DYING, DEATH, AND AFTER

Hospice at home

Jane Woyka

On Friday 31 December 1993 my husband abandoned his car in heavy traffic and jogged the last three miles to his surgical outpatients session. He collided with a lamp post, fracturing two ribs and sustaining a moderately severe head injury, and was found by a hospital porter, wandering confused near the canal beside the hospital. It was the end of months of lurking anxiety about his health—extreme fatigue had been attributed either to his excessive workload or to our new addition to the family. Three short lived episodes of unilateral visual loss in the summer had not recurred, and although his ophthalmologist was concerned about the finding of optic vein hypertension, magnetic resonance imaging of the brain in September was entirely normal. More alarming were the strange attacks I had witnessed: a metallic taste in the mouth, sweating, terror, and collapse without loss of consciousness. Yet all measurements were normal: pulse the usual 45, blood pressure 130/80, BM sticks normal, reflexes brisk and equal. A general physician consulted in December could find no cause and diagnosed overwork, excessive exercise, and poor eating habits.

Temporary elation propelled me into Christmas preparations as I gratefully chose presents for my precious husband. But deep suspicion remained and lifestyle changes were not easy to make, so the call from the accident and emergency consultant telling me of Adrian's accident came as no great surprise. I was almost relieved. While I finished my surgery, Adrian's condition deteriorated and computed tomography was performed. Meeting the registrar on the ward, I sensed discomfort and obtained only cagey answers to my inquiries.

The definitive death sentence came 10 days later, when a 2 cm astrocytoma was removed from Adrian's right temporoparietal lobe. Even the histology was awful, we realised, as the neurosurgeon departed rapidly, drawing the curtains around us. The next question is always, "How long?" The only person I could find as we left was a nurse crying in the sluices—six months?

We got 14 months, during which Adrian completed six weeks of daily radiotherapy, running the 10 miles to the hospital and back, and three courses of chemotherapy, which left his platelets at 80, his white count at 1, and his haemoglobin at 9. Adrian joked that his blood measurements were worse than those of most of his HIV infected patients, and he continued to work, blaming a bicycle puncture for his lateness on the days he had his chemotherapy.

Six weeks before he died Adrian experienced difficulty in walking, with rapid deterioration. Suddenly our home became a hospice. It seemed that everything that had gone before was designed for this purpose: our bedroom, large and sunny with views over the field up to the spire on the church on the hill; an en suite corner bath for comforting aromatic, cramp relieving baths. Within days, social services provided a mattress elevator, a hoist, a wheelie commode, a

wheelchair, and, later, a Spemco mattress and sheepskin. The baby monitor was moved and nappy creams found another use.

As Adrian lost motor function we focused more on sensory pleasures. His appetite was unaffected until swallowing became a problem; at mealtimes everyone gathered in the bedroom taking turns to feed Adrian and enjoying the sort of food one eats only on holidays. I remember our nanny returning from the school run with five children and two dozen cream cakes; a dinner time when I had catered for two of us and ended up feeding 22; my 2 year old carefully spooning shepherd's pie into his daddy's mouth. Downstairs an army of helpers operated a magnificent laundry service with six loads most days, everything perfectly ironed—remember the comfort of smooth, crisp pyjamas and sheets. My precious time came when I was alone with Adrian; he comfortable, calm, dozing; our favourite choral music in the background.

In the early days of becoming bedridden, Adrian would still insist he was just going out for a run with the dog, squirm over to the edge, and fall out of bed. At first I could manage to get him back in on my own but, after eight falls in one night, I realised another approach was needed. The next day we carried him downstairs into his wheelchair and took him out with the dog. He never went far but being able to go showed he was still in control. We brought him that way to church, propped in his chair, barely able to hold his head up; that night his two best friends took him on a

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pub crawl and were nearly thrown out helping him use his bottle in the gents' loo with the wheelchair jammed in the door. These two schoolfriends also set up a night rota. Dinner over, Adrian settled, someone would slip into bed beside him to reassure him, to talk to him, to change and gently turn him during the night, while I gratefully slept a few hours elsewhere. At 6 am they would depart. A different man, a different car every night, I boasted.

Adrian had a fit one morning as we lifted him out of the bath. He slept deeply for several hours and that night sounded very rattly. His beer was sometimes going the wrong way too now, and the chest infection was inevitable. The effort of breathing wearied him, and I cried inconsolably as I lay beside him, head on his shoulder. "Don't be sad," he said. I called my physio-therapist friend. Would chest physio help? She came twice that day and daily thereafter. After her gentle banging he was much more comfortable. Better to die of the tumour than a chest infection, advised the consultant in palliative care. Only now did I feel apprehensive and unsure of my skills, but advice over minor matters was equally forthcoming: do I keep shaving him, or would he be more comfortable with stubble? Did he shave on holiday or prefer to grow a beard? came the reply.

Movement confined to the left arm and speech a great effort, Adrian was still at the helm. He relished his smoked salmon and strawberries and cream, was soothed by his St Matthew Passion, and responded positively to his many visitors. Alone with just our sons one evening, he spoke of his journey. He was on a boat alone, he was not driving, and he could not get off. We felt we were all approaching that world with him. Over the last 10 days, Adrian waited until he had seen all his closest friends and family, and as we sat with him we talked of him constantly; hearing is the last sense to depart.

Our favourite Marie Curie nurse is here tonight, but can I bear to leave him? Young patients often choose when to die, she said. I leave to sleep for two hours, waking knowing it will be this morning. Sunday, head of the river day, Mother's Day, the start of British summertime, yet how can Adrian be aware of these things? I sleep beside him for his last six hours. Our 2 year old joins us, lying quietly holding his father's hand. "Daddy going," he says. But no Cheyne-Stokes breathing. Adrian is breathing faster as he runs towards his destination. He opens his eyes. I see his pupils dilate. "Think of the good things Daddy," urges our 9 year old as his father takes his last breath. "Now you can run, now you can talk, you are home."

The aftermath of disaster

Jane Swire

"Sunt lacrimae rerum et mentem mortalia tangunt" (Virgil)
[There are tears shed for things, and mortality touches the heart.]

Nearly seven years ago Flora, our beautiful and first born daughter, was killed on a PanAm plane over Lockerbie in Scotland by a terrorist bomb. Flora was a rare spirit with an irrepressible sense of humour and that special vibrant energy which always characterises the truly great. And really great I think she would have become if only she had been allowed to live. She did have all the ingredients—a good intelligence, boundless energy, a delightful sense of humour, and most important of all a warm and loving heart but with her feet firmly planted on the ground. Her scientific gifts were already more than promise. She had always gained outstanding marks in both physics and maths, and in medicine she felt that she could combine her love and respect for humanity with the intellectual gifts that she had been given. In her few years as an adult—she was on the eve of only her 24th birthday when she was killed—she gained a first class degree in medical sciences at Nottingham Medical School and had accepted an invitation to do a PhD on evoked potentials at the Institute of Neurology in Queen Square, London. She was writing up her research into patients infected with HIV and patients with Alzheimer's disease at the time of her death.

There is a need for the Floras of this world. We, her family, needed her too. That she would become the victim of an unspeakably cruel act of human wickedness was undreamt of in our worst, most hellish imaginings. When the dreadful news of the plane crash first came through on the television with those pictures of flames at the petrol station there came into my head a powerful and distressing cocktail of emotions—fear, disbelief, paralysing shock, and horror, but above all, a terribly sad feeling of dislocation and longing for Flora and penetrating knowledge that this was something from which there really was no recovery. Even

after seven years I cannot think of the last moments of Flora's life without a pain which is like being burnt alive. I desperately wanted to have been with her at her end, to have held her hand, so that she did not have to face such an appalling death alone. I was driven to read as much information as I could lay my hands on about the break up and disintegration of planes. I read that there might be up to 15 seconds of consciousness. I kept timing this on the kitchen clock. I wanted so much to know that she did not suffer. Even now I am deeply fearful that she did, that her eyes and ears witnessed the terrifying disintegration, that she felt fear and was alone. This thought, and the gutting fear

"The shock and anguish and the intensity of the grief combined to make our individual lives almost insupportable."

that imagination may not match reality, will sadden me until I die. So this for me was what post-traumatic stress was about—an exploding bomb, a fearful plane crash, and a beloved daughter lying dead on a Scottish hillside, and I, her mother, was still alive and I did not want to be.

In the first weeks and months I thought of Flora almost all the time. As if to balance the unbearable separation from someone so deeply loved the power of memory was powerfully and sharply activated. So much which I thought I had totally forgotten surfaced with astonishing and heart rending clarity. I recalled many of the things she had said, both humorous and profound, faces and expressions at different stages of her life. I saw her as clearly as if I could touch her in her pram, at nursery school, playing her recorder, singing carols, riding the donkey, playing her guitar, triumphant and successful in cap and gown, and stunning and