

Supporting Caregivers Through Their Cancer Journey

BY MIKE MCGARRY



Jack's Caregiver Coalition (jackscaregiverco.org) was founded in 2014 by three men who were caring for their wives who had cancer: Kyle Woody, whose wife Sarah was battling colon cancer; Justin Nicolay, whose wife Michelle was in the final stages of melanoma; and Dustin Cesarek, whose wife Kim had metastatic breast cancer.

Caregiving was a lonely place for these men, even when they were surrounded by family and friends. Though their family and friends provided support, this support was directed toward their wives who were receiving treatment for cancer. These men—and new caregivers—found themselves largely in the background, caring for their family and their children often alone, with few people who could relate to their experiences.

Without peers—other men who have been caregivers for their wives with

cancer—these men had no one to relate to, no one to share their struggles with, and no one from whom to seek counsel. They found themselves alone in an unknown territory.

This loneliness created a need to find others in similar circumstances. People these men could share their experiences with and talk through struggles. They wanted others with whom they could celebrate successes and those who could offer counsel and solace.

Woody reached out, determined to find someone else who could relate to his experiences. After learning of an acquaintance who had a friend who was caring for his wife who had cancer, Woody did not wait to introduce himself. He asked via email whether the other man would like to talk, get a beer, and whether he could help in any way. Meeting in person, the two men found a common bond: both were caregivers who were trying to do it all. They soon expanded

their support-like group by posting online, asking whether there were other men like them who wanted to talk. Cesarek responded to this post, and the core group of Jack's founders started meeting. They found one another and discovered that talking with others about their situations often relieved them of the incredible stress and loneliness they each felt. They shared and learned from each other, and they became better caregivers and better men.

Born from Struggle

It was through these initial meetings that Jack's Caregiver Coalition was born with a mission of improving the way guys think, feel, and act through every phase of their caregiving journey. Being a caregiver is one of the largest and most important challenges that a man will face in his lifetime. Jack's Caregiver Coalition helps men meet this challenge and bring their boldest and most confident selves to caregiving.

The Coalition helps members recognize the importance of taking care of their own health and well-being while they are caring for their loved ones. If a caregiver isn't taking care of himself, then their whole family can suffer.

Over the years, Jack's Caregiver Coalition has grown through its membership, as well as its offerings for caregivers. Programs and events are created to help caregivers on their journey and to improve their feelings of self-worth. Jack's member programming includes one-of-a-kind event offerings that bring members together to share a unique and often a character building experience.

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Indoor Sky Diving Jack Event

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Building a Community of Support

Monthly events bring Coalition members together to share and enjoy activities. These events always end in a meal where members can talk, build relationships, and let their guard down in a supportive and safe environment. Jack's Caregiver Coalition provides these programs to offer members time away—those moments of respite from the challenges of caregiving as well as time to recharge.

Caregiver Klatches are unique, co-ed support groups. The welcoming format encourages caregivers to open up and share their journey with other caregivers. The Klatch discussion group is focused on learning, sharing, and exploring the ways that caregivers think, feel, and act in support of their loved ones. Each group is moderated by a skilled facilitator, who is an experienced caregiver themselves and who assists in guiding participants through a structured dialogue around issues that are determined by the group. Each meeting is held at a local establishment where guests are offered food and drink. Klatches are also now offered through Zoom calls, so the Coalition can extend its reach to caregivers outside of Minnesota. Jack's Caregiver Coalition offers two Caregiver Klatches a month. One is titled "Caregiver Klatch," which is intended to discuss general caregiver issues, and the other is titled the "Living with Loss Klatch" and is specifically intended for community members who have experienced loss due to cancer.

Jack's Caregiver Coalition also supports its members through caregiver coaches. New caregivers can team up with experienced caregivers who have "been there and done that." Members meet with these experienced caregivers to discuss their challenges and to discover what they should expect when caring for someone with cancer. This program allows members to share and learn from each other and helps create a community of support for caregivers. Coalition members can also meet with a skilled and experienced healthcare navigator who can help them navigate the complex healthcare paths that exist in oncology care delivery.

Finally, Jack's Caregiver Coalition offers a caregiver crash course, "Help! I'm a

Caregiver." This is a unique 101-type course that is intended to quickly break down the important challenges new caregivers will face. This course is led by experienced caregivers who provide a base of knowledge to those new to the role, sharing lessons learned and hard facts with attendees. Because caregivers are busy people, the course is designed to be concise and offer as much help as possible in a short time span. Participants leave with knowledge on the many resources that exist to help make life easier for them and their loved ones. Though caregiving 101 is a one-time class for those new to the role, Jack's Caregiver Coalition also offers a longer-term program called "Jack-to-Jack." Caregivers select from other experienced caregivers who serve as a mentor and friend. Caregivers connect with one another, as those who were once total strangers meet and share their experiences through every phase of their caregiving journey.

"Mike, Meet Jack's Caregiver Coalition. Everyone, This Is Mike."

I have been a member of Jack's Caregiver Coalition since November of 2017, just six months after my wife Tracy was diagnosed with multiple myeloma. This was six months after I had been a caregiver on my own, not asking anyone for help and just blindly moving my family through our day-to-day crises. In October 2017, I was given a brochure for Jack's Caregiver Coalition and quickly signed up to become a member. Within a day, I received a call from Kyle Woody—founder of Jack's Caregiver Coalition—to learn more about my situation and to see how the Coalition could help me. Kyle talked to me about what I was going through and let me know that there are other people out there who are going through the same thing as me. He let me know that I wasn't alone. There were so many others out there who

knew what I was going through and who could help me in my caregiving journey.

Kyle became a trusted counsel and friend in my time of need. He encouraged me to reach out to other members who were also caring for their loved ones with cancer. Kyle also encouraged me to attend Coalition events. My first event was a great team building opportunity with other members. We met at a local ax throwing venue in Minneapolis, Minn., where we competed to be the "Bad Axe Champion." It was the first time that I had gone out socially during the first year Tracy was diagnosed with cancer. For me, it was such a relief to be able to step away from the incredible and sometimes debilitating responsibility of being a caregiver. I was able to meet other men who, just like me, were struggling through their own family crises and cancer. I then began attending other Jack's Caregiver Coalition events and was supported along my caregiver journey.

Over the years, I have leaned on the Jack's Caregiver Coalition community when times have gotten tough. They've never let me down. Tracy is now in remission after participating in a clinical trial, and I took over the Coalition's blog (jacks caregiverco.org). I began writing caregiving stories for Jack's in partnership with AARP to shine a light on the trials and challenges of being a caregiver. These insights continue to inspire me as I continue through my own caregiving journey. 

Mike McGarry is a caregiver for his wife, Tracy, who has multiple myeloma. Mike and Tracy have two boys, Joseph, 16, and Jacob, 14. Mike has been a member of Jack's Caregiver Coalition since 2017.



Tank Driver's Jack Event