

Finishing Well: Glimpses of Stan Miller's Diary

By Kristiana Donahue

Stan Miller lives on a lovely piece of property dotted with beautiful barns, a farmhouse and even a curious cat. I came to talk to Stan about his life. A polite teenager greeted me with a smile and welcomed me inside. Stan was already talking with his nurse, Jessica. The house was warm and cozy, full of family photos and farmhouse charm. Yet the warmest feeling came when Stan opened up in a vulnerable and sincere way. With genuine transparency, Stan's words challenge us to open up ourselves and allow our common humanity to bind us together.

Stan began journaling soon after his diagnosis with ALS, commonly referred to as Lou Gehrig's disease. Per Wikipedia, "ALS is characterized by stiff muscles, muscle twitching, and gradually worsening weakness due to muscles decreasing in size. Most eventually lose the ability to walk, use their hands, speak, swallow, and breathe." September 9, 2015 was the day he was diagnosed with ALS. Two weeks after the diagnosis, Stan wrote this entry:

I was peaceful with receiving the diagnosis. I felt an urgency to move into action, to do the things that were most important. To do important things, not urgent things. Spend time with family. Write a testimony for God. Finish the barn.

Spending Time with Family

On the ride home after receiving the diagnosis, Stan and his wife, Elvera, began planning a trip out west. Years ago, they took a road trip to California during which the older children raved about the Redwoods. Now, with younger



Stan and some of his family on their farm

children added to the family, they wanted to take the trip again. It wasn't the most convenient time to do it – with crops ready to harvest – but crops were urgent, this was important. Stan noted in his journal:

I am shocked at how fast my condition is moving. My muscles are shrinking fast. An electrical sensation has covered my entire body, making sleep difficult. Fatigue is keeping me from functioning. I was looking forward to this western trip, figuring if we did it right away, I would really enjoy it. I really have to push myself. I can't keep up with my family. They have been so understanding. I have loved being with them. Trying to help the children process what is happening. They're all very angry at God. They have had so much loss.

Stan and his wife are no strangers to loss themselves. They built their beautiful family with the bittersweet pieces of love and heartbreak. They had three biological children; all of them with significant medical needs. Two passed away, and Stephanie lives with them still, needing daily care and support. They've adopted six other children, including several older ones who had moved around quite a bit. It is quite evident that Stan wants to pour himself into the lives of his children – and realizing his "plans" were cut short was tough.

I had this great idea about writing letters to all the children for the important events in their lives that I would not be around for. You cannot take a child further than they are emotionally and mentally ready for. There is so much I would love to guide and teach and pass on, but they are not ready for much of this. So I need to move it to a few things that they can remember.

Confronting Death and Prioritizing Life

Stan's initial prognosis was dire, being told he had only a few months to live. Soon after diagnosis, Stan began noticing his physical decline. He was put on oxygen almost immediately and this affected his perception of his days. He quickly had to confront the imminent possibility of death, and help those he loved do the same.

Tonight, I am struggling to figure out how to respond to death. When I think of all of the important things that should be done, I realize I can never make that happen. Once you're sick with a disease, it is not the time to do extra things. God, I need the wisdom to decide what things to let go of and which things will make the biggest difference. Death is like life. You need to do your best and trust God for the rest.



Stan and wife, Elvera

Life often becomes an endless to-do list that can overwhelm even the most disciplined person. Coming to the end of life can exacerbate the anxiety created by the list, but it also has a keen way of filtering out the unimportant things.

Acknowledging the "Elephant in the Room"

Throughout life we strive to talk about the important things with our loved ones. From faith to relationships to problems in our society - finding a kindred spirit to discuss our ideas truly helps us feel ready for, confident in and content with our decisions. It's no different with acceptance of death and dying. Yet finding people to talk to can be challenging. *"I need to talk about death and dying. You find that death and dying are pretty taboo subjects,"* Stan wrote.

As ALS ravaged his body, his mind was continuing to process all the changes happening in his life. Questions about the future swirled in his head.

How and when will my body change? How quickly will this affect my independence? How will this affect my relationships? How does one finish well? Knowing that I'm dying makes me feel isolated.

Stan would be the first to express that he's had a wonderful support network of family and friends. He's felt truly loved and cared for, which has helped him tremendously. Yet, even with a strong support network and people willing to listen, feelings of isolation are often part of this final journey. Stan shared the often confusing balance of encouraging his family to continue with life as "normal," while daily recognizing the reality of his disease. Even when he has had people that would listen to his inner thoughts, he held back some of the deepest. This illness was his to face, and he didn't want to burden everyone around him with his "elephant."

When I did talk about it, I did not go into it as deeply as my heart would have liked. I didn't want to overwhelm the people I was talking to.

Living with a terminal illness can be hard for everyone. Denial is a very effective coping skill. But, using it indiscriminately isn't healthy. At some point in this life and death play, the primary actors need to admit that everything isn't OK. I get that. But it doesn't mean I understand it.

Many people are uncomfortable talking about death and dying. Even the person that is dying finds it difficult to talk about. Maybe it's because these are subjects we have never heard discussed.



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Stan has thought a lot about this "elephant." He's forced to think about it. But in reality, it's a topic all of us will face at some point. Ignoring it doesn't make it go away. In fact, engaging in healthy conversations about death and dying with those we trust may do everyone good. Stan mentioned that at times he thought there was an "elephant" in the room, when in fact, it was just his perception. We may be surprised that some people may be more open than we realize. Stan has thought about how to address the difficult topics people don't want to talk about, and came up with his own formula.

Verify that the elephant is real. Acknowledge its presence. Consider timing. Make a plan. Have a direct, honest, detailed conversation.

Gradual Detachment

ALS is a journey of detachment. From what I could once do, along with anticipation and preparation for what I will not be able to do in the near future.

Stan's progression with ALS took an immediate toll, but it was also unusual. Soon after his diagnosis he noticed a decline. His voice became so soft it was difficult to understand him. He couldn't roll over in bed anymore and was only able to swallow soft foods. Macaroni became a staple in his diet. Due to the rapid progression, and his doctor's prognosis that he wouldn't make it to February 2016, Stan had to hastily prepare his heart and mind.

Then in January 2016, all those abilities came back to him. He started to roll over in bed, he could communicate clearly and eat anything he wanted. It was like a miracle. However, though Stan doesn't know when, he knows those losses will return one day.

I recognize the fact that I have not even really started my journey with ALS yet. Everything can be taken away from me. But one thing, the last of human credence, to choose one's attitude in any given set of circumstances. I was determined not to let ALS touch my soul or spirit.

While Stan realizes that ALS will take things away from him, it has also given him something else. He has gained some new friends on this journey. The staff from Center for Hospice Care, and especially his nurse Jessica, who has been with him since he started care, are some of those new friends.



Stan and his Center for Hospice Care nurse Jessica

I would have to say my life has been rich and full and rewarding these last several years. I have probably had more, really deep, meaningful conversations in the last several years than I have had for a lot of years. I find that my diagnosis brings people to me that want to talk about deeper things. And it gives me a great opportunity to get to learn their heart and to share my heart.

Finishing Well

Jessica and Stan have been talking about what it means to finish well.

What does it look like to finish well? Jessica helped me with that a lot. I realized that what I really wanted to do is live well. Because if you live well, you finish well. It needs to be a changing target. As I have lost ability, living well is fleshed out in a different way.

Stan continued to encourage all of us to live well all along the way. Why put off the good things that we could do today? Why wait for retirement to take that dream trip? Prioritize the "important" things, not the "urgent" things.

The way you approach death will be how you lived your life.