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## To disabled, wait for aid can be fatal

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Lucy Goodlow hurts every day. It's a sharp pain that slashes across her lower back and down through her left leg, like a knife. It's the kind of pain that makes it hard to concentrate, difficult to sit, stand or walk--and impossible to work.

Because this pain wouldn't go away, Goodlow lost a longtime job.

Because she couldn't work, she stopped getting health benefits.

And with no insurance, it's been months since Goodlow has had physical therapy or an injection of pain medicine. There's no money for that now.

Goodlow is among millions of disabled adults who find themselves acutely vulnerable when their health fails. Ejected from the workforce, stripped of health benefits, snared in the bureaucracy of government programs, they are least able to get help at the time they most need it.

"It's like, you work a person down to the ground and then refuse to help them in the end when their body gets broke," said Goodlow, 58, who had worked for the Tootsie Roll factory, where she had good health benefits, for 37 years.

Estimates vary, but experts suggest that as many as 4.5 million adults are disabled and uninsured. Causes of disability vary, from a catastrophic event such as a stroke or an accident like a car crash to a medical condition such as lower back pain or arthritis that worsens significantly over time.

Losing a job and health benefits compounds the effects of these health crises. Without help, many people like Goodlow forgo medical care, become sicker and end up leaving the workforce permanently.

Two-thirds of uninsured and disabled patients reported postponing medical care in a 2003 survey by the Kaiser Family Foundation, a health-care think tank; almost as many said they went without needed medical supplies or equipment such as power wheelchairs.

Researchers estimate that of the 1.3 million adults waiting for disability coverage from the federal Medicare program--people with cancer, traumatic brain injuries and other debilitating conditions--4 to 12 percent die before that coverage begins.

'They lose hope'

After becoming disabled and leaving a job, workers can continue their employer-based insurance for up to 29 months. But they must assume the responsibility of paying the full premium, including the amount an employer had subsidized.

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Without a regular paycheck, few people elect to assume this expense, which can easily be \$300 a month or more, depending on age.

Instead, most turn to Social Security, a crucial safety net for people with severe impairments. If they qualify, disabled individuals get a small monthly income as well as access to government-sponsored health insurance through Medicaid and Medicare.

But there are significant holes in this safety net. Applying for benefits is rife with bureaucratic difficulties, denials are common, and it can take years to navigate a complicated system of appeals before a final decision is reached.

While waiting, many people get caught in a downward spiral of deterioration.

"Everything starts to break down," said Thomas Yates, an attorney with Health & Disability Advocates, a national advocacy and policy group based in Chicago. "People exhaust their savings, they stop getting care, they get sicker, they lose hope."

To be judged disabled by Social Security, someone has to be unable to work because of a life-threatening condition or a severe impairment that lasts at least a year. Though this strict standard discourages people who might fake injuries, it often excludes needy patients whose prognoses don't neatly fit the specifications.

"We see people with multiple traumas, on a ventilator, sick for nine months, who aren't considered eligible because Social Security thinks there is some possibility they'll recover," said Rebecca Brashler, a clinical educator with the Rehabilitation Institute of Chicago.

Social Security's administrator, Jo Anne Barnhart, has expressed concern about long waits associated with applying for disability benefits and is expected to announce final details of initiatives to ease those delays later this year. The agency said it doesn't have comprehensive data about the extent of fraud in its disability program, but its inspector general's office is conducting the first national study of the subject.

Goodlow filed her Social Security disability application in September, six months after she took medical leave from Tootsie Roll because of back problems and chronic pain.

An MRI scan in February showed that several discs in Goodlow's lower back are bulging and pressing on her spinal cord. In April, she lost her job permanently after she was unable to return to work.

Last month, however, Social Security denied her disability application, and her lawyer, Yates, estimates it will be at least another year before her appeals are completed.

With no income and her savings depleted, the South Side resident is depending on food stamps and money from her four adult children to pay for housing.

"I have nothing," said Goodlow, who has run out of prescription pain pills and who won't see her doctor at the University of Illinois Medical Center because the charge is \$100 a visit.

Going to Cook County's Stroger Hospital is an option, but Goodlow dreads the long waits she knows she'll encounter in the emergency room and is anxious about dealing with a medical staff she doesn't know.

Social Security would help Goodlow by providing a small income; it also would be a gateway to health

coverage. Goodlow would probably be a candidate for Medicaid, a joint state-federal program for the poor, because she's impoverished.

Nationally, 9.2 million destitute citizens with severe disabilities have health-care coverage through Medicaid. But under financial pressure, several states--Missouri, Tennessee and others--are enacting deep cuts to these health programs, threatening to throw tens of thousands of people with lasting impairments into the ranks of the uninsured.

"It's hard to envision how people are going to cope," said Liz Savage, director of health policy for the Disability Policy Collaboration, an advocacy group in Washington.

Wait can top 2 years

Medicare, a federal health plan for 35 million seniors in the U.S., also covers 6 million individuals with serious physical and emotional impairments who aren't entirely destitute.

The problem is, the health program doesn't kick in immediately when Social Security decides a worker deserves disability benefits.

Instead, an individual has to wait five months after being deemed eligible to get his or her first disability check from Social Security. Then, 24 months after that check is received, the worker can be covered by Medicare for medical services.

Some don't make it that far. In South Carolina last September, Stan White died of glioblastoma, a brain tumor, after having spent most of the last year of his life begging for charity care while waiting for his Medicare coverage to begin.

A factory supervisor who drove the church bus in his free time, White paid to continue his employer-based coverage until the company he had worked for went out of business. In the end, Medicare only paid for several weeks of end-of-life hospice services. "It was awful, the things we had to go through," said Shirley White, his widow.

Of the estimated 1.3 million people with disabilities in the Medicare waiting period, 400,000 patients have no insurance whatsoever, according to the Commonwealth Fund. (The rest have some coverage through other sources.)

Carol Welsh, 30, had no idea she would be caught in this bureaucratic limbo when she was diagnosed with a rare brain tumor known as adult ependymoma in 2000, a few weeks before finishing business school in Virginia. Welsh, an accomplished swimmer and Ivy League graduate, had been throwing up and suffering vertigo before doctors discovered the growth deep in her brain.

Covered by her student insurance, Welsh had brain surgery in May 2000 in Washington, D.C. Her recovery was difficult, and she spent seven weeks in the hospital regaining basic functions. It was then Welsh learned, with shock, that her student policy had a payment limit of \$50,000, which didn't even begin to cover the expense.

A persuasive negotiator, Welsh got her surgeon and other doctors to write off more than \$25,000 in fees, and got the hospital to give her a break on its charges. Then, facing the end of her student coverage, she looked for private insurance.

"I called around and I was told, 'You have a pre-existing condition such as cancer or a brain tumor; they

won't cover that condition for several years.' But that was the reason I needed insurance," Welsh said.

Her application for Social Security benefits was turned down because "I was able to walk without a cane and fix my own meals," Welsh said, adding that she didn't appeal the decision because "I hoped I was cured."

Unable to work because of lingering effects from the tumor and brain surgery, Welsh eventually lost the job offer that had been extended by a consulting company.

She concentrated on her recovery until April 2003, when a brain scan showed her tumor had come back. Her surgeon, who had moved to Long Island, N.Y., again was willing to operate at no charge and helped her negotiate cut-rate fees at a local hospital. Her second surgery took place in March 2004.

By this time, Welsh--often in pain, with frequent headaches and problems maintaining her balance--had applied for Social Security disability benefits again and was accepted with a retroactive eligibility date of July 1, 2003.

Under Social Security's rules, this meant another five months before cash benefits were authorized. It also meant that Welsh had to wait two years from the receipt of benefits--until December of this year--to receive Medicare coverage.

#### Asking for favors

Uninsured, Welsh has learned to ask for favors and get help wherever she can find it. A local hospital donated 33 radiation treatments and four rounds of chemotherapy after her second surgery. Family members found a clinical trial at the National Institutes of Health for which Welsh qualified; after enrolling, she has gotten free drugs and brain scans every two months.

But the tumor is growing again, and Welsh faces a new set of problems.

Her neurosurgeon has moved to Seattle, and the closest doctor with expertise in the risky deep-brain procedure is in Boston. There is no guarantee that he or his hospital will undertake the surgery for free, and Welsh's Medicare coverage won't kick in until December, which may be too late.

"With Carol, it isn't a matter of medical care being optional," said Elizabeth Welsh Lasko, her sister. "It's the difference between life and death."

In the meantime, Medicaid has turned down an application for help because Welsh kept some money in the bank as a "down payment" for another surgery.

The intent of Medicare's 24-month waiting period was to make sure only people with severe, long-lasting disabilities were covered, said Jim Verdier, a senior fellow at Mathematica Policy Research, a Washington-based policy group. The cost of adding millions of beneficiaries to Medicare also was a consideration.

But stories like Welsh's have prompted several members of Congress, including Sen. Jeff Bingaman (D-N.M.) and Rep. Gene Green (D-Texas), to introduce legislation that would phase out the waiting period over the next 10 years.

The legislation could cost nearly \$9 billion to implement, according to Verdier's estimates, and Congress is reluctant to add new expenses to Medicare while it is introducing a major new drug benefit whose

estimated cost exceeds \$720 billion over the next decade. So far, the bills are stalled in committee.

Welsh said that for now, her full-time job is finding a way to get the care she needs.

"What's amazing to me is I'm a Princeton graduate, a business school graduate, someone with a close supportive family, and I've totally fallen through the cracks in the system," she said. "What about people who don't have the advantages I have?"

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