

THE DEVASTATING IMPACT ON SIBLINGS & CHILDREN AFFECTED BY MENTAL ILLNESS IN THE FAMILY

Erica Pitman-Smith, ARAFMI Group Development Officer
Rural Mental Health Conference, Broken Hill, March 1997

INTRODUCTION

It's 1 o'clock in the morning. An ambulance pulls into your driveway. There's total chaos in your home - your mother is crying hysterically and your father is trying to keep things under control. You are eight years old and your ten year old brother is going crazy. As the ambulance takes your brother to hospital, a deathly silence falls on your home. No one is communicating any more. You are left totally confused and frightened about what has just taken place.

What are we doing today for the siblings and children who find themselves in this or a similar situation?

My name is Erica Pitman-Smith. My involvement with the Schizophrenia Fellowship began in 1990 in NZ and now in Sydney, with sibling education and support. My only sibling suffered from epilepsy and paranoid schizophrenia from childhood until his death in 1989, at the age of 24. I've completed two years of study at the Australian College of Applied Psychology in Sydney and currently work as the NSW Group Development Officer for ARAFMI.

The topic of children affected by mental illness in the family has become much talked about. Often discussions revolve around the roles children assume within the family, however do we really understand the tremendous impact mental illness has on these children in their adult lives?

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 relative 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 the family has had 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 concern for others, coping with intimacy and developing a responsibility to themselves and society.

That's as technical as I'm going to be today. What I've decided to do is give you some brief examples of real situations and the impact on the siblings or children concerned. Finally I will talk about how we can work together toward healing and prevention.

CASE EXAMPLES

* Siblings and children often comment on their difficulty to communicate what they need. It is not unusual for them not to know what they want, or need and very often they don't know how to ask for what they want. In my own situation I was 16 years old before I finally began to talk with anyone about what was happening in my life. The only reason I finally realised I had to talk to someone was simply because my physical health was suffering so badly.

I suffered constant migraine headaches, irritable bowel syndrome and had major surgery during High School.

Somehow I learnt that the only way to get attention was to get sick. That's an unconscious pattern that is taking a long time to 'unwire'. On a logical level I don't think this way any more, however my body is so programmed to this, it takes hard work to re-wire it.

I remember very clearly wanting to die at the age of 16 years. I can recall two occasions when I drove my mother's car around a particular intersection, where it was difficult to see on-coming traffic, hoping I would be hit. It didn't happen.

I worked on a milk truck, on the dangerous side jumping into the line of traffic and can vividly remember a number of occasions jumping off the truck in the dark, hoping a car would hit me. It didn't happen.

My point is: if a young person is presenting to a health professional with physical conditions that don't seem to have any particular cause, PLEASE ask what is happening emotionally for them. This is particularly important when statistics indicate that approximately 24% of young people who attempt suicide visit their GP the week prior (Cerexhe 1996).

* A young female aged 23 came to a sibling education programme. Her mother, brother and sister all had some form of mental illness, she was in remission herself from leukemia and her father drank heavily as this was the only way he knew how to deal with the family situation.

After a few weeks of education about mental illness and what could be done for her family she took action and instigated some very positive changes for her family.

She is now 26 and has left her home country. She hasn't spoken to her father for over a year as she is so angry with him for his lack of support. However, deep down, she is really hurting. The healing process is going to take sometime for this family.

At the on-set of mental illness, families need guidance, direction and support from professionals. No-one can possibly be equipped to handle the stress that mental illness places on the family, however with the right help initially, most families have the ability to adjust and cope effectively.

This young woman now has a great deal of difficulty trusting anyone and feels an enormous sense of lost opportunity in her life. When I asked her what would have helped when she was younger, she replied, "if only someone had explained what was happening."

* I was talking with a 33 year old female last week whose mother has had a mental illness for approximately 15 years. For the last month her mother has been quite well so this young woman suddenly finds that she is not quite sure what her role is right now, since her mother doesn't 'need' her. Consequently she was feeling rather depressed herself so she went to her GP for some help.

The result was, she was referred to a psychiatrist, diagnosed and prescribed with medication. She came away feeling much worse. Now perhaps the medication may have been helpful for a short while, however what she needed was some counselling. She needed someone to validate her feelings and explain that it was perfectly normal for her to be feeling the way she was considering her circumstances. Once this had happened, she was able to start looking at how she could work through her feelings of depression and also how she could manage this situation more effectively in the future.

* Sexual abuse is an area that is not uncommon in families affected by mental illness, however it is not often talked about. I'm reminded of the words of a song, "looking for love in all the wrong places." This was certainly true in my own situation. I went outside my family to find some love and comfort from a couple who were like my 'second' parents - unfortunately I was taken advantage of for ten years. Had we been able to communicate effectively as a family, this would not have occurred.

I was a 'buddy' for an eight year old girl who had a 12 year old brother with schizophrenia. He had sexually abused her and she was a very withdrawn child. It took almost a year of spending time with her once a month before she was really able to even talk very much at all. The consequences for her in later years are likely to be enormous.

Mental illness impacts heavily on every member of the family. It is important that the well-being of every family member is taken into account.

* Two males in their early 30's have a mother who has been mentally ill since before the boys were born. Their father doesn't have a diagnosed mental illness, however they feel he also has problems. These boys have had no significant role models in their life, not even to explain to them about simple things like wearing deodorant once adolescent changes take place. They suffered tremendous humiliation over something that is generally taken for granted by most of the population.

One of the boys mentioned recently that he has never had a close relationship with anyone, not even a friend; he's never really had a job and he suffers from depression himself.

It is vitally important that families, health professionals, etc. be aware that all family members are profoundly affected by mental illness in the family.

* When speaking with a mother recently, she told me she had just learnt that her 25 year old daughter had made the decision not to have children. Her brother has schizophrenia and she just wasn't prepared to take the risk for fear that her own child may become mentally ill. This is something that all siblings and children are concerned about at some stage in their life. Education and discussion about this is very important for them so they can make informed decisions in this area of their life.

* Ken Alexander (1995) talks about loss being at the very heart of all that has happened to us as relatives of someone with mental illness. The loss we suffered when mental illness so changed someone dear to us that we feel the person we used to know, and love, no longer exists. For others there is the sense of loss for what we never had, eg. the loss of our childhood or the loss of a parent, even though they are still physically present.

We grieve for what we have lost, however many of us do not even realise that we are grieving, and without that insight, some of us may never cope with our loss. We need to know about grief work and understand what it is we can do to help ourselves move to a place of acceptance.

The tremendous impact of these losses was reinforced recently while I was working with two young women, both 30 years old. Their mothers have suffered from mental illness since before the girls were born. They are now working through their own healing process and are going through so much pain trying to accept that they never did have and never will have the mother they needed.

* It is a sad situation that many siblings and children finally seek help when they are in their 20-30's because their life is terrible, relationships aren't working, they are depressed and don't know why, they fear becoming mentally ill themselves, and in some cases are concerned about who is going to take care of their mentally ill relative?

So what can we do to address this situation?

WORKING TOGETHER

Our children/siblings are already secondary if not primary carers and also have the potential to become consumers. It is therefore vitally important that we address the issues they face as early as possible.

The NSW Centre for Mental Health draft policy statement entitled "Caring for Mental Health" states that two of the general goals are:

To improve the mental health and well-being of the people of NSW.

To prevent the development of mental health problems and mental disorders, whenever possible.

It also mentions that children and adolescents are a priority population.

I see that there are two areas that we need to concentrate on:

- Healing for the young adults who have already been seriously affected by mental illness in their family.

- Prevention and minimization of the affects on young children.

The following points will assist with working toward these goals:

- Young people need education, information and coping strategies to assist with managing the impact of mental illness.

- Young people need understanding people to talk with, who will listen to their feelings, help with their concerns, provide them with support and guidance.

- Health professionals need to enquire about other family members. Treatment should include providing advice and referral information for all family members to have their needs met.

- There needs to be a much closer working relationship between health professionals and Non-Government Organisations to best utilise appropriate education and support programmes.

- Non-Government Organisations experience difficulty in accessing young people. Assistance from health professionals and schools by way of referral would ensure young people are aware of what options are available to them.

- Non-Government Organisations need to nurture and develop young people in the 20-30 year old age group who have already worked through their own healing process, so that they are able to facilitate groups for their peers and younger children.

- "Buddy systems" could be organised so that older children/siblings are available to support younger children/siblings.

- Let's work toward helping these young adults use their experiences positively for the benefit of our future population.

- Just as we expect health professionals to be accountable, so too should Non-Government Organisations. There's nothing worse as a professional to make a referral for a client, only to find that they had a bad experience. Feedback is vital to ensure that we are providing the best possible assistance, therefore we should welcome dialogue between each other so that we truly are working together for the highest good of all concerned.

REFERENCES

Alexander, K. (1995). Schizophrenia: Teaching Relatives The 14 Principles Of Coping. Schizophrenia Fellowship of Victoria, Inc.

Cerexhe, P. (1996). Suicide Scourge of Young People. Reader's Digest, August 1996, 15-19.

Hendrix, H. (1992). Keeping The Love You Find - A Guide for Singles. New York, Pocket Books.

YOUNG ARAFMI

Are you a son, daughter, brother or sister of someone affected by a mental illness?

Perhaps there are times when you experience feelings of anger, shame, guilt, fear, confusion, anxiety, frustration or jealousy. These are all normal emotions for young people to experience when living with mental illness in the family.

YOUNG ARAFMI provides you with an opportunity to talk with and listen to other young people who are in a similar situation.

It is a great relief to discover that you are not the only person in the world to have a relative suffering with a mental illness. Merely talking helps. You can even have a chuckle over something you were crying about yesterday.

When are the meetings?

We meet on the last Saturday of every month from 10.30 am - 12.30 pm, followed by lunch at a local cafe. For more information, please phone ~~Erica~~, 9887- 5897 (w), ~~Wed - Fri~~.

Where are the meetings?

ARAFMI Head Office, Block C, Macquarie Hospital, 47-49 Wicks Road, North Ryde.

ARAFMI
Association of Relatives and Friends
of the Mentally Ill, NSW Inc.
Block C, Macquarie Hospital
47-49 Wicks Road, North Ryde, NSW 2113
(P O Box 302, North Ryde, NSW 2113)

Phone: (02) 9887 5897 Admin
Fax: (02) 9887 5766

24 Hour Helpline
Ph: (02) 9805 1883
FREECALL 1800 655 198 (rural NSW)