

A personal story

Like Layers of an Onion

Rosada Simpson has lived with Schizophrenia for 13 years. Here she shares some diary-like thoughts about some of her journey. She wrote via email, "...feel free to share with whom you want to about me/my health issues. We can all help each other."

Cause of grief - chemical imbalance: schizophrenia.

Possibly schizo-effective (bi-polar) - so the mental health team ask virtually no questions. If it is done, or any confrontation, it has been rare.

A workshop - focused on my one instance of conflict I could think of - questions and a whiteboard.

Months at a time in hospital in the end. Looking within when very ill. Technically I'm still psychotic, as I've hallucinated voices for years. It's calming down very recently. It stresses.

Though no longer believing in voices, so now no longer delusional or paranoid. Useful labels, but at times only labels.

Family supports me by listening. When very ill I was not given bad words by family.

Isolation for years with little memory of everything I did.

Insight suddenly got me interested. In an instantaneous brain explosion, I accepted I had schizophrenia and that no one was possibly yelling abuse or picking on me. It opened my eyes and sound to a key to my future.

Though I don't like chewing on, stress about past, present and future - it is schizophrenia.

I push myself, so do my family and friends, acquaintances and medical people, to go forward and develop my skills, my character.

I hurt. I've felt love - a sort that defies hardship.

Respirodol injections have finally reduced voices further. I feel soaring and excited.

Tired - it could be medication. I've felt off-colour on and off for



Rosada (photo by Halimah Simpson)

months. With my insight I just have to patiently persevere and do what I can and use resources given to me at TAFE tutorial or a walk on the beach opposite my Department of Housing flat.

Ocean and blue sky, cafes - by Christmas I'll have changed and achieved.

12th June was the anniversary of my father's death.

I do art classes - I can express without words.

I love my diary. I hope my inner expression helps others.

Thankyou. Rosada



Mardijah Simpson

A mother's story

My middle child, Rosada, has schizophrenia—it first became apparent the year her father died. That was thirteen years ago. We have all learned a great deal since then; she, her brother and three sisters, all our extended family and myself. It has been a rough ride but we survive.

Nothing prepared us for this. It was not that I did not know about the condition—I had read Laing and later Anne Deveson's book about her son. Yet, at first, it did not seem particularly odd that this precious daughter kept quiet in her room and came out at night to sing in the shower. She worked and studied

hard, never drank or took drugs. We were all coming to terms with the loss of her father/my husband, grieving in our own ways and allowing each other space.

One weekend I realized she had gone too far into her own world; she was not sleeping at all and was telling

us all the most bizarre things. Against her will, with her sister's help, I got her to Emergency at the local hospital. As soon as I explained her problem to the duty sister she called the mental health team and then reality dawned and some treatment started—but there was no magic bullet.

During the first ten years she refused to believe she had anything wrong with her ... whilst I, believing in openness, would tell friends and acquaintances of her illness—and was surprised to learn from them, how many had family and friends with schizophrenia too.

I was thankful that my daughter was not a wanderer—I always knew where she was. When things got tough for her she would hole up in her flat. Also—thankfully over the years—she never lost her trust in me or her siblings.

I had a flash of understanding, after all the years of trusting 'the system'—I realized there were two problems: my daughter's health and 'the system' itself.

Everything changed about nine years ago. She only took medication as she was on a community treatment order (CTO). The interstate clinic treating her rang one day apologising that they had forgotten to make the six-monthly application to renew her CTO in time! It was allowed to lapse despite our best efforts.

Over the next six months everything changed: she refused all medication or visits to the clinic, her life got even more chaotic, no mental health workers checked up on her, she nearly got evicted from her flat and she refused to open the door to visiting family. Until one day, it was so bad her brave sister stormed into the clinic and demanded that help be given.

So the horror of scheduling, police coming with health staff and forcing her to hospital occurred. There she became a chain smoker. She was released twice—before the medication had taken affect—without any family members being informed, going back to a cold flat with nothing to eat in the fridge and virtually no money. Finally, she went into hospital for a third time and was given a bit more attention.

I had a flash of understanding, after all the years of trusting 'the system'—I realized there were two problems: my daughter's health and 'the system' itself. There was no coordination between the Departments of Social Security, Health or Housing and, certainly, despite being a large and caring family, we were not included.

We went into advocacy mode after all the years of respecting the professionals and not wishing to disempower my daughter/their sister.

Within days—and with her agreement—the Department of Housing (three years late) found her a beach-side apartment in a quiet block, her finances were put in the hands of the Guardianship Board, Centrelink muddles were sorted out and meetings with the chief doctor on the psych' ward occurred.

My daughter moved into her flat and settled in. Her medication was fine-tuned and supplemented until, to our total amazement, she finally had insight and acknowledged her health problems. She started to do things she had been unable to do for years: to get about and visit people, to go to fitness classes, to undertake TAFE courses (including claiming a training allowance and the right to have extra tutorial support!). She was placed in a sheltered workshop and paid peanuts—but managed to attend punctually and regularly. She gave up smoking all by herself in three weeks.

For two years she went to a pottery class and exhibited in the end-of-year shows. This year, she goes to a painting class each week and is rediscovering her talent for colour and design. She loves to walk on the beach and explore the parks and open spaces. She keeps a diary and sometimes writes poetry.

When I asked her if she would agree to me writing this piece—she said 'Yes'. When I suggested she could write something herself—she was happy to do so and she has.

Mardijah Simpson



There May Come a Time

Inspired by and dedicated to my teenage idol and favourite singer David Cassidy

There may come to one
a time still far from heaven,
when everything I have
will get tossed
into a wild storm.
And find,
that there are truths
in a deep thought,
that we can never go home again.
And still there,
for my first home town
ain't the same.
And on my last visit
I see the truth,
as I'll be the first to say,
never turn away
from who you call your own,
or the friends
life brought,
even for a small while.
Cos I'll be there again.
But to all dreams
that were tossed to the breeze
and I feel too, already,
so many I called 'friend',
have forgotten one
and any name.
But all I need
to see me through,
is you my maker
and love we share.
And that's all
I'll ever need,
to never say 'goodbye'.

Leo Welin

Schizophrenia Can Happen Anywhere, Anytime...

Overseas visitors share their story about schizophrenia

WE WERE visiting Alice Springs from Switzerland and staying with a friend who is involved with the mental health care system [MHACA committee member, Maya Cifali]. She asked whether we would share the story of our own experience to coincide with Schizophrenia Week [in May]. This is our story.

Our son, today aged 34, started at about the age of 27 to show a behaviour most confusing and unusual for a young adult already living independently, with part-time employment and studying at the same time, in the process of writing his final treatise.

The worrying and escalating symptoms we could observe went from an inability to keep his small apartment clean and tidy as it used to be, forgetfulness, giving away his job and studies and lack of personal hygiene, to losing all sense of reality, hallucinations and delirium, feelings of constant fear threat and persecution, withdrawal and isolation, people-phobia, and to violent aggression against people and things, such as deciding to change the place of the kitchen sink and pulling it out by mere force.

we held consultations with his psychiatrist, mental health nurse, social worker and got to accept that his condition was of schizophrenic type. He was fortunately cooperative and accepted to take regularly his medications.

However, more crises were occurring and his illness was becoming more difficult to control, as he had by then become addicted to continuous consumption of marijuana that he was smoking all day long. He was convinced that this was helping him to cope with his feelings, when in fact it was aggravating his mental condition.

For seven years we have managed alternating periods of crisis and normality. The greatest support we have received has been from an association for family and carers called Le Relais in Geneva, similar to Alice Springs' Mental Health Carers, where we are assured of complete confidentiality and can talk freely about our concerns with people affected similarly to us. No guilt and no shame. Don't be afraid to ask for help.

Most importantly, today, is our son's self-determination to give up all drug consumption and his decision to attend a rehabilitation centre. The path to recovery is long and difficult but we keep hope for permanent stabilisation.



Sandro and Anne-Marie, Geneva

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We later learnt that at about that time in his studies and under the stress of writing his thesis, he started using cannabis, first occasionally and then more and more regularly.

The behavioural change that we were progressively witnessing was most alarming and distressing to us as parents, as we could not understand what was happening to our boy and did not know how to react to it.

After a first voluntary admission to a mental health ward in Geneva,

Recently he has started a non-clinical long-term psychotherapy in order to find a path to re-integration into social living and eventually get a job. His friends and close family have never let him down—taking him for outings, helping with housework, making sure he was eating properly—but we all had to learn that we could not become obsessed with his condition and needed to allow for some objective external support so as not to become overwhelmed ourselves.

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