

Looking for Hope

Tajinder's story told by Baksho

*"In life we are not trained for the hardest thing,
which is the inevitable."*



I can't believe it's nine weeks since the funeral this week; and ten weeks this Wednesday since he died. My daughters and I do talk to each other all the time about their dad but we don't cry in front of each other. I'd like someone for my girls to talk to. At least they've got each other. I worry about my son. He's twenty-eight and he'd started to treat his dad like a friend in the last couple of years.

We've set a date now, the end of March, to take my husband's ashes to India. My son has missed most of his first term at university because of his father's illness.

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At the start my thoughts were all jumbled up. I started to make notes of all the things that I wish he'd said and done, that I'd said, my thoughts, things that hurt me. It helps when you write things down. It structures your thoughts. I can't work at the moment. Sometimes I feel angry. We thought we could help him survive cancer. Why didn't God answer our prayers? Why didn't my husband get better?

The start was devastating and went on being devastating.

The Christmas before this last one my husband was experiencing a lot of acid in his stomach. In November the doctor gave him tablets and it seemed to get better. Another doctor gave some antacid tablets but then the condition started again. My husband thought that if both doctors thought it was just acid he must be OK. He left it until July and then asked the doctor to send him to the hospital. There he had a scan. A camera was put inside him. The consultant said that he was 99% sure that he had cancer inside him. He went with my son. They were in shock and decided not to tell us.

One of my daughters was going to study and work in Russia so I said to my husband "I feel there is something you have not told us". "What can I say? I've got cancer" he said. He put his arm around me. "You don't deserve this" I said, and I asked "what happens now?" He said that they were going to send him another appointment for another scan. The next day we had a letter for

an appointment in three weeks time.

I went straight up to the surgery. Time was of the essence. He was bad, he was vomiting, and he was feverish. I phoned the hospital. The nurse said that there'd been a cancellation. We went the next day. He could hardly walk. "Dad, how can they send you home you're not well?" my son said.

They said they'd send another appointment in three weeks. So we had to go to the emergency department. He was so weak; he was feverish. My son repeated that he needed to see a doctor straight away. They put my husband on a drip. Twenty minutes later the doctor said "I'm not surprised by the way you felt. You are in shock".

They kept him in over the weekend. They said he could go home on the Monday. "You have a large advanced tumour" the doctor said and he also said he wasn't sure what their options were. Apparently it was so advanced it was blocking his stomach and he could not eat or drink so they needed him to have a bypass operation. I said that we would be very grateful if we could get an appointment for his surgery. I have seven children and they needed their father.

We came home. The hospital gave him a nutrition drink per day because he could not eat or drink. After the bank holiday in August he did not know what to say to us so he did not say a lot, but on the bank holiday he asked the children if they'd like to go out on a day trip. We had both been working. He loved his gardening – that was the way he relaxed.

Anyway, we decided to go to Ludlow Castle for the day. We all went together as a family. You never think this might be the last time we all do this. We took two cars. We had a good day. He was quiet and withdrawn. I don't drive so my son drove one car and my daughter drove the other, it was her friend's car. When we got there she said "Dad, can you help me park it?" It was so endearing. He just did it. It was second nature to him to help her. He was fifty-three and he had driven since he was eighteen.

He was interested in history. He made a point of taking pictures. We tried not to let it enter our heads it might be the last time. I remember him sitting on the grass near the river taking a sip. It was all he could manage.

I was just feeling I needed to be with him. Normally I wouldn't have gone and I'd have got on with some work at home, but from then on I was always with him. I went to all his appointments. The children found out information. They went on the Internet. They researched. We were looking at all the options even spending money. The consultant said "no, it has gone too far". If the doctors had caught it earlier he may have had five more years. That made me bitter. That is something we have to live with.

It seems there is a higher incidence of people with this sort of cancer for Asian and Japanese people. In Japan they have started earlier screening for this.

My husband was always at work; we never had benefits. He would work night and day to bring up seven children. Apart from his gardening he did not know how to deal with the stress. So there

were things that could have helped but we did not know that. It's heartache to think it could have been prevented.

He had never been sick before; only colds or flu. He didn't even have high blood pressure. It was such a big shock.

He had the bypass operation. For two weeks he had a little to eat but by the third week he started vomiting. We took him to three or four private doctors. We had an appointment every week with consultants at the hospital. Don't believe everything on the Internet!, they would say. The doctors didn't give us much hope. They did hope that he'd put on weight so that he could go on chemotherapy. In that third week on the Monday and Tuesday we saw two homeopaths. On the Wednesday we saw someone at a specialist clinic about 100 miles away. We were given herbal treatment produced in India and other stuff. The consultant saw my husband. We came back and felt hopeful. Where there is hope, you try.

On the Wednesday coming back from there he was sick. On Thursday he went for mistletoe treatment. They also gave us hope. He had one injection there. In the car he vomited. In the evening he didn't eat anything. On Friday morning he was vomiting. The doctor at the surgery thought there might be another blockage. She sent him back to the hospital. He was only given sips of water from that time on. He had eaten his last meal. He was dead six weeks later.

For days he went without any treatment. He could not get any rest because he was on a busy ward. When he did go upstairs in the hospital he was told they would do another biopsy to see if they could do another bypass, but the cancer was spreading.

You hope against hope don't you?

They took us into an empty room and told us that the cancer had spread all around the stomach and that there was no more they could do. They said he had days to live not even weeks. My husband didn't want lots of people there. It was always just the children and me. We didn't tell the wider family he had cancer because then you have to deal with them too. We thought we'd tell them after he got better. His own sister and brother knew. The bulk of pain myself and the children took on ourselves. When the doctor gave us the news my daughters phoned their brother. His dad encouraged him to go back because he was missing his study. I plucked up courage to ask the doctor how long he thought my husband had. "Before I answer think about that question. Do you want me to answer that?" he said.

We thought that if we brought him home we'd give it our best to make for him the best we could. We bought in teas and a juicer and aloe vera juice to add to his sips of water. Also, everybody was running around, up and down to the hospital. We thought we should have him at home. The doctors and nurses said that they did not provide drips at home. I kept saying that we wanted him in our own environment. Eventually the Macmillan nurses said they would provide a drip at home. For a whole week he was burning up. On the Saturday night we had to call the doctor in who gave him an injection for his sore throat. On Sunday he was deteriorating more. I asked if it was possible for my husband to go back to hospital and for him to go back on the drip and the doctor said yes. She called for an ambulance.

He went back. After two weeks I asked if we could have the drip at home but for us to do it. I said I would take the responsibility. "Train me and my daughters up," I said. They gave us the training, which was actually only ten or fifteen minutes at the most. We took responsibility for administering it, changing the needle and other actions.

He couldn't walk. I had to help him even to pass water. They gave him a bed here in this living room. They gave him lots of injections. They gave him morphine and we didn't realise. We felt the morphine was taking his life. We had the morphine removed. They seemed to give him any drugs that would remove pain or quicken his death.

I used to sleep on the sofa night and day. He was taking less and less drinks. It was heartbreaking. Visitors would come. It would exhaust him. I would give him a bath. I'd see his bones. I would think, "how is he going to get out of this?" He had wasted away. I kept thinking how I could make him get better out of this. He had always been fit and healthy and good looking too. He always ate fruit and fish a couple of times a week. That's why we can't understand why he had this condition.

Only in the last few weeks it occurred to me that if he had blood when he went to the toilet, he wouldn't have known – he was colour blind. I used to ask him if he'd passed blood and I'd be relieved when he said no. I tell my daughters to pass this information on for if they have sons who might have colour blindness.

My husband was never very communicative. He wouldn't want to talk. He'd brush things off. He told the specialist palliative nurse he wanted counselling for his wife and daughters. He was always a bit religious. We'd sit around the table and he'd say a prayer. He would explain aspects of life to the children and tell them to put their trust in God. He would say God is everywhere. I think he wanted to prepare himself for passing over. He said that just a few weeks before he died. When he found out about his diagnosis he prepared himself by detaching himself from us as a family. We are Sikhs and in an Asian family you detach yourself from this world.

Over the last couple of years he read about other religions and he believed that for us all there is one God.

When the doctors said there were only a couple of days left he talked to the children when I wasn't in the room. "Look after Mum, make sure she eats. Look after yourselves and believe in God" he said. I think he didn't say anything to me because he was preparing himself. He was thinking about us too.

He was never the sort of person to complain. I was always trying to pull him out of that, trying to get him to talk.

I thought all the crying would stop but the tears keep coming. I don't cry in front of the children because it upsets them more. If they want to cry I encourage them. It's OK to cry, I say. I think there are times when they cry quietly to themselves in their rooms and I cry in mine. We try to protect each other. Sometimes I find myself still telling him that even if you don't love us, we love you. I think men can bottle up their emotions.

In fairy tales we are taught to look up to men. In real life it is the other way round.

But it is such a burden now, such a weight because I think I was gliding through life. I knew he was always there. Now when I go on trips I don't panic but I feel the pain of him not being there. He always knew the way; all the back routes. Now I am the one always looking out, I am always alert night and day. Sometimes I think he's looking down at me saying, "now do you know all the things I did?"

My husband had good qualifications. He had an HNC in metallurgy but he worked for the Post Office for twenty-eight years. He liked that there was less responsibility in the job because he said his responsibility was when he came home. He looked after his mother and us. He always did a lot for his wider family. He was greatly loved by my mother and father. He did so much for his extended family and us. He did a lot for everyone. He used to visit his mother every day even if it was for ten minutes. He worked seven days a week if he could get the overtime. "If I wasn't here you'd have a much harder life" he used to say. I remember that now.

Cancer was the last thing we thought my husband would die from. He had had high blood pressure but over the last couple of years that had normalised.

I used to think you could control factors in life. Now I have come to the conclusion that whatever is going to happen will happen. Maybe too much work isn't good for one.

In our culture they say nothing is guaranteed in life but death. It's even more of a burden in our culture – death. People go on and on saying: it's such a loss, you will never get your husband back again, and your children won't have a father. They aren't doing it intentionally to hurt you. There is a period of five weeks in our Asian culture of grieving. Everyone still comes to visit you and it is like they are saying "you will not forget this!" It feels like they are rubbing your face in it. They are saying: "Look how bad it is!" Western culture is more positive. They say there is hope.

Some mornings I don't want to get up out of bed. I'm thinking maybe if I follow my husband I won't feel this pain any more. So I feel bad enough without being told how bad it is over and over again.

If I had to help someone else who had suffered the same as me this is what I would do differently: I would be positive.

When visitors come it is another ritual. I sit and nod my head as they say all these things even though it feels like it's killing me inside. You are already in a corner. I am looking for hope.

When my husband was very ill visitors would come out of duty and my daughters would say "Dad, if you don't feel like seeing anyone pretend you're asleep". That's what helps you if there is someone there to protect you. My husband's belief and hope was that if you suffer here you have a good after life.

"What is it like at the end?" he asked the palliative care nurse. He was preparing himself.

It was important we did our best for him. My husband wanted to be at home at the end. He died in this room. “Mr. Singh, do you want to go home?” the doctors said. My husband turned around and said “you do want to take me home don’t you?” “Of course we do Dad” the children replied. We could then spend twenty-four hours with him. We could look after him without having to ask permission for things like in the hospital, or travelling, which wasted time.

Our aim was that we’d make him survive. In Asian culture it’s second nature for us to bring him home and look after him. To us it is a privilege.

I would have surmounted any obstacle to make him feel better.

Right at the end my daughter called me from the kitchen. “Dad’s trying to say something” she said. I couldn’t understand him. I was still holding his hands when he died. “You can’t leave us, you can’t leave your daughters” I was saying. Perhaps I could have given him artificial resuscitation.