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There are calls to change the name "schizophrenia"

Here's why those touched by the illness agree

About one in 200 Australians have schizophrenia, a condition shrouded in stigma. Jo Buchanan, 74, tells Beverley Hadgraft how a name change could have helped her family

JO'S STORY

y sister, Christine, was the most beautiful artist and the kindest soul. She volunteered at a soup kitchen for the homeless, worked with animal charities and took people in who had nowhere to stay.

But sometimes she'd tell me the TV newsreader winked at her at the end of the news to let her know he was thinking about her. She also believed her paintings had religious connotations and had her son, Joel, up until midnight praying to them.

I lived next door and became worried. "Joel needs to go to bed," I'd say. "He has to get up for school in the morning." I couldn't think what was wrong until I read a book called The Schizophrenias, Yours & Mine. This is Christine, I thought. I tried to get help but it was the 1970s. I had to go over with a police officer and have her sectioned. It was heartbreaking but I was worried about my nephew.

Christine was put on medication but, back then, the doses were so heavy they turned her into a zombie and dulled her creativity so she couldn't paint. Not surprisingly, she stopped taking them, and the delusions returned. She thought she was the Virgin Mary. I went along with her but often became angry or nervous. That was silly and I'd never do it now – it was just ignorance on my behalf.

Christine continued going on and off her medication. It was hard for Joel. He sought solace in marijuana and, at 17, he was also diagnosed with schizophrenia. Drugs can trigger a genetic predisposition. Like his mum, he kept coming off his medication.

When he was ill, Joel heard voices. One told him that if he killed himself there would be world peace instantly. Joel believed the voices and laid down on a railway track. He was 19.

Christine died eight weeks later. Doctors said it was breast cancer, but she'd been in remission from that. I believe it was a broken heart.

STILL A FEARED DISEASE

It was a dreadful time, but I became avid in wanting to learn more about mental illness. It was now the late 1980s, but there was still a terrible stigma around it.

I studied to become a counsellor and ran workshops for other carers because they often suffered the stigma as much as loved ones.

As time has passed and treatments have improved, stigmas have lifted around many of those illnesses. Manic depression has been renamed bipolar, for instance, and admired household names from Stephen Fry to Andrew Johns have discussed their own battles. As a result, we've seen how mentally unwell people can operate and



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function well in society and we're no longer frightened of them.

However, the stigma hasn't lifted for schizophrenia. Many people still think it's the stuff of horror movies. When there's an inexplicable murder, irresponsible media reports often suggest the killer was driven by schizophrenia. "Schizo" is a term of abuse and carers tell me they're so afraid of being alienated, they pretend their loved one has depression rather than admit the truth.

This is sad because although schizophrenia sufferers today can't be cured, when they get their medication right, they can recover so no-one would know they were ill.

When I heard about the idea that [mental health organisation] SANE has to change the name [of schizophrenia], I was thrilled.

"Cognitive confusion disorder", for instance, sounds less threatening and is more insightful. Suffers would be more likely to get help, be less distressed at the diagnosis and also find it easier to connect with others.

This would be helpful as getting medication right can often take months and they'd have a cheer squad as well as living examples to encourage them to stick at it.

In the process, the public would no longer be misled into thinking schizophrenia turns people into Jekyll and Hyde characters with split personalities. They'd realise they have nothing to fear and that there are lots of creative, kind Christines out there.

People say, "Oh what's in a name?" but names are very important."



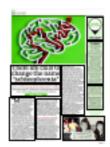
HOW CHANGE IS MAKING A POSITIVE DIFFERENCE OVERSEAS

Two countries have already implemented name changes to improve the stigma around schizophrenia. After being approached by families with and caring for mental illness, Japan changed the name from mind-split disease to integration disorder. Within only two years, psychiatrists said they were twice as likely to tell patients of their diagnosis - they'd felt too awkward before - while 86 per cent said they found it easier to talk to families, discuss the treatments available and get patients to consent and comply with that treatment. SANE's CEO Jack Heath points out that treating patients earlier is less expensive in both human and budgetary terms,

so everyone benefits. He favours the name used in South Korea, where it's changed to attunement disorder, which he says, "has within it the notion that things can be retuned, so it's much more positive".

WHAT YOU CAN DO

Contact SANE (sane.org) to register your support for a new name or to contribute to StigmaWatch, which encourages the public to report both inappropriate and praiseworthy depictions and reporting of mental illness.



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