

HOPE UNLIMITED, NEWCASTLE – Patricia King

Much More Than Coffee and Cake

First and foremost I wish to acknowledge the Aboriginal people of the Wadi-Wadi Nation on whose land we are privileged to gather together for this Turning the Tide Conference. I am mindful of the fact that the Aboriginal people are truly the first people of our country and the custodians of the land.

I am happy to say that I have had the opportunity of visiting this magnificent part of Australia many times as I am fortunate to have had two of my sisters living here with their families for many years. Often when I have needed a little R & R this is where I've headed and, believe me, it works. You might ask me how does Wollongong compare with Newcastle where I come from. Well, I'm definitely not going to buy into that argument. Just suffice it to say that both areas are just great!

Since 1997, Hope Unlimited Group has been actively involved in advocacy and support for people who live with a mental illness and their carers. Hope Unlimited was established by a number of carers of young people who seemed to be 'falling through the cracks' of the mental health system. We had had difficulties getting any kind of ongoing help for our kids through the services that were available at the time and frankly we decided that we had had enough.

We found that going through the regular recommended channels with our concerns was simply leading us on a circuitous route back to where we started – something we found to be most unsatisfactory and completely frustrating. We were told things like 'You have to wait until he/she hits rock bottom before he/she realizes there is a problem and then it's up to them to do something about it.' That was pretty hard to swallow when at the same time relevant health professionals were not giving us as carers credit for our extensive knowledge of our loved ones and much less involving us in any treatment plan in the event of a plan being set up. Nevertheless we, as carers, seemed to be the ones who were expected to be there to pick up the pieces when our young people became unwell.

It also seemed to us that there was another way to go about helping our loved ones. At the time, support services for carers seemed to exclude any consideration of the needs of the mentally ill person and the reverse applied also to consumer support services in respect of carers. In a situation where there can often be some conflict it doesn't help to have a system that further helps to divide the people concerned. We thought that surely we'd all be able to live more fulfilling and less stressful lives if only we could break down the barriers that the system seemed to be setting up between us and our loved ones. Hence our advocacy for consumers as well as ourselves. The central philosophy of Hope Unlimited is that putting our efforts into

ensuring the best possible care for our young adults results in a greatly improved quality of life for all of us.

With these thoughts in mind we set about establishing ourselves as a group, holding monthly meetings in our homes over afternoon tea (that's the Coffee and Cake bit!) giving support in person and over the phone when the dramas in our lives actually happened - no appointments needed. The meetings take the form of support first and business later with an emphasis on flexibility. We combined our abilities and special skills, held the occasional stall at the local markets to help cover our stationery and telephone costs and wrote lots of letters regarding both carer and consumer issues.

Seven years later the group is still happening. We remain a Non Government Organisation in the truest sense as we are still self funded. Our needs may have changed somewhat but the need is still there in the community for someone to speak up for the many people out there who for whatever reason are unable to advocate for themselves.

Once when speaking on ABC National and Radio 2NUR regarding a proposal to scale down the Community Mental Health Team we got up a few noses and were called into a meeting with the CEO of Hunter Health to be given the official story. Subsequent to this meeting, the Community Reference Group attached to Hunter Mental Health was established and we have had representation at every meeting held since. Sadly, the proposed changes were brought in anyway, and our predictions of more people becoming unwell, severe overcrowding in psychiatric hospitals, an escalation of violence in the community and in the hospital setting are coming true today. The evidence is right there in the media but more tellingly so in the recommendations that came out of the Legislative Council Enquiry into Mental Health Services in NSW.

SOME ISSUES WE HAVE TACKLED / RELATED ACTIVITIES

- The restructuring of the Newcastle Mental Health Team.
- The pending and eventual demise of the Crisis Team in Newcastle.
- Appropriately non-stigmatising Police behaviour when dealing with events involving people with a mental illness.
- Police attendance on some occasions when a mental health person would be less threatening and also less stigmatizing, resulting in better outcomes.
- Major input into a submission into the Inquiry into Mental Health Services in NSW.
- Mental Health Inquiry Forum at Parliament House.
- Day of Participation and Action following release of recommendations from this Inquiry.
- Mental Health Conferences in Newcastle, Sydney and Wollongong.
- Law Society Meeting on issues surrounding Forensic inmates in gaol and Forensic patients in psychiatric hospitals.

- Helped a member write submissions to be used as evidence in a Coroner's Inquiry into the death of her son. Support at the Inquiry and by telephone.
- Attended Court and Long Bay Gaol with members.
- Dissemination of information regarding psychiatric medications, treatment and mental health related events that came to our notice via our individual memberships in various organizations, eg Schizophrenia Fellowship, NSW CAG, MHCC. (*Elaborate re lateral distribution of information in long Bay Hospital to empower forensic patients*)

LIAISON WITH OTHER GROUPS AND SERVICES

- The Newcastle Mental Health Team
- Hunter Health
- The Community Reference Group - Hunter Mental Health
- Mental Health Coordinating Council
- The Hunter Fellowship
- Psychiatric Rehabilitation Association
- Lifeline Newcastle
- Australian Mental Health Consumer Network
- NSW CAG
- The Alliance to Improve Mental Health Services on the Mid North Coast
- Court Liaison Officer for Mental Health – Hunter Area (*Emphasise the importance of this service to prevent people going to gaol in the first place*)

On a more personal level one of our most satisfying achievements centres on the release from the Kestrel Ward, Morisset Hospital of my beautiful son to live with me rather than in a group home which would usually be the case for a person with his forensic status. This was achieved as a result of negotiations over many months between his treating team at Morisset Hospital, the Mental Health Tribunal, Supported Recovery Newcastle and me with the unfailing support of Hope Unlimited members.

His personal process of becoming deinstitutionalized is happening, albeit in microscopic steps. Happily, he, the Supported Recovery Team and the rest of our family have together just passed the four month milestone. The future is starting to look good for him at last.

I applaud my son for his extreme courage, strength and persistence in surviving a truly horrible life experience.....It is seven years since he was found Not Guilty Due to Mental Illness by the Court but basically he has been 'incarcerated' one way or another since then. As a parent I can tell you that having one's child go to gaol especially when he has been ill and not been able to get the help he needed ranks right up there on the scale of parental nightmares. However, I remember at the time also feeling so relieved that he was at last in a place where he would receive some assistance. Not the best way to get it but seemingly the only way at the time.

Believe it or not, my son is actually one of the lucky ones.

According to statistics quoted at the Law Society Seminar on forensic mental health issues I attended in February, it has become roughly 3 times harder for forensic patients to move from the gaol environment to psychiatric hospital care and that's only the first step of an increasingly long journey. It strikes me we have some pretty weird ideas of justice in NSW. There's lots more work to be done on that one but let us hope the efforts of the MHCC Forensic Working Party Group will be successful in bringing about true justice for mentally ill people in gaol.

In conclusion, we are all pulling towards the same goal whether we come from larger organizations as do the majority of you here today or from a smaller group such as ours. Surely what we all want is the best possible mental health service for everyone. I am confident that the wholistic and collaborative approach that is encouraged by this Turning the Tide Conference is definitely the way to go.

Thank you for your attention.