

OPEN
CONVERSATIONS

TRUST

PHYSICIAN • NURSE • CARE AIDE

Listen. Know who the patient is—learn about their life; hopes, fears, who are they, where have they been, what are they most proud of. Focus on care that is guided by the patient's values and best interests; taking the time to be present with the patient and family.

HOSPICE

Providing comfort that support the journey—walking with you, your family and friends. Hands that Serve; Hearts that Care allows people to live until they die. Families to live with them and go on living afterwards. Respite relief for family members.

CURIOSITY

COMMUNITY PARAMEDICS

In-home support with pain and symptom management; avoiding hospital transport where possible while increasing capacity in the delivery of end of life care at home, based on the patient's palliative goals of care.

SPIRITUAL & CULTURAL

Help the patient cope better with the hard spiritual questions that come up at the end of life with a goal to help the person feel peace and comfort. Cultural responsiveness respects the culture-based preferences of the patient. A community and extended family experience: respect, communication, appropriate environment.

WRITING THE BEST LAST CHAPTER TO YOUR STORY

COMPASSIONATE END OF LIFE PATIENT/FAMILY-CENTERED CARE

MY
STORY

Helping the patient to remain independent and to live in their own home as long as possible comforting people and their families during the end of life process. Managing symptoms; providing emotional and psychological support.

HOME SUPPORT

Timely provision of medications, assessment of medication plans and counseling the palliative team. Medications play a key role in increasing the quantity and quality of life.

PHARMACIST

EMPATHY

PHYSIO & OCCUPATIONAL THERAPY

Helps manage physical symptoms: pain, trouble breathing, weakness or poor mobility, fatigue. Helps patient continue with daily living activities like bathing, dressing, hobbies.

Assisting end of life patients to return home to die if they wish. Coordinating an integrated collaborative approach to ensure the patient and the family are encircled with all of the supports needed whether it be in their own home or in a palliative facility.

DISCHARGE PLANNING

CONNECTION

IT TAKES A WHOLE COMMUNITY
TO HELP YOU TO DIE WELL.



East Kootenay
Division of Family Practice

A GPSC initiative

SharedCare
Partners for Patients

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.

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.

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.

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.

THE POWER OF STORY-WRITING THE BEST LAST CHAPTER

MY NAME IS PAT. THIS IS THE STORY OF THE LAST CHAPTER OF THE LIFE OF MY FATHER

Ken

Ken was born on December 12, 1933. He was a tremendous athlete growing up, but his love was hockey. He came to the East Kootenays in 1955 to play for the Trail Smoke Eaters. He moved to Kimberley the following season to play for the Dynamiters where he won several league and provincial hockey awards. After hockey, my dad stayed very active participating in golf, curling, cross country skiing and walking. He will also be forever remembered as the sales representative for Labatts aka Kokanee during the 70s and 80s.



On one visit the doctor wanted to meet with me to discuss my father. The floor was busy and the only place that was quiet was the ward TV room. There I was advised that my father was dying and that antibiotics were keeping him alive. The doctor wondered whether we should just keep him comfortable.

Disturbing discussion in a public venue. First time told Dad was dying. Possible explanation: "Your dad has had many illnesses and as we get older they take their toll, so he is dying from all those things."

Listen – **KNOW WHO THE PATIENT IS** – learn about their life, hopes, fears. Who are they, where have they been, what are they most proud of. What would you like your caregivers to know about you?

Later in life, Ken faced several health challenges including bouts with esophageal and bladder cancer and developed poor heart health which led to having a pacemaker installed in 2016.

The beginning of the end began in the summer of 2017 when we noticed a definite loss of mobility and balance which eventually led to several falls in his home and while out walking. His partner, whose health was deteriorating from trying to take care of him, was forced to call an ambulance after a fall from which she could not help him up. He was taken to hospital.

It was suggested that I take him to my home which is not set up for anything like that. So I arranged for him to move into a semi-assisted care facility. After one night there, he collapsed again and was taken back to the hospital by ambulance.

Beginning palliative care would have been helpful at this stage, allowing the family to prepare and identify their wishes. Introduce the palliative process in the latter part of the curative stage. **ASK QUESTIONS – Who would you like to make decisions on your behalf if you can't?**

After lengthy telephone conversations with my brother, we decided not to accept the doctor's recommendation and to carry on with treatment.

The conversations turned to what to do with my father. It was apparent the hospital wanted to discharge him as they felt that there was nothing more they could do for him. He could not go back to the semi-assisted care facility so I was again asked to move him to my home. If he was truly dying, my home and myself were even less prepared to take him than before. I was assured that home support would be provided but I felt that I was being given no options. I again refused.

Finally, I was told that a respite bed had become available. On April 12, 2018 Dad took his last road trip in an ambulance to the care facility where he passed away on October 26, 2018.

Information on community paramedic program; planning for long term care. **WHO CAN HELP** – who needs to be included on the collaborative – integrated team?

Over the next week or so Dad was moved almost daily between the emergency room, day surgery room and the 2nd floor. I would visit my father every day but had no answers as to what was actually wrong with him. He continued to deteriorate and now his speech was becoming confused and unintelligible at times.

Information on services available in community. What services would be most useful at this stage? How can the family be supported to make the right choices for their loved one and for them?

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

Thank you for allowing me to tell Ken's story, and although I feel the system failed us in some ways, I want to acknowledge the tremendous care that was given to my father during his final journey. *It will not be forgotten.*

THE POWER OF STORY-WRITING THE BEST LAST CHAPTER

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

Rod

In 1991 after many years of being a single parent to two wonderful boys, as an invited guest to a gathering, I knocked on the door of Professor Dr. Rod Conklin's condo. My knock on the door changed my life forever. Six weeks later we were buying a condo together and selling mine. Twenty years my senior, Rod stayed young at heart. Rod, being the founder of one of the most successful private schools in the country, was around youngsters who kept him sharp and on his toes all the time. I tell this story of him because when Rod passed, he truly was the healthiest

82-year-old around – nothing wrong with him, no medication, no high blood pressure, no diabetes – except he had cancer.

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Except one. The Cancer, Gleason 10s, had escaped on one edge of his prostate.

Prostate-specific antigens (PSAs) every three months for four and half years – each time his score went up incrementally. Then one day it skyrocketed. Rod had hormone therapy for 18 months and suffered from severe back pain which just couldn't be diagnosed. We hadn't heard from BC Cancer as to next steps so out of frustration we went to Kelowna to try and meet with someone! As it turned out, the cancer had spread so badly it had eaten his tubes to his bladder, and urine had backed up into his kidneys. Two nephrostomy tubes later and five days of recovery, we were sent home to enjoy what ever time we had left, but still unsure of the actual severity of his condition. On the evening before the video conference with BC Cancer, Rod fell three times and I could no longer care for him at home.

Three visits to Emergency, telling our story to three different people caused me to "lose it". We felt we had no advocate. There was too long of a wait for a video conference with a BC Cancer oncologist.



When Rod was 75 years old, he was told he had prostate cancer by his urologist who Rod built a trusting relationship with. Two weeks later Rod had surgery and bounced back with barely any repercussions.

Rod was pain free. He had energy to visit with friends and family as we choreographed the best end of life anyone could ask for.

We asked about Medical Assistance in Dying (M.A.i.D.). We were told there was a ten day waiting period. Rod did not have that kind of time and he was adamant that he wanted to control his parting. With grace and sheer professionalism his medical team were able to speed up the process, so a date and time were scheduled within four days. Palliative care should be based on the needs of the patient; not on the patient's prognosis.

We got to know everyone on the unit. They each had that extra gift of knowing what to do and what to say. My needs were as important to them as were Rod's. If this was a hotel, it would have been given a 5-star for the service it provided!

On the morning of his parting Rod was so accepting of his fate. I always believed he would go out kicking and screaming but no, there was such a peace surrounding him. With the country song *Forever Young* – Country Road compilation playing in the background, his medical team allowed him to go peacefully with his family at his side.

I called the clinic and cried asking for help. Once I did that, action happened. The locum phoned, home care called and a visit to the palliative unit.

Introducing palliative earlier would have been helpful allowing us to prepare; to respond to questions about next steps; to write the last chapter of Rod's story.

The video conference finally occurred and the oncologist said we can do this and that for you, but I said "STOP, here is where Rod is today". With shock in her eyes, the oncologist said – "Oh, you have two weeks at most".

Now the palliative care team came into action! For the very first time throughout this entire process I felt like someone took all the pressure off my shoulders. Rod was comfortably settled into a palliative room at the hospital. Pain medications were administered and for the first time in weeks,

Rod had a choice to make. With the support of his family and a collaborative, compassionate team a very difficult and personal decision was made.

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