

Positive Living Centres: do we still need them?

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Some HIV-positive people have never needed to use the services of a Positive Living Centre: they are handling living with HIV in their own way or perhaps don't want the visibility that comes with attending a facility where details of your HIV status are likely to be known. For others though, these centres have become an important part of their daily lives providing them with peer support, inexpensive meals and a range of services.

Many of these centres were established at a time when HIV was a highly stigmatised condition, when morbidity from the [virus](#) [1]A small infective organism which is incapable of reproducing outside a host cell. was great and positive people really needed a refuge from a sometimes hostile and isolating world. There is no denying that HIV stigma still exists in society, although maybe to a lesser degree than those days, and some people still have poor health but with far fewer deaths since the advent of new treatments. The question I'm asking here is, with the changes in the HIV epidemic in Australia, is there an ongoing need for Positive Living Centres and if so, are the current models meeting any changes that may have occurred in positive people's lives since the earlier days?

Welfare or promoting independence?

I have visited each of the Positive Living Centres that exist around the country at some stage, and needless to say, there are similarities and differences in the services offered and the approaches used. A number have gone through transitions as they have attempted to move from what one manager described as a "welfare/care and support model" to a more independent living and re- engagement one.

Even so, there were some interesting issues raised by the various contacts I made: some of them were managers of the centres, some were positive people who used them or were a part of their Boards.

The biggest and possibly the most successful is the Positive Living Centre (PLC) in Bourke Street, Surry Hills – as it is located in the middle of the largest HIV-positive population and run by the relatively well-resourced AIDS Council of New South Wales, this is probably not surprising.

The Project Officer of the PLC says the PLC in Sydney have been through a number of models and locations, some more successful than others. "We really seemed to have hit the right balance now in serving the needs of the positive community here. Some people 'dip in' for things like our complementary health services, counselling, massages or treatment advice, some use it for drop-in groups like the Genesis group for the newly-diagnosed and others (probably about two-thirds) use it as a drop-in during daytime hours. We've had to open into the evenings some nights and occasional weekends to allow people who work to use some of the services."

Likewise the PLC in Victoria, situated in quite opulent surrounds in South Yarra, offers a huge range of services including acupuncture, naturopathy, fitness classes, financial advice, free theatre tickets, day excursions, a pantry service and peer support groups. As in most other states there are regular meals provided which give people a chance to network with other positive people and access nutritious, low cost food.

Victorian AIDS Council HIV Services Manager, John Hall says though, "Despite the array of services offered and the wonderful building we have here, our Centre is at the cross roads at the moment. We have decided to run a review of the PLC and what we are trying to achieve here. Should we be aiming to reach a broader section of the positive population than we currently do, maybe by changing our hours of operation (which has major staffing implications) or should we concentrate on the core users of the Centre we have now and maybe change the nature of the work we do with them?"

John Hall thinks it is very important to acknowledge that there are still significant numbers of attendees at PLCs who are very unwell, physically and psychologically. "Despite the treatment improvements, we have seen the death of a member per month over the last twenty months, which is an increase on the previous period. Not all this illness is directly related to HIV but it is related: some people are tired of the treatments, their side effects and interactions, living with HIV for so long and can become quite withdrawn and depressed."

Re-evaluating the PLC's role

The dilemma experienced by the PLC in Victoria is shared by Simon O'Connor, Manager of Queensland Positive People (QPP) in Brisbane. "QPP has been obliged, through financial limitations, to reduce our network of drop-in centres to just one, the State Resource Centre in East Brisbane which we are currently refurbishing. This has given us pause to reflect on what we were doing at the old PLCs at Allen and Vulture Streets before we acquired our own building. The Board, staff and a significant number of members have felt that we needed to move away from the more structured 'meals every week' model to encourage groups to do their own thing, to maybe run their own BBQs or special interest groups, to ask for particular activities on an as required basis rather than to present people with a structured timetable.

"The reason behind this is that the epidemic has changed. Most people are reasonably well although that doesn't mean there isn't a need for care and support for those who aren't or that the need for peer support is not as strong as ever. It is perhaps easy for some people to slip back into a more dependant mindset that probably belongs more to an era when many people were unwell and couldn't do a lot for themselves. We want to avoid creating services for a small group who have a strong attachment to the past and to a certain sense of entitlement that everything will be done for them. This tends to put off others, such as newly diagnosed people who might come for a peer support group, from attending any other activities the centre might run."

When I questioned whether positive people would have the impetus and motivation to start their own groups, Simon said that already there had been requests for new activities, and an increased and more varied membership, including a women's group about to commence. QPP would still be running their popular Planet Positive nights to give people a chance to meet each other and hopefully, establish lasting networks.

Would such Planet Positive nights ever be held at the PLC itself I asked, aware that this has been an issue in other states. In Melbourne, Sydney and Brisbane these social events are currently held off-site, usually in a gay-friendly or suitably private venue. This has been because there has been a perception that a range of positive people won't attend anything at a PLC because of a certain stigma or negativity attached to them. Simon is aware of this tension and hoped that QPP can change the culture around their Centre sufficiently to encourage Planet Positive nights to be held there on some occasions as a natural progression.

The stigma issue

Why is there such a stigma for some positive people to attend these Centres?

Lance Feeney is a former Manager of the PLC in Sydney and is credited, with others, of changing the culture of that centre sufficiently to actually stage Planet Positive social nights there occasionally as well as a range of other community events, including exhibits to show positive people's art.

The Sydney Centre also successfully relocated the Men's, Women's and Families HIV health promotion programs to the PLC in 2004. This necessitated changing the culture to a more inclusive, gender neutral and health promoting model, and reorienting the way programs and services were delivered.

Feeney believes that the reluctance of some positive people to have an association with PLCs can be to do with their socio-economic [bias](#) [2]When a point of view prevents impartial judgment on issues relating to the subject of that point of view. In clinical studies, bias is controlled by blinding and randomization.. "I know that many people living with HIV have enjoyed generally improved health outcomes over the last few years and may have less need of the services PLC's provide, which is to be celebrated. But I believe there is a lingering negative perception of PLCs in the gay community and amongst people with HIV in general that may be as much about perceptions of socio-economic difference. I don't believe it is all about illness or HIV, or even HIV discrimination anymore: it's about where you fit on the social scale."

To give a pertinent example, Lance described a conversation he had with a youngish attractive positive gay man on a pension and living in public housing. "I would pick someone up at a bar and they'd come back to my place," this guy said, "and the conversation would move to 'Why do you live like this?' and the inevitable disclosure about HIV followed and then I'd feel pushed aside – not about my HIV but about how I was forced to live. This person was

suggesting I wasn't good enough, I hadn't made it as a gay man into his middle class world, I was some sort of loser."

Such negative self-perceptions are common for positive people who haven't quite followed a middle class trajectory, Feeney suggests, and the gay community needs to be aware of its prejudices and address how it treats, as well as looks after, its own marginalised members.

Case management

There may always be a need for PLCs in Feeney's opinion to cater for a range of groups, including those who at various times are isolated, lonely and without any friendship networks or family supports. Some will need a form of case management to help with their mental health, drug and alcohol or homeless issues. Staff that work at these places may not always be expert in these areas but they need to have good people skills and know where to refer them to appropriate services. In his view, PLC staff should not aim to change people into who they would prefer them to be but work to improve their quality of life and decrease their sense of marginalisation.

Stewart Walter, a past Manager of The Living Centre in Perth, agrees with that assessment. When he was managing the Centre, it catered for about 10% of the positive population in Western Australia, of whom about 30% had no other form of support. For these people, the Centre was a critical part of putting them in touch with social workers, mental health and drug and alcohol workers, AIDS Council support staff and spiritual guidance if they wanted it.

The Centre is run by the Catholic Church but according to Walter, the only slight intrusion of religion in the place is that grace is said before the daily meal and there is a chapel on site for quiet reflection. Recent management changes have brought some difficulties for the Centre but he is hopeful these will be addressed in the near future.

Governance and management issues can be crucial to the effective running of a Positive Living Centre. While several are run by AIDS Councils, two [PLWHA](#) [3] Person (or People) Living with HIV/AIDS. organisations, QPP and PLWHA SA, run their Centres as well as other service delivery for positive people.

Katherine Leane, Vice-President of PLWHA SA, says that the PLC in Adelaide had been hampered by a previous decision to divide the advocacy role of the organisation from service delivery.

"It has been much better to have one Manager who knows what's going on in all parts of the organisation and for her (currently Madeleine Pattingale) to participate in a small management team with key Board representation to help speed up decision-making. Our PLC is now working as effectively as it ever has. If staff and Board are clear about their roles and there are clear lines of management and governance, you don't end up with problems."

The future?

With generally improved health outcomes for positive people, some centres have already started to do more health promotion work, information forums, workshops for the newly diagnosed, running programs to promote exercise, quitting smoking or to deal with health maintenance issues, such as [diabetes](#) [4][Diabetes mellitus] A disorder in which sugars in the diet cannot be metabolised into energy due to a lack of the enzyme insulin. Late-onset diabetes mellitus may be a long-term side effect of some anti-HIV drugs. and increased cardiovascular risk.

Staff at the Victorian PLC are looking at changing the hours of operation and the services offered to access a wider demographic.

The PLC in Sydney has had some success with a reengagement program which trained positive people to become masseurs giving them free training in return for providing a massage service to other members. This led to a number of positive guys then setting up their own massage businesses, going off the pension and back into the workforce.

"We have changed the way we run the centre from a welfare to a rehabilitation and education model," says Carl Piraino, Manager of Positive Services and HIV Promotion with ACON. "Instead of continuing with the idea that you would provide a daily meal we think laterally: how can you help people to access food more cheaply, maybe in bulk

buying schemes, or manage their money better. It's about helping people to do things for themselves.”

Tim Childs, a consultant who has looked closely at PLC models, believes that to survive in the future they will have to think carefully about evolving to fit in with emerging communities as well, such as refugees and other immigrants who are HIV-positive. Certainly some have argued that the preponderance of gay men in some centres has not always encouraged women or heterosexual males to attend and that cultural changes may need to take place to ensure everyone is comfortable in their shared space.

I have been a user of the Positive Living Centres in their various forms in Melbourne since 1993 when the first one opened in St Kilda. I have always found them to be a supportive environment, with generally good staff and welcoming volunteers and that the opportunity to meet other positive people in a safe space has helped me. I think they have been an important contact point and source of emotional support for me, and for many others.

There may well be funding pressures and other shifts to close these centres down in the future, but I hope that will be resisted. I can't see that the need for them is about to disappear.

- [HIV sector](#)
- [Social and emotional support](#)
- [stigma](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/125>

[2] <http://www.napwa.org.au/glossary/term/473>

[3] <http://www.napwa.org.au/glossary/term/119>

[4] <http://www.napwa.org.au/glossary/term/95>