

# Coping with mental illness: a carer's perspective

MY FIRST experience in supporting a family member with a mental illness began almost three score and ten years ago ...

As a child living on a farm as part of a large family, it was an idyllic life...well, almost! There was freedom, fun, our own entertainment, and seemingly endless chores, and our parents were devoted role-models. They were also endowed with an immense capacity to cope with life - and us - through thick and thin, war and peace.

In the 1940s, my sister, who was four years older than me, and in her teens, developed epilepsy. Her unpredictable seizures were severe and frightening. Her disability shattered us all. It saddened me that she could no longer attend school. Instead she did correspondence lessons and was assisted by older siblings. Her social life was limited because of her condition.

Even more devastating to our family was the fact that she developed a mental condition, which in those days was commonly known as "nervous disposition" or "nerves". The treatment for "nerves" was to take a boat cruise around Spencer Gulf on either the *Moonta* or *Minnipa*.

## Feeling helpless

Recently my living siblings - now in their seventies and eighties - and I reflected on the impact our sister's disabilities had on each of us through out her life

(we took turns in supporting her).

Memories and emotions resurged as we recalled the past. We all reacted differently. We agreed however, that for 40 years the greatest frustration was not knowing what was best for her, or what to do, or how to help her. She passed away in her early sixties.

We were most grateful that our sister could experience quality time and live life more confidently for the last 20 years of her life. With great difficulty we found appropriate independent accommodation for her, in a senior village where she received 24-hour care.

Incidentally, the term "care" comes from the German word "kaross" meaning to grieve. There is, in varying degree, a sense of grieving in all caring - and guilt. We all grieved.

## A family of my own

I now move on to the 1970s. I'm happily married with a beautiful husband and kids. We were, I think, a normal fun-loving sharing family. All was going well. We were, however, concerned about our teenage daughter's subtle mood swings and often inappropriate and, at times, bizarre behaviour.

An academically bright student and vivacious - she still is - but at that time emotionally and mentally unstable. While my husband had very good rapport with young people, in the case of our own daughter we were baffled. Gravely concerned for her welfare and

our inability to cope we sought advice from numerous professionals.

We were told - that we were too strict, that we were the cause of the problem. Or, "she'll grow out of it", or "let go". When we reported her as a missing person, we were advised that, because she was of legal age, there was little that could be done. It was a very scary and worrying time for us.

## Trying to make sense of it all

For many months nothing made sense ... until we experienced a crisis. As a result our daughter was diagnosed with manic-depression (bi-polar).

On the one hand we were overwhelmed with relief at the news, knowing or thinking help was at hand. But we soon discovered that very little support was available for parents, and our daughter received band-aid care/support.

We were isolated more than ever before. So we read and read and read and re-read all the material we came across that would assist us in knowing more about mental illness and how to cope. Eventually our home became a mini-resource centre for other parents seeking help.

During these years of learning and upheaval, my husband became ill. We decided that from there on we would live life to the fullest and as normal as possible between his treatments.

Despite our daughter's illness we did this for 13 years until his death in 1990. I learnt so much from the holistic palliative care support received at home and in hospital and wondered why the same principles could not be applied in the area of mental health.

## More grief

Some months prior to my husband's death I observed our son retreating more and more to his room. He was depressed, and understandably so.

After his father's death my son moved interstate as planned earlier.

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Mine is not an isolated carer's story. Over the years I have met hundreds of carers rowing in the same boat, facing their personal tsunamis.

The depression resurfaced dramatically. He became quite unwell, fluctuating between depression, paranoia, suicidal thoughts, attempted suicide and schizophrenia. He missed his dad.

With great resistance my son was admitted to hospital for psychiatric help. His GP at that time recommended that he return to live with me.

After 12 months he was reasonably well enough to return to the workforce. He has struggled on for 15 years, frequently changing jobs and now evading the help he desperately needs in order to remain stable. He has again moved interstate. I know he is unwell. I am helpless as I wait for perhaps another crisis call.

## How do you cope?

Life is what happens when you least expect it. How do you cope? You soldier on, mate ...

After my husband's death I came to terms with my own grief, and soon adjusted to my new self-pronounced title: a freelancing widow on perpetual long-service leave.

There was no question of returning to my former teaching profession. Life was too unpredictable, as were the illnesses of my two children.

For 10 years I became involved in volunteering: my passions were palliative care and mental health. With another carer we began a Carer Support Group,

and at the drop of a hat I travelled.

These were trips with a difference - I experienced the mental health system in a number of different States. More often than not it was recommended that if one of my children required close monitoring, they should return home and stay with me - the reason being, "because our State is in a bad way, we do not have a support system".

My rescue or mercy trips included at least ten interstate ventures and two overseas. That was in the 1990s.

Five years ago I moved to Alice Springs, all in the name of care. I am eternally grateful for the amount of support and encouragement that is available for carers right here at our doorstep.

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As Dr Trevor Cook (a behavioural educationist and professor in the Faculty of Health Sciences, University of Sydney) recognises :

"Family carers do not usually take on this role by choice. We continue to hope that our relative with a mental illness will recover or improve. Carers become trapped - financially, mentally, physically, emotionally, socially, and spiritually over a very long time.

All family relationships are affected. Employment for carers is affected. The effects on carers health are certainly negative - caring is a stressful load. Carers can be stretched to the limit, often with little previous experience when dealing with the chaos for the person with a mental illness. And then they still face the question: What happens when I die?"

We live in hope for a brighter future - here in Alice Springs. ✕

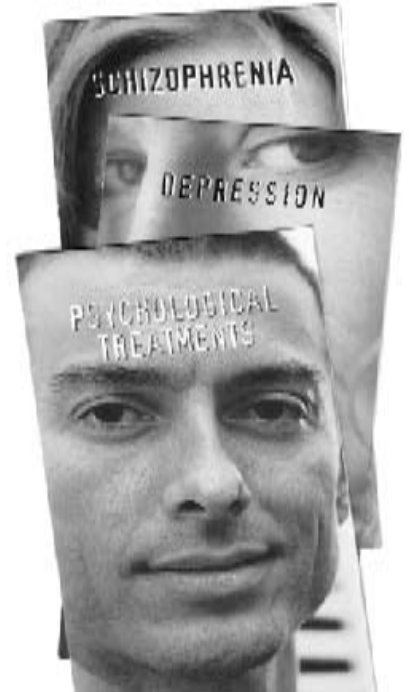
(Name withheld out of respect for family)

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is a national charity working for a better life for Australians

affected by mental illness and has a wide range of resources available. Call the SANE Helpline on:

**1800 688 382**



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\*Charges apply for calls from mobile phones, consult your service provider.



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