

Narrative and illness: the death of a doctor's friend

Anne P Hellman

Story-telling can help doctors cope with the great catastrophe of illness and death

Recently, I was involved in the diagnosis, suffering and, ultimately, death of my friend and patient, "Christie". When I began to write about this experience, I thought that I was writing her story. But soon, I realised that this is my own story. Narrative, a recital of facts in the first person, has been used as a tool for people who personally experience illness. However, I believe it can be used by doctors as they try to understand the illnesses and sufferings of their patients.

Christie's story

I met Christie in my daughter's school playground in 1989. She had recently arrived from Melbourne, and, apart from having daughters of the same age, we shared many interests. There was an instant spark.

Several years after we met, I opened my own general practice and Christie came to see me as a patient. When I asked her whether she would be willing for me to do her Pap smear, she remarked that had we not already been friends, we would have become friends. She was such a warm, friendly and outgoing person that this theory of hers was probably right, although I think that when someone has been a patient first there is more reserve in the doctor-patient relationship.

In September 2000, I fled the sporting mania of the Sydney Olympics and went to New York with a friend. We wine and dined, went to live theatre, saw all the tourist attractions and climbed the World Trade Center. It was a wonderful holiday. It was an abrupt return to reality when, on my first day back at work, I learned that, in my absence, my colleague had seen Christie — and had found a lump in her breast.

The biopsy report was on my desk. I knew as soon as I read it that she was going to die. There was not one redeeming feature. The tumour was anaplastic, there were 38 positive nodes in the axilla, and the tumour was oestrogen-receptor negative. Not only did I anticipate Christie's early death but I also realised that I was going to have to play a difficult, painful role in the process. Already, my self-pity was threatening to overshadow my grief for my friend and her family.

The next three-and-a-half years were, for me, a tragic example of the way an aggressive tumour can destroy a human being.

Christie, of course, handled the whole affair with flair. She had surgery, radiotherapy and chemotherapy. She passed through an era of hats and scarves that hid her hair loss. Through it all, she remained cheerful and optimistic.

I do not try to hide the truth of a difficult prognosis with my patients, but do make an effort to break the news gradually. I also think it important to maintain hope and optimism. So, for me,

making sure that Christie understood the hopeless nature of her cause was incredibly difficult for me.

After the initial flurry of medical intervention, there was a period of relative calm. For about 12 months the only medical treatment Christie received was trastuzumab (Herceptin), known to slow the growth of oestrogen-receptor-negative breast cancer. She resumed her previously hectic social schedule, and her friends would tell me how wonderful it was that Christie had made such a great recovery from her breast cancer. My secret knowledge ate at me like a personal malignancy.

She came to see me as her doctor again in May 2002. She had just had a routine follow-up CT scan and wanted to discuss the result with me rather than her oncologist. There was a mass of enlarged lymph nodes in the left supraclavicular space. The cancer was back. I broke the news as gently as I could, but she was devastated. Her fear for the future was written all over her face. I referred her for radiotherapy and she went through another period of intensive treatment.

Without complaint, Christie suffered the accompanying fatigue and the skin burns. This period of intense treatment was followed, once more, by relative calm. I did not know which of Christie's initial visible fear or her later cheerful front was the more difficult for me to witness.

But the gaps between crises were shortening. The next problem arose less than six months after the radiotherapy. Christie was getting short of breath. A simple chest x-ray revealed the problem — fluid in the left side of the chest cavity. A day-trip to hospital was all that was required to drain the fluid, but pathology analysis confirmed the presence of malignant cells. The cancer was on the march again.

In July 2003, I made arrangements for my own family to have a holiday — two weeks in the surfer's paradise of Angourie, on the north coast of NSW. On my last day at work, Christie came to see me. This time, she was really in trouble: she had a constant burning pain in her left arm and marked weakness. The cancer had begun to invade her brachial plexus. Christie wept uncontrollably in my office. I held her and comforted her as she explained the frustration of having a useless arm. She couldn't cook or hang out the washing. She couldn't do up her bra or pull up her underpants. I did what I could for her neuropathic pain and referred her to the pain clinic. Then, I went on holiday.

During that holiday, I spent many moments thinking about what Christie was going through. Sometimes when I was enjoying a moment in the sun, a walk on the beach, a card game with the family and, once, as I was pulling up my underpants, I thought of her and wept. I wept for her pain and frustration, for the bitterness of terminal illness in those too young, and my frustration in being able to do no more than observe, pity and weep.

Over the next three months, I saw less of Christie. She was deep in the clutches of the medical machine. The most important person was her pain specialist. Every possible pain-relieving drug, including huge doses of morphine, failed to relieve her pain. Finally, her oncologist decided that depression was exacerbating

Beecroft Family Practice, Beecroft, NSW.

Anne P Hellman, MB BS, General Practitioner.

Reprints will not be available from the author. Correspondence:

Dr Anne P Hellman, Beecroft Family Practice, 23 Wongala Crescent, Beecroft, NSW 2119. aphellman@optusnet.com.au

the pain and she should see a counsellor. She went once, but informed the oncologist that, although the counsellor was lovely, she would find it much more helpful to talk to her GP.

So began for me the most difficult period of all. Christie came to see me once a week. We spent at least half an hour together as she discussed the pain and practical difficulties of her situation, as well as the worsening prognosis. Sometimes we met at my surgery; sometimes I would go to her house.

At about this time, she was going away for a weekend with her husband. I think they knew that the end was not far away and wanted some time alone. The day before they left was our counselling day. Christie told me how much she wanted to be sexy one last time for David, but how she was unable to get comfortable enough even to think about making love. Never before had I been required to help anyone with this dilemma and never had I felt so useless.

In the following month, the cancer spread under the skin of Christie's chest and the tumour broke through the skin, erupting into a foul-smelling sore. Nurses came daily to dress the wound and apply antibiotic gel to try to control the smell. I was unable to offer any way of preventing this from getting worse, and I was appalled at the ability of uncontrolled cancer to eat away at the flesh and dignity of such a lovely lady.

Christie's youngest child, "Henry", who was seventeen, came to see me to talk about the way he was feeling. He had clinical depression. Although the management of his depression was within the scope of my expertise, it was beyond my coping skills. I referred him to an adolescent psychiatrist. Christie was severely distressed about her son's depression and we discussed her guilt and grief about it. Her worry about dying and leaving the family was now compounded by her fear that something would happen to Henry. She felt it was all her fault.

As a mother of teenage children, I knew what it was to worry about the effect that your life might have on them. I had spent a lot of energy dealing with the guilt that my commitment to my patients might have interfered with their capacity to become well-adjusted adults.

Over Christmas 2003, Christie's whole family went to their holiday house at Avoca on the NSW Central Coast. They rang me on Christmas Day and again the following day for help to try to keep her pain under control, but we all had to admit defeat and Christie went back into hospital.

Finally, the decision was taken to install a ventricular pump to put narcotics and local anaesthetic directly into the central nervous system. The pain specialist had been promoting this idea for some time but Christie had been reluctant to submit to a procedure that was both invasive and irreversible. Thankfully, it was a successful exercise and, at last, her pain was controlled.

Within a month of this step forward, Christie's oncologist rang me. The tumour was spreading into the epidural space in Christie's neck and the decision had been made to stop chemotherapy and admit defeat. Despite my knowledge at all times of this inevitable outcome, the news, when I heard it, made my heart race and my spirits sink. The end would arrive within a few weeks, and I was not ready to face that.

As I grappled with this news, I found myself able to discuss the theoretical implications of certain types of treatment with the oncologist as though Christie were no more to me than any other patient. It made me angry with myself even while I recognised that

I was displacing my anger at her impending death in the only way I knew.

Christie died, aged 52.

Commentary

In a society that has attempted to remove much of the pain associated with living our lives, illness and death remain the great catastrophe. There has been a recent explosion in illness narrative — the telling of the facts that relate to a personal experience of illness. Broyard wrote:

Always in emergencies we invent narratives. We describe what is happening as if to confine the catastrophe.¹

It would also seem that, with patients, this may be because they need to reclaim their illnesses from our increasingly complex, technological and hospital-based health systems, which consider all illness within a biomedical model.

Illness narrative can help patients to create meaning from memory, validate themselves as people in the role of patient, and reflect on the significance of the experience on their lives. It also helps them to come to terms with pain, whether the pain is physical, emotional or existential. Illness narrative may also have a therapeutic role to play in their illness, although this is not proven.

In *The Wounded Storyteller*, Frank broke illness narrative down into three different types of stories — the restitution narrative (illness interrupts a life, is fought successfully and life resumes), the chaos narrative (no discernible narrative order, no happy outcome and the most difficult kind to read) and the quest narrative, in which not only does the patient overcome their illness but in the process something is gained either for the patient themselves or for the wider good.² Chandler, in her essay on autobiography, describes three aspects of healing which flow from the writing: catharsis, restoration and transformation.³ These can be seen to fit into either restoration or quest narratives in the Frank model.

Narrative can also be used by doctors. Hunter explains how, from the earliest days of medical training, doctors are taught to use narrative, both verbal and written, to understand and interpret the story of a patient's illness.⁴

Medicine is fundamentally narrative...and its daily practice is filled with stories...Much of the central business of caring for patients is transacted by means of narrative...Medical stories are a well established way of sorting through and tackling problems of diagnosis and treatment...In such a scientific discipline it is surprising to find this unexpectedly familiar way of making sense of the facts.⁴

True narrative, rather than case history, can be used to understand and explain the complexities of the person and their reaction to illness, as it affects their lives and the lives of those around them. Of course, the doctor will tell a different version of the story than the patient. The patient tells of the effect of the illness on a life, where the doctor tells, at least, the story of the identification and treatment, but perhaps can tell much more.

In the same way that the 20th century has hospitalised illness, death and dying have also been taken out of the community and relegated to the hospital or hospice. Segal discusses the way in which the public sees death as part of the human experience, while the medical profession sees death as the failure of modern medicine.⁵ It is not only hard for patients and their families to face death and dying — it is also hard for doctors:

The ability to cope with dying patients does not come easily. Society has not prepared one for such interaction.⁶

Medical education does not prepare doctors to deal with death and dying. Remen talks about the way in which medical training may even undo some of the inherent life skills that we have to deal with death and dying.⁷ The emphasis of modern medicine is on cure; and, in a narrative sense, doctors may only want to tell restitution stories. Accepting that death is inevitable for a particular patient usually invokes a sense of failure:

People enter the medical profession to help; when they find that they cannot give good news, they often feel terrible and impotent and they tend to retreat.⁸

Further, discussing the issues that relate to dying and death is hard to reconcile with a professional relationship that emphasises the importance of an emotional distance between doctor and patient.

Although there is a more general acceptance of death as a natural part of life in general practice than in hospitals, the myth that modern medicine can always find an answer persists for both doctors and their patients. Kübler-Ross found that specialists in her hospital were reluctant to refer patients to her program because to admit that the patients were dying was to acknowledge a failure to cure.⁹ It is true that "most of us learn to cope with the life and death scenario with denial"¹⁰; but there is a need for doctors to be taught other, better coping mechanisms.

Dealing with the dying and death of someone close to you creates special dilemmas. Working with a dying patient can create a special relationship. Contact becomes more frequent as death approaches and there are more physical problems to solve. Contact often takes place in the patient's home, which can create an emotional closeness, and there is often more involvement with the patient's family members. McNamara wrote:

Facing death, whether it be our own, that of someone we love dearly or someone we feel responsible for, presents us with a unique challenge...Inevitably the frequent contacts with dying people awaken some personal response...if you've given a bit of yourself to them, you lose that something when they die.¹¹

Loss and disappointment are common experiences in the practice of medicine, and acknowledging this is important. I think narrative can be a good way to express the loss and at the same time to put it in perspective.

Remen strongly believes that grieving is necessary, and not readily undertaken by doctors.⁷ Crying alone or with the patient is the method that she proposes. I believe that writing the story is another way in which the caring professional can come to terms with the grief and distress. I certainly found the writing of Christie's story to be both cathartic and helpful in organising my memories. There is a strong sense in which writing it all down allows one to think about it less. Faber-Langendoen obviously shared that experience with me. Even though she was an oncologist and dealt regularly with dying patients, when confronted by the imminent death of her own mother she found herself ill-prepared to face the issues.¹² She wrote a narrative as part of the "coming to terms" process, but failed to decide whether she had been able to successfully combine her roles as doctor and daughter.

I believe narrative can also help professionals reclaim their caring role in the care of suffering patients. If doctors were to write more accounts of their dealings with patients, it would help people

to better understand the issues faced by them as they attempt to manage the burden of sickness. And, doctors who do not write might take comfort from reading what other doctors have written.

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