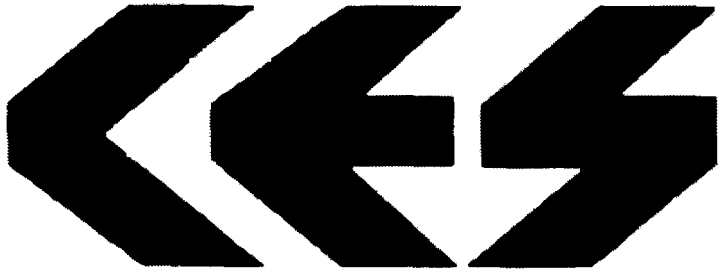


The Hep C Review

Autumn & Winter Edition April - June 1996

Issue 14



and hepatitis C discrimination

Job seekers who have infectious diseases such as hepatitis C have been requested by the Commonwealth Employment Service (CES) to provide medical certificates confirming they wouldn't pose a health risk in an employer's workplace. Potential employers would be informed of the jobseeker's hepatitis C status when a referral is made. Refusal to provide a medical certificate would result in no job referrals and Social Security payments being stopped.

This policy has not been applied in any widespread manner across the State but in the cases we've heard of, the policy has caused a great deal of anxiety, confusion and trauma.

The above CES guidelines appear to be based on a grossly exaggerated interpretation of their *duty of care*.

A worker with hepatitis C poses no great risks to other people - let's face it, the virus is hard to transmit. It requires blood-to-blood contact. Given that all workplaces should have health and safety guidelines to deal with infection control, the issue of whether an individual worker has hepatitis C or not is irrelevant.

The CES guidelines should not be applied to jobseekers with hepatitis C because the end result will be discrimination. This would result because employers will learn of your status before your job interview - and let's face it - when you go for an interview, it's simply not relevant for the employer to know you have hepatitis C or not.

(Continued on page 8)

Company gives \$300,000 for hep C research

In a gesture of goodwill and contribution to the community, a local retail business has recently announced a three year \$100,000 per annum research grant. The grant to Sydney's Royal Prince Alfred Hospital will enable doctors there to screen their hepatitis C patients more accurately before treatment.

David Rickards, a director of the bargain store chain, Clint's Crazy Bargains, contracted the hepatitis C virus more than twenty-five years ago. He said that in his contact with the Royal Prince Alfred Hospital as a patient, he became aware of the need for on-going research and more access to high-tech. testing technology - especially in regard to Interferon treatment.

Mr Rickards, who benefited from a successful course of Interferon - the hepatitis C treatment - said that his company had worked with RPAH's Professor Geoff McCaughan in the development of the research fund. The fund will enable the hospital to offer patients greater access to genetic molecular testing.

Membership fees

Reminder letters were recently sent to all Council members whose fees were outstanding as at 1 March 1996.

Fees help keep the Council running. Without them this newsletter might fold. But, important though they are, we don't want membership fees preventing anyone from becoming a member. See page 35 for more info.

An edition that focuses on discrimination, CES policy, drug law reform, health consumer's rights, the Department of Social Security — and lots of stories highlighting what hepatitis C is like from our perspective!

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Our Council is a non-profit organisation that is independent and community-based. We provide information and support to people affected by hepatitis C and assist in preventing further spread of the hepatitis C virus (HCV). We are primarily funded by NSW Health.


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What do you want to see in the next *Hep C Review*?

Is there a special topic you want us to focus on in the next *Hep C Review*? Why not give the office a call and let us know what you think. Just ask for Paul. Some topics already suggested by your fellow readers include:

- what is a virus?
- relationships and sex
- relaxation
- alcohol and diet.

Our office admin line is 02 332 1853, so give us a call today - it'd be great to hear from you.

Whatever happened to drug law reform?

A guest editorial from Steve Bolt - Coordinator of the Redfern Legal Centre Drug Law Reform Project.

In 1971 in NSW, male homosexual activity was illegal, casinos were illegal, abortion was illegal, prostitution was illegal, books and films were routinely censored or banned, and the use and supply of marijuana, heroin and various other psychoactive drugs was illegal.

In 1996 in NSW, homosexuality is legal, legal casinos contribute to State revenue, abortion is legally available in most circumstances, both street sex work and brothels have been legalised, and censorship is rare. The use and supply of marijuana, heroin and various other psychoactive drugs remains illegal.

In the last twenty five years the law has withdrawn from attempting to control the moral choices of citizens in virtually every area - except the use of drugs.

With 8,000 to 10,000 new HCV infections each year, we must ask why outdated drug laws remain unchanged.

However harmful some illicit drug use can be, the real social harm flows from attempts to prohibit it. Prohibition creates overwhelming barriers to preventing the spread of Hepatitis C and other blood-borne diseases. Most drug overdoses can be attributed to prohibition (through uncertainty about drug purity, or ignorance about the dangers of mixing alcohol and other drugs.) The drugs black market generates enormous property crime and police corruption.

The fate of the recent Victorian Penington Report into drugs again suggests the political process is incapable of dealing constructively with the issue. The Penington Report makes 72 thoroughly sensible recommendations reducing the role of the criminal justice system, improving education and treatment efforts, and pursuing necessary further research.

The Victorian Government has announced a welcome funding increase for drug treatment, education and research. But yet again the

politicians balked at reforming laws and police practices to allow effective harm reduction strategies. Instead, the criminal justice system is left to cope with "the drug problem."

It may be too much to expect the NSW Labor Government, with a Premier relishing an image as tough on "law and order", to show national leadership on far-reaching drug law reform. But NSW has failed to implement even modest changes. Premier Carr has said repeatedly that no one should be jailed for simple marijuana possession. But, no reform has eventuated. So there are still about 75 people jailed each year in NSW for the crime of possessing or using marijuana.

Those who use marijuana for medical purposes - people living with AIDS, glaucoma and cancer - continue to risk prosecution and punishment. HCV positive people who use marijuana as an alternative to alcohol (and so avoid liver damage) face the same dangers.

NSW has offered only tepid support for the proposed heroin maintenance trial in the ACT, despite years of painstaking research and project design work, and a near unanimous recommendation from the broadly based Task Force established to consider the proposal.

And this in a climate where the Wood Royal Commission has revealed overwhelming evidence of the near-total corruption of police efforts to restrict drug use and supply. About 230 police have either admitted being corrupt or have been adversely named in the Royal Commission. About 210 of those have concerned drug matters: stealing money and drugs from drug dealers, taking bribes, fabricating evidence and so on.

The second biggest trade in the world generates such enormous profits (because of prohibition, not the natural economic value of the products) that the opportunities for corruption are irresistible. Commissioner Wood has already called for fresh and creative responses to the drug problem. Yet the NSW Government still fails to act.

The Penington Report has much to offer NSW and the other States. It makes recommendations to improve drug education in schools and the general community; to ensure appropriate treatment for those whose drug use is problematic; to ensure that harm minimisation governs operational practice in law enforcement.

A simple but probably effective proposal is to deal with first offenders on minor drug charges by way of caution, and second offenders with mandatory good behaviour bonds. Such modest reforms could provide a basis for a constructive change in drug policy. In fact, any of the Penington recommendations could and should be implemented in NSW.

But that would take political courage, wouldn't it?

Steve Bolt is a solicitor and the Coordinator of the Redfern Legal Centre Drug Law Reform Project.

Ian's visit to the dentist:

Recently I needed to have a tooth extraction. My wife, Lauren, recently phoned a well known dental clinic to make an appointment for me. Lauren was advised that they required payment on consultation and that the fee for an extraction was between \$50-60. She made an appointment for the next day.

On arrival, I filled out a patient medical form and ticked the box stating I had a medical condition - hepatitis C.

The receptionist wrote this on my form and asked if Lauren or our children had the virus as well. I replied no. I became embarrassed and nervous about what was happening as it was the first time since my diagnosis I had told someone outside our family.

The dentist's assistant and receptionist were both present during my examination. I was then instructed to go over the road to a clinic for a mouth x-ray. As I was leaving, I heard the dentist advise his staff that because I hadn't touched anything, there was no great need to clean everything. I also noticed that my medical file now had brightly coloured stickers on the cover - PATIENT ALERT - and my hepatitis C condition was highlighted in pink highlighter. And get this - my file was on the counter for anyone to see!

After the x-ray, I returned to the clinic. They told me I would be seen last on the list that day so they could clean the surgery afterwards. On hearing this, I was devastated. I felt as if I was some sort of contagious animal. Due to my embarrassment, I just took the appointment card and left.

When Lauren heard of what happened, she flipped. She called the surgery to cancel my appointment, telling how disappointed she was in the way I had been treated.

The receptionist agreed they did panic a bit and my visit could have been handled better. Lauren also spoke to the dentist who apologised for the way I had been treated.

Lauren replied, though, that it was their attitude and not the extra precautions that upset her. The dentist then replied, "It's not our fault he has hepatitis C. He is the one who got it."

After all this I said to Lauren: "I'm not up to going through all this again with another dentist. Let's just phone back and go ahead with the original booking."

When Lauren phoned Pearly Gates to reconfirm the appointment, she was told the eventual cost would include a \$50 'cleaning fee'. They said this fee would be charged because of my having hepatitis C. Lauren replied that was unreasonable, yet the dentist refused to reconsider.

Lauren phoned the Dental Association to check if such a fee was common practice. They said NO, it was not.

Lauren then visited the Clinic and raised the issue with the dentist in person. Still the dentist refused to budge. Lauren said she'd take the matter further. At about 8.30pm that night, the dentist phoned and tried to explain to Lauren that the special cleaning was reasonable, and that many other dentists did the same.

My wife then contacted three dentists in our local area advising them of my condition and asking about costs. All three dentists replied that no additional costs would be made. They all explained how having hepatitis C made no difference. People with the condition would be charged the same price because the dentists have to clean their equipment as per the regulations anyway.

Having found this out, we made an appointment with one of these other dentists who quickly carried out the work with no particular fuss.

My story needs to be told because of the discrimination my wife and I experienced due to my hepatitis C. This was the first time I advised a medical practitioner of my condition. Having been treated so poorly, the whole experience has left me stressed and humiliated.

It's bad enough for me to personally come to terms with this condition. It's another thing to have to deal with such 'off the air' responses from people who should know better. It is such ignorant people that make our lives just that little bit harder. Things are hard enough for myself and my family without being treated like a leper.

Did I do the right thing in telling the dentist? I've been through heaps, but I still think yes.

Abridged from *The Good Liver*, Nov 1995.

See page 22 for a dentist's response.



Hepatitis C set to blow out Government budgets

The hepatitis C epidemic was set to exceed the financial cost of HIV, Dr Nick Crofts reported to the Seventh International Harm Minimisation Conference held in Hobart.

Dr Crofts, of the Macfarlane Burnet Centre for Medical Research, in Melbourne, said that: "A recent study showed that for every 1,000 cases of chronic hepatitis C infection, there is a **direct cost of \$14,000 in healthcare spending added to the health budget.**"

"It is estimated there are between 6,000 - 8,000 new hepatitis C infections occurring in Australia each year. This adds \$100mill in direct healthcare costs to our health budget on an annual basis."

Dr Crofts went on to say that in addition to the medical costs of each hepatitis C infection (which work out at \$14,000 per patient), there is an even larger cost to Australia when you consider the possible social and vocational needs of each patient - which could include time off work, retraining, Social Security benefits or demand on community support services.

Like other serious health conditions, hepatitis C will hurt us in more ways than one. Added to the financial costs to our society, there will be great emotional costs as hepatitis C impacts on relationships and families.

Clearly there is a great need to help prevent further hepatitis C infections - primarily among people who inject drugs - and to help reduce the impact of hepatitis C on those already with the condition.

Stuart Loveday

Getting to know your Council.

Martin, a volunteer with specific accounting skills, comes in on a weekly basis and helps maintain our financial books.

"Not only do I enjoy the work, it helps keep my hand in," he quipped recently.

NSW Blood Bank hepatitis C lookback program - an update

For some time, the NSW Red Cross Blood Transfusion Service (BTS) has been wanting to initiate an extended hepatitis C virus lookback program.

This program would identify and contact people who may have contracted the hepatitis C virus via contaminated blood or blood products between 1983 and 1992.

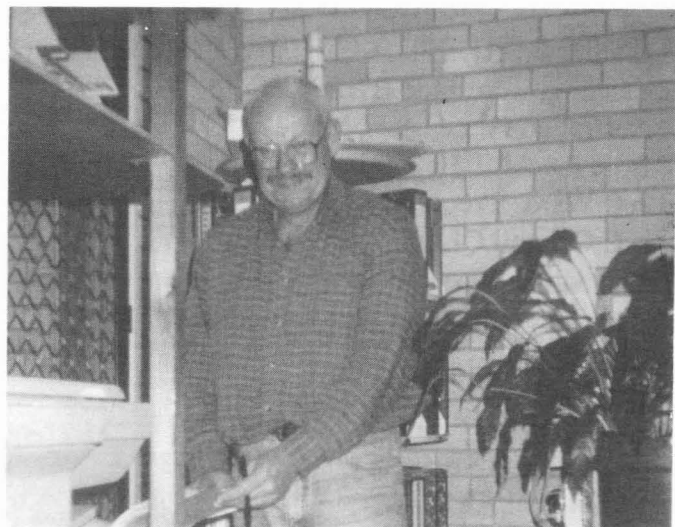
Following much negotiation with State and Federal health authorities, resources have been provided allowing the project to go ahead. Initially, we will look at donor-triggered cases: ie. when a donor is found to have been hepatitis C positive, we will track down where his/her blood went.

The Hepatitis Lookback Unit is located in Clarence St, Sydney, and consists of six people. At present the unit is contacting hospitals, building up the links and 'goodwill' that will be necessary in the time consuming work involved in this project - thousands of searches of unfiled hospital records.

Contact with a person found to have received HCV contaminated blood will be managed by that person's doctor. It will be suggested that people who contracted hepatitis C through contaminated blood contact the Hepatitis C Council of NSW and the TRAIDS Counselling Unit - a service that will provide counselling and support to people who contracted hepatitis C medically.

If you would like any further information on the Hepatitis Lookback Unit, you should contact Dr Susanne Benjamin on 02 291 4114 on Mon, Tues & Wed, or phone 02 291 4116 at other times.

Dr Susanne Benjamin (13 May 1996) ☺



New Federal Health Minister meets with Hepatitis C Councils

Hepatitis C Councils must play a greater role in treatment, care and support of people affected by the virus according to the new Federal Minister for Health and Family Services, Dr Michael Wooldridge.

Speaking candidly with community representatives at a meeting arranged by hepatitis organisations, Dr Wooldridge stressed that the various state organisations needed to work specifically with our respective state governments in order to improve services for those affected by hepatitis C.

At the 2 May meeting, Stuart Loveday, of the Hepatitis C Council of NSW, highlighted the development to-date of our national peak body. "Such a body is especially needed to coordinate the effective delivery of information and support services" he said. "This is especially the case when one type of service can be used in all seven states and territories - such as an educational video".

Professor Bob Batey, a respected hepatologist attended the meeting as a guest and stressed the need for positive action by the Commonwealth. He noted that the community-based hepatitis C councils and support groups were working cooperatively and productively with the medical profession, emphasising there was a need for "greater resourcing of an overall approach to hepatitis treatment and care".

Also at the meeting, were Jude Byrne from AIVL (the Australian IV League), Marie McAuliffe from the ACT Hepatitis C Support Group and Jeff Ward, Executive Officer of the Hepatitis C Council QLD. ☉

Pictured right are Marie McAuliffe, Jeff Ward, Michael Wooldridge, Stuart Loveday, Jude Byrne and Prof Bob Batey.

New broom sweeps through Federal Health

The Commonwealth Department of Health and Family Services (CDHFS) will be closing down its existing AIDS and Communicable Diseases Branch. The branch's \$24mill budget will be reallocated to various programs in a newly formed organisation - the National Centre for Disease Control - which will be based on the US's Centre for Disease Control at Atlanta. The centre will have responsibility for strategy, surveillance, epidemiology and disease management for communicable diseases such as hepatitis C. Other conditions dealt with by the centre include cancer and Creutzfeldt Jacobs Disease.

Dr Cathy Mead who was recently appointed to head the Health Department's AIDS and Communicable Diseases Branch, is the person deemed most likely to take charge of the National Centre for Disease Control.

Prevention strategies aimed to reduce the 8,000 to 10,000 new HCV infections that occur each year will be handled through another newly formed Branch - the National Health Promotion and Protection Branch.

The National Health Promotion and Protection Branch will also deal with education strategies for women's health, diabetes, men's health and environmental health, as well as drug, alcohol and tobacco use.

Although AIDS Organisations have expressed alarm over these major changes to the CDHFS, a spokesperson for Cathy Mead reiterated that throughout the restructuring process, the accumulated skills of long-standing workers would be harnessed. They would remain working in their areas of speciality. ☉



Straight out from the doctor's surgery I rang my girlfriend to tell her the results.

"Well I've got hepatitis C"

"God, that's really contagious. Doesn't it kill you?"

"Hang on! Hep C is only transmitted by blood. You're thinking of heps A&B which you can contract through saliva etc. and no, I'm not going to die. Not unless I take absolutely no care of my liver. I'm going to have to go lightly on the alcohol and stay away from fatty foods. Basically I have to think of my liver first."

"Come over to my place and we'll talk some more."

"Yeah, see you soon."

Twelve months later and I've been regularly drinking Chinese herbs for the liver, drinking only low alcohol beer and eating little or no fat foods. My last liver function test and subsequent visit to the doctor revealed my liver to be functioning normally.

My girlfriend, who has twice tested negative, has been quite supportive however lately we have been fighting a lot, sometimes not speaking for days. Part of this is my frustration at not having a job and little money.

I left my job just before being diagnosed with hep C. I was constantly tired and needed a break. I knew something wasn't right as I've always been an active person.

Since then, even though I am at my healthiest I have been in years, I've slid into this despondency about being ABLE to get a job. With the prospect that my girlfriend and I will break-up is the new thought that from now on when I meet someone I like, I will have to inform them of my hepatitis C status.

"I really like you and would like to see more of you. By the way I have hepatitis C. Let me explain."

Because of its relative newness as a condition there is a lot of misconception as well as confusion with heps A&B.

An example of this is not long ago a friend who has worked in the needle-exchange area and is very knowledgeable about HIV/AIDS issues made a comment in front of a bunch of people about catching hepatitis C from my wetsuit that at some other time I had pee'd in (it's true - surfers do pee in their wetsuits in the middle of winter to warm them up!)

Now this was said as a kind-of-joke but those listening - who were not as informed as my friend - may or may not have taken that information away to share with others at some other time. This is what scares me. I can take care of myself and become a healthy person but I can't control how people will take me when I share my diagnosis with them.

Our society is very frightened by infectious viruses or diseases and with fear comes prejudice. The only way we can conquer this is through education and that should start in the schooling system.

It's so easy yet political, religious and moral groups continue to sweep these issues under the carpet and forget about them. Some moral crusaders even believe that these things only happen to those people who deserve it so who cares? God's wrath.

Sometimes this seems to be the prevailing view but believe me, with education, persistence and strength hopefully we can succeed in having an informed and intelligent society.

Ms T Kollosche, Sydney ☉

CES & hep C discrimination

(Continued from page 1)

An employer should look at other things in making a choice on who is the best person for the job - each applicant's experience, knowledge and job skills etc. For more information on job interviews and medicals, see also the article on pre-employment medicals on page 26.

Discrimination will also result because all CES staff who use the computer records would potentially know of your condition. This may not sound such a big issue - the CES would certainly say that their staff would be limited in their access to the information and they would not abuse their access to it. But if hepatitis C status is irrelevant when the CES makes job referrals, why should this information be on the computer in the first place?

Telling potential employers of hepatitis C status and having this information on CES computers is unnecessary and represent a gross breach of our rights to privacy!

The Welfare Rights Centre, the AIDS Council of NSW and the Australian Federation of AIDS Organisations are all up-in-arms against the CES's current guidelines.

A response from the Anti-Discrimination Board of NSW

The Board has made a number of enquiries about the current status of the guidelines.

It has been confirmed that the guidelines are still operative and will be used until new guidelines have been approved by Senator Amanda Vanstone, the Federal Minister for Employment Education and Training.

The Board feels that the guidelines appear to be in breach of the Anti-Discrimination Act 1977.

Direct disability discrimination occurs when a person with a disability is treated less favourably than someone without a disability - in the same or similar circumstances.

The policy that jobseekers with a communicable disease must provide a medical certificate before they can be referred for a job, appears to directly discriminate on the grounds of disability.

There are limited employment situations where a person's communicable disease would pose a public health risk. In such situations, it is a matter for the employer and job applicant to resolve. The CES's intervention cannot be considered as part of its duty of care.

What's going to happen?

In March last year, the Welfare Rights Centre sent a letter to the then Minister for Employment, Education and Training, Simon Crean, (see next page.) Their letter resulted in an almost off-hand response. Simon Crean's office advised that an Inter-Departmental committee had been set up to examine the guidelines and report back.

We've heard through departmental contacts that the Inter-Departmental committee acknowledged our concerns and reported to the Minister, recommending that the contentious aspects of the CES guidelines be scrapped. The Inter-Departmental recommendations instruct CES officers not to ask if a person has a communicable disease. If such information is volunteered by the job seeker, CES officers are instructed not to record or disclose the information.

The committee's report has been sent to the current Minister - Senator Amanda Vanstone. With the stroke of her pen, the Minister will put the new guidelines in place. **We've all been waiting more than 12 months. The \$64,000 question is ... just when will the changes happen?**

What can I do to help?

Hepatitis C can affect people in many ways - medically and non-medically. This situation is one of many examples of the combination of poor bureaucratic policy and hepatitis C hysteria. If you want to help change this or any similar situation, you have the democratic right to ask our elected politicians what their position is and what they can do.

Write to your local member, or to:

*The Hon Amanda Vanstone
Minister for Employment, Education, Training and Youth
Affairs
The Senate
Parliament House
Canberra ACT 2600*

Welfare Rights Centre's letter to the Minister

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TTY (02) 211 0238
ACN 002 708 714

30 March 1995

The Hon Simon Crean MP
Minister for Employment, Education and Training
Parliament House
CANBERRA ACT 2600

Dear Minister,

I write to express the Centre's concerns regarding the continued existence and application of the Commonwealth Employment Service guidelines, *Jobseekers with Communicable Diseases, including HIV/AIDS* (volume 3, section 10, of the CES Manual).

We understand that your Department has been made aware of community concerns regarding the guidelines and that an interdepartmental committee was established to look at issues arising from the application of the guidelines some time ago.

However, our contact with DEET officers indicates that there has been no change in Departmental policy or practices. In the meanwhile, by bundling together a number of different diseases with totally different epidemiology, the CES is causing jobseekers undue hardship. Further, the guidelines effectively compel CES employees to act in ways which, in our view, breach the Commonwealth *Disability Discrimination Act 1992* and fly in the face of the Commonwealth Disability Strategy.

We have the following objections to the guidelines: [abridged]

- The guidelines are based on the assumption that the CES has a duty of care to notify employers if the CES is aware that the jobseeker has a communicable disease. I understand that your Department sought the advice of the Attorney-General's Department regarding any duty of care, and that the Attorney-General has advised that this is not the case. Despite that advice, the guidelines continue to be applied.
- Contagious diseases like tuberculosis and hepatitis A, are inappropriately grouped with diseases like hepatitis C and HIV/AIDS which, whilst infectious, are unlikely to be transmitted in most workplaces due to their limited modes of transmission. The guidelines are a knee-jerk response to the admittedly difficult problem of [diseases like tuberculosis and hepatitis A] which are highly infectious at particular stages. If a disease is no more likely to be transmitted in a workplace than through public contact, however, we would argue that the CES has no duty of care to a potential employer with regard to advising that the [jobseeker] has a particular condition. [We believe] that it is simply not "reasonably foreseeable" that any damage could occur - whether to the employer, other employees, or the public. [We] consider that communicable disease status should be left, as much as possible, as an issue between employer and employee. This is particularly so in the case of less infectious diseases, like hepatitis C and HIV/AIDS.
- The CES guidelines conflict with Australia's public health approach to diseases like hepatitis C and HIV/AIDS. [Relying on knowing] who does or does not carry these diseases at any given time is necessarily imperfect, and the emphasis must be on infection control measures which treat all people as potentially infected. Stringent measures imposed on those known to be infected (as in the CES guidelines)

(Continued on page 28)

HEP C FUNERALS

It is nearly two years now since my husband passed on. He contracted hepatitis C from an operation and became very ill from it.

I read about DA's agonising experience with the undertakers in the last *Review* and I was taken back to the way things were for my Phillip. Tears came to my eyes.

When Phil went into hospital, he was put into a single room. Food was bought to his door by the maids and the nurse had to bring the meals in for him to eat. Phil was a strong and proud man - he was an engineer - but I will never forget going in to visit one day and finding him crying. The treatment he was receiving was just so hard to bear.

Then he passed away. He had moved to a hospice and the staff there were just wonderful. But when he died, a nurse said that we would have to get the police in - because he had hepatitis C. This turned out to be quite untrue but when we phoned the undertakers, they said my daughter would have to 'plug' him.

Our family was then deprived of a viewing which is what we had always planned on - its what our family has always done, going back generations. It's wrong and its heartbreaking.

I know your newsletter has mentioned this sort of thing before because I remember reading about a mother who had to help carry her dead son because the funeral workers would not. I can only hope that this sort of treatment has stopped.

Mrs A.G.

[Unfortunately, due to lack of staff, we can't do much to address this issue. We can report, though, on what other organisations are doing - see edition 15]

HEP C TRANSMISSION

(To the Editor, Sydney Morning Herald)

The article *Doctors sound new warning on hepatitis C* (21 February) states that "hepatitis

C could be spread even if needles were not shared - for example, by shared tourniquets or close contact."

Close contact with a person who has hepatitis C does not put other people at risk of catching the virus. What should have been clearly stated is that people who inject drugs, steroids or anything else, together with other people, should be aware that if *blood* on a used tourniquet comes into contact with the injection site of the next person to use the tourniquet, it may be that *blood-to-blood* transmission of hepatitis C and other blood borne viruses can take place - even if syringes are not shared.

Similarly, people injecting together need to take precautions to ensure that *blood* is not transferred from one person's injection site to another person's injection site.

These recommendations bolster existing precautions for preventing blood-to-blood transmission of hepatitis C, as do other recommendations that advise against sharing any injecting equipment. They do not allude to some other route of transmission as a cause of hepatitis C.

It is totally inaccurate and inappropriate to print stories that suggest otherwise.

John MacKenzie
Hepatitis C Council of NSW

HEP C HEALTHCARE

(To the Healthcare Complaints Commission, the Doctor's Reform Society and the Australian Medical Association)

I wish to bring to your attention the uncaring medical treatment that my son, 'Robert' received at a suburban Medical Centre.

Robert had an appointment for the removal of a skin lesion He also requested blood tests for HIV, hepatitis B and hepatitis C. My son is not in any of the high-risk categories liable to contract these diseases, but was undergoing testing before entering a close relationship with his girlfriend.

The following week he he again attended the medical centre for the removal of sutures and was told by the attending doctor that he was hepatitis C positive. Robert asked the doctor what could be done and was told there was no treatment and to practice safe sex. No further information, advice or counselling was given.

Robert came home in a distressed state not really knowing any of the implications of the disease - he is only 23 years old. I

am a registered nurse and know that there are instances of false positive tests, especially with people in low risk groups. I contacted a haematologist at St George Hospital.

The haematologist arranged for further blood tests and screening at Westmead Hospital. Last week the results came back as definitely positive. My son is devastated as he has no idea how he could have contracted the disease. He worries about the effects the illness will have on his life.

I have been in contact with the Hepatitis C Council of NSW and obtained information for my son. The haematologist has also given us the name of a specialist for him to see and contacts for one-to-one counselling. At present Robert is in a state of shock and trying to come to terms with his diagnosis.

My reason for writing this letter is to bring to attention, the irresponsible and uncaring attitude of the doctor at the medical centre. I would hope that all medical practitioners have up-to-date knowledge regarding hepatitis C.

I am very angry about how my son's case was handled and cannot believe that a doctor would handle this matter with no compassion whatsoever. I would hope that action can be taken to prevent other people being treated by other doctors in a similar manner. I cannot help wondering if the patient had been myself, would there have been a different approach to my treatment?

Mrs G.H.

[This is an all to common situation which the soon-to-be-released GP Guidelines for HCV will hopefully help address - Ed]

DRUG LAW REFORM

Re your September Issue No 12. It is high time the subject of drug law reform was publicly canvassed and given serious consideration by the government. The present policy of prohibition, interdiction and interception is an obvious failure. All popular recreational drugs are readily available in

spite of the best efforts of the governments, police and the courts to restrict them.

Anti-drug laws violate the rights of the individual to "freedom of choice" and to live their lives as they wish. Individual rights and freedoms are purely a myth in relation to drug use. The present policy costs over \$1 billion per year. As the policy is a failure this is a total waste of tax payers money.

If all recreational drugs were legalised and sold through government clinics or licensed outlets they could realise \$1 billion per year in additional tax income to government.

Two billion dollars in extra disposable income would provide a lot of health care and/or educational facilities in the state, money much better spent than in restricting peoples personal freedom and drug dealer's pockets.

Marijuana, Tobacco and smoking Opium should be restricted to licensed tobacconists in each suburb or shopping centre. Heroin, Cocaine, Amphetamines, Ecstasy etc should be distributed through special clinics according to demand.

There is only one policy which will prove successful and that is freedom of choice.

G.C.

[Let's hope the key people pushing for drug law reform keep on trying. Do you agree? Write in and let everyone know - Ed]

LOCAL SUPPORT

I am 32 years old, married with 6 children aged 11, 7, 5, 3, 2 and 6 months. Four and a half years ago I gave blood to the blood bank only to be told I had Hep C.

My husband and children are all negative. I breast fed all my children. My only support was the infectious disease sister at Camden Hospital. I have LFT's 6 monthly that were normal until November 1995 but then they were rising, I had them redone in December 1995 and they were up higher.

If I had not found your phone number in the phone book, I would have gone out of my mind. As I spoke to one of the councillors he told me all about hepatitis C, sent me information and I am now a member.

I come from Oakdale NSW and don't know anyone with hep C but have lost a lot of friends because of it. Ms K.C. Woodbine in Issue 11 said she would like to start a support group in South Western Sydney, I would also like to do this as not enough is known and it puts a strain on families.

letters

Thank you Hep C Council for helping people like me who have no-one else.

Fran

HEP C INFORMATION

I am a 43 year old man and have been diagnosed with chronic Hep C. I am currently undergoing long term rehabilitation treatment for drug addiction in the Salvation Army's "Bridge Program" at Newcastle. I entered the program on the 15th of June last year and all going well should complete the program in another three months or so.

For the past six months I have been undergoing tests to ascertain whether I am suitable for Interferon treatment and am due to commence this treatment on the 7th of February 96.

Because of the rigidity of the "Bridge Program" I have been unable to attend the Support Group at John Hunter Hospital and access to a counsellor that is available at the hospital has been restricted until just recently.

This has all changed just recently and now I find that I am allowed to attend the hospital for the groups and counselling. As yet I haven't been to a support group meeting as they don't reconvene until the first week in February, but tomorrow I will be having a talk with the counsellor at Byrne House - attached to John Hunter.

I have a lot of concerns about commencing Interferon treatment as I have heard all the horror stories attached to its use - none of them first hand. I am also unable to learn any more about Prof. Batey's trials with the Chinese Herbal Treatment although these results were due out late last year. Unofficially I have been told that his trials were positive and encouraging - full stop.

Tomorrow when I see the counsellor I have a lot of questions to put to him and only hope that he can supply me with some of the answers. I have seen him once before (just prior to Christmas) and he suggested at that time that I give a herbal preparation called

Prol 2000 consideration. Have you heard of it?

Your Hep C Review was given to me by a lady that works for ACON. I found it to be informative and it whetted my appetite for more information but am financially unable to subscribe even as a concessional member.

I would greatly appreciate it if you could send me any materials on your no-cost list that may help me to get a better insight into this disease.

Samuel D.

[See page 35 for more info on membership costs. Although we rely heavily on your fees, we'd rather see you joining up and accessing information, rather than not joining because of lack of money - Ed]

CORRECTION

I would like to congratulate you and your staff on an excellent publication. *The Hep C Review* is a much needed forum for information exchange on the topics of blood borne communicable diseases such as HIV and hepatitis C & B.

I would like to point out, though, that in issue 13 of *The Review*, within the article 'The Inside Story - Law & NSW Prisons', there are references made to the Department of Corrective Services' education, D&A and developmentally delayed programs that contain errors.

John Pagent

Assistant Commissioner (Personnel & Education)
Department of Corrective Services

[see page 22 for corrections - Ed]

DEAR M.M. - A REPLY

In edition 13, you talked about having hep C and asked about Interferon treatment. I was also quite shocked to find out I had HCV. I had only gone for a check up, not because I was feeling poorly or anything, just because I never had a check up before. My liver functions were very high, and after a lot of testing I found out the reason why; I had Hep C.

I had experimented only twice 25 years ago with drugs using needles - with someone else doing the injecting as I was, and still am, petrified by needles. However I also had a large blood transfusion when I was born so no one knows for sure how I got it. I guess its not that important now.

When I was having treatment I had to pay \$3,000 for the six months of Interferon. The people in the hospital, where I had

to go overnight to see how I would respond to the drug helped me overcome my fear of needles because the needles you inject with is only a tiny little one.

My main side effects were:

- aching in the joints (particularly the lower back/hip area) for which I took Panadol on the days I had to inject; occasionally a headache
- after a while, I got a few small patches of eczema on my face (which have since cleared up)
- my menstrual cycle was disrupted
- after about 3 months I had a lot of bowel problems with bouts of diarrhoea (but not lasting long)
- after 3 months my hair started to fall out - I'd lost about 1/3rd - but people said they couldn't notice and it has since grown back. I think that was what bothered me most - the other things you could get treatment for.

Anyway, when I came off of it, my liver functions were high again. It's been 18 months since I finished treatment. My specialist has recommended I go on it again for a year. I've been trying to get on the government program, but my liver functions are too low. In fact out of the last 2 LFTs I had - one was normal and the other only a few points above normal but of course the inflammation is still there. I still would never know I had the disease.

I think I will go back on it for a year but not until next year as I have a lot of overseas travel this year and (as you may or may not know) Interferon has to be kept in the fridge at all times. I am hoping that before next year they will come up with a cure or a breakthrough in treatment. I don't look forward to Interferon but it seems the only hope at the present.

I wish you all the best. Maybe Interferon will work for you if your case is mild. I reckon it's worth a try and if you can get it for free or partially paid for, you're lucky.

Good Luck and God bless. Mrs R.J.

Stop Press - Interferon trials

On page 23 we're running a story on drug treatment trials. This general information relates to what's involved in the hundreds of trials that are run on drug treatments for a wide range of medical conditions.

In the next edition of *The Hep C Review*, we'll have specific articles on the current Interferon trials. These trials are not aimed at validating Interferon's overall benefits - this work was carried out by world-wide trials earlier in the 1990's. The current trials are aiming to determine if different factors can improve Interferon's response rate.

Currently, the overall response rate is around 25% - ie. one in four people who have the treatment has a long-term remission. The current combination drug trial (Interferon and Ribavirin) and twelve month Interferon trial are both in progress and are hoped to show increased benefits for those of us who are affected by the hepatitis C virus. ☺

Call for nominations for management committee positions.

Our Annual General Meeting will be held on **Thursday, 5 September 1996** (formal notice to be sent soon). At the meeting, elections will take place for nine positions on our management committee.

This is a formal call for nominations for election for the nine positions, pursuant to rule 18.1 (a&b) of our constitution.

Nominations need to be in writing, addressed to the secretary, and need to be signed by three people - the proposer, the person nominated and the seconder. All these people must be financial members of our Council.

Nominations need to be received at the office no later than **5pm, Thursday 8 August 1996.**

They need to be addressed to:

**The Secretary, Hepatitis C Council of NSW
PO Box 432 Darlinghurst NSW 2010**

If you would like to stand for one of these positions, please contact our office (ph 02 332 1853 fax 02 332 1730) or write in. We can explain how a nomination should be set out, or can send one out to you. ☺

AMA delivers urgent warning on hepatitis C

Abridged from The Sunday Age (18 Feb '96)
By Ben Mitchell - health reporter

Hepatitis C will be almost impossible to control in Australia unless the major political parties urgently introduce measures to battle the epidemic, the Australian Medical Association said yesterday.

The federal vice-president of the AMA, Dr Keith Wollard, said the bloodborne disease was 10 times more infectious [in a blood-to-blood situation] than the HIV virus and was infecting five to six times more people than HIV each year.

"At present there are more than 100,000 Australians with hepatitis C and a further 6,000 to 8,000 who contract the virus each year," Dr Wollard said.

The head of epidemiology at Melbourne's Macfarlane Burnet medical research centre, Dr Nick Crofts, said the full effects of the virus would not be felt until early in the next century.

"Its not a new epidemic ... it's been around for at least 20 to 25 years in the same proportions, but there are a lot more people who inject drugs now," Dr Crofts said in a recent report on the disease.

The virus is transmitted through contact with blood and is a "sleeper disease", taking an average of 13 years to exhibit symptoms which often leads to chronic illness and in some cases can lead to cirrhosis, liver failure and liver cancer.

The Federal Government established a hepatitis C strategy in 1994 but a progress report of the Australian Health Ministers Advisory council found that little progress had been made in fighting the disease.

Dr Alex Wodak, director of the Alcohol & Drug Service at St Vincent's Hospital in Sydney, said that a national taskforce to address hepatitis C was long-overdue.

"The establishment of an independent HCV taskforce will help make control of the virus a high public health priority and will assist in the acceptance of some controversial, but necessary, prevention policies," he said.

Dr Wollard, supporting Dr Wodak's suggestion, said unless a taskforce was created, hepatitis C would not be considered as a major issue. ☺

What is the big picture answer?

Angela Matheson - SMH 16/5/96

The illicit drug trade is the second largest global industry, beaten only by the arms trade. Before Australia fell into line with US drug policies in the 1930s and 1940s, drugs such as marijuana, cocaine and heroin were not illegal. Heroin was available over the counter in bottles of laudanum to nurse most ailments and was commonly prescribed by doctors for pain relief.

Now, an 80-strong group of MPs from all parties across Australia is preparing a charter calling for sweeping drug law reforms. The group, called the Parliamentary Group for Drug Law Reform, whose members include NSW MPs Ann Symonds and Dr Meredith Burgmann, and former Prime Minister Sir John Gorton, is calling for illicit drug-use to be decriminalised and treated as a health issue.

The charter calls for:

- ❑ The abolition of criminal sanctions for the personal use of illicit drugs;
- ❑ The reform of drug laws in planned stages with detailed evaluation of the effects at each stage;
- ❑ Health programs aimed at educating and minimising the harm caused by illicit drugs through public campaigns and the establishment of rehabilitation centres.

"As a group of MPs, we recognise that prohibition does not work and actually promotes the escalation of the illicit drug trade and the power of organised crime," says Dr Burgman. "Its common knowledge that current drug laws have led to an increase in crimes against property and are a greater threat to community health than a system of controlled availability."

"What we are calling for is a rational, non-moralistic, humanitarian drug strategy that will minimise the adverse health, social and economic consequences of drug use. Throwing people who use illicit drugs into prisons is clearly not the answer."

(Continued on page 27)

Premier suggests heroin 'safe areas'

Abridged from an article by David Sharpe - SMH 12/596

Bob Carr has floated the idea of encouraging welfare groups to provide places where people who inject drugs could do so in a safe environment away from the public.

"We'd all prefer to have people who are injecting with heroin doing so in suitable surroundings, rather than in the parks or on the streets," he said.

He said that parks and streets were increasingly being used following the closure of Kings Cross 'safe houses' because of recent developments of the Police Royal Commission.

"It remains a criminal offence, but one possibility might be that welfare groups, rather than criminal outfits run these venues. The venues could offer a safe space, clean equipment and a range of treatment options for people with a heroin dependency."

Asked if this meant that welfare groups would be asked to allow people to inject on their premises, Mr Carr said: "I don't know, but clearly we want something better than the current situation. The community deserves something better than that."

Mr Carr also stressed he wouldn't block the ACT's plan to test supplying heroin to a number of people dependent on heroin.

He didn't believe the trial would be 'enormously useful' because it would probably not prove that such programs reduce the amount of drug-related crime, or drug-related deaths.

Mr Carr said his government would "continue to emphasise the treatment of drug dependency as a health problem - we'll continue to say that people who've used drugs ought to be offered the opportunity for rehabilitation rather than being locked up."

New approach needed to deal with drugs

Abridged from 'Medical Talk' with Professor John Dwyer, Wentworth Courier, 24/496

Dealing with public health problems involves difficult decision-making. Because many of these decisions are controversial, there is a great need for professional, public and political partnership.

All this came to mind this week when much media attention was given to proposed laws relating to drug use in Victoria and the ACT - and when our Premier publicly endorsed the idea of 'safe injecting' rooms for injecting drug users in our city.

Overseas and local experience has shown that the availability of these safe houses does reduce harm to people who inject and also to the public at large. Fewer infections, fewer deaths from overdoses, fewer needles in parks and streets are but some of the advantages noted.

If political (which means public) support is available for the concept, such a safe haven may be trailed in Kings Cross soon. But politicians will only make such injecting behaviour legal if *you* understand the the pros and cons of the idea and give *your* support. Thus, public debate on the issue is very much needed.

Between 60 and 80 percent of all prisoners in our jails are there because of drug-related offences. We can't stamp out drug use by laws and enforcement. By making drugs illicit and their use criminal, we have compounded a problem that should be regarded as a social and medical one.

I was delighted that Premier Carr publicly supported the idea of establishing a safe injecting centre in Sydney. This pilot initiative would be an experiment from which we would learn whether, in our environment, such an establishment could reduce harm.

As difficult as it is for some people to accept the need for hard political decisions, we owe it to ourselves, our children and our society to do just that.

I urge everyone to inform themselves so that they can give a considered response to the questions now being asked.

These matters are of the greatest importance to our society's health, happiness and stability.

Professor John Dwyer.

Modify lifestyle to manage hepatitis C

What are the implications for a young mother whose partner has been diagnosed with hepatitis C?

Abridged from 'Questions to the specialist' by Professor Geoffrey Farrell, Australian Doctor, 15/3/96.

'Janine' (age 23) requests advice from her GP. She has a six-week old baby and has visited her doctor for a check up six weeks after having her baby.

Her new boyfriend (age 37) isn't the father of her baby and has just been diagnosed hepatitis C positive. He thinks he contracted hepatitis C from tattoos he had long ago when working in the merchant navy. They rent a home in the suburbs. Janine is hepatitis C negative, as will be her baby.

Should Janine use condoms to prevent her contracting hepatitis C?

This is a controversial question. The only certainties are that sexual transmission is possible, although transmission from a hepatitis C carrier to their stable sexual partner appears to be rare in Australia. The risk would be much higher if Janine's boyfriend had acute hepatitis C, but the acute phase occurs only briefly when a person first catches hepatitis C.

The risk of sexual transmission is almost certainly increased in the event of people having any one of the many sexually transmitted conditions that involve genital sores or discharges. Condoms are a method of reducing (but not abolishing) the risk of STDs.

Janine should be given all the relevant information and allowed to make a decision in discussion with her boyfriend.

I'd tell her that if she wanted to be absolutely sure about not acquiring hepatitis C sexually, using condoms would be advised.

I'd also point out to Janine, though, that many chronic carriers of the hepatitis C virus have

had long-standing stable sexual relationships (up to 50 years) without transmitting the virus, and the level of risk is small.

Can Janine catch the virus from other contact?

Janine could catch hepatitis C by using her boyfriend's razor blade and possibly by using his toothbrush. It's almost certain that such cases have occurred and Janine should be advised how to best avoid this happening - her boyfriend should take care to keep his razor and toothbrushes separate, having them a different colour than hers perhaps.

It's extremely unlikely that hepatitis C can be transmitted by saliva, so close physical contact and kissing are not ways of passing on the virus. Neither is transmission via the mouth and stomach, which means there is no problem in sharing cups, glasses and meals etc.

How easy is it for Janine's baby to contract the virus from her boyfriend? Should she take any special precautions?

It would be virtually impossible for the baby to catch hepatitis C unless the boyfriend dripped his blood onto him/her. Of course, the baby would need to have an open cut or be teething badly. The only sensible precaution to discuss with Janine is that if her boyfriend has undressed cuts or ulcers on the hand, it may be reasonable to avoid picking up the baby.

What will be the long-term outcome for Janine's boyfriend? Will he inevitably develop chronic liver disease?

The overall risks with hepatitis C are that about 20% of patients will develop permanent scarring of the liver (or cirrhosis), but this takes 20 years on average. Among patients with cirrhosis, up to half will develop liver failure or liver cancer in the following 10-20 years.

Janine's boyfriend should be strongly advised to have regular blood tests to monitor the condition of his liver. Such tests may be 3-monthly, six-monthly or yearly. Outcome (or prognosis) is impossible to predict without detailed and ongoing information.

If his liver tests are abnormal he should possibly have a liver biopsy. If he does have liver damage he will require further monitoring and may need to consider treatment.

Should he drink alcohol? Does diet affect his prognosis?

Most specialists would caution against heavy drinking, ie. drinking every day, or amounts equivalent to more than four standard drinks for men, or two standard drinks for women -

(Continued on page 27)

Andrew Refshauge launches our new hep C booklet

The NSW Minister for Health, Dr Andrew Refshauge, was VIP guest at our February Open Day / Booklet Launch.

The Minister and other key speakers emphasised the need to develop strategies that will help prevent further infections, and put in place services that lessen hep C's impact on those who already have it.

Strategies that Dr Refshauge immediately approved include the posting of our new booklet to all NSW doctors, and making it available to allied health professionals.

Pictured right, Dr Refshauge officially launches our newly developed hep C booklet.

Photo - Phillip Rosz.



The book launch generated good good media coverage - months later, regional papers were still running stories generated at the event.

Professor Geoff McCaughan, from Sydney's Royal Prince Alfred Hospital, spoke forcefully on the need for greater action: "At the moment, we are tackling this problem - the most common chronic disease for adults - on pre-1990 levels of resourcing,"

"All the way from the general community to governments, laboratories and clinical management - we must all pull together. It requires leadership and significant resources which are not yet available," he highlighted.

Stuart Loveday, our Council's Executive Officer, echoed Prof McCaughan's concerns, pointing out that: "The information, treatment and support needs of the NSW people already affected by the virus are enormous - we need decisive action."

Pictured left, Prof McCaughan, specialist hepatitis C clinician and member of our Council's medical advisory panel.

Photo - Phillip Rosz.



Heroes of the day undoubtedly include all the committed volunteers who helped organise and carry the launch. Some of these people came from outside Sydney, travelling for hours on public transport, so that they could assist with the event.

To all these volunteers, the committee and staff express our great appreciation.

telephone information and support

A new face - Hello! I'm Helen Mann and I'm the new person managing our Hep C Telephone Information & Support Service.

This service has been operating for some time thanks to the great effort of our home-based regional and Sydney telephone volunteers. These workers deserve our congratulations. For 5 years they have 'carried' the service, often taking calls at home, late at night.

Lately, we've been busy organising additional rooms for our new office-based phone service. We've set up the physical needs - desks, chairs, phones, etc. - as well as recruitment, training and support programs. These will help ensure our phone line continues to offer a quality service.

The next training is taking place in mid-June. This probably leaves little opportunity if you are interested in being part - but don't worry - trainings are held regularly. Give me a call and we can discuss following trainings.

With each successive training session, a large and stable core of volunteers will develop. If you want to be part of it all, give me a call. Any other feedback about the service is encouraged - talk to you soon.

Regards, Helen ☺

Since 15 July, the phone service has expanded its hours from 12 hours per week, to 27 hours - more than double!

Rural callers can call in free by phoning 1800 803 990 - Sydney callers should phone 332 1599.



Is there a doctor in the house?

Council members and the general public often phone in and ask about 'good' doctors or natural therapists in their local area. This is understandable as doctors don't have the same level of knowledge or ability to manage every single medical condition.

We don't make recommendations on particular GPs, but we would like to provide a listing of healthcare practitioners in anyone's local region. These lists will not recommend 'good' doctors. Nor will they guarantee that listed doctors are wizards in treating hepatitis C. The lists will simply contain contact details of doctors, counsellors, natural therapists, etc. in your local area who have shown a particular interest in hepatitis C.

If you are especially happy with your doctor, natural therapist, counsellor etc. and want them to be part of our referral listing, please write in or give us a call.

We will then contact the person and check whether they want to be part of this really useful project.

Give Helen a call on 02 332 1853 ☺

A warm vote of thanks goes out to the following companies for their ongoing assistance in the running of advertisements for our volunteer training sessions. Please support these companies - they support you:

The Beat (music/venues guide)

The Wentworth/Southern Courier (newspaper)

Capital Q (newspaper)

Sydney Star Observer (newspaper)

The Glebe (newspaper)

*Thank
you all*

HEPATITIS C, HARD YAKKA, DESPAIR AND HOPE

By Rob.

It is not my intention to promote any profound cure, antidote, medicine or remedy.

It is my intention to let you know that you are not alone and that I, as those of us suffering directly and indirectly from hepatitis C, do think of others.

For this then I share with you a wonderful turn of events that we should know about. An event that has brought me relief, peace and more than hope, a return to myself, as I remember myself before being diagnosed with having hepatitis C in 1990.

My friends are a wonderful lot. Caring, concerned, intelligent people who worry about someone in trouble. I was in trouble. Uncertain about my condition, my normal active day reduced to some short hours and then exhaustion, mental and physical pain, and the uncertainty of any traditional medication to help. It was a nightmare!

I agreed to Interferon, with all its horrendous side effects, nine months of sheer torture, for me, and all around me ... no lasting positive results. I was blessed with a doctor who encouraged, informed and tried to "perk-up" this very sad boy. But, all the "perking" did not improve my condition.

I have a friend who is an alternative type of bloke. Trained as a lawyer, but would rather be an old time "hippie" (he still is). Tenacious in a "laid back" kind of way, and persistent in that you must try every thing possible. Thanks to him and his friend, I relate this story.

He suggested that I once again visit a disciple of a doctor visiting Australia from China who specialised in herbal treatment of hep C (I'd already made numerous visits to a variety of "alternative" therapists).

He suggested two - one in Chatswood and the other in Haymarket. I chose the Haymarket

one since it was closest to my work.

The rooms of consultation and treatment were not unlike the rooms of other doctors I had turned to for help. The simple relaxed and informal office in the rear of a small herbal medication shop was a welcome sign to my comfort and experience of my living in Asia. After all I was seeking help, not pretence.

The appointment started with my history, pulse rate and a look at my tongue. A mildly convincing attempt to cure a disease presumed in my body for over twenty years. It was somewhat of a change from the past five years of jabs, blood letting and other "normal" procedures expected of modern medical technology.

My therapist unassumingly mentioned that she has had success with other patients with hep C but in my case, having the disease for over twenty years, could mean some time in seeing a lasting change. She was convinced she could help me, that I must follow her instructions and seek the wisdom accompanying patience.

I was given a large script of Chinese calligraphy, which I presumed contained my herbal concoction.

After handing it to the attendant I sat down and watched this mystic and overwhelming abundance of seemingly cow fodder put into neatly folded packets. I counted no less than twenty sticks, stones and what seemed like moss and peeling plaster of Paris, along with imaginary animal parts.

I kept thinking to myself, western medication is very new when you compare it to Chinese medication. After all, aspirin (as we take it today) is less than 100 years old, and that derived from elm bark.

The medication I was to experience goes back a long way, over three thousand years. No marketing hype, no competition, no Pure Food and Drug Act, and certainly no *use-by-date*.

I decided that if there are so many Chinese people in the world, and that if so many of them only take this type of medication, there is something to this long standing curing process. Why not!

I rushed home, with packets of medication and the necessary "special" ceramic cooking pot, set about slowly stirring my brew, and opening all windows to remove the lingering pungent smell.

That night I had my first good nights sleep in over five years. I

(Continued on page 29)

Department of Social Security

Some of us will never apply for Social Security benefits or pensions. In general, though, it's really useful that anyone in the general community know their rights.

Here is a simplified version of a guide produced by the Welfare Rights Centre and the Legal Information Access Centre.

Departmental decision making

When applying for a pension or benefit, you need to get an official claim form from the Department.

Your completed and signed form will need to be lodged (taken and stamped by the DSS counter staff) at your nearest DSS office.

Your application would be processed and a written decision on your claim would be given.

Lots of us in the community expect the DSS to usually make correct decisions. But because the law and administrative guidelines are hard to understand, and because the DSS makes a large number of decisions, mistakes are made.

It's important to remember then that the basis of our democratic rights is that people can question decisions made by government departments.

Welfare and legal workers say that many people with complaints about DSS and CES decisions (or treatment) often have really valid grounds for their complaints.

DSS refusal to accept a claim form

If the Department refuses to accept a person's application form, it's acting illegally. Regardless of the opinion of DSS telephone or branch staff on eligibility, all completed forms must be accepted and processed.

If a person accepts incorrect verbal advice from the CES or DSS and doesn't lodge an application form, they may be compensated for payment they miss out on.

Anyone who believes they were given incorrect advice and missed out on payment as a result, should inform the DSS in writing and ask for compensation. (Of course, it's not always easy to show that wrong advice was given by a DSS officer, which is why it's always important to lodge claim forms.)

Applying for the wrong payment

Social Security takes into account the fact that people may apply for one payment which they are not eligible for, when they may be eligible for another.

This means that people should not hesitate to apply for a DSS payment simply because they are not sure which is the correct payment. It's far better to apply for the incorrect payment than to not claim at all.

Client rights

Why is it important for us to know our Social Security rights?

For anyone who depends on social security payments - and any of could at some stage - the relationship with the DSS is crucial.

If you lose your DSS income support you would may have to rely on family or friends. You would also probably have to depend on assistance from welfare agencies and charities. If you were also dealing with an appeal against the DSS, you would imagine the frustration and anxiety you'd experience.

What are client rights?

In dealing with the DSS, you have basic legal rights:

- the right to a decision
- the right to reasons for a decision
- the right to appeal against a decision
- the right to information.

All of these rights are part of our democratic rights to fair treatment by government departments.

The right to a decision

Your most fundamental right in relation to the DSS and CES is the right to receive a formal decision by the Department.

Once you get a decision from the DSS, you can decide to either accept the decision, seek explanation or dispute the decision.

(Continued on page 21)

(Continued from page 20)

Getting a decision sounds straight forward, but it's surprising how many people do not successfully complete this essential first step. There are many reasons for this:

Reluctance to approach the DSS -

Some people prefer to speak to a friend or welfare worker about their possible eligibility for payment because the DSS can seem intimidating. This may be because of poor English skills; a poor understanding of complex ideas; limited social skills; a distrust of bureaucracy; or because a person is from a NESB background.

Accepting verbal advice from the DSS -

Many people rely on verbal advice from DSS staff but staff are not qualified to give legal advice. Clients may receive misleading verbal advice if:

- a DSS officer fails to elicit all relevant information and gives incorrect or incomplete advice,
- a DSS officer does not inform someone of their legal right to a written decision by a qualified DSS decision maker; or
- a client goes to a regional office and, on the advice of a DSS officer, does not lodge a claim form for payment.

It's important that people know their rights and responsibilities, so that this situation can be avoided.

Misleading advice from an interpreter -

Sometimes DSS interpreters unintentionally give advice which exceeds their role of interpreting. Through lack of adequate training, the interpreter may not fully understand the law and may not realise the advantage of getting a written decision or of appealing against a decision.

Whilst DSS bilingual officers have decision making powers, interpreters do not. In some cases they may inadvertently deter a client from getting a formal decision.

Inability to fill out a DSS form -

Forms can be difficult, lengthy and

intimidating. If clients have difficulty with this process then an appointment with a DSS social worker may be necessary.

It's the social worker's job to provide direct assistance to a DSS applicant.

It's very important to fill out and lodge a form promptly rather than waste time collecting evidence which is difficult to get. This is particularly important when a person is applying for Sickness Allowance because delay can preclude backdating.

The right to reasons for a decision

Everyone has the right to appeal against a DSS or CES decision, and they also have the right to be given reasons for any decision made by the Departments which affects them.

The DSS will almost always give a reason when they reject a person's claim, raise a debt or make any other major or minor decision affecting a client.

It's often the case, however, that the department's reasons are not given in a form which people find understandable. It is important that people are aware of their right to be given clear written reasons in a form which is easy to understand.

The right to appeal against a decision.

If you think a DSS decision is wrong you can follow these steps:

- ask your regional DSS office to review your case
- ask for a review by an *Authorised Review Officer*
- appeal to the *Social Security Appeals Tribunal*
- appeal to the *Administrative Appeals Tribunal*.

An initial review by your regional office will probably be carried out by the person/s who made the original decision.

If you are unsatisfied, a DSS *Authorised Review Officer* (who is semi-independent) can review the decision. If you are unhappy with this review, he/she can give you forms and tell you how to proceed further.

The next level of appeal is the *Social Security Appeals Tribunal*. This level of appeal is semi-independent and free, but it is advisable to obtain legal advice from the Welfare Rights Centre (see below).

If you're not satisfied with the previous step, you can appeal to the *Administrative Appeals Tribunal*. This level of appeal is independent of the DSS and is also free. It is advisable to obtain legal advice and representation. For more information, contact the Welfare Rights Centre. They can provide information, advice, representation and referrals.

(Continued on page 29)

Correction

In edition 13, within the article *The Inside Story - Law & NSW Prisons*, there were several factual errors.

Educational programs are presently accessed by 61% of the inmate population rather than the 20% as reported.

The term AEVTI is incorrectly referred to as a program. It is in fact, a registered trade name under which the Department delivers a diverse range of nationally accredited educational programs for inmates.

Our range of TAFE courses is in no way limited by the existence of AEVTI - a joint working party from TAFE and AEVTI has recently developed a policy document aimed at improving and expanding TAFE provision to Aboriginal inmates.

The Inmate Development Service at Mulawa provides a broad range of vocational and educational programs through TAFE/AEVTI. The service is comprised of the following staff:

- 2 x Education Officers
- 2 x Drug & Alcohol Officers
- P/T Aboriginal Drug & Alcohol Officer
- 4 x Psychologists
- 3 x Welfare Officers
- 2 x Chaplains
- 3 x Psychiatric Nurses

Also, sessional Drug & alcohol staff provide approximately 7 hrs additional services per week.

Programs for inmates with intellectual disability are provided in special units at the following centres: (number of participating inmates in brackets) Long Bay (18), Goulburn (12), Kirkconnell (20).

Employment programs for inmates are presently accessed by 70-80% of prisoners as opposed to the 50% reported in your article.

John Pagent - Dept Corrective Services

[apologies for the previous errors - Ed]

The Dentist - not always a horror story

A dentist's response to *Ian's Story*, page 4.

Ian's Story showed there is a striking amount of ignorance in the community about hepatitis C - even among some health professionals.

Generally, dentists are very well informed about viruses such as HCV. Hepatitis C is not a rare condition in the general community and most dentists will treat patients with the condition on a fairly regular basis - whether they know the patient has the condition or not.

I believe that Ian was right to discuss his HCV infection with the dentist, but the dentist handled the situation poorly. The dentist allowed Ian's medical condition to be shown on a visible part of his records. This may breach dentist-patient confidentiality if the records are able to be seen by another patient or staff member. The vast majority of dentists are very careful to properly manage their patient's records in a manner that ensures they remain confidential.

I feel very concerned that Ian and Lauren were told that a 'cleaning fee' would be applied. This is wrong because all dentists must follow accepted infection control guidelines. These guidelines apply before, during and after any treatment of all patients whether or not they have a known infection (such as hepatitis C).

If infection control procedures are followed for all patients there should be no need for further charges for additional cleaning. I was pleased to note that when Lauren phoned other dentists in their area, she was told there would be no such charges. She was also correctly told that cleaning and sterilisation procedures were exactly the same for all patients.

I believe that all HCV infected people should be confident that their dentist is well informed about HCV, and that they will be treated in exactly the same manner as any other patient.

Ian's experience was obviously distressing for him and his family and it was disappointing for me as a member of the dental profession. I feel, though, that this is a rare event and hope that people will be confident in discussing hepatitis C with their dentist and knowing they will not be treated like a leper.

If anyone has queries regarding dental work, phone your dentist and ask directly about any area of concern.

Regards, Dr M Evans

Abridged from *The Good Liver*, Feb 1996.

What's a clinical trial?

Abridged from Paul van Reyk's article in the *HIV Herald*, April 1996.

Trials are studies that examine the effectiveness and safety of new drugs. Many people with hepatitis C virus got access to Interferon treatment through these trials earlier in the 1990's.

Some Interferon trials are still occurring - to work out the best way of using Interferon - and other types of trials will happen as new treatments eventually come on the scene.

What is a clinical trial?

Clinical trials are mainly about gathering information that will ultimately benefit the future of many people - in our case, people with hepatitis C.

Trials usually look at up to four things:

- toxicity - is the drug safe to use?
- efficacy - does it do what it's supposed to?
- comparative efficacy - is it better than other drugs for the same condition?
- drug interactions - can the drug be safely used while you are using other drugs?

Trials are also the way that people can get access to promising treatments. When there aren't a lot of good treatments around, it's understandable that people want to try something new and promising as soon as they can.

Trial protocols

Because the researchers want information, whereas the patients want results, it's important to consider some ground rules.

A trial protocol is a document that sets out how the trial's to be carried out, under what conditions, and who can be in it.

If you're considering being part of a trial, check out the protocol carefully. You may need help if the document is too technical - in this case, ask us here at the Council.

Your rights

You are expected to give valid consent to being part of a trial. Because of this, you have the right to ask as many questions as you want - and to expect honest answers based on the most up-to-date medical knowledge available at the time.

You have the right to be told of any bad reactions that happen to other people on the trial.

Once you begin the trial, you have the right to stop at any stage.

By stopping (or not taking part in a trial), you should not be treated worse off by your treating healthcare worker.

Your responsibilities

It's important that clinical trials are run properly. Your first responsibility is to be sure you agree to the protocols and give valid consent.

It is important that you honestly inform researchers about your response to the treatment.

It is also important that you honestly inform researchers whenever you breach any of the protocols - (eg. not taking the dose, taking other medications, drinking alcohol etc.)

The consequence of not telling the researchers about how the treatment has effected you, or whether you have followed the protocols or not may be serious - (eg. if a treatment has side effects that go unrecorded, the effects on others down the track may be alarming.)

Compassionate access through clinical trials

Drug companies are under increasing pressure to factor into their trials a number of compassionate access places. This is especially the case with conditions that are life-threatening, or potentially life-threatening.

Compassionate access provides the chance for people who fall outside the trial protocols to try the treatment. Whether someone gets onto a trial this way is based on how much their need is.

Afterwards

If a drug is proven to work well, people who have been on the trial often get free access to the drug while it is going through the process of government approval.

For more information -

Hep C Info/Support Line: ① 02 332 1599 (Sydney)
 ① 1800 803 990 (NSW) ②

Discrimination against people with hepatitis C

Abridged from the Anti-discrimination Board's factsheet: Discrimination against people with Hepatitis & other Infectious Diseases.

Is it against the law to discriminate against me because I have hep C?

Yes, in NSW it is generally against the law if someone treats you unfairly or harasses you because:

- you currently have hepatitis C - or someone thinks you have the condition
- you had hepatitis C in the past - or someone thinks you had it in the past
- someone thinks you might get hepatitis C in the future
- you have a relative, friend or work colleague who has hepatitis C - or someone thinks they have it

When is it against the law to discriminate?

Discrimination is against the law:

- in most types of employment - ie. when you apply for a job (also see page*), at any time during your employment, or when you leave a job.
- if you can do the job safely and effectively then you must not be discriminated against. Employers also have a legal duty to provide you with any special facilities or services you need to help you with the job, as long as it won't cause them unjustifiable hardship - if you want more information on what this means, contact the Anti-discrimination Board.
- when you get (or try to get) most types of goods or services - eg. from shops, dentists, doctors, pubs, banks, lawyers, government depts or local councils.
- when you rent (or try to rent) accommodation - eg. a flat, unit, commercial premises, hotel or motel room or caravan.
- when you are studying (or applying to study) at a state educational institution -

eg. government school, college or university.

- when you enter, join or get services from a registered club - note: a registered club includes any club that sells alcohol or has gambling machines.
- if you are hassled by someone for making a complaint to the Anti-discrimination Board or another such body.

If an employer, workmate, service or accommodation provider tells anyone else about your condition when you haven't said they can, this could also lead to discrimination. It would therefore be against the law. It may also be against privacy laws. For more information on privacy laws, contact the Privacy Committee of NSW on 02 252 3843.

What can I do if I'm treated unfairly or harassed?

If what's happening seems to be against the law, try talking to the person or organisation that is discriminating against you. Tell them that you think that they are breaking the law. Use whatever help you can - eg. if it's a work problem, ask your union to help, or an Equal Employment Opportunity officer.

If this doesn't work, or doesn't seem the right way to go, contact the Anti-discrimination Board. They have the legal power to investigate your complaint. If it appears to be against the law the Board can try to conciliate the problem. This means they will speak to all parties and try to negotiate a win-win settlement. Such a settlement may involve:

- financial compensation
- your job back
- an apology
- the employer or service provider running an educational program to try to ensure that people in your position are not discriminated against in the future.

The Board treats all complaints confidentially and their services are free. They will deal with complaints as fast as possible, and with as little stress as possible to you. They will not contact the person or organisation you are complaining about unless you're sure that's what you want to do.

Most complaints are conciliated successfully. If yours isn't, you may decide to go to the Equal Opportunity Tribunal. The tribunal is a court of law that provides a legal judgement. If you feel it necessary, it is possible to keep your name and address confidential.

If you've been unfairly fired or forced to resign from your job, you can also lodge a complaint with the NSW Industrial Commission (if you work under a State award), or the Commonwealth Industrial Commission (if you work under a Federal award).

(Continued on page 27)

The Birthday Song

I KNOW THAT I'M AGELESS

AND MY SOUL IS ETERNAL

AND I HAVE LIVED 1,000 LIVES

AND WILL LIVE MANY MORE.

ON MONDAY ITS MY BIRTHDAY

LOOKS LIKE I'LL PROBABLY MAKE IT

TO 48 THAT'S NOT THAT OLD

THOUGH ITS NOT 24.

I KNOW THAT THIS THINNING GREY HAIR

IS A SIGN OF WISDOM,

*THIS SAGGING SKIN AND THESE LOOSE
TEETH -*

PROOF - I HAVE BEEN AROUND.

ON MY BIRTHDAY WE WILL RECALL

THAT DAY BACK IN THE 40'S

WHEN I WAS BORN BALD WITH NO TEETH

AND WEIGHED JUST A FEW POUNDS.

AND I KNOW THAT IN MERELY 2 YEARS

I'LL BE HITTING 50,

*THAT RIPE YOUNG AGE, THAT HALFWAY
POINT*

WHEN LIFE REALLY BEGINS.

BUT ON MONDAY LET'S CELEBRATE

NEITHER THE PAST OR FUTURE,

BUT THE PRESENT HERE I AM

IN THE SHAPE I'M IN.

LOUDON WAINRIGHT III

My reality versus your imagination

My name is 'Rachael'. I wrote this because I get a bit annoyed at the continual myth that heroin users are hopeless 'junkies'.

I am a 37 year-old art director and consider myself a typical high-income drug user. My work is exciting and demanding. It involves creative, admin and supervisory responsibilities.

I've also been smoking and injecting heroin twice a week for 10 years and have never missed a day at work or suffered ill health as a consequence of it.

Years ago, I tried opium while travelling through SE Asia and have enjoyed heroin ever since. I've never been a big drinker, nor have I ever smoked much grass.

My boyfriend and I have a wide range of friends, some of whom know we use heroin, while others don't. My folks were spun out a bit when they found out, but because over the years they've seen how well we handle it, they are a little more cool about it all.

If you use heroin, you need to be in control. You need to set personal rules of conduct which control how often you use heroin and how much you spend on it.

Our rules are that the mortgage, car payment, food and clothes are paid for each week before we spend money on heroin. I budget very carefully and never spend too much money on drugs. I also have a rule that I never inject alone. I always inject with with my partner which helps keep inbuilt control.

We keep a regular dealer who we trust and always try a small amount first time to check the strength of each deal. We also have an agreement that if either of us is in doubt, we'd call an ambulance. Of course, we always use clean equipment.

I find it hard to picture a typical heroin user and I guess this is the point I hope this story makes. I am not a typical user, but neither is a street shooting junkie.

So please, when you read anything about heroin users, or if it comes up in conversation, don't make the mistake of jumping to the conclusion that there is a 'typical' drug user - and that they are a break-and-enter teenager, hanging out.

I enjoy my life. I enjoy our Mosman apartment and the Maverick. I like the occasional Grange and I like heroin. Please don't confuse my reality with your imagination.

'Rachael'

Abridged from Angela Matheson's article - SMH 16/5/96.

Fido's good for health

A new report says that pet ownership could be saving Australia between \$790mill and \$1.5bill a year. The findings are reported in *Health Cost Savings: the impact of pets on Australian health budgets*, prepared by a research unit of the University of Melbourne.

The work was prompted by previous studies that showed cat and dog owners go to the doctor slightly less often and appear to enjoy better health than people who do not own pets.

The cost saving calculations are based on the finding that people who owned a dog or cat visited a doctor an average 4.4 times a year. This compares with people who do not own pets who visit doctors 5.0 times a year.

This small difference in doctor visits means huge savings because of the overall size of our health budget.

Even greater savings may be the case if family members, other than the main carers of pets, also benefit from their four legged companions.

The report concluded that further research is needed in this area, but highlighted the direct link between pet ownership and better health - a link that has major implications for health policy in Australia. ●

Getting your medical records

The Public Interest Advocacy Centre (PIAC) would like to hear about people's experiences in getting access to their health and medical records. They'd particularly like to find out why you want the records and the problems in applying under Freedom of Information laws.

Your comments will be treated confidentially and even if it's too late for them to be presented in the PIAC report, we'll at least highlight the need for action in this area.

Contact PIAC Medical Records Project -

☎ 02 299 7833 L1, 46 York St, Sydney ●

Pre-employment medicals - do they break the law?

Abridged from an Anti-discrimination Board factsheet.

Many employers routinely use pre-employment medical tests as part of their selection process for advertised jobs. These tests can be a useful part of the selection process, but employers could be liable for discrimination or breach of privacy if they misuse them. Some examples of such misuse include:

- using 'medicals' as a pre-interview culling process.
- at the interview, asking jobseekers about past injuries such as back injuries and repetitive strain injury or previous worker's comp claims.
- letting other employees know of the results of your medical.

What are the main features of a non-discriminatory medical?

- the medical test relates solely to the particular responsibilities and duties of the advertised job.
- any special physical attributes required for the job are clearly spelt out.
- these attributes are reasonable in all circumstances.
- facilities or ways of accommodating people without these attributes have been considered, and where practicable, put in place.
- any assessment of someone's ability to perform the job, is carried out after the previously mentioned facilities have been considered and/or put in place.
- the test only assesses current ability to do the job and does not try to predict any future deterioration of health.

When are pre-employment medicals discriminatory

Designing pre-employment medicals requires careful study of what the job entails and a careful matching of types of medical tests to determine a job applicant's suitability. When designing such medicals, employers should:

- remove any blanket policy (eg. no-one with a particular disability) unless the policy can be justified in all reasonable circumstances.
- study the requirements of the job and identify which are essential and which are non-essential skills and attributes.
- investigate whether there are other ways of doing the job so that people without these attributes can adequately perform the job.
- identify the types of services or facilities that could be used to assist people with disabilities to do the job.

(Continued on page 28)

Lifestyle & hepatitis C

(Continued from page 16)

(a standard drink equals one middie of beer, one nip of spirits or one small glass of wine).

Giving up is not necessarily required but can be advisable if the person has a problem controlling their drinking.

There is no evidence that any sort of diet affects the prognosis of chronic viral hepatitis. Some patients may report a feeling of better well-being when avoiding foods overly rich in saturated animal fats.

Will Janine catch hepatitis C if she wants to get pregnant with her boyfriend? Would the baby be hepatitis C positive?

Janine is unlikely to catch hepatitis C by having unprotected sex with her boyfriend. In the very unlikely situation that she did catch the virus, it would still be unlikely that the baby would catch it from her. The overall risk of a mother passing it on to a baby (vertical transmission) is about 5%.

The risk of vertical transmission depends on how much virus is circulating in the mother's blood (viral titre). There are tests to measure this but currently, they are difficult to get done. The tests should be more readily available within the next year or so.

It is useful to know if her boyfriend is experiencing liver disease and how high his liver function tests are. If the ALT is not especially high, it is unlikely that the viral titre is high.

Professor Farrell is the Robert Storr professor of hepatic medicine at Westmead Hospital, Sydney.

Want to work on the Hep C Review?

We're looking for someone to join our Editorial Committee. The 7 person group advises on planning, layout, stories and direction etc.

The work load is not demanding. The work experience and job satisfaction is priceless.

Phone Paul (02 332 1853) for more info.

What is the big picture answer?

(Continued from page 14)

Forty per cent of NSW's prison population has been jailed for drug offences or crimes related to financing drug-use.

National Drug and Alcohol Research Centre analysts believe that the growth in heroin-use among wide cross-sections of our community may place increased pressure on politicians toeing the traditional prohibitionist line to move towards decriminalising illicit drugs. Recent research suggests that up to 300,000 Australians have tried or are now using heroin - more than 2 per cent of the population. Of these, 17,000 are registered as drug-dependant and are undergoing methadone treatment - roughly 5 per cent of all users - while thousands more users are on waiting lists.

Members of the parliamentary group also support the proposed ACT heroin trial research project now under consideration by the ACT government, where registered heroin addicts would be prescribed strictly controlled amounts of clean heroin instead of methadone.

"The aim of the trial is to assess whether the health and productivity of the person improves, and whether crime declines while on this sort of program," says Ann Symonds, the parliamentary group's founder.

The group's charter has been endorsed by the Public Health Association, the NSW Bar Association, members of the Australian Medical Association and the Anglican Bishop of Adelaide, Ian George.

Hepatitis C discrimination

(Continued from page 24)

One complaint the Anti-discrimination Board dealt with was a student with hepatitis C who enrolled for a course at an educational institution. She didn't know that she had the hepatitis C virus but after students were compulsory tested, she was told she could not continue her course and was transferred to another program. She felt she had been treated unfairly by the college and went to the Board. After a conciliation conference, the student was able to transfer to another course, given an apology and financial compensation, and guidelines were put in place for all students who may experience the same situation.

- ① Anti-discrimination Board: 02 318 5444
02 310 2376 (TTY) 049 264 300
042 268 190 1800 670 812
- ① NSW Industrial Commission: 02 258 0080
- ① Comwlth Industrial Commission: 02 239 8333

Welfare Rights' CES letter

(Continued from page 9)

- only give employers and the public a false sense of security.
- The administration of the guidelines means that all CES employees who access computer records of a client with a communicable disease are alerted to the fact that the jobseeker has such a condition. This represents both discriminatory treatment, and a breach of privacy and confidentiality principles.
- The requirement that a doctor issue a certificate [stating] what the jobseeker can safely do in the workplace attempts to shift the CES's perceived onus of responsibility onto the doctor. In practice, doctors are unwilling to give [any such] blanket guarantees. [This means that hepatitis C positive] jobseekers are forced to get a medical certificate each time they seek referral for a job. This procedure places unnecessary barriers to finding work. [a procedure which] jobseekers perceive to be discriminatory and invasive of privacy.
- The CES can refuse to refer a jobseeker if a medical certificate is not provided on request. Failure to provide a medical certificate can also result in a penalty period and the jobseeker having his/her Social Security payments stopped. This is grossly discriminatory.

We urge you to request that your department ceases this discrimination which effectively breaches your own Government's *Disability Discrimination Act*.

I would be grateful for your attention to this issue and for your reply as soon as possible.

Yours sincerely,

Michael Raper
Director
Welfare Rights Centre

cc. Commonwealth Ombudsman

Pre-Employment Medicals

(Continued from page 26)

- identify proper and relevant tests for assessing the required attributes.

Proper use of medical tests

In order not to misuse their tests, employers must:

- ensure the doctor or person who is in charge of carrying out the medical is aware of the anti-discrimination laws and understands that the tests must relate to the specific job requirements.
- remember that for applicants with a disability, only the attributes relating to the essential duties of the job can form part of the medical.
- ensure that any applicants with a disability are tested while using any physical aids or medications - eg. if an applicant normally uses a hearing aid, the aid should be used during the test. Applicants should also not be expected to refrain from taking any usually prescribed medication.
- ensure that medicals are not used to screen out applicants with certain past injuries or disabilities, or those applicants who have a family history of certain illness - current ability is the only relevant factor.
- ensure that medicals are not used to screen out applicants with past workers' compensation claims, or those considered at risk of making workers' compensation claims in the future - again, current ability is the only relevant factor.
- ensure that all medical results and records are kept confidential.

Medical tests for determining whether an employee can join a superannuation fund should not take place before a person is given the job. These tests should be carried out after the applicant has accepted the job offer. Such tests can not be used for other purposes and should not be allowed to affect an applicant's chances for getting the job.

Want to find out more?

If you want more information about medicals, or other aspects of job recruitment, please phone the:

Anti-Discrimination Board

- ① 02 318 5444
- ① 042 268 190
- ① TTY 02 310 2376
- ① 049 264 300
- ① 1800 670 812

Disability Discrimination Legal Centre

- ① 02 313 6000

Rob's Story

(Continued from page 19)

was able to function for over twelve hours a day without tiredness and exhaustion. I was able to cope at work. My mood changed, noticed by friends and closest associates...in other words, something positive was taking place, a change happened.

HCV, hard yakka, despair and hope.

It is now three months since I started taking the brew. I remain in good spirits and am encouraged that my stamina and mood have positively stabilised. Although my LFT's have not fallen to any appreciable level, and a positive change in my body's biochemistry may take some time, I can now function at a some what normal pace. **I am more than happy.**

The moral of this story is - don't give up. Within reason, try everything, (there are a lot of good people out there who understand and will help you), and sometimes trust a lawyer, even though he be "hippie" minded.

Regards Rob.



Department of Social Security

(Continued from page 21)

The right to information

You have an overall right to information throughout all Social Security processes - whether it be in the form of brochures, verbal advice or instructions on how to fill out forms.

If you have problems with English, you should ask for an interpreter. If you have problems understanding high-level language, you can ask for things to be explained more simply.

Under the Commonwealth *Freedom of Information Act 1982*, you have the right to see information held by Commonwealth government departments that concerns you. In making such requests, you do not need to explain why you want the information.

If ever you are disputing DSS decisions relating to benefits or pensions etc, it is often useful to get copies of the evidence on which DSS officers have made their decisions.

While there is no charge for DSS or CES information, there can be delays of up to 30 days. Some requests for information may be turned down by the DSS, but you can appeal these decisions.

For more information

The Welfare Rights Centre is the best place to get information and/or assistance.

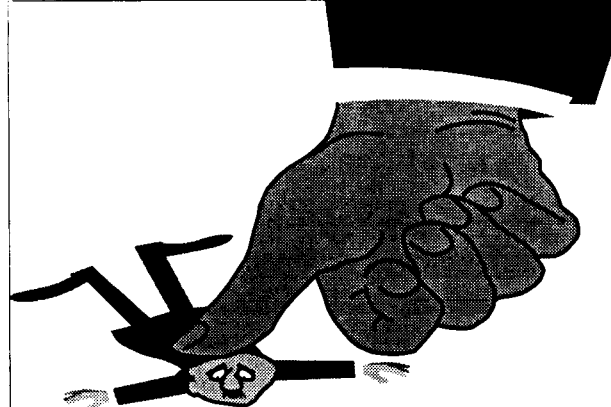
In some situations it's advisable for a person with legal experience to assist you when dealing with the DSS. The Welfare Rights Centre can help arrange such representation.

(Welfare Rights is not part of the Department of Social Security. It is independent and was set up to help people who have problems with the DSS and CES)

Welfare Rights Centre ① 02 211 5300
 ① 008 226 028



Don't forget to write in and let us know what you want to see in the next newsletter.
Hey, you could put it in a 'letter to the editor' and also let us know how things are going for you. Let's all talk more about hepatitis C!



Having no professional photographic camera or any CD-ROM drive means we can't get *The Review* truly on it's feet

If you know anyone who would donate these items, phone in and let us know.

This would mean more use of better graphics, and professional photos like Phillip's on page 3.

regular feature - other states

Tasmanian group

Contact ph no: 002 241 034

In February, Tasmanian health service organisations came together for the first time to discuss hepatitis C in Tasmania.

Organisations have begun to talk together about hepatitis C, what it means, where it is going and what we are all doing about it.

An idea supported at the February meeting, was the formation of a Tasmanian Hepatitis C Council. Such a development will depend on the support and input of those affected by hepatitis C in Tasmania.

Western Australia Council

Contact ph no: 09 328 8216

Our new Coordinator, Sally Northeast, joins the Council having spent the last three years working on a variety of Health Promotion Programs in the UK. She joins our Volunteer Coordinator, Paige Sullivan, and Admin Assistant, Viv Brown.

One project Sally will be looking at is the translation of WA hepatitis C information resources into languages other than English.

WA is also planning to set up a social club/drop in service for people affected by hepatitis C.

Queensland Council

Contact ph no: 07 3229 9238

The Hepatitis C Council of Queensland provides three main areas of services to the community:

A telephone information service, operating during business hours with some after hours access.

Referral onto support groups, doctors, natural therapists and any other relevant services for people with hepatitis C and their families and friends.

Printed information is sent out to callers from all around Queensland. Normally, this

involves an information pack on Hepatitis C, nutrition advice and Interferon information. We also try to meet specific requests for detailed information on particular topics related to hepatitis C.

Victorian Foundation

Contact ph no: 03 9280 2316

Currently, we are busy with a volunteer training program. Our volunteers help people affected by hepatitis C. Later we will be facilitating meetings to expand our support groups in rural and metropolitan areas.

We are seeking to recruit a part-time Information Officer (20hrs per week). If you are planning a move to Melbourne and would like to coordinate the provision of information services and the production of our newsletter - *The Good Liver* - call our office on 03 9280 2316.

The VIC Minister for Health has announced that the Fairfield Hospital, our 'landlord', will close on 30 June 1996. We are therefore considering various relocation options and we are likely to be moving sometime this year.

ACT Support Group

Contact ph no: 06 247 8114

We have recently held elections that led to a new Management Committee line up. We've also instigated a recruitment drive that was tied in with our 27 March *Hepatitis C Public Forum*.

We lobbied against the unacceptable delays in accessing Interferon treatment and are pleased to announce that after 18 months, ACT people can now access the treatment. We only hope we do not have to go through the same process when other/combo therapies become available.

Also important for us, is the continuing development of relationships with local organisations. These include the ACT IV League, D&A agencies, NSEP workers and local healthcare workers.

NT group

Contact ph no: 089 813 988

We are meeting with the NT Minister for Health to brief him on hepatitis C and hopefully gain some financial support to stage a community awareness week.

At the moment we are bringing in guest speakers from other

(Continued on page 31)

(Continued from page 30)

community service organisations. In the future, funding permitted, we will be able to provide workshops for other organisations and the general community.

As with all states, we are suffering from lack of funds. Much of our time and energy is tied into voluntary support. It actually seems as though we may lose some key members because of their unreasonable workload and our poor level of government support.

All in all, things for the NT Support Group are not looking too good, but we are keeping a positive attitude.

South Australian Council

Contact ph no: 08 237 9387

Last year we put in a funding application with SA Health. As yet we have not received any word from them, and remain hopeful that they can see the relevance of organisations like ours.

We also await the release of SA Health's formal response to hepatitis C - *SA Directions for Hepatitis C*. Although pleased to have been consulted in the initial development of the strategy, we are keen to see the final product and how it responds to the needs of everyday people and community groups involved in hepatitis C.

In the meanwhile, in a significant development for our Council, we have accessed our first office space. We owe great thanks to the Adelaide Central Mission for their kind and timely offer of assistance.

All hepatitis C Councils need lots of support. If you live in another state, it's a great idea to join and be part of your local Council as well as NSW.

Local services do not develop without local support and lobbying. Exercise your democratic and social rights to good support and healthcare.

Chinese Herbal Trial update

An update report by Stuart Loveday

Phase one of the formula trial in Newcastle is complete. The trial's coordinator, Prof Bob Batey, Director of Gastroenterology at the John Hunter Hospital and Chair of the NHMRC Hepatitis C Working party expressed cautious optimism. "There have been some normalisations of ALT and they occurred only in the treatment group, not the placebo group, but they're not sustained normalisations at all. There has been no patient in whom we can claim a cure," said Prof Batey.

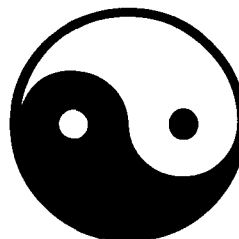
The trial awaits final detailed confirmation of results before a decision on the next phase can be made. It is possible that it could look at a herbal product modified to make the dosing closer to Traditional Chinese Medicine (TCM) analysis and more easily worked with. Prof Batey would also be keen to see whether herbal products plus interferon give some benefits above and beyond interferon alone.

"I can happily say there were no significant adverse problems. There may well be a benefit, mild but measurable for those who are on the herbs; there was good patient compliance and we've had some interesting, encouraging things happen but the information needs to be analysed fully," said Prof Batey.

The clinical researcher and one of the TCM practitioners involved in the trial, Mr Alan Bensoussan indicated a need to do more work on the formula to improve absorption of the herbs. "The pilot trial is offering some hope in that there appears to be a reasonable improvement in the liver function of people taking the real formula, but we need refine the formula further," said Mr Bensoussan.

The ways the success of the herbal treatment will be measured will be in terms of symptom reduction, liver function tests normalisation and PCR measured viral clearance.

Further results will be known by September and we shall carry another update in the next *Hep C Review*.



interferon *what you may need to know*

Treatment

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

- chronic hepatitis proven by liver biopsy (except patients with blood clotting problems)
- one positive antibody test result, then a second test repeated between 4-6 months later
- liver function tests (with ALT readings 1.5 times normal upper limit) done three times over 6 month period
- absence of cirrhosis or other serious liver damage
- absence of HIV infection
- for women - not currently breastfeeding nor any chance of pregnancy while under treatment
- no history of significant psychological problems
- 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, unless currently drug free and stabilised on methadone program for 6 months.

The course of treatment involves giving yourself an injection three times a week. Currently, this lasts for 6 months.

If your ALT readings don't come down after 3 months, the treatment ceases to become available under the PBS.

Treatment Centre facilities

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

Treatment centres must have adequately trained staff.

There are minimum facilities that treatment centres should have before they treat with the drug. These include:

- 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.

In rural and remote areas, there are certain treatment centres for hepatitis C. You should make sure these centres have the minimum facilities listed above.

Treatment centres

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

Side effects

Interferon has side effects. If you are thinking about the treatment, there is written information available. Doctors who are up to date on hepatitis C will provide good information. Our Council also has information available.

If you are keen on Interferon treatment, after seeing a general practitioner you may want to see a specialist. Whatever you do, it's a good idea to find out as much as you can. You might find it useful to write down your concerns and queries so you don't forget to ask about them.

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 for 6 months to determine how successful it was. Currently, around 25% of people who try Interferon achieve a long-term remission.

Natural therapies

have been used to treat hepatitis C and its possible symptoms.

To date, there have been few research trials in Australia to check the effectiveness of natural therapies in treating hepatitis C, but many people report positive benefits.

Natural therapists using acupuncture, homeopathy and/or herbs aim to improve their patient's overall health.

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.

It's also advisable to talk to your medical doctor or specialist and your natural therapist about the treatment options that you are considering.

It's best if they're 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 in Europe is light years ahead of other parts of the world.

Around twenty 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, the standardised extract of 70% flavonolignans 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.

Want more information?

Our Council's information booklet: *Hepatitis C - what you need to know* has general information on natural therapies. We are also working on the production of detailed 'fact sheets' some of which will deal with specific natural therapies.

In the meanwhile, for more detailed information please contact the following organisations:

Australian Acupuncture Association	☎	1800 025 334
Australian Homoeopathic Assoc	☎	02 9415 3928
Australian Natural Therapists Assoc	☎	1800 817 577
Australian Traditional Medicine Society	☎	02 9809 6800
Association of Remedial Masseurs	☎	02 9807 4769
Homoeopathic Assoc of NSW	☎	02 9231 3322
National Herbalists Assoc of Australia	☎	02 9211 6437
Register of Trad. Chinese Medicine	☎	02 9660 7708

Referral?

We are in the process of putting together a referral database for various healthcare workers - natural therapists included. See *Wanna know of a good doctor?* (page 18) for more details.

Sydney Metro Region

There aren't many support services available in the Sydney region. This isn't because there's no great need for local support services, it's because the Hep C Council has never had the funding to coordinate or develop them. So where does this leave you?

If you need particular assistance with something - whether it's help with the kids, housing, finances or home shopping - you should look in the front of the *white pages* telephone book. Here, you'll find a whole range of services that are mostly aimed at the general community.

For information and emotional support you can phone the Council's information and support line

- ① 332 1599 (Sydney)
- ① 1800 803 990 (NSW)

If you want face-to-face counselling on a one-to-one basis, speak to your doctor or contact counsellors.

Counselling is always done confidentially (with Sexual Health Clinics, you don't even need to give your name.) Counselling staff can usually offer a good level of support and if necessary, can refer you to specialist workers if you have any major problems.

Hepatitis C support groups

Following, is a list of contact numbers for the several hepatitis C support groups that have been set up by people in local areas. Please phone these contacts during business hours:

Newcastle:	Leone / Rose - 049 252 511
Muswellbrook:	Robyn - 065 432 677
Tamworth:	Margaret - 067 683 365
Orange:	Phil - 063 617 455
Dubbo:	Nick - 068 828 765
Bowral:	Andrew - 014 419 974
Bathurst:	Christine - 063 315 584
Lismore:	Robyn - 066 221 555
Coonabarrabran:	Gary - 068 422 507
Bowral:	Noelle - 015 491 512

Existing general services

Sexual Health Clinics

Although hepatitis C is not strictly classified as a sexually transmitted disease, the staff at these clinics can still offer you 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).

Sexual Health Clinics can be found by looking in your local phone book (look for 'sexual health clinics').

If you are worried about what it may look like, in going to one of these clinics, remember that your details and medical records are kept strictly confidential.

Community Health Centres

These centres exist in most towns and suburbs. They provide many different services including information on local health and welfare agencies. They also run a range of support and discussion groups for different groups of people. Activities ranging from archery to yoga are open to the general community.

Community Health Centres can be found by looking in your white pages - under *community health centres* - or by phoning the Hep C Information & Support Line.

One-to-one counselling

Some people with hepatitis C may want to make use of a specialist counsellor. These professionals can provide support or therapy when someone has specific problems.

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 phobia that impacts on their hepatitis C infection.

To find out more, contact local GPs or community centres. Our Info & Support Line may also be able to assist.

Family counselling

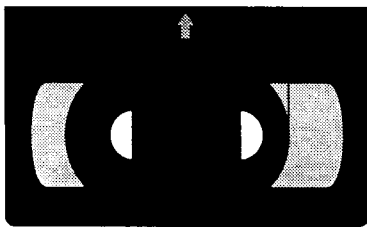
Sometimes dealing with symptoms, or fears about family members catching hepatitis C cause problems in spouse and family relationships. If hepatitis C is impacting on your family, it may be an idea to seek family counselling.

To find out more, contact Family Planning, local GPs or community centres. The Info & Support Line may also be able to assist.

regular feature - available information

These resources are available free of charge, or for a low cost that covers postage.		
Videos are borrowed for two weeks at a time. All you will need to pay is the return postage of \$3.00		
Our postal address is PO Box 432, Darlinghurst, NSW 2010.		
Our phone number is (02) 332 1599 and our fax number is (02) 332 1730.		
Hep C - a brief introduction	An A4, two fold brochure giving an overview on hepatitis C	\$5 per 100
Hep C - what you need to know	An overview of hepatitis C, including testing, treatment, biopsies, haemophilia, lifestyle changes, prevention, drug use, women & hep C, prognosis and a hep C glossary.	no cost
Newsletter back issue pack	Topics include Social Security, Disability Support Pension, Interferon treatment, natural therapies, history of the Council/Support Group	no cost
Video No.1	Prof Geoff Farrell discussing Interferon treatment, & Jennifer Holmes discussing women & hep C.	\$3.00 return postage
Video No.2	Ken D'Aran discussing homoeopathy, & Raymond Khoury discussing herbalism.	\$3.00 return postage
Video No.3	Women and Hepatitis C Forum - featuring Dr Ingrid van Beek, Ses Salmond and Cheryl Burman. This video is temporarily unavailable while extra copies are being made.	
Video No.4	2 Quantum episodes: & hepatitis C and the liver	\$3.00 return postage
Research Pack No 1	Hepatitis C research papers - overview, prevention, diagnosis, serology, epidemiology (1993-1995).	no cost
Research Pack No 2	AGI booklet (1994), Fairfield Hospital healthcare provider booklet (1994), & National Hepatitis C Action Plan (1994).	no cost
Research Pack No 3	NHMRC Hepatitis C Report (1994)	no cost
Research Pack No 4	WA Dept Health HCV booklet (1995), & hepatitis C research papers	no cost
Research Pack No 5	AHMAC - The Nationally Coordinated Hepatitis C Education & Prevention Approach (1995), & NSW Health Taskforce Report (1995)	no cost

Video Tapes are a great way of providing information for people who don't have good eyesight or have trouble with written words. Some people prefer things in a visual form.



Particular episodes above have become a little out of date, yet we have no volunteers skilled in video production. If you know the difference between panning, tracking and zooming and can help with editing and overall production, please give us a call - we all need you. (ph Paul on 332 1853)

MEMBERSHIP FEES

The setting of membership fees has been a vexed issue for our Council since it began. Low funding has meant that our membership fees remain an important part of overall income.

Last year, in an effort to ease the administration of membership fees, it was agreed to make all our memberships payable in advance

and renewable at the same time each year. The membership year begins on March 1.

If members join during the final three months of a membership year, they are credited with the following full membership year.

Depending on when some people join, they may be accredited with only part of a membership year. This is unfortunate but would only

apply to the first year of their membership.

At a recent Management Committee meeting, it was decided more should be done for people experiencing financial hardship.

Members who are experiencing financial hardship should select on their membership form a \$10 concessional or a zero fee membership.

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.

Photocopy, complete and 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			
Street 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?	<input type="checkbox"/>
Other?	<input type="checkbox"/>

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

Renewal	<input type="checkbox"/>	New member	<input type="checkbox"/>
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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.

These are tax deductible. If you make a separate donation, please record the amount here.

\$

6. If paying by credit card, please complete this section.

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Card number

Card type (please circle)

Mastercard	Visa	Bankcard
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Expiry date

month	<input type="text"/>	year	19
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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 the objects and rules of the Hepatitis C Council of NSW and apply for membership of the Council.

Signed

Dated

This section is	Date received	\$ received	Receipt no.	Date entered	Member no.	Info pack
for office use only						
staff initials						