Virginia Coglitore

Living with Pulmonary Hypertension

Virginia Coglitore was diagnosed with pulmonary hypertension (PH) in June 2001, but is now doing well thanks to her treatment at the Stanford University Medical Center and her positive attitude about life and living with the illness.

All her life, Coglitore has had energy to burn. Voted "most active" in her Saratoga High School class, Coglitore has always taken on many projects and responsibilities. So she found it strange and worrisome when she was pregnant with her second child and became extremely short of breath and fatigued in her last trimester. Knowing that most women feel that way near the end of pregnancy, her doctor wasn't worried until Coglitore started losing weight. They decided to induce labor, which lasted a mercifully short 20 minutes, Coglitore says. "Any more and I would have had a heart attack."

After giving birth, Coglitore continued to feel wiped out. "I live in a two story house, and I would run out of breath and have to stop by the third step," she says. "When I got out of my car I couldn't make it up the driveway."

Her doctors first diagnosed asthma, and then suspected allergies. But it wasn't until the allergist pricking her arm saw her purple fingernails that she was referred to a pulmonologist and got the real news...pulmonary hypertension. Cardiologists confirmed that she also had post-partum cardiomyopathy, a rare heart condition that also contributed to her symptoms.

"That was kind of scary because at that point I had a two month-old baby," Coglitore says. "That was a lot to go through, having a baby and then talking about lung transplants, and talking about the possibility of dying." She credits her husband as being her main pillar of support during these difficult times.

Doctors put her in the hospital immediately and started her on a vasodilator that lowered her blood pressure and she was transferred to Stanford to be treated by PH specialists. After eight weeks in the hospital she was well enough to go home, although Coglitore was by no means cured. Every day she refills the portable pump she wears with the drug Flolan, which is continually infused into her bloodstream through a catheter. Flolan is a vasodilator that opens up blood vessels in the lungs, making blood oxygenation more efficient and lowering blood pressure, thereby forestalling the damage that pulmonary hypertension can cause. Wearing the pump is a small price to pay for getting better, Coglitore says. "I've had to change some of the clothes I wear and worry about the kids pulling out the tubes, but it's keeping me alive."

With her PH now under control, Coglitore's energy has returned. In addition to their own children, ages one and three, she and her husband have taken in three foster children: three teenage girls aged 15,16, and 17. "We've got lots of things going on around here...dates, boys, and my daughter just learned to pee in the potty...so there are a lot of milestones around here," Coglitore says. The former lung transplant candidate also recently helped pull together her 20th high school reunion, and took her kids to Disneyland. "I thought I would never travel again, so that was great," Coglitore says happily.

COPING STRATEGIES

1. Become aware of how you are feeling (emotionally and physically) on a regular basis. "Check-in" with yourself whenever possible so that feelings can be acknowledged and expressed. This simple process will allow you to let these feelings go eventually and move on.
2. Identify and notice signs of depression, such as prolongued periods of sadness and despair, frequent tearfulness (without apparent cause), listlessness and lack of interest in normal daily activities, poor sleep patterns, under or over eating. Discuss these with your physician, nurse practitioner or social worker. Seek one -to- one counseling, if available. Speak with your physician or psychiatrist about medications for symptom control.
3. Reach out to other patients and family members for emotional support and practical assistance, through the Wall Center, the Pulmonary Hypertension Association or the Internet. There is really no substitute for the opportunity to talk with and share experiences with someone who is dealing with the same challenges of PH.
4. Gather family together to let them know how best to support you. For some, it may be the opportunity to share and talk through feelings, fears and concerns with a trusted person in our lives. For others, it might be something more practical, such as help with errands, household chores or picking up medications. Only you can identify what would be the most meaningful support for you and, who would be the best person to provide it.
5. Attend a support group in your community. Everyone is welcome to participate in the monthly Wall Center support group, but if distance or immobility is an issue, try to find a group that is closer to home. Support groups are not for everyone, but try at least one meeting to find out if it has meaning for you.
6. Exercise - to the degree that it is possible, find time everyday to move your body. Always clear any exercise ideas with your physician. Once you and your doctor have agreed on a healthy program, jump in and practice as often as possible.
7. Simplify your daily routine - minimize or eliminate sources of stress in your life as much as possible, such as difficult work situations, relationship problems, and chaotic living situations. Not all of these will conveniently go away, but even one change will have a very positive effect on overall coping.
8. Find an activity which will not tax your health or breathing ability but will nourish your mind, body and spirit. For some of us, this may be listening to music, reading a favorite book, meditating. yoga, or prayer. Try to build this activity into the structure of your daily lives.