



Working: Greg Brown ~ End-of-Life Doula

We did a series of articles during *The Crossroads*' first year titled "Working," which consisted of interviews with people who had interesting occupations. We recently reconnected with someone who inspired us to revisit the series.

Greg Brown has found not just an occupation, but a calling. He is an end-of-life doula. In that role, he provides support to individuals who are preparing for death. Brown found his way to this occupation because of personal experiences, and he provides the best account of that journey:

I've come to notice that people who are called to end-of-life work tend to fall into one of two categories. On the one hand, there are those who have accompanied a loved one on a particularly difficult death journey, and who now feel called to help others avoid a similar experience. On the other hand, there are those who've witnessed the deep meaning, love, and lasting memories that can be the unexpected gifts of a more prepared, intentional, and supported death journey. I've experienced both sides of this coin.

My mother died in 2010. She'd been diagnosed with cancer years earlier, but she kept from her family her doctor's most recent prognosis that she only had months to live. She hid her pain from us, and never discussed her impending death. I've learned that there's no right or wrong way to handle such a prognosis, and I don't blame her for her choice. And yet I do regret not making the most of our remaining time together: I would have returned home to see her earlier. I would have asked some of those questions I'll now never have a chance to ask. I would have made sure to let her know she didn't have to face death alone.

Several years later, my father suffered a debilitating stroke shortly after learning his prostate cancer had metastasized. My decision to move back to New Concord, Ohio, from Madison, Wisconsin (which had been my home for nearly two decades), was surprisingly easy. I became Dad's full-time caregiver for the last year of his life, and I quickly learned that I thrived in that role. With the support of my sister, my uncle, Dad's pastor, our friends and neighbors, and a wonderful hospice

team, Dad was able to embrace so many moments of his final months alive. With loving support and time for reflection, he was able to discover profound meaning in the life he'd lived. We took one last heroic road trip to hear his brother sing in a concert in Virginia. We made great memories. We grew closer, and he died at peace. A couple of weeks after he died, we held an incredible memorial service for him. (Any caregivers reading this will understand why we waited two weeks: I needed a nap!) I spent the next year largely processing my grief, decluttering, downsizing, and settling his affairs.

I had learned so much in caring for my dad, and I wanted to share it with others. I was proud that Dad's life had ended well, but I couldn't shake the realization that the reason he had such a good death was because of the resources and support available to him. What about people who don't have family members who can uproot their lives to move back home? They of course matter, too. Who attends to the spiritual needs of someone who isn't religious, who doesn't belong to a church, and who might not be comfortable interacting with a chaplain? How can the support of the community be harnessed if there's no one to answer the door? How does a caregiver connect with services they might not even know exist?

Brown sought answers to his questions and found his way to an invaluable resource: the University of Vermont's popular eight-week, online course which offers successful students an End-of-Life Doula Professional Certificate. (The University also offers a Companion Animal End-of-Life Doula Professional Certificate.) The course started in 2017, and since then,

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"Greg & I walked this labyrinth. He suggested we walk while thinking about a time we grieved and what helped us the most."



nearly 3,000 people have received this certificate. The students have ranged from doctors, nurses, social workers, chaplains and other professionals involved in end-of-life care to hospice volunteers as well as family caregivers.

An end-of-life doula provides special services to an individual facing death (*which, when you think about it, is everyone. A doula can provide assistance to anyone at any time*). Today, researchers are giving increased attention to mind-body con-

nections. We don't have definitive proof, but we do have serious indications that meditation, talk therapy, behavior changes – things we don't view as medical treatments – actually result in physical changes to the brain. If researchers want to explore further, they might consider teaming up with end-of-life doulas!

"My work involves both planning and processing – which I do from a neutral perspective," said Brown. "With respect to processing, I have found that listening to people's stories is a lot more of the job than I initially thought it would be. I never pressure people to tell me stories; I just invite them, and have found that by being a reflective, nonjudgmental listener, I can provide an amazing level of comfort and support. The two initial questions I like to ask someone are (1) What brings you joy? and (2) What keeps you up at night? In addition, maybe because I have extensive training in music, I ask people what their favorite song is and why. That generally makes them light up, and their answer can tell me a lot about their values and priorities."

Doulas hope to provide a measure of peace and acceptance by supporting their clients as they actively consider big questions: Did my life matter? How did it matter? "I've found my background in music helps me identify patterns in the stories people tell me," said Brown. "The patterns often lead me to an understanding of what was most important and meaningful in someone's life. Interestingly, I've found the events that stay with people are often what we would think of as the little things: something like the morning cup of coffee and news-

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paper shared with a spouse, or singing a favorite song in the car with a good friend at the top of our lungs – those are the memories that stick with us even more than the big wedding day or the promotion at work. Reviewing these sorts of memories helps define a sense of life-purpose and bring the person a measure of peace.”

Allowing people to talk without judgment may help them unburden from any unfinished business. “Maybe they need to make an apology, ask forgiveness or tell a secret,” said Brown. “They may not want to share regrets or secrets with a family member, so a doula, being a neutral party, may help the person get things off their chest. Just my being there to listen can lighten the load.”

Brown has found that a neutral individual can navigate difficult family dynamics by being a supportive and calm presence – and by having skills, such as training in mediation. A doula might help families sort out disagreements or just insert the gentle art of compromise into family dynamics. As an example of the latter, Brown talked about how those who are actively dying often don’t want to eat. “Yet what if a caring, loving daughter or son feels they would be helping their parent by getting nourishment into them?” said Brown. “I would gently explore alternatives so the parent wouldn’t feel forced to eat food that makes them uncomfortable, while helping the child find a different way to show the love that food represents. Perhaps all could be present at a family dinner, with the social nature of the meal realized, but without pressure on the parent to consume food – just a moment to take in family love.”

There is no predetermined path for any particular client of Brown’s, but one possible activity is to review the person’s life and think about a legacy project, which could be either something structured or less formal. Stories people tell might be a good gift for friends and loved ones. Could they be written down or videotaped? “Perhaps the individual needs help sorting through material possessions and deciding what they might like to give to those they love,” said Brown. “I can help declutter and organize. Creating a recipe book could be a meaningful legacy from a great cook. We could review and digitize old photos. Perhaps just the process of going through old photos would leave a legacy if, say, the grandkids are invited over to participate in the process. There’s no one-size-fits-all here.

Doulas help figure out what a special individual would like to express to others to show they cared. I’ll always remember the last trip my dad and I took together. As a doula, I can communicate with the medical team to help a client’s family assess the risks involved and to make preparations for a special activity.”

Doulas aren’t a replacement for hospice care, but rather, they supplement the work performed by a hospice team. Doulas do not offer medical support, nor do they provide legal advice. “But I’m happy to help a client formulate questions to ask their doctor or lawyer,” said Brown. “One of the first tasks will generally be to make sure a client has completed and filed their advance directives,” which include medical and financial powers of attorney, a living will, a regular will, etc. “We can be a sounding board – for example, assisting a person to think of and vet candidates to be medical power of attorney. This might be difficult for someone without close family, as they might be worried about creating a burden for a friend. However, we can help the person create a plan with clear instructions for their friend. A clear plan lessens stress because the medical power of attorney can act with the confidence that comes from knowing the person’s wishes. For example, when I was caring for my dad, I knew that he still found life meaningful so long as he was able to eat strawberry ice cream. In fact, we got his doctor to write a prescription for strawberry ice cream so he would be sure to have it whenever he wanted. For me, I’d want to be alive as long as I could connect with others. Even if I couldn’t talk, life would still be meaningful if my friends could come and visit and converse in my presence. As a doula, I would work to ensure these meaningful activities occurred and hope they provided a measure of peace. And if these activities were no longer possible, their designated agent would have confidence there should be no heroic measure taken.”

Doulas might help their clients shed some preconceived ideas about the “right” way to do things. “A lot of us have the idea that the ideal is to die at home,” said Brown. “I too had the idea that I would let down my dad if I didn’t help him stay home until the end. But underneath, I was scared – especially as he physically declined. We were both grateful when Dad’s doctor posed the question during a hospital stay, ‘Why do you want to go home? Do you want Greg to be your nurse or do you want others to be your nurse?’ That got us talking, and I

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learned Dad was scared to go home and worried I couldn't do it all and that maybe we'd argue about how things should go. It was a relief to both of us to have Dad in the nursing home five minutes from our house. It created a safer feeling for both of us, and allowed us to focus our remaining time together on making good memories."

What if a facility doesn't take care of the individual as well as one would hope? The doula can be the advocate to try and iron out problems. Are things too noisy? How about shutting the door and hanging a sign to keep it closed? Is a private room a possibility? Can the atmosphere feel better with art hung on the walls, a birdfeeder outside the window, music in the background? If things get overwhelming, could a visiting schedule prevent everyone from coming all at once? "There are problems in facilities – but there can be problems at home too," said Brown. "The important thing is to understand that no one size fits all. Doulas have a saying: 'When you've seen one death, you've seen one death.' Everyone is unique; I try to open up alternatives for people to consider and talk about."

A doula's help ends as the person draws their last breath. However, Brown has expanded his knowledge to cover services he can offer after death. He recently completed training through the Ohio Funeral Directors' Association to learn skills to be a funeral celebrant, which he is willing to do for his doula clients or others. "Individuals may not be involved with a church," said Brown. "Or complications may make individuals not want a church service. My goal in creating a funeral service – the eulogy, the music – is to learn all I can about the

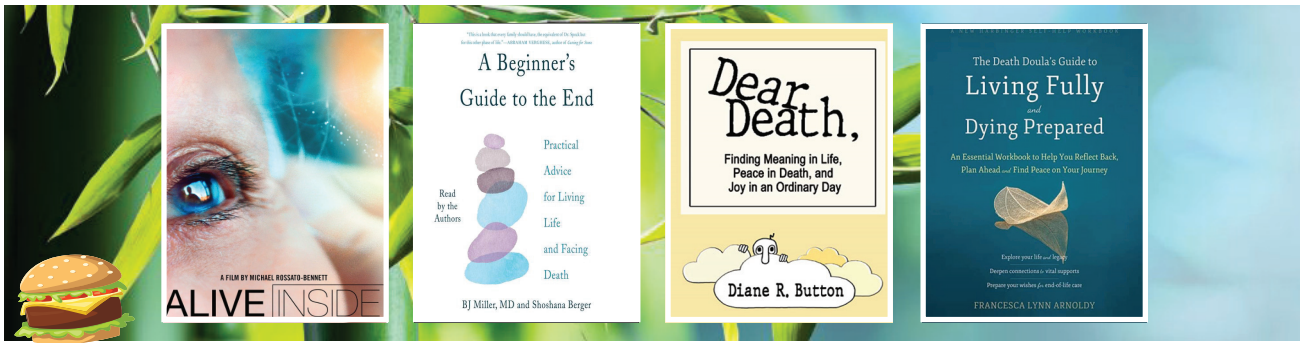
individual and create a very personal reflection about the life of the deceased. I want to make sure their story is well told – and I especially strive to do this when the death is particularly wrenching. People have a hard time talking about the death with the bereaved family – and perhaps no time is harder than when someone is taken too young, or by suicide, or in other complicated circumstances. Friends and families may be at a loss for words and fall back on old platitudes: 'Time will heal; he's in a better place,' etc. But the worst thing for a family is if no one is talking about their loved one, if no one is remembering personal things, if no one is saying their name. I use the funeral service to clearly tell the story of the deceased, and I hope that sets an example that helps others follow suit." Brown can also help individuals plan for the disposition of their body. He's not a funeral director but can provide information about alternatives and, for example, is happy to connect families with funeral directors who can provide a green burial or with a home funeral guide who can offer support to families interested in having a home funeral.

Doulas aren't licensed and are not covered by health insurance. Brown charges according to a sliding fee scale to try and make his services accessible. He cautions that people seeking a doula need to do their homework. One website to visit is the National End-of-Life Doula Alliance (*NEDA at www.nedalliance.org*). "NEDA is the closest thing we have to a credentialer," said Brown. According to their website, they seek to "define roles and responsibilities, attributes, core competencies; set best practice standards and measures of excellence;

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and provide ethical and practical guidelines.” They list doulas who’ve demonstrated those competencies in their directory. They are a not-for-profit organization and don’t offer training themselves, so in Brown’s view, “they aren’t compromised by having a stake in the game, so to speak.”

Besides his practice, Brown is now teaching courses through the University of Vermont’s program – which, by the way, has scholarship opportunities for folks who would have a hard time paying the \$800 for the course and who (*according to the program’s website*) “by their background, work, studies, and/or service endeavors, increase, support, and demonstrate commitment to diversity, equity and inclusion.”

You can learn more and contact Brown through his website for his business, which he has called Armonia Maxima, LLC: www.armoniamaxima.com. (“Armonia” means “harmony” in Spanish and Italian.) His phone is 614-333-6613. Brown now lives in Columbus and is available in person to Franklin County residents and virtually (via online or phone support) to anyone else. “I had thought that I would be less effective if I met with people virtually, but I’ve learned that people are sometimes happy not to have me come to the house. Sometimes it takes a few meetings to establish trust, and some people seem to be more relaxed when I don’t see their understandably messy living space or comfortable old pajamas during our first meeting,” he said.

Whether you actively contract with an end-of-life doula for their services or not, you’ll be well served to learn more about what Brown calls the “death wellness movement.” “It’s not to



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try and make everyone feel death has to be a positive experience,” said Brown. “It’s very, very OK for death to not be a happy thing; it’s pretty typical to be upset and angry if you are dying. But it *is* helpful for us to think about death and its inevitability and to find ways to make memories and keep living until that last breath. Consider taking a short course about this or seeking out books. Regardless of how long I continue to work as a doula, the knowledge I have gained from the people I serve has changed my life for the better. I have more successful relationships with others. It’s taught me how to relate and communicate better. The tools we embrace as doulas can serve all of us, no matter how much time there is ahead for you!”

Brown has provided a few resources for those interested in learning more:

The 2014 documentary “Alive Inside: A Story of Music and Memory,” which is a marvelous film celebrating the ways music can benefit people living with dementia.

The 2019 book by BJ Miller, M.D., and Shoshana Berger, titled “A Beginner’s Guide to the End: Practical Advice for Living Life and Facing Death.” The 2021 book by my friend and colleague Diane Button, titled “Dear Death: Finding Meaning in Life, Peace in Death, and Joy in an Ordinary Day.”

I’m also excited to read the forthcoming (July) 2023 book by Francesca Lynn Arnoldy, my first doula mentor, who developed the University of Vermont’s End-of-Life Doula Professional Certificate Program. It’s titled “The Death Doula’s Guide to Living Fully and Dying Prepared.”

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