The Hep C Review

Spring Edition

October 1996

Issue 15

DOES AN HIV STRATEGY EQUAL AN HCV STRATEGY?

The Commonwealth Department of Health and Family Services (CDHFS) is currently renegotiating and drafting the Third National Strategy for HIV/AIDS. This is the third of such Strategies and the first to specifically mention hepatitis C.

Of great interest to people affected by HCV and those working in this sector, is the question: If the National Hepatitis C Action Plan is meant to address hepatitis C, why is hepatitis C now being included in the National HIV/AIDS Strategy?

Cathy Mead, Head of the Commonwealth Department of Health and Family Services' newly formed Centre for Disease Control has said that surveillance and prevention of HIV and HCV enjoys many similarities, eg. needle and syringe programs. Other than these areas, she acknowledged that the Strategy does not relate directly to hepatitis C.

Stuart Loveday, Executive Officer of the Council met recently with Cathy Mead and Australian National Council on AIDS president Chris Puplick to discuss the Third National HIV/AIDS Strategy. We've also attended a public forum in September where a wide range of people from the HIV/AIDS community debated the Strategy.

At the forum, Chris Puplick stated that several issues needed to be acknowledged and discussed if consensus agreement on the Strategy was to be reached. Such issues include: distrust between Federal and State governments about who's New research highlights need for standardised national surveillance system for HCV

A recent Australia-wide research project has shown that our current method of monitoring HCV infections is inadequate if we are to gain a better understanding of past and present transmission rates.

The study had several aims: to trial a better surveillance system, estimate the number of new infections each year, report on how the virus is transmitted and recommend whether it would be feasible to adopt the new surveillance system.

What was confirmed was that thorough surveillance of HCV comes up against a number of major problems.

- The current system is insensitive it does not pick up people who have caught HCV but remain feeling well.
- In practice, testing procedures for HCV differ from state to state.
- There is no standardised process for following up new cases and finding out how they might have occurred.
- In nearly all cases, researchers rely on patient or GP perceptions of how transmission may have occurred.

PH

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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). Having a staff of four, we are primarily funded by NSW Health.

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Contributions from Council members and the public are welcomed. The views expressed in this newsletter are therefore not necessarily those of the Hepatitis C Council of NSW Inc.

In response to your recent feedback, the next newsletter will focus on diet and nutrition and the following edition (17) will focus on HCV, sex & intimate relationships.

Its our newsletter - we're all part of it. So be an active participant. Please write in now with your views and experiences on the above topics - or anything else to do with having hepatitis (we don't need to print your name.) If you don't want to write it down, phone Paul and have a chat (02 9332 1853.)

Who does the hepatitis C virus affect?

With no mention of additional funding in the recent Federal budget and a similar picture here in NSW, the future is unclear for the vast number of people with hepatitis C.

It's time to remind decision makers who we are and what we rightfully expect.

Up to 200,000 Australians have the hepatitis C virus. Further it is estimated that around 10,000 new infections are occurring annually, primarily through injecting drug use.

Coming from a wide range of ethnic, cultural and economic backgrounds, we reflect the diversity of our Australian multicultural society. We are lawyers, actors, housekeepers, bank tellers, cab drivers, doctors, factory workers, jockeys, unemployed people, teachers, merchant bankers, receptionists, truck drivers, prisoners, wharfies and yoga instructors.

We live in cities, country towns and on outback stations. The average person with hepatitis C is just that - an average person - whether they've contracted the virus through injecting drug use, blood transfusion or other means.

The common denominator for all of us is that we have hepatitis C.

We should be able to walk into any GP or

dentistry practice and expect best standard healthcare - irrespective of our lifestyle or how we got HCV. This applies throughout the Australian healthcare sector - whether private or public, casualty visit or ward stay. We should be able to expect fair treatment from employers and government departments. We should be able to access appropriate social support services. We should be able to socialise in the general community and raise our children without fear of prejudice.

Sure, having hepatitis C means we are covered under the Anti-Discrimination legislation but we shouldn't have to deal with HCV stigmatisation and discrimination. As contributing members of the community, we deserve the respect and care that all Australians can expect.

The best way of dealing with these problems is to prevent them in the first place. Consequently, serious commitment to rectify the escalating social and economic costs of hepatitis C is required now. Otherwise we risk being placed in the too-hard basket.

Community organisations representing people with HCV look forward to genuine opportunities to work with Commonwealth and State governments on public awareness projects that would reduce public anxiety and fear about hepatitis C.

Until these events materialise, those of us affected by hepatitis C need to be vigilant in expressing our dissatisfaction and anger that the present half baked response simply won't do.

Our Annual General Meeting went ahead on 5 September.

The new committee was elected, five members of whom also served last year.

The proposed amendments to the constitution were all passed and Audrey Lamb and Rev Harold Smart were elected as our first honorary Life Members.

As you'll note, a shortened version of the Annual Report can be found in this edition (starting on page 13.) If you wanted the full report, please contact the office.

letters



Witness Jana

I enclose a copy of the letter that I sent to the Witness program and also the reply I got.

Pretty average wouldn't you agree?

Anyway I stand by what I said and that's what the end result is - me being no longer welcome in my sister's house.

I thought that Witness' hep C episode was pure scare tactics - along the lines of the HIV 'Grim Reaper' campaign.

Yours sincerely

Kevin Willis

See page 13 for copies of Kevin's letters. Media representation of hepatitis C is a big issue for all of us. The media helps determine how differently the rest of society views us. Other people's attitudes to HCV can mean we get a harder time whether the virus is effecting us physically or not. Ed.



Clearer info

Three weeks ago I picked up your magazine at our methadone service. It was really great to get some facts on hep C that has affected me for 10 years probably.

The booklet that someone sent was good. It had more info about hep C than my doctor has been able to tell me in the three years I've known I've got it.

But I don't think the book was easy to read. I had to get a friend to help me. It would be really good if you did another one that didn't have all the medical words and everything.

Keep up the good work, KT

One of our goals is to provide better info resources. In time, we will review our current booklets and brochures and possibly reprint them in a more easy to read format for people who prefer their information that way. Ed.



Balanced views

I was very pleased to receive your latest magazine (Autumn/Winter) which was very well done in informing us with the latest hep C information. I believe that the Hepatitis C Council is a non-political and non-religious organisation representing all the people with hepatitis C.

This being the case, I was very disappointed at your overuse of the ying and yang symbols - they appeared on every single page.

The Hepatitis C Council is willing to inform us of the Chinese Herbal remedies, but in order not to be unbiased does this mean that in future editions you will inform us of all other alternative remedies. Do you think it is the Council's place to do this?

On another note, I thought your posters were well done and I will be putting some of them on my doctor's notice board. One poster had me thinking though. You make the statement that hep C can't be passed on by mosquitoes but you don't explain how you know this and what research has been done to back up this statement.

Also, what about when you squash a mossie - how do you know if the blood is yours or its last victims?

Yours faithfully

Mrs WF

There were no spiritual or political motives involved in chosing the 'end of story' symbols used in the previous edition. We attempt to give greater choice rather than endorse any particular approach to prevention, treatment, care or support. See page 11 for more info on mosquitoes and HCV.



Thanks

Thanks to the Council for the information sent out to me. It gave me more information on HCV than all the doctors I've seen since showing symptoms in 1990. I am looking forward to your ongoing updates.

The only people aware of my HCV condition are my immediate family and I want to keep it that way. I appreciate your unmarked envelopes.

VL

I am hoping to eventually involve myself in peer discussion groups to alleviate some of the stresses involved and to find out how others deal with their illness.

Thank you again, this time for just being there for us in need.

Regards,

PA



Tummy info please

I am very appreciative of the Council. Thank you for the booklet What you need to know - it was extremely informative. I also enjoy reading The Hep C Review which I feel is like good wine, improving with age.

In some future issue of the newsletter I would like to read an in-depth article on bowel problems for hep C patients.

I have irritable bowel trouble and my liver specialist, a Macquarie Street chap, agrees that all my bowel problems could be due to hepatitis C.

I think the Council should produce a booklet - Symptoms of hepatitis C. Just the more common symptoms and in depth information would be very useful. I remain greatly appreciative of the team's work.

Yours sincerely

HK

Thanks for the suggestion and feedback. Do other readers experience similar gastro problems? Write in and let us know. We're going to focus on diet and nutrition in Edition 16.



HCV & HIV

I attended the public forum held on 4 September to discuss the 3rd National HIV/AIDS Strategy and how hepatitis C may relate to it.

I for one, am concerned that conflict between HIV and HCV for funds will leave a loser - hepatitis C. I think we should argue very forcefully for as best a deal as possible in the National Strategy?

Regards

The Hepatitis C Council does not see the 3rd National HIV/AIDS Strategy as a hepatitis C strategy. This position is confirmed when you consider that Commonwealth representatives agree this is the case. We acknowledge that the 3rd National HIV/AIDS is nonetheless, an important and strategic document. For this reason we have put much time into our detailed written submission to the Commonwealth Dept of Health & Family Services (see page 1).



hep B and me

I was a bit peeved when I read the last newsletter where it said that it's really easy to catch hepatitis B.

My partner has always been a bit edgy about my HBV status and articles like yours don't help that much. Sure the article was written by one of the other readers but don't you edit these things at all?

Otherwise, keep up the good work.

HT

The reference to hepatitis B was pretty indirect and sorry that it slipped through. Yes, you are correct - although the hepatitis B virus is found in all body fluids, it is primarily transmitted only through blood, semen and vaginal fluids. Thanks for pointing this out.



We really welcome letters to the editor. Ideally, they should be no more than 300 words. Your contact details must be supplied in order for us to confirm authenticity if required. Please write, fax or email us as per the *The Hep C Review* contact details on page 2.

Can you see your medical records?

The High Court has ruled that unless specific laws are passed, patients have no right to access their private doctor's medical records.

Julie Breen took her surgeon to court seeking access to her medical records - she was involved in a class action against breast implant manufacturer, Dow Corning.

Her surgeon would not give access to the records unless she indemnified him against claims arising against him. Rather than accept this condition she took action both in the NSW Supreme Court and the High Court of Australia.

The medical profession has welcomed the High Court finding. Australian Medical Association president Keith Woollard claimed that patient access to medical records would in some cases, compromise doctor's ability to provide high-quality care.

"Unrestricted access to records may not always be in the patient's best interests. This can particularly be the case where psychiatric illness is involved," Dr Woollard said.

Following the High Court ruling, the Consumers Health Forum (a federal body set up to promote patient participation and rights) immediately called for new laws that ensure patients can access their medical records.

But the Government's response following the High Court news seems to have been to side with the medical profession. Health Minister Dr Michael Wooldridge said the Commonwealth had no plans to pass new laws. He highlighted that he was prepared to consider the issue of new laws in consultation with doctors.

How does this effect you? It could be a big issue if you needed supporting evidence if applying for the Disability Support Pension.

PH

Newcastle herbal trial

A brief report on the Chinese herbal medicine trial for hepatitis C, by Prof Bob Batey.

The John Hunter Hospital has now completed its trial of herbal medicine therapy for hepatitis C. This was a placebo controlled trial of a tablet form of herbal extract.

There were 16 herbs in the tablet preparation and the proportions of the herbs will not be available until the results have been reported in the scientific press.

We took into the trial patients who had not been treated with Interferon or patients who had relapsed following Interferon treatment. There were no strict entry requirements apart from people having a definite hepatitis C antibody result and abnormal liver function tests on at least three occasions.

Around 50 patients were treated with 5 tablets 3 times a day. About half were on the treatment and the others on a harmless placebo (a false tablet.) Towards the end of the trial, a small number of patients requested and were given the real treatment for a further 6 months once they found out they were in the placebo group.

The analysis of the trial therefore includes all patients who were treated 'blind' and the smaller number who knew they were receiving the treatment.

None of the patients had any severe adverse side-effects although two patients withdrew from the trial because of side-effect symptoms. One complained of palpitations (that ceased when treatment was halted) and one had significant bowel problems in the form of diarrhoea and bloating.

Overall, patients complied well with the trial, taking the tablets when directed and reporting back regularly to enable good follow up.

Our results to-date show there were no toxic effects as measured by various blood tests etc. and there was a fall in the ALT in the patients on active treatment. Six patients normalised their ALT during the treatment period but there is no evidence that any patient has been cured by the herbs.

At this stage of our analysis, it would appear that the medication has certainly done no harm and may well be offering some opportunity of minimising inflammation in the liver. We need to do more detailed analysis of the results at this stage and I could certainly not recommend the present combination of herbs as the ultimate management strategy for hepatitis C.

I look forward to publishing our completed results once we have a full statistical analysis.

[For more information, phone the info/support line - Ed.]

my name is Brendan.

I'm a person with hepatitis C who caught the bug years ago when I used IV drugs.

I was only diagnosed by accident when I tried to donate sperm. You can imagine my shock but it did explain a lot of things which was a relief for me and my wife.

I've been to see a specialist at my local hospital. He did blood tests on me over a period of time and says my enzyme levels in my liver are not high enough to warrant putting me on the Interferon program. Initially he said I would probably be able to go on it.

Right now I feel like I'm between a rock and a hard place. I get ill every four to eight weeks and it takes me 3-4 days, sometimes a week to get better.

This makes it very difficult for me to hold down a job and I'm too embarrassed to admit my illness to employers. I just know they will spin out and I'll get the sack.

My other problem is that my wife and I want to have children. Although she has previously had her tubes tied, we've been told that we could have a child under the IVF program. Trouble is that we've been told they will not accept people who have hepatitis C or other similar illness.

But we are unable to find out the truth on the matter. The doctors don't seem to know a thing about this disease. Some say that I can father children without fear of infection while others say I can not.

This together with the stresses of paying off a bank loan and other various bills all builds up and when I get stressed, I seem to have an attack of the hepatitis and get ill.

Then I'm back to bed with hardly the energy to get out. I miss out on my usual wages which makes it even harder to pay the bills - back to square one.

All the best, BF

Frank's story

In 1978, well into my 50's, I underwent open heart surgery. The operation involved a simple artery by-pass being the result of blocked arteries.

I had suffered a heart attack at work which was certainly a frightening experience. After release from hospital, my cardiologist suggested the by-pass.

Prior to this operation, I had donated plenty of blood but had never received any transfusions myself.

Following the operation, my GP found me to have a very high reading in particular liver enzymes. He suggested I stop drinking which I did for 12 months. During this time I regained a feeling of good health and believed my operation had been a textbook success.

During later blood tests, the liver enzyme levels were still elevated. My doctor further enquired about my diet and alcohol use - he even asked me if I was eating liqueur chocolates!

Eventually he did a full blood test and discovered I was hepatitis C positive. This was very much a surprise for me as I still felt very fit and healthy. At the time I knew very little about this virus. Something I set about redressing as soon as possible.

Although I remain in good health, I get a bit despondent on the odd occasion thinking about my uncertain future.

Overall, though, I consider my lot to be much better than many other people. I remain in relatively good spirits most of the time.

For my benefit and that of all people with this virus, I am always hoping a vaccine and cure will be developed soon.

I hope others do not give up on such hopes for the future. In the meanwhile we must all take a positive approach to our health and self. There may seem so little we can do but those steps we can take may make so much difference down the track.

In the meanwhile, I wish all people with hepatitis C (and all readers of the Hep C Review) the best of health (or best that can be.)

Sincerely Frank.

prevention

Partying Safely

We all like to let our hair down every now and then. But going to a rave or having a big night on the town should be a good time and not leave us regretting it. A big thing to remember is to do things safely.

If you are Hep C positive, alcohol and other drugs are likely to put added strain on your body, particularly your liver and digestive system. And remember, even if you already have HCV you are still open to re-infection if you expose yourself to the virus through unsafe partying.

If you are hep C negative, do your best to stay that way.

Either way, look after your health by following a few simple guidelines that will help you avoid catching those viruses and other bugs that end up causing a real hassle. These include hepatitis C, HIV, hepatitis B and things like herpes, chlamydia & syphilis.

So how do you best avoid these downers and make the most of your social life?

Thinking things out as much as possible and being aware of the risks involved helps. This is called harm minimisation. It's an approach that's been taken by the government in regard to a range of health issues - including addressing the HIV/AIDS epidemic, and to help combat sexually transmitted diseases (STDs). Harm minimisation means making responsible lifestyle choices, on the basis of sound information.

Injecting drugs definitely gives the best rush - the drug goes straight to the brain. But don't forget, it also gives viruses and bugs a first class, one-way ticket into your body. The best protection is always to use new injecting equipment, which is available from Needle and Syringe Exchanges and chemists throughout the State. Remember, cleaning fits for re-use should be a last option only. If you have to re-use equipment, refer to the three step process explained in NUAA News. It describes how to use a combination of cold water and high strength bleach. Cleaning fits isn't guaranteed to kill the hepatitis C virus.

There is a high risk of overdosing if you are not used to the drug. Sensible users try a small amount first and avoid injecting on their own. Any impurities in the drugs go straight into the blood stream, and can cause major health problems.

Injecting can cause damage such as abscesses and collapsing veins, especially if people inject too often into the same spot. Risks to veins can be reduced by simply changing injection sites and giving the vein a rest.

"The chance of abscesses & infections can be reduced by always using new fits, careful filtering of all drugs, always swabbing before injection, using sterile cotton wool on the site following injection, washing your hands before & after injecting, and taking your time to inject slowly and safely." (*Ravesafe*)

Smoking some drugs can give you a real high. The drug goes quickly from your lungs into your blood stream. But think of your health and be careful - smoking drugs will affect your lungs, and could even lead to serious damage, depending on the drug, how you smoke it, and your own lung fitness. This is especially a danger if you have asthma or similar conditions.

Snorting can have a rapid, intense effect that can even be scary, but it doesn't last as long as other ways of taking drugs. To reduce the risk of damage from snorting, the drug should be crushed up very finely. Give each nostril a rest by swapping from one to the other. It's also a good idea not to share snorting straws as they can become contaminated with blood.

Swallowing drugs is the safest way to go. The high comes on nice and slow, and any impurities or accidental overdose are likely to trigger vomiting - the body's own defence against dangers in the digestive system.

Don't forget to guard against other drug effects. For example, ecstasy brings on dehydration so users should be sure to drink at least 250 ml of water each hour - about 500 ml if they are dancing - and should remember to chill out occasionally.

A great source of information about risks and how to avoid them, is a recently produced booklet called *Rave Safe*, put out by Northern Sydney Area Health Service and the NSW Users & AIDS Association (NUAA.)

It is full of the sort of detailed information that is essential for making lifestyle choices that will lead to least harm.

For more information on 'doing it safe', contact

- * The Alcohol & Drug Information Service ph 9331 2111 or 1800 422 599
- NUAA (New South Wales Users & AIDS Association) ph 9369 3455 or 1800 644 413
 - * The Hepatitis C Council of NSW ph 9332 1599 or 1800 803 990

For copies of the *Rave Safe* booklet, contact Ravesafe project, c/o NUAA

PO Box 822 BONDI JUNCTION NSW 2022

prevention

Shooting clean & avoiding hepatitis C

Around 80% of Australia's estimated 200,000 hepatitis C infections are as a result of injecting drug use.

Some studies have suggested that after a year of injecting you have about a 40% chance of having caught hepatitis C, and after a few years the chance is closer to 80-90%.

Because so many injectors have hepatitis C, some people may take it for granted that all people who inject are hepatitis C positive.

But this isn't something you should take for granted. Remember, it is possible to avoid transmitting or catching hepatitis C when injecting. It means that we have to change the way we inject.

Even if you already are hepatitis C positive, it's important to avoid getting infected again. Being hepatitis C positive doesn't provide you with any protection from getting infected again.

There are several different types of HCV (called genotypes) and many variations within these (called quasi-species.) Every time you catch the virus it is like you have been infected for the first time. People with multiple infections of HCV are often the ones who become sicker. Multiple infections also have a higher chance of leading to cirrhosis or liver cancer.

The key to avoiding hepatitis C is about avoiding someone else's blood coming in contact with yours. So when you inject, you should avoid other people's blood. Not just great pools of the stuff, which is fairly obvious, but also the microscopic amounts of blood that can get on your hands, on the water ampoule, even on the sides of the disposal bin.

So it's not just about using a new fit for

every hit, but also about using new, clean equipment (water, filters, swabs) and making sure you or anyone else washes their hands before and after their hit and before touching anything or anyone else.

To avoid hepatitis C when injecting:

- have a new fit, spoon, water, filter, swab and tourniquet.
- wash your hands with warm soapy water before and after injecting.
- clean the spoon with a fresh swab.
- clean the fingers you'll use to pull off a filter with a fresh swab.
- keep all your utensils separate from your friends utensils.
- inject yourself but if someone else does inject you, make sure they've washed their hands.
- if you get blood on your hands, go and wash them before you touch anything on the table if someone asks you to pass them something, tell them to wait. if you do touch something before you're able to wash your hands, treat it as contaminated.
- dispose of your used fits, filters, swabs etc. properly by putting them into a sharps container - or use an empty plastic drink bottle. If you have nothing, disarm the fit by bending the needle over.
- remember use new equipment every time. Cleaning equipment doesn't always kill the hepatitis C virus.
- remember wash your hands with soap and water before and after injecting. You can't always see minute amounts of blood.
- remember make the bench or table where you're injecting as clean as possible.

If the above list seems too hard to do or remember consider that many suggestions are common sense and others just mean doing a bit of preparation and having new injecting gear on hand.

If you are travelling to Queensland or have friends or family there, QUIVAA (Queensland User's IV & AIDS Association) is a great place for injecting information, care and support.

Phone: 07 3227 7091

Taken with kind permission from *Dart*, vol 3 edition 3, August 1996, published by QuIVAA - the Queensland IV & AIDS Association.

my story

HCV blues

I've had hep C for about 20 years because I think I caught it when I was overseas in India when I got a small tattoo.

The virus has made me feel tired but otherwise hasn't effected my body. It has caused other problems though.

Since I found out about having hep C in 1992, I've had regular blood tests. At first these were every three months but now I have them yearly.

Sometimes my levels go up a bit. Once they hit 70 and I really freaked out but normally they are around 55.

So for me it's a case of off to the doctor every year for the annual blood test. I guess that compared to some people I haven't got much to complain about but let me tell you my story then you can decide.

When I came back from India, I started to do some importing of fabrics and stuff and eventually was having clothes made up in Southern India and importing a container load once every four months.

This was great as I was enjoying the work and making more money at the time than my sister who works as a solicitor (not that we have any sisterly rivalry.)

In 1982 I married my then boyfriend and we were together until I found out I had hep C. He just couldn't cope but I think maybe this was just his excuse. I was so happy, but then he got so withdrawn but I was the one that needed support.

He still helps a bit with the kids. I have two children, a boy and a girl. My boy was from a previous relationship. They are darlings but I am worried because of possible discrimination and how it might effect them. You see, someone who worked for me and who I thought I could trust has been telling many people that I have hepatitis C and that it is dangerous

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and contagious.

I don't think that other mothers trust my children mixing with theirs. I think they are worried they will all catch this 'killer disease.' But what can I do because they don't come straight out and say anything. They say everything behind my back and to their kids.

So I get very depressed because I think that the only thing to do is move out of the area and go somewhere else.

But I can't just do this. Since my husband left I've been depressed and haven't been able to work as much. Because of this, my business has gone down hill. Plus my medication is a problem.

My sister helps as much as she can but she can't be here as often as I would like. She has her own family and also helps look after Mum because Dad passed away three years ago.

If it wasn't for my sister and a couple of friends, I would go crazy. And I sometimes call the telephone service in the phone book.

Most people just don't understand how I feel. Christ, I had everything going for me. A great career, a partner, our family. Sure I'm still with my kids - even though it won't be long before they are grown up - but I've had so many dreams now just gone.

Someone once told me just to get a grip on myself and wake up to myself but its so much more than that. Half the problem is not with me but its with my neighbours and other parents who have crazy ideas about this illness I have. I can't just shout out at them because I don't want my mum to know. She couldn't cope so soon after dad has gone. It would break her heart I just know.

Thanks to the Council, though, because I read each magazine and the booklet you recently sent out and I don't feel so alone. I'm just so glad I have my own home and am not having to rely on the pension like a friend of mine. And I have my children so I guess things aren't too bad.

Best wishes and love to all the readers

BC

Dear BC, thanks for sharing your story and experiences with us all. It may be useful to mention that regarding blood tests: ALT levels are the most commonly quoted readings. Although the normal range for these readings is between 5 - 40, it is not uncommon for people with HCV to have readings of several hundred or higher. Ed.

a hep C web page?

Hepatitis C specialists have told that when attending international conferences, they often discover there are few overseas equivalents to our State-based Councils, Foundations or support groups.

A Council internet web page featuring info, news and chat would help provide further Australian input to what's happening around Australia and overseas.

This could help people with HCV who live overseas where prevalence rates are often so much higher than here.

We regularly produce information resources so why not put our knowledge and experience onto the internet for others here and overseas to benefit?

If you think the idea has merits and want to help, please consider being a part contributor to the production and maintenance costs of an internet web page.

We are currently liaising with several consultants. Of course, though, we're very interested if any Council members can donate time and expertise with this project.

Ed.

For more information,

- ① phone us on 02 9332 1853
- ⓐ fax us on 02 9332 1730
- email us on 100357.263@compuserve.com

Mosquitoes acquitted of HCV transmission

Researchers in the United States have confirmed that the humble mosquito is not responsible for transmission of the hepatitis C virus.

There are two ways that mosquitoes can transmit illness to humans Professor Richard Russell from the Department of Medical Entomology at Westmead Hospital explained.

The first involves 'mechanical' transmission. This is where a mosquito is interrupted during feeding from one human or animal (called the host) and then finds another host from which to feed. In this case, a minute amount of blood may be present on the mosquito's proboscis (or feeding spike.)

The good news is that research shows that this type of transmission does not occur with serious human diseases such as hepatitis C, HIV or hepatitis B.

In warmer regions of the world where mosquitoes are endemic, the levels of hepatitis C, HIV or hepatitis B in children indicate that mosquitoes do not transmit these viruses. The reason that researchers focused on children is that they are not exposed to the same transmission risks as adults - ie. sexual or intravenous transmission risks.

Some viruses are transmitted 'mechanically' by mosquitoes. One that most people may know of is called myxoma. It causes myxomatosis and was used to control rabbits in rural farming areas. Of course, it does not effect humans.

The second way that mosquitoes transmit disease is called 'biological' transmission.

Prof Russell said that studies show mosquitoes certainly swallow viruses into their middle gut. But here, two things can happen.

A virus can remain alive, breaking out of the middle gut and infecting other organs of the mosquito - a case of one parasite being infected by a smaller parasite. The virus eventually infects the mosquitoes saliva glands leading to ongoing infectivity and transmission of that particular virus.

Alternatively, the virus will die in the mosquitoes gut and be digested in the same way that we digest food - by breaking it down using acid.

This is what happens when a mosquito drinks in the hepatitis C virus, HIV or hepatitis B virus. **Kaput! a fitting end to an unwelcome guest.**

PH

a hepatitis C interview

Sharon Taylor -

Chippers & Pickers Outreach Project

Sharon, I was really interested in what the project is all about. Can you tell us about it and how you came to be involved?

Well, its an initiative of NSW Health - of the various rural HIV/AIDS & Infectious Disease Coordinators. I guess there's no need to explain why the project got off the ground. Outside the big cities, health and welfare services are more far flung, and people who move around all the time

have reduced access to them.

The project got out on the road in September last year and will run for a 2 year period. Some of the initial time was spent in planning though.

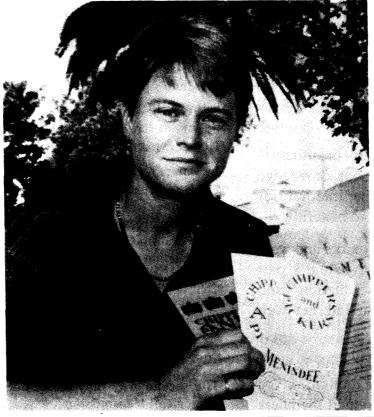
What I do is travel around with my colleague Alister Ferguson, following the seasonal fruit calendar and liaising with the casual fruit pickers and farm workers who move from area to area, and also with the local communities. We deal with a whole range of different people.

Workers come from such a wide range of backgrounds but many are NESB and Aboriginal people, lots of single men, elderly retirees and backpackers.

in the city take for granted. Things like safe sex information and packs, needle / syringe exchange and equipment, STD check ups and all the associated information and education type programs etc.

Also, we aim to more closely link up the itinerant workers and the local community. They have an intimate relationship to begin with as many of the communities would not survive without the seasonal workers. And if we can all build on this relationship, when this 2 year project finishes the project will continue on indefinitely - not through me but through the local communities.

I guess that's one of my personal goals for the future - to see the local town people continue to outbreak with the seasonal workers and take over my work.



Sharon Taylor pictured during a visit to Mildura - photo courtesy of Sunrasia Daily

How did you personally get involved Sharon?

Well, I'd been doing work in Sydney - nursing in a cardiac operation theatre. And then I took a year off. I travelled around Australia for a year, occasionally doing seasonal farm work and odd jobs, and enjoying my hobby - photography.

When I got back to Sydney I wondered what type of work I wanted to do, and I saw the advertisement for this project.

And how have you been enjoying the work?

It's been a very demanding and stimulating time. You develop certain skills but

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every town and region provides new challenges. And I've developed so many good friendships.

And what about in the local communities?

We deal with local doctors, hospitals and clinics; as well as farmers, local councils, Social Security, neighbourhood centres, the CES, Community Services and more. Even local pubs, shopping centres and laundromats.

In the process, we produce brochures, posters and newsletters, and feature in the regional newspapers. And there's so much more.

Our primary aim is to reduce the spread of hepatitis C, HIV and sexually transmitted diseases, and to ensure that seasonal workers don't miss out on all the health programs that we

It all sounds like a good, common sense way to help meet the health needs of these seasonal workers who we often take for granted. Best of luck with the project Sharon and keep us informed of how things go. Perhaps we could do a follow-up story when the project comes to a close?

That would be a great idea, Paul. I'd be happy to let you know how things go. In the meanwhile, if anyone wants to contact the project, they could either phone the North West Health Service on 067 683 379, or myself on 019 457 852. Otherwise look for the dusty looking four wheel drive with all the bumper stickers!

The Hep C Review edition 15 October 1996

95/96 annual report

Following is an annotated version of our Annual Report. If you'd like a copy of the full report, please contact the office.

Introduction

The Hepatitis C Council of NSW grew out of a patient support group set up in Sydney in November 1991.

Over the previous several years the group has attracted ongoing NSW Health funding. This enabled us to provide more effective and professional services to those people in NSW affected by the hepatitis C virus.

Telephone information and support

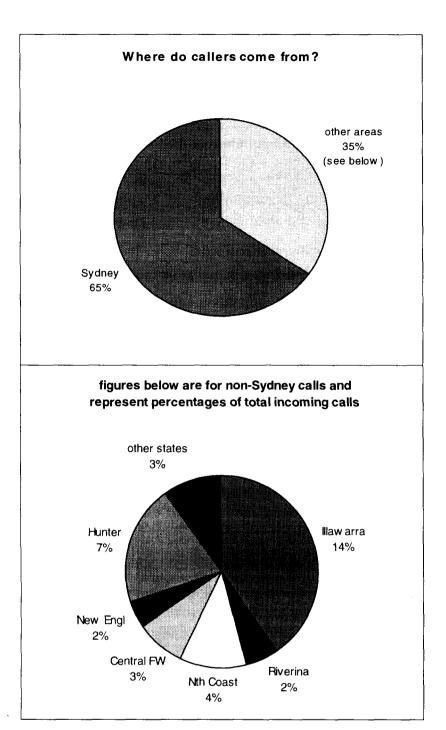
The most important aspect of our work is our Telephone Information and Support Service (TISS.) In December 1995 NSW Health announced an increase in funding to allow us to expand the service.

For most of the year this was operated by our team of 24 Sydney and regional based volunteers and trained office staff.

In July 1996, we brought the telephone service in-house to our Surry Hills office. This now allows regional NSW callers to phone a freecall 1800 line - Sydney callers phone a local number. During the service hours, callers speak directly to a trained TISS volunteer rather than hear a message telling them to phone someone else at their home.

From July 1995 to June 1996, we took 2,358 calls - an increase of 62% over the previous equivalent period. Of these, we referred 41% of callers on to other agencies or services, where a more specialised service was required.

It's clear that the need for further expansion is great. We'll monitor the expansion and changes that took place in July 1996, and assess what further growth is needed.



Public speaking, education and training

Staff, committee members and guest speakers presented 23 information and education sessions in 1995/6 including:

- Two training courses for our telephone information and support volunteers.
- Two CEIDA (Centre for Education and Information on Drugs and Alcohol) information updates.
- Public information meetings in Sydney, Newcastle and Nowra.
- Information briefings were also given at the Leichhardt Women's Community Health Centre, NUAA (NSW Users and AIDS Association,) Dept of Corrective Services, Albion Street HIV/AIDS Centre, HIV/AIDS Multicultural Centre, Sydney

annual report

Sexual Health Centre, Australian Traditional Medicine Society, Sex Workers Outreach Project, pharmacists and general health services, and a Sydney Institute of Technology welfare expo.

Council staff and committee members attended three conferences and seminars in the year. These ensured we were kept abreast of emerging hepatitis C developments.

HCC-NSW information and resource materials

During the year we developed two key resources - Hepatitis C: what you need to know, a detailed easy to understand booklet; and Hepatitis C: a brief introduction, our brochure that gives an overview of hepatitis C.

Both these resources cover prevention, care, treatment, self management and support information. The booklet is targeted for people with a keen interest in hepatitis C, with the brochure targeted at the general public.

These information resources are unique in NSW. They were launched by the NSW Minister for Health, Dr Andrew Refshauge, at a public meeting and media conference in February 1996. NSW Health has endorsed the booklet and will distribute it to medical practitioners and other health professionals in late 1996.

The NSW Dept of Corrective Services distributed 6,000 copies of *Hepatitis C: what you need to know*, to staff and inmates.

We sent out 4,400 detailed information packs (1,500 in 1994/95), and distributed 113,000 brochures, predominantly within NSW.

Our quarterly newsletter, *The Hep C Review*, with a print run of 3,000 covered a broad range of subjects - including drug and prison law reform, discrimination, interferon and complementary therapy treatment, lifestyle and self management, rural and national issues, and women's issues.

A widely read regular journal, *The Hep C Review* remained a source of support, contact and information for Council members, health professionals and the general public.

Two further **detailed information packs** were produced for healthcare workers, peer agencies

and other interested people, providing copies of research papers and the government's planned response to prevention and clinical needs



Pictured above, the NSW Minister for Health, Dr Andrew Refshauge, launches the new booklet: Hepatitis C what you need to know. Picture Phillip Rosz.

Representing the interests of people affected by hepatitis C

During the year, we made detailed submissions regarding the Australian Health Ministers Advisory Council's Education and Prevention Approach, and the National Health and Medical Research Council's Draft Strategy for the Detection and Management of Hepatitis C in Australia. We were also involved in the Commonwealth Dental Services Project.

We have full involvement in the Novel Hepatitides Working Party, a national group keeping a watch on developments of present and future hepatitis viruses. We also enjoy full involvement in the NSW Health's Hepatitis Advisory Committee, and had full input into the NSW Guidelines for Hepatitis C Infected Health Care Workers.

In December 1995 we met with **Dr Andrew Refshauge**, the NSW Minister for Health. At this meeting a funding enhancement for the Council was announced. Regular meetings with NSW and Federal health department officers have meant we've been able to keep them informed of community needs, and highlight the need for more resources.

In May, together with other hepatitis C Councils and AIVL, the national peak body representing people who inject drugs, we met with **Dr Michael Wooldridge**, the new Commonwealth Minister for Health and Family Services. We called for development of a national task force, a national peak body of hepatitis C community organisations, immediate implementation of recommendations coming from the National Hepatitis C Action Plan.

Together with the AIDS Council of NSW, the NSW Users and

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AIDS Association and other community groups we developed and launched *Prisons and Blood Borne Communicable Diseases: The Community View.* This community policy recommended major changes to practices in NSW prisons. Implementation of these recommendations remains an ongoing task.

A range of **TV**, **radio and newspaper interviews** and involvement by Council committee members, other volunteers and staff has kept HCV in the public eye. In 1995/96, the Council was actively involved in 35 media contacts. These led directly to 17 radio and TV and 18 printed articles on hepatitis C.

The Council lobbied, partially successfully, for changes in four main areas of **discrimination** - employment; delivery of health services particularly relating to pregnancy and breastfeeding; public identification of hospitalised people with hepatitis C; and in the delivery of funeral services.

Discrimination remains a huge problem, and one which will require much greater resources, law reform and community support to fight.

Casework and referral was carried out in the areas of employment discrimination, housing and medical service provision.

Working with peer agencies and health and welfare services

Through extensive networking, we've built up our ability to utilise professional and peer support from other services and key individuals. Regular liaison took place with:

Medical sector: gastroenterologists and hepatologists, the AGI and interferon prescribing hospitals, Divisions of General Practice, women's health centres, Kirketon Road Centre, Albion Street Centre, Aboriginal health services, blood banks, TRAIDS, ADIS, methadone clinics, NSEPs, Alcohol & Other Drug agencies, and peak natural therapy professional organisations.

NUAA: (NSW Users and AIDS Association) who along with NSEP and methadone services, help us outreach and network people who inject drugs and who have hepatitis C.

Government sector: Area Health Services, Public Health Units, Infected Healthcare Workers Advisory Committee, CEIDA, HIV and Health Promotions Unit. Also, the DSS, CES, DOCS and Dept of Corrective Services.

Community sector: hepatitis C councils across Australia, AIVL (Australian Intravenous League,) Haemophilia Foundation, ACON, AFAO, Homecare NSW and other HACC services, NCOSS, Gay and Lesbian Counselling Service, translation services, etc.

Legal services: community legal centres, Health Care Complaints Commission, Anti Discrimination Board, HREOC.

In May we took part in the **IDU Forum**, a national conference organised by the IDU organisations and the Commonwealth Dept of Health and Family Services. The forum led to better education and prevention services, and to improved care and support for those already affected.

We actively supported and were involved with two novel Sydney initiatives, in northern and eastern Sydney, to improve the care, treatment and support of people with hepatitis C. Once implemented and trialed, these **models of shared care** should be able to be used in other NSW areas.

Regional and metropolitan support

Regular monthly support groups continued in Newcastle, where the Council's first branch, the Hunter Branch, staffed entirely by volunteers and supported by Hunter Public Health Unit was established in March 1995.

Other less formal support groups met in Bathurst, Central Coast, Coonabarabran, Lismore, Orange, Tamworth, Upper Hunter, Wagga Wagga and Wollongong.

The demand for support and information groups in all areas of NSW was a constant call throughout the year. However without dedicated and adequate resourcing, this call was unable to be met.

One-to-one counselling was provided from the Sydney office for part of the year, but without financial resources this had to be discontinued.

Our human resources

Having voted to accept postal voting, Council members now enjoy a more democratic say in how the Council is run. Being a membership organisation this is important as we all rely on each other's contributions and involvement.

Our dedicated *volunteers*, the backbone of the Council, worked long and hard. Our sincere thanks go to you, our regional telephone information and support officers, our new and past TISS volunteers, our administration volunteers, our Hunter Branch Advisory Committee, the Hunter and other regional volunteers and Management Committee members and staff.

Our heartfelt thanks also go to those professionals in the health and

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welfare sector who actively go out of their way to offer practical help to the Council.

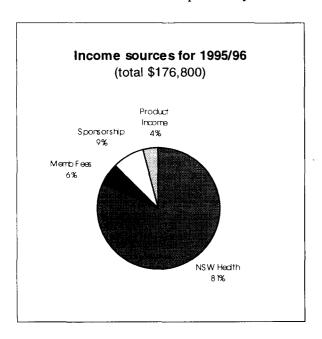
Thanks go to our **Management Committee**, a group of committed volunteers who provided overall direction and management of the operations of the Council.

Our Medical Advisory Panel provided information and expert advice on clinical and related matters. It comprises Professors Geoff Farrell, Bob Batey, Yvonne Cossart and Geoff McCaughan, and Drs Ingrid van Beek and Alex Wodak. Our sincere thanks go to them.

Finances

The Council performed well in the financial year to 30 June 1996. Although we carried over a financial surplus, in accounting terms we experienced an operating deficit of \$14,747 over the 12 month period. This was a positive result as we had been carrying a surplus from previous years. Our surplus arose as a result of late payments and consequent later expenditure of NSW Health Grant increases.

HCC-NSW income for the year was \$176,800, an increase of 50% over the previous year.

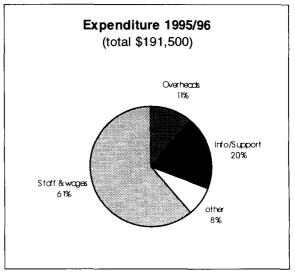


We gratefully acknowledge the support of NSW Health who fund us with a core operations annual grant.

Our sincere also thanks go to our members, sponsors and donors for your ongoing support.

Our expenditure over the year amounted to \$191,500.

Our capital purchase of new computer equipment and a new fax machine enables us to produce high quality information and resource materials and communicate more effectively.



Full financial reports are contained within the full Annual Report available from the HCC-NSW office. Our auditors, Bryan Rush and Co were reappointed at the 1994/95 AGM.

Our financial priority remains to secure a greater level of ongoing funding. This is essential to maintain existing services and expand our primary information and support provision. This is necessary if we are to meet the steadily increasing demand for our services.

The future

General areas of work in the coming year will include continuation and expansion of existing services, and..

- further building of links within state and national strategies regarding relevant health policies, primarily the 3rd HIV/AIDS strategy
- ongoing review and updating of current information resources
- expansion of the telephone information and support service to increase the service's response rate
- continuation of our call for coordinated, well resourced action, in particular, to call for full implementation of the National Action Plan
- increased liaison within GP and pharmacy network

and possible

- development of an education and training unit providing education and training service for health and welfare professionals
- employment of a policy development officer to promote and assist public/private sector organisations develop sound policies and procedures that relate to hepatitis C issues
- establishment of a Complementary Therapies Advisory Panel

Stuart Loveday, Executive Officer

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To Jana Wendt Witness Program Channel 7

Dear Jana,

I am writing to you concerning the backlash that I have copped from my family since your program sensationalized the hepatitis C virus.

Now I am living in a relationship with a woman and we have been together for about two and a half years.

We have a beautiful baby daughter and neither mother or daughter are HCV positive.

Thanks to your biased reporting, though, my sister's family have now banned my brother and I (we both are HCV+) from their house.

Your program scared the hell out of them.

They have known about this for some time and - until your program aired - I had convinced them they were under no danger unless it was through blood to blood contact. Which is unlikely because in general there would have to be an accident for this to happen.

But your program has got me barred from the house.

Your reporter asked me to go on the show and talk about the virus. Thank God I didn't because I can see that I would have been discriminated against.

People out in the community are none-thewiser for your reporting. They are only scared.

Certainly hep C is a problem, but you must remember that the people who don't know they have the virus are more dangerous than people like me who will tell people of my predicament so proper precautions can be taken when, for instance, I cut my hand or some other risk situation occurs. I really think you should have a look at the way you present Witness.

I am very disappointed at the standard of journalism in the program. Please do not fall into the habit of using fear tactics to get ratings.

We have seen enough of that in the Australian media as it is.

Yours sincerely

Kevin Willis



To Mr Kevin Willis

Dear Mr Willis

Thank you for your recent letter; we value feedback from viewers, even when it is critical.

I assure you that we did not set out to sensationalize the facts or to use fear tactics as you suggest.

We treated the subject - a difficult one to portray on television - with the seriousness it deserved, using information supplied by the Department of Health and various medical experts.

With respect, your sister seems to have misunderstood and over-reacted. We said, as you point out, that the only way of catching hepatitis C is through blood contact.

Your distress is regrettable, but I stand by our presentation.

Yours sincerely

Story Editor Witness

Writing stories for any type of newspaper or magazine should always involve finding the right "balance".

Amongst a whole range of issues, there are limitations on how much space or time you can devote to a story. There's also the challenge of attracting the attention of your reader or viewer.

Notwithstanding these considerations, journalists must always respect the power of the media to shape and define public opinion. Journalists must remember their moral and ethical responsibilities to provide <u>balanced</u> news. Ed.

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feature

Stress - the facts

Stress is an area in our life that we all need to keep under control. If stress is allowed to increase, unchecked, the impact on one's physical and mental health can be severe.

Some typical signs of stress are insomnia, headache, neck, shoulder and back pain, heart palpitations, fatigue, irritability, panic attacks, loss of concentration and low self esteem. There are a number of areas in our lives, though, where we can take action to control our levels of stress.

Pressure - the positive sides of stress

Stress is not necessarily always negative. Without the action of positive stress, many people would not attempt to reach their full potential. For example, competitive tension usually keeps a footballer or salesperson working to their best.

There is an optimal level of stress at which a person is likely to be most productive. Knowing one's particular stress level is useful.

Stress - the negatives

When pressure is continual and when the feeling that you are not in control stays with you over a long period of time, you're probably suffering the negative effects of stress. When this happens you'll feel overworked but will actually be contributing less and less.

Physically, pulse rate will increase, blood pressure will rise, perspiration increases and there is an increase in blood adrenalin levels.

Symptoms

You may feel irritable, anxious, nervous or fatigued. There is often a change in appetite and perhaps an increase in cigarette smoking or drinking alcohol.

Other symptoms may include diarrhoea, abdominal cramps, insomnia, trembling, urinary infrequency, increased heart rate and headaches

or backaches. As mentioned previously, palpitations, fatigue, irritability, panic attacks, loss of concentration and low self esteem may occur as well.

To date, surprisingly little long-term research has been done on the effects of stress - although it has been linked to ulcers, infertility, heart disease, mental illness and cancer.

Stress & lifestyle

Stress is a normal response to lifestyle and work, and the general challenges of living. A certain level of stress is fine and even necessary in order to be productive.

However, too much stress can be a health hazard. People need to learn to be aware of when their stress level is unhealthy. Once stress overload is recognised you can assess your current lifestyle, but there are skills you can use to address stress - see below.

Nutrition

When we experience stress and nervous tension, our bodies use up large amounts of nutrients (vitamins and minerals.) This can cause dietary deficiencies which in turn leave us tired, run down, irritable and less able to cope with stress - back to square one!

Nutrients which are particularly related to stress are Vitamin C, the B complex vitamins, and the minerals calcium, magnesium, phosphorus and zinc. These nutrients can be supplemented by eating healthy foods high in vitamin and mineral content, or by taking tablets or medicinal herbs.

Foods to avoid

Certain foods can cause nervous tension or can make it worse. Anything containing caffeine (coffee, tea, chocolate, cola) irritates the nervous system and interferes with with absorption of vitamins, especially vitamin C. Unfortunately, we often crave these foods when we are under stress because they appear to give a temporary lift.

Diet considerations

The best diet to cope with stress contains fresh wholesome foodslots of: fruit & vegetables, beans, lentils, bread & cereals; moderate amounts of: dairy foods, lean meat, skinless poultry, fish & nuts; and small amounts of oils and fats. Salt should be avoided.

Try to avoid convenience and take-away foods, tea, coffee, alcohol, sugar, cakes, biscuits, soft drinks and chocolate.

Counselling

We all live and interact with other people and often cope better with our problems and life stresses by talking and sharing our feelings with other people. This can be as simple as talking with a neighbour or friend over a glass of juice or mineral water [or writing a letter or story for your favourite newsletter.]

Some people may need to phone a friend or relative specifically to talk about a particular problem. Additionally, many people choose to go to a trained counsellor, social worker or therapist.

Acupuncture

Acupuncture has been shown to be a very effective treatment for various conditions as well as a stress management tool. It's best to see a qualified practitioner who belongs to a professional body - see page 25 for details.

Massage

Whether done by a trained professional or just a friend, a massage is a simple and inexpensive way of releasing tension from our bodies.

If done regularly, a massage can also make for a welcome break from a daily routine.

Meditation

Meditation is a technique that offers a structured way to reduce tension and stress. Although it may not provide an immediate release of stress, over time a meditation program will prepare you to handle physical and mental problems and recharge your system.

Structured exercise and concentration programs such Tai Chi and yoga are also very effective in reducing stress.

Choose your attitude

Take some control over the thoughts that go through your mind. We all have such thoughts, some of us more so than others.

Talk yourself out of repeating negative or unhelpful self thoughts. You will be surprised at how much difference this can make after a short period of time.

Relaxation

Relaxation can mean spending time at the beach or local park, doing hobbies or listening to your favourite music. The big obstacle to relaxation is physical tension. Relaxation is often the end result of stress management exercises such as those mentioned above.

Exercise

Physical exercise can often help to release tension and improves your overall level of health. The most helpful thing is to do exercise moderately and regularly.

Any physical exercise is helpful eg. jogging, swimming, gardening, playing team sports. If you have a particular health ailment [ie. hepatitis C], you may find it useful talking to your doctor about which sports may be most suitable.

Some tips to remember

- Be aware of physical and mental stress and recognise the signs.
- Stress is only a problem if it is excessive or if you are not handling it properly.
- You are not the only one who experiences the problems that lead to stress - such problems are a normal part of everyday life.
- Try not to make problems any bigger than they actually are
- Identify situations that are stressful for you deal with them or avoid them
- Practice relaxation techniques
- Find interests that really involve your concentration
- Plug into support networks formal or informal
- Set daily routines, giving yourself time for some of the above ideas
- Grow a garden and get a pet if practical
- Take regular time out
- Talk to others about your feelings
- Live in the present and not in the past
- Cultivate regular stillness and quietness in your life

For further information, contact the NSW Mental Health Information Service

02 9816 5688

Sydney callers

1800 674 200

NSW toll free

Compiled by the NSW Association for Mental Health from Strategies for Stress (Dr David Lake) & Coping with Stress (Leichhardt Women Health Centre)

book review

SICK & TIRED OF FEELING SICK AND TIRED: living with invisible chronic illness

By P Donohue & M Siegal (1994) Norton Publications \$20.95 Adyay Bookshop

Reviewed by Jeff Ward, reprinted from *Hep C News* Vol 1 Issue 4, newsletter of the Hepatitis C Council of QLD.

These two authors are psychologists based in Connecticut, USA. It was their dramatic title that lured me into my local bookshop.

Although this American book contains no specific information about hepatitis C, it does discuss comprehensively most of the wider philosophical approaches to managing chronic illness.

The authors present detailed informative chapters written in simple English. The style is not too scholarly which suits those of us bored with theory. This book is practical.

An interesting feature of the book is where it focuses on how our minds deal with illness - about about how we 'construct' our illness.

It proposes that particular attitudes and emotions we feel may be as important in managing chronic illness as the illness itself!

The book points out this is not a new idea. In the 1960's American matriarch Rose Kennedy is quoted, "it doesn't matter what happens to you in life, it only matters how you cope with it."

I found that some topics were especially interesting in regard to HCV. Chapters like forming and maintaining productive relationships with doctors; issues for your family, friends, colleagues; rational v. irrational thinking; using imagery; effective communication; stress management; and utilising health systems to your advantage.

Overall, quite a useful book.

The Liver Cleansing Diet

By Dr Sandra Cabot (1996) Australian Print Group, \$19.95

Reviewed by Prof Robert Batey

Literally dozens of people have mentioned "The Liver Cleansing Diet" to me as they come for advice on managing their hepatitis C. It was a pleasure to be able to review a copy of the book provided by the Hepatitis C Council of NSW.

There is no doubt that Dr Sandra Cabot has wide community acceptance for her 'liver cleansing' message. Reading the book, though, one is left a little anxious about the scientific basis of her message. I must say that coming to this book as a hepatologist, it is fascinating to even conceive of a diet or any other treatment which could lead to a "cleansing" of the liver. A definition of a "dirty liver" is not really provided in the book and I remain unconvinced at the end of the book that what is being provided actually leads to a cleaner liver.

Unfortunately the book lets itself down in its early chapters by pretending to provide a scientific basis for a low fat or lipid lowering diet for patients with liver disease. I'm not questioning the reality that many liver diseases are associated with fat accumulation in the liver - including hepatitis C. There is equally no doubt that by reducing the fat load in the liver, in some situations there is improvement in liver function. But this is not always the case and it is therefore unfair to presume that by lowering one's dietary fats, their liver will automatically function more effectively.

I have a concern that this book is claiming much more than has ever been proven for a "liver cleansing diet".

I find that many of the statements in the first few chapters are based on reasonable physiology or biochemistry, but some of Dr Cabot's throwaway lines are not so based. One such statement on page 42 was the bland suggestion that if a patient has severe liver disease, then liver transplant is the best solution to their problem. This is clearly not true for a vast number of patients with such a condition.

I am impressed by Dr Cabot's enthusiasm but am unimpressed with her amazement in realising after 20 years that the liver is a supreme metabolic factory which just needs attending to, to solve all liver problems. Most of us working with the liver are daily overawed by by the liver's capacity to undertake so many tasks and deal with so many problems associated with western diets. We are equally amazed at our own lack of understanding as to how the organ copes with disease and regeneration.

In summary, I would suggest that if people are looking for an interesting series of recipes that will lower their fat intake and provide tasty alternatives to their current diet, then this book is of value.

If someone is seeking clear non-personalised information on liver disease and the pathology of liver conditions, they should not buy this book.

Third National HIV/AIDS Strategy cont.

(Continued from page 1)

responsible for what, and the possible loss of identity, control and power over funding if AIDS funding is mainstreamed.

Ross O'Donoughue, Director of NSW Health's AIDS and Infectious Diseases Branch supported an expansion of the AIDS Strategy saying it made sense to build on our successes. He emphasised though that most cross-over occurred in the area of sexually transmitted diseases and not hepatitis C.

Ross added that "there is still the issue of how to cope with a diminishing budget."

He said that Commonwealth-State matched funding arrangements for HIV/AIDS were standing still. Importantly, he said there was a need for dedicated funding for hepatitis C.

Without funding support from the Commonwealth he foreshadowed priority setting that would lead to a piecemeal approach.

Don Baxter, Director of the AIDS Council of NSW spoke at the forum and specifically criticised the AIDS Strategy.

He said that the many of the gains in dealing with HIV made over the last few years were being placed at risk because of the major changes to the strategy.

He added "the new strategy must be more flexible. It creates confusion about politics and would lead to loss of HIV funding."

"The strategy threatens the goodwill, energy, responsibility and further involvement of our community."

Indeed, many community organisations dealing with HIV/AIDS warned that unless the strategy was substantially restructured, they would condemn it as inadequate.

Following are some excerpts from the formal written response hurriedly put together by the Council recently.

In our submission, we support the expansion of particular HIV projects, where appropriate, to enable them to address HCV work.

These include:

- * prevention initiatives (NSEP etc)
- * surveillance, epidemiology and social research
- legal and social justice initiatives
- * international assistance and cooperation

An Introduction:

In principle, we support the broader role intended in the draft strategy because in some areas common strategies can address common goals. The draft strategy has the potential to build on the strengths of strategic approaches used in the past and lend these to a hepatitis C strategy.

We note that the Commonwealth Department of Health and Family Services (CDHFS) has clarified that the Third National HIV/AIDS Strategy 1996-97 to 2000-01 (NAS) is not a hepatitis <u>C strategy</u>.

This is also clear from the draft, where in various places HCV has been amended into sections that relate to HIV. For example, within the National HIV/AIDS Strategy, twelve pages outline the history of the HIV epidemic whereas only one paragraph is given to outlining the HCV epidemic.

Senior CDHFS representatives have confirmed that the draft strategy is not intended to deal at all with HCV care, treatment and support.

Indeed, the draft strategy does not mention that hepatitis C is a liver disease and that essential aspects of clinical services and patient management involve hepatology.

We realise that if the National HIV/AIDS Strategy were intended to address hepatitis C, the HCV epidemic being more widespread would have been given equal if not greater prominence and that specific recommendations would have been made for HCV control, care, treatment and support.

Following are the final summary points taken from our six page submission.

- The draft strategy is not intended as a hepatitis C strategy. In regard to treatment, care, information and support needs of people affected by hepatitis C we continue to look to the National Hepatitis C Action Plan.
- We call for the National Hepatitis C Action Plan to be remodelled into a clear National Hepatitis C Strategy, with adequate resourcing plans for its implementation to be identified and approved.

(Continued on page 22)

(Continued from page 21)

- We call for the establishment of an independent National Hepatitis C Taskforce, responsible directly to the Minister for Health and Family Services and charged with overseeing the effective implementation of a National Hepatitis C Strategy.
- We accept that people with HCV and the affected community have clear roles and responsibilities within the hepatitis C response. We are concerned that the **CDHFS** remains unwilling acknowledge the partnership. We seek to develop an effective and coordinated community response through a funded peak body of hepatitis C community organisations and IDU community groups. Without such a mechanism, adequate community consultation and involvement will not take place. What is more important for the communities affected is a real ongoing partnership with Commonwealth health State and authorities.
- In the event of a National Hepatitis C Taskforce not being implemented, we urge that the remit of ANCA/MAC be restructured to ensure the body deals equitably and fully with HCV. Such a restructured body must be able to oversee a resourced implementation, review and evaluation of the National Hepatitis C Action Plan and its ancillary policies and strategies.
- Our biggest concern is that there will not be adequate financial resourcing to ensure an effective HCV response. In an overwhelming majority of cases, HCV causes chronic illness. The long term nature of the disease, coupled with alarming prevalence and incidence, means that without effective action now, no medium to long term response will ever be sufficient.

For a complete copy of our submission, please phone the office.

That Hospital

written by Loudon Wainwright III published by Snowden Music (ASCAP)

Steve Little Bucky Hurdman Pat O'Boyle and me Drank 2 cases of beer one night the VW hit a tree Bucky wound up in the emergency room this was '64 or 5 Well I hear he's livin' in Florida now lucky to be alive

That hospital

My dad freaked out and he wound up there one Christmas way back when

I remember goin' to see him he was my age now back then
I kept starin' outta that window I could not look in his face
He said, I won't be home for Christmas son
You're gonna have to take my place.

That hospital

I was there again in '76 the wife was havin' a D and C

But in the end she couldn't go through with it so three left, she and me

And that little girl who was born there and who escaped that scrape with fate

A few months ago in Montreal I watched her graduate

That hospital

Yeah my sister was born in that hospital too and now my mother's in there

I took the train to see her, Lord and I sat in that visitor's chair

Mother was angry so afraid this was not a blessed event

Now I'm ridin' back on that train wonderin' where our lives went

That hospital

Yeah I could wind up in there maybe so could you
Anything can happen when there's nothin' we can do
And if you come to see me Lord and you sit in that visitor's chair
Take somethin' home from that gift shop so you'll have a souvenir

From that hospital

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The Hep C Review edition 15 October 1996

PH

Consenting to Treatment

What does it mean when you agree to take a drug or try a particular treatment? What are your legal rights? What should you know about the treatment?

Before you're given any treatment it's required that you give your consent one way or another. This protects you against drugs, remedies or procedures that you don't want - many Australians remember the tragic consequences of Chelmsford deep sleep therapy.

The need for consent also helps ensure that people are given as much information as possible about treatments. In addition, consent can legally protect health care providers if things go wrong.

Laws in all States/Territories say that before any medical treatment is given, people must give valid *consent*.

Anyone who treats you without getting that consent could be charged with assault and battery. Consent doesn't have to be given verbally or in writing however. Sometimes consent can be implied, for example by holding your arm out for an injection to be given or by not actually objecting.

There are exceptions to this general rule. For example, any emergency treatment that is necessary to save your life or prevent serious injury to your health can be given without formal consent.

What is a valid consent?

Generally, once information has been given in broad terms about a treatment and you consent on the basis of that information then that is valid consent.

But there are three important aspects to consent:

Consent must be 'informed'

For consent to be informed, you must be given enough information about a treatment for you to make a proper choice about whether to take it or not.

Where there is some risk of a complication which could have a serious effect on the quality of your life, then information about that risk should be given. Health Care providers must tell you of any risk which you should reasonably know. If they know you would be particularly concerned about certain kinds of risks, then they have to tell you about those risks. If by your questioning you show that you want to know all likely risks, they have to tell you.

In Australia you don't have the right to sue a doctor if you've consented to treatment on broad terms without knowing all the details about the treatment. So, when offered a treatment, it's vital to ask all the questions you want. The doctor must answer those questions to the best of their knowledge.

Consent must be voluntary

If there is some type of coercion attached to obtaining consent, it is not valid consent. Where there is psychological pressure to agree with what medical staff want or not enough time given to decide, it is not valid consent.

Consent has to cover the treatment

If you have agreed to drug A, they can't throw in drug B without getting you to agree to that too.

Getting the right information:

- helps you make an informed decision whether to take a drug or herbal treatment
- lets you know what to avoid doing or taking while on treatment
- helps you understand what the treatment or remedy is meant to do - this helps you monitor yourself for success
- helps you monitor side effects etc.
- helps you to use the treatment or remedy safely

8

Adapted from an article by Paul van Reyk in the HIV Herald, March 1996.

regular feature - interferon

interferon what you may need to know

Interferon is provided for free 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.

The course of treatment involves giving yourself an injection three times a week. Currently, the treatment is given for 6 months.

If your ALT readings don't come down after 3 months, the treatment ceases to become available for free under the PBS. To continue at your own expense, 3 months supply would cost around \$1,500.

Treatment Centre facilities

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

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

- a nurse educator / counsellor for patients
- 24 hour access to medical advice for patients
- an established outpatient liver clinic
- facilities to perform safe liver biopsy.

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.

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.

Treatment centres

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

Side effects

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

Benefits

Currently, around one in four people with hepatitis C who undertake Interferon treatment achieve what is called a long-term remission.

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

regular feature - natural therapies

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, its important to remember that wrongly prescribed medicines can be harmful.

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

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

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

Costs

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

Choosing a practitioner

If you decide to use natural therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well experienced.

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

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

Healthy herbs?

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

In regard to hepatitis, 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.

A recent trial of one particular Chinese herbal preparation has shown positive benefits and few side effects (see page 6.)

Want more information?

For more detailed information on natural therapies, please contact any of the following organisations:

| Australian Acupuncture Association | ① | 1800 025 334 |
|---|----------|--------------|
| Australian Homoeopathic Assoc | 1 | 02 9415 3928 |
| Australian Natural Therapists Assoc | 1 | 1800 817 577 |
| Australian Traditional Medicine Society | 1 | 02 9809 6800 |
| Association of Remedial Masseurs | 1 | 02 9807 4769 |
| Homoeopathic Assoc of NSW | 1 | 02 9231 3322 |
| National Herbalists Assoc of Australia | 1 | 02 9211 6437 |
| Register of Trad. Chinese Medicine | 1 | 02 9660 7708 |

Referral?

We are in the process of putting together a referral database for various healthcare workers - natural therapists included. This remains an ongoing task. Callers would need to phone our info & support line (see page 2 for contact details.)

regular feature - support services

Sydney Metro Region

There aren't many local support services available in the Sydney region. This isn't because there's no great need for 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 aimed at the general community - including you and me.

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

line **3** 9332 1599 (Sydney)

D 1800 803 990 (NSW)

If you'd prefer face-to-face counselling on a one-to-one basis, speak to your doctor or shop around yourself for such 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

Following, is a list of contact numbers. They are either for hepatitis C support groups (SG) that have been set up by people in local areas, or for local agencies offering support. Please phone these contacts during business hours:

Newcastle:

Leone - 049 47 1206 (SG)

Muswellbrook:

Gary - 065 43 2677

Orange:

Phil - 063 61 7455

Dubbo:

Nick - 068 82 8765

Bathurst: Lismore: Christine - 063 31 5584

Coonabarrabran: Gary - 068 42 2507

Robyn - 066 22 1555

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om, 000 /2 200/

Bowral:

Noelle - 015 491 512

Existing general services

Sexual Health Clinics

Although hepatitis C is not 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, blood tests, emotional counselling and primary healthcare (the type of healthcare 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 / Neighbourhood Centres

These centres exist in most towns and suburbs. They provide many different services including counselling and crisis intervention or information on local health and welfare agencies. Some also run a range of support and discussion groups for different groups of people. Activities ranging from archery to yoga are sometimes offered as well.

Community Health or Neighbourhood Centres can be found by looking in your white pages - under *community centres* - or by phoning the Hep C Information & Support Line. Also look up your local Council in the phone book for a listing of their community services.

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

Family counselling

Having to deal with symptoms, or fears about family members catching hepatitis C can sometimes 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 our more, contact Family Planning, local GPs or community centres. The Info & Support Line may also be able to assist.

O

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 admin phone number is 02 9332 1853 and our fax number is 02 9332 1730.

| Hep C - a brief introduction | | |
|-------------------------------------|--|-----------------------|
| 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. | |
| Newsletter | Topics include Social Security, Disability Support Pension, Interferon treatment, natural | no cost |
| back issue pack | therapies, history of the Council/Support Group | |
| Video No.1 | Prof Geoff Farrell discussing Interferon treatment, & Jennifer Holmes discussing women & hep C. | \$3.00 return postage |
| Video No.2 | Video No.2 Ken D'Aran discussing homoeopathy, & Raymond Khoury discussing herbalism. | |
| 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 |

Hep C Review Classifieds

Anybody wanting to come private transport - So if you want to meet along to a Sunday lunch motorbikes and cars. some other Council at picturesque St Albans If you have room for members, give us a call (north of Windsor) please someone in your car or and come along. phone Paul on 9332 1853. on your motorbike, It's going to be held on please let me know.

Sunday 24 November. Of course, Your family classified? Just phone We'll be travelling by and friends are welcome. the office.

The new Management Committee for the year, September 1996 to 1997, comprises 9 newly elected members:

Cheryl Burman, President (re-elected)
Jennifer Holmes, v President (re-elected)
Robert Tinsey, Secretary
Helen Daley, Treasurer
Patricia McLoughlin

Bernard Fischer (re-elected)

Anita Long (re-elected)
Leone Robertshaw (re-elected)
Jan Cregan.

And 2 seconded members comprising:

Stuart Loveday (Council Executive Officer) and Don Griffin (re-appointed)

If you are interested in finding out more about the committee and how it works, phone the office.

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8. Declaration.

Signed

MEMBERSHIP FORM

Please complete as much of this form as possible. Our policy is to respect your privacy. All details on this from 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:

| 1. Please complete either a, b <u>or</u> c. | | | Hepatitis C Council of NSW PO Box 432 Darlinghurst NSW 2010 | | | |
|---|---|--|---|---|------------|--|
| a. For people a | ffected by hep C, or other interested peop | i.a. I | | Hepatitis C Council o | | |
| Name | | · | | · | | |
| Street address | | 2. If you can h | elp with | any of the activitie | s | |
| Suburb / Town | | | | ick the following bo | | |
| State | Postcode | Admin and office | ce work? | > | | |
| hm phone | Wk phone | Other? | | | | |
| b. For individua | al healthcare or welfare professionals. | | | | | |
| Name | | | ewal, or | are you a new mem | ber? | |
| Occupation | | Renewal | | New member | | |
| Postal address | | | | | | |
| | | Membership fee | s are due | nembership fee box. e annually on 1 March. ' | <i>N</i> e | |
| Wk phone | Wk fax | welcome a full y financial hardshi | ear's pay p to prev | ment but would not war ent you from becoming | nt a | |
| Mobile phone | Email | | . If this is | the case, please circle | | |
| c. For agencies | s, companies and organisations. | | \$25 | Professional | \$40 | |
| Organisational | | Waged | \$≥5 | healthcare worker | \$40 | |
| name | | Concession | \$10 | | \$50 | |
| Contact person | | 7 | - 00 | organisation | + | |
| Position | | Zero Fee | \$0 | Public/Private secto organisation | r \$70 | |
| Postal address | | | | | | |
| | | 5. Separate do | | | | |
| Wk phone | Wk fax | accepted by the Council. These are tax deductible. If you make a | | | | |
| Mobile phone | Email | separate donation amount here. | on, please | e record the | | |
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| 6. If paying by o | credit card, please complete this section. | Card type (please circle) | Maste | ercard Visa Bar | kcard | |
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| Cardholder's signa | ture | Cardholder's full name | | | | |
| | re us to send your receipt? Membership for receipts are not normally sent. If you want us | | | | • · · | |

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|---------------------|---------------|-------------|-------------|--------------|------------|-----------|
| for office use only | | | | | | |
| staff initials | | | | | | |

I accept the the objects and rules of the Hepatitis C Council of NSW and apply for membership of the Council.

Dated