

# LEFT SCARRRED BY SCHIZOPHRENIA

What would you do if your child, mother, father, brother or sister was diagnosed with schizophrenia? Torn between a loved one being locked away or left to their own devices, thousands of families face lives of helplessness and despair **FEATURE** Olivia Gordon **MAIN PHOTOGRAPH** The News, Portsmouth

## HE USED TO SAY TO ME, 'AM I MAD, MUM?'

Sonia Taylor, 44, from Hampshire, relates her family's heartbreaking story

My younger son, Daniel, hadn't been right for a number of years before he was diagnosed, at 18, with schizophrenia. He had fits as a baby and was in and out of hospital as a child because he wasn't growing properly. At school he always found it difficult to make friends. I thought, there must be a problem – then I thought, my child is perfect – I couldn't have given him a problem.

When Daniel hit 14, things started changing. His brother Lee, three years older, caught him smoking pot in the park. Daniel also started drinking and taking amphetamines. His father, Rob, and I had long conversations with him about his drug use, but we couldn't stop him from taking them. I think he started using drink and drugs to medicate himself – I knew he had a problem before he ever took drugs.

At 14 and a half, Daniel tried to hang himself. I took him to social services, but they dismissed his behaviour as normal adolescence. Between the ages of 14 and 16, Daniel took a couple of overdoses and wrote suicide notes to me telling me how he wanted to be buried and who he wanted at his funeral.

Daniel started to hear voices telling him what to do, and that's when he started self harming – bashing his hands, cutting his arms, smashing his head against things. He said people in his head were telling him to do these things, and he had to listen to them. Daniel once told me he felt as if he had 'nutter' written all over his forehead. There is still a huge stigma attached to mental illnesses – people do not want to talk about them. He used to say to me, 'Am I mad, mum? There must be something wrong with me.' I would say, 'You're not mad, Daniel, but there is something wrong.'

Then Daniel was excluded from school after hiding a machete in the grounds. I wasn't sure at times what was Daniel and what was an illness. But I knew this was definitely not adolescence. I didn't work for years because he needed care 24 hours a day. Daniel was no innocent – yet his lovely, gorgeous self always shone through all the pain.

As the months progressed, he would cry and I would be up in his bedroom cuddling him as if he was a newborn baby. Extremely

vulnerable with low self-esteem, he needed hugs every day, to hear me say, 'I love you, Dan'. Life revolved around Daniel, and it put strain on the whole family. When I got down, I went to the doctors, but most of the time I told myself, 'I'm living this and I've got to deal with it'.

Daniel was having an on-off relationship with his girlfriend, Lianne, and she became pregnant. Their daughter, Destiny, was born in November 2002 and Lianne needed Daniel to help her look after the baby. Schizophrenics find stress difficult to cope with, and it was now, as things were stressful for Daniel, that his illness worsened. Once he had passed 16, he had been classed as an adult – if he didn't want to go to the doctor he didn't have to. It wasn't until he was 18 – in January 2003 – that Daniel decided he had a problem and needed to do something about it, and that's when he went to the doctor. He was sent straight to a psychiatric hospital for investigation, diagnosed with schizophrenia and put on olanzapine, an antipsychotic medication. I was relieved to know he had a real illness.

DANIEL STARTED HEARING VOICES TELLING HIM WHAT TO DO



Daniel feeding his newborn baby Destiny in November 2002



Daniel, Lianne and Destiny at home during the stressful time just before Daniel was admitted to hospital in April 2003



Daniel's tragic illness continues to haunt his mother, Sonia

I THOUGHT LIFE WAS A NIGHTMARE – NOW I WANT THOSE DAYS BACK AGAIN

Soon afterwards, he lost his job as an apprentice car mechanic – he wasn't able to get out of bed because he was either sleepy or couldn't sleep, due to the tablets' side effects. Daniel put up tinfoil in his bedroom, covering his TV and radio – he said he was getting radiation from them and that they were telling him what to do. He thought people – Lianne and I for instance – could read his mind. Daniel also hit Rob a couple of times. It sounds strange – a son hitting his father – but it wasn't vicious, it was because he wanted Rob to hit him back. We never did hit him, but this is what he wanted – the physical pain to remind him of himself.

One day that April, Daniel trashed his bedroom, bashing his head against the wall and the floor, and punching his hands straight through the door. Rob, Lee and I were all holding him but he seemed to gain immense strength from somewhere. We called an ambulance because we were worried he would hurt himself – but the paramedics couldn't calm him down so they had to call the police. The police wanted to arrest Daniel, but I just couldn't have him put in a cell, so they let him come home again. Only a couple of weeks later, I found Daniel's bedroom trashed again. There was tinfoil everywhere – over the window, over the pictures.

Daniel was admitted to the psychiatric hospital on 14 April and he didn't come out until 24 September. Perhaps now he was in hospital, I hoped, others would see what he was like and things could progress. On the other hand, I felt like a failure. Daniel was my child – I felt guilty. Schizophrenia can be hereditary but there had been none known before in our family. I still have no idea what caused his illness.

In hospital, Daniel didn't have to deal with money or everyday life, which were what he found difficult, and there were people with him 24 hours a day to help him to solve his problems. His symptoms subsided, and I felt that hospital was definitely the best place for him at that time. Meanwhile at home, we had five months of peace – it sounds awful, but, as much as I loved him with all my heart, I couldn't face him living with us anymore.

One night he came home for a visit drunk out of his mind and I took him back to hospital and said, 'I cannot have him drinking.' It later emerged that the hospital also knew Daniel was taking amphetamines, but nobody informed me.

In September 2003, at the age of 18, Daniel came out of hospital and was admitted to a flat of his own near our home, in a hostel for people with mental health problems. It provided daytime care, but ➤



Rob, Sonia and Daniel on a happy family holiday in Bali, 2000



Behind Daniel's boyish exterior was a troubled soul

“ HE PUT UP TINFOIL IN HIS BEDROOM, COVERING HIS TV AND RADIO – HE SAID HE WAS GETTING RADIATION FROM THEM

“ HE SUFFERED FROM PARANOIA AND ATTACKED PEOPLE IN THE STREET, THINKING THEY WERE OUT TO GET HIM. HE ALSO HAD DELUSIONS, BELIEVING HE WAS GOD, HAD CONTACT WITH OTHER PLANETS OR COULD TALK TO DOGS

GETTING HELP

‘People who are caring for a mentally ill relative are desperate for information and help,’ says Mary Nightingale, spokeswoman for severe mental illness charity Rethink. ‘Someone trying to support a relative or friend with a mental illness has a very difficult life. They often feel responsible for the ill person, yet at the same time, the stigma of mental illness means people frequently put off getting help early on.’

Chief executive of mental health charity Sane, Marjorie Wallace, says, ‘We respond to thousands of callers to Saneline who are helping family members, friends and others to cope with schizophrenia. It is important that carers learn as much as they can about the illness and talk to others in the same situation.’

- Saneline  
Call 0845 767 8000.  
www.sane.org.uk
- Rethink  
Call 020 8974 6814.  
www.rethink.org
- Mind  
Call 0845 766 0163.  
www.mind.org.uk
- The Schizophrenia Association of Great Britain  
Call 01248 354048.  
www.sagb.co.uk

informed of what was going on with his drug-taking in hospital and then stopping his medication. It wasn't right.

Daniel's dad, Rob, who works in the dockyards, has always found it difficult to talk about our son's suicide, but I desperately needed to talk about it.

I blamed myself, thought if Daniel had really believed I was there for him, he wouldn't have killed himself. I ended up not wanting to be here anymore. Three months after Daniel died, I went into hospital suffering with depression and stayed there for a few weeks.

You cannot blame an individual for what happened to Daniel, but I believe he was let down. A schizophrenic can live a totally normal, level life with the right medication. I feel Daniel could have had a good life if he had got into his 20s and understood more.

Mentally ill people need to be able to live out in the community, but they need support there. They cannot be put into a hostel and told, 'Here's your life, now get on with it.' And young people need specialised care – they are not yet adults.

Today I am still on antidepressants. I don't want to be here, and I desperately need to be with Daniel, but I also don't want to leave Rob and Lee. When Daniel was alive I thought I was living a nightmare – now I want those days back again.

Destiny is being brought up by Lianne now. She has never known her dad – she was just one when she lost him – but she has the same mannerisms as him. It makes me miss Daniel more, but it is lovely that Daniel left part of himself with me.

■ A study of people receiving treatment for mental illness found that reduction of care – including a reduction in supervision and a cut in drug dosage – was strongly related to risk of suicide. (Source: *British Medical Journal*, 1996)

■ Martin Barkley, Chief Executive of Hampshire Partnership Trust, says, ‘The Trust has launched an internal review into the care of Mr Taylor and the circumstances of his death. I can report that early indications show we were not responsible for any gross neglect in the care of Mr Taylor. There were some areas where our care can improve to ensure that this tragedy is not repeated and we will implement changes.’

there were no medical professionals. The manager said that they wouldn't take Daniel if he was on drugs and drink, so he quit completely before moving in.

Anyone leaving a psychiatric hospital needs a high level of care to readjust to the outside world and all its stresses. Daniel was sent out with nothing. He had no food, no benefits. He was told to go to college but he had no money for a bus pass and had to borrow from me. We were buying all his food, but what happens to discharged patients who don't have family to help them? In addition, Daniel was coming off drugs and alcohol, and had started up his demanding relationship again with his daughter and girlfriend. All of this put him in an extremely vulnerable position.

I later discovered that the hostel didn't even know Daniel was supposed to be on medication. In fact, Daniel had silently decided to stop taking his medication because of the side effects.

On Friday, 21st November 2003, Lianne called on me and we popped into town together for a few hours. As we came home, we could see from the street that there were people standing in Daniel's room at the hostel. I went home to Rob and Destiny, while Lianne rushed to Daniel's to see what was happening. There was no answer when she rang his doorbell, so she knocked on the hostel manager's door. The manager said to her, 'I think you need to come in and talk.' He said that the hostel workers had become worried about Daniel because he wasn't answering the door, but they could see his bedroom light was on. They had gone into the room and turned off the light – and that's when they found him. Daniel had hanged himself.

It was two weeks after his 19th birthday, and seven weeks after he left hospital. He had only been known to mental health services for ten months. The police broke the news to me. Then Lianne came to me, crying her eyes out. And that was that.

I would not believe it. It was not true. I was desperate to see Daniel. I ran round and they wouldn't let me into his room.

Time went very strange. The day seemed oblivious to what had happened. I don't know where that day went. I wasn't allowed to see Daniel until the evening.

I wanted to know, step by step, exactly what had happened. I started going through mounds of paperwork and records on Daniel, getting in touch with mental health charities. Information was missing from Daniel's official documents. I realised I should have been kept

MY VIOLENT BROTHER HAS BEEN LOCKED AWAY

For Sonali\*, 43, who works in social services, caring for her schizophrenic brother is a lifelong duty

My parents didn't like or want my younger brother, Deepak\*. He was highly-strung and always in trouble, provoking fights and being picked on by my parents. I believe if Deepak had had a loving, secure upbringing, his schizophrenia might never have come out.

While Deepak was at university, he appeared to become religious. He started saying that nothing mattered, gave everything he owned away and dropped out. Because he had no money, job or education, he started taking things from shops to meet his needs. These repeated offences landed him in jail for two or three months at a time.

At 19, Deepak was given a brain scan. He was told he had incipient psychosis and warned not to take drugs. In his early 20s, Deepak was diagnosed with schizophrenia. He suffered from paranoia and attacked people in the street, thinking they were out to get him. He also had

delusions, believing he was God, had contact with other planets or could talk to dogs. Unaware that these were hallucinations, he became angrily defensive of his beliefs.

As Deepak's sister, just one year older, I found his illness devastating. We shared a difficult childhood, but our relationship has always been entirely based on me trying to care for him. I have always been the only person looking after Deepak – the rest of the family can't cope. My parents are very judgmental – my mother says that Deepak behaves like an adolescent, and my father blames his problems on drugs.

Deepak has never accepted he was ill – it is other people who suffer from his illness. He can be demanding, angry and aggressive. I was always worried he would kill himself. Once he took a huge overdose and was in a coma for several days. On another occasion he jumped off a motorway bridge and was in hospital for weeks. One other time, he waited on a railway line. I knew he was suicidal and sent the police

to look for him – luckily they found him in time.

Deepak was in and out of hospital for most of his 20s until he was finally given permanent accommodation for ten years in a 24-hour community care home. He was vulnerable but stable there. Because he was controlled by medication, he stopped attacking people.

Two years ago, Deepak had a psychotic episode and was put back into mental hospital. The agency staff employed used to stay in their office and the ward became utterly wild. Drug dealers started targeting the patients and Deepak began taking cannabis, crack cocaine and anything he could get hold of, in any quantity.

The hospital was labelled failing and shut down, and Deepak was put back out in the community – because of his drug problem, no home would take him.

Deepak was housed in a council-owned bedsit with only optional support, which he chose not to take. He painted one of the walls different colours and the council and landlord could not accept this. Eventually he was evicted. Social services gave him £1000 in cash and told him to find himself a place to live within three days.

Deepak went missing with the money and a warrant was put out for his arrest. He came and found me, without any money. I gave him some food and told him the police were looking for him. He

had acquired a huge knife. I said to him, 'Please don't carry that about, it will really get you into trouble.' The next thing I knew, Deepak was under arrest. He had been begging for money. A man refused and Deepak threatened him with his dagger, terrifying him.

While he was in prison hospital awaiting trial, I approached his old consultant and said I couldn't cope with him being in the community if he didn't have adequate support. My daughter was just four years old, and Deepak was quite scary with her. I didn't want my daughter exposed to him, so I used to tell her to go upstairs when he came over to visit. Yet she always refused to leave me alone with him because she was afraid for my safety.

Deepak was sectioned and is now in a locked ward in a prison-like psychiatric hospital for the rest of his life. He has no freedom and has told me he wishes he was dead. It seems you can either be imprisoned with no rights at all, or let out with no help. All he needs is supported housing with staff he can trust. I no longer have any influence in his treatment. But I see Deepak as my endless duty. I spend half a day each week visiting him, and will do for the rest of my life.

\*Names have been changed

WHAT IS SCHIZOPHRENIA?

Schizophrenia affects one person in a hundred. Symptoms can start at any age, but most commonly occur in the late teens or early 20s

A person with schizophrenia may experience delusions, hallucinations, disorganised speech and thinking and chaotic behaviour. They may have little insight into their illness, and commonly do not recognise that they are ill.

It is estimated that around one third of people diagnosed with schizophrenia only experience one episode of illness, another third may have occasional schizophrenic episodes, while the final third may have to live with schizophrenia as a long-term condition.

WHAT CAUSES SCHIZOPHRENIA?

Nobody knows for sure what causes schizophrenia. Overall, it appears that schizophrenia is caused by a combination of factors; someone's genetic make-up could give them a pre-disposition towards the illness, but stressful life events or experiences could trigger the onset of symptoms.

HOW CAN SCHIZOPHRENIA BE TREATED?

There is, as yet, no cure. However, most people improve with drug treatment, especially when combined with support from family and friends, community mental health teams, day centres, social workers, supported accommodation, or hospital admission.

Source: Sane