

## CHAPTER 1

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# SCHIZOPHRENIA: WHAT IS IT?

What *is* schizophrenia? What causes it?

One hundred years since schizophrenia was supposedly “discovered”, many would still argue that we still don’t know.

### **Same Question, Different Answers**

We should say straightaway that the question “What is schizophrenia?” is misleading, because what people are usually implicitly asking is “What causes it?” So, for example, a psychiatrist will typically say it is an illness, but what he is really saying is that “the presentation (of symptoms and so on) is caused by an underlying illness (which is not itself seen)”.

Our approach to the question is to take the reader on an imaginary walk around an imaginary psychiatric hospital to talk to a number of imaginary people – professionals, patients and relatives. This story will enable us to convey the diversity of views that exist.

As we have said, if you were to walk into a psychiatric hospital near you and ask people you met, “What is schizophrenia?” you would very likely get different answers depending on who you talked to. Many people would probably say “That’s a good question, I’ve often wondered that myself”. If you were to ask them whether schizophrenia always develops in late adolescence, some might say: “I’m not sure it does because I’ve met many people who develop psychotic behaviours later in life, for example, in their fifties.” They would be right to point this out. However, as we’ll show later (Chapter 3), between 50 and 80 per cent of people who develop schizophrenia do so in late adolescence/early adulthood. (Sartorius *et al.*, 1986). In this book we are generally writing about that 50 to 80 per cent.

### **Different Perspectives, Different Emphases**

A psychiatrist in the hospital gives you a different point of view: “Schizophrenic symptoms are first seen in late adolescence but the critical cause happens much earlier. It is due to complications with pregnancy and

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birth in people who are vulnerable to that sort of thing anyway. It just happens that these problems aren't seen until late adolescence. Schizophrenic symptoms are due to an imbalance of brain chemicals."

He continues: "As far as I'm concerned, schizophrenia is a brain disease, and generally what is most important for my patients is that they get medication. The newer anti-psychotic medications nowadays are very effective, anyway (as were the old neuroleptics). The newer meds have fewer side-effects, even if they are remarkably expensive."

Perhaps he goes on to assure you . . .

". . . and they do work. Just as well; I'm legally responsible for my patients and if something goes wrong, as they can do very rarely, if they kill themselves or someone else I'm in big trouble. I need something I can rely on. I also need tangible things; medical insurance companies in particular need to know exactly what illness people have, and exactly what treatment will work best. They'll not be very impressed if I say I'm not really sure, they'll go to someone who *is* sure. Medical insurance needs medical precision, medical details, treatments proven to work on huge samples."

If this psychiatrist was one of the more extreme (and out of date) of the profession, he might say:

"One thing that doesn't make a schizophrenic calmer is talking to them about their symptoms. That's the worst thing you can do. Of course you talk to them with some sympathy, about how they feel, how their meds are working, but the more psychotic things patients say are just meaningless speech, they don't mean anything. Listening to them is like listening to the tune a piano makes as you hit its innards with a lump hammer, or douse it with petrol and fry it. There are no patterns there, no hidden meanings. Some mental-health professionals annoy me because they try to collude with patients, talk to them as if people really are out to get them, or they really do hear Jesus's voice, or whatever. And they call this psychological therapy! It just gets patients agitated, makes them worse, and makes them stop taking their medication. You can have someone perfectly stable on their meds, and next thing one of these individuals starts trying to be their best friend. And then as they've found an audience for it, the patient gets more psychotic than ever. So the family gets agitated, and the nurses get agitated and I get agitated because they look like they might do something silly and I have to raise the medication dosage again to control the brain chemicals this individual has stirred up and I have to look like the big bad wolf, sectioning and bullying everyone. And then this 'colleague' gets to look all disapproving of me, and now the patient distrusts me and hates me.

"I would stop some of these so-called 'colleagues' getting near schizophrenics, while they are unwell, they can be a real liability. They stir up

emotions and run the risk of making them a lot worse. Some so-called therapists are always looking for hidden meanings, magic that just isn't there. These therapists don't understand about the medical issues involved. Schizophrenia has always been treated by medical people, since it was first recognised at the start of the last century. We know so much more now, all the research we've done since then, that we can finally put to rest any ideas that it isn't biological. Those myths are now completely disproved. What some of these therapists think is utterly irrelevant.

"I'm a medically-trained doctor and the medical approach is the most relevant one for schizophrenia. Fair enough some conditions have grown to be seen as more psychological – depression, anxiety, eating disorders – but schizophrenia is a different beast altogether. People who have it are so fundamentally different; it just has to be biological."

Perhaps this psychiatrist is holding some scientific psychiatry journals, its pages full of glossy adverts from pharmaceutical companies, showing smiling, attractive, healthy and confident-looking people with the tag-line *I'm happy because I'm taking drug X.*

Alongside the psychiatrist happens to be a representative from the drug company . . .

"I'm in the hospital today to put the finishing touches to the free meal and promotional gifts scheduled for this week. We often put on remarkably good lunches (high quality, I'm sure everyone here will agree), and give away a remarkable amount of pens, post-its, mugs, gadgets, clocks and perhaps trips to major sporting events. We also sponsor schizophrenia conferences, at some cost. I don't think we get as much control over the conferences as we should do, considering that we bankroll them. We do sponsor some conferences that are more psychological, but we get to have a few speakers that are more pro-medication if we sponsor. Of course, we are a commercial outfit, so we are keen to sell our product, but I like to think we also provide a public service, helping people in distress. We bend over backwards to provide financial help for new drug-trials, trying to prove these drugs work. And without absolute rigorous proof they work, treatments wouldn't be provided by insurance-based schemes. It is worth our while helping, though; the market for psychiatric drugs is worth many billions worldwide."

The drug rep wanders off, whistling to herself, and you move on.

Another psychiatrist, this one a bit older and wearing sandals, stops you. This person seems to have a very different story to tell, and calls you to one side, into an office, whispering:

"We sussed a lot of this out in the sixties. That was a great time, everyone

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throwing off their chains and rebelling against the constraints of society. We used to say 'psychosis is just a trip, like acid; you had to let yourself be open to this sort of higher plane. If you went with your psychosis it would take you to where you needed to be.'

The older man pauses, frowns and looks into the middle distance . . .

"Even if where you needed to be was writing mysterious messages on the walls in your own shit . . . (see Barnes & Burke, 1973; Reed, 1977). We used to say 'there's no such thing as mental illness, it's a complete myth, a delusion that society holds.' These are life issues brought on by a society that just doesn't work (see Szasz, 1974, 1987).

"What causes schizophrenia? I'll tell you: the problems are with the pressures society puts on us. In a strange way, people with a psychosis might be seen as very sane. You might even wonder if we are the ones who are mad, putting up with all this rat-race and having these silly pretensions! We all race around like everything is so important, but we forget the important things, the soul, the meaning. And I'll tell you what else: families are generally the problem. Even in the best of families you get all these mixed messages: 'Be successful – but not more successful than me'; 'Be independent – but don't make me feel redundant'. The families of people with schizophrenia are more disturbed than the patients. You should see the way some of my patients' parents act towards them. Families cause schizophrenia."

### **What About the Family?**

The rebelliousness of this older man might appeal to you. Leaving their office, to your horror, you bump into some family members of people with a psychosis who appear to have overheard the man's last comment. They seem to you a varied and interesting group. In fact, a typical cross-section of society's parents, all classes (although perhaps slightly more working-class parents). One of them regards you with a sceptical eye, and referring to the psychiatrist's comments says:

"We're well aware that certain people blame us for our children's problems. Many of us do in fact blame ourselves. I suppose it is only natural for us parents to want to protect our children from harm; I know I just wish there was something I could do to help. By the same token, it is only natural for us to feel it is some sort of failure on our part if our children are chronically unhappy. I do worry that I should be more sympathetic to my son's condition, but he drives me up the wall. He shouts at his mother and me all the time, never washes, his room stinks, he can't keep a job, he talks rubbish, he seems really arrogant and condescending. I'm actually scared of

him, my wife doesn't dare be alone with him; she had to give up her job because she couldn't cope with it all. He's always shouting at us to give him lifts, buy him things. Our lives would be so much better if he wasn't living at home. *And that man blames us? Maybe he should try living with our son before pronouncing on us!*"

Another says:

"Our daughter isn't much trouble, but she just looks so unhappy, I just wish there was something we could do to help. She isn't going out, having fun, meeting boys or enjoying herself at all, and it's such a shame. She just stays at home all the time, murmuring to herself in her room. When she does go out I worry about someone taking advantage of her. I also worry what will happen to her after I'm dead when there's no-one to look after her – where will she live? How will she cope? She certainly couldn't look after herself at the moment."

Another one says:

"It can't be our fault because it's a biological condition. My son's brain chemicals are the things going wrong somehow. And that means we can help because the doctors say his medication should help and we can help make sure he takes his medication. If psychosis wasn't biological, it would be our fault."

They argue amongst themselves about whether this is true, and whether these various premises are logically connected.

## **Can Complementary Skills Mean Different Agendas?**

A psychologist is passing by who seems to have yet another story to tell . . .

"People with psychosis are the victims of society. These are the ones who have fallen by the wayside. Most of them just have phenomenally low self-esteem, which they hide by acting as if they think they're really great. You can't help wondering what their lives have been like.

"We call the people we work with 'clients' or 'services users' to get away from the word 'patient' – that word implies too much that they are medically ill in the traditional sense; it also makes people feel quite down-rank and powerless. I work with clients on a weekly basis, usually for around 10–20 sessions or perhaps longer. There isn't anything like enough psychologists, so only a lucky few clients get to meet with one of us. I talk with them, hopefully make them feel valued and listened to, help them understand the way their mind works. I try to build a client's strength up but there are barriers to this – maybe someone in the street hassles them, or perhaps someone in the Jobcentre is a bit too firm with them and they can

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get really unhappy and paranoid again, be set back for months. Alternatively, the psychiatrist occasionally puts them on a new drug, and then my client is too much of a zombie to speak and they can't remember anything we do.

“On the whole, psychiatrists only see clients for 10 minutes every month, and then tell everyone else who works with them day-in and day-out how that person should be treated. If the client gets better the psychiatrist sees it as due to the medication rather than my psychologising or the nurses' great skill in handling them. If clients get worse it is down to my unsettling them or the nurses' lack of care.”

One of the few professionals you haven't yet met is the Community Psychiatric Nurse mentioned by the psychologist. You manage to track one of these down so as to hear her piece. She looks tired:

“I have quite a large caseload of people with a psychosis I look after, more than I feel I can safely manage because we are short-staffed at the moment. It is a round-the-clock job; I end up working a lot of weekends and evenings. I give them their medications and keep an eye on how well they are doing. I also help them with benefits, housing issues, other self-care issues, although these are often things a social worker does for them. Most of my clients are in the community, although from time to time they might become unwell and they might be in hospital.

“For some of them, I am the closest thing to family they have got; many live miles away from their parents, or their parents have died. I feel pretty close to most of them, and I often end up listening to some odd and fantastic stories; you get used to being sympathetic in this job. If something awful happens involving them, I can get into big trouble, so I am keen for them to take their medication. I don't know what I think about whether schizophrenia is biological or not. I'm not sure I really care about the biological/psychological argument. People rarely listen to what I say, anyway. The psychiatrist is my immediate boss.”

### **The Client's View**

Finally, you meet some of the clients with a psychosis. How do they look? Most of them look surprisingly normal. Some of them seem slowed up, and their speech sounds a bit slurred. Many of them are quite badly dressed, and don't seem to be looking after themselves. One of them says:

“We are a sorry sight to look at; lots of us chain-smoke and are overweight; that's because of the medication. It makes you put weight on and slows you up. And there's nothing else to do but smoke, hasten yourself towards the end. Some of us who have been here longer have tremors . . .”

He puts out a rather shaky, nicotine-stained hand to show you what he means.

“... the older medication used to give you tardive dyskinesia, which is like a form of Parkinson’s disease. Not to mention the dry mouth, and the eye-rolling you sometimes get.”

You interrupt to ask the clients what they think causes schizophrenia. You get a real mixed bag of views. Some of the views are familiar – you’ve heard them from the other people you’ve spoken to here: “it’s a brain disease”, “it’s because of society being unjust and putting pressures on people”, “it’s because my parents never loved me enough”. Some are less familiar: “it’s because the voices in my head have made me mad”, “it’s because people have been saying bad things about me”, “it’s because of something awful I did when I was 17”, “it’s because of a particular person who has always had it in for me”, “it’s because the medication they’ve given me has turned me into a zombie”, even “there’s nothing wrong with me”.

They reason:

“If it’s my brain chemistry, does that mean there’s nothing I can do to help myself? Does that mean I can never get better, and will have to take this medication for the rest of my life? I may as well kill myself now.”

and

“I don’t want to tell people about my diagnosis because I feel sure they wouldn’t want anything to do with me again . . . I’m not even sure I want to know myself. I keep asking myself: ‘Am I this bad person, this danger to society?’ I must be if I am a schizophrenic. In previous centuries, they used to chain people with mental illnesses up in dark cells and crowds used to pay to see them and jeer at them.”

### **So What IS the Answer?**

Coming away from all these different parties with their different opinions and perspectives, you could be excused for feeling your head was spinning. But this brief fictional drama represents what is really happening, and has been happening for the last 100 years. It’s important to be aware of the underlying political issues.

Who is right?

Which explanation is right?

Where can we start to examine these issues?

What, if anything can anyone do to help?

## **SCHIZOPHRENIA OR PSYCHOSIS?**

So far, all the people involved – the stakeholders – have talked in terms of schizophrenia and psychosis, but are the terms interchangeable? Do they mean the same thing? Not quite . . .

### **Diagnosis**

Biological researchers still mostly use the term “schizophrenia”. Schizophrenia is the official, legal, diagnostic category. A diagnosis of schizophrenia can be given if two out of five specific types of behaviour and thoughts are seen and have been present for six months or more (see Table 1.1, page 11).

There are two diagnostic systems, one originating in America called the DSM (the Diagnostic and Statistical Manual of Mental Disorders, now in its fourth edition; APA, 1994), and the more global ICD-10 (International Classification of Diseases, now on its tenth revision; WHO, 1992). The various diagnoses are not described by causes, as you might intuitively think, but by outcomes; this is because causes are not known in any exact manner. The diagnostic criteria are agreed on by committees composed of a wide range of the experts of the day, who thrash things out in light of their clinical experience and on the basis of the latest research.

It is useful for a legal definition of schizophrenia to exist because in legal circles things have to be precise. For example, if there is the question of a person being compulsorily locked up, there have to be clear criteria for what sort of behaviours might bring that about. However, the definition is a little bit arbitrary: one sign out of five and you are not officially “a schizophrenic”; two out of five and you are. This is important when you consider the terms “schizophrenia” or “schizophrenic” have accumulated a lot of baggage over the century for which they have existed.

### **Public Perception – the Myth of the Mad Axeman**

The media almost always portrays schizophrenia as something that makes people dangerous, because the media’s job is to arouse interest, stir drama. A friend of ours who worked in radio news admitted recently that her editor wouldn’t let her do any sort of item on schizophrenia without mentioning the few cases over the last 10 years where someone with a mental illness has murdered a complete stranger. Typically she would be asked to interview a relative of the deceased.

Although such murders are appalling tragedies, the statistics show that in



fact only a very small number of people with a diagnosis of schizophrenia have committed murders. Of the 6–700 homicides a year in the UK, 40–50 will be attributable to schizophrenia (Taylor & Gunn, 1999); i.e. around 90 per cent are committed by people who do not have mental-health problems. By comparison, there are 3500–4000 deaths per year from road accidents. Only 13 per cent of the few homicides committed by people with schizophrenia were of strangers, therefore the risk of being murdered by a psychotic stranger is dramatically less real than the man in the street might feel. The proportion of homicides committed by people with a mental illness has been steadily decreasing by three per cent per year since 1957, according to UK statistics; whatever newspaper editors may think, the data clearly shows that on safety alone, services are improving.

The reality is that people with schizophrenia are more likely to be a danger to themselves than to others. Statistics show a 10–13 per cent greater lifetime's risk of suicide in people with schizophrenia than the general public (Baxter & Appleby, 1999; Gunnell *et al.*, 1999). It doesn't seem unreasonable that the disparity between people with a psychosis being seen as dangerous (when the stats show they are not) plays some part in this exceptionally high suicide rate.

**Table 1.1** DSM-IV Criteria for Schizophrenia

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According to DSM-IV, the diagnostic criteria for schizophrenia are:

A. Characteristic symptoms:

Two (or more) of the following, each present for a significant portion of time during a 1-month period:

- 1) delusions
- 2) hallucinations
- 3) disorganized speech (e.g. frequent derailment or incoherence)
- 4) grossly disorganized or catatonic behaviour ('catatonic' means 'immobile')
- 5) negative symptoms, i.e. affective flattening (i.e. appears to have no social emotions, or just grossly inappropriate ones), alogia (no words), or avolition (appears to have no will of own, or volitional force)

**Note:** Only one criterion A symptom required under some circumstances.

B. Social/occupational dysfunction in one or more major areas for a significant portion of time

C. Duration: continuous signs for at least six months

D. Not suffering from schizoaffective and mood disorder

E. Not suffering from substance abuse or another general medical condition

F. Not suffering from a pervasive developmental disorder (unless prominent delusions or hallucinations are also present)

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Source: From *Diagnostic and statistical manual of mental disorders: DSM-IV* (4th edn) (1994): APA.

## Labels and Terms

Newspapers often use the term “schizophrenic” to describe a mental state when someone appears to hold two conflicting views. Another popular misconception that “schizophrenic” means a person with split personalities, who can act as completely different people at different times. In fact, that condition is generally known as “dissociative identity disorder” and is a different thing to what is properly considered to be schizophrenia. Thus the term “schizophrenia” has a use in day-to-day life that is different to its technical meaning.

The term “schizophrenia” is necessary in legal situations, because it can be tightly defined. Psychosis is a preferable term otherwise, because it has fewer negative connotations, and also doesn’t imply that the person has a brain disease in the way that schizophrenia is traditionally seen. Technically speaking, in DSM-IV the term “psychosis” refers to schizophrenia and, also the “high”, “manic” stage of bipolar disorder (formerly referred to as “manic depression”). For our purposes, the most important definition of psychosis is “a gross impairment in reality testing”.

It is best described in conjunction with another well-known term, “neurotic”, with the old adage that “*neurotic* people build castles in the air, *psychotic* people live in them”.

So these are the differences between the terms schizophrenia and psychosis. Modern services try to avoid using the term “schizophrenia” because of the negative associations; they also try to avoid calling people with a psychosis “schizophrenics” as that’s such a stigmatising label (and it doesn’t even help describe them, as its common usage is so different to the reality). In this book we mainly use the term “psychosis”, although we often use “schizophrenia” where we are referring to some of the established literature that has been published using this label.

So, let’s get back to the central themes of this book: What is schizophrenia about and what can anyone do to help?