

Note to people with scarred and stiffened lungs: Monitor your sleep before severe fatigue sets in

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Family, friends and neighbors remember Lisa Sandler Spaeth as an active mother of two in Potomac, Md., with a lot on the go, juggling her son's baseball games and her daughter's horseback-riding lessons with numerous committee obligations, organizing women's activities at her local synagogue. Add to this Spaeth's thriving home business turned wholesale supplier - making custom hair accessories for children - which she founded with her mother.

But Spaeth was also diagnosed with pulmonary fibrosis, a hard-to-treat disease that progressively damages the lungs and starves the body of oxygen. For two years after her diagnosis, until her death in May 2007, at age 44, Spaeth was beset by fatigue. Her energy levels sank as her lungs deteriorated. Breathing became difficult, and she could no longer attend many of the sporting events, trade fairs and women's groups that filled her life.

It is with people like Spaeth in mind that researchers at Johns Hopkins and elsewhere have found what is likely to be the first evidence linking the extreme fatigue in the lung-scarring disease, which has no known cause, to the poor quality of sleep that results - as much as a 25 percent loss in body-rejuvenating R.E.M. sleep. And they have also gauged the detrimental effects this has on people's daily lives, nearly halving test scores used to assess physical and mental quality of life.

In a report appearing this month in the journal *Chest*, senior study investigator and pulmonologist Sonye Danoff, M.D., Ph.D., who treated Spaeth, found more than twice the amount of nighttime sleep disturbances and double the number of daytime episodes of drowsiness among 41 men and women with so-called idiopathic pulmonary fibrosis than in people with healthy lungs.

"Physicians should strongly consider monitoring people with this scarring lung disease for sleep disorders as part of their standard care, because poor sleep has a profound effect on their quality of life," says Danoff, an assistant professor at the Johns Hopkins University School of Medicine.

The latest study results back up previous research by Danoff and other sleep experts at Johns Hopkins, which showed that 18 of 22 people with fibrosed lungs had problems breathing while asleep. The majority of them dropped out of R.E.M. sleep during the night, losing 25 percent of total R.E.M. sleep time.

It is during the R.E.M. period that rapid eye movements occur (hence the name), that people dream and that the body recovers from the previous day and builds up energy for the next.

Pulmonary fibrosis makes people highly vulnerable to sleep problems, Danoff says, because they often breathe twice as fast to supply the body with oxygen. And just as breathing and other body functions naturally slow down at the onset of R.E.M. sleep, these people who depend on a higher rate of breathing are constantly being pushed to wake up from a lack of oxygen.

"Essentially," she adds, "the body's internal alarms go off as people enter the most rejuvenating part of sleep. And when people don't get a good night's sleep, they cannot function normally the next day. It's a slippery

slope that gets progressively worse over time."

Also in this latest Johns Hopkins study are survey results assessing quality of life and quality of sleep, which showed that people with stiffened lungs and sleep problems have 40 percent lower scores in physical activities compared to the general U.S. population. Rated activities included basic tasks, such as going to the mailbox and walking to the car. Mental and social activities, such as carrying on a conversation with a store clerk or telephoning friends and family, were reduced 48 percent.

Sleep quality was assessed on a scale comprising 36 different sleep measurements, such as the length of time it took to fall asleep and overall time spent sleeping.

Moreover, the team's analysis showed that sleep problems could not be predicted by other demographic factors, such as age, gender, race or weight. Nor were they linked, researchers say, with other lung function and more noticeable disease symptoms, including shortness of breath and cough.

"Because there is so much about pulmonary fibrosis that we cannot yet fix, we need to focus on what we can fix while we wait for research to catch up with treatments that can prevent or reverse the disease," says Danoff.

Current treatments for pulmonary fibrosis are limited to steroids and other immune-system-lowering drugs that help slow down lung tissue deterioration as the thin walls of the air sacs stiffen and lose capacity to freely expand and contract.

More than 200,000 Americans suffer from pulmonary fibrosis, whose cause remains unknown. And the lung disease kills nearly 40,000 each

year.

"If we had been able to treat Lisa Spaeth's fatigue from poor quality sleep, then she might have had more time to lead her life as fully as she had been prior to getting sick," says Danoff.

Despite Spaeth's death, her zest for life carries on. Her mother, Froma Sandler, maintains the business. And through the encouragement of family and friends, more than a thousand people have donated to medical research in Spaeth's honor. The largest-ever contributions arrived in May, just prior to the first anniversary of Spaeth's death, when the Maryland-based Robert M. Fisher Memorial Foundation pledged \$2 million to Johns Hopkins to help fund Danoff's future studies into pulmonary disease.

"This research funding will lay the groundwork for a more consolidated and comprehensive look at the many factors that may improve and extend the lives of patients with pulmonary fibrosis: from rehabilitation of the lungs to the development and testing of new medications to offset losses in quality of life from fatigue," says Danoff.

Danoff plans to use some of the funding to support studies that monitor patients with pulmonary fibrosis for problems in sleep patterns, especially in deep-sleep R.E.M. patterns, to target for treatment.

Another phase of research, she says, involves testing new devices to support breathing during sleep and to see if these devices improve quality sleep time and abate fatigue.

Source: Johns Hopkins Medical Institutions

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