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## NATIONAL DESK

## Treated for Illness, Then Lost in Labyrinth of Bills

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When Bracha Klausner returned home after an extended hospital stay for a ruptured intestine three years ago, she found stacks of mail from doctors and hospitals waiting for her.

There were so many envelopes -- some of them very thick -- that at first, Mrs. Klausner, 77, could not bring herself to open them, and she stored them in large shopping bags in her Manhattan apartment.

When she finally did open some of the envelopes, there were pages filled with dozens of carefully detailed items, each accompanied by a service code: "Partial thrombo 2300214 102.00," "KUB Flat 2651040 466.00."

On the 15th page or so of each bill, a "balance forward" line listed amounts in the tens of thousands of dollars. One totaled \$77,858.04.

Another mailing, from her insurance company, clearly said, in large type, "This is not a bill." But she could make no sense of the remark codes: "G7 -- Your benefit is based on the difference between Medicare's allowable expense and the amount Medicare paid" or "QN -- Your claim may have been separated for processing purposes."

Mrs. Klausner's experience is shared by millions of Americans who, frustrated and confused, find themselves devoting enormous amounts of time and energy to sorting out their medical bills.

Walk into any drugstore, and the next few minutes of your life are fairly predictable. After considering the choices, you make your purchases and head for the cashier. Seconds after the transaction, you are handed a receipt that reports to the penny what you paid for each product, along with its brand, its size, and the date, time and location of the purchase. But become a patient, and you enter a world of paperwork so surreal that it belongs in one of Kafka's tales of the triumph of faceless bureaucracies. And although some insurers and hospitals are trying to streamline and simplify bills, the efforts have been piecemeal.

Medical paperwork is a world of co-payments and co-insurers, deductibles, exclusions and contracted fees. Nothing is as it seems: patients receive statements that often do not reflect what is actually owed; telephone calls to customer service agents are at best time-consuming and at worst fruitless. The explanations of benefits that insurers send out -- known as E.O.B.'s -- are filled with unintelligible codes.

The system is so impenetrable that it mystifies even the most knowledgeable.

"I'm the president's senior adviser on health information technology, and when I get an E.O.B. for my 4-year-old's care, I can't figure out what happened, or what I'm supposed to do," said Dr. David Brailer, National Coordinator for Health Information Technology, whose office is in the Department of Health and Human Services. "I can't figure out what care it was related to or who did what."

Dr. Blackford Middleton, a professor at Harvard Medical School with special training in health services research, said he did not fare

much better than Dr. Brailer.

"I understand the words of diagnoses and procedures," he said. "But codes? No. Or how things are paid or not paid? I don't understand that."

Dr. Brailer said he often used an analogy to describe the current state of medical billing.

"Suppose you walk into a restaurant," he said, "and you don't get a menu, you don't get any choice of what food you'll eat, they don't tell you what it is when they're serving it to you, they don't tell you what it's going to cost."

"Then, weeks or months later, you get a bill that tells you all the food you ate and the drinks you had, some of which you remember and some you don't, and although you get the bill, you still can't figure out what you really owe," Dr. Brailer said.

Some people make valiant efforts to sort through bills and claims, but end up throwing up their hands; others ignore them, until they are pursued by collection agencies; still others, basically healthy but weary at the prospect of a paperwork fusillade, stop going to the doctor altogether.

### Piles Upon Piles

In the days before managed care, most insurance plans operated on a fee-for-service basis. Patients paid 20 percent of medical fees; insurers paid 80 percent. But as health care costs have continued to rise, many patients are being required to pay an ever-larger part of their medical bills, and deductibles continue to increase. And to keep the system churning, close to 30 cents of every dollar spent on health care goes for administration, much of it spent generating bills and explanations of benefits.

"The number of bureaucrats between the point of service and the final cash reckoning is just incredible," said Dr. Thomas Delbanco, a professor of primary care medicine at Harvard Medical School who is a leader in the field of patient-centered care.

For many people, the piles of paperwork they must contend with reinforce a simmering discontent with a system that aggravates tensions among patients, hospitals, doctors and insurers.

Insurance companies are, by and large, unapologetic.

"Even though the amount of paperwork a patient has to deal with might seem to be a lot, it would be much worse if there wasn't a unifying organization like a health plan easing that burden," said Dr. Alan Sokolow, chief medical officer at Empire Blue Cross Blue Shield in New York.

This might come as a surprise to Ellen Mayer, an artist who lives in Chester, N.Y. Ms. Mayer, 54, has a rare type of gastrointestinal cancer that requires constant monitoring through blood work, CT scans and PET scans.

The paperwork nightmare started for Ms. Mayer when her oncologist switched hospitals. Everything suddenly seemed to need a justification, or a new piece of paper with an authorization.

The stacks of papers, folders and Post-It notes related to Ms. Mayer's treatment have started to take over her house. They fill manila envelopes, boxes and files, which fill closets. They spill from the dining room table onto chairs.

"You can't just be sick," she said. "You have to be sick and be drowning in paperwork."

So overwhelming has the paperwork grown that Ms. Mayer has considered giving up and ceasing all treatment because of the bureaucratic hassle that accompanies it.

"It's comical, it's unbelievable," she said. "And I think to myself, 'What if I was an elderly person, or a single person? What if I wasn't healthy enough to handle it?'"

Dr. Michael Mustille, associate executive director of the Permanente Federation in Oakland, Calif., said medical paperwork often delivered "a double psychological whammy."

"People get these things that look expensive that they can't understand," Dr. Mustille said, "and then there's the worry that the people they've paid for insurance may decline to assume responsibility for it."

In Mrs. Klausner's case, her son bought her an elaborate paper organizer, hoping it might help her face the chaos. She never used it.

Creditors began to call. Whenever a collection notice showed up, Mrs. Klausner panicked and wrote a check or reached for the telephone to call her son for help.

In the end, Medicare and United Healthcare paid most of Mrs. Klausner's bills, which added up to more than \$150,000. And although the unwelcome mail has ceased, she cannot bring herself to throw out the bags filled mostly with unopened envelopes dating back to 2002, as if doing so might violate a law.

Dr. Middleton went through something similar with his elderly mother, Dugan Middleton, a former nurse who died of thyroid cancer last February at age 79.

Mrs. Middleton, who had lived alone in Palm Beach Gardens, Fla., preferred to handle the paperwork herself.

"It went on and on, with her reconciling her accounts with a lot of different doctors," Dr. Middleton said.

He said that his mother wrote check after check and that "I'm sure she was paying many of the same bills twice."

His medical credentials notwithstanding, Dr. Middleton was at a loss. "It was ridiculously complex," he recalled.

Finally, in the last months of his mother's life, Dr. Middleton hired a social worker who knew how to navigate the system to help with the bills.

How did things get this bad?

Most health care in the United States is fragmented and profit-driven, a system in which everyone but the patient is meant to benefit financially.

"Fragmentation is a fact of life in health care, and people consider that to be one of the most fundamental problems," Dr. Brailer said. "We pay by the piece. Everybody gets paid individually to do something: to see a patient, to admit someone, to do a lab test, to do a prescription, so health care is swamped by detailed, line-item bills."

After an office visit, a physician sends a diagnostic code to the insurer, which then decides the level of payment. These codes differ from the codes the insurer uses in the E.O.B.'s it sends to patients to explain its decisions.

The billing codes used by hospitals are something else entirely.

"Each of them has their own system of paperwork, with their own billing codes," said Ron Pollack, executive director of Families USA, a health care advocacy group.

"Everyone is bogged down by this: the physicians, the hospitals, and ultimately it reverberates to the consumer," Mr. Pollack said. "And to the extent the consumer sees the bill, it's like reading hieroglyphics."

Mr. Pollack and other health care experts said they believed that only a small percentage of people end up calling their insurance company to inquire about a claim or to dispute a decision. Still fewer call a hospital to go over a bill they believe might contain errors.

The Navigator

In late 2003, Bonnie MacKellar's son Elias, then nearly 2, stopped eating. Then he stopped talking and walking. Elias had stage IV neuroblastoma, a highly malignant tumor of the nervous system.

Though pushed to their emotional limits, Ms. MacKellar and her husband, Thomas Dube, refused to buckle until the bills started to appear in the mail each day: hospital bills amounting to tens of thousands of dollars; invoices from doctors she did not remember meeting; E.O.B.'s from her insurance company that explained nothing.

"It is hard to describe what it is like to be confronted with mounds of scary claims and bills when you have a 2-year-old who is extremely ill, who needs constant nursing and doesn't have a great chance of surviving," Ms. MacKellar said. "And to sit in a hospital room, on hold with the insurance company for 30 minutes or more only to have your child start puking just as you get a rep on the line."

The E.O.B.'s seemed to serve little purpose beyond engendering fear. They were detailed enough ("radiology services 2/19/04"), but when it came to understanding the boxes listing the amounts charged, the amounts not covered, the fees allowed, the available benefit and the remark code (IT, 29, and the ever-mysterious QN ), Ms. MacKellar and her husband were at a loss.

One statement that said, "Plan pays \$00.00, patient pays \$56,750.00," caused panic.

The remark code "07" stated, "These charges are for services provided after this patient's coverage was canceled."

There had been no cancellation of coverage, but convincing the insurance company of that fact was an ordeal.

The breaking point came when the group number on the health plan changed, and Ms. MacKellar was unable to convince the insurance company that it was billing under the wrong number.

In despair, she consulted a social services agency, which put her in touch with Lin Osborn, a private consultant fluent in the arcane language of health care billing. For a fee, Ms. MacKellar was told, Ms. Osborn could take all the paperwork off her hands.

An expert in deciphering insurance and hospital billing codes, Ms. Osborn spent several days straight working on the case and took care of the entire mess, Ms. MacKellar said.

### Still Searching

Although there is no single solution to the medical billing morass, Dr. Brailer, of the Health and Human Services Department, said that the increasing use of electronic records to enable insurers, physicians, hospitals and pharmacies to share data would help.

And in some segments of the health care system, efforts are being made to simplify and cut down on paperwork. Some insurance carriers, for example, are reducing the number of E.O.B.'s they send out, posting them online instead.

For the past 18 months, Blue Cross Blue Shield of North Carolina has been working to reduce the total amount of paper it sends out.

"When there's no remaining financial liability, then we don't send the E.O.B.'s," said Bob Greczyn, president of Blue Cross Blue Shield of North Carolina.

Blue Cross Blue Shield of South Carolina is offering physicians an electronic card reader that lets patients find out how much they owe while they are still in the doctor's office.

In another effort to improve the system, the Patient Friendly Billing Project, led by the Healthcare Financial Management Association, is working with insurance companies on a long-term project to make bills more comprehensible.

Still, Dr. Brailer said that, on the whole, "there isn't a lot under way" in terms of efforts to fix the system.

Dr. Brailer pointed out that there had been frequent calls for a standardized insurance billing form, which would sharply reduce duplication and paperwork costs and "make patient management of these as simple as online checking."

But, he said, "this has not gone beyond the wishful-thinking level because the changeover would cost a lot."

Mitch Mayne, 38, is a marketing executive in San Francisco who considers himself basically healthy.

Mr. Mayne went to his doctor three times between March and June for the same thing: recurring bronchitis.

Yet the explanation of benefits statements he received from his insurer after each office visit differed drastically in the amount he owed, varying from \$10.66 to \$90, with no explanation of the services provided.

"What did I do on June 27 that was different than what I did on April 6 that was different than what I did on March 4?" Mr. Mayne asked.

When he calls for an explanation of the E.O.B.'s, he said, the most tangible result he sees is a new card in the mail with no indication of the amount he owes as a co-payment printed on the card.

"I'm paying through the nose for this premium, and when I go to the doctor it's a roll of the dice as to whether or not they'll pay it," said Mr. Mayne. "It seems like it depends on the mood of whoever happens to be doing the claim that day, or on the phases of the moon."

Mr. Mayne recently grew so fed up that he decided to try to beat the bronchitis on his own. "I can't deal with all this paperwork," he recalled saying. "It's just too much of a hassle." That turned out to be a mistake. Mr. Mayne became so sick that he finally relented and saw his doctor.

What if something truly catastrophic should happen to the state of his health?

"Oh wow, I hadn't even thought of that," Mr. Mayne said. "That's actually a pretty scary proposition. If I can't manage my health care as a healthy individual, the prospect of trying to manage it and be really sick at the same time -- I don't know that I could do it."

## Being a Patient

Later articles in this series will look at bankruptcies caused by medical expenses, how money is easing some patients' experience and difficult doctors. This series, advice on getting help and a reader discussion on what it is like to be a patient today are online at [nytimes.com/health](http://nytimes.com/health).

Photo: OVERWHELMED BY PAPERWORK -- Ellen Mayer's gastrointestinal cancer requires constant monitoring. Everything seems to need a justification, or a new authorization. At one point she considered stopping treatment because each test required so much paperwork. (Photo by Suzanne DeChillo/The New York Times)(pg. A18)