

CHAPTER 4

Schizophrenia: a dialogue on progress

Sandy Jeffs and Margaret Leggatt

Has schizophrenia as a label, an illness, a diagnosis, or even a concept outlived its usefulness? Have we managed to destigmatise it? Or do we no longer mention it because in the public mind it continues to be the most feared and reviled of mental illnesses? This is a dialogue between Sandy, who has lived with schizophrenia for thirty-eight years, and Margie, a mental health advocate since 1978.

Sandy

If you were condemned to suffer a mental illness, which one would you choose? If you chose depression you would have a condition shared by a number of high-profile celebrities, politicians and sports stars, many of whom have been encouraged by Beyond-blue to talk publicly about their struggle with and recovery from “the black dog.” This PR juggernaut has succeeded in drawing so much support as to make depression the mental illness of choice. Now celebrities are coming out with other conditions, like bipolar disorder. It is okay now to speak publicly about mental illness – and this is good, because it shows that mental illness does not

necessarily prevent people from exercising talents in many fields. But only if it is depression or bipolar; schizophrenia continues to be associated with violence and mass murder.

Two recent examples of mass murder in which the perpetrators were immediately associated with schizophrenia were the well-publicised cases of Anders Breivik in Norway in 2011, who murdered seventy-seven people, and James Holmes in Denver in 2012, who shot seventy people in a cinema, killing twelve.

The Breivik case highlights the psychiatry profession's problem with credibility. One team of court-appointed psychiatrists diagnosed Breivik with paranoid schizophrenia, but another team of psychiatrists, also appointed by the court, disputed this diagnosis, saying he was not psychotic but had a narcissistic personality disorder. The court found Breivik to be bad, not mad. Holmes, the Denver killer, was supposedly seeing a psychiatrist who specialises in schizophrenia, so the media and the public inferred that he must have schizophrenia. On the web, people suddenly became amateur psychiatrists, diagnosing Holmes with paranoid schizophrenia on the strength of media reports.

Whenever I see a report in the news of a rampaging killer, or an assassination, or a person acting irrationally in a public place and causing mayhem, I make a silent prayer: *please don't let this person have a diagnosis of schizophrenia*. I don't want to feel ashamed again of this label I must also wear.

The diagnosis and nomenclature of schizophrenia have been controversial since 1911, when Swiss psychiatrist Eugen Bleuler brought the term into the psychiatric lexicon. Bleuler's definition meant "split mind" but lay people misinterpreted this as "split personality." This idea of a person being able to shift between two personae, good and evil, had taken on wide cultural significance since Robert Louis Stevenson's 1886 novella *The Strange Case of Dr Jekyll and Mr Hyde*. The notion had created a fear, in the collective consciousness, of what those labelled "schizophrenic" might be capable of, like morphing into the monstrous Mr Hyde.

Someone once asked me, when she found out I had schizophrenia, “Who are you when you are not Sandy?”

Margie and I became friends through our association with the Schizophrenia Fellowship of Victoria (now the Mental Illness Fellowship), a self-help and advocacy organisation for people affected by schizophrenia, and their families. Since the late 1970s, Margie and I have shared a desire to make life better for people diagnosed with schizophrenia, and their family and friends who care for them. Yet, for all the thirty years we have worked together in our related spheres of interest and concern, we now question what real progress has been made.

Is there any less stigma attached to schizophrenia than there used to be? If so, why is there perhaps an even greater reluctance to use the S word? Why am I hearing the same stories from people diagnosed with schizophrenia that I heard thirty years ago? Why does the concept ignite such fierce debate – about exactly what constitutes the condition, or even, now, whether such a condition exists? Has schizophrenia become the “abandoned illness,” as a report by the Schizophrenia Commission in the United Kingdom declared in 2012?

Margie

And why am I hearing the same stories from family carers – about how they are ignored, not respected, and not helped to cope with difficult situations? Why are they not listened to, when they have valuable information to give? Why are there long delays in getting appropriate help when someone is becoming mentally unwell?

What is schizophrenia?

Sandy

It was 1976 and I was twenty-three. I was sitting in front of a psychiatrist who told me I had “schizophrenia.” This sounds serious, I thought, but what is it? I sat there, perplexed by psychotic

confusion – terrorised by persistent voices telling me I was evil; caught up in bizarre delusions. I was preoccupied with visitations by the Virgin Mary and a hag who kept appearing in my mirror. The outer world menaced and bombarded my inner world.

Sometimes I seemed to be able to do at least ordinary things, like go to the shop to buy bread and milk, meet friends for a meal, see a film or play tennis. At other times I was too overwhelmed, or too distracted, by the ridicule and abuse of persecuting voices, which made me feel worthless, useless. They told me my friends wanted to harm me, so I withdrew from those friendships. Even the radio was giving me cosmic messages – that I had the power to contaminate people with the evil emanating from my body, and that my thoughts were being broadcast to the world. I was terribly alarmed that strangers could read my festering mind. I was admitted many times to a psychiatric hospital.

When I started hearing the voices of my madness, clinicians saw them as random and rambling voices that had no intrinsic meaning, caused by a mind swimming in unbalanced chemicals. I don't recall any psychiatrist asking what my voices were saying to me. All the vitriol and persecution of my voices, all their references to me as a *slut*, *trollop*, *Satan's whore* and *bitch*, were simply to be medicated out of existence. I now believe they were telling me something. Their repeated references to me as a slut and whore surely hark back to myself as a thirteen-year-old girl dreadfully shamed by the man who raped her.

The certainty of my diagnosis of schizophrenia has wavered over the years because one psychiatrist has thought that I may in fact have "schizoaffective disorder," a condition that encompasses mood shifts common to bipolar mood disorder as well as psychotic symptoms common to schizophrenia.

Assuming I do have schizophrenia, what was its cause?

Back in the 1970s, schizophrenia was seen to be caused by dysfunctional parenting; these days the spectre of childhood trauma lurks also.

I am the victim of a traumatic childhood. My mother was an alcoholic and alcohol played a big part in our unhappy family. My father was a wife-beater. This made for a deeply distressing environment in which to grow up. I felt unloved and unlovable. I have two siblings who both experienced the family violence and their own trauma. Why didn't they fall into a mental illness? What was it in me that tipped me over the edge? Did my lesbianism contribute to the mental illness; was it a personal weakness? Was I too sensitive to the world? Was my brain overrun by unbalanced chemicals? And what about the sexual abuse?

Was it an incremental accumulation of all these traumas that made me vulnerable to developing schizophrenia?

Margie

I have worked with countless families with children who have schizophrenia where there is no history of family trauma or childhood sexual abuse. Parents are coping with schizophrenia under the most difficult of circumstances. Often they feel they are not coping; they cannot understand what it is that they are dealing with. They are worried, frightened, desperate and totally bewildered by the inexplicable changes in the behaviour of their sons and daughters; they become very stressed, distressed, isolated, and physically and emotionally unwell themselves in the process.

Evidence has also been accumulating for theories that schizophrenia has origins in brain dysfunction. These theories suggest that the *acute* symptoms – distorted perceptions, like hallucinatory voices and visions; distorted thoughts, like feeling persecuted or spied on, or believing you have special powers; and disordered emotions, like feeling evil, worthless, unloved – result from chemical imbalances in the brain stem. Medications have been discovered that can treat these acute symptoms by removing them, or at least subduing their intensity.

The thinking on *chronic* symptoms is that they are caused by dysfunction in the prefrontal lobes of the brain – the area

in humans for “higher learning.” Dysfunction in the prefrontal lobes leads to personal disorganisation: diminished grasp of abstract ideas (concrete thinking), inability to plan realistically (poor recent memory, loss of the sense of the future), lack of initiative, lack of motivation, reduced conversational ability (lack of expression and spontaneity), indifference and apathy, socially inappropriate behaviour, poor problem-solving, and an inability to integrate thoughts with appropriate emotions. Problems with capacities for focus and attention indicate possible dysfunction in the hippocampus. The chronic symptoms are not helped much by medication.

Nowadays the generally accepted explanation for schizophrenia goes something like this: biological vulnerability plus environmental stressors can result in the development of mental illnesses such as schizophrenia. Mental illnesses are the product of continual interactions between brain dysfunctions and emotional and social phenomena experienced as stressful and traumatic. In other words, mental illness is not caused by either nature *or* nurture, but by their interaction at critical periods of psychic development.

Our fight to destigmatise schizophrenia

Sandy

Over the past three decades the “medical model” of biological causes – chemical imbalances in the brain – has become more widely accepted, and I used to find it comforting. It didn’t blame me, my parents or my circumstances for my schizophrenia. I was mad, not bad. I could hope that I might be helped by medication or, even more optimistically, that my condition was treatable and even curable.

This became the narrative, the story I told myself in order to understand and cope with my wayward mind and incomprehensible behaviour.

Over twenty years ago I started speaking publicly about my schizophrenia. Other mad people like me, burdened by misunderstood diagnoses, stepped out of the mythology to give schizophrenia a human face. I found myself in front of school kids, university students and community groups, telling my story. I was featured in print media, and on radio and television.

If people could only understand that schizophrenia was an illness, we believed, the stigma and associated rejection and isolation would end.

Margie

We determined together to debunk the myths: schizophrenia is not split personality, as per Dr Jekyll; the illness, if detected and treated early, can be ameliorated. Letters to the *Age* railed against the common, inaccurate use of the word, as in, “I feel a bit schizophrenic today because I can’t make up my mind” or “the member of the opposition is schizophrenic – on the one hand he says this, on the other he says that.”

But different problems with public perceptions began to emerge. There were perplexing cartoons: people with schizophrenia were drawn as grotesque caricatures, or menacing, or in dark shadows (mysterious, and not open to communication). Media descriptions were designed to shock: “Rampage man on God’s mission – man fails to take prescribed drugs”; “Feral psychotics will soon be roaming Melbourne’s streets” (on the closure of mental hospitals); “Cease-fire – 8 people shot dead by police this year” (on the inability of police to deal with the psychotic).

Julian Knight, the man who killed seven people and injured nineteen during a shooting spree in Clifton Hill, Victoria, in what became known as “the Hoddle Street massacre,” did not have a mental illness. Yet the media used expressions like “crazy gunman,” “insane attack” and “act of madness” when describing the event. At the time of the Port Arthur massacre – the mass

shooting by Martin Bryant in Tasmania – the media asked, “Does this young man have schizophrenia?”

On the rare occasion when someone with a mental illness did commit a crime, headlines were unrelenting: “Schizo Knifed Mum,” “A Smiling Assassin,” “Murder-suicide Man Refused Medication.”

Labelling people as crazy or mad, implying mental illness, when no mental illness was present, was bad enough. But when someone with schizophrenia did commit a serious crime, all our efforts at getting the true understanding of schizophrenia out into the open were obliterated. Our statements that only a small proportion of people with schizophrenia are violent, or that the vast majority of violent crimes are committed by people who don't have schizophrenia, seemed feeble against the blaring insistence of media reportage.

Sandy

It is pretty devastating to look back at our long struggle to destigmatise mental illness and particularly schizophrenia, to find that bringing it out into the open, speaking about it, may simply have reinforced fears about the nature of schizophrenia rather than fostered a more accurate understanding of it.

Margie

So what needs to be done? What is a way forward? Perhaps a strategy for future “anti-stigma” campaigns is to focus strongly on the abilities and competencies of people with illnesses like schizophrenia.

And you, Sandy, are a superb example. During our long association, I have been aware of your admissions to hospital when the symptoms became overwhelming; I have admired your unremitting capacity to get going when you wake up every morning and have to come to terms with suicidal thoughts. You have a diabolical sense of humour and can make me laugh more than anyone else I know.

Although you suffer great distress from hallucinatory voices, you don't exhibit the chronic symptoms of schizophrenia. Every time you call yourself a madwoman, I want to loudly contradict you. Outwardly, to me, you are anything but mad. You are highly intelligent, well-read, perceptive and great fun. You are an accomplished author of a wonderful book on your experiences with mental illness and the psychiatric system; you have published volumes of poetry; you continue to lecture frequently at conferences, to students, and to community groups. And in spite of your constant struggle with schizophrenia, you are not bitter or angry.

However, as you have said, schizophrenia is as individuated as the minds it touches.

Sandy

Schizophrenia cannot be pigeonholed into one homogenised phenomenon. Each of us diagnosed with it experiences voices, hallucinations and delusions differently. The repertoire of the mad mind is breathtakingly broad, a product of the imagination, which is limitless.

Margie

This complexity is possibly one cause of people's confusion about schizophrenia; and one of the major reasons why overcoming the stigma associated with schizophrenia has so far defeated us.

The story of "Michael," who has one form of schizophrenia, provides an example. Listen to his mother, as we can only learn about his illness from her, because he does not see himself as mentally ill:

When Michael is becoming unwell, I observe confused, irrational thinking, paranoia – he believes that people are "out to get him." He believes the television is talking to him, and his phone is bugged. But he is adept at holding himself

together and appearing rational and in control when he is under threat of hospitalisation.

Michael has what is called “no insight” – an unwillingness to admit he has a mental illness. This is also referred to as “denial of illness,” and is perhaps the most troubling aspect of some forms of schizophrenia.

Recent studies link poor insight to some dysfunction in the frontal lobe. Although the notion of brain dysfunction may sound untreatable, it is actually grounds for renewed hope. Recent work on brain plasticity shows that rehabilitation is possible following many types of brain damage. Rehabilitation specialists are trained in cognitive remediation – the remedying of deficits in the capacity of knowing. Michael has never been offered cognitive remediation to help him develop awareness of his illness and learn new skills for active participation in his own treatment. Michael’s abilities – and he is a very intelligent young man – are not being developed because our system is not helping him in a way that could lead to his recovery.

Trying to reconcile the family’s story with that of the unwell patient creates distressing dilemmas for mental health staff. (Ever heard the expression “house devil, street angel”? Michael’s form of schizophrenia is like that, which is perhaps why the story of Dr Jekyll becomes confused with schizophrenia.)

But something is seriously wrong with our system if we wait until a disaster occurs before we insist someone receives treatment. Michael hates taking medication, which has bad side effects; and, after all, he does not feel ill. For him, being forced into medical treatment when he doesn’t see himself as sick is an injustice, and a denial of his human rights, his dignity. Yet there is no doubt that he is a very mentally unwell young man. The anxiety and stress experienced by his family and his girlfriend (who also has schizophrenia; he has no other friends) becomes intolerable.

A similar situation in Sydney recently ended in appalling tragedy, with the murder by Anthony Waterlow of his father and sister in 2009. The *Good Weekend* ran an article on the murders, “The Killer Inside,” with the introduction “Mental health protocols failed a family who, despite their fear, tried to support their loved one – a man whose final murderous act changed lives forever.”¹

Most notable in the stories of Michael and Anthony was their capacity to persuade mental health staff that they did not need, nor did they wish to take, medication. Even when staff know that medication will help, people cannot be forced to take it if they do not want to; it can only be made compulsory if they are deemed a danger to themselves or others.

But people like Michael and Anthony are not likely to tell you that they may harm someone. You can only discover this by talking to others who know them, and mental health staff often don't do this. Anthony's family were aware of how unwell he was, and close friends were also saying that Anthony would harm someone. He told them voices said his father and sister were conspiring against him. Ultimately he felt so threatened that he killed them. After being arrested and tried, Anthony was found not guilty by reason of mental illness.

Should people who are unable to recognise their mental incapacity be allowed to deteriorate mentally in the name of preserving their choice to decline medical treatment? In so doing, they often infringe the rights of others, particularly those closest to them who are trying to help them.

I know of situations where people have received treatment against their will after committing crimes (and some of these crimes could have been prevented had they received early intervention treatment). Their illnesses are now under control and they are leading useful lives in the community. So, although people with schizophrenia may have no understanding at the time that they are very unstable, they can be turned around.

Sadly, tragic stories like Anthony's colour perceptions of all those with schizophrenia, the majority of whom are not violent.

Medicalising schizophrenia: the good and the bad

Margie

The discovery of antipsychotic medications in the mid 1950s allowed people to leave hospital care when the acute episode of the illness had subsided. In later years, further advances were made in the development of long-acting antipsychotic medication.

In a survey in 1985, carried out by the Schizophrenia Fellowship of Victoria, of 191 people with diagnosed schizophrenia, half claimed to have no problems with their medication, which had allowed a "return to normal."²

But the other half complained of a range of side effects. These included Parkinsonian-type tremors, stiff walking, slurred speech, blurred vision, thirstiness and a dry mouth, eyes rolling back or becoming glazed, and having to pace up and down to relieve restlessness. Another major set of responses described a constant sensation of over-sedation, lethargy, an inability to get up in the morning, feelings of physical weakness, and a lack of stamina.

Sandy

Imagine feeling sedated to exhaustion and that your head is stuffed with cotton wool; your thoughts are slow and jumbled, you feel numb and unresponsive, your feet feel as though they are dragging a ball. Imagine being made to shuffle like a decrepit person, or your libido is dead and your mouth is so dry it's like sandpaper, or your hands tremble and constipation clogs you. This is how it feels for many when taking antipsychotic medication.

Margie

The survey of these 191 young adults with schizophrenia also asked them to describe just what their lives in the community

were like. The sample reported that disorders of emotion (depression and anxiety mainly) were still very troublesome; mental and psychological changes, and interpersonal behavioural problems interfered with their capacity to form close relationships; they felt the need to withdraw socially, which led to extreme loneliness. The majority had found it impossible to return to the workforce or to become involved with further education. Most were living at home with ageing parents, while others continually and fruitlessly sought alternative accommodation.

Most respondents experienced financial insecurity. They received the invalid pension or sickness benefit and were heavily dependent on and subsidised by their family carers. They did not participate in domestic, social or recreational activities to any significant extent. This was in spite of the benefits of medications.

Sandy

A recent government report, *People Living with Psychotic Illness 2010: Report on the Second Australian National Survey*, states rather glibly that the newer medications better control delusions and hallucinations, and people are hospitalised less frequently than when the first survey was conducted in 1998.³ But if this were true, why are the remainder of the findings so depressing? Far too many still experience unemployment, are on government benefits, are socially isolated and have to rely on families – the stories are the same as in earlier reports. For most, it is not so much the illness that bothers them as the unhappy social circumstances in which they are placed.

The earlier antipsychotic drugs were crude but the newer medications, heralded as wonder drugs to transform the lives of people with schizophrenia, have failed to live up to the hype. In my experience, what they do is flatten the illness into a chronic, low-level ongoing condition; they may reduce the florid blowouts but leave us with lethargy, withdrawal and social incapacity.

These newer medications result in higher than average rates of diabetes and obesity as well as other physical health issues such as asthma, circulatory conditions and respiratory problems. People living with psychosis are often heavy smokers and high users of alcohol and illicit drugs – most likely attributable to their ongoing difficulties in finding meaningful social roles. It is no surprise that those of us with schizophrenia die about twenty years younger on average than the general population.⁴

And, of course, the medicines are not curing schizophrenia.

Sadly, nothing much has changed in the lives of people living with a psychotic illness, since the first national report in 1998, or even since the report done by the Schizophrenia Fellowship in 1985.

And now, in the postmodern world of today

Sandy

In the 1960s and 1970s some theorists romanticised people who live with schizophrenia as being on an inner spiritual journey, finding meaning where the rest of society never could; or that this kind of madness was a sane response to a mad, rampantly capitalistic world. It was, for us “schizophrenics,” at least a richer kind of identity than one defined solely by our affliction.

Postmodern intellectuals are again raising the notion of schizophrenia as a metaphor for the fragmentation of culture – the struggle of the creative mad genius against an uncaring, ignorant society. And once-subordinate marginalised groups are again challenging dominant discourses. The mad are not only challenging the discourse of psychiatry but also seeking to have more equal say in their treatment. An example is the rise of the Hearing Voices Network and the Paranoia Network, whose members speak of themselves as “voice-hearers,” or “people living with unusual and compelling beliefs,” and prefer their experiences to be seen as “mental distress.” This is preferable to being classified

by that most stigmatising of psychiatric labels – “schizophrenia.” Part of this new approach is not to medicate the voices or the paranoid thoughts away, but to engage in a therapeutic relationship that helps those experiencing them to gain control over, and live more tolerably with these terrors.

My sense is that the rise of activist consumer organisations such as these is a response to psychiatry’s fierce promulgation of the medical model and over-reliance on medications. Many of us with conditions of “mental distress” would like to see mainstream practitioners consider more holistic approaches, and would like more opportunity to be partners in recovery rather than simply submitting to how others define and therefore treat us.

And what of the families?

Margie

In 1987 another survey carried out by the Schizophrenia Fellowship of Victoria asked 273 family members what their lives were like, now that they were caring for a family member with schizophrenia.⁵

They reported that medical staff did not give them information about the illness, let alone techniques for managing difficult behaviours. Obtaining help when it was needed was always difficult, leading to inordinate delays and often disaster. Emotional relationships with their unwell relative had markedly deteriorated. Attempts by the young person to leave home were frustrated by the lack of suitable supported accommodation facilities; most were unemployed. Many families struggled to meet the added financial burden of an adult relative. The caring role had also severely limited their social lives. And many reported that caring for their mentally ill relative had caused their own serious physical and emotional health problems.

In 2009 a survey by the Mental Health Council of Australia, *Adversity to Advocacy*, revealed fifteen key issues affecting mental

health carers.⁶ I felt angry and frustrated that the issues were the same as those found by the Schizophrenia Fellowship in 1987. The plethora of government reports, policies and strategies for mental health reform had not improved the experiences of mental health carers.

Social research carried out over the last thirty years in the United Kingdom and the United States has shown that astonishingly positive results can be achieved by bringing together those with a mental illness, family carers and clinicians to develop plans of action mutually agreed by all parties.

This working together continues over an extended period until effective communication and problem-solving techniques have been learned. The research results reveal a reduction in relapse rates through the earlier detection of symptoms and earlier treatment, a decrease in hospital admissions, better adherence to medication, and better co-ordination of treatment and care. There are trends towards improved social functioning, increased employment and involvement in community activities, and reduction in the burden and stress experienced by family carers.

Some of the studies have also reported significant decreases in the cost of treating the mental illness, and therefore significant savings for the mental health system.⁷

It is surprising, then, that these findings from social research are not generally well known, let alone implemented into routine mental health practice.

Sandy, somewhat pessimistically

So even though mental health is discussed more openly and widely than when we began the work of reform, and even though there are some positive research findings, the situation for many with the diagnosis of schizophrenia remains enigmatic. And as other mental health conditions become more visible, schizophrenia has retreated further into the shadows. One has to be

brave to say, “I have schizophrenia.” The label remains the one to fear the most, and the stigma is as powerful as ever.

What if the diagnosis of schizophrenia were to be dismissed and the label removed from the lexicon? How would I explain what has happened to me for these last thirty-eight years?

Some names have been proposed as alternatives to schizophrenia: for example, salience syndrome, psychosis susceptibility syndrome, psychotic spectrum disorder, and dysfunctional perception syndrome. Would changing the name of schizophrenia make a real difference to the lives of those who carry its label? The Japanese have adopted a new name for schizophrenia and, by all accounts, it has made a difference to the preparedness of people to seek treatment, because it has less stigma.

But changing the label doesn't change the behaviour associated with a psychotic illness – the bizarre and perplexing behaviour that makes people call us loonies, crazy, cut snakes, idiots. Will stigma only cease when a cure is found for schizophrenia and those who suffer it no longer do “mad” things in the public gaze?

Until a cure is found, or more effective medications are developed with fewer awful side effects, or society embraces people with “mental distress” as just one more different kind of human being equally deserving of respect and compassion, I cannot see us escaping our mind-prisons, or the constant struggle of living with this cruel monster of a diagnosis.

Margie, cautiously optimistic

We need to revive our efforts to bring schizophrenia out into the open. We need to do it with different tactics and renewed energy. We need to push for the improvements that the positive social research results have demonstrated: include families in treatment and care, help people return to work or study, provide appropriate accommodation – all aspects of meaningful living that are not adequately taken into account in either the

intellectual/cultural metaphor or the narrow medical model. With these changes, the illness could become much more tolerable for both sufferers and carers.

Sandy

But then, Margie does not have to fight daily with the monster.

Authors

Sandy Jeffs is a poet who has lived with schizophrenia since 1976. She has been a public face for this often misunderstood condition for many years. *Margaret Leggatt* is a sociologist and has been a mental health advocate since 1978. She has had a special interest in the needs of family carers, and has fought for many years to have families included in the treatment and care of their unwell family member.

Endnotes

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SCHIZOPHRENIA: A DIALOGUE ON PROGRESS

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