

## Young and HIV-positive: getting the hang of treatments

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Daniel Reeders has done shifts for the Connect Line information and referral phone service run by [PLWHA](#) [1] Person (or People) Living with HIV/AIDS. Victoria in Melbourne. One night he received a particularly thought-provoking call...

It was a really challenging call. A young gay man – my age – just diagnosed HIV-positive. It was a Saturday evening in winter, and I stayed nearly an hour past clock-off time, just talking. Contain and summarise? Forget about it. New diagnosis calls are always hard, and we let callers take the time they need. The phone line we operate in Victoria provides information and not counselling, but my caller was already drowning in new information; what he wanted was help making sense of it all. What's going to happen to me, and when? The uncertainty and inactivity of the open-ended timeframe ("sitting around, waiting to get sick") was the hardest thing for him to handle.

The hardest thing for me was getting my head around his view of treatments. It has been 12 years since the treatments revolution and attitudes have changed a lot since then, but the availability of effective treatments still seems reassuring to me. Not so for my caller, for whom the onset of treatments felt like the first harbinger of sickness and death. In particular, he was terrified of side-effects changing his body shape. The tricky part was thinking through what an HIV-negative person in his twenties knows about treatments, and how that is transformed when a positive diagnosis makes it all personal.

### Fear of treatment side effects

For instance, without any fear campaign about treatment side-effects, he clearly knew about lipodystrophy – bad news travels fast.[1] But nobody is telling negative men about newer treatment protocols designed to avoid medications with the side-effects that caused so much distress for treatment-experienced people with HIV. On the contrary, there has been great concern about the possible emergence of treatments optimism, and media coverage hastening to warn negative men that treatments are no picnic.[2] However, the beliefs and attitudes a negative person has around treatments don't evaporate into thin air when they are diagnosed. In fact, they play an important role in the development of self- [efficacy](#) [2](Of a drug or treatment). The maximum ability of a drug or treatment to produce a result regardless of dosage. A drug passes efficacy trials if it is effective at the dose tested and against the illness for which it is prescribed. In the standard procedure, Phase II clinical trials gauge efficacy, and Phase III trials confirm it. around adherence.[3]

Another aspect which struck me about the caller's experience was the passivity involved in waiting for unseen biomedical markers to tick downwards towards a certain abstract threshold, at which point he expected his doctor would make a decision to commence treatment. He and I would both have been in primary school when plwhiv community leaders first began fighting for access to then- [experimental](#) [3](Of a drug) Not licensed for use in humans, or as a treatment for a particular condition. Experimental drugs are studied in clinical trials to determine their safety and efficacy, and are sometimes made available via Special Access Schemes prior to their approval. HIV medications.

### Lessons not passed on

From personal histories communicated by positive speakers, retirement speeches by clinicians and researchers, and the autobiographies (and sometimes obituaries) of plwhiv community figures, I have learned how plwhiv once fought to keep abreast of continually shifting medical knowledge about the best approaches to treatment. But without a similar connection with plwhiv organisations, a negative (or newly positive) man in his twenties would have no reason to know about this fight.

In his work on cultures of care, Michael Hurley has documented how community-based organisations contributed to this fight by digesting and translating biomedical knowledge into everyday language.[4] Telling stories about treatment experience, including missing doses and [resistance](#) [4]HIV which has mutated and is less susceptible to

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the effects of one or more anti-HIV drugs is said to be resistant, and coping with side effects and toxicities, as well as trusting and questioning and even challenging your doctor, seems like an increasingly vital part of this process.

## Treatment decisions: not your own?

As a positive person, if the decision to commence treatments isn't your own, and you don't feel entitled or qualified to participate in the decision-making process, your motivation for adherence might be brittle. Setbacks including missed doses and emergent resistance may further dent your self-confidence, creating a vicious cycle as you move on to second- and third-line combinations with more complicated dosing and side effects.

The solution is not a simple matter of encouraging newly diagnosed people with HIV to take a more active interest in their own medical care. Increasing complexity of HIV treatment technologies is changing the role of the patient and his or her doctor(s). The more we learn about side-effects, the trickier it becomes to juggle the many competing considerations informing the choice of a treatment combination. Genetic testing for sensitivity to certain drugs or the resistance profile of your own personal [strain](#) [5][HIV strain] Any subgroup of the HIV species. Because HIV mutates very easily, there are many different strains (and may be multiple strains within a single person). of HIV adds a whole new layer of terminology.

## HIV complexity also an issue for doctors

As a result, patients are relying more on doctors to make treatment decisions for them. In research conducted in Britain, Marsha Rosengarten and colleagues have shown that HIV doctors themselves feel quite uncomfortable about this transformation, as it shifts responsibility onto them for decisions that could affect their patients' future health.<sup>5</sup> Clearly there is pressure on both sides of the [clinical](#) [6]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. relationship, and more work is needed to understand how this has transformed the patient role in clinical decision-making.

At the same time, HIV Futures shows people with HIV moving away from service organisations and relying more on doctors as their primary source of treatments information. This suggests clinical practice might benefit from a solid dose of User-Centred Design – a discipline concerned with enhancing the accessibility of complex information for non-technical audiences. However, younger and newly diagnosed positive people don't just need information; they need stories and role models showing how to create the kind of treatment relationship that works for them.

## Treatment generations?

After taking that call, I began to wonder how age inflects both positive and negative gay men's relationship to major milestones in the HIV epidemic like the advent of [HAART](#) [7]Highly Active AntiRetroviral Therapy ??? aggressive treatment of HIV infection using several different drugs together. in 1996, and whether the differences are significant enough to produce 'treatment generations'. For instance, guys becoming positive in their thirties were just coming out when AIDS deaths peaked in the early nineties. What happens when guys who came out post-1996 hit their thirties? Unfortunately, there is very little Australian social research on the topic.

One ray of light came from a presentation given by Ben Bavinton and James Gray from ACON at the [AFAO](#) [8] Australian Federation of AIDS Organisations. AFAO is the peak non-government organisation representing Australia's community-based response to HIV/AIDS. AFAO's work includes education, policy, advocacy and international projects. Educators' Conference in May. Recognising very low rates of service usage by young HIV-positive men in Sydney, ACON commenced a year-long consultation process, using an action research methodology and peer leadership development strategies. Over five discussion nights they elicited attitudes and experiences around sex, mental wellbeing, drugs and alcohol, relationships, disclosure, health and treatments.

Interviewed later by phone, James said, 'Only a small number of participants were on treatments; the rest had quite low levels of treatment-specific knowledge, but a high level of trust in their doctors and good communication – they trust their doctors to make a decision about the right time to begin treatment'. Having trust in your doctor is a good thing, but the challenge for positive health educators is making sure it's not a mixed blessing—blind trust. A report on the consultation will be released in October, following a careful process of checking back with participants to ensure the underlying thematic analysis reflects their experience. As for my caller on that winter night, he called

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back a couple of times, and then stopped – I hope because he was beginning to get the hang of things.

### References

1. Cf. Slavin S, Batrouney C and Murphy D (2007) "Fear appeals and treatment side-effects: an effective combination for HIV prevention?" *AIDS Care* 19(1),130-7.
2. Tim Jeanes (2005) "HIV successes pose new problems", AM, ABC News Radio, Aug 25  
<http://www.abc.net.au/news/newsitems/200508/s1447414.htm> [9].
3. Self-efficacy means the all-important confidence you have in your ability to carry something out. See: Bandura (1999) "Social cognitive theory: an agentic perspective" in *Asian Journal of Social Psychology* (2), 21–41
4. Hurley, M. (2002) *Cultures of Care and Safe Sex among HIV-Positive Australians*, [ARCShS](http://www.latrobe.edu.au/arcshs/) [10] Australian Research Centre in Sex, Health and Society, part of La Trobe University in Melbourne. For further information see <http://www.latrobe.edu.au/arcshs/> [11]. Monograph 43.
5. Rosengarten, M. and Imrie, J. and Flowers, P. and Davis, M. and Hart, G. (2004) "After the euphoria: HIV medical technologies from the perspective of their prescribers" in *Sociology of Health and Illness* 26(5):575-596.

- [children and young people](#)

### Links:

- [1] <http://www.napwa.org.au/glossary/term/119>  
 [2] <http://www.napwa.org.au/glossary/term/486>  
 [3] <http://www.napwa.org.au/glossary/term/491>  
 [4] <http://www.napwa.org.au/glossary/term/109>  
 [5] <http://www.napwa.org.au/glossary/term/190>  
 [6] <http://www.napwa.org.au/glossary/term/475>  
 [7] <http://www.napwa.org.au/glossary/term/96>  
 [8] <http://www.napwa.org.au/glossary/term/385>  
 [9] <http://www.abc.net.au/news/newsitems/200508/s1447414.htm>  
 [10] <http://www.napwa.org.au/glossary/term/406>  
 [11] <http://www.latrobe.edu.au/arcshs/>