

## Living Dying Man by Barbara McAfee, Maren Showkeir

Today would have been Jamie Showkeir's 70th birthday.

The music video and conversation below was inspired by his unflinching and curious walk with ALS (Lou Gehrig's Disease).

That walk ended on his 63rd birthday seven years ago today.

The conversation below is between his beloved wife, Maren Showkeir, and his friend, Barbara McAfee.

**MAREN SHOWKEIR:** I really love the way we can have these rich conversations about death. So many people tend to shy away from that topic. What led you to that place where talking about death feels both natural and interesting?

**BARBARA MCAFEE:** I was 31 when my dad died in my arms from pancreatic cancer. I had a very short hospice time with him, which was sweeter than most of our relationship had been. When he died, it was a strong experience, but it wasn't scary at all. At his actual death, I thought, "That's it? That's what everyone says is so horrible?" I got interested in the gap between what society tells us about death and the experience I had with Dad. I found others who were willing to explore the idea and have been having fascinating conversations about death ever since.

**M:** My experiences of death began in my teen years with my grandparents. I had a brother who died when I was in high school as well as other family members and friends. The experience was pretty typical: You don't witness the dying, and after death, someone whisks away the body. You show up at the mortuary or the church and have a potluck after the funeral.

When my mom died, it was completely different. She had been in a serious car accident at 84. Her injuries were too serious to overcome, so we eventually moved her to hospice. My sisters and I were there, telling stories and singing. We listened to recordings of Mom playing the piano. When it was her time, I climbed up on the bed and held her in my arms. It was such a tender moment. I was blessed to have an experience of death that, while painful and hard, was also quite beautiful and sweet.

After Jamie was diagnosed with ALS, we were determined to do everything we could to

give him the death he wanted. As I took care of my living/dying man, we talked about his wishes and what would happen to his body after he was gone. Partly because of you and our conversations, I sat with him a good long while after he died. Friends gathered. We laughed and cried. And it was his birthday, so we also celebrated, in a way. We were so lucky, because he got exactly the death he wanted, dying at home, in a knowing and peaceful way, while I held him close. I am super grateful for your presence in all of that, the times you visited, the ways you held us in every possible way.

B: I felt like I was right in the middle of it with you both, thanks to your writing on CaringBridge. Your words captured many of the deep conversations you and Jamie had. When I came to visit, Jamie also generously shared his experience. He loved sharing what he was learning. It was one of the things that got him up in the morning for his whole life, right? He gave me his unvarnished truth - a true gift.

M: He was so engaged in his own dying.

B: Yes, exactly! I remember telling him that the lessons I was learning from him would follow me through to my own death. I mean, we're all living and dying, right?

M: After he was diagnosed, we had a lot of conversation about how we were going to face the harsh reality that ALS is always fatal. We didn't want to waste our precious time trying to chase down miracle cures or doing things that might extend his life for a few days or weeks. What was the point of a few more days if he was suffering? We decided to live "hope-free," which isn't the same thing as hopeless. It's about embracing the reality of what is. Jamie was very clear that he didn't want to focus on the fact that he was dying. He was alive, and he intended to keep living fully, every single moment, until death took him. For both of us, that meant that we couldn't squander time. It also felt essential not to squander the lessons that living/dying had to teach us. Jamie was all about learning, right up until the end.

B: I remember one of things Jamie said to me during a visit was — he said didn't think about the future anymore. There was no point to it. That's where the first line of the song came from: "living dying man, you're through with making plans."

The final verse came as I was washing windows outside my apartment. There was I was, up on the ladder, crying and singing and wiping windows.

M: It was kind of a love song for you.

B: It was a huge love song. I wanted so much to reflect back the lessons he'd taught us. The song was kind of like the last word between us, even though we talked after that visit. I wanted it to be really good. Not good in a judgmental way, but good in that it would be nourishing for him.

M: Do you remember that moment when you sang it for us for the first time?

B: Oh yes. I was so nervous, but not ego nervous. That moment felt deeply sacred. I sat down at the piano with my heart thumping in my chest, wondering, "How can I possibly do this?" And then I took a breath and began.

M: I don't think I knew that.

B: Oh yes. The whole experience was so intense, Jamie sitting there in his wheelchair with

you, his son, and my friend, Tom, gathered around. The best gift I could think to give him was to create something that said: "We heard you, and we will remember."

Honestly, I don't even really remember the singing. It was a kind of out-of-body experience. The next thing I remember is being clustered around Jamie's wheelchair, hugging and weeping.

M: That was such a tender and emotional moment, because his son, Zak, was there visiting us too. You know, I don't even have words to describe how that song grabbed Jamie's heart and soul. He was so moved by it. We felt so loved. You sang it at his celebration of life ceremony as well. It made us all weep.

I have told this you before, but I just want to say again how grateful I am to you for helping me walk him home.

B: It was really my honor. Thank you for letting me be a part of it.

M: One of the few things I actually remember saying at Jamie's celebration of life, and I've said it so many times since.... If everyone in the world could have that experience of being held in the way we were while Jamie was living/dying, with so much love and caring and support, this world would be such a kinder and better place. What a wonderful world it would be.