

Younger caregivers face unknown futures, unexpected joys

Abbie Kopf, for AARP Published 11:04 a.m. ET Dec. 6, 2017 | Updated 1:35 p.m. ET Dec. 7, 2017

With a new wife and daughter, this millennial took on caregiving for two.



(Photo: Dustin Cesarek via AARP)

For the first part of their relationship, Dustin and Kim Cesarek were like any young couple. They met, fell in love and had a daughter named Reagan. Then, their idyllic story took an unexpected turn.

When the Cesareks' infant leaned against Kim's chest, the new mom felt pain that seemed out of the ordinary. When Kim's doctor suggested she get a mammogram, the results showed a potential abnormality and, after a biopsy, it was revealed Kim had breast cancer that had already spread to her sternum, liver and spine.

The news came as a total shock. "It really shakes your foundation," Dustin said. "It threw our family's plans out the window."



Kim, left, initially learned about breast cancer following the birth of her daughter Reagan, right. (Photo: Dustin Cesarek via AARP)

The couple's time was consumed by doctors' appointments and procedures to determine the extent of Kim's illness, which would later be diagnosed as metastatic, stage IV breast cancer. For Kim, everything became about her health. For Dustin, everything became about Kim.

"I wanted to make sure that Kim was getting the best care she could get," he explained. Dustin stepped into the role of primary caregiver for his wife by taking on additional household duties, driving her to and from appointments and making sure she ate despite a waning appetite. With an 8-month-old at home, Dustin became the caregiver to both ladies in his life.

"It was a lot of adjustment," Dustin acknowledged. "Kim wasn't able to do as much of the heavy lifting as she probably would have preferred."

Beyond the additional duties Dustin took on, he also began to grapple with the gravity and implications of Kim's illness and what it meant for his future. "When you realize that someone you care for deeply is probably not going to get the amount of time that you expected, it's difficult," Dustin admitted. "It's very difficult."



Reagan, left has been a "point of light" for dad Dustin and mom Kim. (Photo: Dustin Cesarek via AARP)

Faced with uncertainty and grief, Dustin turned inward, not wanting to burden others with his ordeal. "Cancer is not something that very many people can relate to," Dustin explained. "It can be isolating as an individual or as a couple." Kim began attending a support group for patients which brought Dustin's seclusion into stark contrast. "All of a sudden, she had friends and was having lunch with people – I was so jealous!" he joked.

Dustin reached out to an online social networking group and found two men in his area who were also caring for their wives. They met for coffee and after speaking for more than an hour, realized that they had only been talking about their wives and kids – none had shared a thing about themselves.

"We wanted to continue to have these meetings and focus it more on our own experiences," Dustin explained. The group grew and eventually morphed into a Minnesota-based nonprofit called Jack's Caregiver Coalition.

Although Dustin initially felt alone in his challenges as a young caregiver, he isn't – according to AARP, 24% of unpaid family caregivers are between 18-34 years old. This demographic differs in key ways from others who provide care. For example, younger caregivers are more likely to experience positive emotions in the role.

This holds true for Dustin, who believes that being a caregiver has made him a better father to Reagan. "I think it's helped me be more present with her because of the perspective shift I've experienced with the cancer diagnosis."



The family has found strength and support throughout Kim's health struggles. (Photo: Dustin Cesarek via AARP)

As his role as a husband and father has changed, Dustin has learned the value of gathering information to help him cope, and has visited the [AARP Family Caregiving site \(https://usat.ly/2nuoCWP\)](https://usat.ly/2nuoCWP) for its caregiving guides and resources. "Whether it's articles, tips, advice columns, that's all kind of helped me."

Now, Dustin hopes to share what he's learned in a professional capacity. Currently, he is pursuing a law degree with the hopes of specializing in estate planning, so he can help people prepare and plan for end-of-life situations.

AARP has information and resources to help caregivers – download their [Prepare to Care Planning Guide \(https://usat.ly/2nAk4hJ\)](https://usat.ly/2nAk4hJ) to get help and support today.

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