Listen to me

Susannah Kahtan, Pat Fitton

Kathy died 18 months ago. She was 28 years old. She had cerebral palsy and a severe learning disability from birth. When she was 4 she developed juvenile rheumatoid arthritis; at 9 she began to suffer from grand mal seizures which became progressively more difficult to control. In her teens Kathy became extremely ill with collagenous colitis. Towards the end of her life Kathy could not speak or walk, and she needed constant attention. At times her colitis was so severe that she had to be fed tiny amounts of liquid formula every 10 minutes through a nasogastric tube.

"There never seemed to be a suitable opportunity to explain the positive aspects of Kathy's life."

Kathy's death was a tragedy to her parents. Whatever the circumstances, it would always have been a tragedy. There were, however, three aspects of her care which could have been managed differently to reduce the trauma suffered by the whole family. The criticisms are not specific to any single hospital or doctor; they are constant findings throughout the many hospitals Kathy visited.

Advocates of quality adjusted life years (QALYs) would make short work of Kathy's assessment. Obviously such a life must be insupportable. When Kathy had yet another episode of pneumonia or a seizure and her parents took her to an accident and emergency department they often had an uncomfortable impression that the doctors could not understand why they should do anything to prolong Kathy's life. There never seemed to be a suitable opportunity to explain the positive aspects of Kathy's life.

According to her mother:

Kathy has a strong personality; she knows what she wants and works hard to get you to understand. She loves music. When she enjoys the music she laughs and claps. When she wants you to change the tape she groans until you get the message. She likes to crawl over the floor examining people's bags and briefcases, shoes, and feet. She loves fluffy jumpers and bright clothes, admiring herself in the mirror. She ruffles through clothes racks in stores, letting us know when she likes something; we hope they don't notice the dribble. She frightened an Australian tourist in Covent Garden because she was fascinated by his hairy legs protruding from minute shorts and grasped one thigh firmly. She loves food, and has gradually learnt that in restaurants you look at a card for a while, then talk to someone, and the food arrives later. When the food arrives she claps the waiter.

Kathy loves baths and swimming pools, and with her armbands she will happily splash in very deep water, enjoying watching the other swimmers. She is a lot of work but she lights up our life, always welcoming us with a smile and one of her happy sounds.

If there had been time to tell doctors about Kathy's life as well as her illnesses perhaps her care would have been better managed.

The first of the three glaring errors was her discharge from the specialist children's hospital. "She is 21," they said. "We simply cannot call her a child any more." Yet in many ways Kathy was still very childlike. Physically, she was far from adult size. Her needs were well understood by people used to treating children. But chronologically, she was 21, so 21 years of doctor-patient relationships went out of the window. If there had been an efficient handover system so that Kathy's care became the responsibility of some other specialist centre this might not have been such a problem, but there was no handover. Kathy and her parents were left to derive the best care they could from standard resources designed for standard adults.

The junior doctors Kathy met after her discharge from the children's hospital were different from those who had looked after her before. Many of them seemed nonplussed by Kathy's inability to talk to them. Kathy's parents were often nonplussed by the doctors' inability to talk to them.

We had by then gained a good deal of experience in looking after Kathy, her mother explained. But if we said, "You probably won't hear wheezes, her air entry is so poor that her chest is often quiet even when she's quite ill," they would often look quite angry, as though we were challenging their façade of being thoroughly experienced. But we knew they'd never met anyone like Kathy before. Because they couldn't talk to her they became mechanical in their approach. Often they looked tired and busy so we felt awkward about demanding time to explain essential information about Kathy, let alone background information about the worthwhile aspects of her life. We wondered whether they were thinking: "Why bother about detailed investigations? If there is an infection let it take its natural course."

Kathy's terminal hospital admission began with malaise, pains in her chest or abdomen or possibly both, apnoeic attacks, anorexia, periodic vomiting, and profuse diarrhoea. She died 16 days later. Her parents were once again upset by the contrast between the care at the children's hospital and the care she received on an ordinary ward. The third major problem they encountered was a lack of contact with medical staff. At the children's hospital there was no need to teach the staff that communication with parents was essential. But in this adult ward communication

with patients was the norm, and when this was impossible there was simply no communication. The doctors caring for Kathy must have been well aware that her death was imminent, as her biochemistry became chaotic and her condition worsened, but her parents had no idea. None of the medical team sat down with them to discuss in detail the probable course of events, the possible interventions, and the arguments for and against them.

We knew we would probably lose Kathy before very long; she had become so frail. And I don't know whether we would have wanted the doctors

"We couldn't bear the feeling that Kathy had been written off by the doctors."

to do any more than they did—we're not selfish, and if Kathy was definitely just going from crisis to crisis we wouldn't have asked for her illness to be prolonged. But we wish that someone had taken time to talk all this through with us before she died, just so that we knew what to expect, and why it was happening that way. We couldn't bear the feeling that Kathy had been written off by the doctors.

We don't want to level criticism at any individual hospital, firm, or doctor. But we would like to see a change in three areas. Firstly, people with multiple handicaps should not be discharged from appropriate care unless alternative appropriate care can be provided. Secondly, medical students should be taught about communication. They should have to see people with communication problems in their examinations, and they shouldn't become doctors unless they have shown an ability to cope with communication problems. Finally, if someone like Kathy is in hospital at least one doctor should be responsible for talking to her carers, in detail, at least once a week when the condition is not serious, and preferably every day when the illness is suspected to be terminal.

Much of the factual information we absorb as medical students is not with us for long—try asking a group of senior house officers from various specialties about the classification of non-Hodgkin lymphomas. We should not pass or fail according to our ability to complete a multiple choice paper; we should become doctors if we have shown an ability to take a history in difficult circumstances; to conduct an examination in an efficient but friendly manner; and to acknowledge our limitations by asking for help when we need it.

Kathy's mother, Pat Fitton, talked to me about her. Pat is currently writing a book about caring for people like Kathy.—SUSANNAH KAHTAN is a director of Medical Education on Disability