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Looking Back: Support Groups for People with Mood Disorders

When I started a mood disorder support group twenty years ago I didn't really think it would be going today. The group started after PALA, a group in the eastern suburbs ran a Festival of Madness to promote critical analysis of mental health care. I talked about my experience of bipolar disorder (then known as manic depressive illness) to about thirty people. A number of people expressed interest in continuing to meet and so the group began as an informal get together in my home.

When the group began I had in mind a six-session experience more or less like a therapy group and never envisaged that the group would continue and grow. The group did continue to grow and outgrew my living room so we moved to the social work meeting room at Gladesville Hospital and eventually to Friendship House at the NSW Association for Mental Health. More groups were set up by people who wanted a local group or a different focus for the group. At the present time there are over 300 names on the mailing list and about sixty people regularly meet in different locations.

Individual initiatives don't usually continue unless there are other people seeking to change things in the same direction and they link into a broader social movement. Support groups for people with mood disorder began to be set up at the end of the 1970s. This probably says something about the availability of effective medication for people with mood disorders. By the mid 1970s more drugs were available to treat mood disorder and lithium was well established as a prophylactic drug. As people recovered from long periods of serious mood disorder and stabilised on lithium, they began to meet with others who has had also survived long periods of mania or depressive illness.

But the spread of support groups for people with mood disorders went beyond support for people living with manic depressive illness. At the time I started the mood disorder group in Leichhardt in 1982 there were a number of social action groups beginning to look at the poor state of mental health services and the limitations of the NSW 1958 Mental Health Act. Magistrates visiting psychiatric centres were unhappy with the poor documentation and lack of medical support for the long periods of detention being asked for by medical staff for people who were brought before them. Civil rights groups were protesting the lack of any legal advocacy for people detained in psychiatric institutions and scandals such as the treatment of patients in the Chelmsford Private Hospital[i] and Ward 10B at Townsville Hospital focussed public attention on the plight of people with mental illness and the vulnerability of people with mental illness to unethical, negligent or inadequate medical treatment. Discrimination against people with mental illness was not covered in state or federal antidiscrimination laws. While employment rehabilitation services had been put in place for people with other disabilities, these services did not exist for people returning to work or study after an episode of mental ill health.

Just a better class of drug?

Manic depressive illness, or, as it is currently known, bipolar disorder, was one of the first of the serious mental illnesses to be effectively treated with drugs. People with bipolar disorder need to take a range of drugs to control and manage symptoms of mania or depression and to prevent future episodes of ill health. Twenty years ago, bipolar disorder was treatable to some extent with a range of drugs. Unfortunately for about thirty percent of people diagnosed with bipolar disorder, the available drugs didn't prevent future episodes of serious mood disorder or had such severe side effects that they were difficult to take for long periods of time[ii]. An increased range of drugs that are effective in all phases of mood disorder has meant shorter periods of illness for some of us, prevention of prolonged severe episodes of mood disorder and increased quality of life.

There is no question that drugs which modify symptoms of mood disorder are essential for successfully living with bipolar illness. But while the range of drugs has increased, there are still some factors that prevent effective drugs from being used to the most benefit.

Access to available, affordable and appropriate health care

By 1993, the United States Depression and Manic Depressive Association had surveyed its members and found that although medication was available to effectively treat episodes of mania and depressive illness and to prevent future episodes, many of their members could not afford the cost of health care or the cost of the drugs needed to maintain their health[iii]. At the same time the Australian Human Rights and Equal Opportunity Commission was carrying out an inquiry into the rights of people with mental illness in Australia and coming up with similar disturbing findings. Although medical science had effective treatments for many mental health problems, many people with mental illness were living in poverty, were homeless, or subject to abuse and exploitation and unable to advocate on their own behalf.[iv] Clearly, medication and medical treatment were not the only issues facing people living with mood disorders.

Training of general practitioners and other health workers

For most people, particularly in country areas, the most accessible health care provider is the local general practitioner. Training of general practitioners in the use of drugs used to treat psychiatric conditions has been given a boost by recent Commonwealth government funding programs to support and train general practitioners in regional Australia. But much information about drugs is still provided by the drug companies. Individual consumers who have access to the internet can find some information about drugs but are still dependent on available medical practitioners to prescribe medication.

Counsellors are often reluctant to work with people who are taking medication for psychiatric conditions because they don't understand the purpose or effects of much medication that is prescribed. Clients may find themselves educating the counsellor about the drugs used to treat their mental health problem.

Current issues facing people living with bipolar disorder

The tone of support groups has changed from the early eighties when the predominant theme in support groups was outrage at the poor quality of mental health services and the trauma of involuntary hospitalisation. People are getting

diagnosed earlier and there are better community mental health services that have substantially reduced the need for long periods of involuntary hospital care.

Better medical treatment and shorter episodes has meant that more people with bipolar disorder are successfully employed. Their presence in the workplace is promoting the changing of attitudes towards workers who have bipolar disorder or other mental health problems. Themes in support group discussions have changed from total focus on medical care and psychiatric hospital issues to a broader based discussion about returning to work, whether or not to disclose at work and how to deal with relationships.

There are still some significant gaps however for people living with bipolar disorder. There is a need for better information about drugs used to treat mood disorder that is independent of drug company information. There is a need for more diverse support for people newly diagnosed with mood disorder and who are coming to terms with living with bipolar mood disorder. After management of medication, many people want access to counselling: common themes are working through the issues of living with mental illness; understanding the symptoms of mood disorder, understanding the changes in thinking that accompany mood disorder and working on relationships often damaged by untreated episodes of mood disorder.

Living with mood disorder - What's changed from the 1980s?

In 1982 when the first support group for people with mood disorder started in Leichhardt there were a number of issues facing people diagnosed with bipolar disorder. Medical treatment was mainly focussed on medication and compliance with medication. The range of medications more limited - many people found side effects of medication worse than the symptoms of the mood swings the medication was meant to control. Counselling was not seen as appropriate and was often limited to paid private counselling. Mental illness was not covered by antidiscrimination legislation at either state or federal level.

Some of this has changed. The challenges faced by people living with mood disorder today are broader with employment and quality relationships as key issues for many people. Medication has improved dramatically although cost and access to the most recently introduced drugs is an issue for many people. Community ignorance about mental illness remains a key factor for many people living with mood disorder who must still explain to friends, workmates and family what they experience and how it is treated. Community education remains a challenge in the years to come.

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[i] The final report of the Royal Commission Report into the former Chelmsford Private Hospital was released in December 1990. Dr Harry Bailey's practice of deep sleep sedation at Chelmsford had been of concern since a number of patients died during the 1970s. Following legal action and media coverage of the practices at Chelmsford, Bailey suicided in 1985.

[ii] (Goodwin, F. and Jamison, K. *Manic depressive illness.* Oxford University Press, New York, 1990.

[iii] Depression and Mood Disorders Association *Bipolar disorder: portrait of an illness* American Psychiatric Symposium, 1993.

[iv] Human Rights and Equal Opportunity Commission Human Rights and Mental Illness: report of the National Inquiry into the Human Rights of People with Mental Illness. Australian Government Publishing Service, Canberra, 1993.