

CONTENTS

Hard Times

BY JOANNE KENEN

How to make ends meet during caregiving.

After flying corporate jets for General Electric for 16 years, pilot Todd Chisholm was ready to spread his own wings. He put the final touches on his financial plan, and set out to run his own business as an aviation safety consultant with a few corporate pilot gigs on the side.

Financially, he was in for a rough landing when his wife of three years, Debbie Charles-Chisholm, was diagnosed with breast cancer at age 41, and she needed her husband's help. He put his business on hold and became a full-time caregiver for eight months as his journalist-wife went through multiple surgeries and a long, painful series of complications. He gradually resumed his own career, but still spends considerable time nurturing his wife. At one point during her chemotherapy, he shaved his own head in a gesture of solidarity and humor.



Todd Chisholm's income dropped by \$50,000 when he became a full-time caregiver to his wife. Photo by Colby Ware.

Charles-Chisholm had good insurance and a flexible employer. But the couple had always counted on two incomes to pay their mortgage and other bills. With his

new venture on hold, Chisholm's income dropped by about \$50,000—at a time when their out-of-pocket medical costs were rising. They dug into savings, tightened their belts, gave up spending on a lot of the things that had made their life together so much fun. “We called it our year of living cheaply,” he recalls.

Two and a half years later, she is cancer-free, though still experiencing pain and side effects from ongoing drug therapy.

The Chisholms were luckier than some families. They had some money in the bank to cushion the financial blow. Plus, a colleague set up a website, and friends, neighbors, and family pitched in to cook, shop, and help out during the toughest times. One friend sent “brain candy,” a six-month gift subscription to *People* magazine.

““ We called it our year of living cheaply. ””

—Todd Chisholm

For families living paycheck to paycheck, the financial burden of caregiving can be harder. “They are operating on fairly tight margins as it is, or they wouldn't be doing as much of the caregiving by themselves,” says Carol Levine, director for the families and health care project at the United Hospital Fund in New York.

The financial costs of caregiving include not just the patient's co-pays and deductibles, but lost wages and travel expenses for both patient and caregiver. There's the time spent on insurance paperwork, researching treatment options, filling prescriptions, making special meals, managing symptoms, and scheduling and driving to appointments, says Bill Given, PhD, a professor of family medicine at Michigan State University in East Lansing. “It really takes quite a bit of time.”

Understanding the hidden costs is crucial so that families can anticipate needs, and figure out how to plug the gaps. The quest for finding help has three tracks. One involves friends and family, similar to the network of people who supported the Chisholms. The second is seeing what kind of flexibility or support is available through the workplace. The third involves the vast, and sometimes fragmented, world of community -resources, social services, church and volunteer networks, government programs, and advocacy groups such as the American Cancer Society and Patient -Advocate Foundation.

In all three realms, the strategy for caregivers is basically the same: “Ask everyone you can think of. And then keep asking more people, even if it feels awkward,” says Julia Bucher, RN, PhD, an associate professor of community nursing at York College of Pennsylvania and co-editor of the forthcoming revised version of the American Cancer Society's *Complete Guide to Family Care-giving: The Essential Guide to Cancer Caregiving at Home*.

Online resources such as Lotsa Helping Hands (www.lotsahelpinghands.com), Share the Care (www.sharethecare.org), and Care Central (www.carecentral.com) make it easy to set up and organize friends and family into a caregiver support crew. Primary caregivers can ask people to share child care, bring over a meal,

run an errand, or check on the patient when they can't be there, which can help defray costs.

Cecilia Lucas, 33, took a leave of absence from graduate school at Berkeley to become a full-time caregiver when her mom, Mary, 62, was diagnosed with pancreatic cancer. Lucas's school was flexible, rearranging her fellowship funding so she could afford to resume her studies later.

Lucas's mother lives in a small town near Asheville, North Carolina, but the best medical treatment was at Johns Hopkins in Baltimore. There was no way logistically or financially that the family could move to a different state for months, until some old friends offered a room in their home in a Maryland suburb for four months.

But Lucas still had to pay rent on her California apartment while she cared for her mom. She scrambled to find a part-time job as she took on the caregiver role.

Most cancer family caregivers are employed outside the home, and some may find their employers are open to a flexible work schedule, telecommuting, or sick leave. Under the Family and Medical Leave Act of 1993, caregivers can take up to 12 weeks off. Although health benefits continue for the employee during the job-protected leave, the law does not require paid time off. It does, however, allow for paid leave to be substituted for unpaid leave. (Read more about the legal rights of caregivers in "[Taking Care of Business](#)" from the Winter 2008 issue.)

That leaves the maze of social services, which even professionals say is frustratingly hard to navigate.

"There is some help out there, some of which can be outstanding, but it's fragmented," says Diane Blum, LCSW, executive director of CancerCare. "I can't tell you, 'Yes, you can get this or this.' It depends on how old you are, what insurance you have, where you live. It's all very individual."

A patient's treatment center is the place to start. Most centers employ social workers who know where to turn and what the patient might be eligible for. Some centers have patient navigators to guide families, while at smaller centers or clinics, nurses can help steer families. But don't assume the hospital or treatment center will give you all the information you need unless you speak up, repeatedly and persistently, Bucher says.

Churches and other religious organizations may also be able to help. Nonprofits focused on cancer can guide you to services and assistance programs, particularly with drug costs. It's worth exploring all avenues, social workers say, and getting help to find the options.