

# Legionnaires' survivor loses limbs, aims to prevent deadly disease

## But health officials say it's no easy matter

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Kent Carson, of Round Lake Beach, who lost three limbs to Legionnaires' disease, works with occupational therapist Sandy Kim at the Rehabilitation Institute of Chicago. It is unknown where Carson contracted the illness, which can spread through water and ventilation systems. (José M. Osorio, Chicago Tribune)

Lying in a hospital bed, Kent Carson woke to find his left arm covered in bandages. His son at his bedside tried to tell him what happened, but Carson drifted back to sleep.

Later Carson woke again in a haze and could not see his feet but noticed they itched. In and out of consciousness he drifted, until he was truly awake and aware.

He was extremely ill, his family explained. Again and again they told him what happened, but he'd suffered a stroke and kept forgetting. Each time they told him, he would cry, until finally it sank in — both his legs and his left arm had been amputated.

His devastating condition, doctors told him, was the result of a severe case of Legionnaire's disease. And nobody could tell where he had gotten it.

Frustrated by the lack of answers, Carson, a 55-year-old branch bank manager from Round Lake Beach, and his family are pushing for measures that would identify sources of the bacteria before it strikes. They are calling for requirements that buildings with risk factors for Legionnaires' get regular testing of their water systems. They hope that would prevent further outbreaks of a disease that is thought of as rare and exotic but turns out to be strangely common.

The bacterial testing would be an unprecedented building code requirement. But health officials are resisting Carson's proposal, questioning its cost and whether it would work.

Currently, health officials don't test isolated cases like Carson's, but instead only take action on cases after there's been an outbreak of multiple victims affected in the same place and time.

That's all backward to Carson. The objections seem insignificant to him compared with the loss he and others have suffered. The Legionella bacteria lurks in buildings that people use every day — and can strike again if not controlled, Carson warned.

"Legionnaire's is still out there," he said. "It needs to be prevented and diagnosed."

While Legionnaires' is an entirely preventable condition and can often be treated with antibiotics, eradicating it turns out to be not so simple.

### **The chills**

On Aug. 4, Carson went out to dinner with his girlfriend but came down with a bad case of the chills. By the time he got to see his doctor three days later, his physician ordered him to the emergency room at Northwest Community Hospital in Arlington Heights.

Though the symptoms can be mistaken for common pneumonia, doctors diagnosed him correctly with Legionnaires', which may have saved his life, because the disease requires a different course of antibiotics.

But Carson's condition worsened, said Dr. John Shanley, an intensive care physician. At one point, Carson's heart stopped, and medical personnel rushed in to resuscitate him.

"He came as close to dying as you can get," Shanley said.

One complication led to the next, Shanley said. Carson suffered a stroke and had blood clots and internal bleeding. He developed acute respiratory distress syndrome. His liver and kidneys began to fail, and he had very low blood pressure, so he was given medicine to preserve the blood

supply to his organs. That restricted circulation to his extremities, which began to turn purple, then black. He developed gangrene, and doctors said his limbs had to be amputated.

Carson's family transferred him to the University of Chicago Medical Center for a second opinion, and doctors there agreed that the limbs had to go: both legs below the knee and his left arm below the elbow. His right hand, miraculously, was unharmed.

Because Carson was sedated, delirious, and in and out of consciousness during this process, his three adult children had to make medical decisions for him. Brennen Carson obtained the power of attorney to sign off on medical procedures.

A former U.S. Marine who saw action in Iraq in the initial assault from Kuwait, Brennen mainly kept his cool in war, but he now was having panic attacks over his father's situation. Brennen knew a number of soldiers who had lost limbs from explosions. They told him the key was to accept what happened and look forward. He made the decision to amputate — the toughest decision he had ever faced.

"We didn't know what he wanted," Brennen said of his father. "We knew we wanted him with us."

The surgeries were successful. After more than a week in a coma and a month without eating food, after once flat-lining, Kent Carson survived, grateful to be alive.

He is now in physical therapy at the Rehabilitation Institute of Chicago. On one recent morning, he winced with pain as he lifted a playground ball between his left arm and right hand, and broke a sweat as he struggled to touch his chin with the stump of his arm.

He cracked jokes during his session, telling his therapist, "You can't quit on me!"

After he was done, he murmured: "That hurt. I never in a million years thought it would be so difficult."

### **What level is safe?**

Legionnaires' is a naturally occurring bacteria that can cause an infection when heated and dispersed through water vapor as in large air-conditioning units or whirlpools, according to the Centers for Disease Control and Prevention.

The number of annual cases of reported Legionnaires' more than tripled from 2000 to 2009, and the CDC estimates 8,000 to 18,000 people are hospitalized each year, though many more go undiagnosed or unreported.

Symptoms include a cough, chills and severe pneumonia. Only 5 percent of people who are exposed get ill, and smokers like Carson and those with weak immune systems are more susceptible. Of those who get sick, the CDC reports, most will recover with antibiotics, but 5 to 30 percent die.

When Carson's family heard that three people had died of the disease after an outbreak at the JW Marriott Hotel in Chicago around the same time in August, they figured that must be where their father caught it. But Carson was never at the Marriott.

Lake County Department of Public Health officials asked Carson's family about where else he had been. But without another case linked in time and place to Carson, department officials said, it's very difficult to establish where he got it. Unless there is an outbreak of multiple cases, the CDC won't investigate.

To try to track down where his father contracted the disease, Brennen Carson has hired Earthwise Environmental of Bensenville to test his home and a casino hotel he visited in Michigan.

Robert Miller, the president of Earthwise, said some hospitals, hotels, offices and industrial sites already do testing, and some hospitals disinfect their drinking water. The process can cost thousands of dollars.

Sending a technician to test for the bacteria runs \$250, and Earthwise does a representative sample of high-risk spots like air-conditioning cooling towers and shower heads, so the cost for one location with 10 samples would be \$2,500.

This month, Batavia school officials discovered low levels of Legionella bacteria at three schools and shut down those areas while they were disinfected. Superintendent Jack Barshinger said the first-time testing was done because of recent remodeling that included a cooling tower, a known potential source of the bacteria.

Testing of 27 sites costs about \$5,000, chlorine dioxide to disinfect costs about \$500, plus staff overtime. While the cost was significant, Barshinger said, the district plans to continue preventive testing in six months.

Still, Barshinger would not advocate a blanket requirement for testing, saying schools are overregulated already, and the need should be determined at each facility.

Currently, there is no general requirement for testing for the bacteria unless there is an outbreak. To address the issue, the American Society of Heating, Refrigerating and Air-Conditioning Engineers has proposed a standard that calls for building managers to identify, monitor and correct critical points in their water systems where the Legionella bacteria could develop.

The proposal would apply to buildings larger than 10 stories, multiple housing units, hospitals, nursing homes and facilities with features like whirlpools and misters — but would leave it up to building managers to determine what would be done.

Both the Chicago and international Building Owners and Managers Association have taken no position on the proposal.

But health officials like Jason DeWitt, chief of engineering for environmental health for the Illinois Department of Public Health, were skeptical of any proposal to require testing for the Legionella bacteria.

"Practically speaking, it's very difficult because there are no standards," DeWitt said. "Legionella is ubiquitous — it's all over the place. So to pass a law to attenuate something that occurs naturally is like trying to eliminate houseflies. We could try, but it's very difficult."

The CDC is participating in developing industry monitoring standards, and the agency's medical epidemiologist Lauri Hicks said existing guidelines recommend proper levels of disinfectant and water temperature.

"Not all Legionella are created equal," Hicks said. Some are harmful while many are harmless, and drinking water is treated very differently than non-potable water, so any prevention plans should take into account the many different risk factors, she said.

"It's complicated," Hicks said. "In an ideal world, testing every single building would be great if we knew how to react to all those results. Unfortunately it's not clear-cut as to what to do."

Brennen Carson was disappointed by those responses. He wrote Illinois lawmakers last week asking them for help. A spokeswoman for Sen. Dick Durbin said his office would reach out to the Carsons to look into the matter.

"With the increase over the last 10 years, enough people are sick and dying — what's the cost of a life?" Carson asked. "It's frustrating. More testing needs to be done to determine what the safe levels are."

Kent Carson is due to be released from the Rehabilitation Institute on Halloween. He and his girlfriend, Cheryl Johnstone, were both divorced with grown kids and hadn't planned on marrying again. But after this experience, they decided to tie the knot.

If he can get healthy enough, Carson hopes to return to work.

His goal is to be walking on prosthetics in time for the next anniversary of their meeting, May 3, so they can get married on a beach in the Caribbean.

"I don't want to lose him again," Johnstone said.

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