

**Central Queensland University**

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**The role of narrative in easing pain: blurred roles of health professional and carer**

Biographical note:

Bambi Ward is a PhD student in creative writing at Central Queensland University. Her creative work is a book-length memoir of her spiritual journey. Bambi is based in Melbourne. She has a background in medicine (in general practice), medical education and oral history, and has written articles for both peer-reviewed medical and creative writing journals

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When health professionals find themselves in the role of carer for a family member who has been diagnosed with a serious or chronic medical condition, it can feel like a blessing, a curse, or both. The health professional may know too much, resulting in them experiencing greater levels of anxiety than a lay person. On the other hand, their health background may make them a more effective patient advocate, as they will often know what questions to ask, what possible treatment options are available, and how to navigate through the often-impersonal health system. Being both a carer and a health professional can also result in blurred roles, particularly if the latter is a medical practitioner. It is not easy for a doctor to sit on the other side of the consulting desk and hear bad news about a loved one's health.

It is therefore not surprising that one of the most challenging and distressing periods of my life was when my father was diagnosed with metastatic prostate cancer. I was working as a general practitioner at the time, and was married with a young daughter. However, Dad's illness experience started whilst I was pregnant with my daughter. Dad had been experiencing urinary symptoms for several weeks, and finally consulted his male general practitioner. He was diagnosed with an enlarged prostate gland and ordered a blood test called prostate specific antigen, or PSA for short. The test came back raised at 5.5 ng/ml; the normal level for the test was 4.0 ng/ml or less. About one in three men with a PSA level between 4 and 10 ng/ml have prostate cancer, although this proportion varies with the population tested. I don't know what Dad's general practitioner told him about the possible significance of his blood test result. Dad was subsequently referred to the same urologist who had successfully treated his benign enlarged prostate gland with surgery ten years earlier.

After seeing the urologist, Dad told Mum and I that the same surgical procedure he'd had ten years ago was being recommended once again. After much thought, Dad chose to delay the surgery for three months, until the busiest time for his work was over. He was a self-employed businessman and had no employees to do the required time sensitive work. Neither Mum nor I know whether the urologist tried to convince Dad not to delay the surgery.

I was five months pregnant with my first child at the time Dad was given his blood test results. Dad didn't want my joy or my mother's joy spoilt by worry, so he chose not to tell us about his test results until several months later. Had we known about the abnormal PSA test, I suspect we would have insisted that Dad not postpone the surgery.

Dad eventually checked in to a city hospital as a private patient three months after seeing the urologist, and had the recommended surgery. Several days later the urologist informed Dad that he had prostate cancer. Dad must have felt devastated by the news, but he didn't let it show. Not to Mum and me, anyway. He maintained a positive attitude, underwent a course of radiotherapy and had minimal side effects. He seemed to cope with everything exceptionally well, and was able to keep working during his course of radiotherapy.

The specialist told Dad he was cured at the end of the course. I felt an enormous sense of gratitude and relief. We celebrated by going out to dinner. Shortly afterwards, Mum and Dad took a well deserved month long holiday to Queensland's Gold Coast.

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One year after the surgery, Dad developed severe pain in the left side of his tummy. He was hospitalised and underwent numerous tests. Dad's pain was treated adequately, but the reason for it remained a mystery. A special kidney x-ray was eventually ordered, and finally established the cause of the pain. The tube (or ureter) from Dad's left kidney to his bladder was blocked. The specialist ordered a scan of Dad's tummy to determine the cause of the blockage. The test was done on a Friday morning. I visited Dad later that afternoon. Mum was there as well. She asked if I could find out the result of the scan because the specialist wouldn't be visiting Dad in hospital until Monday. This seemed a reasonable request to me. After all, we were all anxious to know the result. The doctor within me battled with my role of daughter and won. After all, I had the power and opportunity to intervene and spare my father an anxious night.

I walked down to the radiology department, gave them my name using the title of Doctor, and asked to see the typed report of the scan. I was given permission. No questions asked. As I read the report, the ominous significance of the findings started to register. A large gland had been found. It was compressing Dad's left ureter.

I blinked, and stared blankly at the report.

The enlarged gland was most likely caused by cancer that had spread from Dad's prostate. This was so unexpected. Such a possibility had never entered my mind because the cancer specialist had said Dad was cured. I'd believed him. How could he say such a thing and get it wrong?! Worse still, how could I not realise the scan was looking for evidence of the cancer having recurred and spread? What sort of a doctor was I? The answer was simple. I wasn't thinking as a doctor; I was thinking as a daughter.

Luckily, I was by myself. A feeling of horror and dread started permeating my entire body. My heart started beating rapidly, and I felt as if I'd been kicked in the guts. After taking some deep breaths and wiping away my tears, I felt composed enough to return to Dad's hospital room. My parents looked up at me expectantly. The doctor in me sat down and explained how a gland was pushing on Dad's ureter, and that was the cause of the pain. The daughter in me chose not to explain the significance of the enlarged gland. To my intense relief, they both accepted what I'd said without asking further questions. I was then able to excuse myself and drive home.

I couldn't believe what I'd allowed myself to get into. I felt utterly shattered by the bad news, as well as the way I had found out about it. I also felt like I was shouldering a very heavy load. How could I have agreed to find out the results and tell my parents? I vowed to never put myself in a similar position again.

The specialist visited Dad on the Monday after his scan and delivered the bad news. I have no idea how Dad reacted. He was always a very private person who chose not to show his feelings. Soon afterwards, a stent was put in to Dad's ureter. This relieved his abdominal pain as well as the blockage. Dad was also commenced on a course of monthly hormone injections. He appeared to be in good spirits, and remained reasonably well for several months until he developed increasing leg weakness as well as a speech difficulty, making his words jerky, slurred, and difficult to understand.

Dad was subsequently admitted to hospital and underwent several tests, all of which were normal. The cause of his symptoms remained a mystery once again, and he was discharged on a Friday afternoon.

Two days later I received a desperate phone call from my mother. Dad was much worse, and their family doctor could not be contacted. Mum asked if I could come and see him because they didn't want to wait hours to see a locum doctor who didn't know anything about Dad's history. I agreed to her request, and drove the half hour trip to my parents' home.

I rang the doorbell. Mum opened the door and promptly ushered me into their bedroom. I was not prepared for what I saw. Dad lay on his bed in his long sleeved blue pyjamas. The muscles on the right side of his face were contracting involuntarily. The severe jerking movements were also mirrored in his speech. He had difficulty keeping his balance when I asked him to stand up and walk. He also had significant weakness of both arms and legs, especially on his right side. I'd never seen anyone with similar symptoms and I felt totally helpless. Although I was very distressed to see my father in such a poor condition, I appeared calm as I continued to function in my role of doctor. I rang the home number of the specialist who had looked after Dad during his previous hospital admission, and arranged for him to admit Dad to hospital. This was a relief, because it meant Dad could be admitted without having to wait to be assessed in the accident and emergency department. I then rang for an ambulance. Fortunately it arrived quickly. I handed the ambulance officer a handwritten letter to give to the hospital, smiled reassuringly at Dad and held his hand as he was loaded onto the gurney. The ambulance sped away. My heart sank.

It was a mixed blessing being a doctor in this situation. I'd expedited Dad's admission to hospital, thus saving him lots of waiting around, but once again, it was a very draining experience for me. I wished the family doctor had been available so I could just be an ordinary daughter who needed support, comfort and reassurance.

Dad was eventually diagnosed as having a rare complication of prostate cancer called paraneoplastic syndrome. I'd never heard of it, so I looked up *Harrisons*, my thick red textbook of Internal Medicine. It stated that there was no cure for the syndrome, but the symptoms could be controlled by medicines that had sedating side effects.

The onset of paraneoplastic syndrome heralded the start of Dad's loss of quality of life. Why couldn't he have something simple? It seemed so cruel and unfair. Dad's condition gradually deteriorated over the next few months. During this time, Mum and I willed Dad to fight the cancer. At times, it felt like as though we were fighting the battle ourselves. We would not give up. We would conquer the cancer through sheer determination.

The possibility of Dad losing the battle never entered my head. Such was the strength of my denial. Perhaps things would have been different if someone had taken the time to sit down with me and discuss Dad's condition.

Dad wasn't offered palliative care, but in 1989 it wasn't as widely available as it is these days. However even if it had been offered, I doubt whether it would have been accepted. Mum didn't want to acknowledge that Dad was dying and neither did I.

Dad was readmitted to hospital in April 1989. Mum and Dad were both very grateful for the support and daily hospital visits they received from the family doctor. On the other hand, my experience was quite different. I would have liked the medical and nursing staff to treat me more like a family member who needed support, explanation and reassurance, rather than a medical practitioner who was supposed to understand what was going on. However I also wanted to assist Dad and Mum by positioning myself as an experienced general practitioner when I felt his management could be improved.

Dad spent the last few weeks of his life in hospital. I rang him every day and did the dreaded hospital visit several times a week. Dad had been a strong, intelligent man who supported others. I found it heartbreaking to see him lying helplessly on a bed, totally dependent on the private nurses Mum had hired because Dad had fallen in hospital and sustained several broken ribs. The whole situation just didn't seem fair. Dad was only sixty-five years old. Why him? If only I could change things. I wondered if his illness was partly my fault. Over the years, he said he resented certain things about my relationship with Mum, and how he'd often felt left out of things. The daughter in me wondered if his resentment had caused the cancer. The doctor in me dismissed the idea.

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I'll never forget the first morning in the month of May. The year was 1989. Dad rang me at my surgery. He proceeded to tell me, that he had had enough. He wanted to die and he wanted to be given drugs to hasten his death. He sounded perfectly lucid. Even though I knew Dad was an ardent supporter of the Voluntary Euthanasia Society, it was a huge shock to hear his words. I was with a patient at the time of Dad's phone call, and felt very time pressured. Even though I am strongly opposed to voluntary euthanasia, I told Dad I would contact the Voluntary Euthanasia Society and find out the name of a doctor who would talk to him. Every bone in my body was protesting against doing this, but it felt more important to honour Dad's wishes. I planned to phone the Society later that day and get back to Dad with some news. However I got a recorded message when I rang. I chose not to leave a message.

I was exhausted after a busy day at the surgery and decided not to visit Dad that night. By the time I rang Dad back to tell him I'd contacted the Society and would try again the following day, he was asleep. His nurse told me he'd been asleep for most of the day.

I telephoned Dad's room in the hospital just before 9am the next morning. Mum answered the phone. She said Dad had spoken to our family doctor the previous night and told him he had 'had enough'. Apparently his doctor told him he would have to complain of 'severe pain'. He would then give Dad regular morphine injections for 'the pain'. Dad had eagerly asked 'When do we start?'. I knew nothing of this discussion. Neither Mum, Dad or the family doctor bothered to inform me.

By the time I rang the next morning, Dad had been given the first of several four hourly morphine injections after being reviewed by his doctor. He went to sleep and never regained consciousness. I went through a number of mixed emotions. I was furious that Dad hadn't given me the opportunity of saying goodbye in person. However, he was often abrupt, and didn't like showing his feelings. Perhaps he couldn't handle saying goodbye. I also felt guilty at not having fully understood the urgency of his phone call. I regretted that I hadn't taken the time to talk to him more when he'd telephoned. But the overriding emotions I felt towards Dad, Mum and the family doctor were intense fury and betrayal. I was also angry that the Voluntary Euthanasia Society had not responded to my phone call.

I visited Dad that night after dinner. My mother, great-aunt and great-uncle were at the hospital when I arrived. They left me alone with Dad for a while. Although he was unconscious, I told him what I thought about what he'd done. I was angry that he'd given up the fight. I was angry that he hadn't told me what was happening. I was angry he hadn't waited to start the injections until I could say goodbye in person and I was furious at the doctor for giving Dad what he wanted, because I didn't believe in it.

I expressed my anger to Dad as he lay breathing noisily, unconscious in his bed. It helped to express these feelings, even though Dad couldn't respond. The doctor in me wondered if he'd been depressed and just needed treatment for that. I didn't know. I'd been well and truly left out of the loop and I felt totally powerless. The daughter in me was desperate to keep Dad alive.

Mum re-entered the hospital room after a while. She told me Dad wasn't expected to last the night. 'Go home', she said. 'Okay', I replied. Mum chose to go home as well. We walked to the lift in silence. The thought of spending Dad's last hours at his bedside was too painful for either of us to bear. It was also what Dad would have wanted. He was a loner and we knew he wanted it that way. So Dad died, alone, in the early hours of the morning of 3 May, 1989. And yet, he wasn't really alone. He had a nurse with him all the time, and I believed he was in God's presence, whether he realised it or not.

My husband and I both woke up during the early hours of the morning of Dad's death. Both of us experienced an overwhelming presence of love in our bedroom. This was very unusual, especially for my husband who is not a spiritual person. We later learnt that this incident occurred shortly after Dad had died. I like to think of it as being Dad's loving soul coming to us after he'd left his body. It was a most comforting experience, particularly for me.

It was Mum who rang that morning with the news of Dad's death. I caught a taxi and went to the hospital to view Dad's body with Mum. He looked relaxed and at peace. We didn't stay long. As we left the hospital for the last time, a nurse handed Mum Dad's things: his burgundy dressing gown, his wallet, glasses, comb and other toiletries, in a green hospital bag. I went home in a taxi with Mum. We travelled in silence. When we arrived at her home, we started arranging the funeral and notifying people of Dad's death. It felt like a very long day.

I dreaded the funeral. As an only child, I decided it would be my role to do the eulogy. I wasn't sure I would be able to get through reading it, so I asked my husband to stand beside me, just in case he needed to take over. However, I managed to get through the speech by myself. The encouraging looks of the female minister and the inner strength I felt from meditating earlier that day helped immensely. The process of writing the eulogy and then reading it in public put me in touch with an inner strength I didn't know I had. I felt proud of myself for getting through one of the hardest things I'd ever experienced.

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Life went on. Mum valued her independence and didn't ask me to help her sort through Dad's belongings. Her loyal housekeeper of many years helped her with that. I returned to my busy life: running my medical practice, being a wife, and raising our two-and-a-half-year-old daughter.

I went to see the family doctor to discuss the results of Dad's autopsy once the results were available. Mum and I had consented to an autopsy in the hope that it would explain Dad's unusual symptoms. It didn't really. The doctor treated me more like a colleague than a grieving daughter. He didn't ask me how I was feeling, and proceeded to read the main findings of the autopsy report to me in cold clinical medical jargon. This approach was not unusual for him, but I felt like screaming at him. This is my Dad you are talking about! How can you be so cold? Maybe his behaviour was his way of protecting himself from his true feelings.

I couldn't wait to get out of his consulting room. I never wanted to see him again, but unfortunately I had to. Not only did we attend the same conferences or medical meetings at times, but Mum continued to see him. She thought he was wonderful and thought the world of him. I begged to differ, but my words fell on deaf ears. In hindsight, it would have been useful to debrief to someone about my feelings, but I didn't feel a need for it at the time.

I avoided speaking to him as much as possible, but I found the whole situation to be awkward and uncomfortable.

I also went to see a counsellor, who ran a cancer support group, for some grief counselling about six months after Dad's death. I ended up in tears for most of the session. He encouraged me to do some volunteer work for the support group. That was the last thing I felt like doing when my reserves to give to others were so depleted. It was I who needed the extra support, so I didn't return to see him.

The times I allowed myself to feel the pain of my loss were few and far between. The first Christmas was especially hard. I remember going to the toilet during the celebrations so I could have a good cry. I didn't want to spoil other people's enjoyment of the day.

People were kind and caring towards Mum. They asked how she was and offered her practical help. I was glad she had so many people who cared about her, but I also wanted to say 'What about me?! I'm grieving too'. No-one, not even family or friends, ever

asked me how I was. It was as if I was an invisible only child. I felt angry, unsupported and left out.

I really don't think I realised the full impact of my grief until many years later when I was doing a Graduate Diploma in Family Medicine. Part of the course involved doing some elective subjects. I chose palliative care for one of them. The first assignment (question one) involved describing and commenting on a personal loss. I was delighted to have permission to write about Dad's death and how I felt. This opportunity had never been presented to me in a medical context before, so I made the most of this unique experience. I threw myself into the assignment, putting my heart and soul into it. I was surprised to discover how raw my emotions were seven years after Dad's death. I suspect it was because I had swept my feelings of anger under the carpet rather than being processed.

The act of writing about my feelings felt very cathartic. I felt as though I had explicit permission to express myself honestly, given that the senior palliative care colleague who developed the entire elective had set the assignment. I never sent the family doctor any of my words, but I did finally forgive him, more so for my own peace of mind than for any other reason.

I sent off the assignment, feeling satisfied and grateful to have been given the opportunity to vent my innermost feelings. I felt as though a weight had been lifted from my shoulders once I'd finished the writing. I was therefore surprised to receive a two-page handwritten letter from the elective's author in response to my assignment. He was almost apologetic for having caused me pain as a result of writing about my experiences. He also expressed concern about my emotional state. This was so unexpected because I wasn't used to colleagues or academics treating me with empathy, especially when they didn't know me.

He wrote:

I have, at times, questioned the use of the first question, and one student was strongly critical of asking such a question when there is no direct contact with students. I rarely comment on the responses to question one but accept them as an expression of the student's experience. The purpose of the question, of course, is to help students recognize the intimate nature of caring for dying people.

He then acknowledged the difficulties I wrote about: the tension between my duty as a daughter and my role as a doctor, as well as knowing to what extent a doctor should use their professional standing in seeking information from medical colleagues. He reassured me by writing that he didn't think I acted unethically. What a relief! He also added: 'You certainly acted out of loving care for your father which is more important'. So far so good.

But then came the bombshell.

I note it is now seven years since your father died. Although you maintained your anger concerning his care for some time, you say it is starting to abate. I hope that indicates that you are now able to manage all the mixed emotions which your experience brought



you. I especially hope, as I said elsewhere, that this course has not been detrimental to your wellbeing. I trust that the experience you had in preparing and reading your father's eulogy at the funeral has enabled you to keep that inner strength that is available to all of us if we can tap into it. / I hope you don't mind me writing in this way to you and if you feel the need to talk with me further, feel free to telephone me.

I was taken aback and disappointed when I read the above. It felt as though my honesty had backfired. I felt like shouting: 'There's nothing wrong with me. Your concerns are unfounded', but I didn't have the chance to say so face to face, and I chose not to contact him. It felt too confronting.

As I reflected more on his response, I felt he may have felt defensive and overreacted. I also wondered if his response would have been different if I'd included some remarks about how helpful the process of writing had been for me. In hindsight, it would have been worthwhile to share my experience with him and others.

Sometime later, I undertook a one-day grief writing workshop with a writer who used Harber and Pennebaker's (1992) approach. We were given an A4-sized lined exercise book to write in, and were provided with a wide selection of coloured pencils. He encouraged us to write a narrative about our pain, and guided us through the process, which included writing about a resolution in some form by the end of the day. It was a powerful, intense process, which led to further insights and additional healing. I especially remember choosing a bright red pencil and writing in large capital letters over several pages to express the volcanic anger that lay deep inside me. I still have that exercise book. It serves as a reminder of, and a symbol for, the courage I drew on to write what I did.

As the years passed, I gained more confidence in expressing my feelings. The experience of being a cancer patient's daughter also fuelled my interest and involvement in undergraduate and postgraduate palliative care education. I created de-identified case histories for medical students and general practitioners using lessons learnt from Dad's illness experience. I also wrote a palliative care CD-ROM using case studies, had an article published about my experience of being a cancer patient's daughter in a peer reviewed medical journal, and helped develop a medicine and literature elective for first year medical students.

It took a lot of courage to make the transition from writing about Dad in a de-identified way to being explicit about the fact that I was writing about my personal experiences of being a doctor and a daughter. Being willing to share my vulnerability through writing helped pave the way for me to write about confronting family secrets in the form of a memoir many years later.

The whole experience of Dad's death was shattering, but from the despair there emerged a greater degree of courage, strength and personal growth. The act of writing, despite being seven years after the event, helped me cope with my feelings of anger and unresolved grief regarding the circumstances of Dad's death in my blurred roles of doctor and daughter.

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## **Research statement**

### ***Research background***

When health professionals care for a family member, it can feel like a blessing, a curse, or both. The health professional may know too much information, resulting in them experiencing greater anxiety than a lay carer. Or, they may be a more effective patient advocate, often knowing what questions to ask, about possible treatment options, and how to navigate the health system. The literature has significant gaps in describing methods that can assist health professionals struggling with blurred roles when they experience the illness and death of a family member.

### ***Research contribution***

Narrative can be a helpful tool for a health professional dealing with grief over a family member's illness and death, even if the event written about occurred years before. This work is a creative case study written from the perspective of both daughter and medical practitioner, illustrating how writing about the grief and loss was cathartic, and helped resolve longstanding feelings of anger, helplessness and grief. This supports research about the narrative's healing, cathartic power (Charon 2006, Marini 2016).

### ***Research significance***

This research demonstrates how the use of narrative in a postgraduate elective in palliative care resulted in a medical practitioner/daughter realising the extent of her unresolved grief regarding her father's death. It also highlights the unique challenges that can occur when a health professional's role blurs with that of a caring family member. Having permission to write in an honest way about her feelings resulted in her coming to terms with her anger and unresolved grief. It also paved the way for her to have the courage to write about confronting family secrets in the form of a memoir.

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