Spouses who care for partners with dementia face their own increased risks

Kelly Brewington  Baltimore Sun  (from Spokesman Review, 25 May 2010)

Marilyn, left, and Steve Blum pose for a portrait at their Owings Mills, Md., home. Marilyn is taking care of Steve, who has Alzheimer’s disease. They have been married for 32 years. McClatchy-Tribune

The findings

From the Johns Hopkins/Utah State study of 2,442 married couples:

It found 225 people with dementia after 12 years.

Spouses caring for a partner with dementia were six times as likely to develop the illness.

Stress could play a role in the link.

Caregivers may be neglecting their own health.

For Marilyn Blum, the hardest part of dealing with her husband’s dementia was getting him to give up the car keys. There were the arguments, the denial and that day four years ago when he grabbed the keys, stormed off and started the ignition. He was lost for hours.

During the initial days of Steve Blum’s diagnosis of early onset Alzheimer’s, her triglyceride level rose, her blood pressure jumped and stress took hold.

“The early stage was horrible; it was very rough on both of us,” said Marilyn, 61, of Owings Mills, Md.

The emotional toll of caring for a partner with dementia can be overwhelming – and wreak havoc on a caregiver’s own health.

Now new research from Johns Hopkins and Utah State universities suggests that stress may put a caregiver at risk for developing dementia as well. Spouses who cared for a partner with dementia had a sixfold increase in the risk of developing the disease, researchers found in a 12-year study.
“In addition to all the physical demands of taking care of an ill person, there are the psychological demands and stresses,” said Johns Hopkins University psychiatry professor Dr. Peter Rabins, an authority on dementia and one of the study’s authors.

“This is a loved one, they sometimes don’t know who you are, they accuse you of stealing things, that’s stressful.”

The findings need to be replicated with further study to better understand the possible link, researchers said. But experts have theories about how stress could be a factor.

Alzheimer’s can be latent for years, taking a decade for symptoms to show. Stress might speed up that development, Rabins said.

Other research suggests that high blood pressure, diabetes and high cholesterol can leave a person at risk for developing Alzheimer’s disease, he said. Stress could cause caregivers to ignore their health, exacerbating these problems.

“It seems possible that people who are providing care, neglect their own physical well-being – they don’t go to the doctor, they don’t take their medication correctly,” Rabins said. “And then they are under a lot of stress, which worsens their blood pressure.”

Researchers sought to identify risk factors for developing dementia in a group of 2,442 married couples 65 and older in Cache County, Utah.

In addition to genetics and medical concerns, they looked at the role of stress – from early-life issues and late-life pressures to being a caregiver – as possible triggers for the disease.

At the end of the study, they found 225 people with dementia, and 30 cases where both husbands and wives had developed the condition. While the majority of caregivers didn’t end up with dementia, the increased risk for spouses surprised researchers.

Caregivers of all kinds can face enormous frustration, isolation and depression. But those who care for patients with Alzheimer’s – a leading cause of dementia – face specific challenges associated with the puzzling disease, said Dr. Ronald C. Petersen, director of the Mayo Clinic’s Alzheimer’s Disease Research Center.

Physicians don’t fully know what causes Alzheimer’s, and there is no cure. While some genes have been found associated with the illness, doctors think environmental factors could also play a role.

As for dementia, experts aren’t sure how stress might play a role in losing brain function. Stress might cause the secretion of chemicals in the brain, upsetting neural networks and altering brain function, Petersen said.

Patients with Alzheimer’s don’t get better, so caregivers can spend years putting forth tremendous effort with few rewards, he said.
“It’s a relentlessly progressive disease,” Petersen said. “And because of the nature of it, the patient can’t appreciate all that is being done for him. So rarely do you see an Alzheimer’s patient saying ‘thank you.’

For a married couple this can be especially trying.

“You’re losing your intellectual mate, you can’t talk about the same level of things,” said Petersen. “You can’t even talk about your family. A caregiver might say, ‘Remember when the kids were growing up?’ and the patient says, ‘What kids?’

“Your whole life, everything that person meant to you and you meant to that person just withers away in front of you.”

Add to that the heavy lifting of taking on new responsibilities in a household.

Marilyn Blum was forced to take responsibility for home repairs and family finances, areas that had been the sole domain of her husband, an accountant.

And though the Blums had planned financially for the possibility of Steve coming down with the disease – his father was diagnosed with Alzheimer’s at age 40 – the flood of new tasks overwhelmed Marilyn.

At the same time he began forgetting the names of the streets in the neighborhood he lived in for three decades, Marilyn had sole responsibility of caring for her 90-year-old father, who was struggling with vision loss.

She was already shuttling her father to doctor’s appointments three times a week when she began caring for Steve, who was just 60 at the time of his diagnosis.

It put his world in disarray. He was irritable, confused and upset.

“It’s hard to be around a crabby person all the time,” Marilyn said.

That’s when her blood pressure and triglyceride levels began rising. While she has been meticulous about keeping doctor’s appointments and says her health is better today, she can understand how others might put off care.

“You don’t want another appointment, if you’re going to a million doctors with your spouse,” she said. “Mentally and physically you don’t feel like dragging yourself into the doctor’s office.”

Cass Naugle, executive director of the Alzheimer’s Association’s Greater Maryland chapter, said doctors who care for patients with dementia should ask about the health of the caregiver. But too often, physicians are rushed and insurance carriers don’t reimburse for such tasks.

Caregivers also need a strong network of friends and relatives who offer help on specific tasks – even something as small as relief on Sunday morning so the caregiver can attend church, Naugle said.

Marilyn Blum thinks the Johns Hopkins/Utah State study underscores the risks of stress. Still, she believes it can be managed.
Early on, seeking support was scary and she couldn’t find local support groups for younger couples coping with an Alzheimer’s diagnosis. But over the years, she got Steve into an adult day program and hired a certified nursing assistant to help out around the house.

Today she facilitates a group of spouses whose partners have early-stage disease.

“‘The support group is only once a month, but stress is every day,’” she said. “‘You have to have something pretty much daily.’”

So she goes for lunch with friends and doesn’t miss her Zumba dance fitness classes at the gym.

She learned that her stress harmed not only her health, it affected Steve. When she was stressed, so was he.

“‘Things have actually gotten better,’” she said. “‘You can give in and collapse and let it kill you or you can deal with it.’”