

January 2009

Personal Stories about the U.S. Health Care System

The Susan G. Komen Advocacy Alliance asked its grassroots network to share personal stories about their experiences with the U.S. health care system. More than 3,500 people responded with personal experiences that ranged from inspiring to heart-breaking. All the personal stories will be available in the coming weeks at our website, www.komenadvocacy.org.

The experiences that follow are a sampling of the stories that detail problems with the health system through the eyes of middle class, hard working Americans.

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I cannot afford to purchase the insurance my employer offers so I am on a county health plan which I am very grateful for, but not all doctors accept it and I find myself in the situation where my doctor wants me to go to a gastroenterologist and no one in our county accepts it. So I am in effect flirting with colon cancer because I can't afford to see a specialist. – *Julie, Sparta, MI*

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My sister has had to go without health insurance for years and let her health go while taking care of our elderly parents and disabled sister. Now, she finally got a decent paying job at the post office and thought she was going to be able to afford insurance when initially told the bi-weekly expense out of pocket would be \$37.00 but when she discovered it would be \$212.00 bi-weekly instead, she had to cancel it because she can't afford it. Our developmentally disabled sister has teeth that are so bad they are falling out because Medicaid doesn't cover dental anymore and social security pays for necessities. My dear friend has had to give up his landscaping business, forfeit his home and move in with his girlfriend because he has to use his \$1700 monthly disability check to pay for shots related to lung cancer treatment. He had given up his insurance just prior to being diagnosed a few years ago and couldn't afford it afterward and/or couldn't get it because of pre-existing conditions. I had two other friends pass away from lung cancer that we held fundraisers for because the experimental treatments they were trying to save their lives with were not covered by insurance. These are but a few of the reasons why everyone in this country needs to have access to affordable, quality health care no matter what their health situation. -- *Tina, Royal Oak, MI*

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My family was bankrupted because I became ill with chronic fatigue syndrome when I was 20 and didn't have insurance. Even a state program that was supposed to help people like me didn't because the insurance companies took it over and made it an HMO style deal. Consequently, doctors that used to be covered, doctors that helped me, weren't covered. I was even told that my condition didn't really exist. Without Chapter 7, I don't know how I could have survived all of the bills. That's why the story of Senator Obama's mother was so important to me. I've been on the phone too, fighting insurance companies for my health care. To me, the first priority in health care is making sure those who have no access to health insurance can get some, even if it's just an expansion of the CHIP program. Baby steps. After those who have no chance get a chance, then start reforming health care in terms of those who have insurance, but are underinsured or can't afford the insurance they have. Thanks for trying to help. It won't be easy (ask Senator Clinton about that), but it's worth a try. God bless you all! -- *Barb, Austin, TX*

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When I had health insurance two years ago, an ultrasound showed an abnormality. I lost my insurance and haven't been back. While I am sure it is not cancerous, I don't know. As I told my grown son, would I rather tell myself that I am fine and be happy, or go back for another ultrasound, see that it's grown and have no way to treat it? I will die both ways, just will be ignorantly happy by just ignoring it. It is inexcusable that a working woman with two small children may face a death sentence, because she can't afford to be treated, because her choice is a home and support for her kids, and there is no money left after that. If I didn't work, I would have healthcare of some sort or Medicaid. The government punishes responsible taxpayers. – *Maureen, Daphne, AL*

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MY MOTHER LOST HER BATTLE TO METASTATIC BREAST CANCER THIS YEAR IN PART DUE TO NOT BEING ABLE TO AFFORD HER MEDICAL BILLS. SHE HELD OFF ON BEING SEEN & TREATED SOMETIMES DUE TO THE AMOUNT OF MONEY SHE OWED OR WOULD OWE. HER HEALTH INSURANCE WAS ONLY 80 - 20 & WHEN SHE DIED, SHE HAD THOUSANDS OF DOLLARS IN MEDICAL BILLS. THOSE THAT STRUGGLE WITH BREAST CANCER, SHOULD NOT LOSE THEIR LIFE BECAUSE THEY CAN'T PAY THEIR MEDICAL BILLS. – *ALICIA, PARMA, OH*

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Health care reform is important to me because of my grandmother and because I may lose my own coverage due to cost and lack of a job. My grandmother has had breast cancer since at least 2002. She had a lump a year before that at her last mammogram, but the doctors screwed up and NO ONE TOLD HER. She found out the following year. She had her right breast removed, but it had spread too much and is now in her liver and possibly her lungs. She has done remarkably well for her age (86 now) and was still herself until her latest treatment, which has robbed her of her memory, her energy, and feeling in her fingers amongst other problems. She isn't the first person to have this disease. Her sister, their aunt, and their grandmother all had it too. This puts me at a higher risk, yet Highmark won't cover a mammogram for me until I am 40. That's almost 11 more years.

I may lose my health care soon due to losing my job 7 months ago. I may have to drop it because I am only 29 years old, but it costs me \$200 a month on a *cheaper* PPO plan than what other companies would cost (at least \$330 a month with my last insurance company). What would it cost if I had children or my fiancé on my plan? I hate to think of that. I have no chronic conditions, I am healthy, but I do have a few minor things. I don't take birth control because my birth control is not covered in the state of PA if I use it for birth control, but if I wanted to use it for regulation or other problems, it would be. Paying \$120 a month is a bit steep for birth control which has no generic equivalent. The other types make me sick. My anti-anxiety medication, in generic form, is still \$230 for a 90 day supply. I need nerve testing to see if I carpal tunnel syndrome, but I was told it will cost up to \$1,700 for the testing and my insurance, despite me paying them \$200 month, won't guarantee it will be covered. Oh, and Highmark has filed for *yet another increase* on our costs with the state. The third in at least as many years.

I was born without 6 of my adult teeth, but haven't had oral surgery because it's \$1,500 a tooth and I need four of them "replaced". And guess what? Insurance only covers one tooth a year (despite it being something I was born with not from neglect) despite it being a 2-surgery ordeal for implants. I refused to have *eight* separate surgeries for this so now it is no longer covered and I have to pay for it out of pocket. I need hearing aids, but have never gotten them because my *health insurance* NOT my doctor doesn't think I need them. They're \$2,200 an ear. All of these costs are ridiculous. Most people, and even I with a bachelors degree, and a second income (well, until I lost my job) to help out can't afford this! -- *Robin, Pittsburgh, PA 15239*

It is societal unconscionable and personally heartbreaking that my cancer metastasized because I had to wait for my husband's insurance on his new job to start before I could afford to go to the doctor.

The first time I had cancer -- the "good kind," DCIS -- our insurance went up to \$3,400 a month. Who on earth could pay that??

Unfortunately, they missed getting all of the cancer, and it spread from my right breast -- which, strangely, was not even there, thanks to a mastectomy. By the time I was able to go back to the doctor, it had

spread through all my bones, from my femurs, my hips, ribs, spine, neck, shoulders -- all the way up to my skull. And my ovary.

Lack of ability to pay should not keep anyone away from the doctor. But of course it does, every day. What does it cost our nation in terms of lost years of productivity due to avoidably-early deaths, not to mention costs for the indigent passed along eventually?? If our nation is going to continue this inefficient and expensive system of requiring insurance in order to afford -- or even access! -- medical care, we need to make sure everyone has insurance.

Our is a cruel system. Not civilized. Unspeakably selfish. Heartless. No, not all the time, but certainly a LOT. And EVER is too often.

I also would like to see research on ways to prevent cancer. Low tech stuff -- like emphasizing exercise, eating vegetables, etc. -- I tire of so much of the money going to things that enrich pharmaceutical companies and technical gadget sellers when there are so many upfront, inexpensive things that could be done to save lives -- now and in the future. I also do not want to be written off because "Stage IV" is a label attached to me. So many services apply only to those at lower stages. Why the heck is that???

Anyway, thanks for asking. I have many strong feelings about this issue, and welcome dialogue. –
Barbara, Raleigh, NC

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Medicare is a blessing. Don't decrease these benefits which are granted to all citizens in civilized nations today. Medicare covers 80 per cent. With the increasing medical fees today, even the average person is finding it difficult to come up with 20 per cent of the costs. Many of these illnesses are a result of former administrations (especially GWB) lack of or refusal to control our environment from contaminants. Therefore I feel the USA should pick up a higher medical tab. On the other hand, I have just been told that my cousin in Connecticut is diabetic. He recently lost his job and insurance benefits. His brother found him dead in his apartment, most likely from a lack of medication he could not afford. -- *Allen, Kinderhook, NY 12106*

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I am 55 years old and a 4 year survivor of breast cancer. I was treated very aggressively at Dana-Farber, so I could not work. The chemo gave me osteoporosis so I had to have both knees replaced. Then 2 years ago I died of a heart attack. It was an inherited electrical problem.

I have always been HEALTHY. I grew up on a chicken farm. Worked hard and lived a good life. Now I am disabled, and glad to wake up every morning! Hopeful and at peace with the situation. Free from want.

But as a result, We have serious financial problems because my husband keeps losing his job. I don't think we can refinance anymore. He's looking at getting laid off in January. We've lost our investment values. And we are facing a \$900 a month payment to COBRA, \$100 to Medicare, between \$700-\$900 in co-pays to medications, a HIGH mortgage, groceries, utilities.....Thank God we don't have charge cards and cars, boats, etc. We have to keep the medical. We have no choice. So, we'll live off the charge card, again, until he gets a job.

I wonder where this world is going. We need to keep jobs here and make the essentials affordable. I don't know how families are making it. Did I mention my husband is a professional? In the computer industry where all the jobs are now in India, China, etc.

We used to own a grocery store in Maine but a Mexican migrant worker burned it down. These knocks have been tough. All I ask for is his job and not to have to worry so much about medical coverage. Thank you for listening and God Bless, -- *Alice, East Hampstead, NH*

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I lost my grandmother to cancer in 1994. She went without insurance for several years before her Medicare kicked in. As a direct result, her cancer went undetected and untreated. When doctors at University Hospital in St. Louis made the diagnosis, we were told that even with radical radiation and chemotherapy that her chances of survival were slim. The doctors said that if she had been seen sooner, that the outcome could be quite different. She passed away 15 months later. Even after 14 years, her passing still affects my life. She was my guardian while growing up and later became my mentor. I still miss her. Because she did not have access to affordable health care, my life was robbed of her joy too soon. NO FAMILY SHOULD HAVE TO GO THROUGH THIS! -- *Tina, Santa Fe, TX*

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I have two grown adult children who have no health care and are job-hunting.

While in college, they had none as well and one had to have a tonsillectomy. He started bleeding the next night and had emergency surgery which included an overnight hospital stay. I had to come up with \$15,000 to cover that because there were no Medical Assistance programs to cover it and he was no longer eligible under my work insurance. As a county employee who grosses less than \$45,000 per year, that's been a nightmare for me.

My daughter also had no insurance after she graduated from high school and had a job that didn't offer health care. She had some medical issues and now has over \$5000 in medical bills. Her only recourse will probably be to file for bankruptcy....if she can save enough money in order to file.

There are too many people who do not seek medical treatment because they can't afford it. I myself sometimes question whether to continue taking medications because of the cost.

EVERY American should have health care. PERIOD! -- *Marcia, Minneapolis, MN*

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As a 7 yr. breast cancer survivor, I am held hostage to my health insurance plan. I am self-insured, and the premium has now increased by \$100.00 to almost \$600.00/mo. I cannot look for other plans as my "pre-existing" condition would not be covered. How can this be addressed?
Thank you! – *Marti, Palm Coast, FL*

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Hello, speaking from a family of 5 that both parents work and make about 52,000 a year and just get by paying there bills, we do not have health insurance, we make to much for Medicaid and to much for family health plus our jobs offer insurance but we can not afford it, with our mortgage and electric bill, I feel we need to up the income guidelines for Family Health plus so that middle class if there is such a thing anymore, can have heath insurance., My children have gone with out dental and going for check ups due to no insurance. Thank you. – *Crystal, Binghamton, NY.*