

The Juggling Act

By Lauren Gerstmann, MPH

Having primary responsibility for the health of another person can be gratifying and rewarding; it can also be a terrifying juggling act. If you are a parent earning an income and the caregiver of a chronically ill child, how do you balance the needs of your child, your job, your mate—and still take care of yourself?

In theory, there are U.S. government policies in place to protect parents in this position.¹ Under the Family and Medical Leave Act of 1993 (FMLA), covered employees are entitled to a total of 12 administrative workweeks of unpaid leave during any 12-month period for:

- the birth of a son or daughter and care of the newborn;
- placement of a son or daughter for adoption or foster care; care of your spouse, son, daughter or parent with a serious health condition; and
- your own serious health condition that makes you unable to perform the duties of your position.

You are covered under FMLA if you work for an employer with 50 or more employees or if you work for a public agency or school. Additionally, if you are a federal employee with a medical emergency, and you have exhausted your own leave, the leave transfer program allows other federal employees to donate annual leave to you. Some private employers also

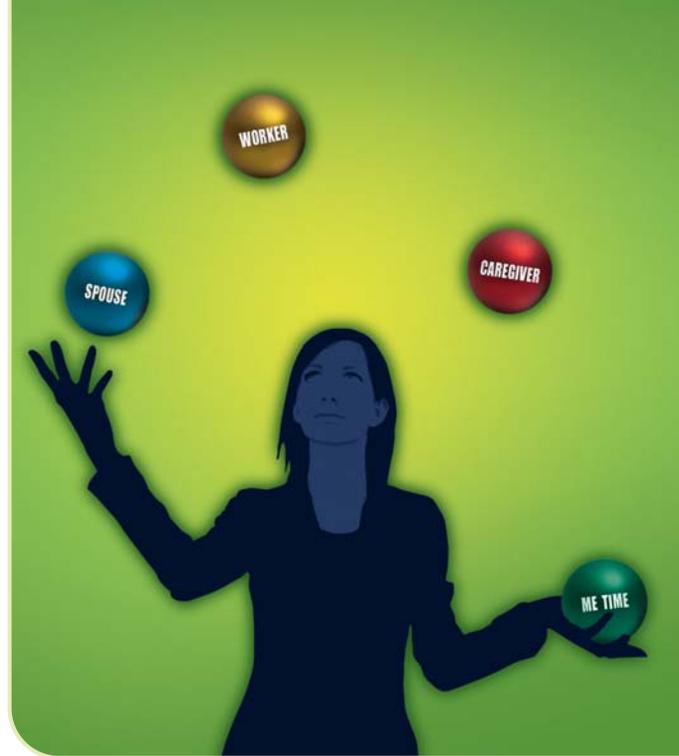
have leave-banking programs. These programs allow members (those who contribute a specific amount) to apply for leave from the leave bank in the event of a medical emergency.

These are helpful policies but may be more practical to allow you to care for someone with an acute illness rather than a chronic illness. Also, since these policies legislate unpaid leave, you may still have trouble if your income is a key family support. Additionally, there are subtle pressures not to use the leave to which you are legally entitled. Jane's son, Stuart,² needed surgery on his airways a few weeks after he was born. Post-surgically, he was incredibly vulnerable to infection and anything he ate could get into his airways and cause an infection. His doctors gave Jane strict instructions that anything other than breast milk could be very dangerous for him. In theory, Jane had access to a very generous leave policy in her office, but the reality was that other people were financially dependent upon her being in the workplace. Jane's funding and her staff's salaries were dependent upon quotas that they could not meet without Jane's direct supervision. Jane went back to work.

It is very stressful when the work that allows you to pay for health

insurance and medical care also can take you away from your child. The situation becomes additionally stressful if your child has a chronic illness that prevents his or her functioning in a group care or group educational situation. Individual Education Programs allow children with special needs to be mainstreamed into public school and give their parents the freedom to return to the workplace. But, if your child is too ill to come into contact with many other children, you need to find a solution that will allow your child to stay at home.

The stress and overwork may end up compromising your own health. Research has shown that women even more than men may suffer health consequences. But, this may be a result of how caregiving is structured rather than due to a true gender difference in health outcomes.³ Traditionally, men have cared for their families by offering financial support, while women have borne the brunt of hands-on care. But more and more families can no longer afford to have one parent stay at home. As a ➤



¹ U.S. federal policy can be found at: <http://www.opm.gov/oca/leave/html/levbro.htm>

² All situations presented in this article are true, but names have been changed to protect privacy.

³ Burton P, Lethbridge L, & Phipps S, "Children With Disabilities and Chronic Conditions and Longer-term Parental Health" <http://atlanticresearchdatacentre.dal.ca/> 2006

result, fathers are increasingly sharing in major caregiving duties. Soon, we are likely to see them suffering the same burden of stress and health consequences. Fathers also face some unique pressures as the emphasis in the literature and in the workplace is on improving the work and family balance for mothers. Men may be less comfortable taking lengthy leave to bond with a newborn child, and may be less likely to discuss their caregiving responsibilities with colleagues.⁴ As a result, the discussion may shut men out, making men feel more alienated and less able to share in childcare. Ironically, this leads to more of a burden on mothers.

Janet Gornick and Marcia Meyers have extensively studied the balance between work and family life in the United States. In their 2003 book "Families That Work,"⁵ they compare the quality of the balance that families are able to achieve here with the balance that European and Canadian families are able to achieve. Gornick and Meyers conclude U.S. federal policies are less supportive of families than are the policies of any of the 12 other countries that they studied. Based on what they have learned from other Westernized nations, their goal is to create a "dual earner-dual career society." They define policies that will support entire families, allowing women more choices in returning to the workplace, making caregiving support more inclusive of men, maximizing children's time with their parents, and making sure that all children have access to high-quality care. Specifically, they advocate more generous family leave policies (for both parents), reducing the number of hours in the work week, increasing the quality and amount of publicly provided early childhood care (for example, public preschool), and matching the time that children are in school more closely to the time that parents are at work. While their work is targeted toward families in general, some of their policies (particularly their suggestions for leave policies) are especially relevant for families caring for chronically ill children.

Unfortunately, our government is a long way away from adopting the ideals of Gornick and Meyers. But some of their suggestions can be adapted to personal use. For example, (when possible) involve both parents in childcare—especially if both parents work. Take turns using your sick and vacation time to care for a child at home. Perform a cost benefit analysis for your job versus

your healthcare responsibilities. If both parents are working, but specialized schooling, increased sick time, and increased payments to professional caregivers total up to more than the income of one parent, perhaps that parent should stay home. Don't automatically assume that this means Mom needs to stay home—Dad may prefer to and should feel equally supported if he makes this decision. Fathers who wish to stay home with their children should know that they have plenty of company. In 2003, roughly 160,000 fathers made the choice to stay at home to care for their children.⁶

Another option, instead of taking the financial hit of having one parent stay at home, is that some families share caregiving by making the decision to "tag-team" parent. Parents stagger their work schedules so that one parent is always home with the children. This approach has a number of advantages. It is very economical because it allows for two incomes without the cost of paid childcare. And, if your children have complicated health needs, it means that they will always be with the people who know best how to care for them. Tag-team parenting may also allow both parents to pursue their careers. But, for all of the benefits, consider this option cautiously as all that time apart can place serious stress on your marriage.⁷

If you are a single parent or if both parents need to work, you might want to think outside the box to consider unusual solutions. Jane, mentioned above, felt obligated to return to her office even though her son was chronically ill and dependent upon her. However, Jane was unwilling to jeopardize the health of her child, so she spoke with her boss and explained that she could come back to work only if she could bring her nursing infant with her. Her boss allowed the baby in Jane's office, and Jane was able to take care of her child and follow through on her responsibilities to her staff.

Another way to spend more time at home is to reduce your hours in the office, either through a reduced schedule or by telecommuting. Part-time work is a great option but often pays less than full-time work and may not provide you with benefits. Sometimes, though, you may be able to reduce your hours without officially working part time. For example, at the University of Southern California, you are eligible for benefits as long as you work more than 50 percent of a full-time schedule. So you could work 21 hours per week and still receive the benefits. There are

⁴ Cooper, M, "Being the Go-to guy: Fatherhood, masculinity, and the organization of work in Silicon Valley" in "Families at Work: Expanding the Bounds." Vanderbilt University Press, 2002.

⁵ Gornick JC & Meyers MK "Families That Work: Policies for Reconciling Parenthood and Employment" Russell Sage Foundation, 2003.

⁶ Census Bureau; 2003 March CPS : America's Families and Living Arrangements <http://www.census.gov/prod/2004pubs/p20-553.pdf>.

⁷ Boushey, H, Tag-Team Parenting: Center for Economic and Policy Research August 2006 http://www.law.georgetown.edu/workplaceflexibility2010/News_Roundup/2006/September/1/documents/tagteamparenting.pdf.

also options to increase your flexibility while working full time. If your work can be done over the computer or telephone, you may be able to telecommute part of your hours. Telecommuting might provide benefits for your employer as well, especially if office space is hard to come by or if your employer is active in preserving the environment. In 1992, AT&T implemented a corporate policy to encourage telecommuting. The plan has been both popular with employees and good for the environment (which is, of course, good for AT&T's reputation!). "Reducing the number of AT&T people in single-occupancy vehicles all day or during rush hour can result in enormous savings in fuel consumption, pollution and traffic congestion," says Kathie Fink, of AT&T's Environmental Health and Safety team.⁸

If you are interested in some of these options but are unsure how to make it work, check out WorkOptions.com.⁹ For a fee, you will find templates and tips for writing a

proposal to telecommute, work part time, job share or switch to a compressed workweek schedule.

So to sum it up, because our government does not provide a comprehensive program to assist you in supporting the health and financial needs of your children, you need to be creative. But there are solutions out there, and which solution is best depends upon your individual situation. If you are in a position to forgo some income, Mom or Dad can stay at home, work part time or make more efficient use of employee leave policies. If you cannot forgo income, try an alternative work schedule, telecommuting, staggered work schedules or working a compressed week. Maximizing your ability to care for your child while earning an income is daunting, and American families do not get a lot of help. But, with creative time management and research into the resources available to you, you can do both of your jobs well. ■

⁸ AT&T website: http://www.att.com/ehs/annual_reports/ehs_report/report96/page11.html.

⁹ <http://www.workoptions.com>.

A Resource Toolbox for Working Caregivers

Alternative work options

Home Based Careers

www.edirectoryofhomebasedcareers.com/dir2.htm

Download an eDirectory of home based careers.

Work Options

www.workoptions.com

Templates and tips for writing a proposal to telecommute, work part time, job share, and/or switch to a compressed workweek schedule.

Caregiver support services

Caregivers USA

www.caregivers-usa.org/db/index.html

Provides an index of local and state caregiver support services.

AARP

www.aarp.org

If you are caring for a spouse or parent, AARP has valuable online resources.

Please see their research report on "Caregiving in the United States" at www.aarp.org/research/housing-mobility/caregiving/fs111_caregiving.html. Links to caregiving resources are also provided at this site.

Financial resources

To help you obtain insurance, medical care or drug benefits:

Patient Advocate Foundation

www.patientadvocate.org

800-532-5274

A national nonprofit organization that serves as an active liaison between the patient and his insurer, employer, and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to his diagnosis through case managers, doctors and attorneys. They offer a pharmaceutical co-pay assistance program to patients who qualify medically and financially.

Families USA

www.familiesusa.org

202-628-3030

A nonprofit organization dedicated to the achievement of high-quality, affordable health and long-term care for all Americans. At www.familiesusa.org/resources/program-locator, they offer a program locator that will direct you to a local program to answer questions and assist you in obtaining health insurance. Programs may also be able to refer you to low-cost or free health care, including prescription drug assistance.

Health Insurance Resource Center

www.healthinsurance.org

A resource for families, individuals and the self-employed, this website provides the tools to become a better-informed health insurance consumer. It is also possible to obtain quotes from reputable, financially stable insurance companies. This website will also help you find insurance if you have a pre-existing medical condition.

The Medicine Program

www.themedicineprogram.com

Volunteers who are dedicated to assisting the growing number of patients who cannot afford their prescription medication established this organization. Their function is to help patients who may qualify to enroll in one or more of the many patient assistance programs that provide prescription medication free of charge to individuals in need.

SKIP: Sick Kids Need Involved People

212-268-5999

This is an advocacy group that helps families receive financial aid, nursing services and government medical services that they may be entitled to for their chronically ill child.