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The Guilt Factor

BY MICKEY GOODMAN

Releasing guilt's grip on the caregiver left behind.

When 7-month-old Cian died in October 2006, just two months after a diagnosis of neuroblastoma, Jennifer and John Crowley of Quincy, Massachusetts, were devastated. Tremendous grief gave way to the couple's decision to have another child after Cian's oncologist and a genetic counselor assured them his tumor was not hereditary. The joy of Pdraig's birth last September came with considerable guilt.

"When I find myself smiling at something he's done, I think, 'Should I be happy?'" Jennifer Crowley says. The couple recently crossed a threshold when their son had his seven-month "birthday"—Cian's age when he died. The milestone has eased their pain and guilt, says Crowley.

The feeling is easy to identify. It's that gut-wrenching reaction when a moment of joy distracts from the tremendous loss. Caregiver guilt can take other forms as well. Some feel guilty they survived while their loved one died. Others blame themselves and wonder if they caused the cancer or could have done something to prevent it.

"Guilt is a feeling that you failed," says Leslie Gorski, PhD, a loss and grief specialist in Duluth, Georgia, and former bereavement director at Kaiser Permanente in Los Angeles. "It's nearly always unfounded and can block good healing."

✕ Guilt is like a warning light on your dashboard. Define the problem and what you need to do to solve it. No one can make you feel guilty. Guilt is an inside job. ✕

—Vicki Rackner, MD

The Guilt Trap

Vicki Rackner, MD, left the operating room to help caregivers and patients embark on a path from illness to health. As founder of Medical Bridges, a company that serves employers by having workers take a more active role in their

health care, and an expert for Johnson & Johnson's caregiver website, StrengthforCarer.com, she is familiar with the power of guilt.

"Guilt is like a warning light on your dashboard," she says. "Define the problem and what you need to do to solve it. No one can make you feel guilty. Guilt is an inside job."

Since unrecognized guilt can eat at the soul, Dr. Rackner recommends former caregivers examine the disconnect between the person they think they should be and the person they are. "Your ideal you might remain faithful to your deceased spouse. The real you may be ready to find another romantic partner."

The double whammy of dealing with grief and worrying about how young children are coping can derail young widows. Before Lin Beaty's husband, Barry, died of astrocytoma, the normally take-charge pediatric oncology and hematology nurse felt that as a medical professional, she should be the one making the decisions for him.

"Barry relieved me of all the guilt when he said, 'At the end of the day, the choice is mine and the consequences are mine,'" says Beaty, who lives in Atlanta. By assuming responsibility, he helped her move on. "I think he would have been proud of me."

Leanne Jones of Solon, Ohio, also avoided guilt derailment. Before her husband, Brian, died of leukemia, he prepared the family to go on without him. "Brian told me that he didn't want me to have any regrets," says Jones. Because of his open discussions, Brian absolved his wife and their three daughters of much of the guilt that normally follows.

After his death, the family participated in counseling at The Gathering Place, a cancer support center in Cleveland. Guilt was a frequent topic. "It helped us all move on," Jones says. While she met with others who had lost spouses, the children found peers with whom they could share their feelings.

The Crowleys also benefited from counseling. During the period Jennifer calls "shock and awe," the couple dealt with the grief and guilt by talking with a counselor and other parents at Boston's Dana-Farber Cancer Institute, where Cian was treated.

They also found relief through establishing Cian's Cause (www.cianscause.org), which Jennifer says gives meaning to his short life by raising awareness about the disease for parents and pediatricians.

"Dealing with parental guilt is often the most difficult," Gorski says. "Couples like the Crowleys will never sever their attachment to the child they lost. They just take care of his memory in a different way, much as parents change their nurturing methods as their children mature."

Caregivers often confuse joy with forgetting their loved one, Gorski says. "But they can't live in a mummified world." If they do, it can lead to severe depression, manifested by isolation, persistent sadness, and an inability to resume normal activities. "When caregivers feel totally consumed, it's time to seek professional help," Gorski says.

Finding Joy

Regardless the age of a “child,” the loss of a parent is traumatic. When his mother died in June 2007 of bladder cancer, Mark Blaustein, 50, sought help at [CancerCare](#).

Despite making careful decisions about his mother’s health, Blaustein says guilt is a recurring topic in the caregiver group sessions. “We talk about how we should have done this or that faster,” he says. “We also agree that it is OK to laugh and smile and cry again—sometimes all at the same time.”

Blaustein has talked to his father about the possibility of a female friend. “I told him, ‘If you are looking for my blessings to move on, you have them. I don’t want you to be lonely.’ ”

Not all adult children feel the same. “Men usually start dating earlier than women, and remarry sooner,” says Dominick Bonanno, senior social worker and supervisor at CancerCare. “It’s often hard for the children. I recommend that the surviving spouse refrain from sharing too many details and advise their adult kids to try and be more open-minded.”

Gorski and Dr. Rackner recommend frank discussions with children. “Validate their feelings,” Gorski says. “But let them know that you feel you deserve happiness. If you stay strong, they’ll come around, whether 30 or 13.”

By embracing change, caregivers can move to a new phase in their lives. “Starting over means doing things differently,” Dr. Rackner says. “Guilt ties you to the past. Give yourself permission to move into the future.”