



## special articles

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### Partners in Care

#### Caring for Richard

A considerable proportion of our work (C.K. as an old-age psychiatrist, P.K. as a general practitioner) is with the carers of people with severe mental illness. In 1999, we unexpectedly became carers ourselves. Our 12-year-old adopted son Richard, who had been living with us since he was only two, developed an early-onset bipolar disorder.

Richard's special care needs did not all emerge at once. We knew before he joined our family that his natural mother had a bipolar disorder. We hoped, though, that our good parenting would protect Richard from developing mental health problems at all. It never crossed our minds that he would become ill before adolescence. By the time he was six, it was clear that Richard had moderate learning difficulties. Since the age of eight, he had also been increasingly hyperactive and impulsive, to the extent of being given a diagnosis of attention-deficit hyperactivity disorder and being treated with methylphenidate. He was able to remain in mainstream primary school (albeit with full-time one-to-one support) and then transferred to a local moderate learning difficulties school that seemed ideal: small, gentle and with a range of abilities that would put him near the top of the class. He had a real prospect of 'doing well' and gaining some self-esteem – or so we thought.

Within a few weeks of starting at the new school, Richard's behaviour deteriorated dramatically. He had frequent temper tantrums, which he explained by saying that the other children there were violent almost all the time, and that he was frightened of them. The situation came to a head when he assaulted a teacher and was suspended from school. Now he was at home full-time, first entirely with us (P.K. taking a month's compassionate leave) and then, when P.K. returned to work, with the help of a carer. Richard became more and more withdrawn, spending most of his time sitting alone in his room with the curtains drawn, playing video games. He said he had been hearing voices telling him to harm himself. Richard's psychiatrist told us that he thought Richard was at real risk of suicide and advised us to watch him constantly. He added that he would be thinking of admitting Richard to hospital were it not for the fact that we had medical and psychiatric experience and could provide expert supervision.

In the following weeks, Richard oscillated between being disinhibited and aggressive, and being withdrawn and floridly hallucinated. We tried to convince ourselves he was 'settling', but when he told us he was having thoughts about putting a needle into his eyes we realised that he needed urgent help – and so he did. Richard was happy enough to come to the emergency clinic with us, but once there he repeatedly set off the fire alarms in the clinic waiting room. He also phoned 999, telling the police he was James Bond. The diagnosis of bipolar disorder (currently manic) was now quite obvious.

Richard was started on an antipsychotic and a mood stabiliser; again he seemed to 'settle'. One day though, he threatened one of us (P.K.) with a knife. Later the same day he ran onto the green in front of our house, smashed a bottle and then ran down the road, brandishing broken pieces of glass. Admission seemed unavoidable. Richard said he would feel safer in hospital. Our first impression was that he was much less disturbed than most of the other children on the unit. Many had autism, some heard voices and most seemed at various times to 'act out' violently and need restraining. As the weeks went by, though, Richard changed from being the easiest to the most challenging patient on the unit – not that we had any wish to compete. He became sexually disinhibited to the extent that several staff refused to work with him. He was placed more and more frequently in seclusion, where on one occasion he broke the electrical fittings in the seclusion room while trying to electrocute himself. In the end, he remained in hospital for nearly a year, much of it as a detained patient.

All that seems a long time ago now. Richard has completed school and finished a year of a catering course at a local further education college. He hardly ever hears voices. He has a network of local friends who value him for his kindness and his sense of humour, and are immensely patient in dealing with his more bizarre and inappropriate outbursts. Yesterday, it was his 17th birthday and we had a family celebration at a local restaurant. Richard was immensely proud of being able to smoke in public and of asking for, and getting served, a cocktail.

Richard's care needs are still very substantial. He remains on lithium, carbamazepine and amisulpride. He

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has a resting tremor and his speech is quite slurred, especially when he is tired. He demands our full, unremitting attention when we are with him, but rewards us with the uncritical love that normally only comes from very small children. He has a carer, funded by social services, who is with him when we are at work. He is often verbally aggressive and very occasionally he tries to hurt us. It is hard to imagine him ever living independently (even with huge support), but that is (and must be) our long-term aim.

Has our experience of being carers been influenced by our work as health professionals? Having professional 'contacts' with local psychiatric staff probably made it easier to ensure that Richard was seen and admitted quickly. It was very painful, though, to feel resented because of the (justified) staff perception that, when Richard's sexual disinhibition was at its worst, he was getting preferential treatment on account of our professional status. It was much harder than we expected to be both 'experts' and care recipients. How different is that, though, from the increasing (and very welcome) trend for internet-supported expert lay patients and carers?

Has being a carer changed the way we work as doctors? It has certainly made us realise how fortunate we are to have 'nice' work that also serves us as respite. We hope that at least we are more aware of the huge

importance that patients and carers place on the brief contact with their general practitioners and their consultants in surgeries, clinics or ward rounds. We have experienced (albeit at second-hand) the stigma of mental illness through seeing how people look at and talk to Richard when they notice him behaving inappropriately. We are also painfully aware of our own (equally inappropriate) shame and embarrassment at those times. Perhaps most important, we are much more aware that 'enduring' mental illness is not just a set of symptoms that psychotropics switch off. We now know from experience that it is a process that affects every minute, and every aspect, of individual and family life. It is also not all bad – sharing Richard's experience and finding ways of coping together has brought us all closer. It has also made us all realise that the notion of mental illness affecting 'every family in the land' is no cliché, just the truth.

### Declaration of interest

None.

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