



National Hepatitis C Health Promotion  
Workshop

Adelaide – February 2004

**New Approaches to Hepatitis C  
Prevention**

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## **OH1 - Introduction**

Good Morning. I would like to begin by thanking the AHC for inviting AIVL to present in this very important session on the theme of “New Approaches to Hepatitis C Prevention”. In order to do this though, it is necessary first to reflect a little on where we are now, how we have got to this point and then move on to what AIVL sees as the road ahead for hepatitis C prevention. In particular I am going to focus on:

- some of the “successes” or positive things we have achieved in relation to hep C prevention over the past few years;
- then I will look at some of the barriers or things that AIVL believes are getting in the way of us making further progress on hepatitis C; and
- finally I will take a brief look at what AIVL believes are the “keys” to hep C prevention and moving forward.

## **OH2 - Successes:**

When faced with over 250,000 people already infected, 16,000 new infections every year and most of those amongst people who currently inject drugs, it is sometimes hard to remain positive and upbeat about hepatitis C prevention. Sometimes we get too focused on what we haven’t done, what we can’t change and how big the problem seems.

While this is in many ways understandable, it is precisely times like these, when the challenge of preventing the further spread of hep C seems almost impossible, that we need to remain focussed on the gains we have made. It is easy to feel like it is all too overwhelming and that the odds are just stacked against us. But it is important to remember some of the small steps forward, to reflect on the efforts by many individuals on a daily basis to fight the further transmission of the virus and to improve the lives of those already living with hepatitis C. Why is this important? Because without those efforts and small steps forward things could be a lot worse than what they are.

## **OH3 Resources/NSP/AHC and AIVL logo**

Just think about it... Without the peer education efforts, well targeted education resources, accessible information, needle & syringe programs, advice and peer support, we could be facing a

much higher prevalence and incidence rates. Without the ongoing lobbying and advocacy work of AIVL and the AHC and their member organisations, hepatitis C prevention and treatment could be receiving no funding and we would have no hepatitis C advisory committees to governments. Without the daily efforts of many and the small steps forward things could be worse.

#### **OH4 HIV vs HepC**

Too often we are tempted to judge our successes and achievements in relation to HIV. It's time we stopped. As long as we compare hepatitis C and HIV prevention strategies and outcomes we will end up disappointed and disillusioned. In dealing with HIV prevention we had the ideal 'disease prevention' circumstances – an extremely low prevalence in affected communities, a virus that could potentially affect the whole community, a virus that is extremely fragile outside of its ideal environment, a condition with a very quick disease progression (which changes the way people view its seriousness) and one of the most important distinctions, swift and comprehensive government response and national leadership.

Now, when we consider hepatitis C the picture is almost the complete opposite. We began our response with a high prevalence in affected communities, a virus that primarily affects one of the most marginalised groups in the community with no major transmission pathway into the broader community, an extremely virulent virus that can survive and be transmitted in microscopic amounts of blood, a condition that in the majority of cases has a slow disease progression (that can lend to a sense of complacency) and a general lack of government response and leadership given the size of the epidemic.

Given this comparison, it's hard to believe we use HIV prevention as the 'yardstick' for our hepatitis C prevention efforts. Beginning with high prevalence levels means that we will not only have to adopt quite different strategies to respond to the epidemic and reduce transmissions but it also means that we need to also measure our successes or achievements differently. We need to accept that, even if we had the level of resourcing and support that was invested in the HIV prevention, it is going to take many, many years to begin to see a reduction in prevalence, let alone in incidence rates. The fact that we don't have anywhere near the level of resourcing and support that was invested in HIV prevention

means that this task will take even longer and we may need to modify what is realistic to achieve with the resources at hand.

This does not mean that we should give up – far from it! However, setting unrealistic and unattainable goals is only setting all of us up for failure and disappointment. As peer and community workers in the hepatitis C sector, I am sure you have all witnessed unnecessary burn out and despondency. It is critical that we guard against this happening to more workers in the field. The best way to do this is to ‘get real’ about hepatitis C prevention, to gain a better understanding of the unique context and environment in which we are working and to be clearer as a sector or movement about what our short, medium and long term goals are and the strategies we are going to use to achieve them.

### **OH5 – Goals – Mouse picture**

For example, some short term, realistic goals for hepatitis C prevention might be:

- Increasing the levels of community support and government leadership in relation to hepatitis C prevention, treatment and support;
- Increasing the level of funding provided for hepatitis C activities and securing more stability in that funding;
- Building strategic alliances and partnerships across sectors to support a long term, comprehensive and integrated responses to hepatitis C;
- Identifying realistic opportunities for change and to implement hepatitis C prevention strategies;
- Taking up opportunities to raise awareness in relation to hepatitis C amongst those affected and in the broader community;
- Improving access to hepatitis C related services and programs;
- Improving access to the ‘means of prevention’ in particular to clean injecting equipment;
- Increasing the level of well targeted research to inform our future goals in relation to hepatitis C prevention.

I have to say that we have been a little bit sneaky in outlining those short term goals for you. The reason is that if you take a minute to consider them, you will see that they are nothing more or less than what we have been doing since the beginning of the response.

The reason they are outlined is to highlight for you that we are already achieving goals in relation to hepatitis C prevention. We are achieving what is realistic to be achieved at this point in the response. So in line with the short term goals we have already discussed, let's look at some of the positive achievements of the past few years that we can feel good about and can help give us the energy and commitment to keep going onto our medium and long term goals...

Due to time restraints, I am not going to look at everything we have achieved, just a few examples to highlight the point...

### **OH6 - \$ symbol**

1. **Hepatitis C Education & Prevention Funding** – although it is no secret that the response to hepatitis C is woefully under-funded, one of the definite achievements of the past six years has been the initial securing of some dedicated national funding for hepatitis c education and prevention. Granted, this funding is just a drop in the ocean compared to HIV funding, but it is really important to remember that this 'dedicated' funding was achieved in an environment where governments at all levels were absolutely against setting up new 'dedicated funding streams'.

Sometimes, it is easy to get too focused on the negative – in this case, \$12.4 million over four years is totally inadequate to get the job done. But, another way of seeing it is that this funding also allowed for the establishment of the national programs and offices for both AIVL and the AHC and, it provided some small, but dedicated hepatitis C prevention funding pots at the state and territory level. I don't know how it is for the AHC, but for AIVL we feel like it is a small miracle that we are funded at all! This funding has enabled change for AIVL, our member organisations and subsequently, for individual drug users utterly and permanently. We have had a 'taste' (pardon the pun) of being able to provide hepatitis C programs and activities on the ground for people who use illicit drugs – and that has to be a positive thing!

In addition, the May 2003 Federal Budget renewed the dedicated Hepatitis C Education and Prevention Funding for a further four years and gave a CPI increase to \$15.9 million. It is important to see these developments as a long term

process of building and consolidation. The renewal of this funding was by no means guaranteed and for months it was touch and go. It was the small achievements and the quality of the work done over the first four years that secured the funding and this includes the work done by both AIVL and the AHC in relation to convincing the government that ongoing funding was needed. The final positive footnote is that both AIVL and the AHC were able to negotiate two year funding agreements based on this funding and the remainder will go to the states and territories for ongoing hep C prevention work on the ground.

Although I am not going to speak about it in detail, we also need to acknowledge that in the same period we also saw the renewal of the COAG NSP Supporting Measures Funding – another important pot of money at the state and territory level.

### **OH7 Prison document cover**

#### **2. Prisons:**

On the face it, it might seem that prisons is one of the blackest areas in relation to hepatitis C prevention. There is no doubt about it, prisons are acting as an incubator in relation to hepatitis C. But recently there have also been some very positive signs that prisons could be the one area where we can achieve some change.

In September 2003, AIVL launched our discussion paper on *Prison-Based Syringe Exchange Programs* (PSE programs) which has been incredibly successful. The document has restimulated the much needed discussions and actions to get a trial of PSE programs in this country. We know that certain State and Territory Governments are using the document to guide their work on this issue. As a result of the interest and demand for the document we have set up a closed Elist for senior workers from the field to discuss and work together, focusing on how we can get a trial underway. AIVL is hoping to enter into negotiations with the ACT and Tasmania who are building new prisons, hoping that they will initiate a trial.

## **OH8 – Hand bridge picture**

### **3. Partnerships and Alliances:**

From AIVL's perspective, the development of strategic alliances and partnerships has been one of the most positive achievements over the past six years. Too often the development of partnerships and alliances are seen merely as 'by-products' or as a 'side issue' in relation to hepatitis C prevention. In reality nothing could be further from the truth.

AIVL believes that partnerships and alliances are the key to the development of a strategic and comprehensive response to hepatitis C. Given the main group affected by hep C, it is very unlikely that hepatitis C prevention activities will ever be funded adequately in their own right. Therefore, the only way we are going to achieve the levels of awareness raising and service provision necessary to reduce hep C transmissions, is through partnerships, collaborations and alliances.

To highlight the point, I just want to give an example of alliance building and partnerships that AIVL has undertaken with the Australian Dental Association (ADA):

- We approached the ADA to endorse the "AIVL Charter of Rights and Responsibilities for Drug Users in Oral Health Settings" which includes a focus on hepatitis C issues;
- The ADA agreed to endorse the AIVL Charter and we will now utilise the ADA to disseminate the Charter through dentists throughout Australia.

## **OH9 – Barriers poster**

### **Barriers to Further Progress:**

Although we have made a range of important achievements and essential breakthroughs in relation to building a hepatitis C prevention approach over the past six years, there have also been a number of issues that have got in the way or have effectively created barriers.

From AIVL's perspective, the two main challenges facing the future of hepatitis C prevention are:

- the ongoing attacks on and erosion of harm reduction; and

- the imminent introduction of retractable needles and syringes.

It is by no means a coincidence that the first challenge relates directly to the second. Let me explain...

### **OH10 - House of Harm Reduction**

#### **a) The ongoing attacks on and the erosion of harm reduction...**

The past six years have seen a number of major policy and legislative shifts in relation to the whole issue of illicit drugs and therefore by default, hepatitis C. This began early in the Howard Government's tenure with the launch of the now infamous "Tough on Drugs" Strategy. This strategy was not only an important turning point in terms of how funding would be allocated on the ground for programs and services but perhaps more importantly, for what it signalled in terms of a change in attitude and an almost complete reversal of the previous ten years of government policy at the federal level.

Over the past six years we have seen a steady, strategic and methodical dismantling of Australia's internationally recognised harm reduction approach to illicit drugs – to the point where harm reduction is now a "dirty word" in many contexts. It began in 1998/99 with a shift in policy – at this time the release of the National Drug Strategy revealed a shift from a focus on harm reduction to something called "harm minimisation".

#### **OH 11 - harm minimisation model**

Harm minimisation was made up of three "arms" – supply reduction, demand reduction and harm reduction, with harm reduction as a third and lowest priority.

Over the past few years we have seen an increasing focus on supply and demand reduction strategies – increased law enforcement, questionable diversion strategies, increased support for and practice of drug testing in the workplace and in selection processes, etc. At the same time, we have also seen the systemic "dethroning", as it were, of harm reduction. Constant attacks on harm reduction programs such as NSPs and methadone programs, the Chair of the Prime Minister's Committee on Drugs, Major Watters, planting seeds of doubt in the minds of the community by publicly attacking harm reduction and accusing harm reduction approaches as "encouraging drug use" and setting

up a false dichotomy between harm reduction and abstinence-based approaches that does not exist in reality. And, we have all witnessed the constant attacks on the credibility and operation of the Sydney Medically Supervised Injecting Centre.

All of this culminated recently in the release of the Federal Parliamentary Committee Report titled “The Road to Recovery” in which it was recommended that even the harm minimisation approach be replaced in the new, upcoming National Drug Strategy with something called “harm prevention”. Of course, “harm prevention” is not really defined in the report except to say that it would involve a two pronged approach including:

1. Prevention of all illicit drug use in the first place via supply and demand reduction strategies; and
2. Drug Treatment that must have abstinence from all drug use as the ultimate outcome.

It doesn't take a genius to see what is missing from this new “harm prevention” approach – what's missing is any form of harm reduction.

This has been the consistent theme of the Federal Government during their term. Nothing the Federal Government does in relation to illicit drugs happens by chance and nothing they do happens in isolation. The systemic dismantling of harm reduction represents the single biggest challenge facing hepatitis C prevention and we need to take it seriously. We are about to begin the development of the 2<sup>nd</sup> National Hepatitis C Strategy and it is very important that people understand the implications of a shift in terminology within the Strategy.

The 1<sup>st</sup> National Hepatitis C Strategy is unique in that it is the only current Government strategy that uses the term harm reduction rather than harm minimisation. This is significant for a number of reasons. We are often told “Don't worry about language, its not important whether the strategy says harm reduction or harm minimisation, what's important is what gets done on the ground.” On the surface this may sound reasonable until you think about it a little more. Language does matter. If it didn't matter, governments would fight over terminology.

The language used in policy documents such as strategies is important because it spells out what will be funded in terms of programs and services. If what you do and how you do it is not consistent with the strategy – you will not be funded to do it. So as you can see, governments tinkering with language here and there, changing a word does matter. It may not seem like a major change at the time but all of those changes add up and they result in complete shifts in ideology and policy approach. Soon, before you know it, hepatitis C prevention begins to take on a very different look... and that, not surprisingly leads on to the other challenge facing hepatitis C prevention which is retractable syringes.

## **OH 12 Retractable syringe**

### **b) Retractable Syringes...**

Unfortunately, due to time restraints and the other issues I still need to cover, I am only going to touch on retractable syringes very briefly. I am sure that most of you know more than you ever wanted to know about retractable syringes anyway, but the main issue I wanted to briefly touch on is the relationship between retractable syringes and hepatitis C prevention.

There are many, many potential problems with retractable syringes for people who inject illicit drugs. The hepatitis C prevention problems associated with the reusing of the current needles and syringes because people don't like using the retractable syringes has been discussed quite a lot. One of major the potential hepatitis C prevention issues that hasn't been discussed very much however, is the risk of large scale hepatitis C transmissions as people struggle to use and manage the completely new, retractable mechanisms.

Those of you who have any experience with injecting drug use will know that there can be a surprising amount of blood present in the average injecting episode - and this is when people are using equipment they are completely familiar with! When you remove that familiarity, it is very likely that the amount of blood in the injecting environment will increase. Add to that, the stress and tension associated with people potentially losing their shot and you have an extremely high risk injecting environment.

This is just one example of the potential hepatitis C prevention problems associated retractable syringes. There are many more. The fact is the Government is determined to proceed with the

pilots of retractable syringes no matter what. The challenge for all of us will be how we adapt and change our hepatitis C prevention education strategies to cope with the issues raised by retractable syringes and I think we know already that it will not be easy!

### **OH13 Car picture**

#### **Moving Forward:**

So far we have discussed the importance of setting realistic goals, acknowledging and appreciating the successes we have and understanding the challenges we face -in relation to hepatitis C prevention. For the last part of the presentation then, I would like to focus on the road ahead for hepatitis C prevention in Australia.

Our work over the past six years has positioned us well to identify and take up some of the medium term challenges in relation to hepatitis C prevention. We have completed the first stage, “set the scene” so to speak and now the really hard work begins! The reason why I am referring to these goals as “medium term” challenges is because they are things we must do if we wish to progress towards some of the long term challenges in relation to hepatitis C, such as a lowering of the prevalence and incidence rates. As was stated earlier, these can only be achieved in the long term due mainly to the large numbers of people already infected.

Of course, there are a range of medium term challenges we need to address, but within the context of this presentation today, I want to focus on the two major challenges that AIVL sees as critical to addressing hepatitis C prevention amongst people who use illicit drugs. These two challenges are:

- Providing access to primary health care for people who use illicit drugs; and
- Developing the relationship between prevention and treatment.

### **OH14 Primary health care picture**

#### **a) Access to Primary Health Care:**

AIVL is constantly involved in discussions about “how we are going to stop people who inject drugs getting hepatitis C”. But more recently we have started to realise that this is not the main question or the main issue. We realise that hepatitis C prevention amongst people who inject drugs is never going to

happen while drug users don't even have access to basic primary health care.

Drug users live with chronic pain, serious illness and poor health as a routine part of life. They do not access primary health care services because of a fear of how they will be treated (or won't be treated as the case maybe) or due to their inability to meet the array of 'requirements' and 'criteria' for these services. The barriers can include cost, the way the service operates, unavailability of treatments, attitudes and values of staff, geographic location, etc. In short, many drug users cannot get their most basic health needs met and while this situation persists, hepatitis C will remain a low health priority.

Even if treatments were to dramatically improve overnight or if we were to develop a vaccine for hepatitis C, we have no way of delivering it to the group most affected by the virus. We know this is true because we have watched it happen with hepatitis B. We have a perfectly acceptable vaccine for hep B but no way to deliver it because of lack of access to primary health care.

If we are going to make significant inroads into hepatitis C prevention, then we must improve the general health of people who inject illicit drugs. Only then will drug users be in position to really prioritise hepatitis C in their lives.

### **OH15 – Prevention and treatment**

#### b) Prevention and Treatment:

As we all know, we are working within a large pool of hepatitis C infections. This presents us with a challenge not only in relation to ensuring that those who are ready for treatment access it but minimising the rate of further transmission. For us to be successful in the latter, the minimising of infections we obviously have to among other initiatives and strategies, reduce the pool of current infections. The only way we have to do this is by increasing the numbers of people who are currently living with hepatitis C receiving treatment and being given the opportunity to clear the virus.

Now for many of you, you may see this as an abstract concept. And there are indeed many issues that need to be explored for example:

- ✓ The cost of treatment
- ✓ Criteria for treatment
- ✓ The numbers of people living with hepatitis C
- ✓ The potential opportunities for reinfection
- ✓ The complexity of genotypes within treatment
- ✓ Efficacy of treatment

Never the less, it is important that we explore all of the potential opportunities that could be available to us to move ahead and succeed.

### **OH16 - Board games - Survival**

#### **Conclusion:**

Many people, a lot of them in this room have worked really hard to get us where we are in relation to hepatitis C prevention. As was said at the outset, it is easy to be negative about our achievements when we are faced with rising infections but we need to reconceptualise the way we think about hepatitis C prevention and the challenges ahead. As long as we continue to compare and contrast everything we do against the Australian HIV prevention experience, then we will continue to be disappointed.

If however, we change our outlook, and begin to conceptualise our own unique approach to hepatitis C prevention, then we can start to see ourselves and what we do in more positive terms. The community is never going to going to view hepatitis C in the same way and with the same urgency as HIV/AIDS. We need to take another approach. We need to stay focussed on the things we can achieve rather than on the things we can't. And we need to make sure that we build a response now that will be capable of meeting the challenges in the long term. There is no such thing as a "quick fix" when it comes to preventing the further transmission of hepatitis C. The name of the game is "survival".