

NAVIGATING THE GUILT

By Lori Jakiela

CAREGIVING MEANS *allowing* **OTHERS TO CARE**

Sometimes the key to caregiving is knowing when to step back and allow others to care, too.

"People want to help. They will offer to help," says Lillian Sweeney, R.N. and educational coordinator for Family Hospice and Palliative Care in Western Pennsylvania. "The key is to know how and when to open up and let them help."

Sweeney, who spent more than 20 years in oncology nursing before joining Family Hospice six years ago, says the best advice she gives to caregivers is: "Make a list."

She remembers one man who was so overwhelmed by the offers of neighbors and friends to help that he never knew exactly what to ask them to do. For a while, he tried to do everything himself. And then, when he realized he couldn't, he made a list and put it by the phone.

The list said: "Go get my mail. Can you pick this up at the drugstore? Here's what I need from the grocery. Can you go to the market? Can you sit with my wife for an hour or two so I can go for a walk?" He learned to look at the list whenever someone asked, "What can I do?" He could immediately say, "Oh, here's what you can do."

Knowing how to ask for specific help, Sweeney explains, can help caregivers alleviate the guilt they feel when they become overwhelmed and need to take a break.

"These people who offer to help — friends, neighbors, family members, people from church — when you know them, when you feel connected to them, you're less likely to feel guilty.

"But it's important to know what you need them to do and to be very specific, because often people don't really know what to do. And if you don't take them up on their offers to help, they'll eventually stop offering.



Lillian Sweeney

"Feeling guilty about accepting help, or even about feeling the need for help, is normal," according to Sweeney. "I don't know that you'll ever be able to absolve total guilt. It's in our nature."

She advises caregivers to get out to remain sane and explains, "It's natural to have anxiety, to think something awful might happen the minute you step away. But remember that anything can happen when you're present, too.

"You can turn your back and somebody can fall or trip. If we're talking about end-of-life issues, you can walk out of the room and the person you love might pass. They might choose to do so. They often do. So there's so much you can't control and it's important to accept that."

Support groups and classes, such as the ones Sweeney leads at Family Hospice, are designed to help caregivers find that self-acceptance.

"By letting people know what to expect, by educating them about the caregiving experience, we help build their confidence. And we let them know they're not in this alone."

Her weekly class, which is in its third year, offers hands-on training to loved ones and family members who are caring for hospice patients at home. The first year, 44 people enrolled; last year, 107. As for guilt, Sweeney says, the classes certainly help caregivers address such complicated feelings.

"Guilt is a difficult thing to navigate. But I think it's so important for people to know that all they can do is the best they can."

Classes are limited to those signed up for Family Hospice and Palliative Care services. For information on services and classes, contact Lillian Sweeney at 412-572-8800.