

When you don't know anyone else who is positive, and you're afraid to approach services because it seems they're not for you, how do you find out about living positively? This is the dilemma faced by positive heterosexuals.

## **NOTES FROM THE TRENCHES: PEER SUPPORT FOR HETEROSEXUALS LIVING WITH HIV/AIDS**

Pozhet (the Heterosexual HIV/AIDS Service) began in 1993 as a tiny NGO with a volunteer peer facilitator running small positive support groups. By 1998, it was a mainstream state wide service funded by NSW Health, and by 2006 in contact with nearly 500 positive straight men and women. How had we moved so far from such a small beginning, and what lessons can we share with others building peer support programs for this group of people?

For over a decade in NSW, from the first diagnosis of HIV to the advent of treatments, heterosexuality and HIV/AIDS were unaccounted for in policy, largely absent in health programming and barely spoken about in the HIV/AIDS media. Yet one in five infected with the virus was living heterosexually with the disease.

At the same time, heterosexuals living with HIV/AIDS remained hidden from mainstream HIV/AIDS services and posed particular challenges for peer support. The reluctance among straight positive people to have any direct, especially face-to-face, contact with HIV/AIDS organisations paralleled their position as 'cultural outsiders' within the HIV/AIDS sector and community.

Since the early days of the epidemic, peer support groups had 'positive only' memberships and were designed primarily for gay men. The standard approach to peer support focused on the needs of the positive individual and did not include those around that person also living with this reality. It generally used one mode of delivery—the 'tell us how you feel' group, seated in a circle and facilitated by a positive person or a health worker.

In the mid 1990s, when combination therapies became available, differing views on what constituted peer support emerged, not only from service providers but also on the part of the HIV positive person. Siebert and Dorfman (1995) discovered that while many HIV infected persons tend to seek group support, the participants' sense of belonging and satisfaction with it could vary greatly<sup>1</sup>.

At Pozhet, we recognised that meeting positive straight people's need for 'belonging and satisfaction', and overcoming their reluctance to take part, depended on understanding the unique characteristics of heterosexuality and the HIV/AIDS experience. It was clear that a new, more suitable model of peer support was needed, one that was uniquely about living heterosexually with HIV/AIDS.

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<sup>1</sup> Siebert, MJ & Dorfman, WI 1995, 'Group composition and its impact on effective treatment of HIV and AIDS patients', *Journal of Development and Physical Disabilities*, 7, pp. 317-334.

## **Changing language**

We started with language, which in the sector had worked to disenfranchise the experience of positive straight lives. The first major challenge was to translate complex medical terms and the gay-specific language in HIV health promotion, media articles and advertising into a spoken and written language that would have an everyday meaning for our target group.

In Sydney, the word ‘heterosexual’ did not appear in the HIV press before 1996. Positive heterosexuals were buried under phrases such as ‘others living with HIV/AIDS’, ‘non-gay identified’, and ‘other people living with HIV/AIDS’. Men and women partners of a positive heterosexual person didn’t rate a mention.

So we coined new words or used existing words in unusual ways. We placed the extremely clunky phrase ‘positive heterosexuals’ front and centre, believing that as it was used more and more throughout the HIV/AIDS sector the penny would finally drop—we existed and our needs were specific and legitimate. We shortened the term ‘positive heterosexuals’ to ‘pozhet’ and ‘serodiscordant’ to ‘pozneg’, running pozneg workshops from the mid nineties. We used the phrase ‘men and women living heterosexually with HIV/AIDS’ to get across the idea that there is a community of people who are living with HIV/AIDS in ways that are heterosexual—that they are not just straight people with a diagnosis tacked on to them, which can be dealt with in the usual way.

## **Everybody is included in the peer support model**

We made inclusivity *the* goal and while around us the HIV/AIDS sector was using the phrase ‘people living with HIV/AIDS’ to mean positive people only, thereby creating a serostatus apartheid, we redefined PLWHA to mean positive people, their partners, family members, friends and colleagues: in other words, the positive person and all those people who because of their relationship with this person also lived with HIV/AIDS. Distinctions between the positive and negative experience then came within that definition, and enabled us to keep sight of the whole truth—that is, that people live with HIV with others, in groups (not matter how small), and not in isolation.

Heterosexuality is about men *and* women, a truism that seemed to have escaped most services, as peer support for straight people was generally conceived of in gender terms. We believed that peer support for heterosexuals began with men and women supporting each other. With men-only and women-only support programs, heterosexuality rapidly disappears, gender-specific issues dominate and concerns around relationships, communication and sexual intimacy become harder to address as the ‘other half’ of the equation cannot be present.

We were also keenly aware that positive straight people do not have a tangible community, with sign-posted meeting places and ways of drawing its members into the fold. Straightpoz people are extremely protective of their sero-identity, and have very little contact with each other outside peer support settings. Thus, peer support becomes the community, because this is the space in which community happens. Thus, peer support for straightpoz people is vital for their health and well being.

In response, we made a paradigm shift in our thinking about peer support delivery, to conceive of it as a process for building a community. We began to focus on the needs of the group, as well as the individual, and chose the metaphor of ‘the village square’ as our guide.

In developing peer support activities, we tried to replicate our picture of this particular space: the village square, where positive heterosexuals gathered together, was an inclusive space, where old and young, male and female, from whatever cultural background, came to talk, laugh, listen, observe, reflect, flirt, eat, dance and sing. A lot could happen in the village square. People come and show their wares. Announcements are made. Secrets are shared. Relationships are formed, and sometimes broken. It’s a place of bustle and of quiet. Once visited, it stays in the mind’s eye, an ongoing source of support.

Thus, we made the Pozhet flagship event not the traditional positive support group meeting, but an ‘open house’, held in the evening, where everyone living heterosexually with HIV/AIDS was welcome. We brought together men and women, partners and family members, friends and workmates, all of whom, whether positive or negative, had the virus in their lives.

At the same time, we created a positive straight presence in the HIV media by routinely providing articles about positive heterosexual life, health promotion, and advertisements for events. This reinforced for straightpoz people across NSW that their community was alive and well and could be easily found, and signaled to the HIV/AIDS sector that the positive straight community was in business.

A freecall line enabled men and women to get in touch with the program, and a monthly mail out ensured that the program stayed in touch with them, even if they could not attend events. We closed the gap in resources for positive men and women and their families by developing and publishing *Changing lives: a resource for heterosexual people living with HIV/AIDS*, and *Sex matters A-Z: sexual health for heterosexual couples living with HIV/AIDS*.

### **Integrated program areas**

The Pozhet peer support program was developed into an annual calendar of events based on five core program areas. These areas were designed as an integrated package that could encompass the newly diagnosed, the HIV veteran, all people within the extended private space of the positive person, the separate issues faced by positive men, positive women, and partners, positive family life, people who could not access face-to-face support, and the ongoing need for the latest HIV information.

The program uses as wide a variety of delivery methods as possible—facilitated peer support in small and large group settings (open house events, and events based on serostatus and gender), retreats and social outings, major workshops, telephone counselling, mail outs, website, and outreach across the state.

We drew upon a range of disciplines in the design and delivery of the program:

- customer service—the client is a consumer and customer, not a patient

- marketing and public relations–Pozhet is a product marketed to these consumers
- relationship management–straightpoz people are wary consumers, difficult to access, and not a captive audience
- adult education–adults prefer learning skills through practical experience, and from each other.

We also modeled the approaches used in vocational education and training to identify what straight positive people and their families needed to be competent in to live effectively with HIV. In designing events and activities, we focused on what participants would learn, as well as what they would experience in support from their peers.

In response to the lack of connection positive heterosexual people have with HIV/AIDS services and to promote their independence around health decision-making, we gave priority to exposing clients to a broad range of health care options. Health care practitioners are programmed to present at events, and up to 30 health care workers a year from a wide variety of disciplines contribute and have contact with clients attending activities.

### **Building history**

Very little by way of a straightpoz community existed before Pozhet began in 1993. To strengthen the sense of community as it grew, we reinforced its history and continuity by celebrating milestones and achievements with special events and media articles. We also worked on building a spirit of place for a group socially displaced by HIV, by using as much as possible the same venues for events, and choosing ones where clients felt safe and secure, and with which they could form an attachment as their own positive space.

### **Lessons we have learnt**

In bringing together a socially and geographically isolated and diverse group, we have learnt there are key ingredients for success in providing them with effective peer support:

- Never underestimate the power of language–change it if it doesn't reflect the reality you're dealing with
- Develop a structured, layered program, with elements working with and off each other to maximise client access and interest and service profile
- Work out the natural groupings of clients (everyone together, men only, women only, and so forth) and create program elements around them
- Make inclusivity the goal, and check that the program has no hidden barriers in it
- Be routine, predictable, guaranteed–if you advertise it, do it!
- Use venues that have accessibility, privacy and safety, and that are straight friendly
- Set up an point of entry into the program, for example, a free call line, that gives clients the option of remaining anonymous
- Stay in touch with clients through regular contact that also gives good quality information
- Routinely ask clients what they want, and listen to them

- Provide variety: it's not all about treatments and health maintenance
- Deliver a balance of events in metropolitan, regional and rural NSW
- Offer scholarships for major events for clients who can't access support
- Maintain a strong media presence

These lessons have been learnt through hard work, constant reflection on practice and maintaining close contact with clients and the insights they bring into living with HIV/AIDS. Hopefully, delivering peer support to people living heterosexually with HIV/AIDS will mature even further, as the experience of straightpoz life is better understood within the HIV/AIDS sector.

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