

# Opening the word hoard

## Editorial: Death, dying, and bereavement

Edited by Gillie Bolton

Death, dying, and bereavement are dark threads running through all literature. Not only are they life's sole certainties, along with birth; they are also the biggest mysteries of biological science. What is gained in conception and birth, and what leaves the body at death? "The body dead is our world's great secret ... it's our condition to not know."<sup>1</sup> Death, dying, and bereavement are written about in many ways: with personal anguish or clinical detachment, spiritually, practically, dramatically, horrifically, violently, lovingly, and gently. A large proportion of all poetry is devoted to these subjects (along with love of course). Fiction often hinges upon a death or a birth.

Medicine and health care pay increasing attention to the way death is managed. Reading is a way of listening and reflecting deeply on the vital experiences of others. This seemingly second hand knowledge can stand a clinician in good stead. Experiences of bereavement, death, and dying are intense and vital to those concerned; it is impossible to correct shortcomings of judgment, compassion or understanding later.

Death, and its associated suffering, is feared in our culture partly because it does not have a role in our everyday lives. The processes of dying, and dealing with a body between death and funeral, are tidied away. Our experience can be widened by reading about the experiences around death and dying: the vast and bewilderingly altering emotions, complex family disruptions and passions, tortuous legal and practical issues, responsibilities and cares, unexpected freedoms. There are many texts for children dealing with death, for example, written and published with an overtly educative function. Death is also feared for its mystery. We belong to a culture which has difficulty in accepting, as Doty does, that it is our condition not to know.

Expressive and explorative writing also have a vital part to play when the writer, or one close to them, is dying. Such writing—for example, a journal, or poetry—can help towards gaining

clarity and understanding. The certainties of life are often stripped away by death, dying, and bereavement. Writing can enable the sufferer to question and begin to find some sort of a route to answering, for example: who am I, where am I going, what am I leaving behind, what do I want to say to whom? It can also help them to celebrate the life that has been lived.

Such writing can help the bereaved, the dying, and also clinicians involved in the care of the dying, to take more responsibility for the stories of their own lives. Stories of our lives are constructed by us, and by others about us; some tend to take more responsibility than others. The wife of an elderly man I knew claimed to "know him better than he knows himself"; some children allow their parents to take such responsibility for their story. It can be helpful to such people to be supported to take more responsibility for their own life stories, particularly at the end of life; and those with a negative focus to their plotline might be helped to rewrite in a more positive mode. Galen Strawson asserts that there is no necessity for those who do not naturally construct their own stories of their lives to do so.<sup>2</sup> If life goes right, I am sure this is so; but it does not always go right, particularly around a death.

A hitherto accepted life story may be disrupted by the death or dying; there may be aspects of this new phase of life which do not work or are difficult to connect with previous aspects of life. A young breast cancer patient I worked with wrote a letter to her husband days before her death, telling him that whatever her pain, she still wanted cuddling.<sup>3</sup> She could not manage to SAY this to him. She got her cuddles, but sadly, he told me after her death, he did not realise he could write back; so many things he wanted to say were left unsaid.

Working with literature, writing, and narrative can be helpful to clinical staff in helping patients to understand and relate to their own lives better. Strawson<sup>2</sup> ridicules the narrative programme at Columbia University as only restating the truism that doctors should listen to their patients.<sup>4</sup> What, as a philosophy academic, he does not seem to realise is that we need strategies for enabling and encouraging doctors to be able to listen to their patients more

effectively. Narrative understanding is just such a route.

The processes of writing offer so much: the story form with its fictive completeness of beginning, middle, and end; the illuminative strength of metaphor and image; the soothing and calming order of rhythm and rhyme; the release of expressing and effectively communicating powerful experiences and emotions: "Give sorrow words: the grief, that does not speak, /Whispers the o'er fraught heart, and bids it break"<sup>5</sup>. There are no more powerful words to support the "o'er fraught heart" than written ones.

Remembered intensities associated with death, bereavement, and birth also present themselves as appropriate writing subjects. When I ask clinicians to write about a vital experience in their lives (reflective practice for professional development), both men and women often write about a death, or the birth of their first child. Dealing with death encompasses the clinical areas most likely to lead to anxiety and burnout.

The two pieces below concern death in very different ways. Judy Clinton writes about the harrowing suicide of her son: the result of no crime, yet society and obstetric medicine were clearly at fault. The clarity and poignancy of the writing are an education to those of us who thankfully will never suffer such blows. Juliet Carpenter writes about a patient's death with reflective understanding and sensitivity. The writing explains and celebrates her full responsibility for her actions. (Readers might also like to reread John Graham Pole's Consent and consensus, about the death of a child patient.<sup>6</sup>)

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Opening the word hoard is edited by Gillie Bolton. Items should be sent to her at the address at the end of her editorial.

## “I can’t cope with life, I’m too different”

At 8.58 am 4 June 2001, the staff at Gloucestershire Royal Hospital accident unit surrendered and pronounced my son dead. He was twenty two. He had been brought in by the police who had gone to pick him up after a householder had reported him behaving strangely. As the policemen approached him he stuffed the plastic bags he had retrieved from bins into his mouth and choked. Those bags contained dog excrement.

Revolting? Yes. To be condemned? No. Not if you knew the story behind what this young man did.

Robbie was born after a mismanaged labour. He was yanked into the world by misapplied forceps which damaged nerves linking his brain to his body. He could not suck, he could not swallow his own secretions. He was termed a “floppy baby” and after multiple tests was assumed to be brain damaged. We, his parents, were told it was unlikely that he would ever walk or talk. I did not believe them—his eyes told me otherwise. The medical profession talked tests, weights, and tube feeding. I talked love, touch, home. I discharged him without medical consent. I’d learnt how to tube feed him, aspirate him, do everything they did for him in the special needs unit. Robbie started to show signs of wanting to live. However, we had now lost the support we might have had, had we been in accord with the hospital. We were, in a real sense, alone. The stage was set for marital strain and individual misery. Well meaning health visitors trotted out advice suitable for healthy babies and were, it seemed, as ignorant as we were of the special problems.

Things improved. Robbie put on weight, and he learned to walk—albeit not until he was well over two—and went to the nursery of a special school in Gloucester.

At three Robbie was showing no sign of talking. The speech therapist said it was “extremely unlikely that he would ever speak”. I did not believe her. A few weeks later it was discovered that he was deaf because of “glue ear” (a catarrhal blockage of the Eustachian tube). It had been assumed that his non-speaking was caused by brain damage. After an operation, he started to speak. What frustration he must have felt before that operation, and what frustration for us at his misdiagnosis.

No wonder he had appeared to understand at some times and not at others—he had learnt to lip read. Through faulty diagnosis he had lost precious time. Now, we knew that added to his early trauma at birth, he had felt cut off from the world by being deaf. As if to compensate, he used to spend hours at our upstairs bedroom window watching people pass. One little girl looked up at him one day, nudged her friend and said: “That’s the little boy who never smiles”.

He didn’t have much to smile about—except for his love of water. By the age of three he had already learnt to swim without armbands and experienced the freedom he did not know on land. Even that came to be denied him by repeated ear infections. He turned his attention to climbing and perpetual ball kicking. This was his outlet for his frustration and disability in fine movements. It was also his intuitive self therapy as he tried to make the connections between his brain and body parts. He was hyperactive and difficult to manage. Thankfully he was also a naturally gregarious child.

At this stage he was unaware of his differences. It was we, as his parents, who bore the pain of worrying about his future. My husband and I began to polarise in how we handled him: me by overindulging him, my husband by treating him harshly. We had no guidance and the seeds of our marriage breakdown were sown.

At the nursery the teachers were kind and concerned and there he was happy until he refused to go any more because he was terrified of a disabled and deformed older boy.

Around this time I discovered alternative therapies. Robbie had been suffering constantly from ear infections, necessitating repeated grommet operations. He was frequently on antibiotics and perpetually miserable. I took him to a homoeopath who told me that he was going deaf because he didn’t have the inner strength to accept what people were saying about him. He treated him holistically and Robbie never again had an ear infection. His general health was poor and it took many years of homoeopathic treatment and osteopathy before he became stronger. A cranial osteopath said that if Robbie had been treated at birth he could have done more to alleviate the nerve damage but

because he was over six his skull bones had already fused. It seemed as if we were constantly finding out information too late.

When he was seven he transferred to the local state primary school. He wore his new school uniform and rucksack and, with a grin, declared: “It’s great to be a normal boy”. He wasn’t, and everybody knew it. The class teacher told the children that there was a new boy coming who was “a little bit brain damaged” and they had to be nice to him. So the children circled him in the playground, chanting “Robbie Clinton’s brain damaged”. To them that meant he was stupid. Brain damaged he might have been but stupid he was not and he was only too well aware of his disabilities.

His age of innocence was over and now he faced bullying and repeated failure. He coped by pretending he didn’t care and becoming the class buffoon. He avoided anything that would show up his inadequacies and identified himself entirely with his failures. He no longer had the individual care of the special school system and he was adept at escaping the attentions of overstretched teachers.

Despite this he did learn to read and was renowned from an early age for his searching questions and verbal contributions. He began to be popular in a way that a friendly dog is loved by its family. The children at school got used to him and he joined the Beavers, Cubs, and Scouts. He even ran in a running club and persevered even though he always came last.

He went up to secondary school where he was happy socially, loved drama, and exasperated his teachers with his lack of organisation and constant “Yes buts”. He became the champion of anyone he felt was misjudged. He refused ever to retaliate for any maltreatment because “That would make me a bully too”, and became “a character”. He left school at 16 and took a course in leisure and tourism. He dropped out. He had lost his school-friends and stability, and he was struggling. His friends, who were intelligent and academically able, went on to higher education. Robbie had a deep philosophical and spiritual intelligence which attracted him to intelligent people but he did not have the corresponding academic and practical skills. That

left him feeling that he did not fit in anywhere.

He got a job carrying a board advertising jeans in the streets of Cheltenham. It gave him the opportunity to talk to everybody. He sat with tramps in doorways, chatted to buskers, observed life, and learnt an enormous amount. His practical skills were not questioned and instead his communicative and friendly personality could flourish. He could not go on like that forever.

He joined up with Youth Training and was given a placement in a unit for adults with acquired brain damage. Here he met Margaret whom he instantly loved. She was in her fifties, a feisty redhead who had contracted a virus which had left her wheelchair bound, ill, and severely disabled. Those two understood each other. They knew what it was like to feel rejected. For once Robbie had found someone who was less able than he was and he put his heart and soul into helping her. It made him feel worthwhile and he was happy.

One day he went into see her. She was in bed and so he sat waiting for her to wake. A nurse came in not realising Robbie was there and had to tell him that Margaret had died a few minutes earlier. A light went out in his life and he never got over losing her.

He refused to continue with Youth Training when he was inappropriately placed in a charity shop—his hand coordination was poor and he did not have enough opportunity to talk to people. Life was bleak. He was unable to do manual work because of poor muscle control and not able to use his intelligence in an academic way. He simply didn't fit in. He wanted to be like other people but he wasn't and he was painfully aware of it.

The break came when he went on a three month course with The Prince's Trust. He blossomed. Robbie became the "ideas man" and the procurer of free paint and materials from large businesses to carry out their project in a nursery. Now Robbie was using his capacities for a positive end, was socially accepted, and felt worthwhile. He was 19. The course finished and as a result he got a full time job at Royal Mail, under the supported employment scheme. His line manager, himself the

father of a disabled son, was caring and supportive. Robbie was proud to be earning and he thrived on the sociable sorting office atmosphere. Life was greatly improved but now Robbie had money in his pocket and he discovered alcohol.

He found that if he was drunk he no longer cared about being different, that it no longer hurt that his friends from school were getting girlfriends, going to university, getting good jobs. He began to drink more and more. He regularly came home drunk and he and I (his father and I had split up several years earlier) had countless rows about it and his general "don't care" attitude. His brother, four years younger and excelling at everything he turned his hand to, was embarrassed and angered by him as the family peace was constantly disrupted.

Eventually I told Robbie that if he wouldn't change his ways then he would have to live elsewhere. He was shocked but eventually found a bed sit and a few weeks later thanked me for pushing him out because he had wanted to be independent. For a while he was more responsible and became more mature. The drinking, however, continued and he was beginning to get frustrated at work. He was an intelligent young man with philosophical and spiritual insights way beyond his years and he simply didn't fit in—or so it seemed to him.

In February 2001 he went to Alcoholics Anonymous, admitting he had a problem with drink. For six weeks he did not drink at all, and became healthy, fit, and proud of himself. He declared that he was "completely changed", that he wasn't an alcoholic, and that AA was "boring". He stopped going to meetings. The drinking began again. When he was due to have two weeks' leave, he feared it, not knowing how to use his time. He asked to have his leave taken away from him. He was told by a manager who did not know him, that everyone needed a holiday and not to be so silly. Seven weeks later he was dead.

During those seven weeks he drank relentlessly and ricocheted from police station to accident unit to psychiatric unit and back out again. My answerphone was full of messages from people who had found him unconscious or

running drunk on the motorway or from him himself, roaring drunk, saying he was dying. He turned away every offer of help. The police could not act because he had not done anything illegal. The hospital could not help because he kept discharging himself. The psychiatric unit could not section him because he was not deemed mentally ill. The alcohol unit could not do anything until he himself wanted to do something about himself. It was a waiting game. He could hit his "rock bottom" and start the relentless struggle back up again or he might die. He died.

Robbie's life ended tragically but, despite everything, it had not been a failure. He steadfastly refused to become bitter, retained his compassion for others throughout, and challenged many both positively and negatively. At his funeral many testified to his unconditional caring and originality, saying they would try to live more in his spirit. He left behind a legacy of searching questions.

I suggest that the answer to Robbie's problems and his suffering does not lie in political reform with its countless rules and regulations, but in a major shift in our consciousness such that love, compassion, and working together replace the desire for personal acclaim, competition and the overriding modern trend for individual independence.

Perhaps then, people like Robbie need not say: "I can't cope with life, I am too different".

## AFTERWORD

My rough draft of this article was a powerful emotional experience—I just let it pour out, and with it my grief and my memories. It was a cathartic and healing thing to do. My re-writing and editing of the piece forced me to be more objective and in so doing allowed me to feel more "whole". I wrote a series of poems at the time, which came to chart my grieving process from just before Robbie's death to about a year later. That was my release.

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## Marguerite

In the dialogue about assisted suicide, euthanasia, and palliative care, there is an often overlooked point of view. It involves opening the door in the patient to his or her own ability to let go of life.

I had been physician to Marg for twelve years and we looked forward to our visits together. Six years earlier, the diagnosis and treatment of pernicious anaemia had led to improved mental activity and resolution of incontinence and vertigo. Shortly thereafter, she had signed a do not resuscitate (DNR) order and made it clear that she never wanted to live in any kind of nursing home or assisted living facility. She was fiercely independent, regal, courageous, and wilful. Well into her ninety first year, she lived alone.

One day she fell; she managed to struggle to the emergency button. She was confused and incoherent. Her oxygen saturation was 67%. At the emergency room, she was diagnosed with pneumonia and admitted. The confusion was new; her speech made no sense. Magnetic resonance imaging (MRI) showed a new stroke in the occipital lobe. Afterwards she went to a nursing home for rehabilitation. She would wink at all passers by in the hall and say: "Marg go home".

When she left the nursing home, now unable to care for herself and administer her own medication, she was sent to assisted living at the facility where she had previously lived independently. She hated it, but refused to go to her daughter's home to live. In less than a month, she fell again, this time tripping over the oxygen tube; she fractured her pelvis. Another admission. She wasn't hungry anymore; even the slightest

movement hurt. She sat tall in the chair after the breakfast she had just sampled. She knew who I was but could not articulate anything. Meanwhile we had started treating the heart failure and pneumonia which had developed over the preceding 24 hours.

I leaned over and rested my temple against hers. I had already asked the usual questions: "Do you know where you are"; "What day is it". We sat like that for a few minutes.

Then I said: "You don't have to go on like this". Silence.

"What will they do to me?"

"Nothing you don't want."

For the first time in two months, she was right there, every ounce of her concentration bringing her to this moment.

Our conversation continued, punctuated by what would ordinarily have seemed like long pauses.

"I don't want to die."

"Are you afraid to die?"

"No", came her reply.

"You won't be able to live alone anymore. Your daughter wants you home with her. You will have to go to a nursing home first, and then to your daughters'. Would you go?"

"Yes ... This is so hard."

"I know. We'll make you comfortable, give you medicine to help fix things; there is only so much we can do once the body is this old."

"So hard."

We sat a few minutes more.

"When you don't want to go on, you can stop eating."

I got up to leave, told her I loved her. She said she loved me too. About an hour later, she developed bradycardia, a

very slow heartbeat, and over the next three hours died peacefully, holding her granddaughter's hand.

### AFTERWORD

Over the years I have been impressed by people's ability to choose to die as if it is a choice that rises out of their spirit nature rather than their conscious volition. It often happens after the last loved one has arrived from far away to say goodbye or after some task or piece of art has been completed or, as in the case of Marguerite, where she had no other option if she were to remain true to her wishes. There is a peacefulness which surrounds death when this happens.

As physicians we often look at issues around terminal illness in a black and white way, either attempting to save life at all costs or to medicate our patients into unconsciousness as they deal with the pain of dying, which then brings up issues of euthanasia and assisted suicide. It is not that I oppose the use of medication to ease pain. I feel there are other options for us, one of which is to help our patients to choose to let go, to give permission. When I say this I cannot lay out some formula. It is something which happens in the precious intimacy which exists between physician and patient, those moments when we look into their eyes, touch their hand, speak from the heart.

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