



**People diagnosed with
'mental illness' doing
things for ourselves**

**OUR CONSUMER PLACE
NEWSLETTER JUNE-JULY 2011**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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Welcome to this June-July Bumper OCP newsletter

Why a bumper edition? We like to keep our readers on their toes ... No, seriously, Merinda has been unwell and in and out of working for several months now, so we are massively understaffed. As you can imagine, the newsletter has slipped down on the list of priorities. And Flick is going away for a month (mid July- mid August), so won't be on newsletter duty during that time. AND, when we started putting this edition together, there was just so much material that we felt a double edition was warranted. We sincerely hope you enjoy it (and apologies for breaking anyone's email inbox)!



INTRODUCING ... <http://whatcausesmentalillness.com> by Bill Moon

In this edition, the indefatigable and inimitable Bill Moon introduces an amazing new website - <http://whatcausesmentalillness.com>. Amongst other things, Bill works as an Information Officer at the Victorian Mental Illness Awareness Council. This website is Bill's own brainchild, but will no doubt grow as more people add to its expanding resources and thinking.

Hi All

Some of you will know me. I've been a consumer for 40 years and in the movement for about 15.

There's now a lot of media and public talk here about 'Mental Illness', but still not a lot of common understanding of what that **means** and the **realities** of mental illness, mental health services and the lives of people affected by both.

So I decided to try to add to the public debate, to **provide a place where we can collect the best and latest information and evidence on recovery, consumer voices, Soteria, and other perspectives, as well as 'orthodox' 'medical model' topics.** I want to include the full range both to attract a wider audience and to inform people about **all** the evidence.

If we as a community decide to 'invest in Mental Health' and fight 'Mental Illness' we **need** to have a shared and realistic, evidence based, collective view of what those things are, and what works to improve them.

So I built a little website, and now it's YOUR turn

The site's got the structure and look fairly OK, I think but I am very aware that it CAN'T work without the help of comrades and colleagues to put together a pool of information and evidence on the topics and promote the site. (That would be YOU.)

Some great people have already offered to help – (There's one whose name I forget - Flick... Black... or is it .. White.... ? Something like that.) **[Ed note: hahaha!]**

But we can use all the help we can get.

WE NEED-

- 1) VISITORS!
- 2) **Suggestions** for sites to link to, references to include, articles, whatever in specific topics, - consumer experience, rights, research about **biological** models etc..
- 3 People interested in **contributing-** writing or help editing submissions
- 4) Help **promoting** the site - links from your website – very important! Also recommending it to others directly or via facebook etc., bringing it to the attention of other sites for linking
- 5) **Especially, should you find it worthy, bringing it to the attention of people involved with education or information, both for tertiary and secondary students and for the general public**
- 6) Places for printed pamphlets I can provide.



IN CONCLUSION

How many times have we said 'I **wish people knew more about the way things really are?**', or 'I wish there was more knowledge of EVIDENCED **alternatives** to the way we do things in the system?'

Well, the time for a discussion of 'mental illness' may be here and, if we work together, that public discussion could be informed by **the best evidence and practice**.

Have a look at the site, and look at what is there, but also **imagine** what we could make of it **together**, If you find it worthy please recommend it and if you don't find it worthy - come and help improve it!

Bill

* Worried by the phrase 'mental illness'? Read the FAQ for my reasoning!

NEWS IN THE CONSUMER WORLD:

(Also, see more in the Thumbs up / Thumbs down section, pp.19-20)

New laws give “Protective Services Officers” powers to use force against people who appear to be mentally ill!

The Victorian government is soon to debate concerning new laws that give increased powers to protective services officers (PSOs) (eg. court security & proposed armed officers on public transport) to apprehend a person who appears to be mentally ill, including the authority to use reasonable force to apprehend them in certain circumstances. Until now, only Police had these powers, under s10 Mental Health Act. The Mental Health Legal Centre will be providing more information about the proposed law and its impact & how you can lobby your local MP!

Link to the Bill, explanatory memo & 2nd reading speech:

www.legislation.vic.gov.au/domino/Web_Notes/LDMS/PubPDocs.nsf/ee665e366dcb6cb0ca256da400837f6b/66dda43b537da01aca2578bd0082a097!OpenDocument

\$4 million for National Mental Health Consumer Organisation

Mark Butler, the Minister for Mental Health and Ageing has announced that the National Mental Health Consumer Organisation will be established, initially within the Consumers Health Forum, but then transitioning to becoming an independent body over two years. \$4 million have been invested into this process. As Janet Meagher (a consumer advocate based in Sydney) said in the press release, “Consumers have waited a long time for this and we are looking forward to consumers having a strong and independent voice in Australia.”

Centre for Excellence Peer Support

The Centre For Excellence Peer Support was launched recently. This website will be a repository and one-stop-shop for all the excellent information, training and discussion around peer support. Congratulations to all involved in getting this site up. We look forward to watching it grow (and being part of nourishing it).

Certificate IV in Mental Health Peer Work

The new Cert IV (TAFE) qualification in mental health peer work is nearly complete (this is what the “expert stakeholders” are being told). At this stage, many details are still uncertain, but suffice to say it is looking like very soon there will be an official, nationally recognised TAFE-level qualification for the consumer (and carer) workforce!

Now, the next step will be making sure it is deeply embedded in consumer perspective, and builds on consumer leadership and expertise. Our Consumer Place has been quite involved in consultations into this qualification and we believe some very strong elements have been included. BUT, we have also discovered that “the Industry” we work in has a diverse array of perspectives on peer work ... We look forward to being part of teaching this Certificate once it has been launched.

Congratulations to Sue Armstrong

Sue’s artwork, “Access to Justice for all” has been unveiled to mark the 30th anniversary of Victorian Legal Aid (VLA). Sue is an artist based in Moonee Valley, co-convenor of Penguin Artists, a mental health consumer consultant and a strong advocate for women’s only psychiatric wards. Sue said that her work promoting the rights of people with a mental illness inspired her painting. “My vision for the artwork was to focus on the general themes of social justice and the part Victorian Legal Aid has played and continues to play in supporting the oppressed.” Her work will be seen by thousands of people visiting VLA’s headquarters each year.



Sue Armstrong’s artwork, with (L-R) Victoria Legal Aid Managing Director Bevan Warner, Victoria Legal Aid chairman John Howie, Artist Sue Armstrong, State Attorney-General Robert Clark and Commonwealth Attorney-General Robert McClelland

Mental Health Act (Vic) Review

Despite the best efforts of many groups – including ourselves, other consumer groups and law reform organisations – it looks like there will be no further community consultation about the new Mental Health Act. So, the next time we will have a chance to look at this incredibly important piece of legislation will be when it is being debated in parliament. The Mental Health Act is such an important law that we are disappointed that the consultations were not deeper and drawing more on the expertise within the consumer community. Many outstanding issues still have not been resolved to the satisfaction of many key participants in these discussions – hence the push to have the consultation period extended. This is all especially frustrating as Guardianship laws are also currently being reviewed (with a much wider scope for change). It makes no sense to have guardianship and mental health laws reviewed separately by completely different bodies as – ultimately it’s many of the same human bodies that are impacted by these laws!!!

INTERVIEW OF THE ISSUE – Debra Wells, NZ

For this newsletter edition, Debra Wells was interviewed by Merinda. Debra is a service user, consultant and educator from New Zealand.

Merinda and Debra were both keynote speakers at the ‘Trauma Informed Care and Practice’ conference in Sydney 23-24 June, which aimed to incorporate the principles of trauma informed care within recovery-oriented practice.



Merinda Epstein: Can you say something about what do you do in NZ?

Debra Wells: Hi Merinda. I live in New Zealand and am a self employed Service User Consultant...which sounds a bit grandiose, but basically organisations contract me in to do pieces of work for them. Generally they want me to bring a service user perspective to the task. I do a lot of training, which I absolutely love, but also auditing, research, service development, and development of training resources... lots of different and interesting things.

ME: What are your thoughts about the Conference you have just attended?

DW: I thought that it was absolutely amazing on so many levels. I guess firstly just even having a two day conference to talk about trauma. Every speaker I heard was wonderful and interesting. The thing that I found most incredible was that even though there were different perspectives everyone was basically singing from the same sheet. There seemed to me to be universal agreement on the need

It was also great to see people acknowledging that becoming a trauma-informed service is complex, not something that can happen overnight but still something that can happen and indeed must happen.

for mental health services to take trauma seriously...how refreshing. It was also great to see people acknowledging that becoming a trauma-informed service is complex, not something that can happen overnight but still something that can happen and indeed must happen.

ME: You are obviously pretty passionate about this area. What do you think are some of the misconceptions about trauma-informed care?

DW: Several spring to mind. The first is that when we talk about trauma in this framework we are only talking about childhood experiences. I hear people say things like “but what about refugees” or “what about people who have been through natural disasters”. A trauma-informed system of care recognises all forms of trauma and its ability to impact on peoples' lives. It feels to me like “but what about” narratives marginalise childhood events because perhaps they are too uncomfortable to think about or seem too complex.



The second thing that springs to mind is that I hear workers say “but I'm not qualified to deal with trauma”. This in fact is probably true for many workers, however it illustrates another misconception. Trauma-informed care is not about working with the historical aspects of a person's trauma, no matter what it is. It is about acknowledging the impact today of past traumas and working with people in a way that firstly doesn't retraumatise them and secondly provides a therapeutic relationship where a different story can be mirrored...an alternative story if you like, a relationship that is safe to be who I am.

I could waffle on for hours about this stuff but the last one I want to talk about is “but what about the people who don't have trauma in their histories”. Firstly most people do and secondly trauma or no trauma, a trauma-informed system of care is more respectful, always seeks to understand the purpose of behaviours, rather than labelling them, always seeks to work

collaboratively with people and always seeks to do no harm. It is also far less likely to use any sort of coercion including seclusion and restraint. How is any of that not good for everyone?

a trauma-informed system of care is more respectful, always seeks to understand the purpose of behaviours, rather than labelling them, always seeks to work collaboratively with people and always seeks to do no harm

ME: What is being done about trauma informed care in New Zealand?

DW: In short, sporadic pockets of activity. There are certainly organisations and people who work from this paradigm but it is not embedded, or for that matter, even really mentioned in our national policy documents. There is however a bit of a change acoming... Te Pou (one of our National Mental Health Workforce Development organisations), is just starting to explore this whole area, which is tremendously exciting. NZ is also writing a new National Blueprint for Mental Health Services. I suspect there will be quite a concerted effort to get it recognised at this level.

ME: In closing do you have any words of wisdom for Australia at this time?

DW: You currently have a government which is putting a lot of focus and money into mental health, which is wonderful. I guess I would say that the sector needs to work really hard at getting trauma-informed care into national policy documents and talked about at a national level, so that it is embedded at this level. The other main thing, I think, is to work together on this, support one another, present a united front. I think that the work Mental Health Coordinating Council has done on this is great. The Outcomes Paper they wrote, “Trauma Informed Care Forum” (September, 2010) has some really good steps outlined about how to forward this Agenda.

In closing, I would like to say, that it was an absolute privilege to be at the Conference and I look forward to seeing how this all progresses. Maybe NZ can learn a few things from our cousins over the ditch.

INTRODUCING ... Are you affected in some way by Borderline Personality Disorder? You might be interested in joining an informal consumer and carer group

In this edition, Janne McMahon introduces the 'Informal Consumer and Carer Group' for people affected by Borderline Personality Disorder

Since 2008 the Chair of the *Private Mental Health Consumer Carer Network (Australia)* Janne McMahon has been lobbying the Australian Government, federal politicians and the mental health sector more broadly to raise awareness of BPD, highlighting the lack of appropriate and adequate services and tackling prejudice, stigma and discrimination felt by many consumers with the BPD diagnosis. Janne's work follows on from 20 years of advocacy by Merinda Epstein, who has been a sole voice for far too long. Together, Merinda, Janne and their colleagues have decided that they will work together to raise awareness of BPD, to tackle prejudice within mental health and the broader health system and to establish appropriate treatment options offering choices.

From the lobbying to date, a national BPD Expert Reference Group was established in 2010 and in February, 2011 the first meeting of the Clinical Practice Guidelines Committee was held to produce an Australian version for the management of Borderline Personality Disorder.

In March, Janne met with Minister Mark Butler, together with a prominent consumer and two dedicated psychiatrists. What they are asking for is \$88 million over four years to establish in all states and territories, a community based Statewide Specialist Service which offers assessment, treatment, secondary consultation, GP support, workforce training and education, clinical supervision, research and carer support and education around BPD. They believe this should be based on the strengths of the 'Spectrum' Model in Victoria which is a statewide specialist personality disorder service.

They envisage this type of service would be able to co-ordinate the statewide provision of treatment and care to people with the diagnosis of BPD and their families. They further believe that any service must also be used to offer 'trauma informed care' where trauma is a major factor.

You may not agree with a specialist statewide service! Janne has not had access to BPD carer and consumer expertise to ask until now. So her Network is currently forming an '**Informal Consumer and Carer Group**' which you may be interested in joining. There is no requirement to provide any personally identifying information and you may choose only to be identified by your email address!

The purpose of the Group is for information exchange and to provide carer and consumer expertise to inform current and future lobbying and advocacy.

In joining this informal group, members agree to be contacted by email. At present there are 52 registered members of the Informal Group who are represented by both consumers and carers. If you are affected by BPD, think about adding your voice too. Just click the following link which will take you straight through to surveymonkey to register.

To join, click onto this link: **Informal Consumer Carer Group for people affected by Borderline Personality Disorder** <https://www.surveymonkey.com/s/QDZRZYN>

The greater the number of voices, the louder we are heard!



My politics start in my body. *By Flick Grey*

In this edition, Flick Grey writes from her experience of embodied politics.

I listened as a gifted, beautifully spirited friend of mine spoke of how her body still carries the experience of violation, over a decade after she was subjected to involuntary “treatment”. Powerfully connected to a collective and yet deeply personal inner wisdom, she said “I’ll never get over that, I *don’t want* to get over that.”

She continued that if it were an intimate partner who had violated her, she could have sought refuge in a domestic violence shelter, but since this was the State, there was nowhere to seek refuge.

Nowhere to seek refuge.

My body carries profoundly different experiences, incommensurate and sometimes challenging to reconcile politically. Mine are not of violation but of invalidation and neglect, starting from day dot.

I rang a community mental health service again recently. I had moved to a new area and with the move came a sense of opportunity and renewed optimism. But I brought my inner darkness with me and it’s been gnawing at me again. I don’t seek the support of psych services when I’m suicidal – there is a clarity of vision when I am in that peculiar darkness. I know too much about coercive psychiatry to entrust them with my fragile desire to live. But I also know too much about exclusive service priorities to believe that my struggles will receive the supports I desire. Except when I’m desperate, and that’s when I try the mental health system again.

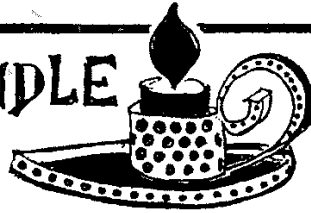
... there is a clarity of vision when I am in that peculiar darkness. I know too much about coercive psychiatry to entrust them with my fragile desire to live.

That’s when the apologies begin. They are very sorry, there are only three workers at the service and so they are very limited. Or they are very sorry, they can only take people with a psychotic diagnosis. Or they are very sorry but there is a very long waiting list. And when they do call back, I’m not deemed to be “serious” enough, because I’m not a “danger to myself or others.” (No, not today.) But perhaps if I went to a GP, I could get a referral for some counselling? Or have I considered psychotherapy? (Yes, I have, on those days when I believe perhaps I might win the lottery.)

So, I am stuck between coercive, crisis-driven, risk-averse acute “treatment” – which my spirit desperately seeks to avoid – and “community based,” sometimes moderately helpful, often terribly patronising and superficial counselling – which is woefully inadequate for the yearnings of my spirit (and often an impossible strain on my wallet). Oh, and of course, there’s always psychiatrists again. Sometimes I think if I had money, the supports I would hope for would be available. Possibly, but I suspect that might be desperate thinking creeping in again. So, again, I look elsewhere, beyond the mental health system.

Some days, I put my body on the line and engage politically, to change this system, if not for myself then possibly more generally. But today I am feeling it all in my body. And I weep – a collective and yet deeply personal despair.

LIGHT A CANDLE FOR:



PSYCH. DRUGS FOR EVERYONE



NOT FOCUSING ON THE SOCIAL & POLITICAL FORCES INVOLVED

SERVICES WHERE YOU HAVE TO HURT YOURSELF IN ORDER TO GET IN

EARLIER & EARLIER INTERVENTION (DRUGS IN UTERO FOR PREVENTION IS BETTER THAN CURE)



AUSTRALIA'S 3 WHITE KNIGHTS OF MENTAL HEALTH POLICY (McGORRY, MENDOZA & HICKIE) DOMINATING THE CONVERSATION

MORE & MORE PROFESSIONAL SALARIES GOING ON INDIVIDUAL 'FIXING'

SPENDING MILLIONS ON 'STIGMA CAMPAIGNS' THAT TEACH US TO DIAGNOSE OUR MATES

MILLIONS GOING INTO BOLSTERING 'BIG PHARMA' & CALLING IT RESEARCH

DETERMINING WHETHER DISTRESS IS SERIOUS (SEVERE & DEBILITATING) BY DIAGNOSIS

NON-GOVERNMENT ORGANISATIONS FIGHTING EACH OTHER IN A TURF WAR.

MILLIONS & MILLIONS ON MORE OF THE SAME

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LIGHT A CANDLE FOR:



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SMOKING MAD

Enforced smoking bans in psychiatric hospitals are a human rights issue.

– by Indigo Daya (www.smokingmad.blogspot.com; email: smokingmad@yahoo.com.au)

Indigo Daya is project manager of a consumer-led mental health program, an independent trainer and speaker, mental health consumer and smoker. She is currently challenging the enforced smoking bans at one of Melbourne’s largest psychiatric hospitals. In this article she explores her own experience with the bans, and looks at why these bans are a human rights and discrimination issue for all consumers.

Last year I was an inpatient at the Alfred psych ward for 56 days over three admissions. These were my first admissions in many years, and I was shocked to realise that smoking is now completely banned in the Alfred psychiatric wards – including in all outdoor courtyards. So here I was in a psych ward, literally out of my mind, feeling very trapped and vulnerable ... and then I was searched, my cigarettes were confiscated, I was handed a patch and a nicotine inhaler and told I’d have to quit. Even if you haven’t been in this situation, I’m guessing you can imagine how I felt.

There were times when the effect of forced quitting was so severe that I would end up sobbing, shaking, enraged, yelling. At other times the smoking ban became more evidence to my shattered mind that I was getting the punishment I deserved, and I would self harm, partly out of desperation and partly to reinforce the punishments of the hospital and my mind.

I didn’t realise at the time, but I have since learnt that cigarettes, while being very unhealthy for our bodies, can have a beneficial effect on our minds. Nicotine affects dopamine production in the brain, and there is lots of research which shows that smoking cigarettes can help to alleviate some of the symptoms of mental illness, and counteract some of the negative side effects of medication. Worse, as official Quit sites all state, quitting can increase the risk of mental health relapse.

So here I was in a psych ward, literally out of my mind, feeling very trapped and vulnerable ... and then I was searched, my cigarettes were confiscated, I was handed a patch and a nicotine inhaler and told I’d have to quit.

“Nicotine has some positive effects on symptoms of psychiatric disorders.... several studies have shown that some symptoms of psychiatric disorders may be exacerbated by nicotine withdrawal. Therefore, attempts to quit smoking pose additional problems to patients with mental health problems.” – Fagerstrom K and Aubin HJ. Management of smoking cessation in patients with psychiatric disorders. Current Medical Research and Opinion. 2009;25:511–8. Ref; Australian National Preventative Health Strategy.

Another important issue is that smoking affects how our bodies metabolise many antipsychotic drugs (eg, olanzapine and clozapine). Quitting smoking can mean that our doses need to be lowered.



Yet when consumers leave hospital and start smoking again, it means our medication will be too low, and some people may be at risk of relapse. Further, there is at least one reported case of a consumer dying from Neuroleptic Malignant Syndrome as a result of quitting smoking without having their medication level appropriately adjusted. I have yet to meet a consumer who has been

Most of us would like to quit, and most of us even welcome some support – but we don't want or need to quit by force, or in the midst of a crisis.

given all the information they need about the interactions between smoking and medication.

This campaign is not about promoting smoking.

At its heart, this cause isn't even about smoking. It's about human rights, freedom of choice, resisting the paternalistic expansion of 'duty of care', and not kicking people when they're down. It's about getting help to deal with distress, rather than having our distress increased by the health system. We all know smoking isn't such a great idea. Most of us would like to quit, and most of us even welcome some support – but we don't want or need to quit by force, or in the midst of a crisis.

Thankfully, I was not alone at the hospital. Other patients often managed to smuggle cigarettes onto the ward and some were kind enough to help me out. We are so often there for each other in ways no one else can understand, and these small acts of kindness remind me of how important the consumer movement really is.

Underground trade in cigarettes is making psychiatric wards a dangerous place.

Within a few days I learnt how to smuggle cigarettes on to the ward, and how to trade for them. I began to hide cigarettes everywhere I could think of, and to constantly be on the lookout for staff who might catch me. Getting hold of cigarettes, and being able to smoke them, was the main focus of my admission. And every time I was searched, or my belongings were searched – looking for cigarettes – I became less trusting of the staff and less honest when discussing my mental health treatment.

The secret trade in cigarettes on psychiatric wards is starting to become a major issue. During my own admission I witnessed a patient offer to give another patient oral sex in exchange for a cigarette – he was that desperate. Instead of a cigarette he was punched, and I remember feeling awful, not just for him, but for all of us being forced into such a dangerous situation by the services who are supposed to be there to help us. I felt unsafe and very vulnerable – as did those around me, even the non-smokers.

Where is a hospital's duty with regards to providing a safe environment?

Since I have started my campaign on this issue, I have spoken to many consumers about what goes on in the wards. I know that people are trading money, possessions, and even sex for cigarettes. Some people are stealing, absconding or threatening other patients. Hospitals claim that banning smoking is actually their duty of care (I address this later in the article), but I can't help but wonder where the hospital's duty of care is in relation to providing a safe environment. It is a well recognised phenomenon that prohibition, particularly in constrained



environments, increases crime and violence. Yet our psychiatric hospitals have created this very situation, and then locked our most vulnerable and distressed people inside it. And, we are told, this is for our own good!

The issue of duty of care extends even further. Just like other patients, whenever I could get my hands on a cigarette, I often ended up smoking it in dangerous circumstances. For example, standing on a chair underneath a ceiling vent so no-one would detect the smell. Being on high doses of antipsychotic medications leads to shakes, instability and balance problems – how long will it be until a patient has a bad accident trying to smoke in this way? Or has it already happened and just not been reported?

The possible dangerous situations are many. I know of patients smoking behind curtains, and having nowhere safe to dispose of cigarette butts. In Western Australia, recent research reported that patients were so desperate for cigarettes that they were putting pieces of paper into electrical outlets to generate smoke to inhale. And the Austin Hospital has had five fires on its ward since the bans were introduced. Of course these issues now mean that every psychiatric patient – not just smokers – are affected by the bans. Wards have become more dangerous places, filled with more desperate people.

Are these bans increasing the risk of suicide and self-harm?

Another known outcome of these bans is that smokers are now less likely to seek psychiatric help – yet services claim they are trying to improve access. A short time after my first admission I became very unwell again. Twice, in fact. And in both instances I went to extreme lengths to avoid returning to hospital because of the smoking bans. I knew that being forced to quit again, especially right then, would just make me feel worse. Unfortunately, that left me with no safety net for my health, and there were some pretty disastrous outcomes. Suffice to say that I'm glad I'm still here today – I very easily might not have been.

While it is true that the rest of hospital grounds are also smoke-free, the issue for psychiatric patients is different. Unlike other hospital patients, we are not usually allowed to leave the ward...

Consumer advocacy services report that this issue is now widespread – many smokers will do almost anything to avoid hospital. Mental health services often talk about 'harm minimisation' – surely this is a case where risk of suicide is a far greater harm than the risk of smoking?

Psychiatric patients need special consideration.

Smoking bans have been implemented at psychiatric hospitals across Australia, and in many overseas countries, for several years now. Health Departments are supporting these bans. And across the world, consumers are starting to fight back.

While it is true that the rest of hospital grounds are also smoke-free, the issue for psychiatric patients is different. Unlike other hospital patients, we are not usually allowed to leave the ward because we are often detained under the mental health act on involuntary treatment orders. So while every other hospital patient has the right to go out to the street to smoke – we do not. Given that we are deprived of liberty, the Victorian Human Rights Charter protects our rights to dignity and to not be treated in a cruel or inhumane manner. We need to use the courts to have this right enforced.

Duty of care... where is the line?

The hospitals claim that it's their duty of care to get us to quit – particularly since the rate of smoking is so high amongst people with serious mental health issues (over 80%) compared to 'the sane' (about 26%). They also claim that the bans exist to protect non smoking patients and staff.

I think most of us would like some help to quit at the right time and place, and of course, with our consent. I do not believe, however, that hospitals have a duty, or right, to force us to quit smoking. This is a legal substance, we are adults, and last time I checked the Mental Health Act, we are supposed to be treated in the least restrictive manner possible. The duty of care argument is also a dangerous precedent for our rights as consumers. What next? Banned from eating chocolate (don't laugh, I know of one case where this has already happened in hospital)? Forced to exercise? Our TVs confiscated?

Duty of care is supposed to relate to imminent risk of harm to yourself or others – this simply does not apply in this situation. And once health services shift from health 'promotion' to health 'enforcement' I believe we enter very dangerous territory in terms of human rights.

*What next?
Banned from
eating chocolate
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Concern about protecting non-smokers is valid, but it is easily managed. Small smoking shelters are very affordable and can be installed in courtyards at psychiatric wards. These would allow patients to smoke and non-smokers to enjoy the rest of the outdoor space. These shelters are even available in 'perspex' (transparent plastic), so staff can still monitor us if they are concerned about safety.

The bans are not helping people to quit.

After my last and final discharge, I lit up a cigarette the instant I walked out the hospital door. I'm not alone. Research tells us that 90% of smoking psychiatric patients light up within 5 minutes of discharge. These figures show us very clearly that these bans are not having any significant impact in actually helping people to quit. No surprise, really, when all of the best information about dealing with addiction tells us that people must *choose* to quit (as opposed to being forced) and that people need to quit at a time when they are at their *best* (as opposed to during an acute psychiatric episode).

An American study followed 100 people with mental illness admitted to a smoke-free psychiatric unit. Most used nicotine replacement therapy while in hospital. All patients resumed smoking - the median time from discharge to first cigarette was five minutes.

(Prochaska JJ, Fletcher L, Hall SE, et al: Return to smoking following a smoke-free psychiatric hospitalization. American Journal on Addictions 15:15-22, 2006.)

If health services really want to help us quit, I suggest that we need voluntary and well supported quit programs in community mental health settings – not bans in hospitals. We deserve the right to make our own choices, and we deserve more than having a patch or inhaler tossed at us – we also need information and supportive counselling. We need to be able to quit when we are at our best, not our worst, and we demand to be treated with dignity and respect.

Some staff and services are seeing the light...

A number of psychiatric hospitals across Victoria have now begun to recognise that the bans are not working, and that they are hurting patients. These hospitals have lifted the bans, and it's my hope

that other hospitals take their lead from them. I strongly suspect, however, that we as consumers will need to do our part to make this happen.

I've also been encouraged by the many psychiatric nurses who are supporting this campaign. They recognise that this issue is not about encouraging smoking, but about protecting rights and providing mental health services which don't increase people's distress. Unfortunately many nurse's employment contracts prevent them from speaking out publicly against hospital policies – but the support is still there.

Fighting back!

In order to do my part, I have challenged the smoking ban at the Alfred Hospital as being discriminatory and a human rights violation; the case is currently before the Victorian Civil and Administrative Tribunal (VCAT), and the full hearing will be held on 27th – 28th October 2011. If you're interested, please come along to show your support.

I am also conducting wide scale research into the impact of the bans. While there is significant research on this issue (most of which supports our case), I don't believe any of the current research adequately examines the real risks and issues. My research project is rather large, but I hoping it will provide the evidence we need for court, and also to apply pressure to government to conduct an independent enquiry into the bans.

Lately I feel a bit like David up against Goliath, fighting the world's most politically incorrect battle! Luckily, I'm quite stubborn and resourceful. Even better, my outrage about this issue has been a great coping strategy– it's hard to be depressed when you're angry. And finally, the support and encouragement of other consumers has shown me how important this issue is, and the importance of standing up for what's right.

If you are interested in following the case, finding out more, completing a survey, or getting involved, please visit my website at: www.smokingmad.blogspot.com.

Lately I feel a bit like David up against Goliath, fighting the world's most politically incorrect battle! Luckily, I'm quite stubborn and resourceful.

YOU MAY HAVE MISSED ... the “Mad People's History” video by the Chang School: *Presenting the consumer/survivor/ex-patient movement:* <http://www.youtube.com/watch?v=9uTbEBPkAAk>

In this brief video, David Reville presents a brilliant overview* of the consumer/survivor/ex-patient (c/s/x) movement. In it, he includes the striking metaphor of “the table” – first the table is set with the key elements of c/s/x movement history, then the table is overturned, we get a place at the table ... then start our own tables!! David Reville teaches possibly the world's only course in Mad People's history (at Ryerson University in Canada).

(*OK, so he does massively over-simplify the key anti-psychiatry thinkers – Szasz, RD Laing and Foucault – but overall he does extremely well for an accessible 5 minute video!)

FROM THE ARCHIVES: *Sight Unseen: Conversations between Service Receivers On Mental Health Nursing and the Psychiatric Service System*

In this new section of the newsletter, we bring you historical snippets – bits and pieces from Australian consumer history that we think ought to be more widely known and shared. This month, we profile the small book: “Sight Unseen” (2003)

This is breathtakingly real research – consumer’s experiences and their reflections on what they want to be different, specifically what they would like psychiatric nurses to learn from consumers.

It was edited by Cath Roper, Australia’s first consumer academic. Cath conducted a series of open interviews with consumers, asking people talk about whatever they felt was important, and publishing the interviews in full (rather than the more-common practice of researchers using consumers’ ideas as “raw data” for their own thinking). The result is a book filled with incredibly powerful lessons for anyone involved in the mental health system. And it’s so easy to read! Here are some nuggets:



L-R: Ms Cath Roper, Ms Evelyn Webster, Bronwyn Pike, and Professor Brenda Happell. [Photo originally printed in the Melbourne Uni’s UniNews: <http://uninews.unimelb.edu.au/news/839/>]

FEMALE: ... what I want more than anything is to feel safe enough to tell someone when I am feeling unsafe. I want to feel safe enough to be able to say that I am unsafe and ‘in a really bad way’ but what I find is that I have to do to survive is keep it all to myself.

...FEMALE: It’s difficult and it’s exhausting every single day – living with the feelings that you have, and pretending to the world that they’re not there, is really hard.

FEMALE: In my head, before my first admission, I did the standard thing – thinking that going to hospital was going to be the one place where I would be looked after and kept safe, someone would be there to sort it out with me and hold my hand while I went through my stuff – such a romantic notion.

MALE: Oh you wish.

FEMALE: You are more alone than ever. (p.42)

We could tell the difference between when somebody was ‘really with you’ and when they were monitoring, and looking at your symptoms and assessing you and your behaviour.

So, for example, if you were nervous or anxious and you might be twisting your hands together or whatever, ... but so often the psychiatrist that would be interviewing me would suddenly look at my hands and you can see them thinking, ‘ Oh, this is a symptom of such and such’, and that automatically makes me think: “you’re not with me, you’re actually looking for signs and symptoms – you can’t hear, you’ve got almost a vested interest in not hearing what I’m saying, or being with me.

My girlfriend and I were talking about that as a common experience for us, and that ‘not being present’ was often about being diagnosed instead of being listened to. (p.56)

If you are interested in getting a copy of “Sight Unseen,” please contact Cath Roper at the Centre for Psychiatric Nursing: croper@unimelb.edu.au; Ph (03) 8344 9455.



OUR CONSUMER PLACE UPDATE: WHAT HAVE WE BEEN UP TO?

As always, it's been a busy time for us here at Our Consumer Place ... there is just so much to be done, supporting consumer-developed initiatives of all sorts and developing consumer-perspective, consumer-control and consumer-leadership. There never seems to be enough time to do everything!

Merinda is back on board – not 100% yet, but rehabilitating well. First her back needed an operation, then her knee and then her teeth! So it's been a terribly rough trot lately for Merinda (and she's endured far more pain than anyone should have!), so please be kind to her as she eases her way back to work.

In terms of what we've been up to, Merinda recently gave a keynote speech at the National Conference on Trauma Informed Care and Practice, which was well received. Otherwise, we've been participating in all sorts of adventures, from participating in law reform to peer support to writing textbooks.

Our Consumer Place booklets

Our first booklet – “So, you've got a Mental Illness? ... What now?” has been so successful, it is now going into its second print run! It can still be downloaded for free from our website - www.ourconsumerplace.com.au, you can fill out an order form for a free hard copy to be posted, or multiple copies can be ordered at the cost of printing (\$7 per copy).

Our next booklet, tentatively titled: ***Speaking Your Mind: A guide to how we use our stories*** is now almost ready to be released – it is out of our hands and into the production pipeline. The plan is for it to be launched at The Mental Health Services conference in Adelaide, in September. So, fingers crossed and stay tuned! There are many more booklets on the way, and a great deal of material going onto the web gradually.

SAVE THE DATE!

Don't forget that OCP is holding a day-long forum on “Consumers As Clinical Educators” on November 11th 2011, at Moonee Valley Race Course. If you are interested in the embedding of consumer expertise into the education of mental health clinicians (including nurses, social workers, etc), then save this date and come be part of the conversation!

But what about Intentional Peer Support (IPS) training?!?

Yes, indeed, the demand for IPS is so great that it's even a little overwhelming. Please know we are doing everything we can to roll out IPS training as soon as possible. With Flick at 2 days a week and Merinda still not at full strength, this is proving to be painfully slow (did I mention we want to do everything NOW? – or as David Oaks puts it, we would like “A non-violent revolution in mental health by Tuesday”)

So, what we are doing is taking down contact details for anyone who is interested in IPS training and we promise to keep you in the loop as soon as we know more concrete details. You can email your interest to: service@ourconsumerplace.com.au. We are planning to run multiple trainings this year.

The best news of all?

Flick is going on annual leave for 4 blessed weeks ... escaping north during the depths of Melbourne winter ... joyousness! So, she'll be unavailable for a month from July 11th. In that time, all OCP enquiries should go to Merinda (merindae@ourconsumerplace.com.au)



A double dose of THUMBS UP/THUMBS DOWN

1. **THUMBS UP:** To the incredible collaborative team effort that has gone into getting the “Centre of Excellence Peer Support” up and running. Check it out here: www.peersupportvic.org (note that it’s only just beginning!) Congratulations especially to the many different organisations who have come together to create this project – collaboration is never easy, but they appear to have done well!
2. **THUMBS DOWN:** to the introduction of legislation into Victoria that means that people who “appear” to be mentally ill can be forcibly detained by armed officers on public transport (and other places too). This legislation treats us like criminals, and is profoundly discriminatory and stigmatising.
3. **THUMBS UP:** to Marsha Linehan – the creator of Dialectical Behavioural Therapy for Borderline Personality Disorder – who recently decided to “come out” as having her own experiences with what could be labelled BPD. This is extremely brave for a prominent mental health expert-by-training to do, and with such candour! Check it out here: www.nytimes.com/2011/06/23/health/23lives.html?pagewanted=1&_r=3&ref=todayspaper
4. **THUMBS UP:** to Indigo Daya’s “Smoking Mad” campaign. She is arguing that people should be NOT forced to quit smoking when they are admitted into a psych ward, as this is likely to *increase* distress at an already distressing time. We know a great deal of distress has been caused by these bans and we wish Indigo well with this campaign (see article on p.12)
5. **THUMBS DOWN:** to all the confusion around EPPIC (Early Psychosis Prevention and Intervention Centres) – what exactly is the “prevention” part? EPPIC staff have been adamantly arguing that it is about preventing the disabling consequences that all too often come with a first episode psychosis. But -the government keep describing it as associated with preventing psychosis. This needs to be made much more clear! (you can follow the controversy at: <http://theconversation.edu.au/early-intervention-for-psychosis-not-just-popping-pills-1859>)
6. **THUMBS UP:** To Melissa Raven’s tenacious efforts at pushing for greater honesty and transparency around the psychosis “prevention” issues (see above).
7. **THUMBS UP:** to the amazing conversations that happen in cyberspace both between consumers and with other people who care about these issues! There is such a capacity for difficult issues to be discussed in these electronic spaces.
8. **THUMBS DOWN:** to the continuing evidence that many workplaces are not sympathetic to the needs of people with mental illness. This is especially concerning since the government is keen to get more of us into the workforce. We deserve respectful workplaces.
9. **THUMBS UP:** to the debates around the merits of Patrick McGorry’s model of “early intervention”, ignited by high profile US psychiatrist (who headed the DSM-IV taskforce), Dr. Allen Frances. Finally, we are actually having public discussion about this contentious issue.

10. **THUMBS UP:** to Dr David Webb's insightful and persistent pushing to have the first-person experience of suicide (those who have tried to take their own lives) seriously listened to in community and professional understandings of suicide.
11. **THUMBS DOWN:** to all the pharmaceutical companies that make huge amounts of money while making psychiatric drugs with loads of horrible, unwanted effects.
12. **THUMBS DOWN:** to mental health practices that are coercive and paternalistic. Do we really need to have our rights stripped away so that we can receive help?
13. **THUMBS UP:** to the media exposés of Prof Graham Burrow's questionable conduct. Any psychiatrists who have had repeated complaints made against them ought to be investigated. Well done to all those who are speaking out.
14. **THUMBS DOWN:** to processes that fail to genuinely involve consumers from the start. It's not OK to ask us to come and join YOUR agenda after the groundwork has been laid. After-thought inclusion and tokenism can be really damaging for us and our wisdom and insights are lost.
15. **THUMBS UP:** to consumers who are questioning some of the ways 'consumer participation' has been conceptualised over the past decade and a half and are questioning the usefulness of the term and the concept. Other terms that are being questioned include: 'representation', 'consultation', 'consumer/carer views', consumer consultants, 'peers', 'stigma' and the jarring and frustrating missed opportunities inherent in the 'Personal Helpers & Mentors Program (PHAMS) – almost the only initiative which includes some consumer workers which has increased funding.
16. **THUMBS DOWN:** to the constant demand that artwork raising awareness about mental health issues must "be inspiring and positive." What about the place of critical thinking, dissatisfaction with the status quo, or confronting difficult questions and experiences? (Specifically, this is in reference to the various competitions for Mental Health Week art)
17. **THUMBS UP:** to Richard McLean's Creative Musing website – what a great collection of creative outpourings. His 2004 book about his recovery from Schizophrenia ("Recovered, Not Cured") is included on the site, but the site is much more broadly about his artistic endeavours. His other work may well resonate for other consumers too – it resonates for me!
18. **THUMBS UP:** to the Mental Health Co-ordinating Council (NSW), ASCA (Adults Surviving Child Abuse) and the Private Mental Health Consumer Carer Network (Australia) for organising a (well attended) conference on Trauma Informed Care. The program included two consumer keynotes as well as a keynote who identifies as a survivor of childhood abuse. Well done.
19. **THUMBS UP:** to all consumers/psych survivors who are driven by a need to tell their story and 'the story' about trauma experienced as children, in psych. services, rape, war, pillage, displacement, victims of crime, and all the other dreadful things the wreak havoc on all our worlds.
20. **THUMBS DOWN:** to those who let ideology run rampant over the sometimes contradictory, complex and meandering realities of our truth.