



Winter Edition
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This newsletter was put together by the staff of the Otago Mental Health Support Trust with contributions from lots of other people.

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OTAGO MENTAL HEALTH SUPPORT TRUST

- Bipolar Network
- Information
- Education
- Peer Support
- Advocacy
- Resource centre for Tangata Whaiora
- Consumer Networking

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The Manic Depressive Papers

Kerry Hand reminisces about the origins of our Trust

In May 1986, twenty-five years ago, I started a new job as director of the Social and Rehabilitation Centre situated in the former residence of the Medical Superintendent of the Hospital Board situated at 9 Union Street, Dunedin. There started a wonderful chain of activity that became the Otago Mental Health Support Trust of today.

SARC as the Social and Rehabilitation Centre was known, was the outreach centre established by Cherry Farm Hospital. The next few years spun out many enterprises including "The Family Support Programme", one of the first activities that recognised families as a stakeholder. "The Work Co-operative" which became the Work Opportunities Trust, now a large operation based in South Dunedin, The Life Horizons Programme, and most importantly for this discussion the "Manic Depressive Education Group".

Most of the SARC clients had lived many many years at the hospital, but there was a different newer group who seemed to have had multiple short admissions. While they did not show the obvious levels of disability, their issues were significant. The structure of their lives were blown away by episodes of significant illness, at which times they had lost their jobs, their relationships and all the assets and context to the lives they had built. Many of these people had a diagnosis of "Manic Depression".

I came across a copy of a publication entitled "The Manic Depressive Papers" which came out of Sydney. The Papers were a yearly publication, collecting articles and personal stories, photocopied and stapled. What fascinated me was they were produced by "Manic Depressives" (more about labelling later) and were not sanitised into meaninglessness as so many health guides were. For Example Page 8 might have a story by somebody who stopped taking the pills, and the disasters that followed. Page 9 would have the story of somebody who stopped the pills, against all advice and it was the best thing they ever did!

No Health Service dogma evident in the Manic Depressive papers. But good good stuff.

Hmmmmh. What to do with such a good resource? Simple. Form a group and add it to the programme of the various things we did at the centre. We formed the "Manic Depression Education Group".

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"What fascinated me was they were produced by "manic depressives" and were not sanitized into meaninglessness as so many health guides were."

...Kerry Hand on the Manic Depressive Papers

The Manic Depressive Papers continued.

For all of 1984 at enormous expense the Hospital Board had sent me away out of town to spend time with 50 of the top nurses in the country. I had returned with some new ideas and not a few new skills. One idea was about what my job was. I determined that "The Social Purpose of Nursing is to enhance the ability of individuals and groups to deal with the realities of their Health situation."

The reality for the "Manic Depressives" was they had long periods of a good life and repeating short periods of quite extreme periods of illness. Short periods that ruined everything and with huge practical difficulties resulting. As a nurse it was my job not only to assist them to deal better with the illness but also to enhance their ability to combat the practical downside, the potential loss of family, relationships, jobs and context to their life.

I was not a doctor. I would do little about the illness itself. But it seemed there was a lot of scope for people to be "better at having it." Maybe we could speed that up a bit.

And so it began. We envisaged a discussion group, with a leader or two, staff from the centre. Five or six sessions, each with a headline topic. "What is Manic Depression", "Staying Well", "Medication", "What to do when things aren't going well" etc. I disremember the names now. For each session there was a guide of two or three pages. We sat in a circle and somebody would read out a paragraph and we would discuss it. The conversation took off like you would not believe. There was not a group I was in that was work.

The ensuing discussion - sometimes it was a wonderful argument - was always vigorous and sometimes disputing. But always with rich learning and example for the participants. Well I remember a time when somebody was talking of what they did when they realised they were getting unwell. The person next to them turned and said. "What are you talking about - nobody knows when they are getting unwell" to the reply "I do know" and "I don't" commencing an extended discussion amongst the entire group. A good thrash around of all the points around that issue. Both were completely right about themselves.

Even a discussion about the bad side of medication helped lift people's awareness and helped them make better decisions for themselves. In every group we ran there was a vast transfer of experience. This was an illness you needed to know about and it was not necessary for you to find all of it out the hard way by bitter experience.

Also I was very aware of those in the group who might not say much on an issue but who sat wide eyed soaking in all the vast experience of the others. Sometimes I would get a telephone call later. "I never knew that" or "I thought I was the only one" People, including family, were building up a toolkit of knowledge, some awareness there were things they could influence, and a lot less self stigma. There were practical things that could be done.

Organisationally the group just took off. We had to start another immediately the first one finished. We started to get inquiries from people we did not know. At one time we were running several groups at the same time. In the first two years we put perhaps about 200 people through the series of discussion groups.

For a couple of years, as intake worker, much of my time was dealing with inquiries. And that was not just a matter of making arrangements. There is a whole emotional mindstep in even joining such a group. I remember an old old man who signed up bringing his adult daughter. Through her childhood he had regularly disappeared to hospital. In the group this was the first time she had heard him discuss that.

I was copying the "Manic Depressive Papers" in volume and posting them to whoever rang. And there was the need to simply speak for as long as it took to those who obviously had spent many months plucking up the courage to make that first phone call.

I needed to be aware that what seemed a brief inquiry might be the most difficult phone call the person had ever made. I hope I got that right enough.

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What's the plan?

There are many people beavering away behind the scenes to ensure that the five year plan for mental health services becomes a reality. Two surveys have been completed recently as part of the information gathering. The first survey, Pathways to Support, was sent to all DHB funded mental health services in Otago and Southland. It attempts to identify the different paths that people have to follow to get treatment and support. It also identifies barriers and bottlenecks that people come up against when seeking help. 90% of services responded to the survey so the information should be comprehensive. The second survey was sent to all people working in mental health services. It is an attempt to characterize the workforce, to find out their demographics, what sort of work they do, what their qualifications are, how well suited they are to supporting people in their recovery. More than 300 workers have replied, from peer support workers to psychiatrists. Read the newsletters updating progress on the project at:

<http://www.southernhdb.govt.nz/index.php?pageLoad=2528>

The Southern DHB Planning and Funding Mission is: To fund and plan Southern DHB Mental Health and Addiction Services in a way that supports recovery, advances best practice and enables collaboration

The Manic Depressive Papers continued

The very argumentative education groups were also very much fun. (Yes that can go together and yes it can be good health education.) People did not want to finish after 5 sessions. So we formed the "Manic Depressive Support Group" which met monthly and was a continuation contact for graduates of the Education Group. We had a programme of speakers and other events. People came as they chose, every time or occasionally, and there were those who had gained what they needed and chose to move on.

I remember well one event. A party, perhaps it was at Christmas. In the lounge there was a big group of "Manic Depressives", glasses in hand, who were bitching about their spouses. In the kitchen there was a group of "spouses", glasses in hand, bitching about their "Manic Depressives", both groups using eyebrow raising detail. When I think about it - it was continuing the rich rich education programme. People were learning they were not alone; others had similar experience to share and learn about. The emotional component of having an illness or living with somebody who did is a vast landscape. It takes a lot of time and information to simply get your head around all that. And the learning happened in many ways, not all conventional.

But it was not all high argument and dramatic emotional learning. We did what New Zealanders do. We of course formed a committee. There were a number of tasks that the group wished to do. In a subtle way, because there are issues of confidentiality the group had started hospital visiting, sometimes helping with practical tasks if a person was unwell.

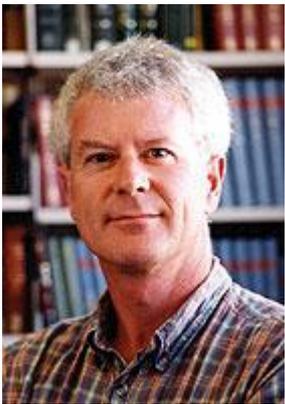
As that grew a little more complex the group thought it would be useful to employ a worker, a "Welfare Officer" to visit people and assist. Accordingly we eventually formed a Trust and raised that money. Funds came from Government although at this time I cannot recall where. I do recall we declined to get some brief seeding money that was offered and successfully stood out for more reliable funding. A decision I believe has ensured the Trust is still here.

To have a trust one thing you have to do is apply for a distinct name to register. At that time there was a newfangled word being bandied about of 'Bi-Polar". Debate was interesting. Some said "Bipolar" is good - it's new and scientific and doesn't scare people because it's not close to "Maniac"

Others liked "Manic Depressive" on the basis of "I am one, been one for 20 years, and proud to be one". We chose the "Otago Manic Depressive Support Trust -OMDST". Even that minor debate would have helped somebody - perhaps to work out how they fitted into the world; how much they wanted to disclose about themselves - or how much not.

The Trust was incorporated; I believe in 1989, three years after the first activities began. It went on to independence and to grow. I stepped back. The names have changed. "Signpost" was one. There was a flirtation with the "Bipolar" word and the Trust is now the "Otago Mental Health Support Trust", with the multiple employees we know today.

That's a story for somebody else.



Mental Health Act Presentation- *Don't miss this!*

We are privileged to have Professor John Dawson of the Faculty of Law at Otago University giving a presentation on the mental health act. John says "The main focus of my research is the law governing involuntary psychiatric treatment and legal relations between mental health professionals and their clients." He is very willing to answer your questions. We have sent John a few questions we have received in advance such as:

- How wide is the definition of "treatment" under the mental health act?
- Could a person under the mental health act be forced to have an abortion?
- Can I still drive while under the mental health act?
- District Inspectors who have acted as your lawyer under the mental health act- Is there a conflict of interest here?
- When will the mental health act be reviewed and what might the changes be?

The presentation will be at the Church of Christ rooms, corner of Filleul and St. Andrews St. 27th July, 10am to 11.30am Please RSVP to 4772598

Professor John Dawson, Faculty of Law, Otago University.

DISCLAIMER

The opinions and articles expressed in this newsletter do not necessarily represent the views of the Otago Mental Health Support Trust or anyone associated with the organisation.

Phobic phone line

This is a 24 hour a day, seven day a week free phone line staffed by volunteers. It is to help people who are experiencing panic attacks or OCD thoughts and need to talk to someone. 0800 142694389

Ketamine: Innovative Care or Clinical Research? - An update

In December Standard Nine requested the Health and Disability Commissioner to investigate whether the use of this drug in Dunedin was research or just part of normal psychiatric care. We also asked the Commissioner to consider whether proper procedures were being followed to get informed consent from people offered ketamine. The commissioner carried out an initial assessment and decided that all is well with the use of ketamine in Dunedin. We do not agree and have requested that the commissioner conducts an investigation. There is widespread interest nationally, not just in the use of ketamine, but in off-label prescribing in general. Enigma will keep you informed.

Peer Support Practice in Aotearoa New Zealand – *report now out*

Last year several Dunedin peer support workers had the pleasure of participating in Dr. Anne Scott's research project on mental health peer support in New Zealand. The final report is now available and it makes compelling reading, supporting the valuable contribution peer support work can make to mental health services.

“The capacity to hold some of our darker moments in a shared space is central to peer support. It allows peer supporters to pick up on issues that other mental health workers might miss. Peer supporters work actively to build the connections and trust that makes this understanding possible.”

Peer support is based on the premise that people who have been through mental illness and experienced recovery are in a unique position to support others with a diagnosis. There are several different approaches to peer support around the world and this report clarifies exactly what it might mean in the New Zealand context. This will be useful reading for many people, including mental health service clinicians and managers who, according to this research often have misconceived conceptions of what peer support workers do.

Read the full report at the Mental Health Commission website:

<http://www.mhc.govt.nz/sites/mhc.govt.nz/files/Peer%20support%20practice%20in%20Aotearoa%20New%20Zealand-%20Final.pdf>

p.s. Be in quick. The news today indicates that the Mental Health Commission will soon cease to exist, one of the government's cost cutting measures.

Generic drugs

Did you know there are three different brands of quetiapine funded by Pharmac? They are Seroquel, Dr. Reddy's Quetiapine and Quetapal. Which one do you take and do you notice any difference between them? In theory the different brands all contain exactly the same active ingredient so should work just the same. Ask your pharmacist if you notice any change.

Many thanks to these people for their support:



ACE Shacklock Charitable Trust, Balance, Dempsey Trust, , Colortronics. DCC, Pat Sivertsen –Dehaan Travel, Lone Hill Vineyard, 17 Frames, DCC Community grants Scheme