right leg . . ."

Two months later James III had recovered enough to be discharged from Scottish Rite. His physical wounds had healed with incredible speed, as is generally true for babies. Scar tissue had formed at his extremities, cushioning the previously exposed muscle and bone. As his bandages came off, he began to move about in his hospital crib, smiling at his parents when they came to visit. He was not quite nine months old — too young to realize how different he was from any other child his age. In a whispered moment, a Scottish Rite doctor confided to the parents that only a tiny child could be so determined to live.

Back in Fairburn, the Adamses put their family life back together as best they could. Lamona kept her civilian job with the army, if only to secure health insurance for her little boy. Her husband quit his job to spend more time at home with his son and to handle the boy's frequent appointments with doctors and therapists. In the parents' hours at home together, away from the stares of strangers who didn't understand what had happened to the boy, they built their own sanctuary. Lamona resumed breast-feeding her baby, while her husband sang lullabies to him. To their great delight, it became clear that their son's energy and intelligence had somehow survived the ordeal. On weekend evenings the whole family — James Jr., Lamona, James III, and

his older sister, Alysia — stretched out in the parents' bedroom and watched HBO movies while nibbling on popcorn. At such times they were almost happy.

When the Adamses told people about the events leading up to their little boy's amputations, however, a sense of outrage began to build. The parents had tried to win timely medical care for a very sick child, to no avail. They had been told to drive 42 miles to a remote hospital — a fact that grated on the parents each time they brought their baby back to Scottish Rite for physical therapy or further surgery. Each day hundreds of parents brought sick children to Egleston, Georgia Baptist, and Grady hospitals in downtown Atlanta. James Jr. and Lamona Adams kept asking themselves: why didn't Kaiser allow us that chance?

At the urging of Lamona's mother, the couple hired a lawyer and sued Kaiser in mid-1993, alleging negligence. It took 18 months for the case to come to trial, but in January 1995, proceedings began. Each day grim-faced doctors and nurses stepped into the Fulton County state courthouse in downtown Atlanta, ready to testify in *James and Lamona Adams v. Kaiser Foundation Health Plan of Georgia Inc.* What had begun as one family's tragedy soon grew into an exhaustive analysis of why a major managed-care plan had handled the case the way it had. The inquiry was especially striking because Kaiser generally was regarded as an industry leader in caring about its members' well-being. But as details about Kaiser's methods emerged, the case suggested that the margins of safety in a giant health plan are sometimes much thinner than people realize.

In court and in pretrial depositions, expert witnesses filled out the missing elements of the Adamses' story. Doctors testified about what modern medicine could do to fight the baby's illness. Other experts pulled back the curtain to explain what transpired at Kaiser at crucial stages. With that extra information, jurors could decide the trial's central questions: were the Adamses simply victims of catastrophic bad luck, as Kaiser maintained? Or was the big health plan — with all its controls and guidelines — to blame in some way?

The very word *meningococcemia* is enough to scare a pediatrician. It is a rare but not unheard-of bacterial infection, striking about 800 infants a year. Its early symptoms don't stand out much from those of ordinary flu episodes: fever, lethargy, irritability, and sometimes vomit-