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## Two memorable patients Matthew and Adam

When I first looked after Matthew and Adam they reminded me of the twins who knew each other's thoughts in *On The Black Hill* by Bruce Chatwin. They would sit in the corner of the physiotherapy room not talking but communicating and were totally content with each other's company.

Matthew and Adam were not twins. Matthew was the younger brother by two years, but they both shared the same potentially lethal disease—cystic fibrosis. They both had a total commitment to Manchester City Football Club and a total dislike of Manchester United.

Their parents had been told that they would die in childhood, but they survived into adolescence and then into their 20s. Sharing the same disease and interests brought them into continuous close contact. They both started to work as sports journalists and were successful.

In the early 1990s *Burkholderia cepacia* took a hold in our adult cystic fibrosis unit, infecting the lungs of our patients. Now recognised as a cross infecting pathogen which can shorten the lifespan of a patient with cystic fibrosis by a decade it has had devastating social and medical consequences. Social and medical segregation has become the best option for limiting spread. The result has been a decline in incidence of cross infection but a total disruption of the life for those patients infected by *B cepacia*.

About three years ago Matthew became infected with *B cepacia*. Matthew stayed at home and Adam moved out to live in rented property. They came to different clinics and stayed on different wards. Matthew would leave the house if Adam came home for meals. They would speak continuously on the telephone, occasionally they would meet at football matches, but kept their distance. This separated way of life was entirely their decision.

Eighteen months ago Matthew's disease began to accelerate in the manner characteristic of those infected with *B cepacia*. He responded less to treatment and stayed in hospital longer. Despite everything we tried he deteriorated. Once, when I gave him some blood he wanted to make sure only that it did not

come from a Manchester United supporter. Apart from the football aspect, he was the most sweet natured of human beings: questioning all aspects of his treatment and care but totally uncomplaining. At Christmas he was on six antibiotics, steroids, oxygen, and cyclosporin. Adam was fully aware from Matthew of his decline and non-response to treatment.

Last week Matthew became fatigued and went into acute type 2 respiratory failure. I asked Matthew if he was frightened and he said, "No." Two years ago Matthew decided that he did not want to be listed for a transplant and had asked me directly how long he had to live. Reluctantly, I had told him about 18 months to two years. Matthew asked me whether that time had come and I said, "Yes." Professionalism was quite difficult to maintain.

The big issue was that Adam wanted to see his brother before he died and we agreed, but suggested that Adam should wear a face mask. Matthew then said that he did not want Adam to come and see him. He used the analogy that after so much effort and sacrifice for them both it would be like bringing on all the reserves in a football match which would result in defeat. Matthew died peacefully 12 hours later.

All patients with cystic fibrosis are special to us. Matthew who has gone and Adam who remains are perhaps just that little bit extra special.

Anthony K Webb *clinical director, cystic fibrosis unit, Wythenshawe Hospital, Manchester*

We welcome articles of up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.