When it's your time, what choices will you make?

By Mike Bernhagen, Rainbow Community Care

Like many families from small Wisconsin towns, the aging journeys of my in-laws and parents were all over the board.

My mother, Rita, died in a nursing home in 2003 from congestive heart failure and vascular dementia at the age of 81. For three years my dad struggled to care for her at home and tried to initiate guardianship via the courts because she did not have an advance directive. He eventually deferred to the local health care system who bounced her back and forth between hospital and nursing home without mentioning hospice as an option. The grief I experienced was so profound I decided to become a hospice worker in 2004 and write an editorial for the Milwaukee Journal Sentinel titled, **A Sad Goodbye**, **But Life Changed**. What followed was a five-year commitment to produce a series of documentaries for public television that intimately explored our cultural struggle with communication and preparation for end-of-life. It was called **Consider the Conversation**.

The phrase "a sad goodbye, but life changed" best describes the bittersweet experience of leaving something behind, whether a loved one, a job, a place, or a stage of life, while simultaneously embracing new opportunities and growth. It acknowledges the pain of saying goodbye while recognizing that change is inevitable and can lead to positive transformations.

My father-in-law, Gene, died at the Rainbow Hospice Care Inpatient Center in 2016 from end-stage renal disease at the age of 83. He was tough, fiercely independent, and politely declined to receive palliative care at home and move to assisted living. Instead, he chose to endure repeated hospitalizations and nursing home stays over the course of three years before finally making the difficult decision to stop dialysis. During his six-day stay at our inpatient center, my family got to experience - *for the first time ever* - what it feels like to have a loved one receive hospice care. I've got to tell you that it was so comforting and meaningful that we decided to inscribe the following message on a brick that lies in the Rainbow Memorial Garden in Johnson Creek:

EUGENE W ALT
FOUND PEACE HERE
SEPTEMBER 16 2016
BLESS ALL WHO
WORK HERE AND
EASE OUR BURDENS





Celebrating Dad's 100th birthday in Gulf Shores, Alabama.

My father, Roland, died in a hospital on April 2, 2020, from pneumonia at the age of 102. He had a gentle fall at home but insisted upon walking into the emergency room under his own power before things took a turn for the worse and was admitted onto hospice in the hospital. Because it was early in the pandemic, only one family member could be there in person, and I had to say goodbye over the phone while my brother held it up to my unresponsive Dad's ear. Immediately afterward, I wept because the kindest, gentlest man I had ever known only received hospice care for less than 24 hours. To this day, I cherish the wedding ring he wore during 61 years of marriage to my mom. It fits me perfectly.

My mother-in-law, Doris, age 91, moved to an assisted living facility shortly after her husband's death. She was diagnosed with Alzheimer's disease in 2017 and my wife, Denise, soon came to dread the phone calls that came from facility staff when something went wrong, and they had to call 911. So, when Doris needed to move to skilled nursing in the spring of 2022, we both decided it would be important to get hospice involved as soon as possible. This time, we knew the hospice

eligibility criteria for her diagnosis and were simply waiting for the significant weight loss that ultimately occurs with advanced Alzheimer's.

Much to our delight, my mother-in-law's doctor, a UW Health internist, beat us to the punch and referred Doris in November of that year! Two and a half years later, Denise and I continue to visit Doris every Sunday and, although she is slowly withering away, we are immensely grateful for the precious gift of quality time we have received.



Denise and her mom on Easter Sunday, 2022.

Nowadays, Denise and I routinely talk about lessons learned from our parents' journeys when getting together with our siblings. Not surprisingly, most of these conversations tend to take place when we're enjoying a meal together, whether during a football game or on a holiday.

It is my hope that the recipes contained in this cookbook provide you with comfort as well as permission to talk with loved ones about how you want to live as you grow old and become seriously ill.

Thanks to my parents and in-laws, I have learned an important life lesson - wellness is possible if we actively pursue choices that align with our values.



Submit to: cookbook@rainbowhospicecare.org

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