Positive Education
Part 2 –
Treatments Issues

This is part 2 of a 3-part document about positive education in 2002

Treatments Issues

In 1996, highly active antiretroviral therapy (HAART) arrived. Its impact on individual PLWHAs was immense – ranging from increased life expectancy and changed expectations, having to engage with a more complex set of treatments information and decisions, grappling with long-term side effects and impacting on a wide range of psychosocial issues. In the intervening period 'new treatments' as they were called were implicated in all sorts of cultural shifts and behavioural change with 'treatments optimism' one of the factors investigated as being possibly linked to rises in unprotected sex. Six years later some of the shine of 'new treatments' has begun to wear off and we are only beginning to understand the dimensions of the cultural shifts that have occurred for gay men and PLWHA in that time.

When 'new' treatments arrived, a number of people[13] wrote about the implications of these treatments for education, and of the need for treatments workers to form a coalition with gay educators to learn from strategies employed in gay education. What most of this writing focussed on was the need to move beyond the provision of complex information as an end in itself to 'education'. As Hurley[13] notes 'Treatments information is often spoken about as though it's simply a matter of how to circulate complex informational content and how to translate this into personalised treatments decisions. In practice it is seen as having little to do with other educational practices and practitioners. Sometimes this results in a fetishising of information, repetitive circulation of already known matters and a disregard for more efficient, peer supportive educational practices and infrastructure building." The Positive Education and Information strategy[14] defines eduction in simple terms as 'the process by which information is conveyed in a way which allows the asker to develop an understanding or skill.' Hurley[13] notes, "How education as the programmatic facilitation of learning is separate from, as well as connected to, information circulation and client services. It is a separate activity in its own right whether used as mode of delivery, implementation technique or a form of professionalised peer support."

The arrival of the protease class of drugs and the increased range of combinations and choices resulted in a huge increase in information flow. The quantity of the information, its diverse nature, and what it means in terms of decision-making and living with HIV meant the demands placed on treatments officers and the providers of information were far greater. And just as the information became more complex, so did the set of issues that were associated with HIV and its medical management. Yet paradoxically, just as the sophistication of treatments information increased, both community focus and the individual interest of people with HIV in treatments information declined. This is only one of the many contextual 'cultural' factors affecting the ability to deliver treatments education.

The rest of this section briefly summarises a number of known issues around which it may be appropriate to develop educational interventions. Recommendations are made at the end of each issue relating to educational interventions although there are often associated policy and advocacy issues. The recommendations are read as ANET although the actual work may be done by one of the other bodies such as ATPA or NAPWA involved in treatments education. In reading each issue it is important to remember that each issue is not automatically solved by the traditional approach of the scientifically dense information booklet, that educational intervention implies not just information but the 'programmatic facilitation of learning' and that changes in the cultural contexts and interests of PLWHA in treatments information necessitate a careful re-examination of the appropriate technologies to deliver information and education.

Treatment issue 1: Compliance and Adherence

When HAART first arrived, two constant issues associated with it were 'treatments uptake' and 'compliance and adherence'. The evidence on the effectiveness of these treatments was compelling, resulting in some fervour about the need to get the message out. And given the hopes about future possibilities – particularly the theoretical notion of viral eradication – then people on the medications needed to minimise their chances of developing any resistance to the medications by 'complying' with the recommended dosing schedules.

It became commonplace to label compliance as the single biggest issue facing people with HIV. A number of reports were commissioned, including a report by Lowe and Malcolm for NSW health and a literature review for AFAO[15,16]. In a paper to HIV/AIDS & Society[17], HIV educators proposed 'a positive capacity model' rather than 'a deficit correction model' for compliance education and outlined the possible role for educational interventions designed to support those that occur in the clinic. Since that time there have been a very small number of compliance educational initiatives in community settings.

As the glow of HAART has gradually worn off, with the promise of viral eradication seen now to be extremely unlikely and an increasing awareness about the long term toxicities associated with these drugs, then the fervour around compliance as 'the single issue' has diminished. It is increasingly realized that in the long term the most effective treatment taking strategy may involve structured breaks from treatments – that is there is a balance between minimising harmful side effects and maximising long-term antiviral effects.

As a result of the changed understanding of HAART in the longer term, the far more common discussion currently is about treatment breaks – and as a result there is a tendency to conflate 'treatments breaks' with 'compliance'. Yet there is now considerable evidence that non-compliance is a significant factor in health outcomes. For example recent data from the UK observational database (ref Gazzard at retroviral conference) showed that a number of repeated short breaks (i.e. episodes of non-compliance rather than structured or planned breaks) from HIV treatments was associated with treatment failure and the development of HIV-related illness. While education about compliance and planned or structured treatments breaks may be given together, the position taken in this paper is that it remains important to keep the two conceptually separate.

Recommendations on compliance:

a. That ANET compile key documents on compliance developed over the last five years and write a brief educators guide to compliance education

interventions in different settings (counselling, one-on-one peer work, peer groups, printed information) and distribute this as a kit to HIV educators

Treatment Issue 2: Changed blood tests including Resistance Assays and Therapeutic Drug Monitoring

Since the advent of HAART, there are new tests associated with its use and different meanings and importance given to some of the results in a standard full blood examination laboratory report.

Resistance assays, that may help determine which HIV drugs an individual is resistant to, were developed in the late 1990s. Considerable quality assurance issues and debate that is ongoing about when and how the tests should be used accompanied their introduction.

Therapeutic drug monitoring (TDM) – that is testing the blood for drug levels – to help make dosing decisions tailored for the individual – is similarly a new test which may become increasingly important in clinical management. There are both quality assurance issues and interpretation issues associated with TDM.

However given the importance of resistance and appropriate dosing, then with increasing experience and knowledge, it is likely that both these tests could become a common part of HIV management.

A number of side effects associated with these drugs are associated with changes in some of the common tests that are part of the standard full blood examination such as cholesterol levels and triglyceride levels.

Recommendation on common blood tests

a. That ANET produce a user-friendly short resource explaining the common blood tests used in HIV management.

Treatment Issue 3: Side effects and their management

The major long-term side effects associated with HAART include:

- Lipodystrophy and Lipo atrophy
- Osteopenia
- Cardiovascular side effects (although this has so far been mostly marked by increases in blood levels of cholesterol more impact is anticipated in the longer-term)
- Persistent Diarrhoea

The medical management of these side effects has often focussed on additional pharmaceutical interventions such as anti-diarrhoeal medications and the investigation of the relatively new drug rosiglitazone as a possible treatment for lipodystrophy.

Many of these side effects have associated risk factors – such as diet, fitness and smoking and cardiovascular disease. There are increasing numbers of case reports of the successful use of diet and exercise programs to both treat and prevent some of these side effects. Most of them usually comment on the difficulty in maintaining these programs and the need for appropriate support mechanisms.

Recommendation on side effects:

a. ANET develop a discussion paper on the role of diet and exercise in relation to side effect management that canvasses both the scientific information and the possibility of doing targeted programs such as ACON's successful gym program for people with HIV both as effective health interventions in themselves and as a mechanism for engagement with people with HIV on a broader range of issues
b. ANET update and reproduce the Victorian PLWA side effects booklet for national distribution
c. ANET develop a discussion paper on smoking and its relationship to side effects that canvasses the available scientific evidence, reviews available anti-smoking programs in terms of their availability, success and costs and investigates the possible location of anti-smoking programs with community based AIDS organisations

Treatment Issue 4: Treatment breaks

There is increasing anecdotal evidence that more PLWHA are choosing to take breaks from their HIV treatments – however data on drug usage rates in Australia does not support the contention that presently this is huge numbers of PLWHA.

Data from the observational database[18] shows that the most common reason for a break is side effects from treatments. The decision to take a break may be influenced by other PLWHA who have taken this decision.

There is an emerging volume of scientific data and theory to better inform this decision – although it will be a few years before large clinical trails designed to test different structured treatment breaks strategies against continuous therapy in particular populations of PLWHA begin to provide the answers necessary to inform clinical practice.

Taking a break from HIV treatments without appropriate monitoring may for some people be a critical (life and death) health decision.

Recommendation on treatments breaks

a. A campaign on treatments breaks is part of ANET's current work plan. Given the likely long-term importance of this issue, there is likely to be a need for follow-up projects that should be identified as part of the evaluation of the current campaign.

Treatment Issue 5: Treatment information for recent seroconverters

There is both increasing consensus and emerging evidence that provided treatment commences soon after infection it may be possible to significantly improve long-term outcomes and that it may not be necessary for the person who has recently become infected with HIV to stay on antiviral treatments continuously. The HIV-specific CTL (cytotoxic T-lymphocyte response) has been shown to be lost quite early in HIV disease due to initially being overwhelmed by the post-infection burst of HIV replication. It is believed that antiviral treatments given close to seroconversion may help preserve this HIV-specific CTL response, and thus improve the body's "natural" defences to HIV in the longer term.

As a result, the treatments decision confronted by a person who has just been identified as seroconverting is time critical. In the past, unless a newly identified HIV

infection was associated with HIV-related illness, then the decision about treatments was one that could wait while the individual adjusted to the personal meaning and significance of a HIV-positive diagnosis.

There was a lot of research on the personal impact of receiving a HIV-positive diagnosis when the HIV epidemic was new and HIV antibody testing began. The subsequent experience was then often described as similar to post traumatic stress syndrome. While that experience may be different, there is no evidence that either improvements in treatments or changes in the cultural context and attitudes, has diminished the magnitude of the personal crisis that individuals experience upon receiving a clinical diagnosis.

It is often the case currently that there will be clinical trials of antiviral drugs designed to answer questions about the optimum way to treat people close to seroconversions.

This often means that at a time of personal crisis a recent seroconverter not only has to make a quick decision about whether to go on HIV treatments or not, but additionally is confronted with the potentially difficult questions of informed consent and clinical trial participation.

The AIDS Council of NSW HIV-positive men's support project has been doing a project aimed at developing resources and educational interventions about the treatments decision for recent seroconverters.

Recommendation on recent seroconverters

a. ANET produce a resource on clinical trial participation and the questions of HIV antiviral treatments targeted specifically at recent seroconverters

Treatments Issue 6: Interactions with anti-depressant medications

Depression and mental health amongst people with HIV has received considerable attention in the last few years. Appropriate strategies to deal with mental health issues for people with HIV have been developed or are under development in some states and territories. This issue is further canvassed in the psychosocial issues section of this document. This item is particularly concerned with interactions between medications for mental illness and their interactions with HIV antiviral medications.

29.7% of the sample of the Futures II survey[19] had been taking medication prescribed for depression in the last six months. A similar proportion (26.5%) had taken medication for anxiety and 5.5% of the sample indicated they had taken anti-psychotic medication.

There are potentially significant interaction between some of the drugs used to treat these conditions and HIV antiviral drugs. Additionally, there are a number of novel (new) antidepressant agents and a number currently in development. Consumer information about these drugs and their interactions with HIV medications has not usually been part of the set of 'technical' treatments information produced by treatments officers or community based treatments publications. Given the high percentage of PLWHA on these medications this should be considered part of the core set of treatments information.

Recommendation on anti-depressant medications

a. ANET produce a brief information resource on anti-depressant medications and their interactions with HIV antiviral medications

Treatments Issue 7: Hepatitis C co-infection

In Australia approximately 10 percent of people with HIV have hepatitis C co-infection. Hepatitis C is usually a slow disease but it is accelerated significantly in people with HIV. The impact of hepatitis C on HIV is less clear.

Treatment in people with both HIV and HCV is more complicated as, paradoxically, in some instances an increased level of immune system functionality can worsen some of the symptoms of hepatitis C (which can be due to the actions of the immune system itself). In general however the goal of treatment is to treat HIV first to build immune function and then treat hepatitis C infection (as hepatitis C treatment outcomes improve with immune system functionality).

Knowledge of treating co-infection is improving all the time, with improving outcomes for many people. Treatments for, and the understanding of, hepatitis C natural history are also improving. This significant improvement in knowledge would lend itself to a targeted resource of Hepatitis C and HIV co-infection.

New research concludes that treating HCV very early on (during acute infection) with a course of interferon can prevent chronic hepatitis C from taking hold in an overwhelming majority of cases[20]. This increases the importance of early detection and regular screening.

Recommendation on Hepatitis C and HIV co-infection

a. That ANET produce an information resource on hepatitis C and HIV co-infection

Other treatments recommendations

a. That given the increasingly 'privatised' and 'individualised' HIV-positive experience, and the resulting increasingly pivotal role of the relationship between a person with HIV and their primary medical practitioner, ANET develop a discussion document on working with GPs in the delivery of health promotion campaigns
b. That ANET investigate the Internet as a delivery mechanism for a treatment associated educational intervention
c. That the treatments component of this plan is discussed with ATPA and NAPWA and that co-ordinated mechanisms of annual planning be discussed.
d. That ANET do an evaluation / focus testing on the current core set of treatments information resources in order to develop a new set of style guidelines for the production of new (and reproduction of old) treatments resources.

13. See references in Hurley, Michael. A Report on the Work of Members of the Treatments Officers Network from an Educational Perspective. Working paper 2. AFAO/ARCSHS Researchers in Residence Program
14.Positive Information and Education Strategic Plan, Australian Federation of AIDS Organisations, National Association of People Living With HIV/AIDS. June 1998.
15. Lowe D. & Malcolm A. (1997). Health outcomes Demonstration Project: HIV/AIDS Treatments Uptake and Compliance. Report for the AIDS/Infectious Diseases Branch, NSW Health Department.
16. Dutertre, S., Petrony S., Dowsett G., and Grierson J. Compliance Education Literature Review. AFAO Monograph Series: No 2
17. Brotherton, A., Murphy D., and Sotiropoulis J. Treatment compliance/ concordance education beyond the clinic – paper to HIV/AIDS & Society Conference, 1998.
18. Australian HIV Observational Database. Biannual Report. Volume 2, Number 2: December 2001. National Centre in HIV Epidemiology and Clinical Research.
19. HIV Futures II. The health and Well-Being of People with HIV / AIDS in Australia. Jeffrey Grierson, Michael Bartos, Richard de Visser and Karalyn McDonald. March 2000. Monograph Series Number 17. The Australian Research Centre in Sex, health and Society.
20. Jaeckel E, Cornberg M, Wedmeyer A et al. Treatment of acute hepatitis C with interferon Alpha-2b. New England Journal of Medicine. 2001:345 1452-457.