

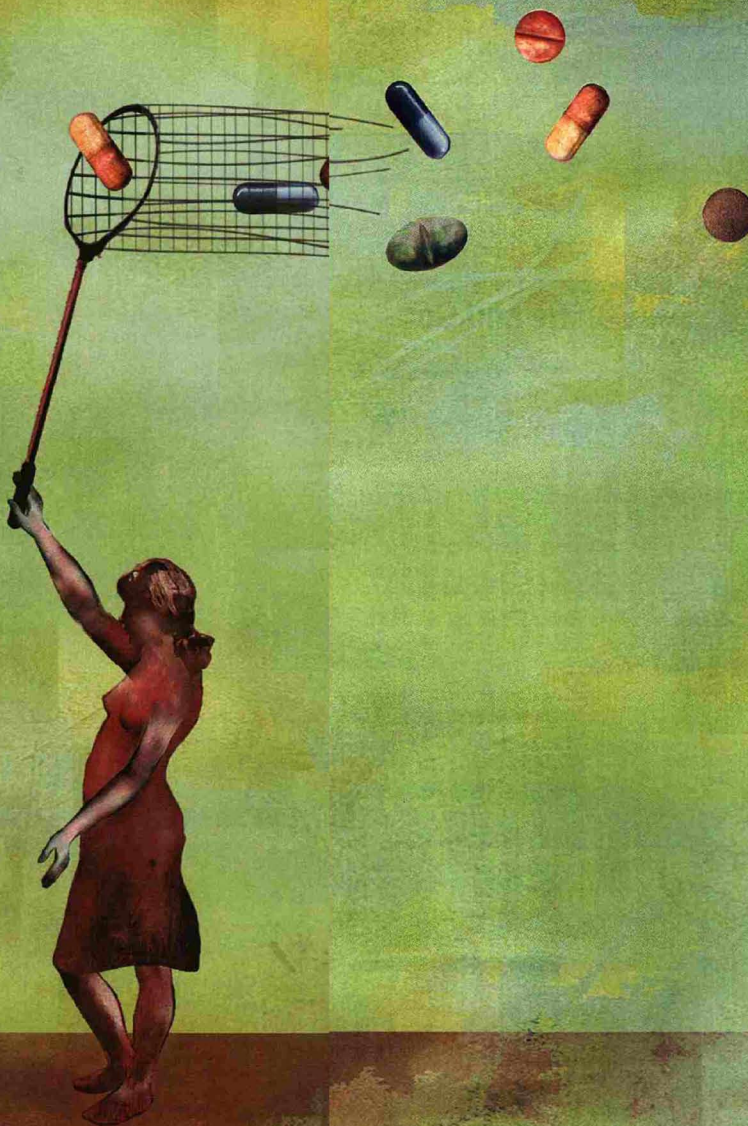
Arthritis Today

April 2009

What to do if you lose insurance – or can't afford it – after life throws you a curve

Getting Care on the Fly

BY MELANIE LASOFF LEVS



As the economy continues to sputter, many Americans are finding themselves in flux – changing jobs, changing insurance companies or changing their level of health-care coverage in an effort to stretch limited funds. Throw a chronic disease like arthritis into the mix and it can be downright devastating to confront a health-care transition.

But even if you've lost your safety net, in many cases there are things you can do to protect your health, your finances and your future. *Arthritis Today* spoke with real people who have faced – and survived – common challenges like skyrocketing drug co-payments, losing a job, being self-employed and aging out of your parents health plan. We also consulted health policy experts and consumer advocates to find out what you can do if you, too, find yourself without a reliable health-care safety net.



SITUATION: Co-Pay Skyrockets

Your insurance company reduces coverage of your biologic medication. Now you have to pick up most of the hefty tab. Find out how you can keep your medication without going broke.

When Laurie Shannon started weekly injections of etanercept (*Enbrel*) in February 2007, she says she got her life back. The 47-year-old Birmingham, Ala., single mom and sales associate for a printing company was diagnosed with juvenile arthritis (JA) at age 2. Over the last few years, its progress had accelerated, she says.

"I couldn't lift my arms over my head. I could barely brush my teeth or put on makeup," Shannon recalls, adding that she began walking with a limp due to swollen knees.

Within weeks, *Enbrel* – for which she paid \$50 a month under her employer's small-business health insurance – virtually erased all her symptoms. "I felt like 20 years had been taken off my age," she says. Her energy level, pain and mental health improved as well.

But a year later, the insurance company, Blue Cross Blue Shield (BCBS) of Alabama, sent a letter to Shannon's employer, stating that it would only pay half of the \$1,800 monthly cost for her *Enbrel* injections – effective immediately. Between *Enbrel* and her other medications, Shannon would have to pay \$1,000 per month.

"I was in a panic," she says. "Once I felt that relief [from my RA pain], I knew I couldn't go back to where I was."

WHAT YOU CAN DO:

When insurance companies suddenly change the terms of your coverage, your first – and perhaps only – line of defense is the state insurance commission. And it pays to complain, says Karen Pollitz, research professor at the Health Policy Institute at Georgetown University in Washington, D.C.

"Some [state insurance commissioners] are more or less aggressive in investigating," Pollitz says. "If you don't say

something, it's hard for the regulator to know what's going on out there."

This defense worked for Shannon. Her employer's human resources director called both BCBS and Alabama's Department of Insurance to contest the new policy; Shannon contacted BCBS and her local Arthritis Foundation chapter. Employees from other small businesses that were also covered by BCBS complained. Before the new pricing structure went into effect, it was repealed.

Shannon believes BCBS withdrew the policy due to consumer pressure, but what if they had not? There are resources that may be able to help if you can't afford your medications (see box on page 77).

SITUATION: Jobs Come and Go

Your line of work means intermittent employment, so you must find insurance on your own. That means you're often uninsured or underinsured between gigs. Here's how to bridge the gaps.

At age 16, Justin Baker, now 27, was diagnosed with ankylosing spondylitis (AS). Regular injections of a biologic drug have helped keep his immune system under control, but he hasn't been able to stay on it since he lost his student health coverage after he graduated from college and left Oklahoma to start looking for his dream job as an actor in Los Angeles.

For the first two years after graduation, Baker says, he had no health coverage. How did he cope without his biologic? "I would lock up every couple of weeks and there were days when I couldn't get out of bed," he says, "but I didn't really know what else to do at the time."

A friend alerted him to a professional association that offered coverage for actors. Baker says he paid about \$275 per month for the insurance, but it did not cover costly intravenous drugs like the one he had relied on for so many years to control his AS.

Fortunately, within a few months, Baker got more acting jobs and became eligible for a better health insurance plan through another professional association, the Screen Actor's Guild (SAG). He says he paid about \$200 per month and had minimal co-payments for doctor visits and prescription drugs. In October 2006 – during his year on SAG insurance – Baker had his left hip replaced, which he says cost about \$60,000 – but he spent just \$3,000. But acting work dropped off, and he lost his SAG coverage.

Once again, he's without a safety net.



"My right hip is acting up," he explains. "If I have to have surgery, I sure as heck don't have \$60,000."

WHAT YOU CAN DO:

According to a June 2008 study by the Commonwealth Fund, a private foundation that researches health-care issues, 50 million adults in the United States are uninsured, meaning they have no health insurance coverage, but an additional 25 million adults fall into another fast-growing and vulnerable group, the underinsured. People who are underinsured, like Justin Baker, may have some health-care coverage, but it does not protect them from high medical expenses.

You may be underinsured if your plan doesn't cover the kinds of care that you most need – like expensive biologic medications, cutting edge procedures or physical therapy.

For people who find it difficult to get enough coverage because of a pre-existing condition, many states have created insurance pools that allow individuals who live with chronic diseases to purchase coverage through a state-run group plan, rather than on the open market. Currently, 35 states offer these high-risk pools to insure those who have been denied coverage and/or who have pre-existing conditions who do not qualify for federally funded or other health insurance programs.

While these programs are better than no coverage at all, they are not perfect. Even though they are more inclusive, that coverage still comes at a hefty price – one that many find they cannot afford. They also don't last forever: California de-enrolls its beneficiaries after 36 months and offers them another insurance product that costs 10 percent more than the high-risk insurance.

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As each state's plan can have wildly different costs and eligibility requirements, visit the National Association of State Comprehensive Health Insurance Plans (NASCHIP) Web site, naschip.org, for detailed information and a list of state plans.

In California, where Baker is waiting for his coverage, beneficiaries pay a \$450-per-year deductible. He also faces up to \$2,500 in out-of-pocket expenses per year and a benefit limit of \$75,000 per calendar year and \$750,000 per lifetime – so that hip surgery could still cost him a lot. And Baker is still subject to a pre-existing condition exclusionary period, meaning

the plan will not cover his expenses related to his ankylosing spondylitis for three months.

Pollitz says consumers should use these pools as a last resort, and recognize that they are a temporary solution to being uninsured. "That safety net," she says, "doesn't always provide a soft landing."

Resources to Reduce the Cost of Prescription Drugs

Nonprofit organizations:
The Chronic Disease Fund
www.cdfund.org
877/968-7233

The HealthWell Foundation
www.healthwellfoundation.org
800/675-8416

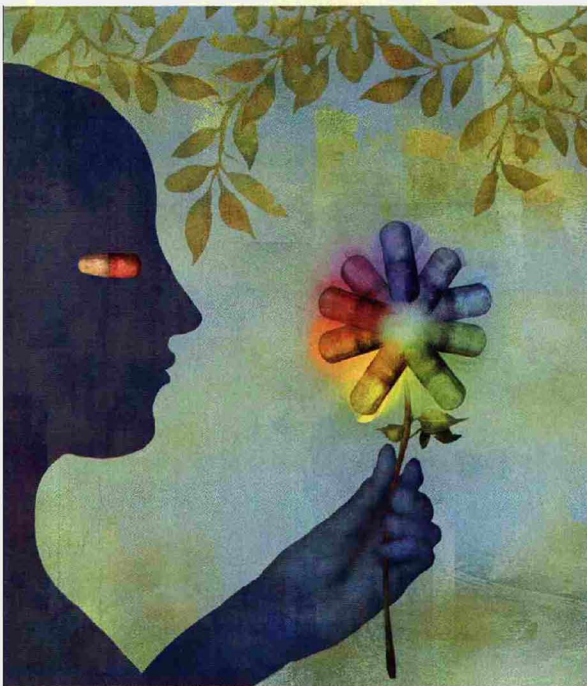
The Patient Advocate
Foundation Co-Pay Relief
www.copays.org
866/512-3861

For specific drugs:
Visit the Web site of your drug (typically listed on the packaging) or, for a directory of programs visit:
www.helpingpatients.org;
or www.rxassist.org

For veterans:
Veterans Administration
Health Benefits Services
Center
www.va.gov/health
877/222-8387

In your state:
To find a program administered by your state, go to the Medicare website and click on your state:
www.medicareriights.org/rxc_hart_states.html

In your county:
The National Association of Counties also has a drug discount program. To find out if your county participates, visit www.naco.advancex.com or call 877/321-2652.



Much has been written about the pros and cons of high-risk pools, including the fact that, though they claim to cover the “medically uninsurable,” they, too, exclude coverage of pre-existing conditions for a time. The Robert Wood Johnson Foundation State Coverage Initiatives project (statecoverage.net/matrix/highriskpools.htm) includes a chart with details about each state’s plan, including the exclusionary periods.

“Even if it’s one night a week, they’d consider if I can go to school full-time, I can go to work full-time.”

Her goal is to become a child psychologist, but that means working through her current situation. “There really isn’t much out there for people in my position, and, quite frankly, it’s scary as all get-out.”

WHAT YOU CAN DO:

You should try very hard to hold onto your COBRA, says Jennifer Jaff, an attorney and founder of the nonprofit organization Advocacy for Patients with Chronic Illness, in Farmington, Conn. Federal law states that if you go from one employer-based insurance plan to another without a break in coverage for more than 63 days, insurance companies can’t deny you coverage because of a pre-existing condition.

Because it is so difficult for people with pre-existing conditions to get health-care coverage, it’s crucial to keep your insurance until you are in a more secure health situation, Jaff says.

SITUATION: COBRA Too Costly

What happens when you get so sick that you can’t work? You’re in a downward spiral of no money and no health care. Here’s how to get back on your feet.

A year after 51-year-old Dianna Marie Chase was diagnosed with severe rheumatoid arthritis, she suffered a devastating flare. “I could not move – it was exhausting,” says Chase, who was working as a customer service agent for a car-rental company in Tulsa, Okla.

Three months later, Chase, who’d been with the company for 15 years, was still unable to return to work. So in February 2006, after exhausting all her legal time-off options, Chase lost her job.

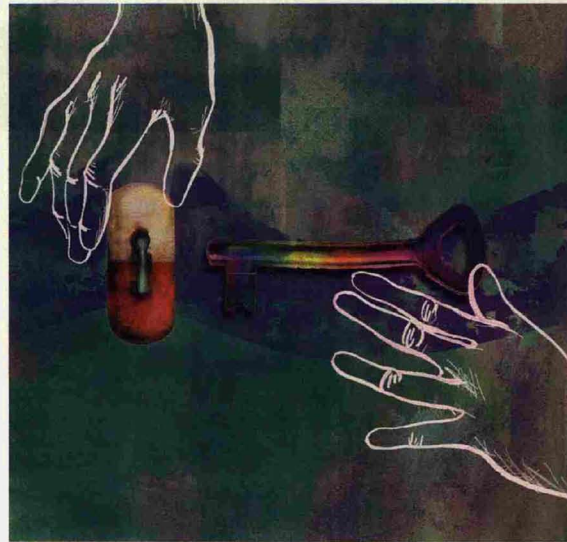
Her company paid her health insurance for three months, after which Chase had the option of going on COBRA, which is shorthand for the Consolidated Omnibus Budget Reconstruction Act, a piece of federal legislation that guarantees most unemployed workers the right to continue the same health insurance offered through their company policy for a limited time.

Unfortunately, COBRA doesn’t come cheap. Those who qualify must pay the entire premium up to 102 percent of the cost of the plan. In Chase’s case, it would have cost \$600 a month, an amount that she could not afford.

Instead, she applied for disability benefits from the Social Security Administration and health-care benefits through Medicaid, a program that provides health-care coverage to low-income children and adults.

She and her two young children did qualify for health coverage through their state Medicaid program, which pays for Chase’s eight medications. But it took some time and a lawyer for her to finally qualify for Social Security Disability Insurance, or SSDI, which covers some living expenses. Chase says the money doesn’t go very far.

Before she lost her job, Chase says she was one year from finishing a degree in psychology. “If I go back to school, I lose my disability and my Medicaid, so I’m stuck” with a limited income, she says.



“If I had to choose between paying my mortgage and paying COBRA, I’d pay my COBRA,” says Jaff. “Other kinds of debt can be worked out – you can refinance your house or give partial payment to your landlord for a month or two – but the minute you let your insurance go, it’s gone.”

If you simply cannot afford to continue COBRA, it’s wise to apply as soon as possible for Medicaid, a program administered by each state for people with low incomes and/or other requirements. You also may qualify for medication payment assistance (see box on pg 77).

Recently, plan administrators have realized that the prohibitions against employment and education that are built into

the disability program prevent some people from getting back on their feet. So the Social Security Administration has begun to offer several programs which could help you go back to work on a trial basis while keeping your benefits.

For information on SSA “return to work” programs, visit www.socialsecurity.gov or call 800/772-1213.

SITUATION: Student Status Gone

As a young adult and full-time student, you’ve been covered on your parents’ health insurance. You’re graduating from college soon, so you will no longer qualify for that plan. Here are your next moves.

Lora Swartzendruber, 27, was diagnosed with arthritis at such a young age that she doesn’t remember what life was like without pain. “All my life, I haven’t known anything other than this,” she says.

The Kansas native also has spent all her life covered on her parents’ insurance, as their dependent and a full-time student. Though she wanted to take a year off after graduating from high school, she knew she would lose her student status and, therefore, her health coverage. Arthritis “really has tainted every decision I’ve ever made,” Swartzendruber says.

After graduating in May 2004 from Bethel College in Mishawaka, Ind., Swartzendruber had private insurance for three months through the Mennonite church, where her family has membership. Her parents helped her pay the \$300-per-month fee and made sure she had methotrexate while she looked for a job.

She landed full-time work for a nonprofit mental health center, which offered a comprehensive benefits plan, she says. A year later, Swartzendruber decided to continue her studies in graduate school at the University of Kansas, a state school with a \$900-per-year student health plan. Though the student plan does not cover specialists like a rheumatologist, Swartzendruber still is able to take methotrexate with a copay of about \$10 per month.

Now, August 2009 is looming: She graduates and loses her student health plan. “I’ll be on a deadline to find a job, in part because of the insurance factor,” Swartzendruber says, adding that her decision on a job also will be impacted by whether she has guaranteed health insurance.

And what if she does not find a job in time? Swartzendruber says her parents will help her pay for private insurance again, but she is ready to be on her own.

WHAT YOU CAN DO:

Census data confirms that people ages 18 to 24 – the age children often phase out of their parents’ plans – are the least likely of any age group to have health insurance. When you have a

chronic condition like arthritis, going without coverage can have lifelong impacts on your health. So how can you keep your safety net?

Start the job hunt early.

Roughly 60 percent of all Americans get health insurance through their employers, though that figure is shrinking as rising premiums are forcing many businesses to cut this important benefit. It is possible to buy an insurance plan as an individual, but insurance plans offered on the open market tend to be more expensive and less generous than employer-provided coverage.

Even if your friends choose to goof off the summer before their senior year of college, you need to pound the pavement to ensure you find an employer and, therefore, health insurance. Under the 1974 Employee Retirement Income Security Act (ERISA), employers of certain sizes are required to provide health and other benefits to their employees. In 1996, ERISA was amended to include the Health Insurance Portability and Accountability Act (HIPAA), offering new protections for group health plan beneficiaries including people with pre-existing conditions.

When you sign up for a plan as an individual, your application goes through a process called underwriting, where an analyst scrutinizes your medical and credit history to determine the level of risk the insurance company will face if they insure you. The bigger your risk, the more expensive you’re likely to be.

If you are deemed to be too expensive to cover, maybe because you have a chronic condition like arthritis, they can refuse you coverage. Or, they may offer you a plan, but refuse to cover any ailments for which you were treated up to six months before you signed up for your plan – so-called pre-existing conditions – for a period of time that can range from a few months to a year.

Many people with JA find it very difficult to find or afford individual coverage, but it may be easier to get health insurance coverage through an employer.

Insurance companies make more money when big groups of people sign up for their services, so they offer groups, like all the employees from one company, or state pools, better rates. Because they are able to absorb the costs of people who have chronic conditions more easily when they are in a pool, they are often less restrictive about who and what they will cover.

So if Swartzendruber is unemployed when she graduates, she will be lucky to continue to get health care with help from her parents. Young adults without that protection face issues such as Shannon’s, Baker’s and Chase’s, who also have some solutions available.

Health-care transitions are scary, and they often strike at times when you’re at your most vulnerable – after the loss of a job, for example, or after you move away from home for the first time. The key to thriving and staying well is to meet the challenge head on.

Karen Pollitz, of the Health Policy Institute, adds, “The more planning you do, the less hysteria you are going to have to deal with.”

Melanie Lasoff Levs is a freelance writer in Atlanta, Ga.