A teenager who wanted to die

'But *how* is it actually done?' It was one of those conversations about euthanasia that Dutch physicians are often drawn into when they travel abroad. Each time the struggle is to explain that some individuals – or even societies – set higher value on individual autonomy than on the sanctity of life, and also that the issue has nothing to do with availability of palliative care or, worse, utilitarian notions. This time we were dining in the hall of an English college and my interlocutor was an internist from another European country. 'Well', I replied, though sensing that an

explanation of technicalities was somehow going to widen rather than narrow the divide, 'in the same way the vet does it – first an infusion of barbiturates and then of muscle relaxants.' My colleague said nothing, but the disgust on his face was only too obvious. He seized the earliest opportunity to start a conversation with his other neighbour.

My personal experience with euthanasia was limited. As the head of a university department of neurology, I had occasionally sanctioned the procedure – four times in 18 years – but had never performed it myself. On each occasion the central issue had been loss of dignity, not pain. All the patients had been elderly. Then I met R. It all started on a Saturday morning, when a fresh resident and I were tak-

ing over from the team that had been on call the previous night. The last reported item was a telephone call that had just come in from a family practitioner, about a 16-year-old boy with a glioblastoma who had tried to cut his wrist. About an hour later the resident phoned me from the Accident and Emergency department. The wound was only superficial (inflicted on the right wrist with his nondominant but stronger left hand), but apparently the patient, as well as his family, were in great distress. The illness had begun 6 months before, when R had gone on a trip abroad with his school class, despite a recent, continuous headache. In Berlin he had been admitted to hospital because of vomiting and right-sided weakness. MR scanning showed a tumour and a biopsy – performed after his return home – confirmed the diagnosis of malignant glioma. Radiation therapy and dexamethasone resulted in some improvement, which enabled him to return to school and to enjoy a journey to the USA with his parents and two older sisters. One month before admission the headache and right-sided weakness again worsened; the scan had shown tumour recurrence. Treatment with a new chemotherapeutic agent was then offered, and was eventually started 2 days before the present crisis. At that moment R refused all drugs and said that he only wanted to die. I agreed with the resident's proposal to admit him because of the tense situation and promised that I would talk to him on the ward.

When I entered R's room, with one of the nurses, I felt utterly confident that this suicide attempt resulted from temporary despair and that it would be relatively simple to persuade the patient and his family that life still had much to

R, a few days after the diagnosis

ted to die

offer him. When I left the room, three quarters of an hour later, it was me who had been convinced – by a dysphasic patient and the united front of his parents and sisters. At first it had been difficult to recognize R, with his Cushingoid shape and sparse hair, as the healthy young boy he must have been not so long ago. He was sitting on his bed, in tears, while the eldest sister continuously stroked his arm. It turned out that he had been her pet ever since he was a baby. Conversation with R was halting because he could understand and utter only simple sentences, but he was adamant in his responses once he had understood me; sometimes his family offered a correct interpretation of what he was trying to say. The picture that began to form itself was that of an easygoing but taciturn and determined boy, who loved soccer and other sports and who had planned to train as a policeman as soon as he had finished secondary school. In his present state he was not only unable to walk, but also, for the last few days, he had increasing difficulties with speaking, reading, writing and even with understanding video films. All he could do was to think, especially about all the simple activities of life that were no longer open to him. In fact he had wanted to die ever since the tumour recurrence had been diagnosed, 3 weeks before. He had confessed this only that same morning. Yes, he did have headache, but no, he did not want higher doses of analgesics or sedative drugs. His present state was the opposite of what he had always wanted to be. It had to stop, it had to stop immediately.

At the end of this first conversation I told him I was now on his side, but that a single person could not take decisions of such importance and that the procedure usually takes several days. He made clear that this was unacceptable.

I came back that evening and found him as determined as before in his wish to die. I arranged consultations for the next day (Sunday) by the neurologist who had seen him as an outpatient, by the psychiatrist, and finally by an independent internist. R made sure he left no doubt in any of them about his wish, notwithstanding his language handicap. I met separately with all the nurses on duty; most could understand R's request, but few were prepared to act on it. Then followed another string of telephone calls, to the family physician, the director of the hospital, the coroner and, lastly, to the pharmacy.

That Sunday evening one of the nurses, whose shift had ended at 4 pm, came back at 8. Together we went to collect and prepare the drugs. On entering R's room for the last time I was briefly unsettled to find him lying down in full regalia, that is, in the shirt of his favourite soccer team. He was now quiet, and wore a contented smile. We sat down for a few minutes with him and his family to make sure that his wishes were unchanged and to explain how the end would come. Before I opened the valve on the intravenous line we made sure they were all as close together as they wished. When R's eyelids finally closed he had a parent at each cheek and held a sister with each hand.

Would this story soften the critical colleague who probably decided that he would never again sit next to me at dinner? I doubt it. But I think I have done something for R. At least that is what his parents and sisters told me when we met once more, a few weeks later.

The picture was supplied by the patient's parents and sisters who also have given their full approval of text.

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