The Silent Treatment

Because state law allows hospitals to keep their mistakes secret, James Williams may never know exactly how his wife went in for routine surgery and came out in a coma

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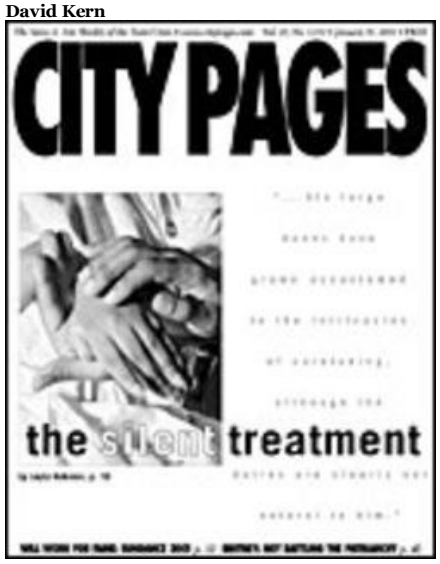
The year 2000 should have been a wonderful one for James Williams. His business, an international development company, was thriving, and he had the endless energy to travel the globe closing lucrative deals. His family planned pleasure trips around the world--a vacation to Hawaii, a trip to the summer Olympics in Sydney. He was an active, respected member of his church. At 45, he looked forward to enjoying the life he had built with Sharon, his sweetheart since junior high, his wife of nearly 22 years. "This is so different from where I ever imagined I'd be," he muses, shifting a quick glance around the private room, a sunny corner of Golden Valley's Vencor Hospital ("The specialty hospital for medically complex patients," the sign reads). "This is so different from where I'd ever been before."

David Kern



As he speaks, Williams balances his linebacker-size body on a wooden stool. He is large, broad-chested and imposing, yet he exudes an easy kindness. His oval face and close-cropped hair highlight golden-brown eyes that gaze from under long lashes. Systematically, almost rhythmically, they dart to his side, to check on the woman with the cocoa skin and vacant gaze resting quietly in a hospital chair next to him. It is an involuntary action for Williams. His heart beats. He takes a breath. He looks at Sharon.

In an instant Williams is at her side. He suctions saliva from around her mouth, swabs her lips and tongue. He dashes to the nurses' station to alert them when the bottle that feeds Sharon through a tube is empty, or when the humidifier that warms her breath is nearly out of water. His large hands have grown accustomed to the intricacies of caretaking, although the duties are clearly not natural to him; he still fumbles a bit as he pulls up the stockings that aid the circulation in Sharon's immobile legs, as he props up her head and hands. "Let's get some sunlight on your pretty plants, baby," he coos, pulling back the pastel curtains, allowing light to fall on the windowsill and the many framed photos of family and friends that adorn it.

He flicks a switch next to the bed, and strains of gospel music brush through the room. There are only two kinds of music allowed in here, Williams explains. Classical, because "it helps with the development of brain cells," and inspirational, "because we need a miracle from God." Every action is gentle, careful, deliberate--a man trying to control tiny details because he has no control over the single, overwhelming thing he'd most like to change.

"There's no reason why we should even be here," he says, "God has his reasons, but there is no human reason." He pauses, dabbing tears from his eyes. "My baby has had to go through so much, just because someone couldn't give us 15 minutes of their time."

Sharon Williams has been in a coma since the afternoon of April 11. After undergoing a successful routine surgery that day--a hysterectomy to eliminate painful fibroid cysts in her uterus--she stopped breathing for several minutes. By the time she was resuscitated, the lack of oxygen to her brain had caused extensive damage. A state investigation later discovered that a nurse in the recovery room had failed to turn on the alarms on Sharon Williams's monitor, then left her alone for an unknown period.

Since May, when Sharon was admitted to Vencor, Williams has come here every day. He has put his business on hold and instead sits with his wife for eight, sometimes ten hours. He talks with her. He prays with her. His world has shrunk from the boundless globe to the nine-mile stretch between his home in Plymouth and this hospital room. There is no way of

knowing how long Sharon might remain comatose.

That uncertainty creates a cascade of problems. There is the cost of her long-term care, which insurance will cover for only the first year. There is a pending malpractice lawsuit against Fairview Health Services. There are Williams's dwindling savings. There are the children, Tenisha, 21, a junior at Augsburg College, and Jahron, 13, still living at home. And there is the loss Williams feels for the life he spent with Sharon, which carried them from their junior-high days in New Mexico all the way to Hong Kong, where Williams was a lawyer for Honeywell, and back to Minnesota.

"It's hard," Williams says, putting a starkly simple adjective to an unimaginable situation. "I come here every day and I will continue to do so until God brings her home to him, or allows her to come home with us. We just exist. We don't live. We can't plan our lives."

As the life he knew--the life he expected to have--is erased around him, the one thing that offers Williams any hope is his faith. It is also the one thing he must strive hardest to hold on to. "I talk to God," he says, full of questions. "When? Why? Why is it taking so long? Why should people suffer so badly who love God? Where were you, God, when we needed you? I don't understand anything anymore. How is this going to be good?"

He and his wife checked into the Fairview-University Medical Center's Riverside campus at about 9:30 a.m. on April 11, James Williams recalls. Sharon's surgery was scheduled for midday. While she was waiting, she sat with her husband, their pastor, Lesley Ford, and his wife Rosella. Ford, a wiry man whose soft voice has a soothing, almost Southern twang, remembers it as a peaceful, even buoyant time. The four laughed and joked, talked about the Williamses' upcoming vacation in Hawaii. And they prayed together.

"It was a happy time. There was no shadow of an indication of anything. This was just a routine thing that happened thousands of times," Ford recalls. "It was a good time, seeing her smiling, holding her hand, praying with her. That was the last thing we did."

The Williamses are a religious family, having gone through a "spiritual revitalization" in the mid-Nineties. They belong to St. Paul's Living Word Church, a nondenominational, charismatic congregation. Until last April Sharon Williams even worked there, having chosen in 1995 to leave her own 12-year career at Honeywell to be a receptionist at the church, to do more meaningful work.

Williams stares straight ahead as he relives that April day, his recollection so vivid he instinctively recoils from its sting. It was around noon when Sharon was taken into the operating room. The Fords left to spend time with two other women from the church who were having surgery that same day. James Williams went into a waiting room. He expected to see Sharon again in about three hours. And so he waited. Three hours came and went, but Williams was not alarmed. Probably the procedure started late, he reasoned. Periodically, Williams and the families of other patients would each check a computerized guide in the room that allows family members to monitor the status of patients.

After three and a half hours, Williams noted that the monitors listed Sharon as out of surgery, but didn't explain where she was. The recovery-room volunteers could tell him nothing. Neither could the nurses outside the operating room. The minutes ticked by, and after four hours and no information, panic had taken hold. "It did not feel right," he remembers. He picked up the phone intending to call someone, anyone who might have some information. A woman he did not know came down the hall toward him. "Are you Mr. Williams?" she asked. "Can we go to a consultation room and talk?"

There had been complications, the woman told him. She didn't know the specific problem. "I'm already nervous, champing at the bit," Williams says, speaking in present tense as he relives the events moment by moment. "We're sitting here in this room and I know something's wrong. It seems like another day has gone by." The door opened and five people entered: a doctor, his assistant, two others, a chaplain. "When I see the chaplain, I'm on edge. They told me there was a complication in the recovery room, that Sharon had stopped breathing."

Williams's mind was spinning. "This can't possibly be happening," he thought to himself. "This can't be real." Aloud he said, "I want to see my wife immediately." The entourage walked him to the room where Sharon lay. "When I saw her, I almost had a heart attack. She was spastic; her eyes were all over. It was the scariest thing I'd ever seen," he remembers. "This was my baby. She looked really bad." As the doctors prepared Sharon for transport to Fairview's University campus, where she would be better cared for in the intensive-care unit, Williams tried to comfort his wife. Through tears he prayed over her, told her everything would be all right.

But things were far from all right. When the doctors at the second hospital reviewed Sharon's chart, Williams says, they were outraged. Someone had failed to perform his or her job, they told him. "They said this should never have happened. They were absolutely hostile about it. Their anger fed into me."

Through the swirl of fear, Williams focused on only a few concerns: "My wife, her condition, how she got into her condition, and how we could get her out." Yet getting information about what had happened proved difficult; what he learned during those first days was about all he was going to be told. Engulfed in his own questions, the lack of answers launched Williams on a quest to find out what had gone wrong--and why.

Anyone who has ever suffered an illness--or watched someone endure one--knows that medicine is not a perfect science. But even if the results of treatments can sometimes be unexpected, we expect to see clear documentation of the steps that were taken that led to the outcome. As he tried to trace what had happened to his wife in the recovery room, James Williams faced obstacle after obstacle.

"We wanted to know exactly what happened," Williams says. The doctors and administrators at Fairview-Riverside repeatedly told him they were looking into the situation, he recalls. "They were allegedly having investigations. It became clear that they knew what happened, but they couldn't come up with a story that would make them not liable." Again and again, Williams says, Fairview-Riverside promised explanations, but those promises went unfulfilled.

Fairview officials bristle at the notion that the hospital withheld information. "We gave them all the information there is about their family member. Your goal is to make sure everyone knows what's going on and that the family does not feel excluded," says Margaret M. Van Bree, chief operating officer of Fairview-University Medical Center, adding that physicians sat down with the Williamses and painstakingly went over Sharon's medical record step by step to explain it. "But it is an unexpected event. There may be questions that we don't necessarily have answers to right away."

The first details of what had happened in the recovery room, Williams says, came from a doctor, unaffiliated with Sharon's care, who had been in the room when the nurses tried to resuscitate Sharon. This doctor, Williams says, called him and talked to him for about 40 minutes, not because he had anything to do with Sharon's surgery, but as a concerned person who was also upset. "He told me that my wife's alarm system was never activated. He said human error was involved. Somebody forgot to do what was required," Williams remembers. "If he hadn't told us, we would not have known today. It was not the institution that disclosed that."

More information would come to light, though, again, not directly from Fairview. The Minnesota Department of Health looked into the incident. Investigators reviewed Sharon Williams's medical charts and visited Fairview-Riverside on three separate days in July, interviewing the staff on duty during the incident. These investigations are generally triggered by a complaint filed with the state; not every complaint is deemed serious enough to warrant an investigation, and not every investigation substantiates the complaint. In this case, however, the Department of Health began its own inquiry after seeing news reports about Sharon Williams.

On September 18 the health department issued a report on its investigation. When Williams read the document, it was the first time he learned the details of what had transpired in the recovery room. According to the report, Sharon Williams, who was then 42, had been in good health prior to her surgery. The operation went smoothly, without complications.

After the procedure, the agency concluded, Williams began to wake from the anesthesia. At 3:17 p.m., she was transferred from the operating room to the recovery room. She arrived at 3:20. "Documentation reflected that her vital signs were stable," the report notes. "Her oxygen saturation was 100 percent, she was moving all extremities, and was responding to and following commands." Williams was one of three patients in the recovery room; there were three registered nurses working, and each was assigned to one patient.

A registered nurse, the report explains, must assess the patient when she arrives in the recovery room, evaluating her breathing and circulation. The nurse is then responsible for connecting the patient to a monitoring device and engaging alarms that sound if her vital signs or breathing drop below an established guideline. The nurse is also responsible for assessing the patient's level of consciousness and pain.

The nurse in charge of Williams's care did, in fact, assess her at 3:20 p.m. (The nurse, who is not named in the report, still works at Fairview-Riverside facility.) Williams was moaning slightly from pain and could move her feet and take deep breaths when asked. The nurse hooked Williams up to an oxygen line and placed a blood-pressure cuff on her. The nurse, the report continues, recalled that she then "hooked her up to the monitor, but I failed to push the button to engage the

alarm." Without the alarms, the monitor would not alert staff to changes in Williams's condition. At 3:25 p.m., the nurse administered four milligrams of morphine to ease the patient's pain (an effective pain medication, morphine causes breathing to slow down). She listened to Williams's lung sounds, noting that they were somewhat decreased, then left Williams and "walked over to talk to another nurse." She estimates that she had her back to the patient for less than three minutes.

The report is less specific about what took place during the next 15 minutes. Another recovery-room nurse came to consult with Williams's nurse, who was getting ready to go on break. The second nurse looked at Williams's monitor and saw that her heart rate and blood pressure were low, and that she was not moving. Williams's nurse engaged the monitor's alarm, which immediately sounded. The two tilted the head of Williams's bed downward 30 or 40 degrees to increase blood flow to her brain, gave her more fluids, and raised her chin to establish an airway.

Documentation about the incident noted that at 3:40 p.m. an anesthesiologist who was coincidentally walking through the recovery room noticed that Williams's head was tilted down, that she was unresponsive, and that she was not breathing. The anesthesiologist, who was not involved in Williams's surgery, began ventilating Williams with an air bag. "Although the anesthesiologist was unable to estimate the exact length of time that [Williams] had been without respiratory exchange, he did indicate that it had been more than just 'seconds...it had been minutes,'" the report states.

While all this was happening, James Williams sat in the waiting room, trying desperately to find out how his wife was.

At 3:41 p.m., Sharon Williams's heart stopped beating, and the staff began cardiopulmonary resuscitation. A breathing tube was placed in her throat at 3:44 p.m. Chest compressions were stopped at 3:58 p.m., when Williams's pulse and blood pressure returned. She remained unresponsive, and at 4:00 p.m. she was placed on a ventilator. Williams was comatose. Her breathing had slowed or stopped for 18 to 20 minutes. The report concludes that Williams's nurse was responsible for the neglect. (The nurse has appealed the finding, but a Department of Health spokesman says the appeal hearing has not yet been scheduled.)

Williams was immediately transferred from Fairview-Riverside to the larger intensive-care unit at the Fairview University campus. On May 5 she was discharged and transferred to Vencor Hospital for "long-term management." "The progress record indicated that [Williams] remains in a deep coma with a very grave prognosis for neurological recovery," the report states. There's no way of knowing whether she can hear or see anything.

To date, this report--a public document released by a state agency, not the hospital--is the only information James Williams has been given offering insight into the chain of events that left his wife in a coma. Williams felt he had little choice but to hire a lawyer and sue Fairview Health Services, the company that owns the hospital. Only through legal findings, it seems, can Williams hope to get Fairview to pay for Sharon's ongoing medical costs. And only in a courtroom is he likely to find out what happened during the 15 minutes that changed his life forever.

Most hospitals belong to the Joint Commission on Accreditation of Healthcare Organizations, a voluntary organization that periodically reviews quality of medical care. The commission mandates an investigation by an internal group made up of hospital staffers, called a peer review, when an incident in a member hospital results in a grave injury or death. This in-house review generally takes place shortly after the incident in question, when memories are fresh. In Minnesota, as in most states, laws ensure that the data gathered in these reviews stays confidential: It is not made available to the patient, or the patient's family. It is not included in the patient's medical chart. It cannot be introduced into a lawsuit.

The idea behind this is that confidentiality allows medical professionals to discuss candidly what went wrong without fear of retribution or liability. "People need to feel safe. If they fear repercussions to their actions or comments, they may not want to be as honest," Fairview's Van Bree explains. "Self-examination has to be done in a sense of getting things to be better for everyone. Peer review is the process that gets that to happen."

But William Tilton, the St. Paul medical malpractice attorney who is representing the Williams family, adamantly believes that the opposite is true: Only full disclosure of mistakes will bring about better health care. "Those laws were passed without a lot of debate and without a lot of thought," Tilton declares. "I don't think they were passed with any proof that medical care would improve. It's been decades that it's been assumed that secret investigations of doctors by themselves is the best way to improve medicine."

The question of medical errors has, in recent years, been the subject of broader study. In November 1999 a prominent medical-research institute released a report that bore startling news: Based on two recent studies investigating deaths due to hospital errors, researchers estimated that the number of Americans who die each year because of medical mistakes ranges between 44,000 and 98,000. Even the lower figure is far greater than more widely discussed killers, such as car

accidents, breast cancer, and AIDS. The report, issued by the Institute of Medicine, a part of the National Academy of Sciences, went on to estimate that the costs of these preventable injuries--lost income, lost household production, disability, and healthcare--fall between $17 billion and $29 billion.

Part of the reason the public seems unaware of healthcare error rates, the report states, is that "patient safety is also hindered through the liability system and the threat of malpractice, which discourages the disclosure of errors.... Most errors and safety issues go undetected and unreported, both externally and within health care organizations."

Raising awareness about medical errors is the first step toward increasing public demand for improvements, the survey's authors conclude. "The goal of this report is to break this cycle of inaction. The status quo is not acceptable and cannot be tolerated any longer. Despite the cost pressures, liability constraints, resistance to change, and other seemingly insurmountable barriers, it is simply not acceptable for patients to be harmed by the same health care system that is supposed to offer healing and comfort."

But even if the records from Fairview's own peer review of Sharon Williams's case are confidential, Tilton argues, the notes made by state health department investigators--notes that Tilton believes include some of the peer review data--are not. On November 3 he asked Hennepin County District Judge John Sommerville to allow him to see the state's files. "This is the best evidence of what happened here," he argued. "The only person who doesn't know it is the Williams family. Why should this stuff be protected? We know more about a plane crash in Taiwan three days ago than the hospital has been willing to give up on what happened to Sharon Williams."

At the hearing, Fairview's attorney, Rebecca Egge Moos, argued that the state's notes on the peer review are also protected under the law. Moos declined to comment for this story, but Van Bree stresses that Fairview is legally obliged to keep the peer-review data confidential. "We take the peer-review process very seriously, and we follow its intent. We have a much better understanding of how to better care," she says. And does the confidentiality help that process? "I think it does. It has worked that way." Fairview disputes portions of the state's report, Van Bree adds. Williams's accident was an isolated occurrence, she says, and even before the state began its investigation, hospital staff had undergone training to make sure it won't happen again.

Judge Sommerville has yet to make a ruling on the discovery motion. Until he does, the suit is at a standstill while Tilton waits to see if he can get access to those fresh details. A tentative trial date has been set for August. Tilton and Williams want to ensure that Sharon Williams's medical costs are taken care of for the rest of her life (on behalf of the Williams family, Tilton is negotiating with Fairview to have the company take over Sharon's medical expenses after her insurance runs out in April and up to the point of trial). James Williams says those costs are $93,000 per month. If the healthcare company doesn't pay, Williams adds, he could end up selling his house and liquidating his assets to continue paying for his wife's care.

Then there are the damages, for the suffering of both Sharon and her family. "They had a perfect life and [James Williams] wants it back. Short of that, I want assurances that she will be taken care of," Tilton says, pausing a moment to think before he continues. "What's it worth to have lost your lifelong partner?"

What do you do when you have no power to help the people you love? Where do you put the pain, frustration, and anger? Even though you may feel helpless in the face of your own personal, untenable situation, perhaps you can turn the sorrow into something positive. Last fall Williams turned his focus to changing Minnesota's laws that allow hospitals to keep the circumstances of their medical errors secret. "God may be using your family to help so many other families," he tells himself.

Because the Williamses have been so active in the Twin Cities' African-American religious community, a group of black pastors took up the cause in support of the family. In October a group of 15 ministers held a press conference saying they wanted legislation to open up hospital records. Since then Williams himself has been organizing others to increase awareness of Sharon's situation and to make sure that her suffering is not in vain. It hasn't been easy to take his family's private hurt and turn it into a political cause, Williams concedes, but he was fed up with what he sees as Fairview's unwillingness to take responsibility for its mistakes.

"They forced us to make this public. This is a very private, painful matter," he says. His anger flares for a moment as he continues. "As much pain as we can inflict on them doesn't come close to the amount of pain our family has suffered for no reason."

With Tilton, Williams has cobbled together an odd assortment of allies, including lawyers, lobbyists, advocates for consumers and for people with brain injuries, and religious leaders, to form a grassroots group called the Citizens for

Patients' Rights. The organization, still in its formative stages, has met a few times and plans to lobby during the 2001 legislative session to make Minnesota's laws more patient-friendly.

On behalf of the coalition, Joel Carlson, chief lobbyist for the Minnesota Trial Lawyers Association, is developing a strategy for introducing legislation that would amend the current law outlining patients' rights. Right now patients in Minnesota healthcare facilities have the right to, among other things, courteous treatment, appropriate care, privacy, freedom from mistreatment, and information about treatment. (The existing bill of rights should not be confused with much-publicized proposed legislation--on both the state and federal levels--that would make it easier for patients to sue health-maintenance organizations.)

"The concept we're embracing here is my right to know information about my care," Carlson explains. "We can try to amend the patients' bill of rights to make sure we have the right to know information about medical errors made against us." To that end, he has drafted a change to the existing law. Specifically, his proposal would add a provision requiring doctors to disclose "any medical errors which may have been committed in the diagnosis, care or treatment provided," as well as any medical and psychological consequences. The draft includes penalties for doctors who fail to provide such information.

The coalition has asked state Sen. Lawrence Pogemiller (DFL-Minneapolis), a Williams-family friend, to author the legislation. "Clearly there's an interest in addressing the issue of medical errors among legislators, especially when they hear compelling stories like the Williamses'," he explains.

Amending the patients' bill of rights would be a solid first step, Tilton says. "That's a realistic goal to hope for in the next year or two. That's a tremendous victory," he says. "But there are other impediments to a patient's right to know." He and Williams want the crusade to go even further, to overturn the law protecting peer-review data from outside scrutiny.

Williams doesn't see this as a fight between doctors and lawyers. "This is not a legal issue. This is a moral issue. It's going to be led by the churches because they have the moral authority to raise this issue," he declares. "We want to make this issue akin to human rights, civil rights. These are basic rights, akin to breathing, that we all should have."

At a time when he must stretch to think beyond Sharon's current situation, Williams has latched on to the battle to change the rules of medical disclosure. If he can't control what happens to his wife and family, perhaps he can at least help change what happens to others in the future. "Each and every one of us is a potential victim. Each and every one of us can find ourselves in the hospital," he cautions. "The healthcare industry evolved to serve patients. Now it seems like it's serving a lot of other folks and the patients are at the end of the process."

Of the many shadows that chase James Williams--doting worry, smoldering anger, despairing sorrow--the one that seems most unshakable is a heartbreaking loneliness. Life has become a joyless chore for him, as he wanders through his 16-room house in Plymouth, the once-proud home Sharon picked out. He has changed nothing since she was last there. The bunnies and crosses Sharon put up around the home to celebrate Easter are still there. Her sparkling voice still greets callers on the answering machine. "The real glue of our family isn't with us the way we want her to be," he says simply.

Pacing the narrow hallway at the hospital where Sharon now lives, there is little Williams can do but wait, hope, and pray. "I don't have the ability to do anything that can change anything," he says. "I used to think I could make things happen. There was no problem I thought I couldn't solve." His legal and business training at Georgetown, Columbia, and Harvard, his years of experience working overseas for Honeywell, none of it prepared him for this, what he calls their darkest hour.

What happened April 11 devastated the Williams family. Every milestone brings a new torment. Mother's Day was hard, Williams recalls. Sharon's 43rd birthday was in August. A week later Jahron turned 13. The stretch from Thanksgiving to the New Year was almost unbearable. Tenisha turned 21 in December. Christmas came, with little to celebrate. (Williams sent his son to visit Sharon's brother and his family so the boy could have a happier Christmas. "I just didn't have the spirit," he explains. "I wanted to put him in an atmosphere, an environment where he could at least experience Christmas.") December 28 marked the Williamses' 22nd wedding anniversary. And with January came James Williams's 46th birthday.

It's morning, and Williams is sitting at his wife's bedside. He faces her, his head bent downward, and stretches both hands out a few inches above her motionless body. In one hand he holds a Bible. He asks God to help her.

When will this vigil end? Rev. Ford has urged him to put more energy into his own life. "He cannot spend eight hours a day at the hospital. He has been doing that since April. He's got to now do something different," Ford opines. "He's got to get back in the business he was in. There's got to be something that feeds your soul."

Sitting in Sharon's room, with the steady gurgling of the humidifier in the background, Williams has trouble reflecting on the notion of returning to his old life, his old self. "I was charging around the world, looking for money, making business interactions, playing the CEO," he says. Now he can't imagine going back to that. "Typically I'm a workaholic. I love to work. I love to do deals. But that part of me has been killed. I don't have the vigor for it. I don't see that part of my life coming back until my wife comes back. And even then I want to spend time rebuilding our relationship.

"I have to be here with my wife. I'm not going to let her be by herself. I'm not going to let her think she's alone. This is my work here, this is my mission," he declares. "All the things that were not important to me before are the most important things to me now. Maybe that's what's supposed to come out of this."

It's an excruciating position to be in, especially for a man whose life had always been about law and business, smooth handshakes and articulate arguments. For the corporate-lawyer Williams, clarity and logic could accomplish all goals. "His life was focused in on reasoning," says Ford. "Now we have to flip it to faith. The evidence of things unseen."

And so the family waits. Williams has turned his energies to studying brain injuries and talking to specialists around the country who might be able to help Sharon. He plans to visit six hospitals he thinks might offer her a chance of recovery.

Still, his hope lies in something beyond medicine. "No doctor can help us," he says. "Only the Great Doctor can help us. We're out in the area where only God operates."

James Williams sits back, a broken giant. He turns his eyes heavenward and raises his hands in a pleading gesture. "I believe that God is still with us, and he has a plan for us," he whispers. "I put my trust and faith in God that he's going to see us through this, that he's going to make a way for us where others say there is no way."

City Pages *intern Natasha Uspensky contributed research for this article.*