

## Life and Death Used to Seem Very Simple to Me

By Kayla Hochstetler, Valley Community Health Center (Grand Forks, ND)

Life and death used to seem very simple to me. You were either alive, or you weren't. A conversation about healthcare directives seemed irrelevant. This changed for me when my 16-year-old brother was hit by a car while rollerblading and sustained a severe traumatic brain injury.

We spent six months in six different hospitals following my brother's accident. He was not expected to live. Doctors told us he would never open his eyes or recognize any of us. My parents believed then and even now, six years later, that a miracle would happen for him.

At the time of the accident, my family was forced to have conversations about his quality of life versus quantity of life. There was a lot of conversation about what my brother would want and unfortunately, he was unable to speak his own truth on the matter.

As a result of our family's painful experience, I set out to increase the knowledge and awareness of the importance of advanced care planning in my life and community. In October 2016, we established an Advanced Care Planning Work Group to encourage members of our community to 'walk the walk' by completing their own healthcare directive. We began with a broad mission to promote care coordination with the ultimate goal of reducing admissions and readmissions through advanced care planning. We also wanted to ensure individual's wishes were honored.

The partners soon defined their aim, 'Fifty percent of adults accessing healthcare in the Grand Forks Community will have a documented healthcare directive on file by December 31, 2022.'

The group identified initial priorities of gathering baseline measurement data to support the aim; a subgroup is working on consistent language to 'start the conversation' in the community. They group is developing strategies for educating and engaging the public and are beginning discussions on how to promote advanced care planning both with their own staff and those they serve.

"This group has great synergy and has come a long way in a short time. From the first meeting when partners were asked to share 'Why is improving advanced care planning in the Grand Forks community important to you?' I have become engaged with each of them through hearing their personal and professional stories. I not only hear, but feel their passion. Each meeting the momentum and excitement builds as stories are shared, solutions are identified and new ideas surface. Each month I leave the meeting saying, "This is why we do what we do," shared Tracey Regimbal, Quality Improvement Specialist with Great Plains QIN.

To eliminate the possibility of avoiding the completion of my own healthcare directive, I created a Facebook event. I invited a few close friends and family members to participate. Life is busy. It was very helpful for me to set aside time to sit down, have the conversation and complete the paperwork. My advanced care directive is now on record at my healthcare facility and in the hands of my designated healthcare agent. There is talk



within my friend group of having another event so those unable to attend the first one will have the opportunity to complete their own advanced care directives.

On a professional level at Valley Community Health Center (VCHC), I have spoken with the Clinical Director about how we can improve/track patients completing healthcare directives. VCHC has now added an alert in our EHR system to remind the nurse rooming the patient to ask about advanced directives. If a patient is interested, they will be provided the necessary paperwork and connected with the Social Services Care Coordinator to guide them.

My brother is still alive and continues to slowly progress at my parent's home in Minnesota. He is wheelchair bound, cannot communicate verbally, has very little control of any of his extremities and requires 24-hour care. It has been and continues to be the hardest thing anyone in our family has ever been through.

Due to my family's limited knowledge and experience with medical settings, we really never thought we were given a choice regarding his care during those initial days and weeks. My brother was incredibly healthy, athletic and gifted at everything he tried to do; almost to an annoying degree. It never seemed possible that he would not have a miraculous recovery. To this day, I do not know if we as a family would or could have made different decisions regarding his care or treatment.

My family acted in what we believed to be my brother's best interests and have peace about the decisions made. However, that experience clearly showed that advanced care planning is not just a "good idea", it gives people a voice in their own healthcare decisions when their family may be too grief stricken to speak.

Having been through this, I believe strongly that people need to consider quality vs. quantity of life, talk with their loved ones and really consider what they value in their life and death.

### **For More Information**

For more information about National Healthcare Decisions Day, visit their website at <https://www.nhdd.org/>.

For local assistance about advance healthcare directives, visit Honoring Choices ND, <https://www.honoringchoicesnd.org/>, or Honoring Choices MN, <http://www.honoringchoices.org/>.