

BACKGROUND

Cancer caregivers are an under-recognized resource and poorly supported by the oncology community despite producing significant benefits to their loved ones with cancer. As the population ages and family structures are more diverse, the need for engaged and educated caregivers is increasing. Clear communication between caregivers, loved ones, and the oncology team is often lacking. Caregivers often report initially being left on the “sidelines” but as the disease progresses, being asked to provide medical care and critical decision making for their loved one. The progression is usually without adequate preparation, education or support. Common sense and easy-to-administer interventions that support collaboration between caregivers and oncology practitioners are needed. Two advocacy organizations are collaborating to meet this need.

IT'S PERSONAL

The principal author started his caregiver role not even knowing he was a caregiver. He viewed himself as a chauffeur and a companion. However, over the following 3 years, he provided medical and post-surgical care, helped to deal with a changing diagnosis (to TNBC), addressed side effects and pain and finally made life and death decisions....all without education, guidance or counsel from the renowned university cancer center where his wife was treated. They were both helped by a friend's referral to Cancer Commons and their PhD scientist navigator who helped them in ways that her MDs were unwilling or unable. It turns out the author's experience is common.

IT'S PROFESSIONAL

Cancer Commons, a nonprofit organization, assists cancer patients and their caregivers in navigating cancer care using the latest scientific evidence, treatments, and resources. Cancer Commons' complimentary services include:

- Personalized navigation by a team of oncology nurses and navigators
- Review by PhD scientists of medical records and current treatment course
- Research of personalized treatment options, when needed, for patients to discuss with their oncology team.

Additional fee and subscription-based services are also available such as expanded clinical trial reviews.

Over half of the people seeking assistance from Cancer Commons are caregivers. These services can remove the burden facing caregivers and their loved ones as they seek to ensure they are receiving the latest scientific evidence related to their cancer type.

INTERVENTION

A complimentary 3 page Dashboard is provided that:

- 1) Suggests a possible road map
- 2) Facilitates communication between loved ones, care team and others
- 3) Engages the caregiver in the plan

To be completed by or with the loved one especially after appointments

Loved One Status

Where is the Loved One...what is *their* experience right now?



Caregiver Status

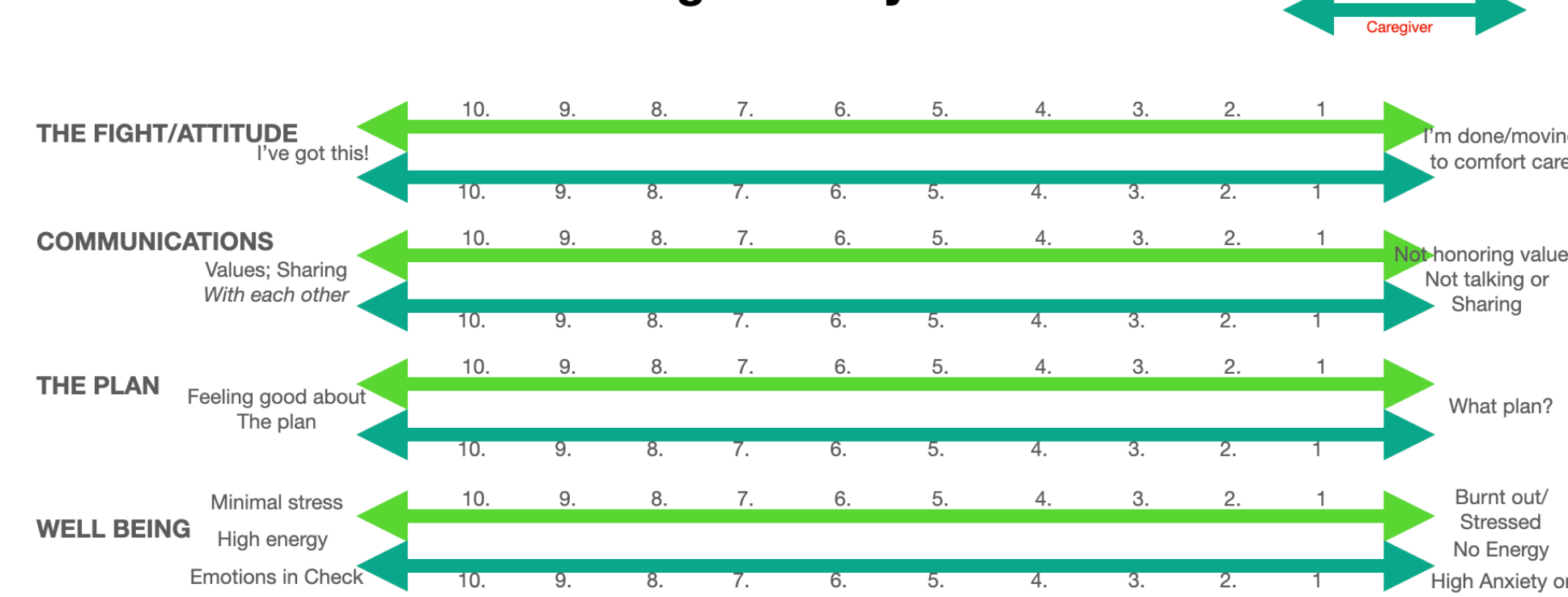
Where is the Caregiver...what is *your* experience right now?



To be completed by the caregiver as the loved one's status evolves
Action: modify plans based on gaps and changes.

Loved One + Caregiver Snapshot

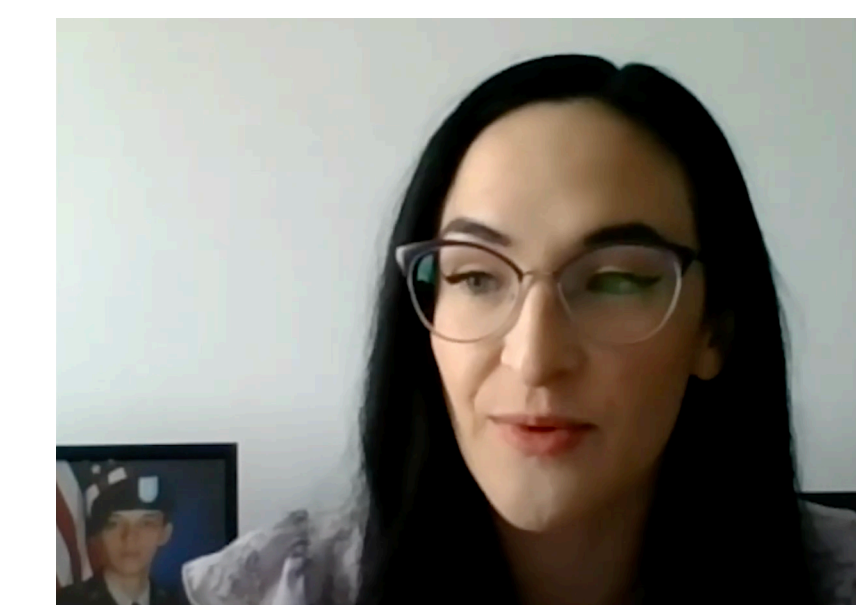
Are the Loved One and Caregiver in Sync?



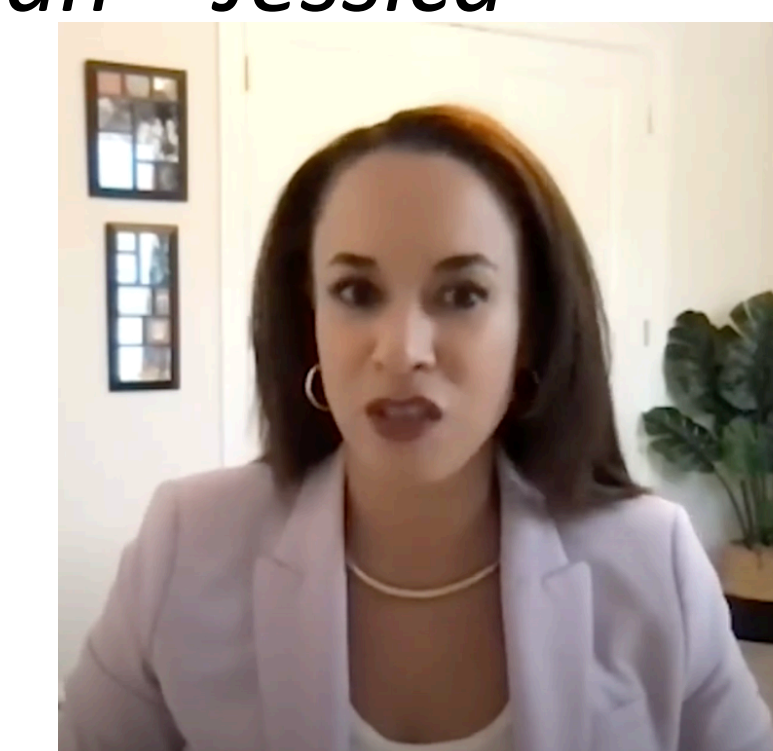
To be completed by both loved one and caregiver on a frequent basis regardless of appointments.
Action: Modify plans/seek help based on gaps.

DISCOVERIES

"I was so unprepared for what I went through - this dashboard would have helped me have a plan" -Jessica



Jessica, former Caregiver for deceased military spouse.



Mindy, Caregiver for family relative

"This helped facilitate our communication - I had to know she was "in it for the fight"—Mindy

IMPLICATIONS

The alliance of Cancer Commons and Courage Groups and the utilization of the Caregiver Dashboard, provides the Advanced Practitioner and their teams a means of guiding caregivers from passive observers to advocates and warriors. We are providing:

- > complimentary utilization and instruction on the use of the dashboard
- > complimentary virtual support and resource groups by caregivers for caregivers
- > complimentary initial analysis and plan development by Cancer Commons

These tools and services will increase a sense of control and mitigate the unnecessary toll on both patient and caregiver. The promise of a more engaged caregiver for the Advanced Practitioner is improved quality of care and quality of life for the patient.

REFERENCES

Reinhard SC, Levine C, Samis S: Home Alone: Family Caregivers Providing Complex Chronic Care. Washington, DC, AARP Public Policy Institute, 2012

van Ryn M, Sanders S, Kahn K, et al: Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psychooncology* 20:44-52, 2011

Berry, Leonard, Dalwadi, Shradda Mahesh, Jacobson, Joseph: Supporting the Supporters: What Family Caregivers Need to Care for a Loved One With Cancer. *Journal of Oncology Practice* 13: 1, 2017