

The Hep C Review

Winter Edition August 1997

Issue 18

HEPATITIS C INQUIRY OPENS

The Parliament of NSW Standing Committee on Social Issues is undertaking an inquiry into the transmission and impact of hepatitis C in NSW.

If you are a person with HCV, a family member or friend, healthcare worker or researcher, the Inquiry needs your input if it is to get the full picture into this epidemic.

Whether you write a ten page manifesto or scribble a few thoughts on a single page, without your views,

the Inquiry won't be able to make effective recommendations to Parliament. The best decisions come from the most complete knowledge - and that includes input from people actually affected.

We urge you to write to the Inquiry. Don't be concerned or overawed about writing to a committee of politicians. They value peoples' personal stories and views as much as the advice of researchers and other experts.

Some people may be worried about confidentiality. If this is the case, just write 'confidential' on your submission. The Standing Committee will guarantee that your comments and identity are kept private and not made public in any way.

In particular, the Standing Committee will look into:

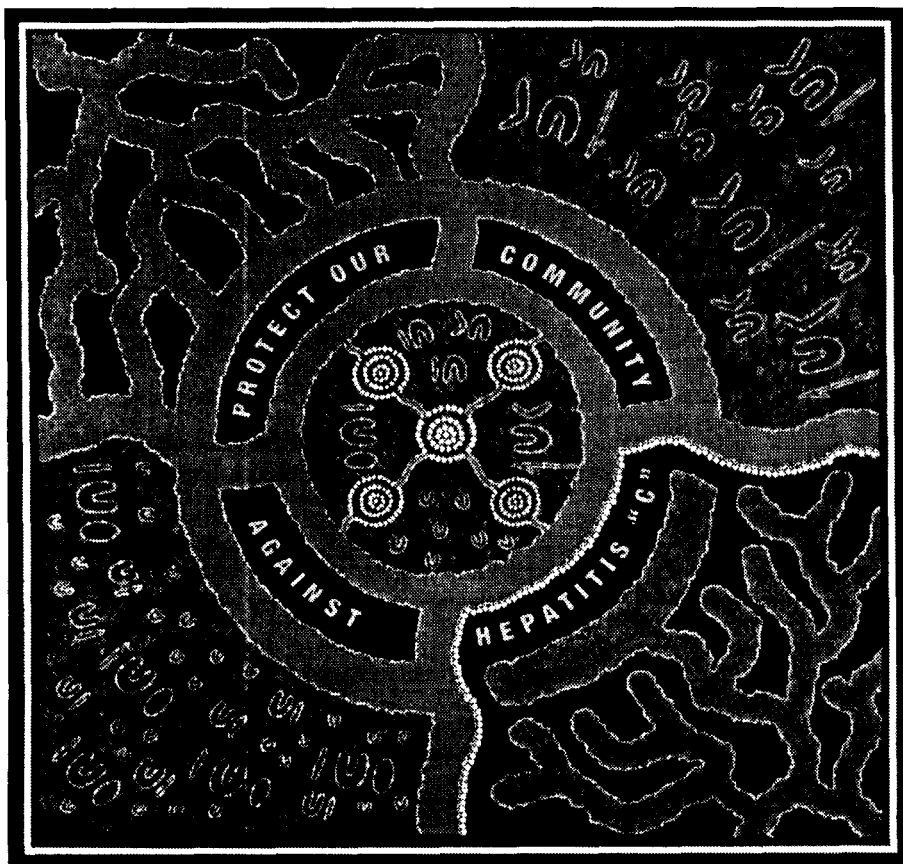
- the social and economic impact of HCV;
- the extent of hepatitis C and how it is transmitted;
- the adequacy of prevention policies;
- the adequacy of diagnostic and treatment services;
- what places people at increased risk of infection;
- adequacy of education, prevention, care and treatment services; and
- the risks for healthcare workers, and adequacies of OH&S policies/procedures.

Send your comments to:

The Director
Standing Committee on Social Issues
NSW Parliament
Macquarie St
SYDNEY NSW 2000

Please note: the closing date for written comment is 30 September 1997.

Detailed brochures explaining how the Inquiry will operate are available by contacting Dr Jennifer Knight:
02 9230 3435 (phone)
02 9230 2981 (fax)
cknight@parliament.nsw.gov.au
(email) *



The above painting, by Heather Kumarre Shearer, forms the basis of a new hepatitis C poster. Information on the poster is available from the South Australian Aboriginal Drug & Alcohol Council: ph 08 8362 0395

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The Council is an independent, community-based, non-profit membership organisation. We provide information and support to people affected by hepatitis C and assist in preventing further spread of the hepatitis C virus (HCV).

The Hepatitis C Council of NSW is primarily funded by NSW Health.


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'MARLTON' comics are by Andrew Marlton,
Doggy Times Cartoons: 02 9810 1757

Contributions from Council members and the public are welcomed. Other than for editorial comment, views expressed in this magazine are therefore not necessarily those of the Hepatitis C Council of NSW.

Drug Law Enforcement - and Reform

a guest editorial by Nicholas Cowdery QC,
Director of Public Prosecutions for NSW

Parliaments do some odd things from time to time. In 1809 the Alabama (USA) State Legislature passed a law forbidding any man and wife from having sexual intercourse in any but the 'missionary' position.

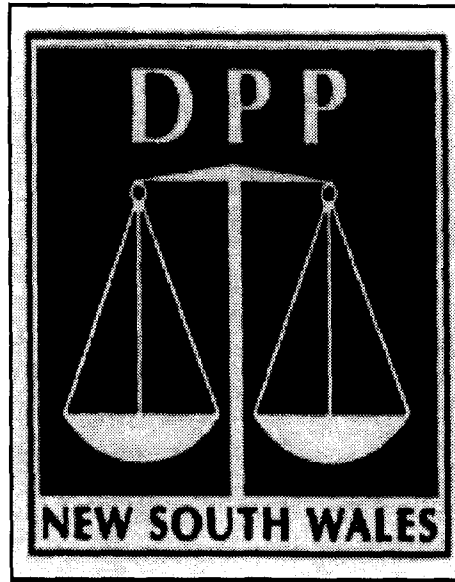
The prohibition of certain drugs is an equally futile gesture.

Recently an 80 year old Victorian wrote to me about his early days in a country town where alcohol could not be sold after 6 pm, lotteries were illegal and there was no off-course betting. He visited it recently and watched people drinking into the late hours, buying Tattslotto tickets in the newsagent and betting at the TAB. He wrote:

"Some folk may take the view that the town has 'gone to the devil', but I could see no physical evidence that this was so ... In looking back it seemed amazing that in the 1920's we had spent so much time and energy in trying to ban and prevent things which most of the population knew were taking place ... It seemed to me that the actions of the law-makers in those days were as futile as trying to stop the tide from changing twice every day.

My thoughts then turned to our present-day handling of the illegal drug trade and it seemed to me that our present-day efforts are just as futile as our efforts in the 1920's. However in the present case the results of our mistakes are very much more dangerous as our actions are putting the lives of drug users at risk and are diverting billions of dollars into the pockets of criminals..."

For 50 years or more in this country, blindly following the United States of America's moralistic 'war' against selected prohibited drugs, we have spent ever increasing amounts of public money, passed more and more laws to facilitate the detection and prosecution of offenders (at cost to the human rights of all of us) and increased penalties available - all to no avail. The 'war' has been lost. The 'collateral damage' is ever increasing. Common-sense dictates that we should look for alternatives that will be better for all of us.



Humankind has always had drugs and it always will. We cannot banish them. We must face that fact. Accordingly we must learn to live with them in a way that does us all the least harm. Prohibition does not and cannot be made to improve our overall position. Regulation is required, coupled with improved education and treatment and discouraging propaganda.

Arbitrary divisions of drugs into *legal* and *illegal*; *soft* or *hard* are not helpful. A drug is a drug is a drug. 'Decriminalisation' and 'legalisation' are not useful

words either. Prohibition has had its day - all drugs must simply be regulated, each according to its effects, social acceptability, availability, method of use and so on. Yes, some work is required to plan for and to do that. For a start, perhaps, heroin could be included in Schedule 8 to the Poisons Act: that would at least increase our treatment options in the short term.

The NSW Police Royal Commission in May made recommendations that:

- there be a national summit or commission to plan a national approach to our present problems;
- safe injecting rooms (in conjunction with needle and syringe exchanges) be established for users: places where advice and medical help would also be available;
- support be given for the ACT trial of medically prescribed heroin; and
- consideration be given to "decriminalisation".

We have yet to see constructive responses from our community leaders - especially from our elected representatives (with some exceptions) - to these or any similar proposals. More information is needed before coherent plans can be made. A lot of information already exists - and a lot of opinions are vying for public attention. That all needs to be harnessed.

Trials of prescribed heroin, morphine and methadone in other jurisdictions (eg Switzerland) have already yielded much information of assistance and have routinely enabled many users to stop. Similar expectations are held for an ACT trial.

Politicians and policy makers need encouragement to actively consider the issues in an appropriate way. They need to know that wide sections of the community have had enough of wasteful and expensive war and wish to examine thoroughly the possibility of change for the better for all concerned.

Each of us needs to provide that encouragement.

We can do better.

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Hijacked?

I recently received your booklet, Hepatitis C - what you need to know. It represents written confirmation to me that the treatment of serious debilitating diseases is being hijacked by non-medical practitioners further confusing the public.

The listing of natural therapy organisations whose treatment of HCV is at best ineffective, at worst quackery. Also the turning of a blind eye to illegal practices such as injecting drug abuse disturbs me.

I find it bizarre that a council has been set up for the promotion of one sub-category of disease process affecting the liver. The government department that funds this council is obviously run by non-health professionals.

DS

Your honest feedback is appreciated although we do not share your views. Councils such as ours do not seek to 'hijack medical treatment'. We seek expansion of existing services, and improved resources for HCV-related healthcare and welfare workers. We are not out to build up power or control over any aspect of hepatitis. (see edition 17's editorial).

We discuss natural therapies within the context of individual choice. We do not make specific claim to the effectiveness of natural therapies. We do advise that people discuss their natural therapy with their GP.

The nature of HCV transmission means we're all confronted with the issue of injecting drug use. Injecting illicit drugs is currently illegal but does this mean we should turn a blind eye to the alarming ongoing rate of HCV transmission, or people's access to treatment, etc.? We think not - Ed



Bedside manners

My letter is about the attitude of some doctors that I have had the displeasure of being a patient of.

After my doctor diagnosed me with hep C, I was naturally upset.

I asked "so what does that mean?" He said that it was a virus that affects the liver causing cirrhosis and probable death within fifteen to twenty years.

I was in shock, and felt distressed. The doctor didn't offer any more advice but referred me to the hepatitis clinic in Newcastle. The doctor in Newcastle was great. He was able to answer a heap of questions and made me feel at ease with some of the answers too.

After Newcastle I decided on a new doctor. I visited the doctor for a few reasons including a blood sample for my liver function test. I told him that the hepatitis clinic advised me so. He said that there was no reason to have these tests unless you are ill.

I didn't know what to say, except that the clinic had advised me to do so. He then went on and explained what the test is for. I walked out of the surgery confused and pissed off at the attitude he displayed.

I'm glad to say that I have now found a wonderful local doctor who understands the need for regular blood tests.

I think it's important to find a local physician that you feel confident in and comfortable with.

Yours faithfully, VN



Over the hard part

Thank you for sending me your information. Along with your telephone support, it was of incalculable benefit at a time of great distress.

My doctor had just thrown me in the deep end with words to the effect of "we'll retest in three months to confirm the hepatitis C positive result of your blood tests."

In all my 58 years, nothing previously had shocked me as hard. However I am grateful for his expertise in finding this thing quickly and in the face of my extremely low risk profile / lifestyle antecedents.

I am now on interferon via the PBS S-100 and am showing a marked reduction of ALTs after four weeks. I've also overcome most of my fear of needles.

Thanks for your help so far. I intend to contact your office to offer help with your activities as soon as I am well enough to do so.

Regards, AH



Missing my mailouts

I was sorry not to have been of help with the volunteer work this year but I've moved to Melbourne for work.

After my treatment finished in September, last year, I went to Nepal for a couple of months. I had never felt better while I was there. I spent my whole time on rivers, rafting and kayaking. It was an experience of a lifetime.

On my return at Christmas I needed to find full-time employment again. I was feeling fit again and looking forward to work. So now, I find myself in Melbourne working for a computer software company.

Although I have become symptomatic again, they've only been mild and my levels are being monitored at the Alfred.

They did suggest treatment but I turned it down. I'm concerned that under treatment, I may not feel up to working full-time, and I certainly don't feel as bad as I did in '95.

I'm going to remain a member of the NSW Council and look forward to when there is a national body. Congratulations on your work. It has been, and will always be appreciated.

Cheers, CW



the road ahead

I support the work of the Council and would like to suggest the following priorities for 1997/98:

- Funding for research
- Availability of PCR quantitative tests for monitoring treatment
- Wider availability of interferon & ribavirin - especially to people with chronic hepatitis C

(shown in liver biopsies) who have normal liver function tests.

- Option to treat with bigger doses for longer periods when cases warrant it (eg. type 1 subtype, or fibrosis or moderate cirrhosis).
- Media campaigns and community education.
- Drug law reform.

I hope my comments are helpful.

RI

Very timely suggestions. We are currently planning readership and membership surveys that will assist in the Council's strategic planning, and provide valuable social research to guide individual projects.



LOSS OF HEALTH

Loss of health is just as traumatic as the loss of a spouse, parent or child. Not many people realise this, often thinking "You are only sick and can do something about it."

Some time ago I met someone who was very angry with doctors, colleagues etc. How do we live with hep C? How do we get rid of the anger? For some people it is easier than for others. May be by accepting the fact, that for the moment, hep C is not curable and learning to accept that fact, is the first step one can take. Being angry is stressful and stress is not good for the immune system.

Being angry with your GP won't help either, if he is not well informed give him the information you have and give him the Booklet "Hepatitis C: What you need to know". I passed the information on to my GP and he was very grateful. Changing GPs won't help much unless you were not happy with him or her in the first place.

Being angry; could it be you're angry with yourself? Try to come to terms with the past - one can't change the past, but we can try to make the most of today.

Friends avoid you? Ring them and explain about your hep C or send them above mentioned booklet. They might not know how to deal with your problem. They don't know if you can or want to talk about it. They still avoid you? Forget about them. Of course it hurts, it is another loss you have to cope with.

One of these days a cure will be found and a vaccine for the ones who are at risk. Please keep this in mind!!

Wishing you all the best,

MT

Congratulations to NSW Health, who during June, posted the booklet "Hepatitis C: What you need to know" to every medical doctor in NSW. See page 33 for a listing of other resources and projects that are currently being developed.

Cocaine users risk hepatitis C

Cocaine snorters who share straws or other sniffing implements risk contracting the hepatitis C virus, new United States research suggests.

The findings identify a potential new risk group for hepatitis C, which is mostly spread through injecting drugs.

Cocaine snorting has traditionally been dubbed a 'stockbroker's habit' because it largely involves a different socio-economic group.

And a separate study at Kings Cross found that many people who inject cocaine do so at levels which have shocked even local medical services. On average, the 60 users surveyed injected cocaine 15 times a day.

Dr Ingrid van Beek, the director of the Kirketon Road Clinic, said the findings highlighted the need for regulated injecting rooms to minimise the health risks associated with such alarming rates of injection.

The US study estimated that 3 to 5 per cent of people with recent 'community-acquired' hepatitis C virus in the US had contracted it through blood spread via shared cocaine straws.

Australian experts say the potential risk has not been widely appreciated here, although the figures are unlikely to be as high as in the US, where cocaine use is more widespread.

by Melissa Sweet (SMH 30/05/97)

New NSEP for Kings Cross CBD

A shopfront needle and syringe exchange has been approved in Kings Cross.

The approval by South Sydney Council follows months of negotiation and community backlash over the proposal which will see the NSEP placed under the well known Pink Pussycat Club in the heart of the Kings Cross CBD area.

The exchange will not be signed as such and will be called 'K2', relying on word-of-mouth advertising among drug users. It will be operated by the Kirketon Road Centre (KRC), a

health service located on the fringes of the Cross. As well as providing clean fits, it will also offer emergency medical, counselling and referral services and will house the KRC outreach team, project, research and administrative staff.

KRC director Ingrid van Beek said it was essential to have a shopfront NSEP in the heart of the Cross. "Over the past few years an increasing number of commercial establishments in the CBD of Kings Cross have been providing drug users with sterile injecting equipment and/or rooms to inject," she said.

"As a result of the Wood Royal Commission, these establishments have largely ceased to operate, resulting in a significant shortfall in the supply of sterile injecting equipment in central Kings Cross."

"This came at a time when cocaine injecting had become endemic in the area, with some users injecting an average 15 times per day," Dr van Beek said.

These users were unlikely to make the trip to KRC for new equipment, even though that NSEP catered for 150 clients each day.

The new NSEP should be in operation by late April.

(Connexions April/May 1997)

Tattooing linked with infections

Tattooing may be a high-risk activity for the spread of blood-borne infections, according to research.

An evaluation of 35 tattooists in Victoria found serious breaches of infection control standards, including poor barrier protection and use of unsterilised instruments.

Research findings concluded that only 74% of premises had an autoclave (for sterilising equipment), and that only 57% of these passed accepted standards.

Only 55% of tattooists washed hands with an antibacterial skin cleanser before tattooing.

A survey of frozen blood samples of 41 tattooists taken in 1984 and retested in 1996 found 46% had been exposed to hepatitis B and 5.7% were positive for hepatitis C.

Dr John Carnie, researcher from the Victorian Health Department and manager of the infectious diseases unit, said compliance with infection control standards had improved through education seminars for tattooists.

"However, there is still room for more improvement," he said.

"In principle we expect tattooists to comply to the same standards of infection control as doctors, but compliance to guidelines is most likely still being practised at a lower level

largely because doctors enjoy better education and training programs," he added.

Enforcement of infection control standards was the responsibility of local government environmental health officers who had prosecution powers to close down tattoo parlours, Dr Carnie said.

The preferred strategy was raising awareness among the public. He said that customers might have accepted lower standards in the past but this was changing.

by John Kron, Australian Doctor 4/97

[see page 33 for info on national tattoo project]

New hepatitis C treatment?

Amantadine - a drug that's been available in the US since the 1960's - has been recently trialed on 22 patients in a four year pilot study at the Penn State University's Hershey Medical Centre.

Speaking at an annual meeting of the American Gastroenterological Association, Dr Jill Smith, Associate Professor of Medicine at Hershey, claimed that of 22 patients enrolled in the pilot study, there were six responders, eight partial responders, six non-responders and two drop outs.

Smith claims that amantadine treatment involves few side effects - a major drawback with interferon treatment. Amantadine side effects include difficulty in concentration, constipation and rare cardiac symptoms in some elderly patients.

"We need support for further studies," said Smith. "It would be great to see a multi-centre controlled study, making amantadine available to people across the country [US] who have hepatitis C."

The Hepatitis C Council of NSW welcomes news on any new treatment possibilities but stresses that studies such as the above don't always provide grounds for optimism. Other research trials have shown less promise: *Short term administration of Amantadine Hypochloride in patients with hepatitis C*, Gastroenterology, Vol 112, No 4, "... Amantadine is not as effective as previously reported."

Until larger trials are carried out - including Australian based research - we have to treat such news with cautious optimism.

We'd call on our national advisory bodies such as ANCARD and the NHMRC to support research into amantadine's effectiveness.

[Prof. Bob Batey reports that amantadine is currently being studied by several overseas groups, and that the NHMRC does actively support such research]

NJ v AUSTRALIAN RED CROSS

On 14 July a hearing began in the Victorian Supreme Court. It is a test case class action on behalf of 30 people seeking compensation from the Red Cross after allegedly contracting hepatitis C from blood products.

The litigants feel that although HCV antibody test screening was not developed until 1990, Australian bloodbanks should have followed overseas leads and adopted universal ALT testing of donated blood.

This blood screening strategy was adopted throughout the US in 1986. Queensland bloodbanks began ALT screening in 1987, with the rest of Australia lagging behind until 1990, when the HCV antibody test was universally introduced.

by Derek Mortimer (Australian Doctor 6/97)

BLUE MOUNTAINS SUPPORT

The Counsellor at the Blue Mountains Sexual Health Centre will be starting a support group for people with hepatitis C in August in Katoomba. Times, dates and venue for the group are yet to be decided.

The group will be structured to meet the needs of the people attending. Therefore the counsellor would like to interview interested people beforehand to discuss these needs.

Anyone interested in attending the group please contact:

Lesley Hohnen - Counsellor

Blue Mountains Sexual Health Clinic - 047 80 6060

Mondays, Tuesdays or Wednesdays

This is a free and confidential service that hopes to provide collective support. However, anyone wanting individual counselling can also contact the counsellor on the same number.

Hepatitis C to have or have not

Five years ago I was diagnosed as having hepatitis C. An old friend from the past called me in a state of hysteria saying she had discovered she had it and that it could only have come from the few times she had injected drugs with me and some others. She was sure that if she had contracted it then so must I.

At first I was blasé towards the fact, even when I was tested positive to having chronic hepatitis C. My friend however, was immensely angry and refused to believe that an error in her ways nearly thirty years ago was affecting her lifestyle now.

She was due to marry and would not consider informing her husband-to-be (an act at that time incomprehensible to me) but instead set to with a passion towards finding and trying anything that could erase this from her present life.

Sometime later she informed me that she had been told about the drug interferon and that she had managed to be included at much persuasion, in a trial program. She had been told that interferon had been used with some success and indeed in some cases had cured the disease completely. On her insistence, I sought medical advice and was accepted into a program.

Interferon is an expensive drug and otherwise I would not have been in a position to afford it and so thought myself extremely fortunate. I often suffered from fatigue but really didn't make much out of it, preferring to ignore it and get on with things, not realising that there was a real reason behind the cause.

The interferon however really made me sick. I had to inject it subcutaneously in the stomach three times per week. After four months I was withdrawn from the program due to severe side effects - I suffered mainly depression and suicidal tendencies.

Apart from temporarily lowering my ALT levels slightly, it really did little for me. I have since learned that it is really only effective for people who have recently contracted the disease, not for

chronic sufferers like myself and my friend. I decided to live with it and not to let it interfere too much with my life and my state of mind in the future.

I have always been honest with health workers and in questionnaires etc that wanted to know if I suffered from any infectious diseases. I found people sympathetic and understanding on the whole, even if not a lot was known about it. Recently, however, I began a new relationship, the first for a long time and it was wonderful to have at last found someone to break the loneliness of rural life and someone with similar interests with whom I could do and share things.

It began to worry me that I was not being entirely honest with this person I was sharing my life with and I felt that it was his right to know about the hep C, so three months into the relationship I decided to confide in him.

I actually played down the ramifications and made light of the whole situation. He seemed to take it in his stride and I wondered why I had taken so long to tell him.

*"when I
went to
touch him,
he brushed
me off"*

The next time I saw him, which was an unusually long time later, he was a different person. He had become aloof, rude and what really shocked me was when I went to touch him, he brushed me off.

I didn't immediately connect his behaviour to our conversation as it had never in my life before occurred to me that someone would discriminate against me for something that at that time thirty years ago I had done with absolutely no knowledge of the consequences.

When I questioned him as to his behaviour, he would not say what it was, but that it was something he had to work out. Then it dawned on me that of course it must be the hep C and when I asked him if this was so he admitted that it was. I tried to tell him that I always took every precaution, which I did and that if we were careful and indeed aware, that there was no reason he should contract it.

But the damage had been done and I am again on my own. The relationship was never the same after that and now we rarely see each other. I have also heard that there is increasing discrimination amongst health workers now and I have been advised from other people with hep C not to be honest anymore about it.

This has left me confused and depressed. Perhaps my old friend was right after all in never confiding in her now husband and two small children, so that she can live her life without being shunned and keep the hep C secret firmly locked in the closet as long as possible.

**Name withheld
Armidale**

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Hepatitis C and injecting drug use

There is a range of issues around injecting drug use (IDU) and the hepatitis C virus (HCV).

Injecting drugs is now the main transmission route for new cases of HCV and most people with the virus have injected drugs at some time. Consequently, having hepatitis C is often taken to mean that a person is, or was, someone who injects drugs. For many in the general community, injecting drug use conjures the stereotype of habitually dependent 'junkie.'

People carrying an 'IDU' label often experience a poorer level of access to healthcare services. At times, irrational fears about transmission further impact on access to services.

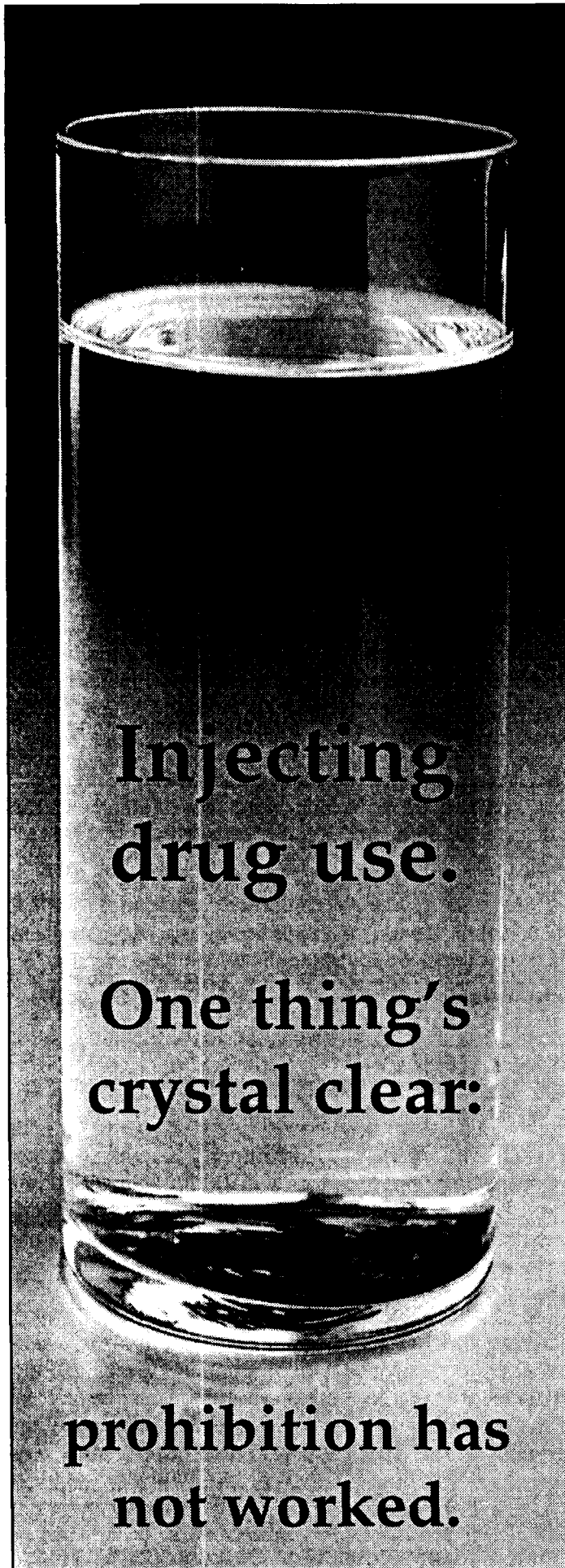
This edition of *The Hep C Review* attempts to promote discussion on such issues. There are differences of opinion in this field and we acknowledge our limitations in that we're unable to publish articles representing all points of view.

It is evident that reducing further HCV transmission will require a combination of different approaches. Major strategies will all focus primarily on injecting drug use.

Listed below are *some* of the questions that people are debating (and in too many cases, ignoring) in current community discussion.

- How do we effectively prevent HCV transmission?
- How do we effectively address HCV & IDU related discrimination?
- What should be the legal response to drug use?
- What are the issues around people beginning to inject drugs?
- What range of people inject drugs?
- What treatment options are available for people wanting to deal with a problematic drug habit?

We hope that increased, quality public debate will help address many misconceptions and stereotypes around injecting drug use, and the possible harms associated with it. This can only assist in an improved response to the HCV epidemic. *





My race against time

I am fighting for my only child's life. My daughter is a heroin addict, and in my fight for her life I hope she will get the strength to fight for her own.

I climb the stairs of the hotel, a shooting gallery and brothel where she lives on the main street of Kings Cross, and pray she is still alive. The anxiety I feel is indescribable as I knock on the door. I enter and she staggers to her bed and collapses into total squalor.

The bed is filthy and the room is chaotic. There are containers of old food, ashtrays spilled over, make-up, dirty clothes, candles, condoms, garbage, some pathetic tokens of house decorating and everywhere there is drug paraphernalia: spoons, swabs, tourniquets and a large container of new syringes - and an even larger yellow hazardous waste bin the size of a large garbage bin for the used syringes.

And there in another bed is my beautiful daughter looking like an angel that fell into hell. We are in a race against time; she is now on the waiting list to go into detox at a public clinic. The rule is to ring every day until they give her a bed. There is a compulsory wait of two weeks, then the clinic will let her know when she can be admitted; this is the third attempt at detox. I am hopeful, and anxious; did she remember to ring today and if so is she telling the truth?

The drug is really powerful and she is in its control and struggling to fight back. Yes, she has emotional problems and has played around with other drugs before this, and we have been struggling to help her win the battle to survive. My daughter is from a loving family: we live on the North Shore, she went to a nice school, and, no, it wasn't all perfect but nothing warrants this outcome to any child's life.

How can I win this battle when speed and heroin are so cheap and so available?

The hotel where my daughter resides is full of young people who look like they are barely alive and are totally exploited by drugs and prostitution. The fact that the Government buses in tourists to view this desecration of our youth selling the sleaze like some romantic form of bohemia - young girls

stripping, smacked off their brains and perhaps selling a blow job to a tourist for that extra buck makes me weep.

My heart aches for the other families (SMH letters). Their tragedies, however, have inspired me to speak of my own in the hope that the public and Government will start to look at what is happening to our young people and children, and I too fully support legalisation and decriminalisation of heroin use, with government and health workers totally controlling its use and output.

My plea is for my daughter's sake; you might have seen her some time, standing, somewhere in Kings Cross selling her body to support her heroin habit, or she could have been nodding off in a doorway; she is only 20, mere fodder for the dealers - just another junkie.

My husband and I love her very much. (SMH, 6/6/97)

Dangerous dichotomy

After reading about the drug-addict daughter of the North Shore couple, [above] I am amazed at the dichotomy [contradiction] expressed in the following two sentences: "How can I win this battle when heroin is so cheap and so available?" and "I too support full decriminalisation of heroin use".

Does the parents' plea for their daughter's sake really imply that, were heroin given to their daughter, and were it more readily available, that she would be in better circumstances?

I say *don't* promote the drug, *don't* make trafficking legal (and respectable) and finally, *don't* consider heroin use to be normal and understandable. That is how to save your daughter and someone else's daughter from making the same tragic mistake.

RG Wollstonecraft (SMH, 7/6/97)

Crying within

I refer to the letter "My race against time", [above]. For the past 20 years, I have practised as a barrister at the Sydney criminal bar, the first 14 as defence counsel, the last six as a Crown prosecutor. I thought that I had become sufficiently inured to the woes and miseries of life.

The day I read the letter, I cried - not literally but within my very soul. There has to be a better way to combat drugs and the evils that accompany their distribution and use. Surely it's time the Government looked at what is happening to our youth, to our society and decriminalised the use of heroin and other like drugs, and regulated the control and use thereof.

John Kiely
Deputy Senior Crown Prosecutor, Sydney (SMH, 7/6/97)



Exploding the myths

by Simon Lenton

Most people who inject drugs have had little to do with drug treatment yet much drug research is done on people who've experienced lots of treatment.

Over a six week period from mid September 1995 FITPACKs sold through 193 community pharmacies state-wide were accompanied by an anonymous questionnaire designed with input from injecting drug users (IDUs) and pharmacists.

Much information about the people who responded is inconsistent with the stereotype of a drug injector held by many in the wider community (the following figures are approximates).

- The most common age of respondents was 26 years.
- 45% were married or living with their sexual partner.
- 40% had at least one child.
- 24% listed senior high school as their highest level of education completed.
- 22% listed trade or technical school.
- 7% had completed a university or college course.
- Only 30% were unemployed.
- 47% were currently employed, the majority of these being in full time employment.
- Only 7% said they were involved in drug dealing or other crime.
- Trades and labouring were the most common occupations.
- 53% of people earned \$20,000 or less in the last financial year with 30% earning over \$30,000.
- Those in the higher income brackets were more likely to be trades persons than those in the lower income levels.
- Whilst 60% of the sample lived in rental accommodation, 17% owned or were buying their place of residence, and 15% lived in their parents' home.

- The most common age when people first injected a drug was 19 years.
- The most common length of time that people had been injecting was 7 years.
- The drug that was injected by most respondents in the past month was speed (amphetamine) followed by heroin.
- Eighty percent reported that they usually injected in their own home.
- Most people reported that they disposed of their used fits by locking them back into the Fitpack - a plastic container containing 5 new syringes.

"information we found challenges the 'them and us' view which marginalises and stigmatises drug injectors"

This study demonstrates that there are many people who inject drugs and do not fit the stereotype held by some in the community.

The information we found challenges the 'them and us' view which marginalises and stigmatises drug injectors. It contrasts with views which stereotype injectors, treating people who inject as if they were the same.

While some injectors are affluent, others are financially poor. While many can afford the price of a five

needle Fitpack, at times others may not and as a result may share. Whilst most will inject at home, others will in a car or a public toilet without access to swabs or sterile water. While some may not have problems accessing clean equipment, others may be less likely to share if FITPACKs are available in vending machines.

Among the many recommendations coming out of the study, it was recommended that:

there is acknowledgement that people who inject drugs constitute a widely diverse group, emphasising the inaccuracy of stereotypes about drug injectors;

those who aim to reduce the spread of blood borne viral infections among drug injectors recognise that this is a very diverse group and that a range of strategies will need to be available for drug injectors across the demographic spectrum; and

that the study, prevention and treatment of hepatitis C continues to be a priority in this country.

- Based on the report, *The Fitpack Study: a study of 'hidden' drug injectors with minimal drug treatment experience* by Simon Lenton and Anita Tan-Quigley, National Centre for Research into the Prevention of Drug Abuse, Curtin University of Technology, Perth, WA. (For more information contact 08 9368 2055) *

Rural reality

I live in a rural area and my work brings me into contact with lots of people, many who are IDUs and who have HCV, contacting me in regards to discrimination issues with GPs and dentists. Issues have included medicos not providing a service - on the grounds of someone's HCV status - and isolating people in waiting rooms not wanting to have the person with HCV pass on the virus! Clients have also contacted me wanting information just after diagnosis, due to results being given to them over the phone.

Some GPs and dentists presume if someone has HCV they inject drugs, even though the person's past may be well in the past.

One woman whilst in hospital had her status highlighted on her medical report at the end of the bed and was given a fluoro wrist band which also identified her status. When her Dr came to visit her pre and post operative he discussed her status openly and loudly so other people in the ward with her could also hear.

I've had a lot of complaints from methadone clients with some having hepatitis C and wanting the dose they're on reduced to alleviate the toxicity on the liver, and the prescriber not allowing them to reduce their dose.

One person on methadone went to a dentist in a small outlying community and told them of their status. The dentist refused them treatment and then told the real estate agent they were renting a house from. The person - with a partner and 5 children - was evicted and shunned from the community and had to relocate to another area.

Users in my area need better transmission information. I've been really surprised at the risks they continue to take with sharing injecting drug equipment. There is little awareness of the various virus subtypes and people risk picking up other strains of HCV and becoming more unwell. Many of these people are also not aware of the basics with not sharing toothbrushes and razors etc, creating unnecessary risk with family members especially with toothbrushes.

Rob

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Anyone for macramé?

As a person who has been a recreational drug injector for twenty years and who has probably had hepatitis C for nearly as long I would like to make the following comments about drug use.

Personally, I'm sick and tired of the continuous portrayal of drug use as a one dimensional issue - ie as a nefarious and seedy activity, undertaken by defective people in need of rehabilitation and treatment. Even promoters of drug reform seem to fall in this trap.

No one (other than for user organisations), seems to be willing to acknowledge that drug use is an activity that involves a wide spectrum of experiences, many of which can be relatively safe and enjoyable. Further, hordes of well adjusted people partake in those experiences. No wonder that so much drug education fails to engage its target audience.

Of course there can be a downside to drug use. Obviously, I would prefer not to have hepatitis C, and I would encourage current and future users to adhere to initiatives for safer drug use.

Take it from me, being chronically ill isn't fun and radically changes your life and options. While I still think that injecting your drug of choice is an immensely pleasurable pastime, I've also found that the after-effects and increasing nausea, incurred courtesy of my liver's reaction to that pastime, aren't.

Consequently, after much listening to my errant liver, I've recently decided that it's time to stop hitting up and pursue some less intense interests. (Gosh, now where's that application form for the Ned Flanders Origami and Macramé Challenge Club? I think I left it with the Trainspotters' Handbook)

My opinions and experiences aren't necessarily representative of any one else, however, I do hope that they illustrate that there is a myriad of possible issues and outcomes when examining drug use.

Finally, I would also like to thank those people who staff needle exchanges and who therefore give many people the option of, unlike me, remaining disease free. Whatever your opinion of drug use is, the fact is, that needle exchange programs save the community vast amounts of money. If only therapeutic services for HIV, hepatitis B and C were so effective and cheap.

Thanks, A T

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Out of Your Arm? Into a bin!

What to do with a finished fit.

By Tim Baxter.



Most injectors want to get rid of their needles safely and simply. Obvious? Well you wouldn't think so to see the reports in the press about discarded syringes. If all of your information came from mainstream TV and newspapers (sound familiar) you would be led to believe that users deliberately go out of their way to dump fits in the street, and that's only when there's no play grounds or beaches to hand!

The fact is that out of the thousands of needles and syringes given out by Needle & Syringe Exchanges each week, the overwhelming majority are disposed of safely in a variety of ways.

Unfortunately, some fits are dumped and it's never a good look.

With possession of drugs illegal, and possession of injecting equipment putting users at risk of being hassled into admitting 'self administration', it is

sadly true that some fits do get left near the 'scene of the crime' and for those homeless or 'in a hurry' users, that means leaving them in the street.

Harm minimisation, however, does not end with users alone but is an issue for the whole community. Needle exchanges have a duty of care to ensure that risks to the wider community are minimised by giving out the best possible information on safe fit disposal for all community members.

This includes providing help and information in a way that all users can read and understand, as well as letting users know that fits are the property of the needle exchange and that they can legally return their fits to exchanges without having to admit to self administration. Users can also help update their needle exchanges on places where fits are dumped so that exchanges can identify the best solution for that area.

As when using safely, safe disposal is a matter of avoiding contact with blood and other body fluids. Just like safe using, there is also a hierarchy of safe disposal from "best practice" to "better than dumping".

Fit packs and fit bins are available from all exchanges and chemists participating in the Needle & Syringe Exchange Program. If users have a home base or somewhere that they regularly inject, the best practice is to pop fits into packs or fit bins as soon as they have been used and when full the packs/fit bins can be returned to the nearest exchange. But what other options are there?

- straight into a fit bin or pack and then put the pack/bin into the garbage.

- no fit pack or bin? Put the fits in a secure plastic bottle (don't use tin cans or glass bottles - people collect them to recycle and glass can break) and then return the bottle to the exchange or put it in the garbage.

When handling a fit, always pick it up by the barrel where it is no more dangerous than a pen. Avoid touching the pointy end! Grip the barrel firmly (ie, take care not to drop the fit on yourself) and deposit the fit in a fit bin or secure plastic container. It's now ready to be returned to an exchange or to go in the garbage. Don't recap or bend the tip as these are common and easy ways to a needlestick injury.

Is it a bust? What about my fit bin? Possession of clean fits is not illegal. If you admit to using, used syringes can be used as evidence. Rinsing immediately after use is an option.

What about injury? Don't panic. Wash the wound with soap and running tap water as soon as possible. Apply antiseptic and sterile dressing. Seek medical advice.

Want more advice? If you're not sure about your local Needle Exchange, phone ADIS (*Alcohol & Drug Information Service*). They operate a 24 hour statewide service - ph 1800 422 599 or 9331 2111.

- **Tim Baxter is Information Resources Editor at the Kirketon Road Centre, King Cross.** *

AFTER 17 YEARS - THE STORY SO FAR

I hope my story shows that life does go on after contracting hepatitis C.

Seventeen years ago I was involved in a road accident, suffering major trauma necessitating multiple blood transfusions and several amputations of my right leg. After two weeks in intensive care and four months with a full-length cast, a bone graft to my femur and bone-growth stimulating battery in my tibia were later attempted.

These were not comfortable times. It took all my physical and emotional energy to withstand the onslaught upon my body. Family, relatives, friends and colleagues were outstandingly supportive.

Being diagnosed with nonA/B hepatitis in mid-1981 suddenly added a new dimension to my life. Here I was at 30 years of age, a strong, athletic teacher with a permanent disability that destroyed any chance of future athleticism - and with a [then] unknown virus.

I was very lucky to have been diagnosed quickly by my local GP when I finally escaped from hospital after 18 months. Agreeing to trial an alcohol free, vegetarian existence, I recall vividly the daunting challenge of consuming steamed Brussels sprouts.

Over time I have adopted a very low fat, high fibre diet. Alcohol consumption has varied greatly over the 17 years - from nil to too much to some to none in the past two years. Alcohol is toxic to the liver - so why exacerbate your situation?

I have also tried herbal cures including Silymarin tablets (containing St Mary's Thistle). Unfortunately, these had no effect upon my situation.

In order to measure what was happening in my liver over the years, doctors have studied my liver function tests (LFTs). The two main indicators, ALT and AST, are graphed to demonstrate what

has happened over this time. You need to know that my normal ranges are 10-45 for ALT and 12-31 for AST.

Notice how the line graphs fluctuate. This could be directly related to such things as alcohol consumption, stressful situations at home or in the workplace or in rare situations, faulty laboratory techniques.

If you examine the graph around the period July - December 1996 you will notice a significant pattern. It was during this time that I agreed to be a participant in a combination drug trial. The trial involved Interferon with ribavirin or Interferon with a placebo. As it transpired I now know that my 24 week course involved both Interferon and ribavirin - a very demanding combination! Given that I also needed to travel by car 285 kilometres each way to the treating hospital on each of 17 occasions, you would appreciate that this was a major commitment for me and my supportive family.

While on the combination drug trial I responded as only a perfect patient should. My test results were very controlled and quickly descended into the normal ranges. Additionally, my PCR test results have gone dramatically from 1.65 million copies to 65,000 recently.

In the post trial period, it appears that my LFTs are fluctuating once more. To me, this means that I am not HCV negative and not going to be in the approximate 25-40% of patients who are likely to successfully eradicate the virus by undertaking this combination drug program. And what does this mean and where does it leave me?

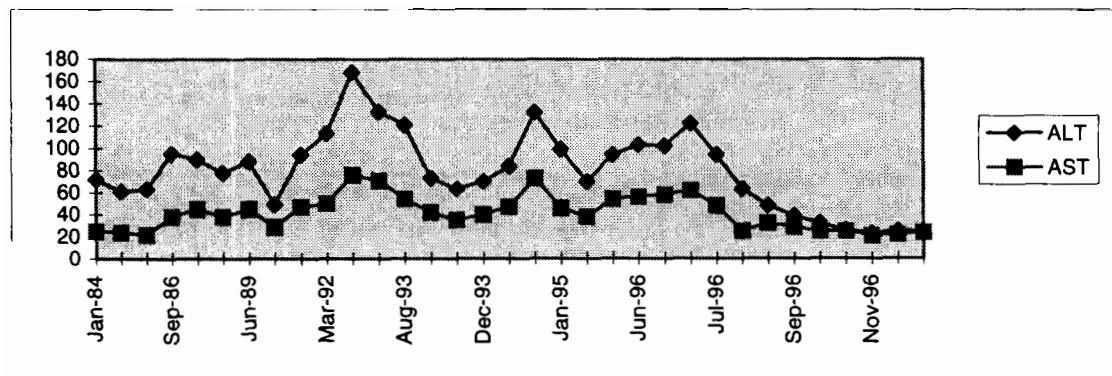
For my family it means that I have taken a gamble and not succeeded fully. An ulcerated mouth, extreme fatigue and flu-like symptoms, as a result of the Interferon/ribavirin are now dim experiences of the past. But was it worth it?

If my participation in the trial has arrested or at least slowed the rate of damage to my liver, then it's probably been worth it.

Incidentally, I'm about to have my fourth liver biopsy since 1993. The first was for initial quantification purposes; the second to gain entry to a treatment program - I didn't gain entry because the biopsy result turned out to be not recent enough for the program; and the third and fourth as part of the protocol for the Interferon/ribavirin drug program.

The first three biopsies have revealed that my liver is inflamed, that there is a small amount of scarring but that there is no evidence of cirrhosis. I expect that the fourth biopsy will produce similar results and that in another 17 years I will be in the same position.

Until then I will continue my low fat, high fibre, alcohol-free diet and enjoy life as best I can. My medium term goal, by the way, is to compete successfully in the 1998 National Cycling Championships for Amputees where I expect to race 50 kilometres in less than two hours.



Let me leave you, however, with some thoughts.

Firstly, it's of no benefit to apportion blame. Life's too short to dwell on what has happened or how you contracted HCV. Come to grips with your particular situation. The challenge is to decide what to do.

Secondly, actively seek expert advice. Consult the medical fraternity, natural therapists and support groups. Read widely and understand the terms used.

And thirdly, formulate your options. Write them down, if necessary. Look at the pros and cons of each. Examine the costs involved - financial, mental and physical - and the time frames involved.

Consulting your family should be the fourth consideration. Any decision you take may impact significantly upon them. Include them in your decision-making process (in general, be selective as to whom you disclose your HCV status - it's not easy to deal with discrimination).

Fifthly, be committed to whatever option is chosen. Being committed is more likely to result in a positive outcome than being half-hearted.

Lastly, be aware that your situation may not improve. Accordingly adopt the best positive attitude to life that is possible.

Remember what Charles Darwin said: "It's not the biggest and strongest that survive, but the ones that adapt the best".

Anonymous

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NEW SPECIALIST GROUP TO ADVISE ON HEPATITIS C

The Australian National Council of AIDS and Related Diseases (ANCARD) has formed a specialist sub-committee to advise on the best means of managing hepatitis C in Australia. ANCARD Chair, Chris Puplick, said the sub-committee would ensure ANCARD's responsibilities for detection, management and treatment of hepatitis C were met.

"Accurate figures on how many Australians are already affected are difficult to obtain as there is a high incidence of asymptomatic infection in the population and current testing methods are unable to identify between new and old infections. Data collection methods differ from state to state and treatment options for people identified with hepatitis C are few."

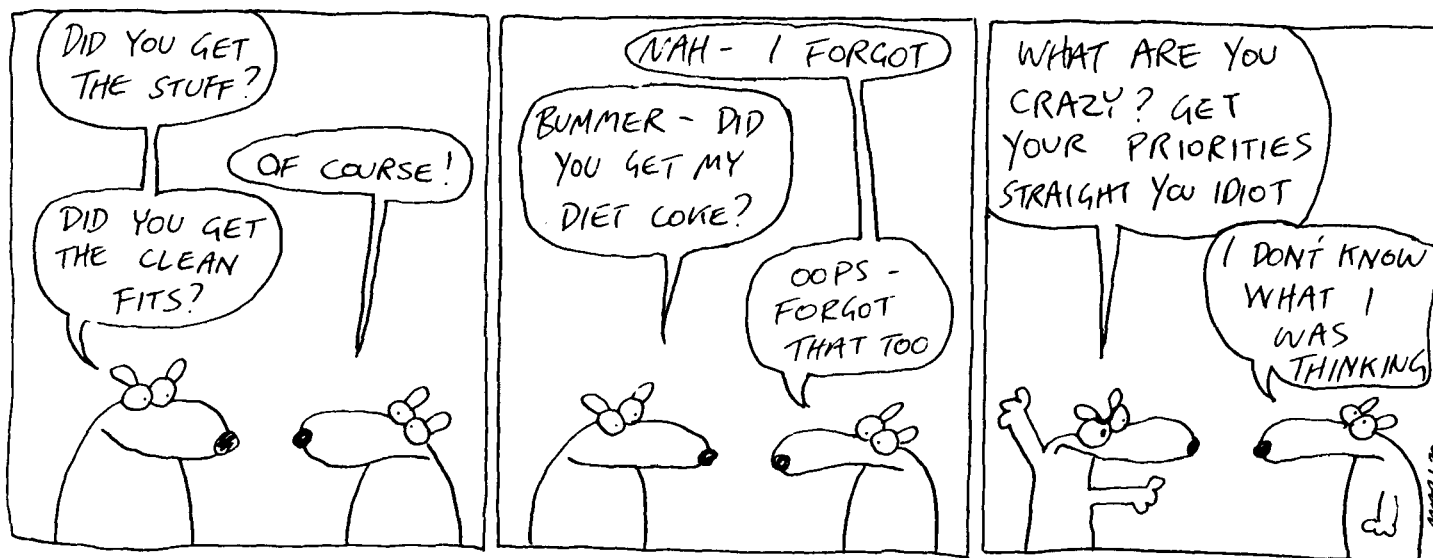
Acknowledging the current limited treatments, Mr Puplick confirmed the sub-committee will comprise experts in detection and treatment of hepatitis C. He also confirmed the sub-committee won't deal with prevention and education as these issues are being considered within the review of the Hepatitis C National Action Plan by the ANCARD Education Sub-committee.

ANCARD has endorsed a comprehensive Work Plan to guide its operation over the next four years.

"This is the first time a key advisory body to the Minister on HIV/AIDS and related diseases has developed a work plan to guide its deliberations and to make it transparent and accountable for its actions," he said.

[In our next edition, No 19, we'll carry a much fuller update on ANCARD's hepatitis C developments. Do you have any specific questions? - Ed]

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HEPATITIS C IN AUSTRALIA

By Dr Alex Wodak

There is no getting away from some basic facts about hepatitis C in Australia. Almost 90% of both old and new cases result from drug injecting. For many, if not most, of those with long established hepatitis C infection, a brief period of injecting drugs is buried long ago in the dim, distant past. It is self evident that any serious attempt to try and control hepatitis C infection has to substantially reduce the number of new infections among injecting drug users from the current alarming level of one per hour across the country.

The good news for prevention is that there is growing confidence that the protease inhibitors which have transformed treatment of HIV infection may do the same for hepatitis C in a few years time. But why should optimism about treatment be good news for prevention?

Pharmaceutical companies have only a few years to recoup the massive expense of research and development. So expect to see shock horror headlines about the high costs of these drugs in years to come, and of course, Hep C Councils will lobby Ministers for Health seeking access to them. Expect to see long, growing queues of people lined up for treatment. Anticipate Ministers for Health crying poor, asking where are they going to get the money to pay for expensive treatment for 200,000 Australians.

When even some of the above starts to happen, you can then expect growing interest in making sure that prevention is made to work.

At many hepatitis C meetings and medical conferences, prevention is barely dealt with. It's just too difficult. Pages are devoted to discussion of nuances between testing algorithms and there are usually a few pages on discrimination. A few more on alternative therapies. But prevention? Who is ready to tackle that challenge?

We had better all be interested in prevention whether we like it or not. One way to reduce discrimination against people with hepatitis C is to make sure that there are fewer people in that category to get discriminated against. One way to improve the access to treatment is to make sure that there are fewer people that need treatment. One way to reduce the grid lock in

waiting rooms of hepatologists and liver clinics is to make sure that prevention works.

At the 1996 International Conference on Reduction of Drug Related Harm in Hobart, I gave a speech which called for expansion of prevention measures which had been so effective in controlling HIV infection in Australian injecting drug users. I also advocated consideration of non-injecting routes of administration of drugs (NIROA) as a way of controlling hepatitis C.

Although my comments about NIROA produced some severe criticisms, I am unaware of any alternative proposals recommended to control hepatitis C in Australia. Despite criticisms about some details of the argument and the way some comments were expressed, I am unaware of any rebuttal of the basic arguments themselves.

One of the major misconceptions was that doctors appeared to be telling drug users how they might administer drugs. Somehow, the notion that the range of options could be extended from the present was regarded as deeply offensive. The prospect that, in Australia, *one drug user per hour would continue to become infected*, paled into insignificance for some.

We have moved on over the last year from this sterile (no pun intended) and polarising debate. For opponents of NIROA the question is how else can hepatitis C be brought under control. For supporters of NIROA the question, how can NIROA be achieved?

As a supporter of NIROA, I would answer that NIROA is already being partly achieved. The pre-conditions for NIROA - falling prices and rising purity of street drugs - is happening even without drug law reform. Pamphlets (developed by drug users) are being distributed to drug users explaining NIROA and blackened tin foil is now being found occasionally in public toilets.

"NIROA is already being partly achieved"





This year I attended meetings on HIV and injecting drug use in Pakistan and India. In both countries, NIROA is the most common mode while injecting drug use is a minority practice.



In both countries, speakers commented (without any provocation from overseas guests) on the self evident necessity of trying to prevent drug users switching to injecting, and encouraging drug users to switch from injecting to NIROA.

NIROA will clearly not be a single answer for all countries under all circumstances. We must, as I tried to emphasise in Hobart and have tried to emphasise ever since, expand all of the prevention measures which worked so well for HIV.

There is, in my view, no substitute for a big-bang campaign along the lines of the Grim Reaper. Although that campaign was criticised at the time and subsequently for arousing anxiety, there is no doubt that it transformed HIV/AIDS from an issue that occasionally occupied a tiny paragraph on the inside pages to one that involved banner headlines on the front page. And without that attention, Australia would probably be struggling with an AIDS epidemic of US proportions.

We need expanded needle exchange and methadone treatment availability - as well as alternatives to methadone. But limits of community tolerance are being reached on some of these issues. We need articulate and influential exponents of hep C treatment to stand up and be counted for these parts of prevention.

And we need to get cracking with practical information so that people who cannot or will not stop using drugs at least use them in ways which are less damaging. That was and always will be the meaning of harm reduction.

Even if effective prevention measures are adopted in Australia today and implemented vigorously, it will still take many years to bring this dreadful epidemic under control. The sooner we start to get real about hepatitis C the better - there is not a moment to be wasted!

- **Dr Alex Wodak is director of St Vincents D&A Unit, director of the NSW Alcohol & Drug Information Service, and honorary senior lecturer in community medicine at the University of NSW.** *

Time to change drug laws

An open letter to the Premier, Bob Carr, by Jim McClelland.

Today the decriminalisation of heroin and its dispensation to addicts under controlled conditions is increasingly close to being a mainstream opinion.

Great health scourges of our time include AIDS, hepatitis C and heroin addiction. In our approach to the first it is generally conceded that Australia has set an example to the world.

Why can't we also be trailblazers on the other scourges? I was disappointed by your initial reaction to the proposal by Justice Wood that the Government should set up safe and sanitary injecting rooms or "shooting galleries".

You were reported as saying that acquiescence in such a policy would send the wrong message about the Government's stance on drugs - a stubborn adherence to the failed policy of prohibition.

You later modified this stand by stating you would set up a bipartisan working party to consider legalising shooting galleries. Why should you and your party, one that claims to be more socially enlightened than its opponents, need opposition support to give leadership?

I don't know what your private polls tell you but I feel a politician of your standing could win the support of an overwhelming majority of the electorate to such a change in the law. One matter on which there is already a broad consensus it is that the so-called "war against drugs" by the present method of prohibition and prosecution is well and truly lost. The findings of Royal Commissioner Justice Wood confirm this obvious conclusion. When one battle fails, a sensible general orders a change of strategy.

You also showed no interest in Justice Wood's call for a national summit to explore a new approach to the drug problem, and you continue to stand back from support for the ACT heroin trial. All the indications are that you remain stubbornly mired in a policy morass on one of the most urgent problems of our times.

I am not suggesting that decriminalisation and controlled dispensation will supply a total answer to this awesome problem, but it would trigger an enormous improvement in the present hopeless situation. These arguments have been stated ad nauseam but let me repeat them:

- It would greatly reduce overdosing, which claims the lives of 500 Australians every year.
- It would assist in controlling the currently estimated 9,000 new cases of hepatitis C that occur each year - the majority of which occur here in NSW.
- It would, as pointed out by Justice Wood, remove or at least drastically reduce the most potent source of police corruption.
- It would take the sleaze out of addiction. It would not be necessary to finance addiction by prostitution or theft. It would be possible to be an addict and still be a useful member of society.

Concurrently, other measures should be maintained - the methadone maintenance program, detoxification units and counselling services.

Of course the policy carries some risks and implementation would be complex. But to persist in the present policy is to abandon all hope of amelioration, let alone solution.

- **Jim McClelland is a former Chief Justice of the Land and Environment Court, and a Sydney Morning Herald columnist.** *

my story

The call ...

Ate now refer to it, came at four minutes past midnight. I was sound asleep, but as soon as I saw the red light on my digital clock, I knew it had to be the call.

"Sharon?" a woman's voice asked. "This is Cindy from California Pacific Hospital. We think we have a donor for you."

"Okay," I answered, the reality not hitting me. "What do I do?"

"Get up, get dressed. Do not eat anything. They are checking the liver and we'll let you know in two hours if it's suitable."

I sat on the edge of my bed for a few seconds. What does one do to get ready for a liver transplant?

My husband, Peter, was in Fresno on business, about 120 miles away. My mom was staying with me whenever he was out of town. The last couple of months my parents and husband felt I shouldn't be left alone. It was probably those high ammonia levels and that lactulose syrup I kept downing that scared them.

I went to the guest room door to wake my mother. She sat straight up in bed. "What? Are you okay?"

"We got the call," I said, repeating Cindy's conversation. Then I called my husband and friends, Norman and Sherrill, who had volunteered to drive me to San Francisco if Pete was out of town. Even though we wouldn't know for two hours, they said they'd get up and drive into town, picking up my father on the way. Dad was going to stay at my place and take care of Pepper and Sumo, our dog and cat.

I ran in circles around the house, not knowing what to do. I posted a message on [a US support-group email bulletin board] that if they didn't hear from me, I was on my way to California Pacific Hospital. I then took a nice warm shower, knowing that if the liver transplant was a 'go', it would be a long time before I took another.

My husband decided to leave Fresno and head toward Lodi. I was to call him on his mobile phone when Cindy called back. He

would then cut across to San Francisco or come on home if it happened to be a false alarm.

Now ready, Mom, Dad, Norman, Sherrill and I sat by the phone: it rang at 2.04am.

"Sharon, this is Cindy; the donor is a perfect match. Blood type AB, same size as you. Go now to the California Pacific and enter through the emergency entrance. The staff there have been alerted and will direct you. Good luck and drive safely."

Now my heart started pounding. I called my husband. He would now turn off and head for San Francisco.

Norman threw my suitcase in the boot; it had been packed for a year and three weeks. Sitting in the back seat, ready to head off, I carried a list of people I was supposed to notify when I got the 'call'. I didn't want to wake them in the middle of the night; I would phone them later that morning.

I had, however, promised my oldest daughter in Pennsylvania I would call her no matter what. She works the night shift at Alcon Surgical, so I called her from the car phone. I told her not to fly to California until we knew for sure the operation was going to take place. Debbie agreed, but very reluctantly. We had a very tearful good-bye with lots of 'I love yous'. (Later I found out she took the next plane to California.)

There were few other cars on the road that early morning on the way to San Francisco. We seemed very alone. It is very difficult to describe the rainbow of emotions that coloured and clouded my mind. I was happy. I was scared. I was desperately sorry for the donor's family. I was ecstatically happy for my family.

Sherrill thought it best that we stop for a cigarette and a break but her husband was adamant that every second counted. We didn't stop. We made it to San Francisco in record time.

We walked into the emergency room and my husband was already there. He'd made it there about fifteen minutes before us. Nearly all the way, his speedometer [MPH] hadn't run under three digits.

As we went through the doors, we were directed to the sixth floor; the transplant floor ...

This story is to be continued in editions 19 and 20 of
The Hep C Review.

If you have hepatitis C, please do not be unnecessarily alarmed by Sharon's story. Around 95 of every 100 people with hepatitis C will never require liver transplant.

In edition 20, we'll also run an overview of liver transplant services here in Australia. *

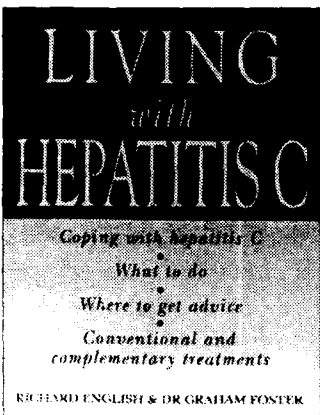
Living with Hepatitis C

by Richard English & Dr Graham Foster

Reviewed by Sanguine Syd

I'm grateful for the opportunity to review the book *Living with Hepatitis C*, having the virus proving invaluable qualification for the task.

Up-to-now, most of the knowledge I have gained has been either through treatment procedures or most importantly from the *Hep C Review*. Reading this book has increased my knowledge and understanding.



Living with Hepatitis C is available in Australian bookshops, published by Random House. RRP \$16.95

The book explains the different types of hepatitis and gives a good definition of and the differences between HCV and HIV. (The virus that causes AIDS, HIV is in a family called retrovirus, whereas HCV is in the flavivirus family.) I found the subject of hep C genotypes and their geographical prevalence enlightening.

The book is written in an easy style which is readily comprehended. I am not aware of any areas the authors have left uncovered or unexplained. Although it is addressed primarily towards people affected by HCV, I can see reading it as a great benefit to all who are involved with hepatitis C.

• 'Sanguine Syd' is a Hepatitis C Council member. *

The Hepatitis C Handbook

by Matthew Dolan

Reviewed by Steven Clavey

The whole book looks great and very accessible. Specifically, regarding traditional Chinese medicine (TCM) for treatment of hepatitis C, Matthew Dolan has done an excellent job of introducing a rather complex topic in a simple yet accurate way. He addresses both the potential of TCM as an effective hepatitis C treatment and the reservations some patients may have before trying it.

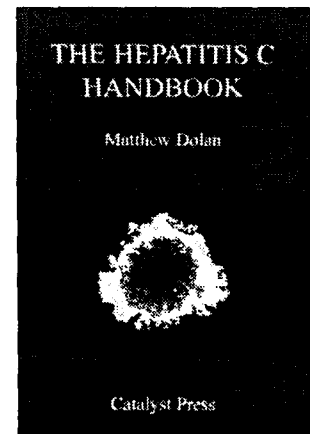
He points out that Chinese medicine is a complete system of medicine with an internal coherence that allows practitioners to classify and treat a wide range of symptoms, which in Western medicine would require the attention of a number of specialists. This in itself, he remarks, may make TCM an attractive option for many patients.

My sole reservations about the book's Chinese medicine section involve the examples of herbs and formulas Dolan lists. These are fine, as examples (despite minor errors in Latin names of herbs) but there is some encouragement to self-experiment with the herbs and formulas.

It must be stressed that Hep C patients will get far better results if they have a proper Chinese medicine diagnosis first, and will probably save money despite the cost of a consultation. The real strength of Chinese medicine is its ability to tailor treatments for an individual's needs, addressing their own special strengths and weaknesses.

As far as finding local practitioners of Chinese medicine, the Sydney College of TCM has been very active in training around hepatitis treatment, including a seminar by Prof Chen Jian-Jie, a well-known hepatitis researcher from China [see edition 12] and maintaining an on-going hepatitis student clinic. I hope that my comments are useful, and not too shameless a plug for Chinese medicine! Notwithstanding my bias, I really do believe it is an excellent option which has not even yet been fully realised in its potential.

• Steven Clavey is secretary of the Australian Chinese Medicine Education & Research Council. *



The *Hepatitis C Handbook* is available from Central Books, London, UK
ph: 0011 44 181 986 4854
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email: peter@centbks.demon.co.uk

Walking a Tightrope: Law Enforcement and Health

By Lory Price, co-authored by Carol Major.

While the increases in blood borne diseases have created wide spread concern, they have also challenged all of us to consider new ways of dealing with drug use. It has become more important to look after the health concerns of drug users than to impose moral judgements on their behaviour. Australia is one of the forerunners in adopting a harm minimisation approach to drug use.

Nevertheless, the community is still deeply divided on this approach, a fact that is reflected in the ongoing debate on law reform and objections to projects such as needle and syringe exchange and the proposed trial on the provision of heroin to people who are dependent on this drug.

The police walk a fine line between the arguments in this ongoing debate. They are asked to uphold existing law, while simultaneously being asked to support the efforts of health workers who are working with people who are breaking the law.

In 1994 the NSW Police Service established a unit to assist police in this area. The Drug Programs Co-ordination Unit runs education programs for police and is involved in a number of community programs aimed at reducing drug related harm.

Deborah Munro, education officer in the unit, says that the education programs go a long way to reduce police fear of contracting diseases such as hepatitis C and HIV/AIDS. The sessions debunk the old myths about injecting drug users and how blood borne diseases are spread. This improves police relations with drug users as well as police understanding of the value of initiatives such as needle and syringe programs and methadone maintenance.

Ms Munro explains that the nature of police work raises many occupational health and safety

fears in the advent of the HIV/AIDS and hepatitis epidemics. Police are present at scenes where there is blood and vomit. They are spat upon. They sustain needle stick injuries from apprehending someone who is hiding needles and syringes in their clothes. Naturally, they become very concerned about contracting diseases present in body fluids and can develop defensive attitudes about intravenous drug users.

The drug education program helps defuse these fears and create a better understanding of issues affecting drug users. On the other hand, Ms Munro stresses the need for some give and take on both sides. Health workers and intravenous drug users support groups must be aware of the issues facing police. Open communication that acknowledges the constraints on all sides will go a long way to achieving the aims of harm minimisation.

"[police] are asked to uphold existing law, while simultaneously being asked to support the efforts of health workers"

To this end the Education Program provides police with guidelines on how to interact with such needle exchange and methadone programs, encouraging them to talk openly with health workers to pre-empt difficulties developing.

For instance, police are often on the receiving end of complaints about needles being left on the ground, increases in break and entries in areas surrounding needle and syringe exchanges and "addicts" lounging about the street. The community can see harm minimisation as pampering "addicts" and want the police to step in.

Ms Munro says these situations can be diffused if the police negotiate with the service to come up with solutions, such as employing a clean-up service or talking with clients about loitering in the streets around the service. She also encourages workers at these clinics to share their concerns with police.

Ensuring that these operations are safe and do not cause community problems will go a long way to changing attitudes to harm minimisation approaches and reducing the spread of blood borne diseases.

While the Drug Programs Co-ordination Unit offers training and resources to support police in their efforts in this area, there is still a long way to go. As Ms Munro explains, police are new to the concept of harm minimisation. Much of what they are being asked to do, such as using accountable discretion at the scene of an overdose, falls into an area where there is no black and white policy. Police must feel that they will be supported when they use their discretion.

Health workers are asked to acknowledge the difficulties police face in performing this delicate balancing act.

- Lory Price is Coordinator of the Drug Program Co-ordination Unit, NSW Police Service. *

It's around two in the afternoon on the day of Mardi Gras and Matt, Steve, Georgie and I are in the middle of preparation for the big night.

My last dealer was heaven and did home deliveries to boot, but he got busted last month and is sitting on remand waiting for a possible ten year sentence.

I can't believe it. He was the most professional dealer I've had. He never ripped you off, the gear was always good and he never left you waiting around on the street.

But the cops heaved one of his customers and they narked on him and then set the poor bugger up.

Anyway, my current dealer's nowhere near as reliable but what can you do? I just keep my eyes and ears open all the time for someone better.

Georgie's starting to whinge about how long they are taking and her legs are starting to ache. I hate the bullshit around scoring - why can't they just treat all drugs users the same as tobacco and alcohol users.

I mean people who are addicted to nicotine have full on physical withdrawals and feel sick and shitty when they can't have a hit of nicotine; so why is that okay while wanting heroin is just so damned shitful to this world?

Damn this dealer, I've got better things to do than sit around thinking about userphobia.

After a short while, here comes the dealer and we do the business. A bit of negotiation and I hand over \$300 for the heroin and \$300 for cocaine to get us up there dancing.

As I hop back in our car, Georgie already has the spoon and two new fits out. I'm worried because we've been sitting here for so long already, so we agree to drive around the corner for the taste.

We only ever share a spoon when there's new fits 'cause Georgie's tested positive for hep C and she doesn't want to give it to me. So each time, I dip in and draw up first out of the spoon. But when we've got no clean fits, and it's late at night, it's a hassle.

I haven't always got the car and when the local chemists are closed, it's a fair way up to the Kirketon Road vending machine. We've cleaned with bleach a few times but you're never sure if it kills the hep C and we spoil the rush worrying about the virus.

Once I had to smoke the gear because we just couldn't get any new fits, so we used the bottom of a coke can. We still got really out of it and had a great night, but I'll always prefer using needles. It was fun trying it a new way, 'chasing the dragon' like Dylan out of Beverly Hills 90210, but mind you Dylan used alfoil and that stuff is so light that it burns too.

Then I guess, you get a nice metallic rush along with your drugs. Not my idea of a drug cocktail!

Finally, Georgie and I sit back and relax and enjoy the rush. One of the worst things about shooting up in a car is worrying about cops and other people, so once I feel okay again, we head off home.

Finally, we arrive home and the boys are positively jumping. Waiting for us, they've poured a nice warm bath and have laid out all their gear. We mix up a wicked mix of the coke and heroin together and all join in to have a blast together.

And the party? Well, we partied hard but 'cause we went prepared, we partied safe. It still didn't prevent us from some wicked hangovers the next day, but that gave us a good reason to head to the recovery party.

•• An abridgement of "In the Car" by T.R, from NUA News, Edition 20. *



Witness a drug debate

Federal Liberal MP Dr Brendan Nelson attacked his own Government yesterday over lack of willingness to tackle narcotics abuse.

Participating in a forum on injecting drug use shown on Channel Seven's Witness show, Dr Nelson agreed that injecting drug use, in particular heroin use, which accounted for more than 500 overdose deaths a year, was a major problem.

Dr Nelson was one of two MPs who attended the forum. The other was Ms Janice Crosio (ALP) who repeated the call she has made in Federal Parliament for a national forum on the problem.

The host of the debate, Paul Barry, was scornful of the failure of health, police or justice ministers at State or Federal level to participate. But assembled before him was a gathering of people from many areas, including drug users, welfare workers, doctors, a former chief magistrate, and the parents of victims, such as the Ecstasy victim Anna Wood.

Mr Barry showed Geoff Owens, representing the NSW Police Drug Enforcement Agency, a sample of heroin which Witness reporters had bought in an undercover operation in Cabramatta, an operation so easy that the reporters were able to buy three times in 10 minutes.

Enforcing the law was "an extremely difficult job", Mr Owens said. "Clearly, it is not working on its own."

His espousal of the "harm minimisation" aspect of drug law enforcement brought an immediate retort from Mr Tony Wood, father of Anna Wood, who said that harm minimisation was "killing our kids".

But the former top NSW public servant Mr Gary Sturgess was more sympathetic, saying the police were "stuck with enforcing an impossible law".

Various strategies were advocated, such as Police Royal Commissioner James Wood's recommendation for legal and supervised "injecting rooms", and the ACT heroin trial.

by Malcolm Brown (SMH 16/6/97)

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An Oasis

The Salvation Army's Oasis Youth Support Network offers support to homeless young people at risk of HIV and HCV infection, and other harms. Our services include streetwork, drop in facilities, case management, employment support and accommodation ranging from crisis to long term.

One part of our network, working predominantly with young injecting drug users is the Salvation Army Outreach Service (S.O.S.) and the drop in centre located at the Oasis youth centre in Surry Hills. The outreach service operates six days per week providing information, support and referral to young people on the streets of Kings Cross, Darlinghurst and Surry Hills.

Its aim is to provide young people with a safe environment for time out and contemplation of troubling issues (the age group we cater for is between 12-25 years of age). Our workers provide information and education on HIV/AIDS, hepatitis and safer using, and safer sex practices on a level that young people understand and relate to. Although lots of young people we come into contact with are not yet ready to contemplate change, it is emphasised that workers will be available for support and guidance when they are ready to address these issues.

Referral to other services is an integral part of our work, so if someone has specific needs, our staff may suggest referrals to services catering to those needs.

Our drop in facility at the Oasis centre offers a variety of services including information, referral and counselling, meals, showers, laundry facilities and access to Department of Social Security and CES staff and advice. As well, Oasis offers shopfront services such as literacy training, education and vocational skills, and medical services. This service is available 12 midday - 9.30 pm, 7 days a week.

We also offer VITEL, which is a motivational and educational programme offering the opportunity to face individual issues through various outdoor and adventure activities. This can provide young people who inject and want to make a break from their old environment with the opportunity, support and motivation to help reach, and maintain, positive life choices.

Another integral part of our Network is to offer accommodation to young people who are homeless. Crisis accommodation is available through the Oasis centre with medium to long-term accommodation being offered through the Irwin Centre, in Surry Hills.

Our services offer ongoing case management and support from workers with the goal of enabling people to move on to independent living. Overall, our network endeavours to promote harm minimisation practices and to enable young people to initiate positive changes in their lifestyles.

• by Phil Bebbington, Oasis Youth Support Network (9360 9000) *

Cellblock Youth Health & Arts Service

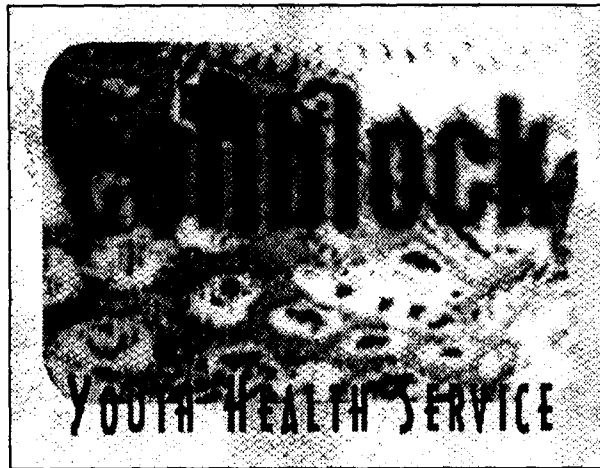
- an interview with Janice Bagot,
Arts & Cultural HIV Health
Promotion Officer

What's the service all about, Janice?

Cellblock is a holistic health service for homeless and marginalised young people, 12-20 years old, within the Central Sydney Area Health Service. We're a confidential service and our clients don't need Medicare cards.

We utilise a whole range of creative arts that work in combination with our health and medical services.

We offer young people a multidisciplinary service in the visual, music, video and performing arts; general practitioner services; counselling; and health promotion. We also offer part-time dental therapy.



How do young people find out about the service?

We do a lot of liaison with people and other services in the local community - GPs, school counsellors, youth refuges and other youth services.

And word of mouth is another common way young people find out about Cellblock.

Is harm minimisation Cellblock's principal aim?

We aim to improve young people's awareness of their options and their negotiating skills so that they can make the best decisions for themselves.

One example of our approach with arts and health is the Tribes project we're planning with young people interested in Hip Hop and health promotion.

Funded by NUAA, it will involve a Cellblock Drug and Alcohol Health Promotion Officer and Stephen and myself - also Cellblock workers - as well as Hip Hop artists and the visual artist, Khaled.

We'll all be involved in the production of Hip Hop resources for other young people. Resources such as CDs, music video clips,

website, legal graffiti, and whatever else the group decides to create.

How successful is the approach?

It works well. The feel of the service makes it really relevant for young people - for example, we have a studio for bands, drama, multimedia, internet access and video making.

The combination of arts and health really add to each other. Many of the young people who come to the centre benefit from such an approach.

They can access healthcare services, in-house, from our doctors - services like HCV/HIV testing, referral and support; contraception and general healthcare and dental checks.

In regard to Cellblock's work, how would you like to see the future, Janice?

It would be great to see more services like Cellblock around, and also more resources for general youth services in the community - like refuges and youth centres etc.

Also, it would be great to see the whole range of healthcare services that young people use, consider how they could make their services more relevant to young people.

And I'd really like to work more with young people, developing HCV and HIV resources that they find useful and empowering.

Cellblock Youth Health and Arts Service:
142 Carillion Ave, CAMPERDOWN
Phone: 02 9516 2233

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A price of progress?

By Richard Eckersley

People use drugs, including injected drugs, for many reasons. In most cases, this use may not pose a threat either to the users personally or to society - apart from the consequences of the illegality in the case of illicit drugs. Nevertheless, drug addiction (that includes alcohol as well as illicit) is one of several issues that are exacting a growing toll of death, ill-health and suffering among mainly young Australians.

Despite years, even decades, of political action, we are not solving drug addiction and problems like suicide, especially among young people. The prominence of these problems in the news and on political agendas over the past year or so makes that clear. We are still losing the war against drugs and depression among young people is increasing. Crime remains a serious social problem. The epidemic of youth suicide continues.

This is clearly visible in growing death rates associated with opiate use (mostly heroin). These rates, occurring mainly in the 15-34 age group, have increased more than tenfold since the mid-1970s and have continued to rise since. While viral hepatitis accounts for few of these deaths, it is an increasingly important cause of chronic and debilitating ill-health among people who have injected drugs.

Suicide remains a very rare event. However, new research is revealing it is just the tip of the iceberg of psychological pain among young people. The research shows that this pain is not an aberrant personal response to life; nor is it confined to marginalised or disadvantaged young people.

While less than one in every 20 thousand young people take their own lives each year, research shows that up to one in ten will attempt suicide and possibly up to two-thirds will think about it.

To give an idea of the scale of the problem, there are about 20,000 hospitalisations each year as a result of pharmaceutical poisoning, much of which is intentional and self-inflicted. This figure is roughly the same as the number of hospitalisations as a result of road accidents.

A recent report by the National Health and Medical Research Council states that depression should not be regarded as a normal part of adolescence. It says that depression in young people is a source of immense suffering. The report cites research findings that up to a quarter of young Australians

will suffer major depression by age 18, and that in any six month period, about 40 per cent will suffer depressed mood (not a clinical condition, but a prolonged period of sadness or unhappiness). A recent major international review suggested that likely explanations for youth unhappiness were: family conflict and break-up; increased expectations; and changes in adolescent transitions. In particular, it implicated the emergence of a youth culture that overly isolates young people from adults and increases peer group influence; more tension between dependence and autonomy; and more breakdowns in romantic relationships.

I believe this situation also reflects a growing failure of modern western culture to provide an adequate framework of hope, belonging, meaning and moral values in our lives, so weakening social cohesion and personal resilience. There are profound tensions, contradictions and gaps in our culture and way of life that can create a very confusing picture, especially for young people, who are at that stage of life where they are making sense of the world and their place in it. For all the complexity of modern life, we are failing to provide youth with well-marked pathways, rites of passage and clear reference points to guide them through the often difficult transition from childhood to adulthood.



The key purpose of culture - the values, myths, stories and customs that define who we are and what we believe - is to help us to develop a rich network of enduring personal, social and spiritual relationships that give our lives

broader and deeper meaning and significance. Yet modern western culture increasingly encourages us to invest meaning in the individual 'self'. It also fails to promote a positive vision of society and its future to serve as a source of inspiration, focus and identification for the individual. Thus our culture has left the 'self' exposed and isolated because it has weakened the very bonds that nurture and sustain us.

Psychological well-being is also linked to meaning in life, with positive life meaning related to strong religious beliefs, self-transcendent values, membership in groups, dedication to a cause and clear life goals.

We need to pay closer attention to how key features of our society could be degrading qualities such as hope and meaning in life, and hence contributing to drug abuse and other psychosocial problems among young people. In other words, we need to acknowledge that if we really want to get to the heart of these problems, we will have to change fundamental aspects of our culture and way of life.

- The above article is abridged from Richard Eckersley's work. He is a Canberra based strategic analyst who has written extensively on youth and futures issues. *



YOUTH, IDU AND HEPATITIS C

By Jenny Melrose

Foley House (Surry Hills, Sydney) is a short term residential service for people at risk of contracting or transmitting blood borne viruses. The majority of our clients are current IDUs and/or sex workers. Using harm reduction principles, we aim to facilitate a positive change in our clients' self-caring skills and to improve their expectations about their personal well-being and safety.

A review of the clients' files from the last nine months has shown that 67% of our clients reported being HCV positive. Of our clients aged 25 years and under, 62% have HCV (males, 71%; females, 59% and transgender, 0%).

However, 13% of these young clients reported that they had not been tested and therefore did not know of their HCV status. If these residents are not included when working out the above statistics then we see that 71% of our young clients, who have been tested, are HCV positive.

For many of our young clients a positive hepatitis C diagnosis does not seem to worry them. Few of our young clients report experiencing symptoms or have raised ALTs (possibly due to not being positive for very long). However, since a majority of older residents are HCV positive (81% of those who have had an antibody test) and are often symptomatic, one might hope that our younger residents would see that HCV can affect peoples' lives and would become concerned about contracting the virus.

However, we have not observed this to be so. Since most of our clients are currently using, it would appear that their focus of attention is on getting their next shot rather than concerning themselves about their health. Also, considering that most of our older residents have difficulties with self-care themselves, they may not be particularly good role models for our younger residents.

As a worker these points are of great concern to me. If being HCV positive is considered to be the norm, and there is no perceived liability in being positive, current IDUs, particularly young people, will place little emphasis on safer ways of injecting drugs.

This is evident by some things I have discussed with the younger residents of Foley House. For example, some residents have told me that becoming positive means that at least they will be part of the crowd (this is not surprising considering the above statistics). Furthermore, when telling a young male client about the importance of using cleanly with his positive partner he stated that he did not use safely because it would be something near "romantic" if he were to contract HCV from his partner.

Many of our clients believe that they know how to use cleanly since they can recite "a new fit for every hit" and they report accessing all equipment for safer using (fit, spoon, filter, swabs, water).

However, when probed, it is evident that they do not realise WHY they need to use such equipment or in which ways contamination can occur in the process of mixing up and injecting their drugs. When we systematically go through the mixing up procedure with our clients many say that they have never thought about the process nor had any previous education in this area. This indicates that many IDUs do not know how to use safely when missing some piece of equipment, such as separate spoons. Since it is very difficult for NSEPs in the Surry Hills area to get hold of water vials at present this is a concern.

Considering the above anecdotal evidence I believe that when current IDUs access agencies, more emphasis needs to be placed on harm minimisation. All users require education on safer using techniques, especially in regard to what to do when all safer using equipment is not available.

Also, it is of great importance that all sterile using equipment be available to anyone who injects since it would be impossible to educate everyone on this matter. Furthermore, there is a need for social research in regard to why young IDUs continue to use unsafely even when educated about the liabilities of such practices.

It is possible that the theory of "optimism bias" (in which people believe that it won't happen to me) could explain the above, however, further research is necessary to establish if this is true. I would hope that coupling accurate information and harm minimisation techniques could lead to safer using for current IDUs and a decrease in the spread of HCV.

- Jenny Melrose works as a Residential Support Worker at Foley House. *

Hepatitis C virus among Kings Cross injecting drug users

By Robyn Dwyer & Ingrid van Beek

The Kirketon Road Centre (KRC), a primary health care facility in Kings Cross, Sydney, targets "at risk" youth, injecting drug users (IDUs) and sex workers for the prevention, care and management of blood borne and other transmissible viruses. Since 1992, KRC has been offering hepatitis C virus (HCV) antibody testing to all IDUs presenting to the centre.

Between February 1992 and December 1996, 1078 IDUs were tested for HCV, with 490 (45%) testing positive for HCV antibodies. This figure represents the *prevalence* of HCV infection among the people tested at a particular point in time who show evidence of exposure to the virus.

Prevalence, however, does not provide an indication of the rate at which new infections are acquired. To determine this, *incidence*, which is a measure of the number of new cases in a population over a period of time, needs to be calculated.

Among the 572 HCV initially negative IDUs tested at KRC, 201 returned for a subsequent HCV test, allowing us to estimate incidence of HCV among this population. Forty five of these IDUs tested HCV positive at a subsequent test, giving an incidence rate of 17.6 per 100 person years. This means that 17.6% of IDUs retested became newly infected with HCV each year.

We also examined incidence according to age and found that IDUs under 20 years had an incidence rate of 89.3 per 100 person years, compared to 12.2 per 100 person years among IDUs aged 20-29 and 6.6 per 100 person years among IDUs aged 30 years or more.

In effect, these findings mean that among IDUs tested at KRC who were less than 20 years old, almost 90% became infected with HCV within twelve months, clearly an unacceptably high rate.

This high rate of spread measured in a prevention centre that offers needle exchange

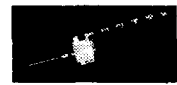


and other primary health care suggests that current NSEP efforts, while apparently effective for the reduction of HIV transmission have not contained HCV infection among attending IDUs.

While such high rates of HCV incidence may be explained by the fact that KRC targets a particularly "at risk" group of IDUs, it nonetheless has implications for the wider population of IDUs in Australia, given that a significant proportion of this population is likely to pass through the Kings Cross area at some stage. By the same token HCV infection rates must be controlled in other key areas of transit such as Cabramatta and the gaol system if the overall pool of infection (prevalence) and the risk to the greater IDU community is to be reduced.

National surveillance studies of NSEP attendees (Macdonald et al, 1997) have found reported rates of needle syringe sharing of 30% indicating that sharing has not been eliminated among IDUs. Other research at KRC among cocaine injectors (Malcolm et al, 1997) suggests that unsafe injecting is circumstantial rather than the norm.

This has also been demonstrated in overseas ethnographic research (Grund et al, 1991) where it was found that while planned needle sharing in which two or more people shared the only available needle syringe was never observed, occasions of unplanned use of another person's needle syringe did occur. This was in situations



Hepatitis C & Pregnancy

Written by a hepatitis C positive user from NSW Users & AIDS Association (NUAA).

Probably the most important thing a pregnant, hep C positive woman can have is access to factual information.

There are people out there who will tell you that if you're pregnant and positive, then you should have an abortion, or else your baby will get it too. Or that you can't breast feed if you're hep C positive. A lot of myths are circulating about pregnancy and hep C, and I'd like to clarify some of the crap I've heard.

If you're pregnant & positive your baby would be born with your antibodies to HCV. Most babies who are born with hep C antibodies will lose them from their system by the time they're 12-18 months old. This is because when a baby is born, it has all its mother's different antibodies in its blood - this is to help fight infections. The chance of a baby contracting the actual hep C virus from its mother during pregnancy and delivery is very low - less than a 10% chance.

They say that breastfeeding is best for babies, but it can be a really confusing issue if you've got hep C.

What are the actual chances of your baby catching HCV through breast milk? Well, the chances are slim. World wide, researchers have not discovered any cases of transmission through breast milk. It's an option you have to weigh up - the benefits of breastfeeding versus the chances of the baby contracting hep C.

Think carefully about it, and remember *THE DECISION IS YOURS. YOU DON'T HAVE TO LISTEN TO ANYTHING OTHER THAN WHAT IS RIGHT FOR YOU AND YOUR CHILD.*

If you're hep C positive and have older children, you might have thought about having them tested - it's a difficult dilemma.

The virus is blood borne, and it is unlikely that older children would get it in ways other than pregnancy or through direct contact with infected blood. Is it worth putting them through the ordeal of blood tests if the result is likely to be that they don't have the virus?

✱

where new equipment was expected to be available and then discovered not to be or when an accident occurred, damaging one of the needle syringes.

The authors concluded that IDUs can and do get into situations where sterile equipment is unavailable and surmised that young or novice injectors were likely to be less competent than experienced injectors at managing those situations, rendering them as most "at risk", a supposition consistent with the findings at KRC.

The high HCV incidence rate among younger injectors and the demonstration of continued circumstantial sharing among IDUs highlights the need for sterile equipment to be more readily available and accessible to IDUs. This could be achieved by situating NSEPs close to (or where) drug injecting actually takes place.

Injecting rooms (IRs), which provide IDUs with a safe place to inject have the potential to reduce circumstantial sharing by offering a ready supply of sterile equipment so that if accidents occur, more needle syringes can be accessed immediately. IRs also potentially reduce the likelihood of accidents occurring as a result of the hurriedness of injecting when it takes place in poorly lit public places with the threat of interruption by police or others.

The high incidence of HCV among younger injectors also points to the need to gain a better understanding of new injectors who are often not seen at NSEPs until they have been injecting for some time. Understanding the transition to injecting would be of benefit for the effective targeting of health promotion activities to this high risk group.

The continued spread of HCV among IDUs is of considerable public health concern and rapid and creative responses are needed if the successes achieved in the prevention of HIV are to be translated to the HCV epidemic.

- **Robyn Dwyer is Research Manager at KRC; Ingrid van Beek is Director of KRC.**

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INJECTING DISCRIMINATION

By Tony Rance.

Hepatitis C positive people who use drugs illicitly experience discrimination when attempting to access the whole range of healthcare and welfare services - both government and non-government.

This systemic discrimination can have a devastating effect on individuals and whole groups of people. Hepatitis C positive people who use drugs illicitly have to deal with multiple episodes of discrimination. They have to deal with society's often harsh and negative attitudes towards people with communicable diseases such as hepatitis C, as well as the discrimination they receive for choosing to use drugs.

These episodes of discrimination and what we call "userphobia" occur for most hepatitis C positive users in all of the areas outlined above. (Hepatitis C positive people who use drugs illicitly are even discriminated against within the wider hepatitis C positive community.)

Discrimination can often result in positive users having a general distrust and fear of receiving negative treatment from most members of society if they find out about their disease status or their drug use.

Access to treatment

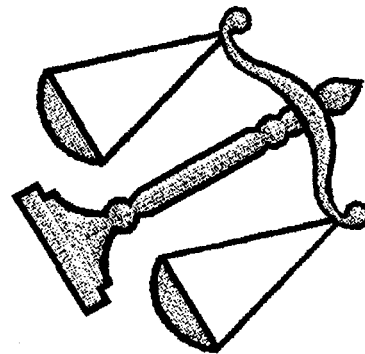
For instance it is difficult for many hepatitis C positive users to find and keep a regular doctor. Many doctors have difficulty in accepting a person's choice to inject drugs. Often if positive users do disclose to their doctor that they are using they are told that **FIRST** they must get treatment for their "**DRUG ABUSE PROBLEM**", before they can be treated for their medical conditions.

Doctors often refuse medical treatment, saying "if you are going to continue injecting drugs I don't want to see you, you are a waste of my time". People have been told they are not eligible for interferon treatment if they are using because "you will only go out and reinfect yourself and interferon treatment is very expensive - treatment would be a waste of money".

Although the NH&MRC report on the detection & management of hepatitis C recommends that the interferon treatment exclusion clause for current injecting drug users be removed, many hepatitis C positive users are still being excluded from the only form of medically prescribed treatment currently approved and available.

If someone has a very real fear that they will experience systematic discrimination if they disclose their drug use, there is not much incentive or encouragement to be honest and disclose. Because many hepatitis C positive users won't tell their doctors that they are currently injecting drugs, their symptoms and conditions are often misdiagnosed. The physical effects of their drug use go unnoticed, misinterpreted and mistreated.

These kinds of experiences can leave hepatitis C positive users disillusioned with the medical profession and often results in a choice to cease seeking treatment until they absolutely have to - which is usually too late.



The same can be said for most types of welfare services. Many supported accommodation and crisis centres refuse to service people who inject drugs unless they consent to detoxification before being accommodated. The fact is that for a hepatitis C positive person who uses drugs, detox can sometimes cause more health and social problems than if he/she were to maintain a manageable level of drug use. This is particularly relevant for those people who are opiate dependent as detox can place a huge strain on their body and state of mind.

Hepatitis C positive people who use drugs illicitly have been refused counselling and support services, being told "I can't do any work with you if you are drug affected, you wouldn't be able to take in what I say or process anything, (again) it would just be a waste of time". Being turned away like that is one of the worst things that could happen to someone seeking support. They may have just needed someone to listen to them. They may not have wanted to be "worked on", and just needed a little empathy and support.

Often if hepatitis C positive users ask for counselling they are automatically referred to a drug and alcohol service without any consideration of what their real needs are. They may be entirely

happy with their drug use and not want to be abstinent, just needing some counselling to help deal with an HCV diagnosis.

These types of attitudes and assumptions only serve to further alienate Hepatitis C positive people who use drugs illicitly from the health and welfare system.

Access to pain relief

One of the most harmful consequences of discrimination, userphobia, prejudice and ignorance is the refusal by some healthcare workers to prescribe adequate pain relief medication to hepatitis C positive people who use drugs illicitly.

An Australian National Council on AIDS bulletin (number 13) contains guidelines and recommendations for the prescription of analgesic pain medication for people who have a history of injecting drug use.

It emphasises that following prolonged exposure to opiates (heroin, codeine, morphine, methadone, etc) and other psychoactive substances, most people who inject drugs will have developed a considerable tolerance to analgesic pain killers. Their pain medication requirements, therefore, will be greater than someone without opiate tolerance - sometimes 4 or 5 times that of a non dependent person.

To achieve adequate levels of pain relief the dependent person will need higher doses of analgesic pain killers, more frequent administration, or both.

These issues and recommendations must be acknowledged and taken on board to adequately address the needs of hepatitis C positive people who use drugs illicitly.

Many hepatitis C positive users report being offered aspirin or paracetamol for quite severe pain either because "the doctor doesn't want to give a person with a history of drug use an addictive substance", or because "the doctor sees the positive users complaint about their pain as simply drug seeking behaviour".

For hepatitis C positive people, high doses of paracetamol or aspirin can have negative effects on their liver, which may already be damaged.

Hepatitis C positive users have had to discharge themselves from hospital when they are very ill so they could go and buy heroin because they are in severe pain and have been refused pain relief or

consistently been given an inadequate dose.

It is incredibly disempowering to be talked down to, often verbally abused, told you are a liar or a hypochondriac and that your complaints about pain just aren't real.

Denying hepatitis C positive users appropriate pain relief won't stop them from using. Most will attempt to relieve their pain anyway they know how (who wouldn't?). Doctors who refuse pain relief when a user is in real pain are only encouraging the user to go out and use whatever they can get their hands on in an attempt to get some relief.

These attitudes and beliefs have resulted in positive users being left for prolonged periods of time in severe pain. This is unacceptable, adequate pain relief is a basic human right.

Isn't it far safer and more responsible to have a positive user receive a medically prescribed dose to ease their pain, administered under medical supervision and in a sterile environment? I feel it is, and certainly more compassionate.

- **Tony Rance is Positive Users Development Officer at NUAA (NSW Users & AIDS Association)**

(See also Doctors & IV drug users story, page 30)

Inquiry begins into Safe Injecting Rooms

A NSW Parliamentary Committee has been set up to:

- advise Parliament of the costs and benefits to the public of the establishment or trial of safe, sanitary injecting rooms under the licence or supervision of the Department of Health and of amendments to the Drug Misuse and Trafficking Act 1985 accordingly, and
- make recommendations to the Parliament as to whether or not such an establishment or trial should proceed.

The committee needs your input if it is to get the full story and make the best recommendations. It is especially interested in hearing from people who inject drugs.

You can pass on your views in writing (whatever your writing skills) to:

The Senior Project Officer
Joint Select Committee into Safe Injecting Rooms
Parliament House
Macquarie Street
SYDNEY NSW 2000

or you can arrange to speak directly to the 10 person committee at an agreed location. In either case, your comments will be treated entirely confidentially should you wish.

The closing date for comment is 12 August 1997.

For more information, contact:

Ms Susan Want
02 9230 3054 (phone)
02 9230 3052 (fax)

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Doctors and IV drug users

An AMA perspective by Dr Steve Flecknoe-Brown.

There's been a view around for a while that most doctors "have trouble" with injecting drug users. People offer all kinds of glib explanations for this, usually based on out-of-date assumptions about a class struggle that never happened in this country.

When you visit your doctor, he or she has a legal duty of care to you. Whatever their private thoughts, they must do their best for you. But, apart from the questions asked for clinical purposes, these questions may be asked unconsciously:

Are you telling me the truth?

Therapeutic relationships are based upon trust. Most of our diagnosis is based upon what you tell us - your medical and health history. It must be accurate. Your doctor can't lie to you, cover up anything about the diagnosis or mislead you about the effects of treatment prescribed. The same frankness is reasonable in return.

Your GP can't prescribe medication which is going to be much use for your habit. Please don't try to trick them into some 'less dangerous narcotic'. There's no such thing, really, is there?

Part of the problem between IDUs and doctors is the many small lies that have passed between the parties. There have been good reasons for this - fear of disapproval; dismissive words and gestures by the doctor; the doctor's own fears (see below). But there have been bad reasons too, and they must be put behind us.

Are you taking me for granted?

The GP: You come into my office with more complex problems than most of my other patients, but then I'm offered in payment a Medicare card and some discount entitlement card. Come off it - I have an idea how much your habit costs. Do you have

any idea how much my surgery costs to run? If you did, you'd see that in most cases I can't afford to give you the care you need for the Medicare bulk-bill rate.

The hospital resident: I am working long, hard hours looking after people who have no choice in the misfortune visited upon them. Sorry, but you have exercised choice in getting into IV drugs. I'll do my best for you too, but please don't ask me for more than the others get.

The specialist: I've trained for years to learn how to give you the best treatment available. Please stick to appointment times, take the medication as directed and have the tests done at the times indicated. It is likely to be in your interest, not mine, that you do so. Please ask questions about the treatment I'm prescribing, and show an interest in my answers.



Are you a danger to me or my staff?

All of the cases of occupationally-acquired HIV in this country have come from syringes filled with the blood of patients. Though I'm expected to practise good infection control procedures, my fears for my safety are well-grounded. Please tell me if you know that you have any blood-borne viruses. We'll get along a whole lot better if you do.

And allow me to show normal human concern about the crime associated with IV drug use. I don't want to live in fear of my patients. If you see fear in my eyes, please reassure me that I am in no danger.

The AMA has been concerned for many years about what we call the de-medicalisation of many areas of health care. We would prefer to see patients cared for in their own communities by their family doctors, rather than social workers and faceless bureaucracies. This is one of the reasons we support the ACT legalised heroin trial. Those who are sincere about addressing the complex issues associated with IV drug use should welcome the opportunity to take parenteral drugs out of the hands of criminals and put them back into the hands of doctors.

But please don't take us for granted, don't threaten us and please do your best to foster a trusting relationship between doctors and IDUs. We'll be doing our best.

- Dr Steve Flecknoe-Brown is Chairman of Council of the NSW Branch of the Australian Medical Association.

[Do you agree or disagree with the views of Steve Flecknoe-Brown and Tony Rance? We would like to hear from you on the whole issue of injecting drug use and doctor-patient relationships.] *

My HCV story

I first contracted hep C three years ago, sharing a fit with my girl, who was already positive. At the time, it meant nothing to have HCV as I'd watched my partner live with it for years with no problems at all.

We've had two children since she contracted HCV and they were delivered fine and healthy, and thankfully with not a problem in the world. "So what's the big deal in having HCV?" I thought at the time. "Everyone is fine and looking healthy!"

Now I look back and realise how stupid I really was. My partner and the kids were actually the lucky ones. She has never suffered a day with her HCV, but even though I contracted the same strain of the virus as her I am sick with it for at least a week in every month. At times, when I am feeling the full effects of it, I wonder if I will ever return to a state of (at least) semi wellbeing.

Lethargy is a major factor with me. I become totally exhausted and feel unable to do anything at all. Just to get out of bed in the morning takes extreme effort. At times I also suffer severe abdominal cramps that leave me in extreme agony.

Telling people that I have hep C is a major issue. Most of my friends know that I have it, but I had to educate most of them about what the virus actually is, how it can be contracted, and what precautions to take so as not to catch HCV themselves.

With personal relationships, I've been lucky that it hasn't been a problem. With me contracting it from my partner to begin with, it is something that we share together. But when it comes to my mother, I have not yet had the courage to tell her I have HCV.

It would break her heart knowing that her son has an incurable virus, and more so because she knows nothing about it. Mum is from the old school where you don't talk

about drugs, addictions, sex, diseases, etc. I feel like I would be making a major confession to a mortal sin, where telling her is concerned.

There is no problem where my sexual relationships are concerned at the moment and, at this stage, I can't foresee any in the future. My partner and I constantly have unsafe sex because we have been together for years now and we

don't foresee ourselves ever being apart. Our relationship is extremely stable and secure. If it ever came to the stage where I wanted sex with another woman I don't know how I would go about disclosing my HCV status - not only with the sexual side of another relationship, but in all aspects of a relationship with a new partner. I'd find it very, very difficult indeed to talk about.

I have come across many people who think they can get HCV from pulling cones with me, sharing my cutlery, or sitting on a toilet seat after I have. There are so many

people who are ignorant about HCV and how it can be transmitted, as well as the short and long term consequences of contracting hep C.

At the moment I am in prison - a closed community where the risk of contracting the virus is much higher than in the community outside. About 0.5% (1 person in every 200) are infected with HCV out there, compared with about 40% (80 in every 200) in prison. So it is very important to adopt a safe lifestyle in here. This includes people already infected with HCV, because they risk catching another form of the virus which will place even greater stress on their health.

I disagree with the figures provided by the Health department. In my personal experience, both inside and outside of prison, 8 out of 10 people I have come into contact with suffer from hep C. I feel that hepatitis C is already in plague proportions in New South Wales and the authorities must do something about it immediately.

We need education about all aspects of HCV in our schools, and we also need stronger measures in our prison system to help stop the ever increasing number of hepatitis C cases breaking out in prison.

Anon.

*

*"many people ..
think they can
get HCV from
pulling cones
with me [or]
sharing my
cutlery"*

Calling all HCV healthcare workers

Are you involved with the care of hepatitis C patients and want to meet others involved in the same area? Or would you just like to find out more about hepatology?

If the answer is yes to any of these questions why not come and join the Clinical Hepatology Research Nurses' Association of NSW & ACT. We are a group formed by nurses in the field of hepatology.

We meet four times a year at different locations. Each meeting involves an education session on a topical issue as well as getting to know others in the field.

The next meeting will be held at Concord Hospital on the 25th August 1996 at 6.00pm. We are inviting any health care professionals who may be interested in joining this group to contact Tracey Jones on (049) 214789 or Sue Huntley on (02) 9736 7911. *

stop press stop press stop press

The Federal Parliamentary Liaison Group has been called upon to review statistics on hepatitis C such as the number of people infected (and at risk of infection) and the personal, social and economic costs of hepatitis C in Australia.

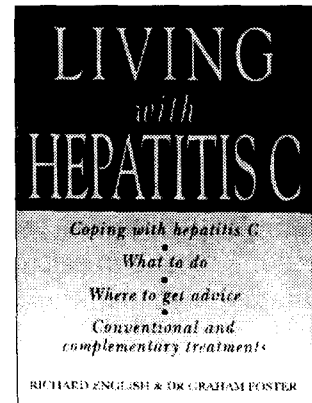
DO YOU WANT TO SEE MORE BOOK REVIEWS?

Several Council members and guest reviewers were able to respond to our recent call for book reviews.

Unfortunately there was not enough room in this edition for all reviews so we've held them over to the next edition of *The Hep C Review*.

So, in the next edition, we'll carry reviews from:

Prof Bob Batey, Pam Shipway and Tanya Majzoub. *




SPAN
SOUTH PACIFIC AND ASIA NETWORK

healthy & happy

SPAN's web site, *HEALTHY & HAPPY* aims at promoting information networking within the Asia-Pacific region, and can be found at: <http://www.span.com.au>

Within SPAN, our Council has a web page that can be found at: http://www.span.com.au/hepatitis_c/info.html

Our site contains general information taken from *Hepatitis C: what you need to know*, and will soon feature the Council's new graphics.



looking after your health **when you need help** **for health professionals**

A veritable smorgasbord of information about diet and nutrition, fitness and exercise, relaxation, healthy recipes and a whole lot more.

A wonderfully information-rich area providing a huge database about condition groups and medical resources. The most definitive site of its type in the southern hemisphere.

A great research tool for the medical professional. Find links to professional groups, research projects and grants, medical and allied health journals.

AN UPDATE ON NATIONAL HEP C PROJECTS

Projects already undertaken

Meeting the Needs of people in Australia living with hepatitis C national needs analysis, by the National Hepatitis C Councils Education Reference Group. A project which identified the education and related needs of people with hepatitis C, and which identified strategies and recommendations as to how those needs can be best met.

Projects underway

The Diagnosis Booklet: an information booklet for people newly diagnosed with hepatitis C.

Projects proposed

Australian Hepatitis Council: the Commonwealth is working with the hepatitis C councils of Australia towards the establishment of a national peak body of hepatitis C community organisations. It's intended that some or all the following national projects, together with other initiatives, will be developed by the Australian Hepatitis Council with funding from the Commonwealth Department of Health and Family Services.

Health monitoring and maintenance booklet: a practical information booklet that will give detailed information on how best to monitor and maintain the health of all people with hepatitis C.

Pre hep C diagnosis / testing pamphlet.

National 1800 information and referral line: a national 24 hour freecall line in addition to state and territory based personalised telephone information and support services.

Blood borne viruses training pack for health professionals.

Computer and internet network for all hepatitis C councils.

Posters: anti discrimination, prevention, health management etc.

Video: a series of short education videos focusing on specific aspects of hepatitis C, ranging from testing to health monitoring and maintenance.

Hepatitis and your rights: a national written resource that explains to all people with viral hepatitis what their legal rights are concerning things like testing, consent, disclosure, discrimination, insurance, superannuation, welfare benefits, medical treatment, employment, wills and funerals.

Workforce guide: a national written resource that gives information to people with hepatitis wanting to leave the workforce, plan retirement, work part time, rejoin the workforce.

Travelling with hepatitis: a national written resource that explains to people with hepatitis wanting to travel abroad or to migrate to Australia, their rights and obligations and advice on how best to prepare for travelling.

Secondary prevention initiatives: eg posters, linked in with public awareness of 'blood awareness'.

IDU groups national projects underway

Australian Intravenous League: (AIVL) has submitted a proposal to the Commonwealth Department of Health and Family Services to implement a national hepatitis C education and prevention strategy for people who use drugs illicitly. This includes:

Positive users' lifestyle resource, a nationally consistent resource comprising 5 booklets:

Positive using booklet: a comprehensive, context specific guide to how to use safely. This will contain the updated blood awareness messages.

Staying healthy booklet: nutrition, vitamins, detox etc.

Discrimination and legal issues: based on NSW Users & AIDS Association's Complaints Pack.

Future directions: wills / funerals / self delivery (*Future directions* is an informal working title only).

Treatments for positive users.

The revised *Handy Hints*, latest edition, will be available soon.

Commonwealth Health Dept projects and other national projects (underway or proposed)

National tattoo guidelines: bulk copies of these national tattooing resources have been distributed to State and Territory Health Departments and to professional tattooists. The guidelines focus on infection control in the tattooing industry.

National Health & Medical Research Council Strategy for the Detection and Management of Hepatitis C in Australia: Complete and approved but no date set for release. There'll be recommendations for expansion of interferon treatment Section 100 eligibility criteria, including from 6 to 12 months.

National Hepatitis C Action Plan: the Government's main policy document on hepatitis C education and prevention, epidemiology and surveillance, testing, care, treatment, management and research was published in 1994 and is to be reviewed and revised in 1997.

ANCARD, the Australian National Council on AIDS and Related Diseases has set up a specific hepatitis C sub-committee, in addition to hepatitis C inclusion in existing committees. This sub-committee will advise the Government on the detection, management and treatment of hepatitis C in Australia. ANCARD has published a detailed workplan 1997-1999 to be reviewed and updated annually. This plan meshes with Australian Health Ministers Advisory Council National Hepatitis C Action Plan.

Federal Parliamentary Liaison Group to review statistics, such as the number of people infected and at risk from infection, and the personal, social and economic costs of hepatitis C infection in Australia, when Parliament resumes later in 1997.

National Public Awareness: CDHFS have developed a general community education pamphlet. May be stand alone, or may be linked in with a national awareness campaign.

Renewed 2 year national HCV funding: Part of \$33m for 4 areas of health. HCV does not have its own specific budget any longer. Out of the \$33m over 2 years we need to compete with other areas of health and whoever makes the strongest case gets funding. A funding extension to June 1999 brings hepatitis C in line with the expiry of other health funding arrangements eg HIV/AIDS, when the Public Health Agreements are up for renegotiation.

Royal Australasian College of General Practitioners GP Education Project: A 2 year project to develop a training and education program for GPs.

National Needs Assessment of healthcare workers: draft report to be published in September.

Gastroenterological Society of Australia booklet and pamphlet review.

Haemophilia Foundation: national HCV information and support project.

Summary of HCV relevant research and epidemiology.

Vietnamese Injecting Drug Use Project: this project, nearing completion, has developed a series of messages addressing injecting drug use, safer sex and overdoses in the Vietnamese community

Targeting youth: a program is planned to target youth on issues about sexual health, hepatitis C and incorporates unsafe drug use messages. *

Living with Hepatitis C

By Richard English & Dr Graham Foster.

Reviewed by Peter de Ruyter.

This is a book, which despite being packed with valuable information about hepatitis C, may be rather too brutally confronting for a lot of people living with the condition, especially if they are in advanced phases of their disease.

Although knowledge is power, it can also be a double-edged sword, depending on how knowledge is transferred to people. It can make or break the learning process.

The book is factual, covers a lot of ground and the information around the pros and cons of a liver transplant are particularly clearly presented. The general media tends to make transplants sound routine, but the authors do rightly point out the seriousness of such a procedure and the life-long consequences both positive and negative.

Another strength of the book is the coverage of psychological aspects that often confront people when first diagnosed, as well as the day to day living with hepatitis C. The reader should find this information empowering.

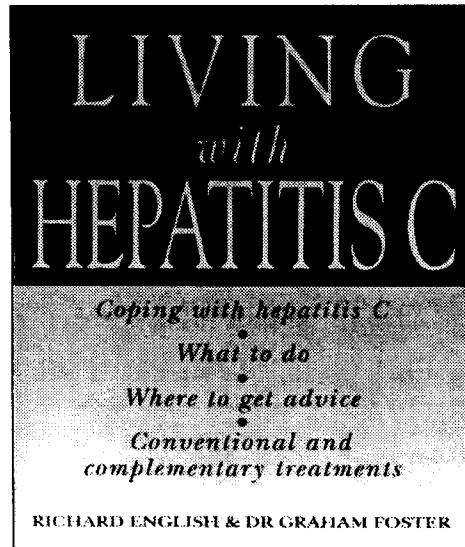
The responsibilities of, and ways in which someone with this disease can prevent infecting other people is also well covered. One comment made by the authors though is controversial, in that they state that household bleach is very effective in killing the hepatitis C virus. Although this strength of bleach may kill HIV (the virus that causes AIDS), it appears not sufficient to kill the hepatitis C virus, which is why so many injecting drug users have caught hepatitis, often despite having followed suggestions around cleaning their syringes and needles with household bleach.

In regard to the use of more natural therapeutic approaches to dealing with hepatitis C, don't look to this book for support in such a choice. The authors have obviously touched on this area for no other reason than

it would have been politically incorrect not to do so. A rather jaundiced view is presented around the worth and use of western natural therapies, with an over-emphasis of their dangers and costs. Ironic when compared to the toxicities and cost of interferon or ribavarin! In comparison, traditional

Chinese medicine is given a slightly more positive coverage.

Such views are obviously those of outsiders who have had very little direct, clinical experience in this area of therapeutics and who are quite happy to keep perpetuating the standard myths about the dangers and basic uselessness of natural therapies. The reader is told to keep an open mind, and although the authors don't actually directly say it, the overall insinuation and sense you are left with is that if some people do happen to get results from natural therapies, these are probably more due to a placebo effect.



Living with Hepatitis C is available in Australian bookshops, published by Random House. ISBN 1-85487-913-8. \$16.95

In comparison, the use of interferon therapy - being a medical approach - is given a far too optimistic coverage. It is rather sad that in the last section, not a single case history is presented of someone who has done well on the use of natural therapies for their disease. This is an unfortunate omission because although neither side has the total answer in this condition, there are nevertheless many people who have done extremely well on the use of various natural interventions.

The concept of complementarity is also totally ignored, whereby combining the best of both therapeutic worlds, a person can often do much better on the interferon, with far fewer side-effects.

Altogether, the book is overly clinical and cold, with very little human warmth, empathy or compassion coming from the authors. Their blunt style and the use of the word 'you' throughout the text, has the effect of making the reader feel as if their face is being brutally shoved into what are often a lot of delicate issues.

Another rather astounding point for a book purported to have at least one medical author, is that although a lot of facts and figures are presented, there is not one single reference given within the entire text to back up their claims.

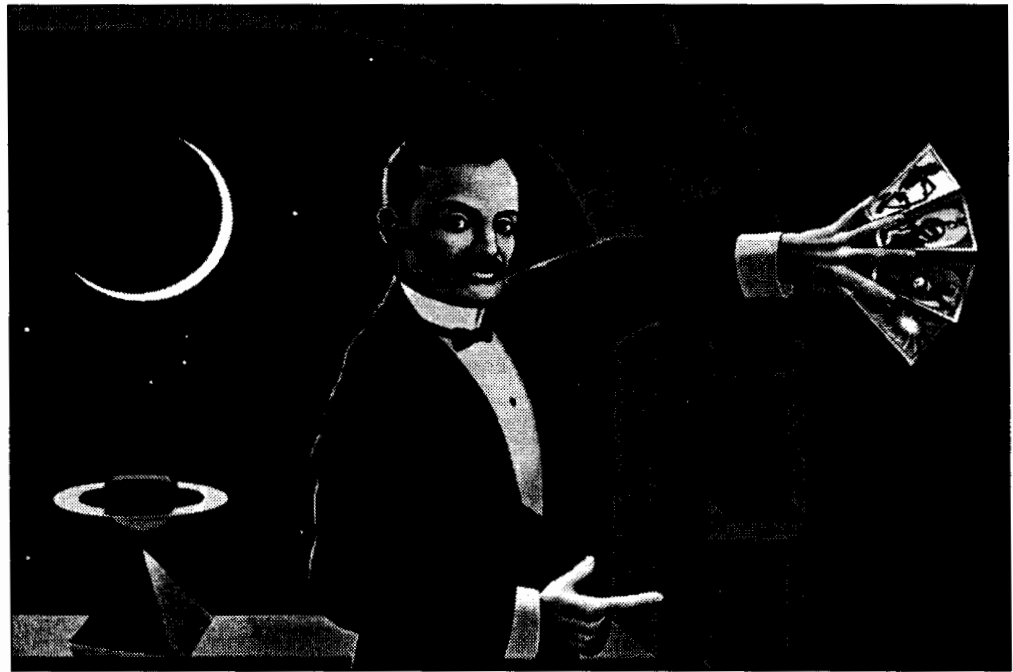
Peter de Ruyter, a practising herbalist for 15 years, works from the Bondi Junction Wholistic medical & Yoga Centre, and specialising in hep C, HIV and chronic fatigue. *

Want to help
deal others into
the bigger
picture?

Come on in and
be part of the
edition 19

mailout on the

3rd, 4th and 5th of November. Book early - places go quick!



The Edgecliff hepatitis C support group has been very successful - so much so that the participants have requested the six month group keep on running!

Rolene Hovsha, the group facilitator, and the Council have agreed to set up another group. It will be less formal and open to many more people, being based on peer support.

If you are interested in the new group, please phone Paul on 9332 1853.

Diet and HCV

I've found an interesting research paper that relates to Edition 16's focus on hep C and diet. I have ordered the article, but don't have it as yet. Below is the abstract and reference information.

Diet and liver disease - a glimpse into the future,

by: Macdonald GA. Lucey MR. It can be found in the Journal of Clinical Gastroenterology, 18(4):274-276, June 1994.

The complex interaction between liver disease and food intake is not well defined. There are two aspects to consider: how liver disease affects food intake and whether or not diet can affect liver disease.

Acute and chronic liver disease have been shown to influence taste, smell, food preference, and appetite. The liver may also play a role in food selection through reflex pathways.

Intake of various macronutrients can alter serum liver enzymes and bilirubin without necessarily being associated with changes in pre-existing liver disease.

Nonetheless, there is evidence that diet can be associated with both adverse and beneficial changes in outcome in animal models and patients with liver disease. These issues are difficult to unravel; however, there is potential for significant clinical advances from examining this area.

Regards Grenville

Interferon

is provided through the Pharmaceutical Benefits Scheme (PBS) Section 100 Highly Specialised Drugs Program. To access the drug through this program, people must have:

- Chronic hepatitis proven by liver biopsy (except patients with blood clotting problems).
- A repeatedly positive antibody test.
- Liver function tests (with elevated ALT readings) three times over a six month period.
- Absence of cirrhosis or other liver disease.
- Absence of HIV infection.
- For women - not currently breast feeding nor any chance of pregnancy while under treatment.
- No history of significant psychiatric illness.
- Must be able to attend regularly for treatment & follow-up.
- Alcohol use of no more than seven standard drinks a week.
- No history of injecting drug use in the previous 12 months.

The course of treatment involves giving yourself an injection three times a week. As from 1st August, six or twelve months of treatment is currently available.

The course of treatment must be continuous and excludes retreatment of non-responders or people who relapse. Consequently, people eligible for the 12 months course will be new patients and current patients who have not completed their 6 months treatment.

If your ALT readings don't come down after three months, the treatment ceases to become available under the PBS. To continue at your own expense for the remaining nine months, the interferon would cost about \$4,500.

Treatment centre facilities

Interferon is classified as a potentially hazardous drug with possible serious side effects. Accordingly, this treatment is monitored closely.

Treatment centres ideally should have certain minimum facilities before they treat with interferon, including:

- A nurse educator / counsellor for patients.
- 24-hour access to medical advice for patients.
- An established outpatient liver clinic.
- Facilities to perform safe liver biopsy.

Treatment centres for hepatitis C exist across the state (see below). You should make sure your centre has the minimum facilities listed above.

If you're eligible and have decided on interferon treatment, you'll then need to go to a treatment centre where you will again be briefed on the treatment and its side effects.

After clinical assessment which may take a couple of weeks, you will be given take home supplies of the drug.

You'll have to return for regular monitoring and further supplies. After treatment, your condition will be further monitored to determine how successful it was.

Treatment centres

Bankstown Hospital	Liverpool Hospital
Blacktown Hospital	Concord Repat. Hospital
Corrections Health Service (Long Bay)	Mt Druitt Hospital
Nepean Hospital	Prince of Wales Hospital
Royal North Shore Hospital	Royal Prince Alfred Hospital
St George Hospital	St Vincent's Hospital
Sutherland Hospital	Westmead Hospital
Bathurst Base Hospital	Campbelltown Hospital
Bega District Hospital	Illawarra Area Hospital
John Hunter Hospital (Newcastle)	Lismore Base Hospital
Orange Base Hospital	Wagga Wagga Base Hospital

Side effects

Interferon makes most people feel ill and side effects can be serious. If you are thinking about this treatment, seek information about side effects from doctors who are up to date on hepatitis C and read the Council booklet, *Hepatitis C - what you need to know*.

Benefits

Currently, up to one in five people with hepatitis C who undertake interferon treatment achieve what is called a long-term remission.

This means that the virus seems to be cleared from your blood and your liver function returns to normal. Symptoms related to the hepatitis C disappear as well.

[This information routinely validated by Commonwealth Dept Health & Family Services, Pharmaceutical Benefits Branch] *

Natural therapies

have been used to treat hepatitis C and its possible symptoms but to date, there've been few research trials in Australia to check their effectiveness.

Certainly though, many people report positive benefits.

Natural therapists using acupuncture, homeopathy and/or herbs aim to improve the overall health of their patients.

Good results have been reported by some people using natural therapies but others have found no observable benefits - and, as with any treatment, it's important to remember that wrongly prescribed medicines can be harmful.

Some people choose natural therapies as a first or a last resort. Others may not use them at all. Some may use them in conjunction with pharmaceutical drug treatments. Whichever way you choose, you should be fully informed. Ask searching questions of whichever practitioner you go to:

- Is the treatment dangerous if you get the prescription wrong?
- How have natural therapies helped people with hepatitis C?
- What are the side effects?
- Is the practitioner a member of a recognised natural therapy organisation?
- How much experience have they had of working with people with hepatitis C?
- How have they measured the health outcomes of their therapy?
- How do they aim to help *you*?

Remember, you have the right to ask any question of any health practitioner and expect a satisfactory answer. If you're not satisfied, shop around until you feel comfortable with your practitioner.

Costs

You cannot claim a rebate from Medicare when you attend a natural therapist. Some private health insurance schemes cover some natural therapies. It pays to ask your natural therapist about money before you visit them. Many will come to arrangements about payment - perhaps a discounted fee?

Choosing a practitioner

If you decide to use natural therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well experienced in working with people who have hepatitis C.

It's also advisable to continue seeing your regular doctor and/or specialist. Talk to them and your natural therapist about the treatment options that you are considering and continue to have your liver function tests done.

It's best if your doctor, specialist and natural therapist are able to consult directly with one another. If a natural therapist suggests that you stop seeing your medical specialist or doctor, or stop a course of pharmaceutical medicine, *consider changing your natural therapist.*

Healthy herbs?

The use of herbal medicines to treat a wide range of conditions is being promoted world-wide by the World Health Organisation.

In regard to hepatitis, around 20 years of clinical research in Europe has already been completed on the herb *milk thistle*, which some people are using as a liver tonic here in Australia. In Germany, a standardised extract has been approved for treatment of various liver disorders including cirrhosis. There are no known adverse side-effects associated with short- or long-term use of this herb.

A recent Australian trial of one particular Chinese herbal preparation has shown positive benefits and few side effects (see edition 15.)

Want more information?

Contact any of the following organisations:

Australian Acupuncture Assoc.	☎	1800 025 334
Australian Homeopathic Assoc.	☎	02 9415 3928
Australian Natural Therapists Assoc.	☎	1800 817 577
Australian Traditional Medicine Society	☎	02 9809 6800
Assoc. of Remedial Masseurs	☎	02 9807 4769
Homeopathic Assoc. of NSW	☎	02 9231 3322
National Herbalists Assoc. of Australia	☎	02 9211 6437
Register of Trad. Chinese Medicine	☎	02 9660 7708
Australian College of Acupuncturists	☎	046 77 2358
NSW Assoc. of Chinese Medicine	☎	02 9212 2498
Australian Trad. Chinese Medicine Assoc.	☎	02 9699 1090

Referral?

We are in the process of putting together a referral database for various healthcare workers - natural therapists included. This remains an ongoing task. Callers would need to phone the NSW hepatitis C Info & Support Line (see page 2 for contact details).

*

regular feature - support services

NSW Hep C Info and Support Line

For confidential and anonymous information and emotional support you can phone the NSW Hepatitis C Information and Support Line.

The service gives you the opportunity to chat with trained phone workers and discuss those issues important to you.

The service also provides referral to local healthcare and support services.

- ① 9332 1599 (Sydney callers)
- ① 1800 803 990 (NSW callers)

Sexual health clinics

Although hepatitis C is not classified as a sexually transmitted disease, the staff at these clinics can offer a wide range of services including pre- and post-test counselling, antibody blood tests, counselling and primary healthcare (the type of service that GPs provide).

They are listed in your local phone book under 'sexual health clinics'. If you are concerned about confidentiality, these clinics do not need your surname and keep all medical records strictly private.

(On page 7, there's news of a hepatitis C support group in Katoomba. On page 35, there's news on a support group in Sydney's Eastern Suburbs)

Community health / neighbourhood centres

These centres exist in most towns and suburbs, providing many different services, including counselling and information on local health and welfare agencies. Some neighbourhood centres run a range of support and discussion groups. Activities ranging from archery to yoga are sometimes offered as well.

Centres can be found by looking in your *White* or *Yellow Pages* - under 'community centres' - or by phoning the NSW Hepatitis C Information & Support Line. Also look up your local council in the phone book for a listing of its community services.

Local support services

There are few hepatitis C specific support services. This isn't because of lack of need but because there have been inadequate resources to help co-ordinate or develop them. So where does this leave you?

For particular assistance, whether it's help with the kids, housing, finances or home shopping, look in the *White Pages* telephone book. In the front, you'll find a whole range of services that are mostly aimed at the general community.

Following is a list of infectious disease Coordinators. These people work within local Area Health Services and can possibly refer you to local services:

Mid Nth Coast:	Robert Baldwin,	065 83 0789
Western NSW:	Chris Bourne,	068 85 8947
Hunter:	Marilyn Bliss,	049 24 6477
Mid West NSW:	Jeanine Buzy,	063 32 8576
SE Sydney:	Colin Clews,	9382 3694
Mid Nth Coast:	Lee Davidson,	065 51 1251
South West NSW:	Dalton Dupuy,	060 58 1700
Nthn Rivers:	Wendi Evans,	066 21 7231
New England:	Margaret Gearin,	067 66 2288
Sth Wst Sydney:	Ken Wong,	9827 8033
Lower Mid Nth Coast:	Liz Meadley,	065 51 5400
Central Coast:	Karen Nairn,	043 20 3399
Illawarra:	Brian O'Neill,	042 28 8211
Wentworth area:	Elizabeth O'Neill,	047 22 2255
Western Sydney:	Chris O'Rielly,	9843 3118
Central Sydney:	Lesley Painter,	9515 3202
Nthn Sydney:	Anthony Schembri,	9926 8237
Far West NSW:	Darriea Turley,	080 88 5800
Southern NSW:	Greg Usher,	048 27 3148

One-to-one counselling

Some people with hepatitis C may want to make use of a specialist counsellor. These professionals can provide special support or therapy when people have specific problems they find difficult to deal with.

Some situations where this may be useful include where someone has excessive anxiety about the outcome of their hepatitis C, or if they have a particular problem that impacts on their hepatitis C infection.

To find out more, speak to your GP, or contact your local sexual health clinic, community and neighbourhood centres, or the NSW Hepatitis C Information & Support Line.

Family counselling

If hepatitis C is impacting on your family relationships, it may be wise to seek family or relationship counselling.

To find out more, speak to your GP, look in the *Yellow Pages* under 'counselling' or contact Family Planning, your local community and neighbourhood centres, or the Hepatitis C Information & Support Line. *

regular feature - available information

These resources are available free of charge, or for a low cost that covers cost or postage.

Videos are borrowed for two weeks at a time. Please do not send payment for videos.

Just pay for the return postage when you post them back to us.

Phone or write and tell us what you'd like. See page 2 for our contact details.

Description

Newsletter back issue pack - Editions 1-8

various topics / historical interest

The Hep C Review - Edition 9

Chiron's patent / living with grief

The Hep C Review - Edition 10

natural therapies

The Hep C Review - Edition 11

genome subtypes / life insurance / Terrigal symposium

The Hep C Review - Edition 12

drug law reform / HCV fatigue / women & HCV

The Hep C Review - Edition 13

HCV & prisons / 94-95 annual report

The Hep C Review - Edition 14

HCV discrimination / drug law reform / DSS / clinical trials

The Hep C Review - Edition 15

partying safe / informed consent / stress / Nat AIDS strategy

The Hep C Review - Edition 16

diet & nutrition / DSP changes / IDU & hep C Councils

The Hep C Review - Edition 17

study grants / HCV & relationships / Australasian conference

Description

Hepatitis C - a brief introduction

(brochure @ \$5 for 100, \$50 for 1,000)

Hepatitis C - what you need to know

(booklet @ \$1 each; free to members)

Video No.1 - Interferon / HCV & women

Prof. Geoff Farrell / Jennifer Holmes

Video No. 2 - homeopathy / herbalism

Ken D'Aran / Raymond Khoury

Video No. 4 - Quantum episodes

hepatitis C / the human liver

Research Pack 1 - research papers

HCV / epidemiology / prevention / serology / diagnosis

Research Pack 2 - HCW booklets & strategy document

AGI & Fairfield Hospital booklets / National Action Plan

Research Pack 3 - 1994 NHMRC Hepatitis C Report

Research Pack 4 - HCW booklet / research papers

WA Health booklet / HCV notifications / post-transfusion HCV

Research Pack 5 - HCV policy documents

AHMAC Education for Prevention / NSW HCV Taskforce Report

Chasing up changed addresses is a time consuming task. If you are planning to move in the near future, please don't forget to phone or write and let us know of your new address details (our contact details: page 2)

Thank you everyone for your wonderful response to our recent annual membership recruitment and renewal drive. Financial membership (even \$0) allows you a real voice in our organisation.

Hep C Classifieds - keeping you in touch

Lots of love and best wishes for dad who is in hospital with a temperamental ticker - from mum, me and my brothers, the grandkids, all your friends, and Beau.

Get well soon, dad, and don't forget the fruit!

this space is yours

and its free!

this space is also yours

and its also free!

MEMBERSHIP FORM

Please complete as much of this form as possible. Our policy is to respect your privacy. All details on this form are treated in the strictest confidence and all communication is carried out discreetly. Please return this form with your cheque, money order or credit card details to:

Hepatitis C Council of NSW
PO Box 432 DARLINGHURST NSW 2010
Make cheques out to Hepatitis C Council of NSW.

1. Please complete either a, b or c.
a. For people affected by hep C, or other interested people.
Name
Postal address
Suburb / Town
State Postcode
hm phone Wk phone
b. For individual healthcare or welfare professionals.
Name
Occupation
Postal address
Wk phone Wk fax
Mobile phone Email
c. For agencies, companies and organisations.
Organisational name
Contact person
Position
Postal address
Wk phone Wk fax
Mobile phone Email

2. If you can help with any of the activities listed below, please tick the following boxes.
Admin and office work?
Other?

3. Is this a renewal, or are you a new member?
Renewal New member

4. Please circle one membership fee box.
Membership fees are due annually on 1 March. We welcome a full year's payment but would not want financial hardship to prevent you from becoming a Council member. If this is the case, please circle the concession or zero fee box.
Waged \$25 Professional healthcare worker \$40
Concession \$10 Community-based organisation \$50
Zero Fee \$0 Public/Private sector organisation \$70

5. Separate donations are gratefully accepted by the Council.
If you make a separate donation, please record the amount here. \$

6. If paying by credit card, please complete this section. Card type (please circle)
Mastercard Visa Bankcard
Card number
Expiry date month year 19
Cardholder's signature Cardholder's full name

7. Do you require us to send your receipt? Membership fees are not normally tax deductible. To reduce postage costs, receipts are not normally sent. If you want us to send your receipt, please tick here. ->

8. Declaration. I accept the objects and rules of the Hepatitis C Council of NSW and apply for membership of the Council.
Signed Dated

Table with 7 columns: This section is, Date received, \$ received, Receipt no., Date entered, Member no., Info pack. Rows include: for office use only, staff initials.