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INSURANCE

Some Policies Quit Paying For Key Parts of Treatment

By **AMY DOCKSER MARCUS**
Staff Reporter of THE WALL STREET JOURNAL

When Lisa Keaton was diagnosed with leukemia a few years ago, she didn't worry about paying for her bone-marrow transplant. She has health insurance through her job at Valdosta State University in Georgia.

Then the 42-year-old mother of five learned that her plan covered the transplant -- but not the search for a bone-marrow donor. The search alone cost her close to \$10,000 in out-of-pocket expenses. Along with the other costs not covered by her insurance, the operation put her family into debt that will take them years to erase.

The plight of the uninsured has always been a focal point for critics of U.S. health care, but a vexing problem is on the rise for people who thought they were well prepared for any medical calamity: A growing number of policies now exclude critical but expensive aspects of care, from hepatitis drugs to even pacemakers.

Some plans limit the number of "episodes" they will pay for -- such as covering a single mastectomy. But later, if a tumor is found in the second breast, it's considered an out-of-pocket expense.

Insurers, health plans and employers have always limited the kinds of things they cover, often excluding risky, experimental treatments. But now, employers are excluding more and more procedures in an effort to hold down costs.

Among other key treatments no longer included on some policies: ventricular assist devices, which help the heart pump while a patient awaits a heart transplant, and coverage for drugs that are necessary to treat chronic medical conditions such as hepatitis C, hemophilia and Crohn's disease. If you suffer a stroke and need speech therapy, you may not be covered for all the sessions you need.

COVERED?

More insurance policies are now excluding expensive but critical aspects of care.

Among them:

- Pacemakers
- The search for a suitable transplant donor
- Hepatitis drugs
- A masectomy on a second breast
- Pre-transplant heart pumps

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For their part, insurers say they're willing to provide the coverage, but companies aren't always willing to pay for it. James Coates, senior medical director for [Aetna Inc.](#), says that Aetna's standard policies include coverage for "all the essential things for transplant," including the search for a donor, but that employers choose which benefits to buy.

Frustrated Doctors

For doctors trying to treat these patients, there is growing frustration over the expanding list of exceptions. "I liken the situation to someone who needs a heart-valve replacement and the insurance company saying we cover all the costs of the operation but you have to go to the hardware store and buy the valve yourself," says John Wingard, Mrs. Keaton's doctor and the director of the blood and marrow transplant program at the University of Florida College of Medicine in Gainesville, Fla. "In the case of transplants, it's hard to do a transplant without a donor."

But as the number of loopholes in policies grows, "you are likely to find yourself having to pay large sums of money out-of-pocket," says Nancy Davenport-Ennis, president of the Patient Advocate Foundation. Around 80% of the 25,000 cases nationwide handled by the Newport News, Va.-based foundation last year involved insured people who had trouble paying for physician-approved treatments because of policy limitations.

Mrs. Keaton says she realized that too late. When told her health insurance didn't cover the search for a donor, she handed her Discover card to the bone-marrow transplant coordinator at Shands Hospital at the University of Florida, where the transplant was done, and said, "When it maxes out, tell me." At a cost of around \$850 per person for DNA high-resolution testing to find a donor with a suitable tissue type, Mrs. Keaton quickly reached her credit limit.

First her three siblings volunteered to be tested. Her sister was a perfect match but has hepatitis; doctors were worried that Mrs. Keaton might not be able to fight off the infection in her weakened state. So the center kept looking, searching through registries of potential donors all around the world. Eleven donors were typed, for which Mrs. Keaton paid out-of-pocket; none of them were suitable candidates. Another 20 donors were typed free of charge because the transplant coordinator got Mrs. Keaton enrolled in a study being done by the National Marrow Donor Program.

In the end, doctors decided to use her sister as her donor, despite the risks, because there was no suitable match. She is now recuperating in the hospital from a successful operation.

Fear of Catastrophic Claims

Undercoverage has become more pervasive as sophisticated new medical procedures become more commonplace. Charles Crispin, chief executive officer of Evergreen Re Inc., a health-care consultant in Stuart, Fla., says he has noticed more restrictive policies recently as companies struggle to protect themselves from catastrophic claims. He points to one client that provided coverage for a hemophiliac teenager whose drug bill was over \$16,000 a month. "It all comes back to the company's ability to finance it," says Mr. Crispin.

The problem is increasingly acute with bone-marrow transplants, which are used to treat a wider array of diseases than ever before.

Sometimes excluded expenses are deemed nonmedical, but are nonetheless a critical part of care. For instance, bone-marrow transplant patients must live near the transplant center for at least two months after the operation. Though hospitals often get reduced rates on accommodations for their patients, "people often have to go out and fund-raise, have garage sales, ask for help from their church just to pay for housing," says Becky Gaa, the bone-marrow transplant coordinator for Shands Healthcare System.

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Even when there is coverage, co-payments can add up. Many people have 15% to 20% co-payments for prescription medicines, but medications to insure a patient doesn't reject transplants can sometimes run \$3,000 a month -- making medication as costly as a new car loan.

To safeguard against shortfalls, consumer advocates recommend asking for a complete copy of your employer's plan and then expressing any concerns about gaps in coverage. Groups like the Patient Advocate Foundation can step in and negotiate on behalf of consumers, and state insurance commissioners can sometimes assist patients.

Model Policies

Changes are already under way. Last year, the National Marrow Donor Program in Minneapolis initiated a round-table discussion involving key insurance-company representatives, transplant doctors, and some patients to raise awareness of the gaps in transplant coverage. Eventually, working with insurers, the donor program hopes to come up with so-called model insurance that would include donor searches in standard transplant coverage and that could be adopted by all insurers.

For Mrs. Keaton's employer, Valdosta State College, the Board of Regents says that not covering the search for a donor wasn't a deliberate omission. But recently, though it's too late to help Mrs. Keaton, the board decided to adopt search coverage as part of its transplant benefit. As of Jan. 1, employees at Valdosta State College are covered up to \$10,000 for the costs of searching for a donor.

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