

LIVING ON THE EDGE WHEN YOUR BROTHER HAS SCHIZOPHRENIA

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ABSTRACT

Few studies have addressed the impact of a mentally ill brother or sister on siblings. Yet over time, adult siblings often assume increasing responsibilities, both for their ageing parents and for their mentally ill sibling. This often causes great concern for siblings and may cause considerable conflict within the family.

For many siblings the impact of having a sibling with a mental illness can be life-long. It is critical that we understand the impact on a young sibling's psychological development and how attitudes developed in these formative years influence their adult lives. Many aspects of sibling adult lives may be affected including relationships, career, having children, and where to live.

Supporting siblings from an early age with age appropriate information, emotional support, peer support and the development of life skills increases their level of resilience. However it is important that developing resiliency is not seen as the ultimate outcome, in isolation from attaining quality of life.

Many young adult siblings could be described as being resilient, yet they would not necessarily describe themselves as being happy or fulfilled. Working through a healing process for these young adults and their families can greatly improve outcomes for all concerned.

This paper will encompass the speaker's personal experience as a sibling and her professional experience working with young carers and adult carers for many years.

INTRODUCTION

I awoke startled by the sound of a ringing telephone. "Are you sitting down? Is anyone else with you?" words uttered by my mother at the other end of the phone. It was 7.30am on 30 July 1989 – I was waking up in London while Mum & Dad were coming to the end of a shattering day in New Zealand. The next words that followed were, "Glen is dead."

Suddenly my head went into a spin, questions flowed, tears streamed down my face – I couldn't believe what I had just heard. My 24 year old brother was dead, I was on the other side of the world and suddenly I just didn't know what to do.

I had left home five months earlier under very difficult circumstances and was going through a very lonely and emotional time in London. I was now faced with making a decision about going home, although Mum and Dad certainly weren't pressuring me to do this. I felt a tremendous sense of being torn apart – I wanted to go home "to see if this was real", be there for the funeral, support Mum & Dad, and to have support for myself from family and friends. Yet, I knew deep down I couldn't go home, now.

Glen was 18 months older than I was and we had never been close. He struggled with epilepsy and paranoid schizophrenia from childhood so our family life had been extremely disruptive for as long as I could remember. His death began a new stage in my life cycle.

What are some of the common impacts experienced by siblings?

It is important to note that each person's experience is different. Many factors will determine the impact on a sibling, including the following:

- your age and your siblings age at the time of illness on-set
- the quality of your relationship prior to illness on-set
- how the entire family responds to the situation
- your own ability to cope with challenging situations
- previous life experience
- the quality of mental health care provided for your sibling and family

It is critical that we understand the impact on very young sibling's. The first seven years of a child's psychological development are critical. The stages of self-development (Hendrix 1992) help a child develop emotional security, intact curiosity, a secure sense of self and a sense of power to achieve. It is important that we are aware of the long-term impact on this development, when a young person is living with a sibling who has a mental illness.

The attitudes developed in these formative years influence the next stage of the journey, that is, the ability to relate with others.

When there has been little or no education about the illness and no support for the developing child, the likely consequences are that the child will have great difficulty with developing a 'healthy' concern for others, coping with intimacy and developing a responsibility to themselves and society.

The following points summarise some of the information we do know about the impact on siblings:

- Few studies have addressed the impact of a mentally ill brother or sister on siblings. Yet over time, adult siblings often assume increasing responsibilities, both for their aging parents and for their mentally ill sibling. This often causes great concern for siblings and may cause considerable conflict within the family.
- Siblings are not generally considered, even though clinical and lay literatures emphasise the confusion, disruption and grief sibling's experience when there is mental illness in the home.
- How a sibling experiences living with, and their understanding of mental illness, is important because this can affect approaches to caring for the illness and thus can impact on illness outcome.
- Recognition of a sibling's mental illness can be a bewildering and frightening experience.
- Everyone in the family is focused on the ill sibling; no one lives their own life.
- A sibling's mental illness could be described as a 'cloud over your life'. You're never totally exuberant ... you always have a little bit of a heavy heart'.
- Studies have shown that families coping best with mental illness have some kind of acceptance. An important factor in being able to attain some kind of acceptance is the amount of emotional support they are given – siblings need emotional support as much as their parents.
- There is a need for somebody that really listens to you and can share your experiences and concerns.

- Siblings and adult children often report that their relative's illness has had an impact on their educational experiences and career plans. Possible consequences include poor school performance due to preoccupation with problems at home, super achievement at the expense of personal life, altered educational and career plans and a sense of unfulfilled potential.
- As a result of their experiences with mental illness, siblings and adult children report an enormous personal legacy that permeates their adult lives. Specific issues may include concerns about identity (eg. an impaired sense of self); fear of becoming mentally ill themselves; poor self-esteem and self-confidence; risk of emotional anaesthesia (numbing) and anhedonia (inability to experience pleasure); excessive need for perfectionism and control; 'replacement child syndrome' (the need to compensate parents for the ill sibling); and personal mental health problems, such as depression.
- Difficulties may be experienced in relationships. These include problems with peers, poor social skills, social alienation and isolation, fear of rejection, and excessive concern with pleasing others. Not surprisingly, this interpersonal legacy often undermines intimate relationships. Potential risks include an inability to trust, avoidance of intimacy, ambivalent and conflicted relationships, difficulty making a commitment, emotional paralysis, inappropriate continuation of the caregiver role in adult relationships and sexual dysfunction.

The following example from Julie Tallard Johnson's work highlights the plight of adult siblings.

"My brother Steve has a schizo-affective disorder which is presently controlled by medication. He's been stable for a few months, the longest since his first psychotic break eleven years ago. But it's the future I'm concerned about. Who will care for Steve when my parents no longer can? I'm in my final year of college, and I want to move away and start a life of my own. But I feel awful leaving Steve with my parents. One time, he threatened to burn the house down when they asked him to move out. So, out of fear, my parents let Steve live with them. They are also afraid he will just end up on the streets if they make him move out.

My other brother lives in another state and has no contact with the family. He's a successful attorney and claims he has no time for Steve's problems. Either I take care of Steve or he will end up in some state institution or on the streets. And I can't live with that either. I wish my parents would get Steve out of the house and into treatment. Maybe then the future for him – and me – wouldn't look so gloomy".

Themes emerging from Carers NSW mental health project sibling focus group

Deanna Pagnini, external consultant for Carers NSW, has been working on a Carer Cycle Framework which has involved conducting focus groups with various carer populations. Deanna conducted a focus group with siblings and the following are the major themes that emerged:

- The impact of having a sibling with a mental illness is **life-long** – and affects numerous aspects of adult lives including relationships, decisions about where to live, work, and the future. For example, a number of siblings moved out of their family home earlier than they would have because of the ill sibling.
- Siblings spend a great deal of time worrying about their parents, and often try to protect them.
- Anger, grief, and loss are some of the emotions that siblings would like to be able to work through.
- There is often tension **between** well siblings as they deal with the illness in different ways.
- Hurt, anger, and frustration at their parents for having (understandably) focused on the sibling with the mental illness – they recognise why their parents did it, but felt that there was nothing left for them.
- Ongoing peer support emerged as the number one need, rather than information.

- The importance that the Carer Education & Training Programs, (14 Principles of Coping, Seasons for Growth, and 8 Stage Healing Process) provided by Carers NSW Mental Health Project, played for the siblings who participated, and for their parents who participated. They stated how much their lives improved after their parents did the courses.

What are some strategies for improving outcomes for siblings?

Within the mental health arena, developing resiliency is identified as a protective factor for children at risk of developing mental health problems. Resilience is described as follows (Australian Infant Child Adolescent & Family Mental Health Association 2004), *'Capacities within a person that promote positive outcomes, such as mental health and wellbeing, and provide protection from factors that might otherwise place the person at risk of adverse health outcomes. Factors that contribute to resilience include personal coping skills and strategies for dealing with adversity, such as problem-solving, good communication and social skills, optimistic thinking and help-seeking'*.

Supporting siblings from an early age with age appropriate information, emotional support, peer support and the development of life skills increases their level of resilience. However it is important that developing resiliency is not seen as the ultimate outcome, in isolation from attaining quality of life.

Many young adult siblings could be described as being resilient, yet they would not necessarily describe themselves as being happy or fulfilled. Working through a healing process for these young adults and their families can greatly improve outcomes for all concerned.

After many years of experience and rigorous program evaluation, we know that the following programs offer appropriate and suitable support for siblings who have a mentally ill brother or sister:

- Carers NSW Young Carer Project (Includes Young Carer Camps & Talk-link Programs). For further information phone 1800 242 636 or email yc@carersnsw.asn.au or visit www.carersnsw.asn.au (see young carer project)
- SMILES (Simplifying Mental Illness + Life Enhancement Skills) Program for children and young people who have a mother, father, brother or sister experiencing a mental health problem. For further information contact Erica on (02) 6360 7890 or email ericap@ix.net.au or erica@carersnsw.asn.au or visit www.carersnsw.asn.au (see mental health project).
- Eight-Stage Healing Process (for adult siblings). For further information contact Erica on (02) 6360 7890 or email erica@carersnsw.asn.au or visit www.carersnsw.asn.au (see mental health project).

CONCLUSION

I didn't return to New Zealand for Glen's funeral and for weeks I experienced feelings of anger, hurt, resentment, guilt, sadness, sometimes all within the space of a few moments. When I read and heard the things that people said about Glen, I realised there was a side to my brother that we had never known or seen. Despite his anguished mental state, in his own way he had actually touched and changed the lives of many people.

Glen's death started a whole new journey for me and allowed me to finally start my own healing process – a process that is on going, at times painful, yet always worthwhile. Glen's life and death have had a tremendous impact on my life and this has given me new meaning to my life. I know that Glen came into, and left my life, to provide me with the necessary experiences so that I can now make a difference in the lives of family members living with someone experiencing a mental illness.

'Life can make choices for us. Sometimes these choices seem unhappy or unfair, but in the end we control our own destiny because we can decide how people and events affect us.'

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