

# THE POWER OF STORY-WRITING THE BEST LAST CHAPTER

MY NAME IS MELODY. THIS IS THE STORY OF THE LAST CHAPTER OF THE LIFE OF MY HUSBAND

*Dick*

Dick wanted to be at home and I wanted him to be at home; to be together, and of course with our little dog. I wanted to be the one to care for him and he was comfortable with me looking after him. Some people are not comfortable with their spouse or family members performing some of the more personal and intimate care and prefer the more anonymous, professional, dispassionate assistance.



That he /we made the right choice for us was confirmed for us. When he came home, we expected he'd have a week to 10 days and it turned out to be just a few days short of a year. Dick said he really believed that he would have been dead if he had to stay in the hospital. But more important than the length of time was the quality of time. The decline was inescapable, but Dick was LIVING HIS life right to the end.

This is a very difficult time. This is a very personal decision. For us the decision was clear and obvious and we were in complete agreement.

At home we were able to do everything on his time: sleeping, eating, dressing (or not), bathing, watching TV, going to his computer, everything. Even visiting with neighbours and friends.

Dick felt validated in having his decisions for the end of his life just as he had for the rest of his life. We were completely open and honest with each other, our family and friends, so everyone understood what he wanted and was on the same page. That was important for me because everyone supported me supporting him. He even went with me to the funeral home.

We just said: "If the blinds are up, then we're up. C'mon in, and if he's up for a visit, then all's good. If it's not a good time, we'll tell you and you can try again later." There was no arbitrary schedule to be adhered to.

Palliative still means medical care, but with the objective being comfort, not cure. It was more important to Dick that he remained "himself" than that he be completely pain free, and I was attuned to read his signs and signals and familiar with his preferred distractions. Home Care does not come up the lake where we lived, but we had lots of support from the medical community.

Our PHYSICIAN was available "whenever!" HOME CARE (we came in to the basement of the hospital) with bandages and butterflies as well as supplies, walker, lift chair, lift belt.

NUTRITIONIST suggestions for food choices and preparation.

PHARMACY kept ahead of the meds and sometimes sent them home with neighbours.

NURSE LINE (24 hours) which I called at 2:30 one morning for recommendation on pain meds. (She called back personally the next day to check how we were doing.)

The AMBULANCE / EMERGENCY room is always available.

Not under the umbrella of the medical community, but just as important was the support and help of our community, our friends and neighbours.

The end was the next step along the same road, and felt like the natural transition. The experience was very personal and intimate. It was very hard for me but very rewarding. I knew that I had done the best that I could and that I had "done right by him". There was nothing left undone or unsaid. I have not had the experience of wishing for "just one more day". We were together, he was not alone, and it was clear that his life had run out naturally and completely. My grief is intense, but it feels clean and pure; it is not muddled with any guilt or regrets.

In the spirit of complete honesty, I will share that early on there were a couple of episodes of anger and frustration, on both of our parts. I don't know if it was his frustration with being sick or if he resented his declining abilities and having to give over what had always been his jobs to me. Maybe I just pissed him off. But I do know that passed and we grew even closer and more intimate at a deeper level than ever.

Every person's story matters. Loved ones need to be listened to and wishes need to be respected.