A Carer’s Perspective: The View from Australia

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I am a carer of a relative with schizophrenia, who was born in 1975, diagnosed and hospitalized in 1994, and referred to here as “M.”

I have a doctorate in anthropology and have read extensively on psychiatry and have found the Schizophrenia Bulletin particularly valuable, particularly the “First Person’s Account” feature, which commenced in 1979, as enabling a nonsufferer to understand the experience of a major psychiatric illness.

Ten Strategies

From our own observations and extensive reading, we identified 10 strategies that we found particularly helpful for a person suffering:

1. Accept you have a disability.
2. Take appropriate medication.
3. Exercise regularly: walking, jogging, cycling, or swimming.
   (a) Get a trainer or join a gym if possible.
4. Access social support such as regular weekly church or religious worship.
   (a) Discuss values and a system of belief and meaning, such as in a church or religious group.
5. Arrange appropriate supported housing with 1 or 2 other people.
7. Have a pet, and if you can have a dog, walk it daily once or twice.
8. Undertake training or educational projects, such as music lessons.
9. Access part-time voluntary employment if possible.
10. Access part-time paid employment if possible.

However, the principle of a founding father of medicine, Galen who lived from 131 to 201 AD, still holds: he used empirical evidence to find what works best for a given patient and modifies this to help healing.

M’s Experience

M passed secondary school at 18 years of age with a B—average before becoming ill. Many years later, we learnt that one of his grandmother’s 8 siblings almost certainly had the same illness. Even today M does not understand why he had the misfortune to become a person suffering from this illness.

M also experienced neuroleptic malignancy syndrome from having a 1-month injection of stelazine injected as an outpatient at Canberra Hospital in 1994 and therefore needing treatment in intensive care for 10 days with a high risk of death.

Upon his discharge from hospital in 1994, M then spent 1 year in a supported State hostel that has since been demolished, but we found it most helpful. He then lived in a Richmond Fellowship house for 1 year, with some 5 housemates who all were suffering from a severe mental illness and who had support from sensitive and knowledgeable carers. The program required all patients to leave after 1 year.

M has been taking 600 mg clozapine and 400 mg amilsupride, and 10 mg escitalopram with slight variations to the amounts, since 1994. He is extremely conscientious in adhering to prescribed medication and avoids all alcohol and illegal drugs and does not smoke.

We live in Canberra, Australia’s capital, and assistance was limited. From 1996 until 2005, M lived in a 3-bedroom government flat with 2 people more disabled than himself. For 3 of those years, he was able to obtain landscaping work in a government run program for 3 hours per week. (About one-quarter of all disability support pensioners in Australia have a mental illness. There are a total of 825 000 Australians aged 18–65 on the disability support pension [ABC News, April 13, 2013]. Only 9% of them access 1 hour or more paid work each week [Productivity Commission The Disability Support Pension 2010. Appendix K. www.pc.gov.au].)

There was 1 person called a “caseworker” who worked part-time and attended to some 30 clients. Apart from the welcome employment assistance, other assistance or rehabilitation was severely limited. Case studies of M, Australia’s famous cellist David Pereira, and a person suffering from a severe mental illness in Victoria, Australia and how practical support can be accessed are contained in the book Odysseus’ Labours, which I wrote with...

We found it almost impossible to obtain private rental accommodation for M in Canberra. Private rental accommodation is limited and expensive, and people were unwilling to rent accommodation to a person with a severe mental illness.

M left his government housing, attempted to obtain private rental accommodation, and was hospitalized for some weeks after an extensive period of being free of hospital admissions, possibly connected with the stress of his changed circumstances.

In January 2006, we were able to secure loan funds in order to purchase a modern 3-bedroom, 2-bathroom town house for M near the center of town, on the L’Arche model, whereby accommodation for one or more mentally ill persons is provided long term to live with those who are mentally well.

Political Action

We also learnt how political action can sometimes be extremely effective in securing very helpful assistance.

M had been very unwell and flew from Canberra to Melbourne, which is Australia’s second largest city with 3 million people. When he arrived at Melbourne airport, authorities realized that he was suffering from a psychiatric illness and took him to Prince Alfred Hospital, a well-equipped hospital in an affluent suburb of Melbourne. The team of doctors and professionals who helped him recover over the following 3 weeks said that in many parts of the world, M would be able to secure employment and would receive help at home from government-funded programs.

After 11 years of writing letters to Canberra’s Minister of Health and failing to secure a positive response, M and I returned to Canberra. I informed senior government health officials in Canberra of what Melbourne psychiatrists had told us, and I said “I will put on a suit and sit outside the Chief Minister’s office for 40 hours each week, until parliament can pass an appropriation and provide suitable support for the mentally ill.”

Within a day, M became the first person in Canberra to be provided with wonderful assistance from the Tandem organization, which since then provides a total of about 4 hours every week of assistance with shopping, cooking, cleaning, and organizing his house.

Champions for the Mentally Ill

Previously, Tandem had only been allowed to support the physically disabled and the frail aged. There are about 6000 people in Canberra aged between 18 and 55 on disability support pensions, and one-quarter of them are disabled due to mental illness.

M was the first person to receive assistance from Tandem due to a mental illness. There are now over 60 people (of the 1500 severely mentally ill people on disability support pensions) who receive such assistance in Canberra.

We wish to pay tribute to many excellent psychiatrists who work in the State hospital system in Canberra, including Dr Kalyana Rodrigo, Dr Florian Wertenaer, and the Tandem team led by Jeremy Smith.

A Rehabilitation Program

It has been particularly helpful that M has had a pet, in his own house since 2006, a golden haired poodle, who serves as a constant companion.

M was baptized and confirmed in 2008, and we both attend the local episcopal (Anglican) church. We find the Sunday worship and fellowship most helpful.

Most of the assistance that we found to be extremely valuable, such as supported housing, is typically not available from government and requires enlightened family and friends to work out a rehabilitation program and to fund the program.

The regular weekly support from the dedicated and skilled Tandem staff is most welcome.

I call on M every morning and evening at 8 am and 6 pm and provide a few minutes of assistance with tidying and organizing, and we are busy weekends together.

M has an organized week, with music lessons Tuesdays, personal trainer at gym Wednesdays, and 7 hours of paid landscaping work Thursday and Fridays. The illness is episodic, and it is important for a sufferer to learn to manage their stress levels.

Apart from taking daily medication and recognizing that you have a disability, the other 8 guidelines for healthy living listed above apply to everyone. People with a serious mental illness need assistance.

Recovery

With regard to recovery and cure, outcomes can be elicited from studying published research, eg, Schizophrenia Bulletin. One-seventh to one-third of sufferers recover completely in terms of symptoms and social functioning, but this often takes many years.

The economist John Nash, whose life was celebrated in the movie A Beautiful Mind, recovered after 20 years. At the age of 83, he continues to write and lecture. Other sufferers typically achieve substantial improvements with the right support.

Realizing the joy in supporting and helping M has enriched our lives. We are therefore optimistic about M’s continuous well-being and improved future quality of life.
References


