PROLOGUE

My son got schizophrenia – if it makes any sense to say that anyone 'gets' schizophrenia – some time between 1988, when he graduated from university, and 1990 when he was admitted to hospital as a psychiatric patient for the first time. That is to say that it was during this period that he began to behave in ways that were strange and inexplicable beyond anything I had ever known, beyond anything I had the language to account for. He began to say and do things that appeared to belong in a different, even alien dimension of existence. He began to inhabit a world where I simply could not follow. I tried to keep up: I tried as it were to put my arms around him and protect or save him. He was not gone all of the time, but for much of it I simply could not reach him. I felt as if I had been left behind, baffled and hurt, on some far shore while he lit out into unknowable, desolate regions.

This book is the story of that strange voyage, his illness, as told by and, largely, as experienced by me. I cannot really speak for him for obvious reasons and I have not tried to speak for his mother or his sister, the two other people most affected. Others have played a part too, grieving, succouring, providing sympathy and love: friends, cousins, aunts and uncles; my wife Camilla, my brother Robin and my old friend Geoff in particular.

I have tried to give some idea of what it is like to live with such a tragic illness that typically strikes youngsters in the first full blossoming of their adulthood, blighting their lives like a late frost catching a tree in blossom, preventing its burgeoning fruit from ever setting and coming to maturity: striking them down in those first heady moments when full of hope and innocent excitement they reach out for selfhood, for fulfilment, for identity in love and work; and of the isolation, alienation, frustration and abandonment by friends that it brings.

I have also written at some length of the practical frustrations caused by the pitiful inadequacy of the provisions made in our society for looking after people disabled by illnesses of the mind. I have quoted, extensively in places, from the correspondence I have exchanged in the course of these twenty years with various spokesmen of the health and social services. I do not believe that they were malevolent or deliberately unhelpful, but I do think that their almost universal inability to express themselves either clearly or correctly, their penchant for unintelligible jargon, their failure to co-ordinate their activities or even ensure that their own guidelines are followed and their general neglectfulness are shameful and an awful indictment of the nation's education system.

What is schizophrenia, people ask. The short answer is madness: what we used to call madness, loss of reason. Someone who yesterday was quite rational, normal, as we say, is found in the night, naked in the street, distributing pink marzipan piglets to the queues of youngsters waiting to get into a dance hall, making the sign of the Cross and blessing them

as if he were the Pope. And that is not much of an exaggeration about the first florid onset of this illness.

What causes it I cannot say. I have not attempted to explain the science of the illness, because I do not know much about it and do not really understand the little I have read. I believe also that not too much is really yet known about its causes, its mechanisms: what exactly goes wrong where to bring about such devastating consequences for those afflicted.

The classic age for the onset of the illness is between eighteen and twenty-five. Usually there is very little warning that anything untoward is about to happen: it strikes, as it seems, out of the blue. There is no way of predicting who is likely to be vulnerable. There is no cure. There are a number of drugs available, discovered by chance, which control, more or less effectively, the most extravagant and melodramatic symptoms, the hallucinations: the hearing of voices, which can impel people to the most drastic of actions like throwing themselves under trains, and the sort of delusional thinking that leads you to believe you are Queen Maeve. They inhibit the production in the brain of the neurotransmitter dopamine which is central to the development of psychotic symptoms. They are however less effective in alleviating the more low-key but in terms of everyday living equally disabling symptoms, like depression, lack of motivation, loss of concentration and memory, a certain dulling of intellectual capacity and paranoid feelings about other people that can transform even routine transactions like shopping into almost unmanageable ordeals.

We used always to hear that the incidence of schizophrenia was pretty much universal, with around one percent of the world's population affected regardless of climate, creed or culture. But this is not true; there are marked variations. For example, city people suffer more than country people, big city people more than small city people, men more than women, migrants more than native populations.

There is a characteristic pattern of symptoms and the illness is diagnosed on this basis. It is a syndrome rather than a single disease which causes pathological changes in people's brains, as many have believed. There is a range of ways in which you can develop these symptoms. The problem as far as curing the illness is concerned is that we do not yet know the pathology of it.

Genes certainly play a role in determining who gets the illness; one or two have already been identified. It seems most likely that the culprits are fifteen to twenty small 'susceptibility' genes rather than a big one that causes the illness. And the variety of schizophrenia that you get – whether you suffer more, for example, from the crazier symptoms like delusions or the more affective ones like depression and lack of motivation – will depend on the hand of genes that birth has dealt you. It is not that the genes cause you to develop schizophrenia, but rather predispose you, make you susceptible to the influence of certain environmental factors.

Among them are difficulties at birth, drug abuse (cocaine, cannabis and amphetamines), growing up in cities and migrating from one country to another. Again it is not that these factors cause the illness but in interaction with genetic susceptibility they can provoke psychotic reactions. Lots of people smoke cannabis regularly and get away with it, but if you belong to the vulnerable minority (around 25% of the population) you could be in trouble. Certainly, among the people I know, many of their schizophrenic sons and daughters smoked a lot of dope in their adolescent years.

'Hearing voices' is the classic symptom. 'Do you hear voices?' is the question patients are asked time and again. The implication always was that you are hearing things which do not exist, which are not there. But an interesting discovery has come about through the development of brain imaging: schizophrenics 'hearing voices' are indeed hearing voices, with the difference, however, that their brains are misinterpreting as coming from external sources sounds which they are really 'hearing' in the part of the brain where we all 'hear' internal speech, as, for example, when silently saying a poem to ourselves. In other words they are not making it up when they say they hear voices; it is rather that their brains are functioning in an abnormal way.

Professor Robin Murray of the Institute of Psychiatry at Kings College in London, the pre-eminent researcher into schizophrenia in this country, said in an interview given to the American Schizophrenia Research Forum in 2005 that he believed schizophrenia was a disease of the mind as much as the brain. 'There is brain dysfunction in schizophrenia, but that dysfunction makes you more vulnerable to particular toxic factors in the social environment. What I find interesting about it is that it is a disorder at the interface between the brain and the social environment. I suspect,' he said, 'some schizophrenic people carry particular susceptibility genes that make them vulnerable to particular environmental phenomena, while other people with schizophrenia do not carry these genes and, therefore, can withstand these particular environmental factors, but are vulnerable to others. That greatly interests me, and I think we're going to be able to identify other such gene-environmental interactions in the next few years.'

Asked whether he thought we would be able to cure schizophrenia, he said, 'I don't think we'll be able to cure it with a single drug. Possibly, a combination of specific pharmacological and psychological interventions tailored differently for different patients may return most people to normal function. Even more excitingly, we may be able to prevent the development of the psychosis. We already have some weakly predictive childhood markers... but we will have more powerful predictors. Will it then be possible to screen such children and carry out neurophysiological or imaging or genetic tests, and identify the children who are especially likely to develop schizophrenia? Will we then be able to intervene before overt symptoms show up?'

There is hope. We must hope. I am sure Prof Murray is right: it is early days. No one has put anything like sufficient money into research into mental illness. How much further on might we be by now if schizophrenia had attracted the funding that cancer has or AIDS?

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Lastly, I would like this book to be seen as a tribute to the sheer dogged bloody-minded courage and independent spirit of my son. I take my hat off to him.