

CQUniversity, Australia

Janene Carey

Excerpt and research statement: *A hospital bed at home*

Biographical note:

Janene Carey has a BA (Sydney University), an M.Ec (UNE) and is currently completing a PhD in creative writing at CQUniversity, Australia, on the topic of home-based palliative caregiving. She also works as a journalist.

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By the time Chloe was six months old, Ben and Lynne were fed up with having to squeeze all their family time into the weekends and decided to seek a less pressured lifestyle on the north coast of NSW. Ben had been offered a job at a large pharmacy in Forster-Tuncurry as well as the opportunity of eventually buying into the business. With Ben's workplace only five minutes from their new home, Lynne could sleep in while father and daughter enjoyed a couple of hours together each morning.

Towards the end of 2000 they decided to have a second baby, and a third came along in 2003. Lynne continued to be a stay-at-home mum: they had agreed this was best.

"I always wanted to provide for my children the situation where the mother was available for them," Ben tells me. "I didn't really want Lynne to work while the kids were growing up. Besides, it didn't matter what job she got, I'd be earning several times the hourly rate that she was."

I inquire about Lynne's view of the matter.

"She felt the same as I did, until about 2003. Then she really needed to get away from it all but she didn't know what she wanted to do. She was saying, 'I'm not happy just looking after the kids and the house—this is not the life I want.' One week it would be: 'I might think about applying for a job.' The next week: 'I don't want to do that, I want to study.' The following week: 'Maybe I'll go and do some charity work.' And what happened was that nothing happened. After we left Canberra, she never worked again. And she never did any study either."

Ben explains that once he was established at the pharmacy in Forster, he rarely spent more than forty hours a week at work. He obviously regards this as verging on part-time for someone in his profession, especially for a younger partner in a very busy practice.

"Lynne could have utilized a couple of days—or one day a week—to do other things, but she never chose to leave the kids. She was incredibly houseproud too. I think she felt it was her job to look after the house and the children. Naturally she got a lot of pleasure out of the kids but when it wasn't going right it was an extremely heavy burden. But she would not have liked to say that. She really struggled with motherhood. She'd often ask for assurances that she was a good mother, and as a partner trying to be loving, you do that as best you can, but she knew she wasn't the mother she wanted to be."

As I listen to this, I notice I am feeling increasingly sad about how things transpired for Lynne. During the years that Ben was enthusiastically bounding ahead with his professional career, achieving business success, winning medals for excellence and flying off to be on government committees, it sounds as if Lynne was sinking into the scenario described by Betty Friedan in *The Feminine Mystique*, losing her sense of self in the role of wife, housekeeper and mother and becoming increasingly discontented with her lot in life.

Apart from intermittently proposing solutions but failing to act on them, and occasionally speculating about separation, Lynne's main way of expressing her unhappiness was through stony silences, a method Ben found quite unnerving.

“There were periods where everything was going along seemingly okay and there were other days that were just dark. I’d come home from work, might get here at ten to six or something, and find Lynne was so cross that she couldn’t speak. It was almost like she was peeved that I hadn’t been there to help all day. She wasn’t one to carry on with a great deal of fanfare; she just wouldn’t speak to me. Which was a thousand times worse. I would rather have had a dressing-down. I’m an extroverted person, I like to be involved in an open way, so for someone to close up shop and not talk, and you don’t know what they’re thinking—you’re not carrying a crystal ball—naturally your own mind starts going off in tangents. Lynne knew it tortured me. So if she was cranky, she just said nothing.”

I ask, “Didn’t Lynne leave the kids with you sometimes so she could have some time for herself?” When I’d been at home with small children, the front door barely had time to close on my arriving husband before I was pushing it open to make my escape, off for a long vigorous walk, to choose new books from the library, or to see a movie with a friend.

Ben’s answer leaves me dumbfounded. “Not really,” he tells me. “If she did, it would be to go shopping, to do the groceries; not what you’d call a real recharge.”

Lynne’s ovarian problems surfaced when she was pregnant with her second child. A benign cyst the size of a grapefruit was aspirated early in 2001, when the fetus was at twelve weeks gestation. The growth returned, so after Nick was born Lynne had an operation to remove the entire ovary. Surprisingly, she conceived again within a year, and Luke arrived in March 2003, on his sister Chloe’s fourth birthday. At first, everything was rosy. Ben says this particular Friday was “the most magical day you could ever ask for”—the birth went smoothly; Chloe and her friends had a great party; Lynne and the baby were home from hospital in time for a family dinner. But as the weekend progressed it became clear that Lynne was not at all well.

“By Sunday she still looked fully pregnant. I took her back to hospital and by Wednesday she was so weak that I was holding Luke to her breast so she could feed him.”

The staff at the hospital tried to suggest that the distended, flaccid stomach and the extreme fatigue could be symptoms of post-natal depression. Lynne and Ben refused to accept that diagnosis. On Friday afternoon Ben revved himself up for a confrontation, aware that if he didn’t act immediately, nothing would happen until the following Monday. Lynne’s gynaecologist came in and agreed to operate the next morning.

“He came out from the procedure and informed me that they’d pulled out a tumour that was 3.4 litres in size. It was a mucilaginous tumour, a very soft balloon filled with water and when you pushed it, it changed shape. So that meant it hugged around Luke in utero and that was why it was never picked up.”

Ben listened to this, appalled. The gynaecologist had spent the last five days telling them it wasn’t a gynaecological problem. Lynne was a longstanding patient of his, but some of her operations had been performed by other doctors because he hadn’t been

available. Ben knew that those doctors had recommended Lynne receive close monitoring.

“I said to him, ‘Lynne has a history of ovarian problems. You tell me what Dr. H wrote after her last operation.’ I pressured him till he eyeballed me and admitted he’d never read the reports. He couldn’t even remember that she’d had an ovarian cyst. I was in total disbelief so I was emotionless. If I’d been in any other state I probably would have laid him out on the floor.”

The excised tumour was cut up into one centimeter cubes for analysis. The results indicated that it was borderline malignant and no further treatment was required. This diagnosis was wrong—but the tumour was so large that someone could have spent six months cutting it up without discovering the truth. Seven months later the gynaecologist sent Lynne to an oncologist because her cancer markers were elevated and she had an umbilical hernia.

“He opened her up and the cancer was all over the remaining ovary, all around the uterus. There were nodules all through the omentum, the fat layer that surrounds the uterus and the organs. It’s like a sponge, so you can imagine it would have looked like a cauliflower, when he opened her up.”

Lynne had a full hysterectomy in November 2003 and chemotherapy every three weeks from January through to June. Her parents, who lived in Sydney, came and stayed each time to help her get through the worst of it. A capable, good-natured local woman, Tracy, began working in the house two days a week, doing housekeeping tasks and caring for the children so Lynne could rest. Ben says Lynne was very positive throughout these months and all the blood tests were encouraging. They drove down to Newcastle together for the treatments and enjoyed the chance to chat during the two hour trips. On the 1st of July, Lynne went with a girlfriend for the final appointment.

“She felt everything was sweet, and afterwards they were going to shop and have lunch,” says Ben.

The plans collapsed when the specialist announced that the chemotherapy had only temporarily stunted the cancer: it was now back in a more aggressive way and there was no further treatment available.

The following weeks were dark and desperate. An extreme heaviness descended on Lynne. She was resentful and angry and unhappy. She felt she would not survive without making drastic changes in her life: she spoke again of splitting up. Ben sharply curtailed his days at work, only going in once or twice a week, and organised to sell his share of the pharmacy so he would be free to devote himself to caring for Lynne and the children.

Lynne’s prognosis was six months, but she plummeted so severely, psychologically, emotionally and physically, that Ben thought she might die before the end of July. Her stomach swelled and she began suffering from night sweats so profuse that the liquid dripped from her clothes. One particular night, Ben was roused from sleep seventeen times to see to her or the children, and the next morning he had to get up and go to work. “There were twelve lots of clothes beside the bed so I must have been up

twelve times, because Lynne was too exhausted and too distressed to get the clothes herself. And I got up five times that night to the kids.”

Ben used his private school contacts to arrange appointments to seek opinions from the leading medical specialists in Sydney. One of the radical treatments offered was to open Lynne up, peel the peritoneum off her internal organs, pour chemotherapy drugs into the cavity and let them swill around for an hour before sucking them out and sewing her up again.

“It was real hero medicine, a slim chance of success but if it worked the doctor would come out the hero. He was excited about the opportunity to do this. He said, ‘You’re young, it might make a difference.’ But we decided against it because the potential for suffering was too great.”

They investigated alternative medicine options—naturopaths, Chinese herbalists, psychics—grasping at any possible hope. They made plans for the coming months, trying to fit in as much as possible. They both knew that the estimate of how much longer Lynne had to live was based on averages and might be wildly inaccurate. “We had this attitude that it could be three days, three months, three years,” Ben says. “But the back of our minds were saying—do things now!” They arranged for Lynne’s parents to mind the children for a week so that they could attend the next Quest for Life program and booked a family holiday on the Sunshine Coast in Queensland.

In early August, Lynne had a startling resurgence of well-being. She was vibrant and happy, brimming with energy. Ben could hardly believe the turnaround in her mental and physical state. I ask what might have caused the change: was there a shift in her attitude towards hope or resignation? Ben speculates that having things to look forward to might have helped Lynne to manage her emotions, but notes that at the time he’d been treading cautiously and hadn’t liked to enquire too closely. “July was really heavy. It wasn’t the sort of thing where you’d say, hey last week was as bad as it could ever be, and this week it’s good, let’s sit down and talk about it for three hours.”

From the middle of September, Ben watched Lynne growing physically frailer: eating less, spending more time in bed, her threshold for claiming ‘a good day’ dropping week by week. Ben wanted to be encouraging, he wanted to affirm that she was going well, but he found it heartbreaking to agree that she’d had a good day when he could see her plummeting.

Lynne suffered from diarrhoea, breathlessness, nausea, cramps, pain and night sweats. In the struggle to ease the discomfort and help her sleep, Ben would massage her feet and rearrange her pillows, and fetch teas, heat packs, ice, water, herbs, medication, and dry clothing. Although Lynne was failing physically, she did not sink back into the misery of July. “I suppose subconsciously she knew the end was in sight, but she wanted to ignore that and keep doing things as best she could. She seemed a lot happier. All her friends would attest to how positive she was and so do I. That’s probably in a strange way one of my fonder times. She was so upbeat and inspirational.”

It was during this period that Lynne began preparing a book of memories for her children. One of the entries concerns a particular day in 2001, long before she became ill, when Ben and Chloe had left the house early on a furtive errand:

I was having a sleep-in but unfortunately the phone kept ringing. I finally got up to answer it and found a poem sitting at the top of the stairs inviting me to head to Burgess Beach (our favourite beach). When I arrived I looked down onto the beach where your dad and Chloe had written "Marry Me" in flowers—too romantic.

Lynne accepted, but the idea went onto the back-burner and the wedding didn't actually take place until a month before she died. They were married at a registry office in Newcastle on the 16th of November 2004; a quiet affair with a couple of close friends and a meal afterwards. Ben took a wheelchair for Lynne but she managed to get through the day without it. In the photos she is wearing a cream halterneck dress that reveals how gaunt she had become, but she is smiling.

In the final month of her life, Lynne was surrounded by friends and family for much of the time. Her four closest girlfriends came and stayed for a week early in November, then returned at the end of November for two more weeks in response to Lynne telling them she really was going this time and they needed to come up again to say goodbye. However, the extra people in the house did not lead to any lessening of Ben's workload. If the visitors tried to help with the domestic tasks or the childcare Lynne would say, "Oh no, you're not here to do that. You're here to spend time with me. Ben can do that."

"Did you ever feel you were overworked?" I ask. "I mean, given the broken sleep on top of everything else?"

"At the time I just would have done anything for her to be peaceful and calm and happy. So, at the time, no. But later, after she died, reflecting on it, I felt it was unfair that she had driven me so hard. I was probably at the stage where maybe, if I didn't have a strong constitution, I would have been crook as well. And I thought, geez, that was a senseless thing to do. When we had lots of people here. They could have taken care of the kids and I could have taken Lynne out for a coffee or to sit down and look at the water for half an hour if she wasn't up for a walk. Or I could have done something for myself. I didn't need to be doing breakfast, lunch, dinner, full-time care of the kids, full-time care of her, making sure I settled things if there was an issue with her mum—just trying to be all things, to cover everything."

I ask my next question very cautiously. "Would there have been a sense that you were being repaid, for all the times when she thought that you hadn't done enough?"

"Mmm. Maybe. And look, maybe I was carrying a bit of guilt? You know, that the load had been too much for her in the past, and I was trying to make up for it? Later I resented the fact that I didn't have the courage to stand up and say no, this is getting ridiculous. But at the time I just thought: I want her to be happy."

On one occasion, Lynne's girlfriends took pity on Ben and surreptitiously sent him off for a run along the beach, offering to tell Lynne that he was out fetching milk if she noticed his absence. He remembers the feeling of dry heat on one side of his face and a cold wind from the sea on the other side. He remembers it because the contrast of

sensations was repeated several weeks later when he ran on the beach again, on the afternoon of the day that Lynne died.

“I was running along, crying, thinking—why? Why couldn’t we have just come down for a walk together? We had so many opportunities and she never wanted to. Why didn’t she want to do that? It was ridiculous that we didn’t take those chances. Because now I can’t ever get them again.”

Research statement

Research background

Surging interest in the topic of death and dying has been attributed to the rising median age of the baby boomers, now confronting mortality as they head into their sixties (Wyndham 2008). As storytelling animals, humans have a natural tendency to find narratives of lived experience an appealing way to make sense of complex phenomena (Polkinghorne 1988). However, striking a balance between the interpretive authority of the writer and the ethical treatment of the subject can be problematic when ‘using lives’ to craft creative nonfiction, particularly when sensitive emotional territory is being negotiated.

Research contribution

This excerpt from a story about home-based palliative caregiving was produced within the interpretive paradigm using an iterative cycle of gathering information, sharing the evolving draft with the participant, and negotiating changes. The outcome demonstrates that, contra Janet Malcolm (2004), creative nonfiction writers can take a non-exploitative, non-maleficent, collaborative approach to the task of producing non-superficial, non-rose-tinted, nuanced accounts. Avoiding the ‘cloven tongue’ of collaborative autobiography, where the narrator takes on the persona of the subject and tries to ghostwrite their thoughts and feelings (Couser 2001), the story incorporates multiple voices and allows readers to draw their own conclusions.

Research significance

Excerpts from the manuscript ‘A Hospital Bed at Home’ have been published in the anthology *Re-Placement* (Carey 2008) and in the peer-reviewed journal *Current Narratives* (forthcoming). A full story of approximately 6,000 words was shortlisted for the 2010 Calibre Prize for an Outstanding Essay and published in *Australian Book Review* (Carey 2010).

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