

## Appendix 4

### A. Poles apart

So here I am, entering the autumn of my years and without my soul mate, my talented wife who used to write stories. We didn't have anywhere near enough time together – you see she was taken from me quite suddenly; there wasn't time to say goodbye nor time for me to say how much I love her. We were together for about 10 years, she was my truest love, the person who I believed would grow old with me and one of our favourite songs was Shania Twain singing “Forever and For Always” which was filmed on a beach. I didn't know she was that ill, nor did the GP. It took a nurse to suggest she felt something more sinister was going on. The 3rd anniversary of her death happened earlier this year and it's ironic that we are meant to be celebrating the “Happy New Year”.

To state that she had secondary cancer would be an understatement – my wife had multiple cancers – she wasn't diagnosed properly let alone early enough. To say I feel let down by professionals would be an understatement! And so I feel angry, guilty, full of regret. I should've said that I loved her more often; I could've said where I was at and now it is too late. I continue to live with this regret. Trust has flown away when it comes to GPs – ours was complacent and didn't take the time to explore and therefore diagnose correctly which I believe, think and feel stole precious time for us both and the opportunity to fight cancer. OK, I shall admit that although they are human, we as other beings tend to put “professionals” on the top of the sandcastle. I thought they knew best; how wrong we were.

I sometimes feel her presence, usually when I fall asleep on the sofa and I swear I have felt nudged – she used to nudge me to say “It's time for bed my darling”. I'm not that religious, my wife was a non-believer. I believe though that she is with me sometimes and what hasn't helped at all is that her cat, aged over 20, died recently. He was my connection to my wife and so the grief grew. People say he was only a cat; I disagree. The cat was my last physical connection to her and now he's gone too. I feel severed.

As my wife was dying, I felt we were both on a precipice looking down into a crevasse where there was no light – there was lots of snowy blizzard though. She was going somewhere else, perhaps to a room I couldn't enter. I was destined to walk alone, make foot prints in the sand alone – my eyes welling up remain and salty water persists. It's cold down here and the coldness is like a blizzard which stings my eyes... it's like a paradox – sand and snow; I'm sure my loss will continue to impact my life but I am still here still alive and the tears still make tracks down my face. Guilt and recriminations are sometimes my companions – I wish I had said I loved her more than I did – the sand in the egg timer ran out and I sometimes feel like the song “I'm a man of constant sorrow”. Perhaps you saw the film “O Brother, where art thou”?

I grappled with the Arctic precipice and the quick sand under foot and contacted Cruse in Oxford; I enabled myself further by rekindling an old friendship – we were both on similar beaches. This encouraged me to keep going, even when the night was dark and cold and ever so long; January will always be hard and I rarely feel like saying “Happy New Year”. What did help was becoming a Cruse client; we had a few sessions and sand castle by sand castle, the terrain underfoot became more sturdy. I began to unwrap my cotton wool shield and look at my different compartments of feelings – my feelings resemble a mask – Beano comes to mind. Counselling helped a lot and since then, I have been encouraged to build a new life where I am now a telephone helper – it gets me out of the house, with

its big garden and enables me to connect with others who are embarking on their quick sand experience.

I felt disabled when witnessing the many carers at Katharine House Hospice; I know they were only trying to help her in our last few days together but when you are standing on quick sand, similar faces and continuity suddenly becomes vital. Another negative experience was when my wife had to have her lungs drained and was thereafter placed inappropriately within an Alzheimer ward at the Horton General Hospital – I tried to complain but to no avail. Empathy and care was poor.

I believe that what is missing in the Banbury area is a Cruse office, where people can pop in, call, be heard and understood. I had to go to Oxford for help and it's quite a way. I wish GP's, particularly those with decades of experience, would watch out for complacency and attend regular training where they can empathise and walk on quick sand with their patients.

## **B. D's story**

When my lovely partner of 16 years died suddenly and unexpectedly in his sleep from a heart attack, I went into a state of deep shock and despair. I found it so difficult at first to be on my own although my friends helped me through the first few weeks by phoning me each day or meeting for a coffee or a walk. It meant a lot to know that others cared, especially as without R I felt utterly alone in the world. I helped myself by trying to eat healthily, do more walking and go swimming. Writing poetry about R with tears streaming down my face, reading familiar books, prayer, and Buddhist thinking and mindfulness, all helped bring some relief into my life.

I was off work for the first two months after R died and I'm very grateful that I had this time to sort myself out a little without the pressure of also concentrating on my job. When I did eventually go back to work the routine was a comfort, and I found instead I dreaded the coming of the empty weekends and endless time on my own. At work I was mostly able to put R from my mind, but as I drove home at the end of the day, and when I opened the front door of my empty house, I was engulfed again by the pain of my grief and the longing for R to still be in my life.

Although I was supported by my friends, I knew very soon after R died that I needed extra help. Not having any close family in this country, and the desire not to burden my friends too much with the rawness of my grief, led me to contact CRUSE very soon after R died. I had to wait 6 weeks before I was able to begin counselling with a wonderful lady from CRUSE. My relief was immense when I heard I was going to start receiving professional help. My counsellor was so kind, flexible with the time of her visits, caring and professional. The sessions in my own home helped so much as a means for me to discuss honestly how I felt, talk about things that were particularly difficult, and suggest ways of getting through. And most of all it was so good just to talk about R. As time went on she suggested some books by people who had also lost their partners and had written about their experience. I found these stories from people who had survived to rebuild a happy life very encouraging, and I felt not quite so alone when I was able to recognise many similarities between their stories and mine.

When the counselling sessions eventually came to an end I felt a bit scared at no longer having that support. Thankfully my counsellor suggested I look at the Way Up (Widowed and Young Up) online group for people over 50 who have lost their partners. Joining this national online support forum was a lifeline for me. It is very comforting to see posts from others going through similar situations to myself and read the caring responses from other members of the group. When I first posted a message myself I felt hugely supported by messages from others who understood what I was going through. Some members organise social gatherings and I have found it uplifting to meet others in person who are all at different stages of bereavement. It is so nice too to enjoy a meal out with others, something I missed when R died. People are very kind and supportive and I have made a lovely close new friend at one of these events.

There have been many things which have helped ease the pain of bereavement for me, but at the beginning I did feel let down by the lack of support from my doctor and surgery. The only help I got at first was from my doctor signing certificates giving me more time off

work and prescribing sleeping pills. I do think they should have been able to offer more assistance at a time when I felt so low.

What I think is missing locally in terms of bereavement counselling was a lack of choice. It is wonderful that CRUSE offers one to one counselling in people's own homes, and I very much hope this will continue. However I do think it could be of help to others if there was an opportunity to receive counselling via group sessions. I feel also that it would have been helpful if there had been a local CRUSE office where I could have perhaps gathered more information and left messages more easily for my counsellor.

Next week is the second anniversary of R's death and I still miss him so very much. But I am so grateful for all the support I have received over the last 2 years and I am so glad that there is some happiness in my life again and hope for the future.

## **C. Marilyn's story**

### How I helped myself:

By building my own support group, although not local to Chipping Norton, through joining an Art Group, Horticultural Society, Single file – a place where people meet and are aged between 45 and 70 who were divorced, bereaved, single.

### What encouraged me:

Friends, Katharine House Hospice Bereavement Counsellor who offered me open ended and free sessions three months after the death of my husband, hearing other people's stories. Learning that we can be in different stages of loss with different experiences. I had support from a friend who lives in a different part of the country. I have lived in Chipping Norton for only a few years.

### What I found helpful at the time:

My family who lives nearby; as a grandmother in my late 60s, I do have a purpose and am needed by my daughter and her teenage children. My daughter works full time. There are some groups available to me although this requires effort, taking a risk of connecting and being in unfamiliar places.

### What I find unhelpful at the time:

Finding a safe enough place. In retrospect, I struggled in the end of my fit and healthy husband's death. There was a distinct lack of pre-bereavement counselling. I felt pressured, avoidant, anxious, the fear of what it would be like to be alone and living life without intimacy.

I continue to find it hard to break into a new group whilst feeling so vulnerable – predators are out there, people who try to take advantage of someone like me.

The MacMillan nurse was unable to connect; I sense she was new to the job and lacked experience – I felt she was supporting me and my husband through a text book and I didn't like that. I complained and I was sort of heard – my complaint was heard and is, I think, being acted on.

### And... what was missing?

I would like to see a place to meet, exchange feelings, particularly for people in the early stages of grief. It could be good if I could meet other people who are similarly recently bereaved. I would like to see a drop in place in my North Oxfordshire area where there are cushions, refreshments, events, gatherings – an opportunity to connect! Low cost could work and I know I am lucky enough to have free, ongoing counselling within the Katharine House Hospice. Fran, my counsellor is good.

**D.**

About Me: Age 51, Male, British, date of bereavement August 2016

How I helped myself:

I was very close to my Dad when he passed away – I was devastated. Positivity helped me through as well as strong bonds with partner, Mum and family.

What encouraged me:

My Partner, my Mother, my friends and immediate family – they were all fantastic.

What I found helpful at the time:

My GP was very supportive. My Mother had just moved house and we had to focus on organising everything which was stressful but gave us purpose. Humphries Funeral Service were great too.

What I find unhelpful at the time:

It didn't help that my Dad passed away the day after their house move. It was a very difficult time.

And... what was missing?

N  
o  
t  
h  
i  
n