

Kathleen – Caregiver Edited Transcript

My name is Kathleen Martin and my husband, Ian, passed away almost five years ago. He had cancer of the tongue and after two rounds of radiation he then had an operation followed by chemo. All of these worked for short periods of time. But over two and a half years the cancer reoccurred. As a caregiver, I see the journey as a long one for him especially when he couldn't speak very well in the beginning and towards the end really couldn't speak at all and couldn't eat and swallow very well. As much as they were a loss for Ian, I came to realize the loss was just as difficult for me. The medical part is seen as 90 percent but I think the social/emotional part has a greater value than the 10 percent.

Three things

I had sort of asked for a hug in the morning, a dance in the evening — because we like to dance — and it would be a slow dance, and 'I love you' at bedtime. And that was what I needed for me and we were able to do this. So these were constant in the beginning. The more the cancer came the more this stage passed, but this stage began. There was all new learning for each new stage. So we continued what was known — we could still have a hug, we could still have a little standing on the spot dance — it was just the fact that you were connecting again. And that just said volumes about the need for the touch. I mean in bed we would, you know, he would have a habit patting my bum goodnight, that type of thing, but this was really in each other's arms. So for me it was free, we didn't have to go anywhere, it was easy to do and 'I love you' continued for as long as speech continued. Until he pressed a machine and it was some other guy saying 'I love you' on the machine.

Nurse Nightingale

Communication and eating became a real wedge, I call it a wedge, between us. Because I became almost like a police, policing the number of tins of liquid food for Ian because swallowing was very difficult. The tongue was raw but I would do a lot of pureeing and liquefying... I jokingly say this but I'm never proud of myself ... but I went from Nurse Nightingale to Nurse Ratchet, some days, where I was relentless on the food. You know I felt for him that he couldn't speak and articulate how he was feeling, but I felt more for myself that if you don't eat... this is your lifeline. And you're putting me in charge of your lifeline. And I didn't want to be in charge of it. So the solution was that after Ian's afternoon nap we would have couple time. And that would be whether Ian was writing notes, or listening to me or we would sit through here. And if he wanted to feed that was his choice because he could still write notes. We'd listen to some of his music, we'd listen to music, we would look up our photo albums, but it was our time.

Getting help

I'm very good at knowing what I need and how to compensate. I just wasn't good at knowing how... I was still having the odd dance were still doing that and our hugs and that... but some nights 'I love you' was very hard, it was hard for Ian to say it and he's not going to write a note, so it was kind of a one-sided, you know, 'I love you.' So — it became more a conscious awareness that I was needing help. More for my emotions. And then I got a call. And I met with a very, very fine young intern at Princess Margaret who, when she we got a little bit of the background — told her about the dance at night— and told me and said to me, that she saw that our dance floor had become uneven. And it was no longer level. And neither, you know, neither were we. And that just put things in perspective – it gave me license not to feel that things had to be level any more. Also gave me license to view that I was still okay and I wasn't as mean-spirited as I was feeling I was... so I tended every time Ian had an appointment I made an appointment before hand to see her and after a few weeks she asked if Ian would come. And I was, 'Well, I'll ask.' And I think he maybe thought because it was for me it was something he could do for me. And it was excellent because it allowed me to take myself out of myself. With someone there as someone that could be totally objective when it would just be Ian and I trying to converse on, 'Well you're saying', 'Well you didn't say', 'Well if you told me,' but all of these things that we tend to maybe shield when somebody's sick or you shield your own feeling.

The F-word

I was Nurse Nightingale and they say 'Oh you're so patient Kathleen,' and then I'd swallow all this guilt again because I know I'm a patient person but this changes — I say it brings out the worst in you when the journey becomes too long and it brings out feelings that maybe lie dormant. I don't know... but this just scoops them up and you find yourself ...I mean, I never swore. I worked with children. I would say 'sugar' because I would never want — but I've even said the F-word during this journey and I'm honest about it in my writing. I just say what I'm saying here, that times I didn't like me, why would anybody else like me? And I think I'm gradually forgiving myself.