THE OTHER SIDE OF THE SHEETS

DYING WITHOUT DIGNITY: MY HUSBAND'S STORY

The aim of this section is to provide a forum for health care professionals to describe the care received by a dying friend or family member. The objective is to provide readers with good and bad examples of nursing management during the dying process in order to encourage reflective practice. The authors will remain anonymous in order to protect confidentiality. Vicky Robinson, Consultant Nurse at St Christopher's Hospice, will provide a response at the end of the article. If you would like to contribute to this section, please contact the Editor, Helen Scott, at helen@healthcomm-uk.com

On 17 September 2004 my husband collapsed at home and was admitted to the stroke assessment ward of a district general hospital. He had suffered a massive cerebral haemorrhage.

I was out of the country at the time and arrived at the hospital 20 hours after he had been taken ill. I was told that my husband was not going to be resuscitated in the event of cardiopulmonary failure. I had not been involved in the making of this decision. It was made following discussion between the medical staff and my two, young adult, children. After my husband's death my children admitted to me that they had not understood the discussion and so were not fully aware of the decision they were being asked to make. They were overwhelmed. Their only concern was that their father should stay alive long enough for their mother to arrange a flight and return to the UK

The following narrative details my impressions of the care my husband received. I am a palliative care practitioner, with 20 years' experience.

The first member of my family to arrive at the hospital was my niece who lived locally. My children had to travel from their homes in the North and South of the country and arrived later. My niece recalls being seen by a nurse who gave her a very detached and technical description of my husband's condition. However, parts of the explanation were extremely unprofessionally delivered. At one point the nurse said, 'if he is well enough in the morning, he'll go for a…thingy!' She eventually remembered that the 'thingy' in question was an MRI scan, which made it all the more clear to us that the nurse was unfamiliar with the details of my husband's case. He had already undergone an MRI scan, following his admission from the accident and emergency department.

I was informed of my husband's collapse when my son telephoned me. I contacted the ward 30 minutes after the initial call from my son. Despite my obvious distress, I was met with complete reluctance to divulge any information about my husband's condition. I was informed that he was 'no better or worse than anyone else here'. Having explained that I was currently outside the UK and that my sister was desperately trying to secure me a flight home, her attitude softened, but only slightly. She acknowledged that I must be concerned. However, when I asked if my husband's life was in danger she replied, 'no more than anyone else on this unit'. When I informed her that it was unlikely I would be able to return to the UK until the following morning, but that my children were currently on their way to the hospital, I was curtly informed, 'this ward does not have an open visiting policy!'

I arrived at the hospital shortly after 1pm the following day. I immediately saw that my husband's condition was critical. The doctors were compassionate and informative. I was given access to the medical notes in order to understand everything that had happened. I saw the investigations that had been undertaken. I was given the opportunity to view the MRI scan. I read the neurological report and the opinion of all the doctors involved. It was clear that my husband had suffered a catastrophic cerebral bleed that had caused a mid-line shift in his brain. Vital structures of the brain had been compromised. Further bleeding had occurred since admission. My husband was dying.

I requested that my husband should be permitted to die with dignity. The consultant assured me that my husband's symptoms would be reassessed on a regular basis and treated accordingly.

My husband had a urinary catheter *in situ*. Electronic equipment was being used to monitor his vital signs and a naso-pharyngeal airway had been inserted. Oxygen was being given via a mask. Intravenous fluids were being administered. A fan had been placed on a nearby locker.

From the time of my arrival at the hospital at 1.15pm until 8pm that first evening, I sat with my husband. He received absolutely no physical care from the nursing staff. He was mouth breathing. Nobody attended to his mouth care. No record of observations was made. The intravenous line and urinary

catheter were unmonitored. During the afternoon it became apparent to me that my husband was in pain. It appeared that the pain was centred in his abdomen. The only prescribed analgesia was paracetamol. I spoke to a staff nurse and explained my concerns. Thirty minutes later I went to find the staff nurse again, as he had done nothing about my husband's pain. I requested that diamorphine should be prescribed, but was informed that this was inadvisable, as it caused respiratory depression.

At this point I requested the palliative care team be contacted as a matter of urgency.

The palliative care team attended my husband about 30 minutes following my request. The support that they gave to my husband and our family was outstanding. They concerned themselves with the physical and emotional care of my husband and family. My husband was in an assessment ward with five other patients. Every effort was made to obtain a bed on the palliative care unit. Sadly, this proved to be impossible due to occupancy levels. The palliative medical consultant and registrar, both personal acquaintances, explained the medications they had prescribed and spoke to me in professional terminology. However, they made a deliberate effort to paraphrase discussions in language that my children would better understand as my children have no medical experience.

Following the administration of a small dose of diamorphine, my husband settled. He received no further care from the nursing staff that day.

My son asked about the possibility of his father being moved into a side-room to give us all some privacy. He was informed that no side-room was available. The unit did have two side-rooms, one occupied by a 'disruptive patient' and the other 'commandeered by the physio department and full of their rubbish'.

At the start of the night shift, two health care assistants (HCAs) asked if they could change my husband's position in the bed. This was the first approach anyone had made to offer my husband physical care, so we readily agreed. We were asked to wait in the relatives' room and were provided with refreshments.

Thirty-five minutes later we were still in the relatives' room. No one had informed us that my husband's care had been completed. I noticed the HCAs in another area of the ward and asked if we could return to the bedside. We were told, 'yes we did him ages ago!' I was then told that my husband had vomited as they were moving him and that he had vomited again after he had been repositioned. They said they would have to repeat the manoeuvre. (My husband had a number of episodes of haematemesis during his admission.)

I returned to the bedside and saw, immediately, that my husband's condition had deteriorated. He was lying partly on his side. He had increased respiratory tract secretions gurgling in his trachea. His colour was poor. Blood was running from his nose. He had suffered further haematemesis. In my clinical estimation, he was extremely restless and required his airway clearing.

I approached the ward manager, explained my husband's condition and requested that his excess respiratory secretions be removed with suction equipment. I was told by the ward manager that he would have to wait because she was doing the medicines. It was only after I insisted that my husband was in need of prompt attention that my request for assistance was met.

When the ward manager saw his condition she immediately reprimanded me. She said: 'He is like this because you let him be turned'. During the delivery of her care she resentfully said, 'This always happens on my shift'. The suction procedure took some time and required another nurse to obtain more suction catheters. The ward had run out.

While using the suction equipment, the ward manager removed the oxygen mask from my husband's nose and mouth and left it on his forehead, causing one of his eyelids to be pulled upwards. Blood, which had collected in the mask, ran down my husband's forehead into his open eyes. The ward manager paid no attention. I had to remove the mask myself and clean the blood from my husband's eyes and face.

Although my husband was unconscious, I made every effort to reassure him. I told him that he was being very brave and that the suction would soon be over. I was immediately censured. The ward manager simply said, 'don't say that, I might need to do it again'. At no time during the delivery of her care did she address my husband personally. She did not reassure him. She did not acknowledge me, or my children.

Eventually the procedure was completed, but my husband remained very agitated. I was forced to make a further request for midazolam and hyoscine to be given, to reduce my husband's agitation and respiratory distress respectively. The ward manager had made no attempt to mitigate these symptoms. Hyoscine was given almost immediately, but it was about 30 minutes later that the midazolam was given. There was none on the ward, in spite of it being prescribed many hours earlier. When my husband's symptoms were relieved, my family and I were able to spend some quiet time with him.

Later that night, we became aware that somebody was attempting to gain access through the curtains that had been drawn around my husband's bed. An elderly, confused woman appeared. Her gown was undone. Her body was exposed. She tried to remove the covers from my husband's bed. She was escorted away by my family and an attempt was made to find a nurse. My son became extremely distressed and asked again whether it would be possible for his father to be moved somewhere with a little more privacy. The ward manager's response was completely abrupt, 'you have already been told; that isn't going to happen'.

My husband's pillowcase was contaminated with blood and vomit. I asked for it to be changed. My children were visibly distressed by my

husband's continued blood loss. Two HCAs returned and began to wash my husband's face and neck. Neither spoke to him. Their method of washing was harsh. It was as if they were scrubbing a car clean.

In order to change the pillowcase they decided to lower the head of the bed, which had been previously elevated. Immediately the bed was level, my husband suffered a massive reflux haematemesis. I grabbed hold of him, attempting to raise his head in an effort to stem the blood flow. He died 3 minutes later.

No attempt was made to comfort us after his death. It was left to us to turn off the cardiac monitor, having witnessed it 'flat line' for some time. As we were leaving the ward later, I was given an information booklet and asked if we needed anything.

My husband died without a shred of dignity. His nursing care was shamefully poor. The communication from the nurses was minimal, grudging and curt. Every nursing intervention had to be requested and was carried out resentfully. The distress my family was experiencing was unacknowledged. The nurses showed us no respect.

Two years have passed since that dreadful night, but its legacy remains. I documented these events in the days following my husband's death. I realised I would have to bring these matters to the attention of the trust. I must add that the trust managers dealt with the matter of the appalling neglect of my husband in an extremely sensitive way and, after a thorough investigation, took appropriate action within their organisation. We were offered an unreserved apology. My intention, in retelling these events, is simply to share my experience in the hope that others will not have to endure anything similar.

Vicky Robinson responds

Every nurse who reads this account should be horrified by the events that took place during the last 48 hours of this man's life. Why was the situation so poorly managed? Perhaps the nurses in the stroke assessment unit were intimidated by the knowledge that their patient's wife is a senior palliative care nurse. It is possible that this knowledge was overwhelming, leading them to act with rudeness and unprofessionalism because they did not know what else to say or do.

Were the nurses too physically and emotionally exhausted to be able to recognise the discomfort of their patient and the horrific nature of his predicament? Were they so exhausted that they did not recognise the anguish of their patient's wife and children?

Perhaps the nurses were unfamiliar with the fundamental principles of symptom control and the importance of communication. Did they know that it was their role to be with the family and listen to its distress? Did they know that it was their role to mitigate the patient's symptoms and to care for his family? Did the nurses simply not care that their demeanour degraded this man and insulted his family.

It is likely that no single factor created their malpractice. It is of utmost importance to reiterate the fact that the trust managers dealt appropriately with the staff members involved and the man's wife felt she had received an adequate apology.

Hopefully lessons have been learnt resulting in the eradication of this kind of attitude towards patients within the trust. However, it is deeply concerning that something like this could happen at all, when professional development and clinical supervision are supposed to be central to nursing practice. Where were the fundamentals of care in this episode?

The one question that should have been asked of every nurse involved in this case is, 'what were you thinking at the time?' What seemed to be missing in the care that the man and his family received was the empathy that makes people want to nurse in the first place and the basic nursing skills that are fundamental to old-fashioned caring.

Before they interact with patients, nurses should think for a moment. 'What if this was me? What if this was my mother or father? How would I want to be treated?' This is not a difficult concept to grasp. All this family needed was accurate information about the plans for investigations, acknowledgement of the shock and disbelief that every family goes through on receiving devastating news, some understanding of the difficulties families have in coming together when people have to travel many miles to visit, mouth care, repositioning, clean linen, prompt administration of analgesia and the ward manager acting as a role model by demonstrating effective communication and technical skills.

Nurses cannot have a bad day when caring for the dying and the bereaved. Everybody has one death. Nurses have one chance to get it right for patients and families. Nurses need to remember that they are privileged to be able to care for people in extreme distress. They should honour the importance of death in their practice. This case clearly demonstrates that the bereaved remember things. They remember dirty sheets and dismissive and uncaring comments. They remember malpractice. They remember being misinformed. They remember feeling demeaned.

Practice tools, such as the Liverpool Care Pathway for the Dying Patient, have been developed to structure the care of people who are dying during the last few days of life. These tools are simple to understand and implement. It is incumbent on nurses in all care settings to familiarise themselves with these tools. No patient or family should experience what happened in the above account. EOLC

Statistics

Every year in the UK over 130,000 people suffer a cerebrovascular accident (http://www.stroke.org.uk/information/index.html), about a third of whom will die in the first 10 days. Cerebrovascular disease is now the second biggest killer in the UK (http://www.statistics.gov.uk/pdfdir/hsq0506.pdf)