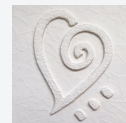


Faces of Help

Resources
for Leading a
Digital Stories
Discussion



Transcripts
Faces of Help Digital Stories



Compassionate Ottawa
Compassion Ottawa

Introduction

Care Beyond Cure is a small charity situated on the North-West Coast of Tasmania. It was set up to relieve the suffering and distress of individuals with a diagnosed progressive life limiting illness and their family carer/s, regardless of age or disease type, through the provision of practical assistance.

In 2022 individuals were invited to share their experience of giving or receiving help while

caregiving, dying or grieving. These five *Faces of Help* videos are *their* stories. The videos can be viewed by going to the *Faces of Help Digital Stories* tab online at <https://carebeyondcure.com.au>

These transcripts go with the videos. Viewers can read these before, or after watching the stories. We hope you enjoy these moving stories.

Sophie

by Gina McKinlay

I'd smile as I watched her snuffling on the verge. You were still the grubby orange colour that you were at the beginning, I thought. Minus the skin infection and the smell - 'aww the smell' I quietly said outloud.... 'I love you'.

Initially she was indifferent to her surroundings, my presence and the care I gave her. She shrugged the kindness off for three months until one day she approached me for attention. That was her turning point. She was different to most other hurt dogs as she did not respond incrementally, but rather took a long period of non trust before deciding that I could be relied upon.

Sophie had been mistreated and neglected, but I had accepted fostering her for what was expected to be six months until her case went to court.

Dogs have been my constant companion most of my life, but I have been living with cancer for a long time and fostering seemed the only course for me to enjoy their company.

We went everywhere we could together, including scary places which stressed Sophie but, she was learning to trust all the time. Sometimes there are still moments of aggression, like her occasional nipping of shoes under the table and she low growled at something that displeases her.



Recently, cancer number three arrived, was controlled and then just six weeks later along came cancer number four. Not a good sign.

I spent many weeks in hospital and Sophie went to friends. She is an old girl herself so I am not sure how much she is aware of things going on around her. But it was such a relief that Sophie loved this couple and that love is reciprocated.

I have now decided that more treatment isn't for me and moved to another town to live with two dear friends until I require hospice care. Sophie of course is with us and we are both loved by many.

I can experience my current journey with contentment and untroubled mind knowing that Sophie and I have each other



Dearest Dementia

By Joan Errington-Dunne

"Won't someone take him from me" I shouted to the sky ... and it happened ... a room became available in a secure dementia unit close to home but ohhhh, the torture in my heart ... how could I do this to him?

When seven years old, Thomas and his older brother were taken, in police custody, to live in an Industrial School in Dublin until they were sixteen. Within days he was being sexually abused by a trio of 'Christian' brothers, under threat he would never see his brother again.

Thomas was now seventy-nine, ten years diagnosed with dementia and needing secure permanent care.

The first week in a secure dementia unit he escaped three times.

He pleaded GET ME OUT OF HERE.

Tears streaming down my face, I asked another long time carer *How Do You Keep Going? How Do You Stand The Pain?*

He said *You must remember A and D ...*

A? I said through my sobs ... *Accept It!*

... *and ddddddD?* I stuttered.

Deal with it!

He brought me to my senses, this wasn't about me.

The second week I was ushered into the office and after telling me to SIT, the duty nurse, standing, said *Thomas has a girlfriend. He calls her Joanie.*

Tears filled my eyes. *I'm so sorry* she said gently.

No I said, *it's wonderful ... he's got a friend*

He was an accomplished tenor, she sang in musicals, they roamed the Lodge singing.



They sat together heads touching. I tell her how happy I am that he has a friend and thank her. She says *I love him so much*. He says looking at me, *I love this place and is this our home?*

Later he says, *when are your leaving?*

That night I slept well, dreaming I massaged lanolin into the delicate skin of a wounded lamb.

This was the beginning of his healing, of learning to trust. No longer fighting the world to protect those he loved, but allowing himself to BE loved.

With his dementia his trauma fell away. In it's place, the sweet, open acceptance and trust of a child and for the next ten years in permanent care, he enjoyed the childhood he'd never had ...

And I fell in love with him again.

"The beginning is the end , the end is the beginning"



Compassionate Ottawa
Compassion Ottawa

Sharing

By Mara

Thank you she said.

It was a few years later and we were catching up as we did, when we could.

It was precious to be there, to be with you both.

This made me teary. Annie flying over to be with us at the hospital was such a relief ... but I hadn't known what it meant to her.

Annie and I have been friends since we met in first year uni, both away from home, 18. We've grown up together, shared lots of years. She's also a nurse. She knows the hospital world. She could read Sue's medical chat, talk to the staff, help me make decisions.

I hadn't been alone.

Sue came out of the coma... and seeing Annie there she said... 'It must be bad, you're here'.

Sue let people care for her.

Through the treatment and the dying.

But then that was how she was. She brought people in to be part of her life, and her projects.

Whether building a deck or making her art, Sue gathered people around. Maybe to have a cup and see what she was doing, or to actually help out.

I had a roster those last weeks. At the hospital then at home. Sue was confused and anxious... and having someone beside her helped.

I needed our friends too. To be beside me.



I can be quite private. Even as a child I held things in. We didn't talk about feelings a lot.

With Sue I could talk - say all the things inside me.

Annie said, 'Shall I come'. I'd said yes.

To care and be cared - it's part of the same circle.



Not On My Watch

By Marianne Horvat

When my mother developed dementia, she moved into the flat under our house so I could care for her. As her dementia progressed, her needs grew ... and then ... all of a sudden my husband was diagnosed with a brain tumour. He needed an operation.

I couldn't care for both so my mother had to go into a nursing home. After all, I knew my husband would not want to go into a care facility.

I met my husband after I had moved to Australia from Germany with my family in 1962 as a young twenty-two year old. He was from Croatia and had arrived in Tasmania eleven years before me.

He was a fairly strict person, but he was happy and relaxed when he had a drink or two!

He was most cooperative and easy going when he became sick. I believe in a balance of natural therapies and modern medicine. My husband accepted all those I made for him.

The Community Nurses strongly advised me to have a break, so I went to Hobart for a few days. My husband had to go into a nursing home for that time to be looked after. Though, I was worried ... I knew my husband in a way the nursing home couldn't.

Before leaving, I prepared more than enough of his natural therapies to last while I was away and left them with the nursing staff. They assured me they would give them to him.

But when I got back I hardly recognised my husband. He had had a seizure in the hospital two days before he went to the care facility and his anti-seizure medication had been increased.



However it was not reduced by the home as it should have been after the right level had been reached, so he became over medicated.

Before I left for Hobart my husband had energy and was having conversations with people and was able to read a book. Now he just sat with his head hung down, barely able to make eye contact or speak.

Then I saw the remedies I had prepared, the herbs that had helped him at home were still there ... almost unused.

All the progress he'd made after his operation had been lost and so he had to go back into hospital to detoxify.

I was full of regret. I should have known better than to leave him in a nursing home. Still, there was no other option for respite.

After lengthy detoxification he was able to come home. With the assistance of great community nursing, I was able to care for my husband at home where, after about two months he died peacefully.

The last few months of his life could have been so much better.



Just Us

By Lynne Jarvis

The week before you died, you mentioned the word burial with a questioning look on your face. We were holding hands at the time as you lay in your recliner. I said, “when I die, I am going to be cremated and my ashes will be up with Jayde at the family plot in Penguin - would you like to be cremated and we can all be there together one day?” You gave me the thumbs up and smiled.

Aunty Julie then piped up and said “Yeah Daniel, we can be neighbours. I'm going next door with Dad and Bernard.” We all laughed.

Medication only became available 24 hours before you died. Zoe had taken charge, collecting the scripts. It wasn't long before you were comfortable. The bed had arrived earlier that day and help from community nursing, at that point, was welcomed.

Megan played your favourite music while Zoe taught Jonathan how to help. Time was spent caring for you, sleeping beside you, just loving you. Laughter, stories, facetimeing with Marlow - of course we cried - lots.

And it was reciprocal. We had learned and experienced much from your journey in life with all its complexities from the age of 12. And we continued learning, even if unknowingly, from spending this precious moment with you.

Obtaining the second signatory required for your cremation was a bit of a challenge given we cared for you ourselves, but we got there.

You would have laughed knowing it was completed by a lovely and gentle psychiatrist – she smiled, as we did, when Zoe said “the only time you get to see a decent one Dan and you're dead.”



It was a beautiful candlelit vigil in the lounge room, on the Esplanade. Just us. Your family. The way it had been for most of your life.

You laid on a homemade shroud. A simple white sheet, painted with hands by those who loved you. It had hung in the front porch for six days following your death. Lily's gift to you. We wanted to make sure your body was wrapped in loving support when it left your home for the last time. This was important to us.

You had drawn a very short straw when it came to receiving medical assistance in the last few years of your life, and for that, there are no words - only deep feelings of loss, anger and sadness.

We know you loved us all, deeply.

