Caring for caregivers

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If your parent, spouse or best friend developed dementia this year, would you be prepared to care for them? How would you know if they wandered outside in the middle of the night and couldnt find their way home? How would you feel if they no longer remembered your name?

Most people know very little about dementia and even less about the challenges of being a family caregiver. Dementia is a loss of brain function that can be caused by conditions such as Alzheimers disease. Alzheimers is a degenerative neurological disorder, meaning the brain damage a patient suffers cannot be reversed. The symptoms of a progressive dementia like Alzheimers often become more severe over time and can be highly unpredictable.

"We cant tell people exactly whats coming next, but we can teach you ways to more effectively manage what does come next," says David Coon, a psychologist and associate dean of ASUs College of Nursing and Health Innovation. Coon has worked for more than a decade to create and improve interventions for chronically ill patients and their caregivers.

People over the age of 60 are most at risk for developing dementia symptoms, which can include a loss of mental function in the areas of language, memory, perception and emotion. In the context of everyday life, these losses translate into getting lost while driving a once familiar route, or forgetting how to balance a checkbook. In severe cases, dementia patients are unable to recognize loved ones or remember details about themselves.

Dementia is extremely expensive on a global scale. The Alzheimers Association reports that the worldwide cost of dementia is $604 billion. If dementia were a country, it would have the worlds 18th largest economy.

In addition to the economic impact of dementia, there is a physical and emotional cost of the disease that is often overlooked – that of the loved one providing informal, round-the-clock care to a family member or friend.

"These folks are the backbone of long-term care," Coon says. "They are truly serving society because if we had to pay people to do what theyre doing, it would cost billions of dollars."

But providing this care does come with a price. In a 2003 study published in the *Proceedings of the National Academy of Sciences*, researchers found that the stress of caregiving can negatively impact a persons immune system for up to three years after the care ends. Other studies have shown caregivers have a weaker immune response to the flu, a greater risk of developing heart disease and hypertension, and even that they may die sooner than non-caregivers.

To help caregivers cope with the severe stress their job entails, Coon has developed an intervention program for family caregivers of people with moderate to advanced Alzheimers or other forms of dementia. The research-based program, Care Partners Reaching Out (CAREpro), is designed to teach family caregivers how to take care of themselves through relaxation techniques, positive thinking and effective communication with their loved one to reduce stress and improve quality of life for both partners.

For caregivers, a major source of anxiety comes from not knowing which behaviors are caused by the disease and which are due to the personality of the patient. This uncertainty is made worse by the inconsistent nature of dementia.

"Its not as if the losses experienced are a smooth decline," says Coon. "Theyre what I refer to as a saw-tooth curve," with periods of a surge in particular symptoms, followed by several days that may be relatively problem-free.

Not only is dementia unpredictable, it manifests differently in different patients.

"Your mother might be really engaged in repetitive questioning and pacing, while my mother is trying to wander and is hiding things," Coon says. The disease can take on so many forms that each day presents a new challenge. However, caregivers who participate in CAREpro learn to identify what triggers these behavior changes in their loved one and how to respond more effectively.

For example, one caregiver reported being able to avoid conflict over giving their spouse a bath by heating the bathroom and playing music. Another figured out that taping their loved ones favorite television shows during the day and playing them at night would end a cycle of negative behavior in the evenings.

CAREpro also teaches caregivers to reduce stress by looking for ways to incorporate more pleasant everyday activities, either by themselves or shared with their loved ones. Another key is staying positive.

"We run thoughts through our minds that are unhelpful – particularly when were under stress – that either amp us up in anxiety or drive us down into sadness or blues," Coon says. CAREpro teaches caregivers to think more constructively and avoid getting bogged down in negative thoughts.

Cathy Griner, director of the Southwest Chapter of the Alzheimers Association, collected feedback from caregivers who participated in CAREpro workshops. Caregivers reported that spending time with other caregivers made them realize theyre "not crazy," and relationships between caregivers and their loved ones improved after the experience. Connecting with others who understand the unique stress that comes with being a caregiver had a hugely positive impact on the group. Griner says she heard from one caregiver: "CAREpro saved my life."

Coon is now developing a program aimed at people diagnosed with an early-stage form of dementia and their care partners. Early stage Partners In Care (EPIC) will

allow caregivers and loved ones to work together to clarify care preferences and prepare for the future.

"They will begin to feel more confident about their decisions with regards to this journey theyre taking together," Coon says of EPIC, which launches in June.

Coon plans to expand CAREpro to address the challenges of those caring for loved ones with other chronic diseases, such as HIV/AIDS or cancer. He also hopes to develop a program for people who are caring for a loved one while struggling with a chronic illness themselves.

"Were looking at ways we might combine these interventions for one-stop shopping in behavior change," Coon says. The number of people caring for loved ones while dealing with their own illness is expected to grow, in light of research showing the impact of caregiving stress on health. Still, even in the midst of intense stress, Coon says caregivers often say they feel as though they are gaining something valuable from the experience of caregiving.

"Thats why I see it as a real privilege to work with these people," Coon says. "They step up to the plate day after day because they truly care about those individuals."

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