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AT THE EDGE:

NEAR-
ELDERLY
AMERICANS
TALK
ABOUT
HEALTH
INSURANCE

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THE KAISER COMMISSION ON
Medicaid and the Uninsured

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The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

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THE KAISER COMMISSION ON
Medicaid and the Uninsured



AT THE EDGE:

NEAR-ELDERLY AMERICANS TALK ABOUT HEALTH INSURANCE

As the baby boom generation ages and more adults move into their fifties and sixties, the nation as a whole has become more aware of the challenges this life-stage brings to what are now 26 million “near elderly.” Those who are approaching retirement are not all comfortably prepared for it. About a third of the near elderly (ages 55–64) have already begun to change their work lives. While some are retiring early because they can afford to do so (19%), others are out of the workforce because of illness or disability (14%). But the majority are still working and despite their years, many are not financially stable. More than a fifth of the near elderly are in low-income families, with incomes less than 200% of the federal poverty level.*

Regardless of their employment situations, the majority of the near elderly are living with one or more chronic conditions. Access to health care, and the means to pay for it, become even more critical issues as the kind of health needs that go untreated at this age are often more costly—not only are the medical interventions expensive, but the costs of appropriately managing a chronic condition are by definition, never-ending. When necessary care is postponed or forgone altogether, health problems can grow into life-long disabilities and even shorten lives.

In our employer-based system of health insurance, it is perhaps ironic that the near elderly who are still working have the most difficulty accessing health insurance. Early retirees have access to health

coverage through their past employers and are the least likely to be uninsured. In contrast, only a third of the near elderly who are ill or disabled have employer-sponsored insurance, but half have either Medicaid or Medicare coverage because of their disabilities and low incomes. The near elderly who remain working are the most likely to be uninsured because they do not qualify for public programs (although many are from low-income working families) and they are less likely to have job-based coverage than their healthier, retired peers.

In a 2003 study, Susan Sered, an anthropologist, and Rushika Fernandopulle, a physician specializing in health policy, went beyond the statistics in order to understand why so many Americans are falling through the cracks in the health care system and what it means to try to scrape by without consistent access to medical care.

Traveling to Idaho, Illinois, Mississippi, Texas, and Massachusetts, Sered and Fernandopulle conducted in-depth interviews with more than 120 uninsured men and women as well as several dozen health care providers and administrators. Most of this research will be published as *Uninsured: Life and Death in the Land of Opportunity* in January 2005 by University of California Press.

The following narratives were prepared separately for the Kaiser Commission on Medicaid and the Uninsured, to specifically focus on the experiences of those who are both near elderly and uninsured. They

* Holahan, J. “Health Insurance Coverage of the Near Elderly.” Report for the Kaiser Commission on Medicaid and the Uninsured, July 2004.

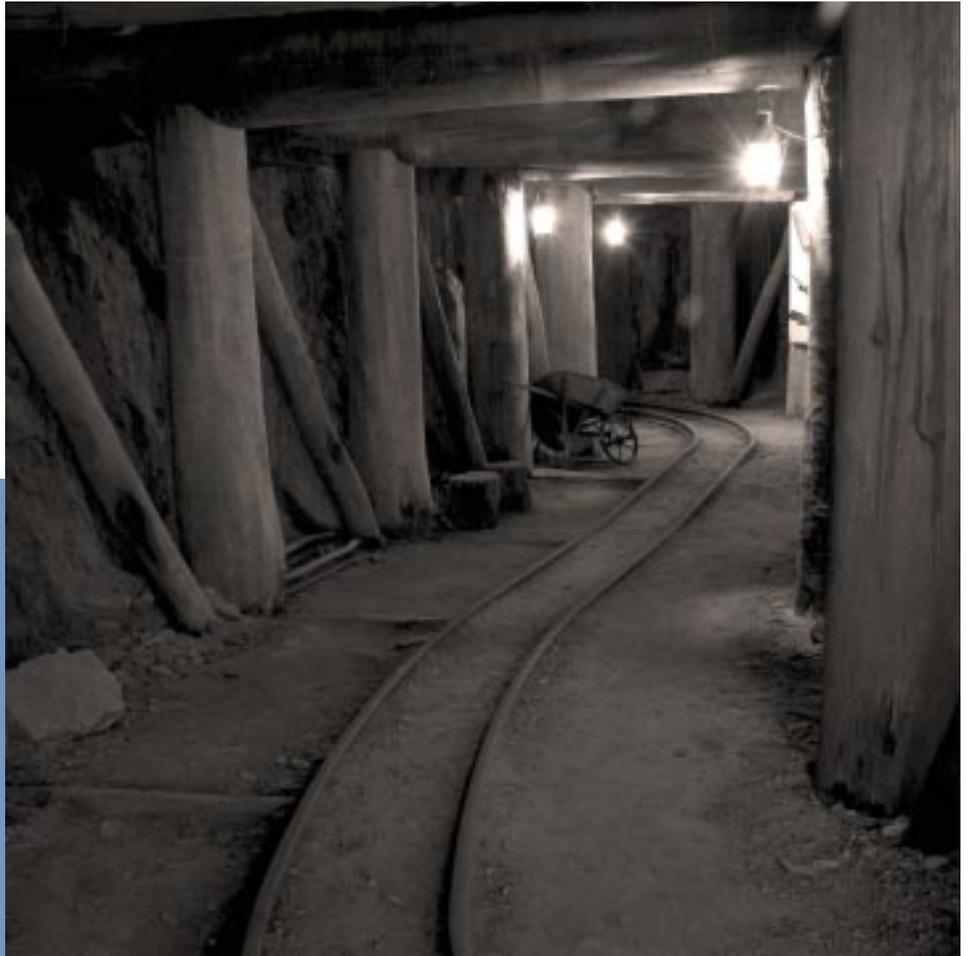
profile six individuals who are struggling to keep their bodies, homes, and lives together during the years preceding Medicare eligibility. Their stories highlight a number of problems faced by large numbers of men and women in their fifties and early sixties:

- ❖ the onset of chronic conditions,
- ❖ the cumulative physical toll of a lifetime of hard work,
- ❖ the slower recovery from accidents, injuries, and illness,
- ❖ the double burden of working and caring for an elderly, disabled, or ill spouse,
- ❖ finding that medical providers may not take the complaints of older people, and especially older women, seriously,

- ❖ no longer having the right skills for the kinds of jobs that come with health benefits (for example, computer skills)
- ❖ the loss of a late spouse's income or benefits, and the loss of health insurance when a spouse (typically a husband) retires and shifts to Medicare, while the other spouse (typically a wife) is too young for Medicare.

These people's lives inform us in a way hard facts and data analysis cannot. Their expression of life's challenges, and how they manage to cope, fully fleshes out our understanding of this health and social policy issue. ✖

GRACE



Grace has decided that it's more important to make small payments to the hospital than to buy food.

GRACE: PAINFULLY THIN

Grace's air of elegance—understated earrings, tasteful make-up, well-groomed hair, and stylish scarf—almost disguises the fact that at age 64 her monthly income barely covers her utilities, health insurance premiums, and token payments on medical bills. Her painfully thin frame does hint at the truth: She cannot afford to buy food, and is dependent upon sporadic gifts from friends and neighbors in order to eat.

Grace's late husband had worked for Sunshine Mine in northern Idaho. As a hoistman, his job was to take the men down to their levels inside the mine. The room he worked in was at 5000 feet underground. While the work itself was not terribly dangerous under regular conditions, if there had been an accident in the mine he would have been the last one out. The hard work and risk of accident were tolerable, in their eyes, because while they were never well to do, he did have a secure job with good benefits.

When he passed away from heart disease at the age of 69, Grace was 59 years old, and was not eligible to receive his pension or Social Security. Still, they always lived within their means: they owned the 1977 trailer in which she still lives, and they saved a bit of money for their retirement. With that small store of security, plus the money Grace earned as a waitress at a local Chinese restaurant, she assumed that she would be able to scrape by until she turned 65 and would be eligible for Medicare and Social Security.

... when the mine filed bankruptcy, eliminating the insurance programs for retired employees and their spouses.

Her modest savings proved ephemeral however, when the mine filed bankruptcy, eliminating the insurance programs for retired employees and their spouses. Shortly thereafter, Grace suffered two heart attacks. Without the health plan that the mine provided, Grace



learned that because of her pre-existing condition she had few options for health insurance. Blue Cross Blue Shield, her insurance company of 40 years, was willing to keep her on in a private, non-group plan, but her cost sharing (she calls it her “co-pay”) soared to 20% for each treatment or office visit. Even if she were healthy enough to continue working at the restaurant, she explains, it would not help with insurance—at the restaurant they cut the waitresses’ hours off at slightly less than 40 hours a week of work and do not provide health insurance.

With one year to go until Medicare kicks in, Grace lives on the \$868 per month ... out of which she pays \$440 each month for her insurance premium.

As a result of the heart attacks and inadequate insurance protection, she has accumulated \$57,000 of hospital debt, plus thousands of dollars of debt to various doctors and clinics: \$500 for the cardiologist, \$581 for the medical center in the closest large city, \$135 for radiology services, etc.

Afraid to amass more debt, Grace often skips her regular appointments with the cardiologist because they are too expensive. Last year she was supposed to have had a stress test, but because the hospital insisted that she pay up front, she skipped the test. With one year to go until Medicare kicks in, Grace lives on the \$868 per month (a combination of survivor benefits that she now qualifies for and a small pension) out of which she pays \$440 each month for her insurance premium. She takes seven different medications that—if she were to purchase them consistently—would cost \$350 each month out of pocket. Doctors do give her some free samples, but she often is

compelled to skip doses when she cannot afford to purchase refills. Because of her history of heart attacks, it is imperative for her to take her medications regularly and consistently. By skipping doses, she is endangering her health both in the short term and in the long term.

In any case, once she pays her health insurance, medical bills, and utilities (which come to approximately \$200 each month), she is left with less than \$100 for food, her prescription drugs, and other expenses. While Grace has always been slim, at this point her frame is close to emaciated and she doubles her belt around her waist to make her clothes fit properly.

Grace has always paid her own way and has trouble accepting that she can't continue to do so. A friendly and warm woman, she has close friends who try to help her out. However, many of them are in the same boat that she is, widowed or married to older men who have health problems or who are retired.

Like many near elderly, Grace needs optical and dental care that she cannot afford. Because her dentures need alignment, she has trouble chewing and sometimes is embarrassed to open her mouth to speak. In the wake of two eye surgeries, she needs trifocals. Although terrified of credit card debt, Grace eventually broke down and charged her glasses on a Sears credit card that she cannot pay off.

Grace keeps her monthly budget, neatly typed up, folded inside of her wallet, a reminder that the purchase of even a bag of groceries will put her further in debt than she ever had dreamed possible after a lifetime of hard work. Up against the wall, Grace has decided that it's more important to make small payments to the hospital than to buy food—"If you don't send them money every month, a certain

amount, they usually want a certain amount, they turn you in to a credit bureau."

In many ways, Grace is lucky. Her daughter tries to help her out whenever she can, but she too is struggling to get by on a minimum wage salary and without health insurance for her husband and children. Her son-in-law, who was laid off when the mill he worked at went out of business, has been fixing the roof of her trailer. Now over a quarter of a century old, her home is no longer a very suitable domicile for a woman in her sixties. Her son who lives in Dallas does send her a bit of money every now and then, but with money so tight, Grace has not yet met her Texas granddaughter.

Grace finds some comfort in her church. Though raised Catholic, she now attends a Pentecostal church where an active healing ministry is a great attraction. Grace speaks with enthusiasm of how prayer at the church healed her of shingles. However, she is not comfortable telling members of the church how difficult her financial situation is, and in any case, many members of the church have been laid off or lost insurance when mines, mills, or logging shut down in northern Idaho.

By the time she is eligible for Medicare and Social Security next year, it is likely that both her health and her finances will have deteriorated even more. Worry about money and health is chipping away at Grace's sense of dignity and independence. This is hardly the transition to old age that she and her husband envisioned during the years in which he worked deep down underground in return for secure benefits and a secure future. ✕

LEE ANN



She also was on a charity program in a neighboring town for a while ... but her “turn” ended.

LEE ANN'S STORY: CYCLES OF POVERTY AND ILLNESS



Scattered right up alongside the modern highway that transverses the Delta, the jumble of furniture, kids, dogs, an elderly man in a ramshackle wheelchair, confederate flags, shanties, and a broken sign proclaiming “YARD SALE” have the timeless look of rural poverty. Lee Ann’s Mississippi household could in fact serve as a poster board for rural poverty. Time, people, and objects seem to move slowly here. A few weepy-limbed trees stand in the yard, a couple of rusting automobile shells are scattered around the property, and two dilapidated trailers serve as extra living space and storage sheds. All seem equally neglected; all radiate the same air of depression.

Lee Ann is a gray-haired white woman in her early sixties. While her family has always been poor, they have owned land in the Delta for as long as she remembers. Her husband is a mechanic, 64 years old, but retired early because of a shoulder injury on his job. He has had surgery three times and now he draws Social Security Disability Insurance (SSDI), which makes him, but not her, eligible for Medicare.

Lee Ann has worked in retail for most of her life, earning between \$3.25 and \$5.00 per hour. No employer has ever offered her health insurance.

Lee Ann and her husband live on a fixed income of \$600/month that Lee Ann tries to augment through the yard sales which bring in perhaps \$25/week. Most days they sit at the sale for 6 or 8 hours, though custom is sparse in the impoverished Delta. Their home is a trailer a ways up the highway from the yard sale site. Their expenses are minimal, they do not even have a telephone, and at this point in their lives, Lee Ann and her husband sometimes have trouble affording food.

A few years ago Lee Ann began to suffer from heart trouble and seizures, and she is now no longer able to work. She does not receive SSDI. “No, they won’t give it to me. I’ve tried for four years and they will not give it to me. They turned me down every time.” Lee Ann explains that the main artery of her heart is 50% blocked, which puts her at significant risk of having a potentially fatal sudden heart attack.

Lee Ann had experienced these seizures for several months before going to the doctor.

But that is not what prevents her from working; the real problem is the seizures. “You never know when they’re going to happen. And if I go to a regular job and I have one and I don’t tell them, then they’re going to fire me. If I have one and they know about it, I’m still probably going to get fired.” The doctors don’t know what causes the seizures. “They don’t know. They really don’t know. I don’t pass out, I just go in a blank stare and I just smell this god-awful odor. And when it’s over with I don’t know anything that’s happened. When it is going on I’m just like sitting there.” This lasts for about three to five minutes, and then she sleeps for several hours afterwards.

Lee Ann had experienced these seizures for several months before going to the doctor. “I couldn’t afford it. If you can’t afford to go, you don’t go. Just like this morning I got up coughing up blood and green stuff. And I can’t go to the doctor, I don’t have

Continued on next page

insurance.”* Lee Ann knows how expensive medical care is: They are still receiving bills, which they cannot possibly pay, for the MRI and other tests that were done when she first reported the seizures.

The doctor put her on Tegretol, a medication to help prevent recurrent seizures, and told her that she would probably have to take it for the rest of her life. However, Lee Ann can't afford to purchase the medicine, so “I don't take anything. I just go with it day by day.” Lee Ann was also told to take heart medicine. “I couldn't take everything. They had me on heart medicine, aspirins and, I don't know, whatever I'm suppose to be taking.” In addition to these problems, Lee Ann suffers from migraines, which sometimes become so unbearable that she goes to the emergency room to get a shot that gives her relief from the pain. Each emergency room visit costs \$160. All in all, she estimates that of the \$600 monthly income she and her husband share, they spend at least \$150/month on medicines and doctors.

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Lee Ann has never had her eyes checked, but she knows that her vision has become poor because she has trouble seeing the nickels and dimes that she needs to handle at the yard sale. She purchased reading glasses from Wal-Mart and they help somewhat. Still, she is afraid that she is going blind and is frustrated that she can no longer crochet, something she does both for pleasure and in order to sell the afghans she makes. She has no teeth—her top teeth have been replaced with dentures, but on the bottom she has nothing. This prevents her from eating fruit or other hard foods.

Lee Ann has tried to arrange free care for her health problems. At the hospital she has been put on a program that covers her hospital bills, but she still is expected to pay the doctors who treat her there. She also was on a charity program in a neighboring town for a while. This program helped with the doctor bills, but due to the large number of people needing the service, her “turn” ended and she is now waiting to be re-enrolled. She estimates that she owes close to \$5000 “over in Jackson” from the catheterization that found the blockage in her heart. But more troubling than that is the \$38 she owes to a doctor in nearby Greenwood. This doctor, through a collection agency, is threatening to take her to court. Lee Ann finds this ridiculous: “Now \$38. I mean, he could pay that out of his pocket.”

Lee Ann comes from a long line of rural story-tellers. She is skilled at relating her and her family's personal life experiences with flair and drama. Like most good story-tellers, she doesn't need to connect the dots for her listeners: Couched in personal anecdotes is a wider tale of how a lifetime of poverty is a prologue to poor health, and how the people who most need good health care may be least likely to receive it. Lee Ann is not scared of much and she has great faith in her ability to make do. Yet when she talks about the possibility that she will have a seizure or her husband will have a heart attack, and they won't even have a phone to call an ambulance, the vulnerability lurking in her eyes gives lie to the bravado in her voice. ❧

*Standard medical practice dictates that when a person experiences a new onset of seizures, it is critical to do a number of tests including a head MRI to figure out if there is a reversible or dangerous cause for them, some of which can be very serious such as a brain tumor or cranial aneurysm. A delay such as Lee Ann's could have been fatal.

CAROL



“I never thought that at my age I would be in my situation.”



CAROL: BAD LUCK, MEDICAL BILLS, AND BANKRUPTCY

A trim and attractive woman in her early sixties, Carol wears her hair in a perky 1960-style flip, and has a penchant for open-toed shoes that flatter her slim feet and reveal brightly polished toenails. Hidden beneath the sandal straps, however, are discolored bruises, swelling, and deformations at the base of her toes.

This is her story—a story that may at first read like a tale of bad luck that left scars on her body, her credit, and her hopes for retirement. But, as Carol has come to learn—and her growing activism with a community health advocacy organization attests to this lesson, her story really is not so much about luck. Rather, it’s about the frailty of human bodies, especially as they grow older, the vulnerability of individuals caught between large and powerful institutions, and the vagaries of luck and fortune.

Here is her story.

“I have always been an active woman. I didn’t even have a doctor, I didn’t have a need of a doctor for the last 25 years. I was a typesetter for about nine years. I think we had insurance there. I never had to use it. I didn’t go to the doctor at all. If nothing was bothering me, I’m not going to bother it. Two years ago I was just working to make extra money, which was my goal at that time, being 60. My car was paid for. I was virtually debt-free, had money in the bank, and excellent credit. I was just going to work what’s called ‘extra help’ with the University of Illinois [Champaign-Urbana]. It’s like temping. You work for six months and you take a month off. And I was set with money in the bank to take that month off every six months. I thought that would be perfect until I did something else. The work at the university consists of temporary

“And then I was in two car accidents in a month.”

assignments and most of the time, because I am good at what I do, I have back-to-back assignments. But you can’t work more than six months; you have to take a month off. No benefits, no health, no vacation, no anything, but I figured that month off would be something.

“And then I was in two car accidents in a month. Both were the other person’s fault. The first accident, I was hit by a car while out walking, was just soft tissue and the other driver’s insurance company settled, and I got the settlement and everything was fine.

“In the meantime the second accident happened. The driver just pulled out in front of my car.

“The second accident damaged my foot. When I got out of the car, I knew something was wrong with my foot and I thought I’d sprained my ankle. Well, evidently the doctor did, too, and he just treated me like an old woman complaining.

“When I was in the Emergency Room, they did an x-ray, but never did detect that the toe was broken. My foot was actually hyper-extended, and I just feel they didn’t have the time or take the time to really think about what happened.

“I kept complaining to the doctors about different areas of my foot, and they just kept ignoring me. So by the time, in July six months later, they finally sent me to a podiatrist, they found that this toe was broken and it was separated, and the bone looked like it might be dying. I was put into a cast and I had to sit with my foot up.

“I had to go back to the podiatrist and I kept complaining to her, too, that all this was always swollen and hurt me up here. So finally, I had to have x-rays or CAT scans or I don’t know what all I’ve been through. And they found a dark mass across my foot. Then they realized there was bruising and bleeding and torn tendons and ligaments and the whole foot was damaged. In the meantime, I was off of work. I had to keep the foot extended because I wanted the toe to heal.

“I wasn’t even a month in the cast and I called the doctor and told him that my toe was laying on my other toe. So she took the cast off and put me in a walking cast. I couldn’t walk in that.

“Then, on July 19th, I fell on my crutches, broke my ribs, and then they found pneumonia.

“The auto insurance company was refusing to pay. And then, of course, not having health insurance, the medical bills were in my name. There was no way I could pay them, because I was living on cash advances from my credit card. It was pretty scary and I couldn’t do anything.

“Well, then they diagnosed RSD, which I had never heard of either and it’s some kind of a nerve problem. It’s chronic.* They sent me to a pain doctor. He put me on [a very strong medication]. I’m a woman that didn’t ever take any medicine. I don’t take any pills. I hardly even had aspirin in my house. I just didn’t need anything.

“I was very healthy and very physical and very active before the accident, but why didn’t they think of

how much medication they were giving me? I also had ibuprofen with codeine. And at one time, I was taking 24 milligrams a day. But they don’t think about those things for you as a person. You know? And that’s, so I had a bizarre reaction. It started around Thanksgiving, and I was almost bedridden with that. It attacked everything in my body. I guess

it was the strong medication or the combination of all of the medication. I have a whole bag of pill jars that I had. And you have to take them when you’re in a situation like this because if

you don’t, then when it comes around to the insurance settlement, they say that you don’t follow through, and you’re detrimental to your own health, and it’s your fault.

“So I had a bizarre reaction, which laid me up again. I went to physical therapy but I had to stop that because everything hurt. My whole body. It affected my hair, my eyes, my arms. It seemed to me when I was on crutches, it affected my elbows and my wrists. Couldn’t even pull up my own pants. Couldn’t comb my hair. I couldn’t shower myself. Thank God my daughter lived with me at that time, so she stayed with me and took care of me. And they finally sent me to water therapy. In the meantime, the bills are on me, the credit card bills on me.

“Anyway, I was off work for a whole year, back and forth.

“You know, it’s all confusing because I have so many accidents, and paper work and everything at the same time. It was terrible.

“I had to have a lawyer because I couldn’t work, and because of the dynamics of the accident and the after-effects of it.

“But you can’t work more than six months; you have to take a month off. No benefits, no health, no vacation, no anything ...”

* Reflex sympathetic dystrophy (RSD), also known as complex regional pain syndrome (CRPS), is a chronic progressive neurological condition that affects skin, muscles, joints, and bones. The syndrome usually develops in an injured limb, such as a broken leg.

“I wasn’t released to go back to work until July. It was about a year after the accident that I was released to go back to work. But the summer at the university is not as busy, so I couldn’t pick up a steady enough assignment till about February and I couldn’t keep up with the credit card payments mainly.

“I was trying to pay the credit card bills and I couldn’t do that. I was making money and borrowing money in order to make payments just to stay afloat. So I filed bankruptcy in February. And I included all my medical bills and everything in the bankruptcy.

“When I went for an ultrasound they told me that I had to pay more because I don’t have insurance.”

“So now, I’m to the point where I have to go back to work and I went to see the foot doctor in November because I needed a final report. You know, something saying I’d been released, there was a final report now, so that we can get on with this case. When I saw the doctor she told me I had to go and have an ultrasound made because I have a neuroma under the toe. I’ll have surgery for that later. It seems it’s worsened instead of getting better. And then I had to go to the pain clinic, you know, to find out if I did indeed still have the RSD for the insurance company benefit.

“The ultrasound was like \$426 and the doctor was \$135, and they were going to send me to collection for that \$135. So here’s these bills against me again. I can’t and I don’t want to make payments. This was not my fault. Why do I have to go without eating and go without my necessities and everything else just so I can pay these bills?

“The insurance company never paid anything. And it’s got a lot to do with maybe even my lawyer, not being a very good lawyer, but I mean, who are good lawyers? I don’t understand why they haven’t paid either, why they haven’t paid all along, because obviously it’s the

driver’s fault. He got the ticket. Why didn’t they at least pay my medical bills? But they didn’t. They didn’t. So, those went into my bankruptcy.

“The other driver’s insurance company will eventually pay the bills. Then I’m going to have to turn around and have the bankruptcy reversed to get it out of my name. In the meantime it’s blackened me. I live near poverty.

“And you know the insurance company is going to try to beat me out of everything, my wages and all of it. They said my health problems are not automobile-accident related. It’s like, yes it is. I would not have been on crutches had it not been. So I don’t know how it’s all going to come out. I’m really quite concerned.

“It’s a game. This is a big game. They just stall you off and stall you off until you’re so destitute that you’ll take just about anything they’ve got to offer. Before this happened, I wasn’t involved with doctors. I didn’t need to so I had no idea this kind of stuff was going on.

“It’s just gouging the part-timers. It’s like they’re trying to get money from the little people who are not making as much money for whatever reason. When I went for an ultrasound they told me that I had to pay more because I don’t have insurance. It doesn’t make sense. Why they would charge me more for my ultrasound when I don’t have insurance? So obviously, if you don’t have insurance, you don’t have a lot of money, you know!

“I never thought that at my age I would be in my situation. I am doing yard work for an elderly couple so that I can buy food. I have a home, and that’s good, but sometimes I’m out there working and I’m kind of resentful because it’s hot, hard work sometimes. You think it would be more fair in this world, and it’s just not so.” ❖

HAZEL



If she can't get the treatment she needs, she won't be able to work and will not be able to provide for and look after her husband, Don.



HAZEL: WHO CARES FOR THE CAREGIVER?

Hazel's struggle to get the health care that she and her ailing husband need is a story of personal sacrifice, community dependence, and trying to stretch the value of a dollar.

In the mid-1990s Hazel and Don moved to Idaho from Spokane, Washington in order to be closer to their grandchildren and their son Benny.

In Washington, life had been good. Between Hazel and Don they were making more than \$70,000 a year. But those good days ended when Benny developed an alcohol and substance abuse problem, and not long thereafter, Don fell into a deep state of depression and psychosis causing him to lose his relatively well-paying job as a logging truck driver. While in substance rehabilitation, Benny "found the Lord," entered into the ministry, and moved to Coeur D'Alene to establish his now growing family. Hazel was left alone with her husband whose acute fears of heights and of trucks grew increasingly worse, making it impossible for him to climb the trees or drive the logging truck. By age 48, Don stopped working altogether. Today, Don is 63, and has been suicidal and home-bound ever since.

Hazel recalls, "We let our car go back, we sold our home before we lost it. Then we just used the money from the other stuff that we sold to live on, until it ran out. And then you learn to be humble very quickly."

Five years after Don stopped working he was granted Social Security Disability Insurance (SSDI) coverage, and for about 7 years, he received good psychiatric and other clinical services. They were able to pay on a sliding fee scale at \$5.00 per visit for his psychiatrist and therapist, and in Washington State the in-patient

psychiatric facilities served as a reasonable back-up during the times in which Don was too ill for Hazel to care for him at home. This allowed Hazel to cover the rest of their living expenses on her single limited income as a telemarketer. Though Hazel had worked at other jobs in the past, telemarketing turned out to be her best option. Despite the poor pay and lack of health insurance, it allowed her to be home with her husband during the day. Because of his history of suicide attempts, she felt that he needed to be supervised most of the time.

Don and Hazel have incurred bills of close to \$10,000 for services and medication that were not covered by his Medicare, and have no means of paying them.

But Hazel felt far from her family and so she and Don sold their home in Spokane, and bought and moved into a home in Coeur D'Alene. Ever since the move, good and affordable psychiatric care for Don has been difficult to find. In addition, not long after their arrival in Idaho, Don began to experience heart problems and needed open-heart surgery with a hospital stay of 32 days. From this, Don and Hazel have incurred bills of close to \$10,000 for services and medication that were not covered by his Medicare, and have no means of paying them.

Hazel has her own health worries as well. In addition to the stress of looking after her husband, she finds that two decades of speaking on the telephone for up

to ten hours a day has taken a toll on her throat, head, and shoulders. It was only in the past two years that she has been able to afford to purchase a headset, and the cumulative neck pain from holding the phone to her ear for hours a day endures. In addition to being physically stressful, the job is emotionally stressful. “People are very rude” Hazel says. They hang up on her, curse at her, and even yell at her to go get a real job. It’s this last insult that has driven her to answer back, saying, “Well, I could sit and then could get on welfare and then you could pay for me.”

Even more troubling to Hazel is her desperate need of hip replacement surgery and her recent diagnosis as pre-diabetic.

Because they live on Native American tribal lands, Hazel and Don have access to free primary care at the local clinic (even though they are not Native Americans) where they are able to receive check-ups and see a doctor who writes their prescriptions. The rub is that they cannot afford to fill the prescriptions for all of the medicine they need, nor can they afford the medical procedures that are necessary to get them on the road to better health. The doctors have repeatedly told Hazel that she must have the hip replacement surgery or she will end up seriously disabled, and they have prescribed pain medication in the meantime, but there simply is no way for her to pay for the surgery. Often enough she can’t even afford the pain pills.

Both Hazel and Don have dietary concerns. Don suffers from high blood pressure and Hazel from low blood pressure and borderline diabetes. As a result, they must plan their meals carefully. Their conditions call for increased consumption of fresh fruits and vegetables, but these items are too expensive for Hazel’s budget. For the most part, they are dependent upon food from local food banks and from the federal commodities program available to people living on reservation land. While these programs are helpful, they primarily distribute carbohydrates, canned food, and items that are high in sodium, sugars, and fats.

Hazel has given thought to how to manage their situation. One possibility is to travel the three hours north to Calgary, Alberta in Canada to have their prescriptions filled for much less money than if they were to have them filled in Coeur D’Alene. But for Hazel the road north is a scary and expensive route. She does not have the money for the gas it would take for the trip, nor can she leave her husband behind given his history of suicide attempts.

A second possibility is to declare bankruptcy. But Hazel does not believe in declaring bankruptcy: “I just don’t like to feel like I have been cheating people [by not paying the bills covered in the bankruptcy]” she claims. Nevertheless, the reality of it being her only way out of the deep medical debt she and Don have incurred is becoming increasingly clear.

The one thing that brings Hazel solace is her church-life. Unlike the Idaho health care system, which Hazel has found far less accessible than Washington’s services, the people she has met through her Idaho church are friendly and supportive. Members of her church community have helped out in various ways, including with home maintenance tasks that are too heavy for Hazel and Don to manage. Hazel explains, “They are going to till the garden and I have some flower beds that I just can’t get down and do it, so they are going to work on the flower beds and some are going to wash the windows.” Additionally, every once in a while, church members let her know that they feel for her, quietly placing \$10 or \$20 in her hand during a handshake, and thus showing her that despite their own struggles, they see how hard she is trying to make it all work. The warmth and help of the Church community is a life rope, but unfortunately that rope is all too thin. Most members of the community are barely scraping by themselves, and an occasional \$10 bill will not pay for Hazel’s hip replacement or Don’s psychiatric treatment.

...two decades of speaking on the telephone for up to ten hours a day has taken a toll on her throat, head, and shoulders.

The doctors have repeatedly told Hazel that she must have the hip replacement surgery or she will end up seriously disabled ... but there simply is no way for her to pay for the surgery.

Like many near elderly Hazel has health problems that are growing progressively more debilitating. As time goes on, she is approaching a situation in which she will be unable to work. Although her job as a telemarketer offers her the flexibility of working from home, there are no job opportunities for her that will offer health insurance coverage, thus she sees no way to avert what increasingly looks like an inevitable health disaster. Hazel is also the primary caregiver for

a very ill spouse. She does not worry only about herself. If she can't get the treatment she needs, she won't be able to work and will not be able to provide for and look after her husband, Don.

While it is true that in a few years Hazel will have Medicare coverage, one senses that by then it may be too late to undo the damage that her current ailments are causing her today. Hazel is keenly aware of this and believes that changes must be made at the governmental level. "The government has to help people out," she says driving home the point that despite her and Don's efforts to work towards their dream of a good life, the reciprocal effects of health problems and limited employment options are forcing them into a life of pain, hand-outs from friends, and bankruptcy. ❖

DEBORAH



“I wasn’t making a lot of money and I didn’t have any to pay the hospital. So they took me to court ...”



DEBORAH: A MODERN DAY TRAGEDY

They say that disasters come in threes. Deborah would have been happy if her cluster of disasters had remained at that number. Over the past five years Deborah has lost her mother, her father, her boyfriend, her dog, her house, her car, her job, and her health.

Deborah, 59 years old, grew up in a middle class Jewish family in a small town on the outskirts of Boston. Her father was an engineer for a large military equipment company, and though he did not have a college education, he was smart enough to make it in a profession where most of the competition has university degrees. Deborah recalls that her family always had health insurance, and that whenever they were sick they went to the family doctor without concern.

After a year or so in college, Deborah realized that she would be better suited to office work. Throughout parts of her twenties and thirties she worked as a secretary at a law firm, earning a reasonable salary and enjoying good benefits, including health insurance. Never having married, she continued to live with her parents, contributing to the household income but relying on her mother to pay the bills and manage the house.

When she was in her mid-forties, she and her boyfriend, a bus driver, decided to start their own courier business. As Deborah explains it, she and her boyfriend did not own the business, nor were they employees of a larger company. Rather, “We were what’s called independent owner/operators, which means we’re not true employees. They don’t have to pay us benefits. We pay our own expenses but we get paid for the job according to the mileage. They dispatch the work but we pay for gas, tolls, repairs, car insurance, and car payment. We would gross about \$500 a week.”

It was about eight years ago that Deborah’s dominos began to fall. First, her father was diagnosed with colon cancer, and she took a year and a half off of work to tend to her father.

“We were what’s called independent owner/operators, which means we’re not true employees. They don’t have to pay us benefits.”

Then, her boyfriend suffered a sudden aneurysm that “ruptured in his brain. They operated on him and he lost his memory and he ended up committing suicide by jumping off the hospital roof. Oh, I don’t know how he had the presence of mind to even think of that but he did. He just couldn’t bear it any more. Plus he had no insurance either and they were giving him the runaround. They were keeping him at the hospital. We were trying to get him into a rehabilitation place but nobody would take him because he had no insurance and they weren’t doing much for him at the hospital. And I went and told his doctor about a week before he died that he was very depressed and he said, ‘No he isn’t.’ And I said, ‘I can tell he is, he really is.’ Once you’ve been with somebody for a long time you get to know them. His doctor says to me, ‘You don’t want to be with him.’ He says, ‘You’re not the kind of person to be with him.’ ‘Huh?’ He said, ‘He’ll never be able to do anything.’ It sounded like the doctor didn’t want to rehabilitate him at all. He was 55 years old when he died.”

After her boyfriend's death, Deborah tried to keep the business going, but about four years ago, while doing courier work she lifted some heavy boxes and injured the sciatic nerve in her leg. "In my right leg and I couldn't walk. They had to take me in an ambulance to the hospital and that's when I found out I had the sciatic nerve damage and I was using a walker for about five months."

For that visit to the hospital, she still owes \$1,600. "I wasn't making a lot of money and I didn't have any to pay the hospital. So they took me to court and they've got a judgment, \$1,600 against me. And I don't understand where the \$1,600 came in because all I did was sit in an emergency room."

We ask her whether she applied to the hospital's charity care program.

"Yes, but they told me I made too much money. I made \$100 more than what the limit was. The limit was \$7,000 annually, I think."

Now Deborah feels that she cannot go back to that hospital, and she resents that her credit has been muddied by the hospital bill.

Deborah did not receive worker's compensation (technically she was not an employee). She applied for Social Security Disability, but received a letter from Social Security saying that she had not worked long enough to qualify for disability. "I don't understand. I had a lot of money into Social Security from when I was working earlier at the law office. But they said they don't count that. I don't understand why."

The next blow was her mother's death, which came suddenly as a result of pancreatic disease. Deborah had been very close to her mother. And while still in shock from her death, she found that she couldn't keep the house anymore. "After my father died, we had to take out a mortgage on the house because things started to go wrong with it. It was an older house. And I couldn't afford the mortgage myself." Though the house sold for \$200,000, once Deborah paid off the mortgage, property taxes, inheritance

taxes, and other bills, she was left with a sum of money far too meager for a down payment on a smaller home.

The next hit that Deborah took was her dog's illness and death. Especially after the death of her boyfriend, the dog had become Deborah's beloved companion. Together, they would go for the long walks that Deborah needs to try to keep her weight under control. Unfortunately, the dog developed arthritis in his back paws, and then was diagnosed with cancer. "I had to put him down last year. I still owe the vet money for that, too."

Despite the loss of her boyfriend and business partner, and the sciatic nerve injury, Deborah continued to scrape by as a courier, picking up mostly light work from the dispatcher. "But then business got real slow with the economy and everything. And after September 11th, they stopped using couriers a lot because people didn't want to send packages and stuff. And so I got laid off."

Deborah would like to go back to work. "I've checked into going back to work in a law office, but I can't because I don't have any computer experience. I left office work before computers came in."

"And after September 11th, they stopped using couriers a lot because people didn't want to send packages and stuff. And so I got laid off."

At this point Deborah is living on very little money. The local Jewish Family Services has been helping her pay her rent, which is mercifully low at the municipal senior citizens' housing complex that she has been allowed to move into although she is not yet officially a senior citizen. She also receives food stamps, but that is the only public aid for which she is eligible.

Deborah describes herself as "healthy," but she does suffer from fairly frequent chest pains which she

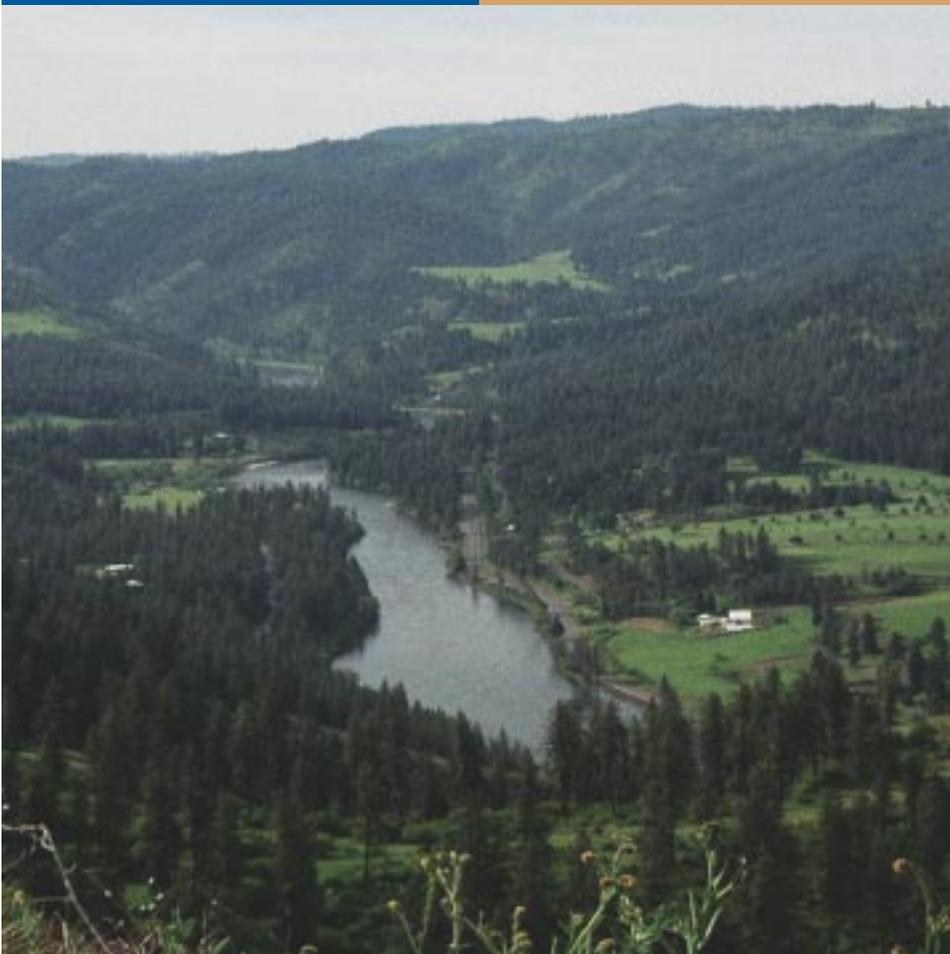
would like to have checked. She does not receive any sort of on-going or preventive health care, relying on a for-profit walk-in clinic the few times a year that she feels she must go to the doctor. At the clinic the fee is \$65 per visit, plus additional payments for any tests, etc. The clinic will not allow patients to run up a bill or make partial payments; the \$65 must be handed over before one can be seen by the doctor.

Shortly after her boyfriend's death, about five years ago, Deborah suffered from a bad case of shingles. Particularly affected were her eyes. At that time she went to an eye specialist who gave her a prescription for tri-focals. She assumes that she needs a new prescription now, but cannot afford either the eye exam or the glasses. More than the doctor, she wishes

she could go to the dentist. Missing several teeth and suffering from frequent tooth-aches, she can no longer afford visits to the dentist.

Deborah clearly has suffered terribly at the loss of both parents, her boyfriend, her dog, and her house, all in a ten year period, during which time, in the wake of September 11th, her job had become obsolete. Concurrently, both as a normal function of age and as a consequence of an injury on the job and her multiple losses, her health is deteriorating rapidly. With little to look forward to, Deborah clings to the thought that if she can just hang on a little longer, in less than ten years she will at least be able to enroll in Medicare. ❖

ROB



After the first surgery, Rob was told that he needed to return to have his skin checked every six months. ... Almost ten years later, he has not yet been back.



ROB: TRUE LOVE LOST

Rob is a well-spoken, educated, 53 year old man who spends most of his time volunteering with children and teenagers in his mid-sized town in northern Idaho. Rob has made it his personal mission to expose these kids to a wider world of culture, books, music, and art by organizing after school activities and trips to the nearest city (Lewiston). Part of that mission is to offer local kids the attention that they often lack at home, where overworked and underpaid parents may not have time to take their kids to the library, do homework with them, or simply talk about their dreams for the future.

Though he is a very articulate man, Rob does not like talking about himself. He prefers discussing the hardships faced by families trying to keep their lives together in this once thriving mining and logging community where the jobs have dried up and the funds available for public social services don't begin to meet the needs of local residents. The reasons for his reticence regarding his own life are two-fold: First, he'd much rather use his skills to reach out to outsiders who might be able to help his community. And second, he knows that people in this working class community see him as different—as educated, middle class, as somehow above their own struggles.

Rob's own story is a sad one. In his last year of college he married his long time sweetheart and only true love. Passionate about one another and about the prospects of developing a business, they left school and put their minds and their hands to work. Together, they built up a thriving gift shop business with branches in several states and a large warehouse filled with a variety

of imported gift items. Rob and his wife did not have children; they had one another and felt content and complete in their relationship as husband and wife, and business partners. For the two of them, life was a shared adventure.

Life was good until the day his wife was killed in an airplane wreck.

The story of their coming to this Idaho town is a case in point. In the mid 1980s they decided to choose a place in which to settle down. “We actually sat down with charts, vegetation charts and climate charts of areas that we knew that we liked, and we spent about a year just traveling around the United States looking at those different areas that we thought we liked. Living in them each. We went around, oh we eliminated about 5 or 6, and we spent summer or spring in each one, some of fall and some of winter in each one.” In the end they chose northern Idaho with its beautiful rivers and mountains, and its entrepreneurial spirit.

Life was good until the day his wife was killed in an airplane wreck. Rob explains, “After that I didn't have the heart to keep the business going. I just hated it, it wasn't the same. You don't feel that drive anymore. It wasn't ours anymore. And it's hard doing your own small business, when you're small enough so that you don't have managers working for you. I didn't quit running it and it kind of hung on for a while. A lot

of the gift shops that I sold items to were owned by people who didn't want to give up on me. So I still have a warehouse in town, and I still have stuff in it, but I haven't done any business at all for 2 years I guess."

Rob and his wife had saved up some money, which has allowed Rob to hang on for about a decade. They were not, however, wealthy—his joy in the business came from working together with his wife rather than the drive to accumulate lots of money.

At this point, Rob lives on about \$6000 per year, which, in his very modest way, he feels is just about sufficient to meet his needs. He is beloved in town and often receives gifts of meat from friends who hunt and fish. He owns his home, does not take vacations or buy new clothes, and he drives an ancient, beat-up car.

Six thousand dollars does not, however, allow him to pay for health insurance.

And like many adults in their fifties and sixties, Rob has found that his body, which he always has taken good care of, is beginning to fail him.

Ten years ago Rob was diagnosed with skin cancer. According to his doctor, this kind of cancer most likely is the result of exposure to the sun when he was a child.¹ Whatever the cause, the current reality is that Rob had cancers growing in a number of places on his face and shoulders. The most frightening were the cancer on his eyelid and the cancer near a lymph node.

At that time, he still had some money saved, and using his local connections, the expertise of his sister (who is a physician), and his business skills, he convinced a dermatologist, plastic surgeon, and oncologist to work together and bill him for a relatively modest sum.

After the first surgery, Rob was told that he needed to return to have his skin checked every six months.

"I was told it will be a forever thing until I die." Almost ten years later, he has not yet been back.

His failure to go back to the doctor is not because all is well. He sees the cancer growing again on his face and back. "The doctor told me back then that if I don't have them removed they will get worse and worse and worse, and they will kill you eventually."

The second time around, his money has run out, and he hasn't been able to talk his way into reduced fee surgery.

Like many skin cancers, Rob's condition is not painful at this time. What bothers him most is the appearance, especially the lesion that bleeds. "It is embarrassing more than anything else. Then of course just the thought of every time you look in the mirror you see them getting a little bigger and a little bigger. Everyday you think about it. If I was covered right now, I would go in to the doctor and do it [the surgery]. I would be there as soon as they could get me in."

Rob explains what it is like trying to get medical care when you don't have insurance. "Well, you're a leper when you go into the office and you don't have insurance. First of all they're surprised actually, if you don't have insurance, and then they want to know why. For most of them, if you're dealing with a doctor or a professional situation they have insurance at work so unless they are working in the finance office they have no idea of the cost it is to have insurance. It's kind of an assumed thing, that it's just a little perk and they don't realize it is so expensive. Maybe just uncomfortable probably is the word you could say.

¹ Rob did not recall the exact name of the type of cancer. Based on his description and on the lesions he showed us, we suspect that these are actinic keratoses, which are often benign, easy to treat early, but can become malignant and be potentially fatal if left untreated.

First of all they're surprised actually, if you don't have insurance, and then they want to know why.

There was always that surprise and they'd even ask you a second time, like you're trying to avoid something or you don't want to turn in a claim or something. And they even ask you again like, 'Are you sure you don't have insurance, not even at work?'

For the most part, Rob simply does not go to the doctor anymore. He used to call his sister when he was ill, and she would phone in a prescription to the local pharmacy. But nowadays he is embarrassed to call her. She also has been diagnosed with skin cancer, and she is furious at him for not following up with his own treatment.

At this point, Rob realizes that he must have health insurance, and he has applied for several jobs in order to be eligible for insurance.² The one he feels he stands the best chance of getting is as an information officer for the Forest Service. Still, he knows that his competition for the job includes applicants much younger than he, and veterans who will be given preference in hiring.

The last time Rob spoke to his doctor, the doctor showed him pictures of what the cancer will look like if it goes untreated. "He showed me some pictures to motivate me, some of the pictures were pretty bad."

The tactic worked and Rob is motivated, but despite his business savvy and college education, he really does not know what to do next. And that has pretty much been the story of his life since his wife's tragic and premature death. ❌

² Purchasing insurance privately is beyond his financial means. Rob isn't sure how much private insurance would cost him, but we ran a quote online using his demographic information, and found that a Blue Cross policy for a man his age which covers office visits, but has a \$1000 deductible and 20% coinsurance would cost him a bit over \$300 per month.



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