

# Living With Purpose: Leading Others Through the Aftermath of a Brain Cancer Diagnosis

Shelly Kuhlmann's Story  
By Sarah Morgan

Shelly is, by now, a professional at telling her story: "My world was turned upside-down 10 years ago when my husband was diagnosed with a brain tumor the weekend of my 50th birthday party."

She uses a sailing metaphor to explain how you deal with a terminal diagnosis, comparing pessimists, optimists and realists. "The pessimist complains about the wind; the optimist expects it to change; the realist adjusts the sails." When you and your loved one hear news like this, she points out, you have to become a realist.

**"I was adjusting those sails every single, solitary day."**

After 31 years of marriage, and 22 months after his diagnosis with glioblastoma multiforme (GBM), Shelly's husband Mike died in August 2008. Shortly after, her father passed away. Then, her brother was diagnosed with GBM and passed six months later. Fifteen months had passed in total.

Through this time, Shelly co-founded a nonprofit, Brains Together for a Cure,

which funds brain tumor pilot research studies and offers support for patients and caregivers at the nearby Mayo Clinic.



She moderates her organization's caregiver support group monthly and believes that peer support is vital for both caregivers and patients. For caregivers in particular, she shares, "So many emotions, so much crying, so much 'how do I get through this' happens in that room. I see so many people who need to unload."

Many GBM patients experience personality changes, which can be especially troubling for their loved ones.

Shelly and Mike had family support, but, she notes, many do not. "It's tremendously important if people are able to communicate to others. We'll be in that room, and someone will have a fantastic suggestion for a fellow caregiver." She downplays her part: "I just facilitate, keep the conversation going," but notes the power of the



sessions. "When it's over, I'm always so glad we did this."

She understands her role is fraught. "I always say to new people,

**'I represent something you don't want. I've been to the end of the road. Don't let that deter you. I hope whatever I've been through can spark something for you that can help you in your journey.'**

This is often a hopeless diagnosis – but you want everybody to have hope."



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