

Dianna Oden, Mosier, Oregon



“Sometimes I feel like I’m 90 years old.”

If Dianna Oden went to a doctor every time she didn’t feel well, she’d be buried in debt. But Dianna, a 52-year-old divorced grandmother, harbors a deep fear of debt and won’t even apply for a credit card. “I must sound like a dinosaur, but I know that if I had a credit card, I’d be tempted to use it,” she says. “I know how hard money is to come by, so I don’t want to do that.”

Instead, Dianna, a \$6.50-an-hour waitress, sees a doctor only when she can afford to, which isn’t often, and takes the drug samples he gives her only every other day, so they’ll last longer. Because she suffers from a disorder called fibromyalgia, she’s almost always in pain.

Fibromyalgia is one of those invisible, poorly understood syndromes that leave their victims looking perfectly normal, but often wracked with pain. At the moment, there's no cure. Doctors aren't even sure of the cause, though the condition often follows a trauma of some sort.

Dianna's condition developed five years ago while she was recuperating from neck and shoulder injuries suffered when a recreational vehicle broad-sided her car. The injuries forced Dianna to miss work for a year. Her job didn't offer sick pay, so she lived on savings and disability payments from her auto insurance company, which also paid her medical bills. When the year ended, however, she was on her own. Because she had no income, Oregon provided health coverage through its medical assistance program. A small settlement from the other driver's insurance company, along with food from emergency food banks and fish gleaning organizations, enabled her to get through another year without working.

Three years ago, though still in pain, Dianna went back to work part-time as a waitress at a family restaurant in The Dalles, Oregon, a retirement community in the scenic Columbia River Valley, about 15 minutes from her home in the small town of Mosier. "I had to," she says. "I was out of money." Gradually, she worked herself back up to a 40-hour week. Although she was only paid minimum wage, her income became too high for her to continue to qualify for the Oregon Health Plan, Oregon's Medicaid program, and she lost her coverage.

Dianna's employer doesn't offer health insurance, so to continue being insured, she would have had to buy coverage privately. When she looked into the price of an individual policy, she says, she found that "it would have cost me \$189 a month for a nominal policy, which wouldn't have been nearly as good as the Oregon Health Plan. That's not a possibility for me."

In her last two-week pay period, Dianna brought home \$322, including tips. In 1999, she grossed \$14,400 and took home about \$8,400. "I basically live from paycheck to paycheck," she says. When asked if she has a savings account or a 401(k) plan, she simply laughs.

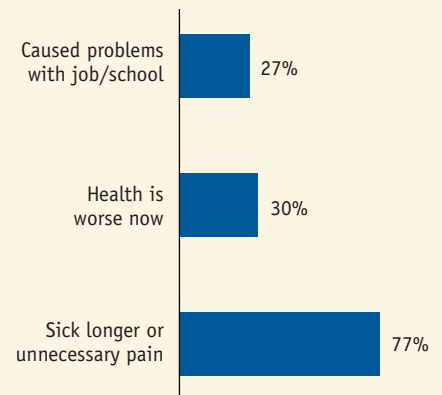
Dianna believes that her inability to pay for regular medical care delayed the diagnosis of her ailment, since after losing her Oregon Health Plan coverage, she was able to visit her doctor only intermittently. With little discretionary income to apply to the \$40 cost of an office visit, she went only when she was in a crisis, like "having diarrhea for four weeks straight, or headaches so bad that I was vomiting and I'd get these lights in my eyes, or leg cramps that woke me up at night." Because she came in with a different complaint each time, the doctor didn't see a pattern, and just treated the current symptoms.

Drugs that cost too much

Finally, about a year ago, Dianna made an appointment to talk about the pain that was keeping her from sleeping more than an hour or two at a time. When the doctor asked her what had brought her in that day, she didn't know where

Many of the Uninsured Suffer Serious Consequences from Inadequate Health Care

Percent of uninsured with unmet needs* reporting consequences

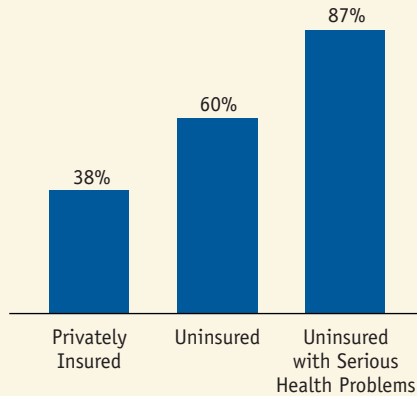


*The uninsured with unmet needs include those delaying or going without care from a doctor and/or going without medication.

Source: Kaiser Survey of Family Health Experiences, Round 3, 1997-1998.

Medications Are the Hardest to Obtain for the Uninsured with Serious Health Problems

Percent Not Getting or Having Difficulty Getting Medications



Source: Kaiser Survey of Family Health Experiences, Round 3, 1997–1998.

to start. “I broke down and started sobbing,” she says. “I told him, ‘If I tell you everything that’s wrong with me, you’ll think I’m a hypochondriac.’”

The doctor urged her to talk, and Dianna told him what her life was like. “I think he realized I’d been suppressing things, and he wasn’t getting the whole picture when I came in with just one specific complaint,” she says. The doctor did tests to rule out conditions such as lupus, and then told her it sounded as though she had a textbook case of fibromyalgia. She had all the characteristic tender points—the sides of her neck and breastbone, the tops of her shoulder blades, the outsides of her upper buttocks and hip joints, and the insides of her knees—as well as chronic inflammatory bowel disorder and disabling headaches. He prescribed anti-inflammatories and painkillers for her muscle and joint aches, and a sleeping pill to enable her to sleep through the night. But he warned her that there was no actual cure, and that she’d just have to try to control the symptoms.

Even now that Dianna knows what’s causing her chronic pain and stiffness, her lack of insurance means that she can’t afford to buy Celebrex®, the only drug that provides relief. “Celebrex® helps so much,” she says. “My doctor gives me samples whenever I go in, and it makes me feel wonderful. But I just simply can’t afford it.”

When Dianna gets the samples, she generally takes one pill every other day, instead of the recommended daily dose, in an attempt to stretch out the period of relief. “The most he ever gave me was a month’s supply, which was like getting a whole new lease on life,” she says. “I called him up and said, ‘They really work, and I want a prescription.’ But then when the pharmacist filled it, he told me it would cost \$149. I told him, ‘I can’t afford to buy them all,’ and he asked me, ‘How many can you afford?’ I said, ‘Six,’ so that’s what he gave me. I took it for six days straight, and it got me through a bad time.”

To try to get by without the expensive prescription drugs, Dianna starts every morning with a regimen of stretching exercises that help her muscles relax and her joints loosen up. Then, before she heads off to work in the afternoon, she takes over-the-counter painkillers and anti-inflammatory drugs “by the bottleful” to get her through her shift. As long as she doesn’t sit down, she can usually make it through her 3 to 11 p.m. shift without anyone noticing her discomfort. But not always. “I need to be able to carry three plates of food on my left arm, but there are some nights when I can’t, when I can just do two because it feels weak,” she says.

At the end of her shift, Dianna heads home, aching and exhausted. “It takes me 15 minutes to drive home, and after sitting down that long, it’s sometimes hard for me to even get myself into the house,” she says. “It’s like my whole body just seizes up, and I can’t move. Sometimes I feel like I’m 90 years old. There are times that I don’t think I can make it through another work day.”

Health care on the installment plan

Even though Dianna hasn't been buying the medication her doctor prescribed, the last year has been a bad year for health care expenses. Altogether, she's spent about \$1,000, more than 10% of her take-home pay. That includes the cost of two outpatient surgical procedures. In the first, a podiatrist removed the nail of one of her big toes because it was irritating a bone spur on the toe's tip, causing so much pain that she couldn't even bear to have a blanket touch it. That procedure cost \$290, plus several follow-up visits at \$40 each. Dianna paid part of the cost in advance, and then paid the rest off in installments. "If I had a good week in tips, I'd give him \$50, and if I had a bad week, I'd give him \$10," she says. "I was real up-front with him about my situation, and he was understanding." (The procedure he initially recommended—removal of the actual bone spur—would have cost even more, so Dianna chose a less expensive option.)

More recently, Dianna developed a cyst that required two visits to her gynecologist, at \$55 each. "The doctor wanted to send me to the hospital for the cyst, and when I heard the word, 'hospital,' I thought, 'bills,' and I asked him, 'What else can you do?'" she recalls. Instead, he put her on antibiotics and removed the cyst in his office.

Dianna's medical bills would be even higher if she were getting the regular physicals that most doctors recommend for someone her age. In the last 15 years, she's had only three Pap smears to test for cervical cancer, despite a history of uterine cancer that caused her to have a partial hysterectomy. "At \$55 a visit, I can't afford it," she says. She hasn't had a mammogram in four years, back when she was covered by the Oregon Health Plan. And she hasn't had her eyes examined since then either, even though she knows she needs a stronger prescription for her glasses. "I know my eyes are changing," she says. "I have to use a magnifying glass with my glasses to read the newspaper. But an exam costs \$95, and that doesn't even include new glasses."

Dianna has also had to put off seeing an arthritis specialist whom her primary care physician wanted her to consult. "When he brought it up, I told him I didn't think I could afford it," she says. "Then, while I was going through a really bad time, I felt desperate, and I told him I'd go in. He made the referral, and the specialist's office sent me the paperwork. It would have cost me \$300 for the first visit, which did not include any of the lab work he'd have to do. When I found that out, I just called up and said, 'I'm sorry, I can't keep this appointment.' It really upset me to have to cancel because I was hoping he'd tell me that I have something besides fibromyalgia, something that could be cured."



Although only minimum wage, Dianna Oden's income became too high for Oregon's Medicaid program.

Periodically, Dianna treats herself to a visit to a chiropractor, because having her spine manipulated makes her feel so much better. “I don’t see him very often, because it costs me \$40, but it really helps,” she says. “With my muscles being so tight, my spine gets out of line.” Knowing of her financial situation, the chiropractor agreed to a barter arrangement the last time she went in for an adjustment. In lieu of paying him, Dianna is making him a Victorian-style fringe lampshade, one of the crafts she became adept at while she was recuperating from her accident.

Planning for the future

With the promise of Medicare coverage still 13 years in the future, Dianna does a lot of thinking about how she’ll be able to meet her medical needs until then. “This fibromyalgia is not something I’m going to be able to get over, because there’s no cure,” she says. “And I worry about a major illness or injury. I’m not one who likes to dwell on these things, but I have to be honest about that. If I walked out into my yard and broke my leg, I’d have all these medical expenses, plus I wouldn’t be able to work. Or if I had a heart attack and had to go to the hospital, I’d lose my home because they’d put a lien on it.”

“Don’t get me wrong. I feel fortunate in a lot of ways. I own my car and my own home. I don’t know what I’d do if I had to pay rent.”

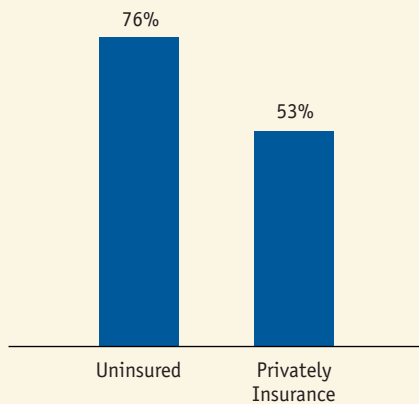
Dianna’s two grown children have families of their own, and she doesn’t ever want to become a burden to them. She recently put her bungalow on the market with the idea of investing the proceeds in a duplex. That would give her both a unit to live in and a unit she could rent for additional income, which might be enough to enable her to buy health insurance. Alternatively, she could reduce her hours at work to a level that enables her to qualify for the Oregon Health Plan. In Oregon, a single adult can earn up to 100% of the federal poverty threshold—\$8,350 in 2000—and be eligible for state-subsidized coverage, with a \$6 to \$28 a month premium charge.

But reducing her income by more than \$6,000 a year would leave Dianna struggling even harder to pay her bills than she is now. And the whole idea goes against her work ethic.

“I’ve worked for 35 years,” she says. “It’s what I do. I really want to work, and I need every dollar I make. If it means not going to the doctor when I’m sick, then I guess that’s the way it has to be.”

Among Those with Serious Health Problems, the Uninsured Are More Likely to Go without or Have Difficulty Getting Care From a Physician Specialist

Percent with Serious Health Problems Reporting Barriers to Specialist Care



Source: Kaiser Survey of Family Health Experiences, Round 3, 1997–1998.