A memorable patient and his carer

I was a house surgeon nearing the end of my surgical internship. I was brimming with knowledge on medical science though I was naive and inexperienced in practising the art of medicine. A young man in his early thirties was brought to the casualty ward with multiple abscesses. He was weak, cachectic, and disabled. His skin was covered with hundreds of neurofibromata of various sizes. Multiple neurofibromatosis had led to spinal deformities, paraplegia and neuropathic ulcers. Since he was bedridden his brother was by his side helping him. It had been like this for several years. He had been in and out of hospital for various problems related to his debilitating illness. His family members were in the fishing industry and his illness had been a heavy burden on the family. He was from Beruwala and the cost of travelling to Colombo in a hired vehicle alone was heavy.

While in hospital he had several surgical procedures, many antibiotics and various supportive measures. It was a long hospital stay and control of sepsis was difficult. Naturally the young man was depressed and preferred death to the regular visits to the operating theatre and the much more frequent and agonising injections. His brother who was looking after him was becoming anxious and inquired repeatedly whether it was necessary to buy medicine or anything else that was not available in the hospital but might be useful for the patient.

At that time euthanasia was a hot topic in the media. Ending the ward round the specialist surgeon questioned the medical students about euthanasia and its relevance to this patient. There were different views. But in my mind there was no doubt. I was convinced that it was not only the wish of the patient but also of his family.

The surgeon who was more experienced argued vehemently against euthanasia. Whatever our opinions, we all worked hard to save his life.

On a Monday morning when I arrived there was a big commotion in the ward. My patient had died the previous night. His brother who was with him could not bear the grief and punched the glass window. The window was broken and the patient's brother had sustained injuries to his fingers requiring sutures. I was greatly puzzled by the events.

A little later I had to write his death certificate. Most of the family members including the brother who was with the patient and broke the window were around me awaiting the death certificate. After I finished we began chatting. He apologised for what he had done and offered to repair the window without delay. I was keen to know why he became emotional. After all, he knew very well about the chronic disabling nature of his brother's illness and its poor outcome. Then he told me the story. They had inherited their father's fishing venture after his demise. The business was progressing well since they were working together even after marriages of the individual family members. It was his brother's illness, which kept them together. The desperate need for money and support necessary for the brother's care ironed out the petty conflicts which arose among family members and threatened the family business. His late brother was the incentive for them to work hard and remain together. Now that his brother was no more he was scared about the disintegration of his family and the business.

Taking the history was black and white; listening to the patient's story added colour. Until then I had considered chronic, disabling illnesses as a nuisance leading to disharmony among family members and a hindrance to the their financial success. But that day I realised that chronic, disabling and disfiguring illnesses can also touch hearts, unite minds and bridge family divides. Medicine is not only a science used to heal human bodies but also an art, which requires many subtle intuitive skills during its practice.

Anuruddha Abeygunasekera, Urological Surgeon, Colombo North Teaching Hospital, Ragama. (Telephone + 94 1 763427, e-mail: amabey@sltnet.lk).