My Son - One in a Hundred

(One person in a hundred is affected by schizophrenia. This is the text of an article printed in the Autumn 2000 issue of *Scotland's Carers*, the newsletter of the Carers National Association of Scotland. Our thanks to them for permission to use this material.)

My 24-year-old son N-- is blond and blue-eyed. He is highly intelligent and at school he excelled in sports and mathematics.

He is one in a hundred. - Unfortunately for us all.

At 17, after what we believed was typical teenage stroppy behaviour, he left home for Edinburgh (where his elder brother R-- was at university) and made little contact with us until he returned a year later, looking emaciated and ill and requesting money towards a deposit on a flat.

As he was clearly ill we tried to get him to stay at home but he refused and took off back to Edinburgh. Three weeks later, when my husband was due to retire and we were both away from home, a close neighbour phoned to tell us that N-- was sitting on our doorstep, not looking at all well and had refused her offer of help.

In these three weeks, he had slept on the floor of R--'s room in a student flat but when R-- left town to go south to work experience, N-- had no support system left and was penniless. Thinking that he was about to be evicted for non-payment of rent he somehow managed to get home to the North of Scotland.

Newly retired, our lives were turned upside down by the bizarre behaviour we now had to live with. Our lively son with a normally quick wit and good sense of humour had become reclusive and uncommunicative, making no attempt at social interaction or even basic civilities. From previously being fastidious and highly fashion conscious, he lay in his bedroom for hours with the curtains shut and with no interest in washing himself, far less washing or changing his clothes.

He emerged from his room only to raid the food cupboard (he wouldn't eat with us) or to pester us for money for cigarettes (the purchase of which was the only thing to make him leave the house). His concept of time was non-existent and he turned night into day.

If we managed to sleep through his nightly wanderings, the debris from his nocturnal fry-ups littered the kitchen by morning. Despite holding long and animated conversations with the air when he thought he was unobserved, he refused to concede that he might need help and my husband and I were baffled and worried.

Our life was a nightmare.

He did at last agree to see a doctor who prescribed some medication and we tried to live with this hostile stranger in our son's bedroom. His behaviour was unpredictable and we felt as if we were walking on eggshells most of the time in case we upset him. Our social life ceased to exist, our pension now had to support an unexpected third person and my husband was rushed to hospital with an emergency heart problem.

After two years of this existence when we thought N-- should be in hospital but the consultant he was referred to maintained that she could see no reason to admit him, an acute situation arose in which he was compulsorily detained. - Sectioned under the Mental Health Act! The Section should never have been necessary and we know now that we could (and should) have challenged it, but by then we ourselves were exhausted and the hospitalisation was a relief

Eventually, after some months, there was a diagnosis. - Schizophrenia. The shocking diagnosis came along with some facts and figures.

The onset for males is usually in the late teens or early twenties, later for females.

25(of sufferers recover after one episode of illness.

50% may experience further episodes of illness.

25% are likely to need long-term care.

Six years down the line with N being in hospital care for the last four years our hopes and expectations for the future have been radically altered. He is now 24 and is just about to be discharged into the "caring community".

He comes home regularly for long weekends and far from being mad, bad or dangerous, as screaming media headlines portray the victims of this illness, he is instead very reclusive, almost scared of life and needs constant reassurance on a whole range of mundane things before being able to make a decision for himself. Much of his time at home is spent in his bedroom. He emerges for meals, never waits for anyone else to eat but starts his own and leaves the table as soon as he has finished.

His medication makes him sleepy - not lazy, as relatives and friends sometimes infer. He needs to be reminded about personal hygiene and to bathe and change his clothes. He is grossly overweight but according to his consultant, this is a result of his medication, but that and the fact that he smokes and is short of breath is an apparently acceptable trade-off for having better 'Mental' health.

While the local health Trust have a non-smoking policy in their general hospitals, patients in hospitals for mental illness are not actively discouraged or helped to stop. As one nurse told me, "It would be stressful for patients to try to stop smoking and for some of them smoking is the only pleasure they have!" While this may be the case, we dislike the smell and mess of cigarettes and the proliferating burn marks on our home furnishings.

During all this time we have lived through the painful disintegration of our son's personality and been told that at the moment there is no known cure for schizophrenia. We have no feeling of stigma for ourselves but feel the pain, which this diagnosis has caused him along with the feelings of depression, and despair at the waste of a life, which has hardly begun. New jobs, family weddings and christenings which are normally joyful occasions are also painful reminders to us all of milestones which currently he is unlikely to pass.

In a few weeks time, he will be discharged into the community into supported accommodation - in a city 45 miles from where we live. We will still be carers but at a distance. Already he has indicated that he feels he will be lonely, but in the small village to which we had arranged to retire there is neither accommodation nor understanding for his condition, so, despite being assured that he will be supported, we fully expect to be spending a lot of time travelling to the city where hopefully he will settle.

As family and friends have little appreciation of the awfulness of this 24hours a day existence and our treatment by various professionals has varied considerably, our main support and encouragement has come through membership of NSF (Scotland) and contact with other relatives who know exactly how we feel. They have had similar and sometimes worse experiences.

We count ourselves fortunate that N was eventually admitted to hospital and therefore into the 'system', and we never had the grim task which many other relatives have had, of having to search the streets because a loved one has become ill and gone missing or of finding the police on the doorstep because something has gone wrong in a location far from home.