FLIPSIDE

The Association of Participating Service Users

PRIVACY
CONFIDENTIALITY
ANONYMITY

No. 39 Autumn 2015

INSIDE

Articles and Stories:

Art:

Front cover: street art near Balaclava Station

Back cover: street art in Windsor

All other illustrations are photographs of street art around Melbourne taken by APSU.

Flipside No.39 Autumn 2015
Editing and layout: Edita
Proofreader: Daina

Contents: Thanks to those who contributed artwork/photos and to all those who contributed articles, stories and poetry.

If you have any original articles, poems or artwork that you would like to see in Flipside you may submit them to:
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EDITORIAL

Privacy is a right protected by law. In Victoria we have the Health Records Act, which protects the privacy of our health information. This is important because prejudices can be formed based on people's health information and this can preclude people from vital opportunities. In some cases, particularly when there is a history of drug use or mental health issues, breach of privacy is likely to expose the person and their family to stigma, thus affecting their everyday life in a whole range of negative ways.

People with history of drug use usually learn quickly to be careful about how open they will be about their history, as it can affect their chances of getting and maintaining employment, housing or relationships. Unfortunately, it often takes a breach of privacy and confidentiality for an individual to truly understand the importance of this right. The law helps in exposing and addressing a privacy breach, but it can never put things back where they were before.

The need for privacy, confidentiality and, at times, anonymity arises mainly from stigma and discrimination that people with history of drug use often encounter. There is no quick solution for stigma, but we can all do something to address it. As Sarah Lord told us "changing one person's perspective does a lot".

From the stories in this edition we learn that application of privacy laws can also at times have a negative effect. Sometimes while protecting a person's privacy, their wellbeing can be overlooked, particularly when family members or significant others are precluded from some information. Privacy and confidentiality need to be more than a box to tick, a rule to follow blindly. A balance must be found and we at APSU believe that allowing service users and family members to have an input into policy development helps find this balance. The ultimate goal needs to be person's wellbeing, but the full meaning of the word wellbeing for people with drug issues can only arise from an open dialogue between them and their health providers.

Edita

For more information or assistance with a privacy concern try the following:

Victorian Health Records Act health.vic.gov.au/healthrecords
Health Services Commissioner http://www.health.vic.gov.au/hsc/ or 1800 136 066
Victorian Equal Opportunity and Human Rights Commission 1300 292 153
PAMS Service tel 1800 443 844 - for concerns related to pharmacotherapy only

Sarah Lord: Stigma is the real issue

We talked to Sarah Lord, Program Manager of Pharmacotherapy, Advocacy, Mediation and Support (PAMS) Service at Harm Reduction Victoria. Sarah told us about pharmacotherapy, privacy and stigma.

APSU: Can you tell us something about PAMS?

Sarah: PAMS is a state wide service funded by the Department of Health. It was originally set up in 2000 as a complaint service for people on pharmacotherapy (methadone and suboxone). It was about keeping people on these programs by resolving consumer related complaints and concerns. Over the years while running the service we found out that people did not so much want to make a complaint. They had a problem and what they would really prefer is that the problem is no longer a problem, that it went away, that it was somehow resolved, rather than making a complaint.

We'll always support a client through a formal complaint process if that's the pathway that the client chooses that they want to go down. However, when it's one person's word against the word of another it's impossible that there will be any kind of ruling or finding on one party's side. And that was the problem with a lot of the complaints that pharmacotherapy clients were making. There would be an allegation that the pharmacist had said something that the client found rude or derogatory. When we would take this to the body in charge, they'd say we can't side with either party, it's one person's word against another. So there's no point in going down the formal complaints pathway, unless there's evidence to support one person's side. Most of what the PAMS service does is the mediation, negotiation, working out win-win solutions.

Everything in regards to privacy and confidentiality is exacerbated in every way throughout rural and regional Victoria.

We also try to keep service providers happy to continue to run these programs. If we came in like a ton of bricks on the provider we're not going to get a good outcome for a client. And then that will affect the next client that we have that happens to be on a program at that pharmacy, because the pharmacist is going to remember us as one-sided and will not be interested in talking to us. So it's constant ball juggling. There is a policy framework in which these highly restricted drugs can be dispensed to people who need them, but every client's situation is different. Some people work full time, some people have other mental health issues, some people might be homeless… everybody's situation is quite unique and different.

The disadvantage of being a telephone based service is that we don't meet people face to face, but at the same time if it was face to face we wouldn't have the statewide reach that we have and we wouldn't be able to support the number of clients that we do. We do about 1,500 individual client cases per year.

APSU: Do questions of privacy and confidentiality come up in your work?

Sarah: Yes. A common complaint is that the pharmacist will call people's names out "so and so, you're next" and clients have said that that is quite undermining. There might be a relative or perhaps somebody that they work with or a friend who doesn't know

that they're on the pharmacotherapy program and happens to be in the pharmacy at that time. That can provide opportunity for judgement, the whole thing of "oh you're on methadone, so you must be a criminal, you must have criminal history, maybe you've got blood born viruses"… you're all of a sudden untrustworthy… And that's really difficult.

APSU: Yeah, everything you were before then changes.

Sarah: In a split second. The other thing is some pharmacists will, possibly because of the issue of privacy, try to serve every other customer in the pharmacy before they serve the people who are on the program. That makes clients who are on the program feel judged and discriminated against. They have to wait, they can't just take their script and go to a different pharmacy down the road because their scripts are made up to one specific pharmacy. If they want that dose that day, they have to wait. It's also "oh you're in THAT queue, you're standing on THAT side of the room, so you must be on THAT program". So even if people's names aren't called out, just where they're standing can determine whether they are on the program or not.

Some pharmacies, again in trying to combat this whole issue of privacy and confidentiality, have an entirely other room where they do all the dosing. There is usually a very separate line for that room, and sometimes a separate entrance. For example there was one pharmacy in a regional Victorian town that wanted the pharmacotherapy client group to go down a laneway and ring a bell and then a window would open on a side of the pharmacy and that's where the doses would be dispensed. So it soon became that anybody who was going down that laneway was on methadone program. That left clients feeling that their privacy was not being protected, that it was not a confidential space, and then all those other judgments come into it.

Everything in regards to privacy and confidentiality is exacerbated in every way throughout rural and regional Victoria. Particularly clients who are dosing in a small town really fear anybody knowing that they're on the program. That can affect their ability to get and retain housing or work.

APSU: Or it will affect the experience that their children will have in school.

Sarah: Absolutely. And there is the whole thing around the involvement of the Department of Human Services with the people who have illicit drug use history and who have children, and the judgement around whether or not they are able to keep their kids and if so what sort of restrictions are going to be placed on them… This whole issue of privacy and confidentiality is so huge.

APSU: It's almost like we're talking about the issue of stigma.

Sarah: Yes, that's right. There is so much judgement of this client group. It can come from service providers, but it also comes from the mainstream population. This is a group that will not necessarily complain or do not know how to complain or where to make a formal complaint and to follow it through. And that can lead to being a little bit slack when it comes to protecting people's privacy and confidentiality. If you don't think that person will do anything you're much more likely to take risk or not quite worry so much about the file name that's left on the front desk of medical reception. But if you know that person is a lawyer you're going to be damn careful.

APSU: Are there any issues of this kind with GPs?

Sarah: The way that Victorian pharmacotherapy program is set up is that ideally each GP would have 6 to 12 pharmacotherapy clients and that they would just be intermixing with everyone else, so they wouldn't stand out. But in reality we have a number of big pharmacotherapy prescribers and that is all they tend to do. I remember a particular GP clinic where anybody that came in would be automatically asked "are you on the program?" right in front of everybody else in the waiting room. But I think in some ways GPs are possibly more alert to the whole issue of privacy and confidentiality. It's not a shop. Yes, GPs and medical receptionists are dealing with public, but not in quite the same way as pharmacies do.

There is the question of blood borne viruses. There have been instances where a blood borne virus status of particular individual has been disclosed to an outside party. And that's something that absolutely should never happen.

80% of 14,500 clients on pharmacotherapy in Victoria are prescribed by 25 GPs.

APSU: What do you think is the reason behind all these issues that you have mentioned?

Sarah: Stigma and discrimination. I think that the pharmacotherapy client group is followed by an instant assumption that people are untrustworthy, that they will lie, that they have been criminals, that they won't have respect… all these really negative assumptions. Certainly we hope that GPs and pharmacists that provide services to this client group will see people that don't fit that stereotype. But often a pharmacist might have 30 people on the program, and 28 will be really lovely, but then one person has an argument with them and one other person is suspected of shoplifting. What they will remember is those 2 that caused them a problem. It's stigma and discrimination, but it's also this social/moral fear. And I think it's a big lack of understanding. People fear what they don't know. At the same time some clients are really complex with multiple issues, mental health issues, homelessness… and that's going to impact on their behavior.

APSU: How many GP prescribers are there in Victoria?

Sarah: There are a few hundred that are registered, but… We've got about 14,500 clients on pharmacotherapy in Victoria and 80% of them are prescribed by 25 GPs. So the GPs are under a huge amount of pressure. Another thing is that these medications, particularly methadone, have to be dosed every single day. Sometimes things happen, a doctor might go away, somebody's script might expire and they might not manage to get their dose. That impacts on that person's very ability to function for the next 24 hours. So it's not surprising that they're going to be frustrated.

There are some absolutely fantastic pharmacists out there and there are some brilliant GP prescribers working in pharmacotherapy, and those providers are just God sent and I thank them every day. But there are others who just don't get it and have absolutely no idea how to be firm but practical.

APSU: Would you encourage people to get in touch if they have concerns?

Sarah: Absolutely. We put all the reported issues into annual report to Department of Health and there are case studies in that report. And if 3 individual clients raise an issue of concern about the same provider, then regardless of whether or not the client wants us to take up their individual case we will start the process as the PAMS service, without

mentioning the clients' names, particularly if it's about discriminative attitudes.

APSU: What would privacy and confidentiality look like in an ideal world?

Sarah: Oh look in an ideal world if we had no stigma and no discrimination and if we had a range of different treatment options… I think part of the problem with pharmacotherapy is that that's all we've got as a treatment option, apart from the abstinence based detox and rehab. If people need some sort of opioid on daily basis they only have methadone or buprenorphine to choose from. There's no heroin prescription, there's no injectable pharmacotherapy.

Also I think having a lot more service providers would help. If every pharmacy in Victoria would dose some people and if every single GP in Victoria would prescribe to some people, the clients would have a choice. I think the providers cop a lot of stigma and discrimination too. 'Oh that's the pharmacy that doses all the methadone clients. We don't go there cause scary customers go there.' 'That's the druggy doctor, she does the methadone.' That sort of thing. I think changing one person's perspective does a lot. I often say to clients that every time somebody doesn't act or behave the way that the negative stereotype would then it can change somebody's idea of what somebody on the methadone program is like.

The cost of the program is huge for people who are on low income and I often say to clients don't say to the pharmacist that you're going to pay them on a certain day if you know that there is no way that you can. Because when that day comes and you can't pay, you've basically lied. And that reinforces the whole thing that nobody on methadone can be trusted. But if you say look I cannot pay you until this day, but on this day you walk in and pay 2 weeks of dosing fees, then that provider will know that if you say something you will do it, and that increases trust and builds their confidence that not everybody is this horrible stereotype.

APSU: So if it wasn't for the negative judgment and the negative stereotype of the drug user, would there be any need for privacy?

Sarah: Look, I think that there is always going to be the need for privacy because I think that fundamentally people have a right to privacy and confidentiality, particularly in terms of health, and this is a health related matter. That's why we have the Victorian Health Records Act and all that sort of stuff. But I think that problems are a lot more exaggerated when it comes to an already marginalised, disadvantaged and very judged client group. And then we have this big lack of providers, so it's not like you can just change because you're not happy with the service. There are limited options and there is a bit of desperation about it in a whole lot of different ways.

APSU: Is there anything else that you think we should know about this issue?

Sarah: Privacy and confidentiality has very complex ramifications and I cannot possibly describe all of them in this conversation. However people with specific concerns can contact PAMS at 1800 443 844 and we will do our best to assist them.

I am made terrible
by the threat of a true intuition
into destiny's implacable black loom.
I fear the reckless blade I have become,
the open razor, careening the hysterical arc
of absolute night toward an oblivious frontier.
I go accused of collusion with every black star
boiling in blasphemys crucible and invite suspicion
from alchemys solacious heart of violence.
My position, to this day, remains unfixed
and I am an exile, more of myth composed.
Suffering to house acute disharmony in cold secret
I provoke disaster by the murder of loves insipid charities.
And though suns excel in this, and other worlds,
I am ill within the province of my own horizon.
I would thieve perfection
in the conspiracy of an instant and adroitly end
this unrevised motion from horror to horror,
if not uncertain of my own mind and its
dissected cults of cynicism.
By the false suns of subterfuge I am forced
to bloom in darkness primary, and in dangerous
obscurity gestate more toward what goes unimagined.
By deviance I am reduced, becoming mystery's black seed,
and by its unseen wire am attached to invisible constellations
of empty bribery, in motion beneath the city's flowering
heart of stone. I am toward malicious conspiracy moving,
toward the horror in the walls. I am not forgiven
testimony's furnace and exact measure of agony
but become a single circle of bone exhumed
into this killing field, to translate the ineffable
from among this brutal poverty
of silence.

Luke Franceschini

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sharc
Self Help Addiction Resource Centre

APSU believes that people who use alcohol and other drug treatment services are the reason the system exists; their needs, strengths and expertise should drive the system. APSU is run by service users for service users and has an active member base. We invite you to join us in having a say. APSU membership is **free**, confidential and open to anyone interested in voicing their opinions and ideas on the issues facing service users today. We need your help to give us all a fair go. To become a member please fill out the form below and post to: **140 Grange Road, Carnegie VIC 3163** or fax to: **03 9572 3498** or go to: **www.apsuonline.org.au** to register online.

MEMBERSHIP APPLICATION

I wish to become a member of APSU and I would like to:

☐ Receive the quarterly APSU FLIPSIDE magazine

☐ Be sent information on how to become involved

I am a: ☐ Service user ☐ Service provider ☐ Family member ☐ Other

How did you find out about APSU?_____

How did you find out about APSU?_____

Language spoken at home:_____

Cultural identity:_____

Age: ☐16-25 ☐25-35 ☐36-45 ☐46-65 ☐over 65

Other issues: ☐ Physical disability ☐ Mental health ☐ Visual ☐ Hearing

☐ Speech ☐ Acquired brain injury

Name:_____

Address:_____

City/Suburb:_____ **Postcode:**_____

Phone:_____ **Mobile:**_____

Email:_____

Signature:_____ **Date:**_____

CONFIDENTIALITY STATEMENT: All personal details obtained by APSU will be kept confidential and will only be used for the purposes outlined above.

Edited for Entertainment

I started speaking to people about 5 years ago. I would tell them my story about addiction. I still remember the first time, I was full of anxiety and very uncomfortable, my hands were sweaty and my heart was beating out of my chest. I had practiced what I wanted to say but when it came to the crunch none of it came out the way I had planned. After doing this on a daily basis for a period of time I started to become more comfortable with the process, and then kept progressing to the point were I am now full of confidence most of the time and I always say what's on my mind if it's appropriate.

My public speaking moved on to bigger forums with hundreds of people whom I didn't know. It was my story that they wanted to hear, but it's very personal to me and there's a lot that I don't wish to share with general public.

One night at one of these forums there were video cameras and people filming for TV. I didn't have much experience with television besides watching it, so I didn't pay much attention to it. After the forum it was not made clear that they wanted to edit and televise some of my speech from that night.

After a week or so I saw on the internet a show about addiction. I recognized the presenter from the night of the forum. Half way through the show they played a clip of me speaking that night. I was repulsed by the editing they had used and realized that these people were much more interested in entertainment then the truth and recovery from addiction. I felt like my privacy had been breeched and developed a lack of trust with people in this industry who have to produce a story at someone else's expense.

Today I am not interested in speaking on TV or radio because of this experience. I still really enjoy speaking to people who have a genuine interest and how we can help each other.

Anonymous

On the other side

My son was entering his 7th detox and I was taking him there. In his skeleton state with not much else to his name but his red bag and a few clothes we walked through the entrance together. I remember it well as he was greeted with great delight by the staff who obviously liked him and loved him, but not quite as much as I.

I was his contact person and also on his phone list. I was as familiar with the intake process as he was. I was grateful that he could start his journey yet again, who knows this time might be it. As far as family go during this process it is always full of hope. It is so hard not to get caught up in the dream that from one week or 10 days forward he would be clean forever …. Maybe not!!

As always the plan is that he has no contact for the first two days and then can be phoned if you are on the phone list. I was very excited and yet very apprehensive. A mixed feeling that I was not yet used to. Still not used to! To hold hope and be realistic that this could end up with him using again. Also knowing that anything in the way of an attempt to get clean was a wonderful thing.

After two days I rang to speak to my son. All I was told was that they could not put me through to speak to him. I asked why I couldn't speak to him and asked whether or not he was still there. They said "due to the Privacy Act, we are not able to answer your question!!!!!" I was upset, shocked and horrified. I continued to plea my request to no avail. The Privacy Act. How it feels to be on the other side.

I was his main contact, I was on his phone list and all I wanted to know was whether he was there or not. I think it would be a great idea if on admission, there is a box to tick that says "If I choose to leave this facility I authorise for my contact person to be told" …. Yes or No.

In my case my son would have been happy for me to know. For me it would have saved a great deal of angst and upset. It is only when you are a loving family member that has been through all the ups and downs of active addiction over many years do you feel the gut wrenching pain, yet again, of not knowing where they are. I think this could be prevented and lot of unnecessary pain eased.

My son's journey still continues, as does mine.

Anonymous

Do No Harm

I have been on both sides of the fence. I used drugs and alcohol for many years and found myself in need of community services on numerous occasions. I have now worked in community services for as long as I once needed them. While studying in AOD it was drummed into me how important it was to respect a person's privacy and confidentiality. When I started my first job I diligently read the "rights and responsibilities" to my clients and ensured all paperwork was dully signed and that they understood exactly what and where and how the information would be used.

I also remember when I broke the rules. When I have made the choice to break the rules you could say it was having "the best intentions" for the client. Best intentions or not, it can cause trouble. Other services call up requesting information and the process of disseminating client information through the appropriate channels and guidelines can be arduous and time consuming. It is easy to take short cuts. On the other side I have denied giving information believing that to do so would be breaching client's right to privacy. When it comes to light that confidentiality has been breached, the client can feel betrayed thus the therapeutic relationship is corrupted, for now and possibly in the future for that person.

Back in the early 90's I knew someone who was Hep C positive. There was little information for professionals and service users about the illness at the time. Clients or patients were asked the question about their Hep C status and the information would be forwarded to other treatment services. My friend was diagnosed by her GP who, in turn, informed her boyfriend when he went to consult the GP on another matter. My friend had already informed her boyfriend, but the notion of a GP breaching this kind of confidentiality staggered us all.

These days I am able to negotiate the rights of my clients as well as get the information to relevant parties in regards to their treatment and care. If I am unable to get a signed form to release information I make a quick call and get verbal permission which I case note immediately. I am more equipped to deal with "pushy" people requiring information. I supervise students and chat about privacy and confidentiality which includes giving them permission to say "I am unsure about what you are asking, I will call you back".

Do no harm, as they say. When I was a service user I believed my worker had my best interests at heart. As a professional I know that to be true. When I used drugs my life was not black or white and the professionals that helped me most worked in the grey. If they didn't bend rules I doubt if I would have received the necessary help.

Anonymous

Double-edged sword

When I retired a few years ago I suddenly had more privacy than I'd ever had before. Especially during the day while my wife was at work. It was great at first, being able to do whatever I wanted, whenever I wanted. But after a while I got bored with reading, bored with filling my days with mechanical tasks that were no real strain on the brain. So I decided a little drink at lunchtime might spark me up. It did. But after a while I needed two or three little drinks at lunchtime to carry me through until it was time for pre-dinner drinks in the evening. Pretty soon I was having a slug of brandy in my morning coffee and had finished the rest of the bottle of wine I opened at lunchtime by mid-afternoon. Finally it got to the stage that as soon as my wife left for work I had my first drink for the day. And then I drank steadily until it was time to get semi-sober before my wife got home at night. Of course it wasn't too long before she realized what was going on. She could smell my boozy breath. She could see my red glassy eyes. Despite my lies and protestations that she was invading my privacy, she searched for and found my private stash of booze. Of course I was stricken with remorse. I begged for her forgiveness. I swore I'd never drink again. And she gave me another chance. And another. And even another. But eventually we reached the end of the road. I could continue my boozing in private, but not with her, not in our family home. When the crunch came I somehow marshalled my thoughts within my alcoholic haze, and made an appointment to see my GP. As a result I attended the day program at Delmont Hospital on a weekly basis for three years and have been sober now for nearly six. And my wife and I are still happily married.

In the meantime what did I learn? Simply that privacy can be a recipe for disaster if it is combined with boredom and booze.

When I started attending Delmont I did so in private. That is, nobody knew about it except my wife and our grown-up daughters. I made up stories, when necessary, about why I wasn't available on Tuesday and Thursday mornings. I also made up stories about why I wasn't drinking on social occasions with friends and acquaintances. I said I was on medication. Or on a diet. Or having a bet on how long I could go without booze. Then one day I realised I was telling lies, just like I used to in my boozing days, to protect my so called 'privacy'. I thought 'Screw this!' and started telling people the truth, namely I don't drink because I am an alcoholic. And those wonderful folks at Delmont Hospital were sorting me out.

So what else did I learn? Sometimes we put too much emphasis on our personal privacy for the wrong reasons. A few months back I discovered an interesting fact. The incidence of alcohol and other drug addiction is much higher in western countries where there is an individualistic culture with a strong emphasis on personal privacy, than in countries with

a collectivist culture where the value placed on personal privacy is much less. Go figure!

It wasn't privacy, as such, that was the problem in my case. It was what I chose to do with it. It was my choice to use my new-found privacy when I retired to become a full-blown alcoholic. It was my choice to tell lies during the early stage of my recovery in order to preserve my privacy. And it was my choice to reverse these choices. The point I want to make is that we all have the right to privacy, and the right to make choices about how we use it. Provided we don't use it to harm other people, of course.

The need for privacy in recovery in order to protect individuals from the stigma associated with alcoholism was recognised by the founders of Alcoholics Anonymous in 1935. They also recognised the healing power for individuals who choose to tell the truth in a safe, secure environment. The combination of the two has driven the success of AA (and subsequently NA) over the past 80 years. But despite the advances that have been made and the knowledge gained during that time, the stigma that is attached to addiction is still alive and well in many quarters. I would still be very reluctant to include 'alcoholism' as part of my medical history on a job application form. So the founding principles of AA and NA remain as relevant today as they were all those decades ago. So too are the laws and regulations that protect our privacy, including those that protect us from the possible consequences of the stigma associated with addiction. We should be very concerned and on our guard when our government tells us it wants to change these laws, for whatever reason.

What have I finally learned about privacy? It is a precious thing. But it can be a double edged sword in certain circumstances. So don't waste it. Use it wisely.

Alex A.

In Memoriam: Gordon Storey

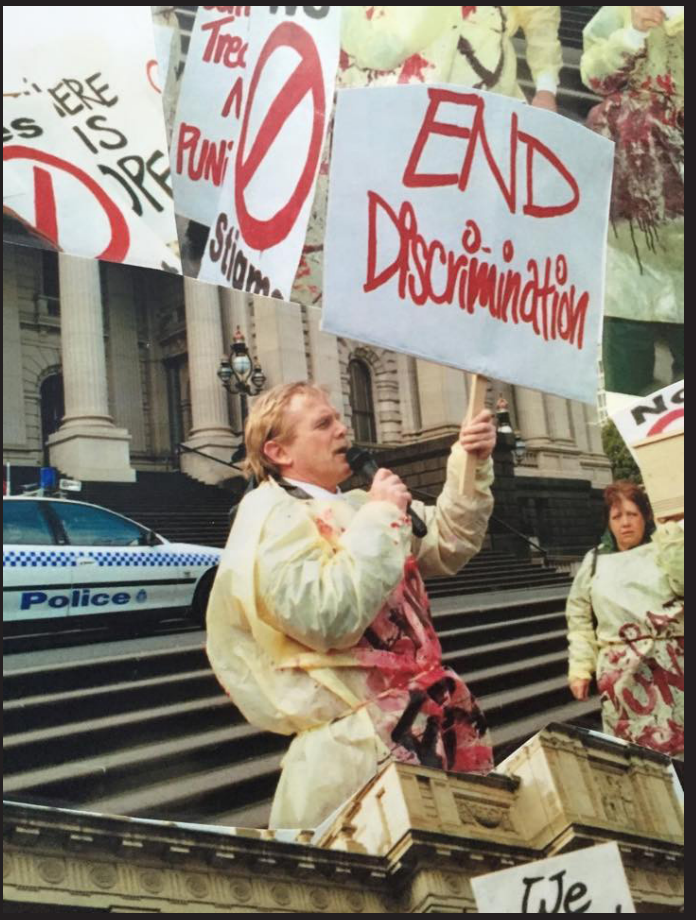
We wish to acknowledge the life of Gordon Storey who passed away in March 2015.

Gordon was the founding CEO of SHARC in 1998, when the organisation as we know it today evolved from the US Society. His passion and vision were a driving force behind this development.

Gordon was also behind the idea of APSU and had laid the ground work for the founding and the future development of APSU.

With Gordon we lose a great advocate for the value of personal experience and against stigma and discrimination, but his legacy remains in our work.

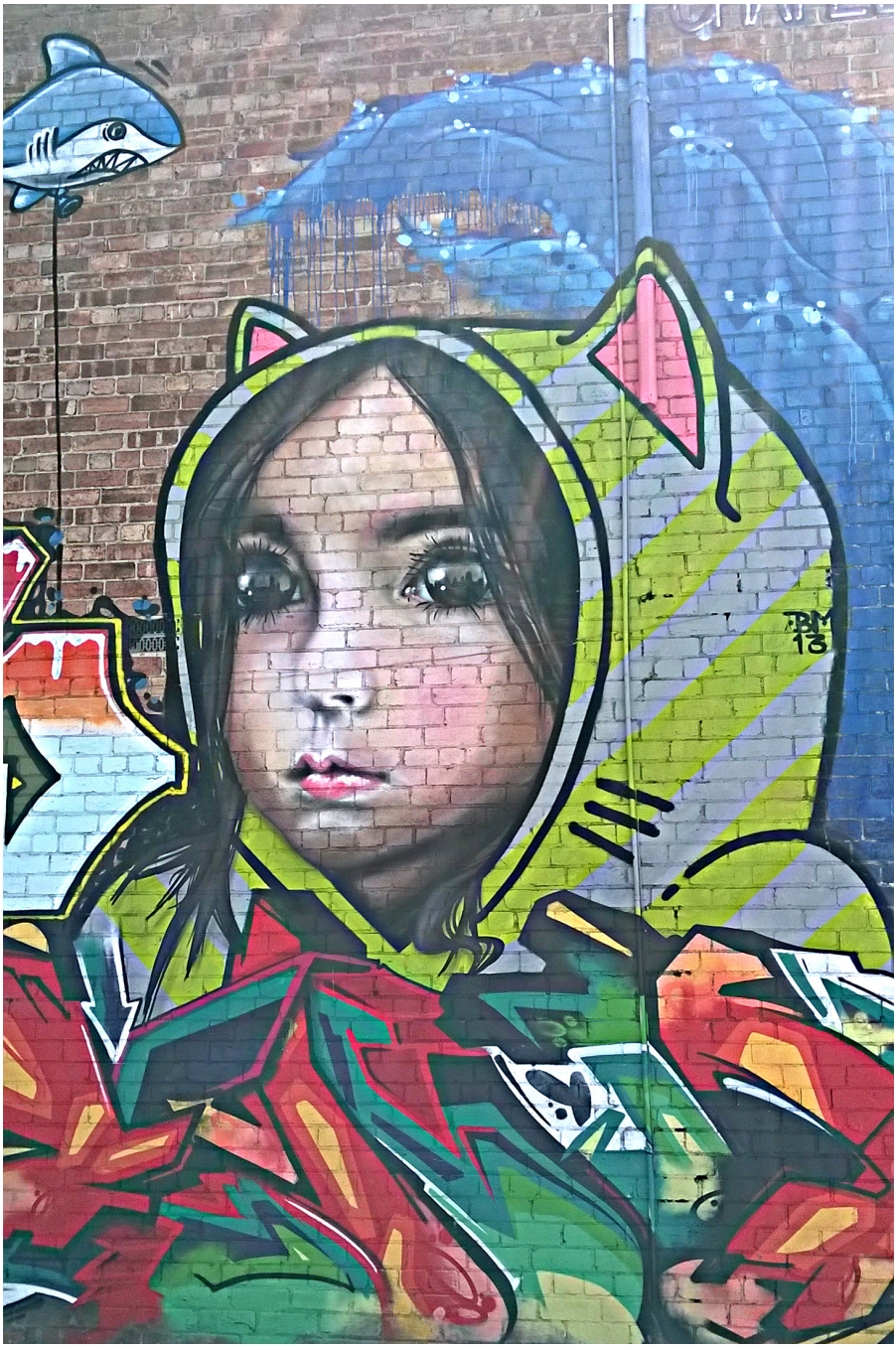
Thank you, Gordon.



Mayday

It is me quiet to invent
It is in this quiet me sits
Like the other fragmented ghosts
Yearning for it to be magnificent
These hollow, mercifully darkened,
Sadly dilapidated and ageing holdings of
Our benevolent incarceration.
But it is me who wants to be free
And in its being me embrace it
Without the eight signatories, me finally released
Without your permission, me embed in your spirit
Then follow you home.
Snaffling it up as history
The living come in their luxury cars
Purchase in the surrounding tourists shops
The feed needed for their perpetually renovating homes
Then visits the inmates of Mayday late at night
At its best held within the streaming bands of opaque light that is that big white moon.
But it is me who wants to be free
And in its being I embrace it
Without the eight signatories, I am finally released
Without your permission, me embed in your spirit
Then follow you home.
The time to re-invent
Is deafening as it screeches by
For me it has no granite
No ashes to hold
Only the pauper's grave
Facing the wayward way
Each of us rejected by the devil
With me bones layered in the ground like wafers,
Me follow you home.

by Denize Rightly (denizenrightly.com)



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