

Quality help available for stressed caregivers

By MICHAEL MAZUR
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JASPER — Our parents took care of us as we were growing up, making sure we were happy and safe. But as little people, we probably never thought our future roles would reverse and it would be us to ensure our parents are happy and safe, living a quality life the best they can.

"We feel as children it is our responsibility and duty to take care of our ill and/or aging parents, no matter what," said Amy Gehlhausen, executive director and co-owner, with her husband Chris, of Qualicare, a family home care service based in Jasper.

In today's family dynamics, children may be spread across the country with families of their own to raise, and trying to fulfill their obligation to take care of their parents becomes a stressful juggling act.

Family situations are different. There may be only one child. One sibling may be the primary caregiver while the other siblings may share in the caregiving tasks. Sometimes, the children might start to argue amongst themselves, fracturing relationships. Tempers rise and decision making can be impeded. Sometimes, children quit their jobs to become full-time caregivers and as stress begins to take its toll, they may withdraw and participate less in family gatherings, according to Gehlhausen.

Their perspectives differ, the primary caregiver absorbs the day-to-day challenges that the long-distant siblings do not see and may make judgments about the quality of care being provided by the primary caregiver.

And according to Gehlhausen, moms may not want their son helping them with their personal care. It makes them, as well as the son, uncomfortable. A mom or dad suffering with Alzheimer's disease or other dementia will go through a personality change, making them likely to lash out at their children, being mean and even biting them. Gehlhausen says the children and friends need to understand that this is not them, it is the disease that is taking over. "They (parents) are just as frustrated (and) confused not understanding what is happening to them," she said.

Many children wait until their nerves are frayed before admitting they need help and feel that they failed, Gehlhausen added. "Admitting you need help is not a sign of failure but one of strength."

Debbie Wilson, who has been using the home care service the last few months, said she waited too long to seek help with caring for her 82-year-old mother diagnosed with dementia seven years ago.

"It was on my list, but I hesitated because I thought I should be able to take care of her. I did not want to admit that I couldn't do it alone," Wilson said. "To my surprise, the guilt went away. I could be her daughter again and not the caregiver."

This is how a third, unbiased party can come into play. Home care professionals can take over or aid in the many daily tasks involved in caregiving, from transporting the parents to doctor appointments, grocery shopping, cooking, cleaning and personal hygiene care. Qualicare caregivers play mind-stimulating games like cards, solving crossword or putting together jigsaw puzzles.

"When sons or daughters take care of any aging or ill parent, they have to remember to change

hats," Gehlhausen said. "They have to take off the son or daughter hat and put on the caregiver hat, meaning if Mom stubbornly refuses to take her medicine the son or daughter may let it slide because they feel uncomfortable telling their mother what to, as they were told as children. But wearing the caregiver hat reverses that role where they become the parent and must be responsible and ensure their mother takes her medicine for her well-being."

Gehlhausen says Qualicare takes a holistic approach, looking at the wellness and welfare of the family as a whole. Sometimes, the family as caregivers are more stressed than the ones they are taking care of, especially those who are not physical ill but suffer from Alzheimer's or other levels of dementia.

"I am an only child and because I also work and had an hour commute each way, I felt constantly stressed trying to live two lives — mine and my mother's. I was trying to do too much, stretched too thin, not being able to do all things for her that I wanted to," Wilson said.

The initial meeting or conversation involves the entire family, getting better insight into what type of care the family member needs and wants. The client's condition, what medications they are taking, their favorite foods and music are all taken into consideration. Music is good therapy, Gehlhausen said. They take in the whole spectrum to develop a program.

Marie Weinel, director of health services and a registered nurse for 17 years, attends all initial meetings using her medical perspective to the help analyze the situation before she develops and oversees each program. "No two programs are alike," Gehlhausen said. "They are individualized and unique to the person and the situation."

The meeting is really an educational process, Weinel said, "many family members don't know what help is out there." She says their caregivers will also go to nursing homes and to the hospital to be with their clients if the client wishes, but making sure they stay within their scope of practice.

Some caregivers may become a surrogate member of the client's family. Weinel remembers one client wanting his caregiver to be with him and his family before he died. The caregiver was able to spend some time with him before he passed away.

Weinel also trains the caregivers. She is a certified CNA instructor. All caregivers are certified in CPR and first aid, licensed and bonded and covered under Workers Compensation, protecting the client in case of an injury to the caregiver and providing security and peace of mind to the client. And they all must pass extensive background checks. Qualicare maintains an A+ rating from the Home Care Standards Bureau.

Our caregivers must be compassionate and empathetic. After meeting the requirements, Gehlhausen and Weinel ask themselves if they would feel comfortable having a potential caregiver take care of their own mother. If they answer is yes, they are hired. When setting up the programs, personalities and skills of the caregiver are matched as closely as possible to the needs and personality of the client, with changes made as needed. "So far we have been pretty good with the matching," Weinel said.

Qualicare caregivers cross all demographics: male or female, young or retired. Some are retired nurses, others cross many professions and some have experience taking care of a loved one. Some work full-time and others work only evenings or weekends. "We are extremely flexible in our staffing, Weinel said. "This allows us to be more flexible with our services."

Margie Andry has a caregiver be with her 83-year-old mother and likes the fact that the same caregiver sees her four to five hours Monday through Friday. "It allows her (mother) to be more comfortable knowing it is the same person every day," Andry said. "It gives her an extra friend."

Services can be as singular as providing transportation to and from a doctor's office or to a bingo game or just being a companion playing card games or it can involve a 24/7 live-in situation.

The home caregivers do not want to take away the things done by a mother or father. "If mom loves to cook, we don't cook for her we just supervise making sure

she is safe. We never take away but provide help where needed," Gehlhausen said.

For children who live long distance and their family and job obligations prevent them from giving the quality of care they want to, this service can be a facilitator or case manager. Staff will go to doctor and medical test appointments with their parent(s) and provide a report to the children.

"We are unbiased," Gehlhausen said, "and just give the facts and our observations for them (children) to make the decisions."

Gehlhausen says that many times it is better to get help at the early stages rather than waiting until things get more severe. "It allows the family to be a family as much as they can. The children can still be children."

It can also prolong the quality of life of a parent who is being the primary caregiver for his or her spouse. If dad is in his 80's and has Alzheimer's and mom who is a little younger, becomes the primary caregiver, as time goes on she starts to deteriorate physically and mentally with all the added stress shortening her quality of life, according to Gehlhausen.

"I have never heard a client say they got help too early. Many said they wished they had done this sooner," she added. With a third party, children don't have to wonder if mom has wandered off or left the burner on or dad found a way to start the car.

"It is such a burden lifted," Andry said. "Anytime a burden is lifted it frees up time to do other things."

Andry was elated to find out that a caregiver will take her mother who doesn't drive any more to her doctors' appointments and blood tests during the week rather than having to wait and plan everything for a Saturday. The caregiver also plays cards with her mother, does some light housework and takes her mother shopping and to hair appointments.

Ninety to 95 percent of Qualicare's caseload are Alzheimer's and dementia cases. Gehlhausen

says that one in three people older than 85 will be diagnosed with Alzheimer's or another type of dementia. She sees the need for services like hers with aging baby boomers, their children working longer and raising their own families.

Not all long-term facilities are equipped with Alzheimer's and dementia units and those that are have limited space, according to Weinel.

More than 5 million Americans are living with Alzheimer's and as many as 16 million will have the disease in 2050, according to the Alzheimer's Association. Indiana alone, in 2015, has 110,000 people aged 65 and older with the disease which is projected to increase to 180,000 by 2025 and it is the sixth-leading cause of death in Indiana.

In 2014, the number of Alzheimer's and dementia caregivers, hours of unpaid care and the costs of caregiving were staggering.

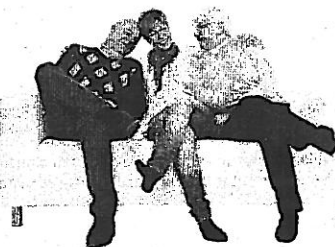
Long-term health care policies cover many of the home-care services and Medicaid provides assistance. Indiana Medicaid pays for some home care, but what and how much is covered is determined on a case-by-case basis, according to Gehlhausen. Medicare does not cover home health care if it is not a service provided by a skilled person such as a nurse. So cooking and cleaning would not qualify.

For families who feel that they are in a vise with taking care of their aging and/or ill parents and raising their own family, there is help available through reputable home care services. Andry "absolutely recommends families who have similar situations to check the service out."

Wilson was to the point where she was starting to think she "would go before (her mother)" with worrying about her own health with all the stress.

Her mother gets better care now, seems to be thriving and is happy now. "This help has been the light at the end of my tunnel," Wilson said.

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