

# PATIENTS UNDER PRESSURE:

Profiles of How Families Affected by Cancer Are Faring in the Recession



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**The Kaiser Family Foundation** is a non-profit private operating foundation, based in Menlo Park, California, dedicated to producing and communicating the best possible analysis and information on health issues.

**The American Cancer Society** is dedicated to eliminating cancer as a major health problem by saving lives, diminishing suffering and preventing cancer through research, education, advocacy and service. Founded in 1913 and with national headquarters in Atlanta, the Society has 13 regional divisions and local offices in 3,400 communities, involving millions of volunteers across the United States.

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PROFILES OF HOW FAMILIES AFFECTED BY CANCER  
ARE FARING IN THE RECESSION**

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## EXECUTIVE SUMMARY

The number of unemployed individuals has risen by 7.2 million during the current recession. Since employer-sponsored insurance covers more than half of all people under age 65, the rise in unemployment puts health insurance at risk for millions of workers and their families. Cancer patients and others with serious health problems are especially vulnerable during this recession because even short periods without health insurance can have serious consequences on their health and finances.

The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) was designed to help people temporarily continue their employer-sponsored coverage, but premium costs and eligibility restrictions have limited the number of people maintaining coverage through COBRA. Individuals who are unable to keep their previous coverage can try to purchase their own coverage, but in most states those with health problems such as cancer will likely find that private plans charge them a higher premium or will not offer them coverage at any price.

The original COBRA legislation required that those who wanted to maintain coverage through COBRA had to pay the full insurance premium, which averages more than \$1,000 a month for a family policy. To help laid-off workers and their families keep their insurance during this recession, a temporary COBRA premium subsidy was included in the American Recovery and Reinvestment Act of 2009 (ARRA). The nine-month federal subsidy covers 65 percent of the cost of COBRA premiums for individuals who involuntarily lost their jobs and for their dependents.

Since December 2008, the American Cancer Society Health Insurance Assistance Service has experienced a 30 percent increase in the number of calls from cancer patients and survivors when compared to the same time period a year ago. Most of this increase can be attributed to the economic downturn. This report tells the stories of six cancer patients and survivors who have called the American Cancer Society Health Insurance Assistance Service after losing their jobs or health insurance during the recession. It is a follow-up to the previous report written by the Kaiser Family Foundation and the American Cancer Society, *Spending to Survive: Cancer Patients Confront Holes in the Health Insurance System*.<sup>1</sup>

The six patients profiled are:

- **Debra Keown:** Debra is a 51-year-old lung cancer survivor who lost her insurance after her husband's employer stopped offering benefits.
- **Darla Snyder:** Darla signed up for COBRA, but she lost that coverage after her employer went bankrupt.
- **Fred Hughes:** Fred is a kidney cancer patient who was recently laid off and is unsure if he can afford to pay for insurance while also paying his mortgage.
- **Larry Carey:** Larry is a lung cancer patient who was laid off and then lost his COBRA coverage when he did not have enough money to pay his premiums.
- **Ellen Snopkowski:** Ellen is a breast cancer survivor whose previous employer filed for bankruptcy, leaving her searching for coverage for her family.
- **Diana W.:** Diana (who did not want her last name used) is a breast cancer patient who is worried about being able to afford coverage once her COBRA subsidy ends.

Several of the individuals interviewed for this brief have delayed treatments or incurred medical debt to pay for care with potentially adverse consequences in their struggle against cancer. Those who have lost their insurance may not be able to purchase their own coverage due to their history of cancer and may face pre-existing condition exclusions if they regain employer-sponsored coverage.



## INTRODUCTION

Of the 7.2 million people<sup>2</sup> who have become unemployed during the current recession, cancer patients and survivors who depended on employer-sponsored coverage are among the most vulnerable. These individuals, along with others who have serious illnesses, face additional challenges when trying to maintain health insurance because insurers often refuse to sell them health coverage. In addition, even being uninsured for short periods of time can force them to delay needed care or incur medical debt. A recent survey found that nearly one in three people under the age of 65 with a history of cancer has been uninsured at some point since their diagnosis.<sup>3</sup> Cancer patients who are undergoing treatments may have additional trouble finding employment in a tight job market.

This brief focuses on the challenges that cancer patients and survivors are facing as a means of gauging how the recession is affecting workers who are most in need of ongoing medical care and who have difficulty purchasing their own insurance. Although maintaining coverage is crucial for those affected by cancer, the individuals profiled in this report faced several challenges as they tried to avoid becoming uninsured:

- **Restrictions on COBRA eligibility:** Three of the individuals profiled in this report are unable to continue their coverage through COBRA because their employers either stopped offering any health insurance or went out of business.
- **Cost of COBRA:** The individuals in the report who are eligible for COBRA are struggling to pay their premiums. While the temporary subsidy is helping those who are eligible, the premiums are a strain on these individuals and once the subsidy ends it will become harder for them to afford COBRA.
- **Difficulty purchasing non-group coverage:** Several of the cancer patients and survivors in this report are unable to find private health insurance in the non-group insurance market that they can afford. In most states, insurers in the non-group market can use information about a person's health status to decide whether to offer someone a policy or what premium to charge.
- **Limited availability of public coverage:** Although some of the individuals in this report are receiving disability benefits or unemployment, none of them qualify for Medicaid. While individuals who are unable to work due to their cancer diagnosis or a disability may eventually qualify for Medicare, waiting periods typically delay eligibility for more than two years.

The stories of the six individuals profiled in this report illustrate these challenges and explore why maintaining health insurance is so difficult during a recession. The individuals profiled in this report provide examples of the range of problems faced by cancer patients and survivors during the recession, and are not a representative sample of the more than 25,000 people who have called the American Cancer Society Health Insurance Assistance Service. This report uses a similar methodology to the previous report by the Kaiser Family Foundation and the American Cancer Society, *Spending to Survive: Cancer Patients Confront Holes in the Health Insurance*

*System*, with this report focusing on the impact of the recession. Since the start of the recession in December 2007, calls to the American Cancer Society Health Insurance Assistance Service have increased. In the six months from December 2008 through May 2009, the Health Insurance Assistance Service experienced a 30 percent increase in the number of calls from cancer patients and survivors when compared to the year before. Most of this increase can be attributed to the economic downturn. Individuals are calling because they are struggling to maintain health insurance coverage as the economy worsens.



*“Once you get cancer you are terrified you will get it again.*

*I would feel a lot better if I knew I was cancer free.”*

**— Debra, who became uninsured after her husband’s employer stopped offering coverage**

## Part I: Extending Employer-Sponsored Coverage through COBRA

COBRA was designed to allow people to keep their employer-sponsored coverage, however some individuals are not eligible for COBRA and others may have difficulty affording the premiums. While maintaining health insurance is crucial for cancer patients and survivors, many individuals—not just those affected by cancer—are worried about keeping their insurance. A recent Kaiser Family Foundation survey found that 30 percent of those who are insured are very worried about losing their coverage.<sup>4</sup>

### Limits on COBRA eligibility

#### **Patient Story: Ineligible for COBRA because employer dropped coverage**

*Debra is a 16-year lung cancer survivor who lost her insurance coverage when her husband’s employer dropped its health insurance plan. Debra does not have any affordable health insurance options available to her, and her husband has since been laid off from his job. Going without health insurance has forced Debra to delay important follow-up care to monitor whether her cancer has recurred.*

Since COBRA enables people to continue their previous coverage (see Basic Facts about COBRA), it is not available to individuals whose employers have stopped offering insurance coverage or have gone out of business because there is not an employer-sponsored plan to continue. If COBRA is not available, cancer patients and others with serious health problems may not be able to purchase their own insurance in the non-group market since insurers in most states can charge higher premiums or not offer coverage based on an individual’s health status.

As employers such as the one who employed Debra’s husband look for ways to cut costs during a recession, some may stop offering coverage while others may try to lower their premiums by increasing employees’ deductibles and cost-sharing or offering plans with limited benefits. Since cancer patients often require a lot of expensive medical care, they may see large increases in their health care costs due to higher deductibles and cost-sharing.

#### **Patient Story: Loss of COBRA when employer filed for bankruptcy**

*Darla was diagnosed with breast cancer in October 2008 and had a mastectomy. Just one month before her scheduled reconstructive surgery, Darla was laid off from her job at a sportswear manufacturer. She signed up for COBRA so that she could continue her coverage and undergo surgery as scheduled, but her former employer filed for bankruptcy six days before the surgery. It is unclear whether her former insurer will cover the surgery. Darla is now uninsured for the first time in her life. “I didn’t ever imagine at this age that I would be in this type of situation,” Darla says.*

## BASIC FACTS ABOUT COBRA:

**How does COBRA work?** Under COBRA, former employees and their dependents can continue purchasing their previous employer-sponsored coverage after leaving a job or experiencing another qualifying event, such as divorce. People who qualify for COBRA have 60 days to enroll in the coverage after they otherwise would have lost their insurance or are notified about COBRA, whichever comes later.

**Who is eligible?** Individuals with employer-sponsored insurance through a firm with the equivalent of 20 or more full-time employees are eligible for COBRA after a layoff or other qualifying event. In 39 states and Washington, D.C., employees in firms that are too small to offer COBRA are eligible for other continuation coverage, but state continuation coverage may not last as long as COBRA coverage. Employees who lose a job because their employer goes out of business cannot qualify for COBRA because their employer is no longer offering a health plan. Similarly, an individual whose employer stops offering health insurance to any employees is not eligible for COBRA.

**How long does COBRA last?** Those who elect COBRA coverage can usually maintain that coverage for a maximum of 18 months. Individuals who qualify for Social Security Disability Insurance may be eligible for an additional 11 months of COBRA coverage beyond the usual 18 months of coverage by paying 150 percent of the full COBRA premium.

**How much does COBRA cost?** Under the original legislation, individuals maintaining their employer-sponsored insurance coverage through COBRA are responsible for the full premium—including both the employee and the employer share—as well as up to 2 percent of the total premium to cover administrative costs. In 2008, the full monthly cost of maintaining the average employer-sponsored health insurance plan through COBRA averaged \$400 per month for individual coverage and \$1,078 per month for family coverage.<sup>5</sup> Under the COBRA subsidy in American Recovery and Reinvestment Act of 2009 (ARRA), the monthly cost of maintaining the average policy would be \$140 for an individual and \$377 for a family.

**How does the subsidy work?** As part of the ARRA, the federal government is providing a nine-month subsidy for 65 percent of the total COBRA premium. Former employees pay their 35 percent share of the premium and the federal government reimburses insurers and employers for the balance of the premium.

**Who is eligible for the subsidy?** In order to qualify for the COBRA subsidy, an individual must be eligible for COBRA and must have been involuntarily terminated from his job between September 1, 2008, and December 31, 2009. Both laid-off workers and their family members who were covered under the worker's employer-sponsored insurance plan are eligible for the subsidy. In order to be eligible for the full subsidy, a person's same year income cannot exceed \$125,000 for an individual or \$250,000 for married couples. Individuals with incomes above \$145,000 and married couples with incomes above \$290,000 are not eligible for any subsidy. If a person gains access to other group coverage or becomes eligible for Medicare, he is no longer eligible for the subsidy.

Workers, such as Darla, whose employers have gone out of business are not able to continue their previous coverage through COBRA because the plan ceases to exist. These workers are facing unemployment, making it particularly difficult for them to find other affordable coverage. Workers who were already enrolled in COBRA when their employer went out of business may suddenly lose coverage that they had planned to continue. Cancer patients who find out that their employer is going out of business may need to find new coverage quickly so that they can continue their treatments. In most states, they face very limited coverage options due to their medical history. Any lapse in coverage may continue to have consequences even if they regain employer-sponsored insurance through a new job. Individuals who have been uninsured for 63 days or more can face pre-existing condition limits on their new employer-sponsored coverage that typically last for one year.

## **Trouble affording COBRA and the COBRA subsidy**

### **Patient Story: May not be able to pay for COBRA and keep his home**

*Fred, a kidney cancer patient, lost his job in February 2009 after exhausting his short-term disability leave. While he is eligible to continue his previous insurance coverage through COBRA, he is worried that he and his wife will not be able to afford his \$180 share of the monthly premium and keep their home on their monthly income of about \$1,500. Fred is eligible to receive the nine-month federal subsidy that covers 65 percent of the cost of COBRA. "The subsidy will help, but I am just not sure it will be enough," Fred says.*

If Fred is able to continue to afford his premiums while he is eligible for the federal COBRA subsidy in ARRA, he may still be unable to pay the full COBRA premium once the subsidy expires. Cancer patients who are unable to pay the full COBRA premium once the subsidy period ends are at risk of becoming uninsured and forgoing needed cancer treatments.

During the current recession, many individuals will face added challenges when they try to pay for COBRA. As stock market declines cause retirement savings to lose value and home prices drop, it will become increasingly difficult for some people to tap into their assets to pay their insurance premiums. In addition, the number of long-term unemployed is rising as the economy declines, which leaves more people trying to pay COBRA premiums for six months or longer as they continue to look for jobs. In June 2009, 4.4 million people had been unemployed for 27 weeks or more.<sup>6</sup>

Maintaining insurance coverage is crucial for cancer patients and they may sacrifice their financial well-being in order to keep their coverage and access to medical care. Along with COBRA costs, cancer patients also may be struggling to pay the deductibles and cost sharing associated with their employer-sponsored plan. For cancer patients who are undergoing treatment, frequent appointments may make co-payments difficult to afford while also paying COBRA premiums.

## Dangers of missing a COBRA premium payment

### Patient Story: Loss of coverage after premium check bounced

*Larry, 63, went on long-term disability in October 2007 after he was diagnosed with lung cancer. In May 2008, he was unable to return to work and was ultimately laid off from his job. Larry tried to maintain his previous coverage through COBRA, but the \$300 monthly premiums were difficult to afford once he was no longer working. In July 2008, Larry's COBRA check bounced and he lost his insurance coverage. Larry was later able to purchase coverage through a subsidized plan offered by his state, but the coverage is less comprehensive and does not include a prescription drug benefit.*

The unemployed are typically struggling to pay their usual household bills, such as rent or mortgage and utilities, along with their health insurance payments. COBRA beneficiaries, such as Larry, who miss a COBRA payment and do not pay it within the grace period, which must be at least 30 days, can permanently lose their coverage. If they have been receiving the COBRA subsidy, they also lose their eligibility for that subsidy.<sup>7</sup> In this situation, the individual would have no federal right to purchase other coverage and may not have another coverage option.

### Difficulties of paying for COBRA while on disability

Larry and other workers who are laid off while on disability leave are among those who are most vulnerable. Workers without long-term disability insurance can be laid off when they exhaust their sick leave, short-term disability leave, or family and medical leave if they are unable to return to work. The Family and Medical Leave Act (FMLA) provides certain employees with up to 12 weeks of unpaid, job-protected leave a year and requires employer-sponsored insurance be maintained during the leave. Not all employers are required to provide FMLA leave and not all employees are eligible to take FMLA leave.

Those with long-term disability insurance can continue to receive disability payments after being laid off, but they would likely no longer qualify for employer-sponsored insurance. A 2002 Mercer Human Resources Consulting study found that 27 percent of the 723 employers surveyed lay off employees immediately after they go on long-term disability and 24 percent lay off employees after a set period—typically six to 12 months.<sup>8</sup> Individuals who qualify for Social Security Disability Insurance (SSDI) may be eligible for an additional 11 months of COBRA coverage beyond the usual 18 months of coverage. Those who are eligible for the disability extension may pay up to 150 percent of the full COBRA premium. In order to qualify for this extension, the Social Security Administration must declare that a person became disabled within the first 60 days of COBRA coverage and the individual must send the insurer a letter with the Social Security Administration's ruling within 60 days of receipt.

### Limits on subsidy eligibility

Not all COBRA-eligible workers who lose their coverage due to an employer action are eligible for the COBRA subsidy. For example, workers cannot receive the subsidy if they are no longer eligible for employer-sponsored insurance because their employer reduced the number of hours they can work. However, if a worker decides to quit in response to a reduction in hours, that worker may be eligible for the subsidy.<sup>9</sup>



*“My husband and I are hard-working people who did everything we were supposed to do and still find ourselves in debt and with few options for getting health care.”*

**— Darla, who is unable to afford health insurance through her state’s high-risk pool**

## Part II: Other Insurance Options

Cancer patients and survivors who are unable to continue their previous coverage through COBRA face limited other insurance options. Federal protections for those who previously had employer-sponsored coverage may not shield them from high premium costs and public coverage may not be available.

### HIPAA protections and the non-group insurance market

#### **Patient Story: Unable to find affordable and comprehensive coverage in non-group market**

*Ellen Snopkowski is a breast cancer survivor who lost her job when her employer filed for bankruptcy. Since her employer went out of business and terminated all of its employees, there is no health plan for her to continue through COBRA. Ellen has had trouble finding affordable and comprehensive coverage. She eventually signed up for a state-supported health plan, but she is spending about one-quarter of her income on the insurance premiums and she still does not have adequate prescription drug coverage.*

Employees, such as Ellen, who are not eligible for COBRA when they lose their employer-sponsored insurance plan may still qualify for some protections under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). This law guarantees that qualified individuals are offered at least two health plans from each insurer selling in the non-group market in each state that do not impose pre-existing condition exclusion periods. However, states can make alternative arrangements to guarantee consumer protections under HIPAA, and many have chosen to do so. For example, 27 states only guarantee coverage for HIPAA-eligible individuals through the state high-risk pool.

An individual is considered HIPAA eligible if he was continuously insured for 18 months and most recently had group coverage, elected and exhausted COBRA (if eligible), is not eligible for a group or public insurance plan, and applied for the HIPAA plan within 63 days of losing previous coverage.<sup>10</sup> There are no federal limits on what insurers can charge for these HIPAA plans, although some states do limit premiums.

Cancer patients who do not meet the HIPAA eligibility criteria or who are unable to afford HIPAA coverage may try to buy their own coverage in the individual insurance market, also known as the non-group market. However, cancer patients and survivors in this situation are very likely to have trouble buying their own insurance because insurers in most states can deny them coverage based on their medical history. If cancer patients are able to find a non-group health plan, it may not adequately cover the services and treatments they require. For example, Ellen’s insurance plan only covers \$3,000 of prescription drugs each year. Some insurance plans may also have deductibles and cost sharing that would make it difficult to pay out-of-pocket costs for treatment and follow-up care.

## High-risk pool coverage

### Patient Story: Uninsured and unable to afford high-risk pool coverage

*Darla lost her employer-sponsored insurance when her employer declared bankruptcy and she is now uninsured. Even though her early-stage breast cancer was treated successfully, she has been denied coverage in the non-group market due to her past cancer diagnosis. Her only option is the state high-risk pool, but she cannot afford the \$688 monthly premium. "My husband and I are hard-working people who did everything we were supposed to do and still find ourselves in debt and with few options for getting health care," Darla says.*

Cancer patients and survivors in 35 states may also be eligible to purchase coverage through their states' high-risk pool.<sup>11</sup> In order to qualify for one of these plans, individuals typically have to have been turned down for private coverage, have been charged substantially higher premiums, or have been offered restrictive private coverage. In most states with high-risk pools, this is the coverage option for those who have been rejected by other insurers and are eligible for HIPAA protections. State high-risk pools provide government-subsidized coverage and vary substantially by state along many measures, including eligibility, pre-existing condition limitations, and funding sources. Despite subsidies, these plans have premiums that usually range from 125 to 200 percent of the standard market rate for insurance in the state.<sup>12</sup> In addition to the cost of premiums, the cost sharing can be unaffordable for people with serious conditions, such as cancer. Deductibles for state high-risk pool plans vary, with more than half the states only offering plans with deductibles at or above \$1,000. In addition, about a third of the state high-risk pools offer lower premium plans with deductibles that reach \$10,000.<sup>13</sup> While some states have total out-of-pocket expense maximums for beneficiaries, most do not. Cancer patients and survivors purchasing high-risk pool coverage may also face pre-existing condition exclusions that typically last from six to 12 months.

## Public insurance coverage

When maintaining private insurance coverage through COBRA or a non-group policy is not an option, cancer patients and survivors may turn to public coverage. However, individuals whose employers dropped coverage or who have been laid off often are not eligible for public coverage since their income or unemployment benefits may disqualify them from Medicaid or other public insurance coverage. In addition, they may not fit into one of the Medicaid eligibility categories. To be eligible for Medicaid, individuals under age 65 must fall into one of the following groups of low-income individuals: children, people with dependent children, pregnant women, and people with severe disabilities. In most states, adults who are not parents of dependent children do not qualify for Medicaid or other public coverage since states are not required to provide coverage for even the lowest income childless adults.<sup>14</sup> While each state must cover parents, states have a great deal of flexibility in setting eligibility levels. In 2008, 27 states had set the eligibility cutoff for non-working parents below 50 percent of the poverty level (about \$11,000 a year for a family of four).<sup>15</sup> None of the cancer patients and survivors profiled in this report qualified for Medicaid.

Cancer patients who are unable to work may eventually qualify for Medicare, but the route to Medicare eligibility is complex and lengthy. While Medicare primarily provides coverage to those people 65 and older, it also covers individuals under the age of 65 who are receiving Social Security Disability Insurance (SSDI) once they have been receiving those payments for two years.<sup>16</sup> Since individuals in this two-year waiting period are unable to work and have serious health problems, they may have limited access to private coverage if COBRA is not available or affordable. In 2002, an estimated 30 percent of the 1.3 million people with disabilities in this two-year waiting period were uninsured.<sup>17</sup>

### Options once COBRA coverage ends

Workers typically qualify for 18 months of COBRA coverage when they lose their jobs. For those eligible for the 65 percent subsidy through ARRA, the first nine months of coverage are subsidized, but they must pay the full premium for the remaining nine months of COBRA eligibility.

#### **Patient Story: Limited Options Once COBRA Is Exhausted**

*Diana is undergoing treatment for breast cancer and has been covered through COBRA since her husband, Mike, lost his job. When Diana exhausts COBRA, she will probably be denied insurance policies in the individual market, making HIPAA her only option. Diana lives in Missouri, where the HIPAA plan will likely be more expensive than the full cost of COBRA coverage. She and Mike are already having trouble paying the subsidized COBRA premiums on their \$1,500 monthly income from unemployment and disability payments. "We are not quite keeping our heads above water," Mike says. "We are exhausting our savings to pay bills when they come due because we just don't have enough income."*

After the full 18 months of COBRA coverage, cancer patients such as Diana may have trouble finding affordable insurance. Up to 63 days after COBRA coverage ends, individuals are eligible for HIPAA coverage. However, the cost of those plans can be substantially higher than other plans because there are no federal limits on the premiums that can be charged to HIPAA-eligible individuals. By the time an individual's COBRA coverage expires and he or she qualifies for HIPAA coverage, the individual has already paid for 18 months of coverage and may not be able to afford to continue paying relatively high HIPAA premiums.

## Conclusion

The current recession is having a broad impact across the economy, leaving many people struggling to find or maintain health coverage in the wake of a job loss or decline in income. Since unemployment rates are expected to remain high after the economy begins to recover, some Americans will struggle to keep their coverage after a layoff and others will exhaust their savings while maintaining coverage as they try to find a new job with employer-sponsored insurance.

Cancer patients and survivors are among those who most need the access to medical care and protection from high health care costs that adequate health insurance provides. Research shows that being uninsured can lessen the chances of survival for cancer patients. Numerous studies have shown that patients without insurance are less likely to receive cancer prevention services, are more likely to be treated for cancer at late stages of the disease, are more likely to receive substandard care and services, and are more likely to die from cancer.<sup>18,19,20</sup>

When these individuals lose a job or lose their employer-sponsored health insurance, they must try to avoid losing their coverage while also paying for other basic needs. Since cancer patients and survivors in most states would find it difficult or impossible to purchase their own insurance, it is especially important that they maintain their coverage through COBRA when possible. The COBRA subsidy will help some people retain their previous health insurance, but it may not be sufficient to enable all those who need coverage to afford it. Gaps in COBRA eligibility also leave some jobless individuals unable to maintain their previous employer-sponsored coverage.

As the recession continues, more people will likely find their health insurance in jeopardy. Although cancer patients and survivors understand how crucial it is to remain insured, some may not be able to keep their insurance coverage. Others may risk their family's financial well-being in order to devote the necessary funds to maintaining health insurance. Improving the availability of other public and private options for those who lose their jobs or their health insurance would help cancer patients and others with significant health needs to preserve their access to medical care during a time of economic instability.

## Appendix: The Cancer Patients' Stories

### Larry Carey

#### Pennsylvania

##### ***Laid off from his job while on disability and lost coverage after missing a COBRA payment***

Larry, 63, was diagnosed with lung cancer in October 2007. He immediately had surgery to remove his right lung and soon began chemotherapy. Larry and his wife, Marie, didn't realize the toll cancer would take not only on their health, but also on their finances.

*"Having cancer and losing the insurance is like having the bottom fall out from underneath you," Marie says. "We are simply stuck in the middle of losing our jobs to cancer and struggling to get access to health."*

Larry went on long-term disability leave from his job when he was first diagnosed with cancer. Marie left her job in April 2008 to take care of Larry full time while he was recovering from his cancer treatment. In May 2008, he was still unable to return to work because of his reduced lung capacity and was ultimately laid off from his job. Larry and Marie elected to continue their employer-sponsored health insurance coverage through COBRA at a cost of more than \$300 a month.

With Larry unable to work and Marie providing full-time care, their income was reduced and they couldn't make ends meet. In July, Marie found out that one of their COBRA premium checks had bounced and they lost their coverage.

*"Trying to manage the finances is horrible," Marie says. "After losing the COBRA, I realized that should have been the first bill I paid, but managing all the bills is overwhelming."*

Marie was eligible for Medicare when she turned 65 and elected coverage immediately. However, she could not find any coverage options for Larry. After more than four months without insurance, Marie signed Larry up for Pennsylvania's state-subsidized health insurance program, AdultBasic, which has a \$264 monthly premium. Although Larry is now insured, he is still having trouble accessing care. None of his specialists are in-network, and he has delayed having follow-up visits with his doctors to monitor for cancer recurrence. In addition, the plan does not have a prescription drug benefit, so Larry must pay \$246 a month for his Advair prescription.

*"Now we are looking for a new oncologist and pulmonologist for Larry," Marie says. "Losing the doctors you have grown to trust is devastating. Larry should have seen the doctors three months ago, but they don't accept the new insurance."*

Marie was eventually able to find an in-network pulmonologist, but Larry will have to wait another two months before the specialist can see him. In the meantime, Marie continues to look for an oncologist that will accept Larry's health insurance.

## Fred Hughes

Tennessee

***Laid off after running out of disability leave and worried about how he will continue to pay for COBRA when the subsidy expires***

On a fishing trip last summer, Fred Hughes thought he had a pulled muscle in his groin but it turned out to be stage IV kidney cancer. Fred, 59, went on short-term disability after he was diagnosed with cancer in August 2008. His cancer treatments have included radiation and chemotherapy.



Fred lost his job at the end of February 2009 because he ran out of disability leave time. He was offered and elected COBRA, but is worried he will not be able to afford it. Fred's income includes his Social Security Disability Insurance payments of \$944 a month and his wife's retirement Social Security of about \$600 a month.

Fred and his wife live in a house they built and pay approximately \$825 a month for the mortgage. This house is more than just bricks and mortar—they built their home with their own hands.

Fred is eligible to receive the federal COBRA subsidy that was included in the American Recovery and Reinvestment Act of 2009, but he originally had trouble getting information from his employer about the cost of continuing coverage through COBRA. More than three months after he lost his job, Fred was able to sign up for COBRA at a subsidized cost of \$180 a month.

*"The subsidy will help, but I am just not sure it will be enough," Fred said. "It is just going to have to be affordable, but I am not sure what I will do when in nine months the costs go up."*

## Debra Keown

### Michigan

#### ***Employer dropped health insurance benefit, and no affordable option was available***

Debra Keown is looking forward to celebrating her 16th year as a cancer survivor, but the celebration is clouded by her current struggles to find health insurance. Debra, a 51-year-old lung cancer survivor, had coverage until her husband's employer dropped their health insurance when the premiums became unaffordable for the business in February 2008. With no other affordable health care options available, Debra lost her insurance coverage.



It has been more than a year since Debra has received her recommended annual chest X-rays and blood tests to monitor whether her cancer has recurred. Debra lives with the constant worry that her cancer could come back. She has also delayed important preventive care, such as her annual mammogram.

*“Once you get cancer you are terrified you will get it again,” says Debra. “I would feel a lot better if I knew I was cancer free.”*

Since she first lost her coverage, the recession has continued to impact Debra and her family. Less than a year after Debra's husband's employer dropped their coverage, her husband was laid off from his job. She then contacted the state Medicaid office for help, but was told that her husband's unemployment income was too high for her to qualify for assistance. Debra looked into getting health insurance in the non-group market, but it was too expensive.

The toll of Debra's lung cancer treatment makes it difficult for her to work. She suffers from severe asthma and has been able to find a doctor to treat that condition and provide her with an inhaler at minimal costs. However, this doctor is unable to provide the follow-up care for her lung cancer.

*“The only doctor I have is the one that treats my asthma,” says Debra. “He provides his services to me for free out of the goodness of his heart, but I cannot find another doctor who would be willing to help me get the chest X-ray I need.”*

Debra does not have any affordable health insurance options available to her. Her husband is actively seeking a new job, but is having difficulty finding work. For now, Debra will continue to delay her care.

## Ellen Snopkowski

New York

### ***COBRA not available because employer is going out of business***

Ellen Snopkowski's employer of six years filed for Chapter 11 bankruptcy in February 2009. Ellen lost her job in June 2009, and she has also lost her employer-sponsored health insurance. Ellen, who is a 52-year-old breast cancer survivor, will not be offered COBRA because the health plan no longer exists, and she is worried about being able to afford other health insurance options.



*"[I] was told that I am not entitled to COBRA because the company is filing Chapter 11 and then being liquidated," says Ellen. "I will lose my health insurance on the day that I am terminated. I am struggling to find affordable health insurance for my daughter and me."*

Ellen completed active treatment for her cancer in May 2007 and will be taking Arimidex until 2013 to prevent her cancer from recurring. She is also taking three other prescriptions to treat her high blood pressure and high cholesterol. Because of the cost of Arimidex, Ellen is exploring every health insurance option in New York.

Ellen is eligible for a number of health insurance options, but most are unaffordable or do not meet her needs. One insurer she contacted offered her a policy that would cost more than \$800 a month. That premium would consume most of her unemployment income, which she expects to be about \$1,200 a month.

Ellen is worried that her unemployment income will be too high for her to qualify for Medicaid, and she is waiting to hear from the Medicaid office as to whether she is eligible. In the meantime, she signed up for the state-supported Healthy New York insurance program. While this option is available to her, it will be a financial strain. The \$300 monthly premiums will consume about a quarter of her income and the prescription drug coverage is limited to \$3,000 a year, which is inadequate for Ellen. To make sure she can continue her Arimidex, Ellen has contacted prescription assistance programs to get samples of the drug at a low cost. She is not sure how much longer she will be eligible for this program.

*"I will file for unemployment. Not only am I trying to manage my health insurance coverage, but I also need to find coverage for my daughter who is in college," says Ellen.*

Ellen is actively looking for a new job that would provide health insurance, but she is concerned that there will not be many jobs available because of the current economic climate.

## Darla Snyder

Iowa

### ***Became uninsured when her former employer went bankrupt, which ended her COBRA coverage***

Darla Snyder, 49, was diagnosed with early-stage breast cancer in October 2008. She decided to have a mastectomy and needs no other treatment for her cancer.

She had been scheduled to have reconstructive surgery in April 2009. In March, she was laid off from her job along with everyone else in her office.



*“The branch of the sportswear manufacturer where I worked closed its doors and I was laid off after 21 years of service as an office manager,” Darla says.*

Darla decided to continue with her planned surgery and chose to maintain her health coverage through COBRA. However, six days before her reconstructive surgery, she received word that the corporate office filed for Chapter 11 bankruptcy and was closing completely. Because the insurance plan no longer existed due to the company’s closure, Darla lost access to her group health insurance.

*“I proceeded as scheduled with the surgery because my insurance company told me they had received my COBRA payment and I would be covered,” Darla says. “But after the surgery, I found out that my former company had not paid the insurer. After many hours on the phone and on e-mail, I still don’t know if I was covered during the month of April at all.”*

Darla recently found out that she may be responsible for \$25,000 to \$30,000 in medical bills related to her reconstructive surgery. For the first time in her life, Darla is uninsured and facing serious financial debt.

*“I didn’t ever imagine at this age that I would be in this type of situation,” Darla says. “My husband and I are hard-working people who did everything we were supposed to do and still find ourselves in debt and with few options for getting health care.”*

Darla needs physical therapy to regain full use of her left arm, but without insurance she will forgo this necessary care. Darla contacted her local insurance agent to look into buying coverage in the individual market, but was denied because of her past cancer diagnosis. Insurers turned Darla down for coverage even though her cancer was caught early and treated successfully. Darla was told to apply for Iowa’s high-risk insurance pool, but at a cost of \$688 per month, she cannot afford that coverage.

Darla is looking for work, but has been unable to find jobs within 90 miles of her home that are in her area of expertise. She worries that if she finds a job with health insurance, she may face a pre-existing condition exclusion period because she is now uninsured.

## Diana W.

### Missouri

#### ***Currently receiving COBRA subsidy, at risk of being unable to afford coverage once the subsidy ends***

Diana, 53, was scheduled to start chemotherapy for breast cancer when her husband, Mike, unexpectedly was laid off from a company that manufactures and assembles truck cabs. When Mike—along with others—was laid off in February 2009, he received no compensation and was concerned about keeping his health insurance for his wife.

Mike and Diana qualified for the COBRA subsidy under ARRA. With the subsidy, Mike pays about \$200 a month for the first nine months of COBRA coverage. The household income for the couple is estimated to be \$1,500 a month from Diana's Social Security Disability Insurance payments and Mike's unemployment payments. As a result, they are struggling financially.

*"We are not quite keeping our heads above water," Mike says. "We are exhausting our savings to pay bills when they come due because we just don't have enough income."*

Mike is actively looking for work, but there are just not many jobs available.

*"I am looking for work, but a lot of the places don't want to hire the old guy when they can hire the young guy," Mike says.*

Diana would like to return to work, but since she is under active treatment, she is not physically able to do so. As of June 2009, Diana had finished chemotherapy and was scheduled for surgery to find out how invasive the cancer is and what further treatment will be needed.

Even with insurance, Mike and Diana have mounting medical debt. When Mike found out he was going to be laid off, he applied for a \$10,000 unsecured loan to pay off all the outstanding hospital, doctor, and credit card bills the couple had accumulated. Since then, they have amassed \$2,000 in debt to the hospital where Diana is being treated. The hospital is working with the couple and has set up a payment plan, but they are still struggling to make ends meet.

*"Things are really tight right now," Mike says. "And, I don't see an end to it."*

By November 2009, their COBRA subsidy will expire and Mike will be responsible for the full \$569 monthly premium. With a history of cancer, Diana's options for coverage are limited. She does not qualify for Medicare until March 2011 and is not eligible for Medicaid. Due to medical underwriting, Diana would be denied coverage in the individual market, and the state's high-risk pool would likely be more costly than COBRA.

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- <sup>2</sup> U.S. Department of Labor. "Employment Situation Summary." 2 July 2009.
- <sup>3</sup> Lake Research Partners and American Viewpoint conducted survey on behalf of the American Cancer Society Cancer Action Network. National survey among families affected by cancer, conducted May 1 – May 11, 2009.
- <sup>4</sup> Kaiser Family Foundation. "Toplines: Kaiser Health Tracking Poll — April 2009." 2009 (#7892).
- <sup>5</sup> Schwartz K. "Health Coverage in a Period of Rising Unemployment." Kaiser Family Foundation. 2008 (#7842).
- <sup>6</sup> U.S. Department of Labor. Employment Situation Summary. 2 July 2009.
- <sup>7</sup> Internal Revenue Service. IRS Notice 2009-27, 2009.
- <sup>8</sup> Pereira J. "To Save on Health-Care Costs, Firms Fire Disabled Workers," *The Wall Street Journal*, 14 July 2003.
- <sup>9</sup> Internal Revenue Service. IRS Notice 2009-27. 2009.
- <sup>10</sup> National Endowment for Financial Education. *Understanding Private Health Insurance*, 2006.
- <sup>11</sup> The 35 states include Idaho's high-risk reinsurance plan and Florida's high-risk pool, which has been closed to new enrollees since 1991. For more information see National Association of State Comprehensive Health Insurance Plans. *Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis: Twenty Second Edition, 2008/2009*. 2008.
- <sup>12</sup> National Association of State Comprehensive Health Insurance Plans. *Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis: Twenty Second Edition, 2008/2009*. 2008.
- <sup>13</sup> National Association of State Comprehensive Health Insurance Plans. *Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis: Twenty Second Edition, 2008/2009*. 2008.
- <sup>14</sup> Some women can qualify for Medicaid through the Breast and Cervical Cancer Prevention and Treatment Act of 2000. This legislation allows states to provide full Medicaid benefits during cancer treatments to uninsured breast or cervical cancer patients under age 65 who are diagnosed through the Centers for Disease Control and Prevention's early detection program for low-income women. However, in some states, women who would have qualified for the screening program, but whose cancers were not detected through the program, are not eligible for this Medicaid coverage. The women in this study do not qualify for this Medicaid coverage because their cancers were not detected through the CDC's screening program.
- <sup>15</sup> Medicaid eligibility levels are based on a national survey conducted by the Center on Budget and Policy Priorities for the Kaiser Commission on Medicaid and the Uninsured in 2008.
- <sup>16</sup> Individuals with end-stage renal disease and amyotrophic lateral sclerosis (Lou Gehrig's disease) are exempt from the two-year waiting period.
- <sup>17</sup> Dale SB and Verdier JM. "Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs." *The Commonwealth Fund* 2003.
- <sup>18</sup> Halpern MT, Bian J, Ward EM, Schrag NM, Chen AY. "Insurance status and stage of cancer at diagnosis among women with breast cancer." *Cancer* 2007; 110: 403-11.
- <sup>19</sup> Halpern MT, Ward EM, Pavluck AL, Schrag NM, Bian J, et al. "Association of Insurance Status and Ethnicity with Cancer Stage at Diagnosis for 12 Cancer Sites: A Retrospective Analysis." *Lancet Oncology* 2008; 9:222-31.
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