The Hep C Review

Autumn Edition March 2000 Edition 28

Decline in HCV prevalence

New hepatitis C infections among people who inject illicit drugs have declined by almost 20% in the past five years, according to a national survey of those attending needle and syringe programs.

Prevalence of the virus has decreased from 63 per cent of people who used the programs in 1995, to 50 per cent in 1997.

Among people who had been injecting opiates for fewer than three years, infection rates have dropped from about 70 per cent in the late 1980s to 20 per cent.

In addition, the number of people sharing needles and syringes in the preceding month halved between 1995 and 1997, according to a survey of about 20 needle and syringe programs published in the latest Medical Journal of Australia.

The survey by leading communicable disease researchers provides results from the first three years of a national system set up to monitor hepatitis C infections among people who use needle and syringe programs.

Some 979 clients were surveyed in 1995, 1463 were surveyed in 1996 and 1699 were surveyed in 1997.

The results provide further evidence of the benefits of the, at times controversial, needle and syringe programs that are central to the harm reduction approach adopted nationally in 1985.

An extensive network of needle and syringe programs has been set up around Australia. In 1994-95, about 700 programs distributed 6 million syringes while pharmacists distributed another 4 million.

The researchers, led by Margaret MacDonald, at the National Centre for HIV Epidemiology and Clinical Research in Sydney, say the survey suggests prevention efforts encompassing education, drug treatment and needle programs need to be enhanced to improve consistency and coverage.

- By Belinda Hickman. Taken with thanks from the Australian newspaper, 17/01/00.

Hep C awareness campaign draws near

The NSW Health Department will be conducting a significant new public awareness, health promotion campaign targeting hepatitis C in partnership with a range of government and non-government organisations during March and April of 2000.

The NSW Health Hepatitis C Public Awareness Campaign includes a statewide television advertising campaign and represents a significant step forward in dealing with hepatitis C.

The campaign will target the complex issues of increasing awareness of hepatitis C, reducing misinformation and creating an environment supportive for hepatitis C prevention programs using social marketing techniques.

It is hoped that the campaign will also encourage people concerned about hepatitis C to seek advice and where appropriate testing from their local General Practitioner.

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Preventing hepatitis C virus transmission in Australians who inject drugs

Prevention, through harm minimisation, remains preferable to cure

This editorial was written for the *Medical Journal of Australia* and abridged for *The Hep C Review.*

Hepatitis C virus (HCV) infection is an uncontrolled epidemic in both the developed and the developing world. However, it is only in the developed world where average life expectancy is long enough to be influenced by the *sequelae* (outcome) of HCV infection. The disease is very slowly progressive, and causes cirrhosis in approximately 15% of infected people over two or more decades; in approximately half of these cases, it then causes *hepatic decompensation* (see below) or *hepatocellular carcinoma* (cancer of the liver) over another one or two decades.

Most people currently dying of HCV infection in Australia are middle-aged or elderly immigrants from Southern Europe, the Middle East and Asia. To date, 31.3% of liver transplants performed for hepatitis C infection in Australia and 52.4% of hepatocellular carcinomas diagnosed in people with HCV infection in Victoria have been in this group. These people have acquired the infection in their country of birth from cultural practices involving skin penetration, or medical interventions, including injections.

However, current transmission of HCV infection in Australia is occurring largely within the culture of injecting drug use. Although the risk of transmission by an individual needlestick is not high (up to 6.1%), the high prevalence of HCV infection among users, the frequency of injecting and the practices used have established a self-perpetuating system of transmission. Thus, it is likely that the future disease burden of hepatitis C-related illness in Australia will be carried largely by current or past injecting drug users.

In the Medical Journal of Australia (see below), MacDonald et al examine the influence of harm reduction programs by measuring *seroprevalence* (current levels) of HCV in people who attended a cross-section of needle and syringe exchange programs throughout Australia in 1995, 1996 and 1997. Their findings, which show that seroprevalence fell from 63% in 1995 to 50% in 1997, are encouraging. There may have been selection bias, but, if one assumes that this bias applies equally to all three years studied, there has been a 21% reduction in seroprevalence during that time. The results were even more striking in recent users, in whom there has been a 41 % reduction.

"Maintenance and expansion of needle and syringe programs will remain the single most important component of Australia's harm minimisation efforts"

For some reason there was no additional reduction between 1996 and 1997. Does this mean the effect of harm reduction programs has plateaued? That there is a limit to their efficacy? That only a certain proportion of users can be influenced by education programs? While further studies are needed over the next two or three years to clarify this, these data strongly support the need for ongoing efforts at harm reduction and maintenance of needle and syringe exchange programs.

Can we do more to reduce seroprevalence of HCV in people who inject drugs? There has been a great deal of debate in the public domain about the various prevention and treatment strategies for drug dependency. There is little to add, except to emphasise the need for continuing support services and harm-minimisation programs for those people who decide to embark on or continue with an injecting drug habit. Such support includes widespread

availability of needle and syringe exchange programs and ready access to counselling and education facilities. Education includes strategies for primary and secondary prevention of injecting drug use, including diverting users to non-injecting routes of drug administration.

Does antiviral treatment have anything to offer as a strategy to prevent transmission? The combination of interferon alfa and ribavirin has now become the benchmark for treatment of HCV infection, with a long term response rate of over 40% - double that of interferon alfa monotherapy. As the marker of response (the polymerase chain reaction test for viral RNA) measures viraemia, it can be assumed that those who "respond" are not infectious. It is expected that the combination therapy will be licensed for treatment-naive patients in Australia in 2000. Currently, combination treatment is licensed under section 100 (s100) of the National Health Act 1953 (Cwlth) for people who have relapsed after interferon alfa monotherapy.

With a response rate of over 40%, should we not be using this treatment in injecting drug users? The current s100 criteria for interferon alfa do not preclude treatment of current injecting drug users. However, there are three major potential problems which lead to caution in liver clinics.

Firstly, there is the risk of reinfection: an injecting drug user needs to use scrupulous technique 100% of the time in order to avoid reinfection.

Secondly, there is the risk of serious psychiatric effects with interferon alfa (psychotic reactions, cognitive impairment, severe depression including suicide attempts, and homicidal ideation), with suicides having occurred in Australia and overseas. Psychiatric reactions are more common in people with pre-existing psychological problems, chaotic lifestyles and those who lack social networks and supports. Interferon alfa can cause recidivism to injecting drugs, particularly in recent users, and this recidivism has been associated with major psychiatric problems. Unfortunately, funding for interferon in Australia has not been tied to any funding for counselling or psychiatric services.

Thirdly, the other drug, ribavirin, is clearly *teratogenic* (able to cause birth defects) at low dose in all animal species studied, and can potentially cause *embryotoxicity* (damage to embryo) from either male or female parents.

Additionally, ribavirin may be present in semen and cause teratogenicity in a woman already pregnant. It has a large volume of distribution and a long half-life. Thus, people contemplating a course of ribavirin must be counselled about contraception - both men and women must make sure no pregnancies occur during treatment and for six months afterwards, and additionally there should be no unprotected intercourse with a woman already pregnant. The product information for ribavirin advises two separate methods of contraception, one for the male and one for the female of a partnership.

Clearly, at this stage, antiviral treatment cannot be safely advocated as a widespread public health method of reducing transmission of HCV in people who inject drugs. As a general rule it is safer to defer treatment until individuals have stopped injecting drugs for a long time, particularly as the rate of progression of HCV-related liver disease is so slow. While antiviral treatment may then be effective in clearing virus in those who have stopped injecting, it will have no effect on transmission, as these individuals are no longer part of the injecting population.

The emphasis must therefore remain on concerted efforts to reduce the number of Australians who inject drugs, to provide support during this period in their lives, to reduce the number of times they actually inject, and to promote a safe, "self defence" injecting technique with every injection. Maintenance and expansion of needle and syringe exchange programs will remain the single most important component of Australia's harm-minimisation efforts. Adherence to the principles of harm minimisation is the only way to control this epidemic until a vaccine becomes available - and this is unlikely to occur within a decade.

• Katrina J R Watson
Deputy Director, Department of Gastroenterology
St Vincent's Hospital, Melbourne, VIC

(Abridged from the referenced original) Watson, K. **Preventing hepatitis C virus transmission in Australians who inject drugs.** MJA 2000; 172: 55-56 ©Copyright 2000. *The Medical Journal of Australia* - reproduced with permission.

*** Decompensated cirrhosis:**
Our livers can often endure a certain amount of *cirrhosis* (scarring of liver cells) before their ability to carry out their normal functions is affected. The term 'decompensated cirrhosis' refers to when level of damage has started to interfere with the liver's ability to function properly (as shown by blood tests like albumin, prothombin and bilirubin) and is causing severe illness (weight loss, fluid retention, stomach swelling, bleeding problems) ... Ed.

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The Hepatitis C Council is an independent, community-based, non-profit membership organisation. We provide information and support to people affected by hepatitis C and assist in preventing further spread of the hepatitis C virus. We are primarily funded by NSW Health.

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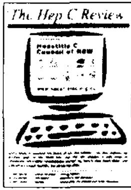


Disinfecting against HCV?

I refer to a research update "disinfecting against HCV" in *The Hep C Review*, Edition 27, December 1999.

In this article it is stated that *"until clear Australian guidelines emerge for effective chemical de-contamination of blood contaminated medical equipment, heat sterilisation through autoclaving is recommended"*.

This statement is incorrect. NSW Health, the National Health and Medical Research Council and Standards Australia have clear guidelines on the disinfection and sterilization of medical equipment.

In NSW, health care workers are required to use disinfectants and sterilizing agents specified in the Australian Register of Therapeutic Goods. The type of processing for an item depends on its intended use. In general, items that touch only intact skin need only be cleaned by a neutral detergent.

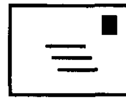
However, items that come into contact with non-sterile tissue (other than intact skin) must be disinfected before use. Disinfection must be achieved by either thermal or chemical methods. Currently, glutaraldehye is the disinfectant most widely used for high-level disinfection for reusable items.

Further, any equipment used to enter sterile tissue must be sterilized before use. Sterilization of equipment can be achieved by a number of methods of sterilization including autoclaving.

Persons requiring further information on medical disinfection and sterilization should contact the NSW Infection Control Resource Centre on 02 9332 1090.

Yours sincerely
Kim Stewart
A/Director, AIDS & Infectious Diseases Unit

[Many thanks to NSW Health for clarifying this situation ... Ed.]



Share it round

In response to the statement that you should not donate blood, blood products, semen or organs (*Hepatitis C and* disclosure, Ed 27, P16), I'd like to point out that forward-thinking organ transplant centers here in the United States are rethinking excluding hep C patients from donating organs.

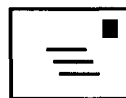
A person with a recent diagnosis of hep C who is otherwise in excellent health may be the donor of a heart to someone who has well-compensated hep C but is in imminent danger of dying from heart disease.

However, a person who has hep C and received a liver transplant is no longer considered a potential organ donor as there would be complications resulting from the immunosuppression medications.

Regards

Tim H - hepper and liver transplant recipient.

[Thanks Tim - given that Australia enjoys one of the poorest organ donation rates of 'developed' nations, your comments make good sense ... Ed.]



High Court hijinks

Happy New Year to you and all at the Council.

I've forwarded a summary of the recent High Court decision in "X" v. Commonwealth about discrimination/armed forces/HIV. As you know, the armed forces policy, the subject of debate in the case, extends to personnel with hep C.

The summary should not be considered as having any authority beyond that given to a personal point of view on the decision.

Wishing you all the best at the Council.

Douglas Barry.

[Douglas's summary provides a very detailed legal analysis of the case. Interested readers can contact the office for a full copy. Also see the news item on page 7 ... Ed.]

Interferon under spotlight

Happy New Year, Happy Ramadan etc.

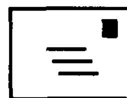
Thank you for your excellent magazine which continues to be an invaluable resource for workers in the sector as well as Positive people.

I am attaching an article I have drafted in consultation with Professor Stephen Locarnini. It seems that Interferon (including in its Rebetron form) is being used in a way which does not meet basic therapeutic standards.

I hope you will be able to run it in the next issue of the *Hep C Review.*

Mary Burns - Hepatitis C Helpline Coordinator (Victoria)

[See article on this topic, page 15, and Mary's article on page 23 ... Ed.]



Stories that heal

Hi to everyone at the Hep C Council. I would like to let readers know of a good book that I've just read - "Kitchen Table Wisdom, Stories That Heal" by Rachel Naomi Remen, M.D. (Pan Macmillan).

For people with or without an illness, it's quite illuminating. You probably need to order it in from your local book shop but it is well worth it.

All the best, Kay.

Did you know?

Scientists at Schering-Plough (USA) were the first to 'discover' an organism by detecting its genetic makeup as found within samples of infected blood.

The corporation went on to *patent* (register an invention) HCV's genetic structure. This was the first time ever that a living organism has been 'patented'.

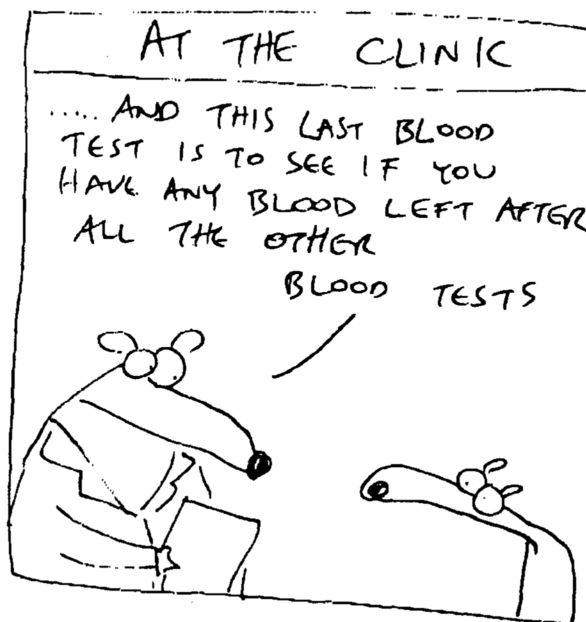
Pill problems?

My doctor recommended me against using the oral contraceptive pill. Instead, I now use something called a 'Mirena'.

It's a slow release hormonal IUD. Unfortunately, it's not covered on Medicare, but after the initial cost I don't have to think about it for ages!

If you're having problems, this may be good news for you too.

Regards - Fiona



Hepatitis C

NSW Directory of Education Resources

NSW HEALTH

Directory of hep C resources now available

Hepatitis C NSW Directory of Education Resources, a directory designed for those working in NSW within a broad range of health related fields, is a quick and easy reference guide for accessing available resources on hepatitis C.

It is an outcome of the NSW Health Hepatitis C Education Resources Project which was funded by the Commonwealth Department of Health and Aged Care and undertaken by CEIDA (the Centre for Education and Information on Drugs and Alcohol).

An audit of hepatitis C resources through surveys and consultations with workers in NSW assisted in identifying useful hepatitis C resources in a range of formats - including pamphlets, books, posters, videos, manuals and comics. In addition to these, the directory also includes unique resources from other states/territories and a range of national and international websites.

The directory has been widely distributed in print form to organisations working with hepatitis C issues throughout NSW. A dynamic, searchable and up to date version is available on the internet <http://www.ceida.net.au/hepc/index.htm>, providing an opportunity for workers to provide feedback and advise of changes and additions. The directory will also be viewable online via the NSW Health website at www.health.nsw.gov.au and will be linked with the Hepatitis C Council NSW website at www.hepatitisc.org.au.

For a limited time, those in NSW working with hepatitis C issues can obtain copies of the print version from CEIDA by phoning 02 9818 0444 (or fax 02 9818 0441).

Other readers can access a copy by phoning the office on 9332 1853.

Studies bring warnings about a popular herb

New York Times

Results of two new studies suggest that St. John's Wort, a popular herb for depression and anxiety treatment, can interfere with both an AIDS drug and a drug used for transplant recipients.

The herb may affect the protease inhibitor indinavir, which is sold under the name Crixivan, by causing levels of drug in the blood to drop "dramatically," according to Dr. Stephen Piscitelli of the National Institutes of Health. This could allow HIV to strengthen or develop resistance.

In the second study, researchers from University Hospital in Zurich report that St. John's Wort could conflict with cyclosporine, a drug that helps prevent organ rejection in transplant recipients.

- Taken with thanks from the internet email list, HEPV-L.

Ban on positive soldier

By Andrew Shaw

Concerns have been raised over a decision of the High Court which allowed the Australian Defence Force to dismiss an HIV positive army entrant because in a combat situation he could not bleed safely.

In 1993, the Australian Defence Force (ADF) dismissed the soldier, known as "X", on the basis of this risk. X lodged a complaint with the Human Rights and Equal Opportunity Commission (HREOC), which found that his dismissal was unlawful. The Commonwealth appealed the decision to the Federal Court. In response to the Federal Court's findings, X subsequently appealed to the High Court.

However, a majority of the High Court recently held that the proceedings must be remitted back to HREOC on the basis that the Commission must take into account whether the risk the soldier posed interfered with his ability to fulfil the "inherent requirements" of a soldier's job.

However, in his dissenting judgment, Justice Kirby said that the matter should simply be remitted back to the Commission for a determination of relief on X's behalf. He was critical of the exclusion of the soldier on the grounds of his HIV status, noting in particular, the presence of anti-discrimination legislation in Australia along with drawing a comparison with other countries where defence forces could not discharge HIV positive personnel.

"Decision-makers in this country should be as firm and principled in the application of such legislation as their counterparts in other civilised countries have been with their laws," Kirby said.

Rodney Croome, the co-conveyor of the Australian Council for Lesbian and Gay Rights also disagreed with the majority decision, saying that it was "obviously made on the basis of prejudice and not common sense."

He said that it was absurd for the ADF to claim that an appropriate position could not be found for HIV positive soldiers, which eliminated the risk of transmission. He gave the example of the police force, where HIV positive officers are allowed to serve. "The police force deals with the matter sensibly, given that there is perhaps a greater risk of transmission here than in the military, given that we are not at war."

- Taken with thanks from *Capital Q Weekly*, 10/12/99..

  [ADF recruits are counselled during induction about the possibility of dismissal if they test positive for various health conditions. Currently serving ADF personnel are not summarily dismissed if found to be HCV positive. Certain options are open to them, of which we shall report in our next edition .. Ed.]

Health advice book

A new book, *Smart Health Choices*, looks at how consumers can make informed health decisions, whether you are considering taking vitamins or having surgery. It is written by Judy Irwig and Les Irwig (Professor of Epidemiology at the University of Sydney) and journalist, Melissa Sweet. The publisher is Allen and Unwin and the recommended retail price is $17.95.

- Taken with thanks from *healthUPdate*, Dec 1999.

Women & hep C study

Little is known about the personal, social and health needs of women who are living with hepatitis C in our community. The Women Living with Hepatitis C study, being conducted at Deakin University and Australian National University, aims to explore these issues so that we will have a better understanding of how hepatitis C impacts on the lives of women.

The study will involve surveying 600 women in both Melbourne and Canberra regions, and asking them about their experiences as women living with hepatitis C. This study is completely anonymous and participation is voluntary.

The results from this study will give important information about developing better strategies and services to ensure that education, support and care services meet the needs of women living with hepatitis C.

The principal investigators of this project are Professor Sandy Gifford, School of Health Sciences, Deakin University and Dr Gabriel Bammer, National Centre for Epidemiology and Population Health, Australian National University, Canberra. Professor Gifford and Dr Bammer lead a team of multi-skilled investigators who are experienced in women's health research, and some of whom are themselves living with Hepatitis C.

Anti-Oxidants may delay combo therapy related anemia

A recent study has suggested that people on hepatitis C combination therapy who took the antioxidant vitamins C and E delayed the onset of anemia. *Hemolytic anemia* (blood disorder resulting from destruction of red blood cells) is a serious side effect of combination therapy, attributable to the ribavirin component in the combination. This complication necessitates a reduction in the ribavirin dose for about 15% of all people, according to Edward Piken, M.D., Director of Research at South Bay Gastroenterology in Torrance, California.

"When patients become anemic, they feel short of breath, become weaker, are unable to do their normal workload," Dr. Piken says.

One hypothesis is that ribavirin accumulates in red blood cells. "Because of the medications, the red blood cells are under what's called an oxidative stress, and they break down at an earlier point in their life cycle."

To investigate a solution to this problem, Dr. Piken enrolled 12 previously untreated HCV patients in a study to look at the effects of antioxidant vitamins on anemia. Patients received 1,200 milligrams of ribavirin daily along with 3 million units of interferon alfa-2b three times a week. They also took two common over the counter vitamins daily - 1000 milligrams of vitamin C and 800 *IU* (international units) of vitamin E.

"We chose these antioxidants because they have essentially no side effects, and many people are already taking them," Dr. Piken says. Results were compared to a control group of 14 relapse patients who received combination therapy without any antioxidants.

According to Dr. Piken, patients receiving the antioxidants showed an initial benefit from the vitamins, although that benefit declined by the end of three months of treatment. "The antioxidants appear to delay the onset and severity of the anemia, and patients receiving antioxidants do not require ribavirin dose reductions, compared to 22% of the people in the control group," he says.

Dr. Piken says the results merit further research. "We plan to run a larger study and also are currently making a decision on which type of antioxidant to use," he says. "We would like to use better forms and perhaps stronger antioxidants."

- Taken with thanks from the website: http://www.highlights.wellweb.com/article10.html

Drug debts the big fear in jails

By Debra Jopson

Nearly six in 10 NSW prisoners surveyed in an internal departmental study have admitted using illicit drugs while in jail.

Their drug of choice is overwhelmingly cannabis, but the NSW Department of Corrective Services survey of 235 prisoners also found that more than one in five had used heroin in prison, 17 per cent had used pills and 11 per cent medication not prescribed for them.

An unpublished departmental research summary obtained by the Herald reveals a prison drug sub-culture which appears to be frightening and dangerous for users.

Comprehensive interviews with the inmates, all of whom were shortly to be discharged into the community, revealed a social code of conduct governing drug use. Its paramount rule seems to be: "Don't get into debt."

Secrecy was another important part of the code, with 34 per cent agreeing that in prison you should "keep drugs to yourself' and 30 per cent saying: "Don't tell others about it."

The researchers found a dramatic drop in injecting drug use when they compared inmates' use before imprisonment and on the inside. Fear could be one factor in this, they speculate.

"The violence associated with defaulting on drug debts, as well as intimidation tactics from others to obtain drugs, was reportedly a strong deterrent to continued drug use in prison," their summary said.

However, just under one in four of the inmates surveyed continued to inject drugs in prison. But while just 5 per cent said they shared injecting equipment in the community, this rose to 12 per cent in prison.

"Those who continued to inject drugs in prison ... without proper cleaning were at risk of contracting blood-borne viruses (such as hepatitis C and HIV) and in turn infecting others," the researchers said. They noted that all wings in NSW prisons have access to bleach solution for needle-cleaning.

The researchers further identified the depth of the drug problem when they found that more than four out of five inmates stated that the crimes for which they were currently serving time were drug-related.

Alcohol was the most common drug involved in crime, with more than half of inmates citing it, while heroin came in a close second, mentioned by 45 per cent.

The researchers recommended that the severity of penalties over cannabis use in prison should be reviewed.

Special drug treatment units within prison should be expanded and injecting drug users targeted for employment and other opportunities.

"Prison provides a unique opportunity for therapeutic intervention with those who continue to practise high risk drug use," they said.

- Taken with thanks from the *Sydney Morning Herald*, 6/12/99.

  [A 1999 study (Awofeso, N. et al, 2000) shows an HCV antibody prevalence rate within NSW prisons of 47%. A 1996 study showed that 38% of prisoners were HCV positive ... Ed.]

Liver bleeding after deep tissue massage

By E Mundell, Reuters Health

An otherwise healthy US woman developed bleeding in her liver following deep tissue massage, according to a report in the December 23rd issue of *The New England Journal of Medicine*.

Although he described the case as "very rare," Dr. James F. Trotter of the University of Colorado Health Sciences Center in Denver, said, "If people are having (massages), they should be aware that (they) can develop these problems."

In his report, Trotter notes that the 39-year-old patient went to the hospital suffering from nausea, abdominal discomfort, and a pain in her right shoulder 72 hours after undergoing deep tissue massage.

Computed tomographic (CT) scans revealed "a large hematoma" - a collection of blood - in her liver, caused by a burst blood vessel. The woman received a blood transfusion, but continued to suffer from nausea and fever until her eventual recovery more than 6 months later.

Trotter stressed that "in general, I think that 99.9% of folks can get massages and have no problems." However, he said, massages -especially massages conducted with some measure of force - can cause harm. Previous reports have linked massage to the inadvertent dislodging of an arterial stent (a surgically implanted device used to open blocked arteries), blood clots, bruising, and thyroid problems.

The bottom line, Trotter said, is "be careful." He advised that patients on anticoagulant blood-thinning medications, as well as patients with any type of liver tumor, should avoid deep tissue massage.

- SOURCE: The New England Journal of Medicine 1999;341:2019-2020.

  Taken with thanks from the internet email list, HEPV-L.

Northern Sydney Area develops local hep C plan

Following acknowledgement of the need for improved HCV-related health services in the Northern Sydney Area Health Service, the region has put together a Hepatitis C Action Plan.

Clinical input to the plan was provided by the Royal North Shore Hospital (RNSH) Liver Clinic and an associated working group.

Key recommendations within the plan include increasing the opening hours, appointing a Clinical Nurse Consultant and improving access to counselling services at the RNSH Liver Clinic.

Additionally, there is a call to establish an area-wide HepNet coordinator, someone who would coordinate and support HCV training, recruit GPs especially interested in HCV, ensure quality information resources are available, and promote better HCV health care protocols across the area.

Australian Family Practitioner supplement

An HCV information supplement - over 80 pages in size - was distributed within the most recent edition of the medical journal, *Australian Family Practitioner.*

Posted out to all medical practitioners across Australia, the supplement provides healthcare workers with the valuable background necessary to diagnose, monitor or treat hepatitis C.

The Commonwealth Department of Health and Aged Care plans to have the supplement on the hepatitis C WebPages of their website (http://www.health.gov.au.)

Health care workers can access copies of the supplement from the NSW Better Health Centre (9816 0452).

Other readers can obtain copies from the Council office (9332 1853).

Pre-menopausal women may have better response to interferon

by Harvey S. Bartnof, MD

A team of researchers from Loyola University in Chicago led by Dr Alessandra Colantoni have determined that pre-menopausal women have a higher response rate to alfa interferon monotherapy than post-menopausal women or men.

Involving over 150 people with HCV, the trial results showed that 57% of the men and 69% of the women responded to therapy. Pre-menopausal women had a significantly higher response rate (74%) than age-matched men (56%). The pre-menopausal women also had a significantly higher response rate (74%) than post-menopausal women (47%). However, there was no difference in the response rate of post-menopausal women with age-matched men.

The results suggest that the presence of estrogen and/or progesterone (female hormones) may be a beneficial co-factor(s) in the response rate to alfa interferon for women with chronic hepatitis C.

Given the poorer response rate in post-menopausal women and men, perhaps a study with hormonal manipulation for these two groups would be interesting. Supplementing post-menopausal women with female hormones would be an easy intervention. Testing the same hormonal manipulation for men would be more problematic.

- Taken with thanks from the internet email list, HEPV-L.

A secure future seemed suddenly fragile

I found out I had hep C in 1993. I'd been working as a nurse in intensive care units for about ten years and thought my fatigue and general unwell feelings were just related to shift work and stress. But during a routine checkup with my GP she noticed my liver was enlarged. She just looked at me when she felt it. She knew I knew what she'd found. My blood test confirmed HCV.

My GP was great. She discussed everything with me and my partner and made herself available to both of us at any time we needed to talk about it. I was seeing a Hepatologist and on an Interferon trial by the end of the year and she helped me with my claim against Workcover (which succeeded after I retained a solicitor).

I was devastated by this discovery as was my partner. Four kids, a mortgage, a blossoming career and a secure future all seemed suddenly fragile. I could no longer get any life insurance and when we restructured our home loan I was refused mortgage insurance. I voluntarily informed my employer about my HCV and there were no problems. But I felt that if I ever tried to get a job at a different hospital, having hep C would ruin my chances.

Workcover would cover my medical bills, so I thought I was much better off than a lot of others with HCV. But I was only covered for 26 weeks loss of work time over the rest of my life, after that - an invalid pension. The thing that upset me most was that if I had lost a little finger at work I would have been awarded $10,000. Having my liver slowly destroyed was not considered to be worth anything.

Three years later my marriage broke down. My partner had threatened to divorce me if I ever had interferon again after the first time. We'd had counselling together since my diagnosis, and I'd kept on working and looking after the kids throughout. I couldn't pass up a chance for a cure, however slim the chance was. I owed that to myself and my children.

So six years down the road, here I am. Three lots of interferon, Chinese herbs, ribavirin, vitamin C injections, and silymarin later I've just about given up.

I work part-time now to reduce the effects of fatigue from shift work and stress. I've lost my home, my children and my career. I have no assets, no car, no insurance and no prospect of any improvement over the next 15 years.

I can't afford to keep up with the herbs and vitamins I was taking, as child support takes 34% of my gross earnings.

I get the *Hep C Review* and it's a comfort to know that something is being done to address the issues raised by hep C in our community, especially the recent research initiatives.

But the latest issue of *Hep C Review* has hit me hard in a peculiar way. I noticed there are research proposals to explore the effects of hep C on the lives of many groups. Women, gay men, indigenous people, IV drug users and youth. It's great to see this work being done. But I see no-one has bothered to investigate the effects of hep C on white, heterosexual men.

I guess we don't have any special issues worth considering.

Yours sincerely
Rabel

[Although there are no social research projects specifically targeting white, heterosexual men, we've seen various studies into the social or psychological effects of hepatitis C infection that have looked at general populations. The crux of Rabel's comments above, would be that HCV does not recognise any gender, racial, class or other social boundaries. It can have a dramatic impact on any one person, no matter their background ... Ed.]

HCV - The Evolving Epidemic

2nd Australasian Conference on Hepatitis C, Christchurch, New Zealand, 17-19 August 1999

Abridged by Dr Greg Dore

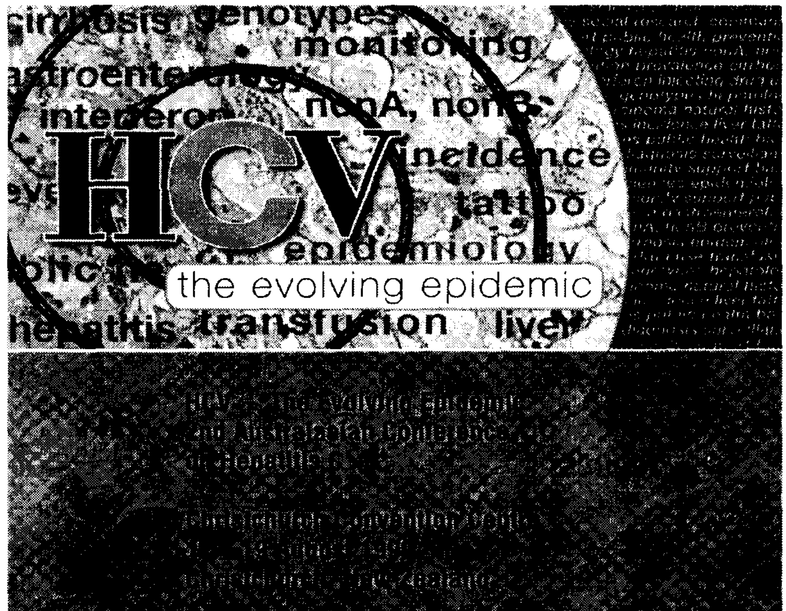
The 2nd Australasian Conference on Hepatitis C highlighted an evolving consensus among research, practitioner, government, and community groups that a multi-disciplinary (or inter-disciplinary) response to hepatitis C provides the best way forward. The final plenary panel discussion entitled "Co-operation in care, prevention and support: new partnerships for a new millennium" encapsulated the strengthening collaborative response to hepatitis C through the 1990s in Australia, as seen with HIV/AIDS in the 1980s. This conference, almost uniquely in the field of hepatitis C internationally, brought diverse groups together to discuss a broad range of issues.

Basic sciences / virology

Eric Gowans summarised developments in the virology of hepatitis C virus (HCV). The major impediment to a greater understanding of HCV virology has been an inability to establish HCV cell culture systems (to 'grow' the virus) and/or small animal models with which to study the virus. Despite this, the replication cycle of HCV, including the viral components which control this mechanism, has been partially defined. Two viral components, the protease enzyme and the internal ribosome entry site (IRES), are seen as potential targets for anti-viral therapy.

Two further presentations from Gowans' group at the Royal Children's Hospital in Brisbane discussed developments in understanding of how HCV enters liver cells and HCV vaccine development. CD81 has been identified as the putative HCV receptor (a key that lets the virus in), and liver specific cell lines are being developed to study HCV binding and infectivity. Preliminary vaccination studies by Gowan's group in mice using virus-like particles have generated weak but reproducible responses.

The stability and associated infectivity of HCV is an area of immense interest, but again impeded through the inability to develop cell culture systems. Scott Bowden presented work undertaken at the Victorian Infectious Diseases Laboratory examining the stability of HCV on prolonged storage at room temperature. Both HCV and bovine viral diarrhoea virus (BVDV) - a virus with similar properties to HCV and thus an infectivity surrogate for HCV - were examined over a nine week period. Infectivity of BVDV could still be detected after three weeks of storage and HCV-RNA was detected by PCR throughout the nine week period. However, the infectivity of HCV may be quite different in dried blood, and will depend on several other factors such as dose, viral concentration, and type of contact. It is also difficult to *extrapolate* (apply) these findings to situations such as needlestick injuries from discarded injecting equipment, where the general risk of HCV transmission is almost certainly low.



Epidemiology and Public Health

A presentation on the molecular epidemiology of HCV by Peter Simmonds from the University of Edinburgh was one of the highlights of the conference. Based on the degree of difference within HCV genotypes, evolutionary reconstruction methods suggest that HCV has been transmitted for several hundred years. HCV genotypes are of importance in predicting the response to therapy (for example, response is considerably lower for genotype 1), and may also influence the natural history of HCV-related liver disease. There is no evidence, however, of differential infectivity among HCV genotypes.

The application of molecular epidemiological techniques in the investigation of HCV transmission was clearly demonstrated in a presentation by Scott Bowden. Following diagnosis of HCV infection in a person with no identifiable risk factor other than a minor surgical procedure, testing of all other people on the list found the prior person to be HCV-infected. Confirmation of HCV transmission was made through evidence of a high degree of HCV similarity on analysis of their HCV strains. This was despite the episode having occurred several years prior to the investigation.

Miriam Alter from the Centers for Disease Control and Prevention, Atlanta in a somewhat controversial opening plenary session described global trends and differences in the epidemiology of hepatitis C. Three broadly different patterns of HCV transmission were outlined:

- transmission, predominantly through injecting drug use, in the last 30 years (with the vast majority of people currently infected aged 20-50 years) in countries such as the United States and Australia;

- transmission, predominantly through unsafe injection practices and contaminated equipment used in health care and folk medicine, and often occurring 30-50 years ago (therefore, producing increasing HCV prevalence with age) in countries such as Japan and Italy;
- and higher level and ongoing transmission in countries such as Egypt, largely as a result of prior and continuing unsafe injection practices and contaminated equipment used in health care. This latter pattern also has produced increasing HCV prevalence with age, but, to an extent where many areas of Egypt have HCV prevalence above 20%.

The controversial aspect of the presentation was not these broad descriptions of HCV transmission patterns, but, the claim (based on people's self reporting of "risk factors" for HCV infection) that 20-25% of HCV transmission in the United States is due to sexual transmission. This produced considerable debate on the plenary floor and in the hallways, with an alternative explanation of unreported injecting drug use (especially in a country where stigmatisation of drug use is heightened) being strongly made by many conference participants.

A study of risk factors for HCV transmission among the general adult Victorian population was presented by Campbell Aitken from the Macfarlane Burnet Centre. Based on phone interviews of randomly selected adults aged 15 years or above the prevalence of blood-borne illness risk factors was injecting drug use (once or more) (2.2%), tattooed (4.8%), and blood transfusion prior to 1990 (11.4%). The prevalence of a history of injecting drug use in this study was very similar to the 2.1% for the Australian adult population from a National Drug Strategy Household Survey conducted in 1998. This prevalence translates to a figure of approximately 300,000 people with a reported history of injecting drug use in Australia.

Margaret MacDonald, on behalf of the Collaboration of Australian Needle Exchanges, made several presentations of results from their annual surveys of injectors over the period 1995-1998. An overall decline in HCV prevalence was seen from 63% in 1995 to approximately 50% in 1996-1998. Encouragingly, HCV prevalence among people who reported injecting for less than three years almost halved over this period. In concordance with a reduction in HCV prevalence was a decline in reported sharing of injecting equipment. A further presentation, however, described the increasing prevalence of cocaine injecting, in particular in New South Wales (6% in 1995 to 17% in 1998), and the an increase in HCV prevalence among cocaine injectors over the period 1995-1997 (61 % to 70%).

Based on a presentation by Alison Rodger from the Macfarlane Burnet Centre, and other population based studies presented in a review of the natural history of HCV infection, the risk of progression to advanced liver disease appears to be considerably less than initial studies (predominantly liver clinic based) had suggested. In a cohort of patients hospitalised for acute hepatitis at Fairfield Hospital Melbourne, in 1971-1975, with a median follow up period of 24 years, cirrhosis was present in 7% of those with HCV antibodies, and 12% of those with evidence of chronic HCV infection (positive HCV RNA on PCR testing).

Clinical management

William Sievert from the Monash Medical Centre in Melbourne presented an overview of treatment for chronic HCV infection. Recently published randomised trials have demonstrated a more than doubling in the sustained response (SR) rate - measured as clearance of HCV viraemia and normalisation of ALT levels 6-12 months after completion of therapy - with the addition of ribavirin to interferon. Combining results from two large trials provided SR rates of approximately 15% for interferon alone (48 weeks), compared to 35-40% for interferon plus ribavirin (24-48 weeks). Predictors of response to therapy included HCV genotype, HCV viral load, and degree of fibrosis on liver biopsy. People with HCV genotypes 2-3 have a SR rate of 65% with combination treatment, with no difference in SR between 24 and 48 weeks. In contrast, even with 48 weeks of combination treatment, people with HCV genotype 1 have a SR of only 30%.

Other treatment strategies which are currently being trialled include induction dosing - using higher and/or more frequent (daily) dosing of interferon for the initial month of therapy - and the use of pegylated interferon which is a slow release form of interferon requiring only weekly dosing. Australian clinical centres are currently involved in trials of these alternate interferon strategies in combination with ribavirin.

Stephen Locarnini from the Victorian Infectious Diseases Reference Laboratory followed on with a presentation on future therapy for chronic HCV infection. Although protease inhibitors (a type of antiviral drug treatment) have provided major advances in HIV therapy, development of HCV-specific protease inhibitors has been slow, predominantly due to the more superficial and diffuse nature of the protease site on the surface of HCV. Other possible therapeutic classes include helicase and RNA polymerase enzyme inhibitors, but it could be several years before these agents reach the clinical trials stage.

A consensus has emerged among clinicians that interferon monotherapy, the only currently funded therapy available for the vast majority of people with chronic HCV infection, is of limited benefit, and should not be considered standard of care.

The role of complementary therapies, predominantly Chinese herbal preparations, in the management of HCV infection, was discussed in several presentations. Although initial trials have demonstrated some biochemical response (approximately 30% of people normalise their ALT levels), no anti-viral effects have been demonstrated with these preparations. Further randomised trials have been planned, with assessment of histopathological and symptomatic response. Several preparations are being studied, with Silymarin (St Mary's Thistle/Silybum marianum) a common component.

- Dr Greg Dore is a lecturer in epidemiology and infectious diseases physician at the National Centre in HIV Epidemiology and Clinical Research and St Vincent's Hospital Hepatitis Clinic

Abridged with thanks from the referenced original by Greg Dore, Stuart Loveday and Alison Rodger in the *Australian HIV Surveillance Report*, October 1999, Vol 15 No 4 (pages 1-8).

Alcohol & hepatitis C

Chronic alcoholism in patients with chronic hepatitis C hastens disease progression toward development of cirrhosis and hepatocellular carcinoma.

Approximately 30% of alcoholic patients with liver disease are infected with the hepatitis C virus (HCV), the primary risk factor being a history of injection drug use. The histologic pattern in alcoholics is typically indistinguishable from nonalcoholic patients similarly infected with chronic hepatitis C. The mechanism(s) involved in alcohol-induced enhancement of chronic hepatitis C have not entirely been established but may involve increased viral replication, iron overload, and immune suppression.

Still to be determined is the minimum amount of daily alcohol intake, if any, that can be ingested without enhancing progressive liver injury. However, chronic hepatitis C patients undergoing treatment with interferon must abstain from any alcohol intake, because the efficacy of interferon therapy is significantly lower in those who continue to drink. Future research efforts are needed in order to further delineate the epidemiology and pathogenesis of chronic hepatitis C in the alcoholic patient.

Schiff ER, Department of Medicine, University of Miami, Florida 33136, USA.

- SOURCE: Am J Med 1999 Dec 27;107(6B):95S-99S

  Taken with thanks from the internet email list, HEPV-L.

Adverse reaction: milk thistle

A 57-year-old woman presented with a 2-month history of intermittent episodes of nausea, abdominal pain, watery diarrhea, sweating, and weakness. The attacks lasted up to 24 hours, and she felt well before and after the episodes. Physical examination and laboratory test results were unremarkable.

Questioning revealed that the episodes began after she had starting taking milk thistle (Silybum marianum) capsules for both headaches and liver cleansing, and that each episode had occurred shortly after taking a capsule. The attacks resolved after she stopped taking milk thistle.

Discussion: Milk thistle, a plant native to southern Europe and other areas, has been reported to be useful for the prophylaxis and treatment of some liver diseases. The active ingredients of the fruit, a group of flavonolignans known collectively as silymarin, alter the outer liver membrane cell structure to block toxins from entering the cell. Silymarin also stimulates RNA polymerase A, which promotes regeneration of the liver. Although a recent review suggested that no serious adverse effects from herbal milk thistle medications had been reported, the Adverse Drug Reactions Advisory Committee of Australia has received a report of a woman who experienced nausea, abdominal pain, listlessness, and insomnia after taking milk thistle (Medical Journal of Australia 1999;170 March 1:218-219).

- Nurses' Drug Alert 23(7):51, 1999

  Taken with thanks from the internet email list, HEPV-L.

  [It is generally acknowledged that Milk Thistle does not involve significant side effects but as with a wide range of commonly used medications and preparations, some people may be susceptible to an adverse reaction. We always suggest that people continue having their health monitored by a General Practitioner, and that they discuss all treatments and medications they are using or considering using... Ed.]

45-year follow-up of hepatitis C

The *sequelae* (illness outcome) during the first two decades after acute hepatitis C virus (HCV) infection have been well studied, but the outcome thereafter is unknown.

Our study objective was to conduct an extended study of the natural history of HCV infection by using archived *serum* (blood) specimens originally collected between 1948 and 1954. Thus we were able to identify and study a group of people who we now know were already HCV positive approximately 45 years ago.

Background: 8568 US military recruits were evaluated for group A streptococcal infection and acute rheumatic fever between 1948 and 1954. Blood samples were taken from the recruits and, after testing, were stored frozen for almost 45 years.

The blood samples were tested for presence of HCV antibodies in addition to *polymerase chain reaction* (PCR) for HCV RNA. People's *morbidity* (level of illness) and *mortality* (death rate) were also assessed.

Results: Of 8568 persons, 17 (0.2%) had positive results on enzyme-linked immunosorbent assay and recombinant immunoblot assay. The rate was 1.8% among the African-American persons and 0.1% among the white persons in the total sample. During the 45-year follow-up, liver disease occurred in 2 of the 17 HCV-positive persons (11.8%) and 205 of the 8551 HCV-negative persons (2.4%).

Seven of the 17 HCV-positive persons (41%) and 2226 of the 8551 HCV-negative persons (26%) had died by December 1996. Of persons who were HCV-positive, 1 (5.9%) died of liver disease 42 years after the original blood sampling was carried out, 5 (29%) died of non-liver-related disease a median of 37 years after the original blood sampling, and 1 (5.9%) died of unknown causes. One hundred and nineteen HCV-negative persons (1.4%) died of liver disease.

In conclusion, the rate of HCV infection from 1948 to 1954 among a sample of military recruits parallels that among present-day military recruits and

Many readers want to see more highly detailed information on hepatitis C. The above articles attempt to meet this need. Although some individual research articles may appear to contradict current HCV beliefs, such scientific debate is of great benefit, leading to a better

volunteer blood donors. During 45 years of follow-up, HCV-positive persons had low liver-related morbidity and mortality rates. This suggests that healthy HCV-positive persons may be at less risk for progressive liver disease than is currently thought.

Authors: Leonard B. Seeff, MD; Richard N. Miller, MD; Charles S. Rabkin, MD; Zelma Buskell-Bales, BS; Kelle D. Straley-Eason, MPH; Bonnie L. Smoak, MD; Leslye D. Johnson, PhD; Stephen R. Lee, PhD; and Edward L. Kaplan, MD

- Source: Ann Intern Med. 2000;132:105-111.

  Taken with thanks from the internet email list, HEPV-L.

Stress & infectious disease

US researchers who have spent years studying the effects of stress on the body's immune system now believe they know enough to show that stress actually does weaken a person's health.

Reporting in the Journal of the American Medical Association, a team of researchers from five universities argue that stress can lessen a person's immune response and that change can make them more susceptible to infectious diseases.

They also say that increased stress may lessen the effectiveness of certain vaccines. "The evidence so far suggests that while the immune changes associated with psychological stress are generally small, they look like they're important enough to have biological consequences and increase health risks," explained Ronald Glaser, professor of medical microbiology and immunology at Ohio State University and lead author of the study.

The JAMA paper points to the important role that compounds known as cytokines play in regulating the immune response. In some cases, they stimulate the release of other compounds essential for inflammation. In other cases, they maintain the balance of other components of the human immune response.

Researchers know that psychological stress can alter the level of certain hormones. These alterations induced by stress are responsible for the changes in cytokine concentrations since stress hormones alter the synthesis and the release of the cytokines, the authors explained.

Glaser suggests that while in vitro tissue cultures have taught us much about the immune response, that system may function differently in the whole animal, or person.

The researchers pointed to recent research involving vaccinations for Hepatitis B and for influenza. They showed that stress could suppress T-cell responses and lower antibody levels, two factors necessary to develop a strong immunity to these diseases.

The study team suggested that future research should explore whether improving the concentration of certain hormones in the blood might produce an improvement in immune function.

They also said that enough is known now to show that certain changes in lifestyle can increase a person's resistance to some infectious diseases.

Most of these changes -- gaining social support and companionship, maintaining a proper diet, regular exercise and enough sleep -- are not expensive, Glaser said.

At the same time, clinicians need to remember that when a patient fails to live up to the strong lifestyle change suggestions made by their doctor, they may develop guilt feelings about that failure, he said.

- SOURCE: Ohio State University press release

  Taken with thanks from the internet email list, HEPV-L.

Daily interferon and ribavirin combination

The optimal dose, frequency and duration of interferon and ribavirin combination for the treatment of chronic hepatitis C is still not clear. This report documents the preliminary findings of an investigation to evaluate the benefits of long-term (12 month), daily interferon alpha 2b and ribavirin combination therapy for people with chronic hepatitis C, who have either relapsed (relapsers) or not responded (non-responders) to previous interferon therapy.

METHODS: 25 non-cirrhotic HCV patients were enrolled. Patients were administered 3 million units IFN alpha 2b subcutaneously and ribavirin 1000-1200 mg PO on a daily basis.

RESULTS: Four patients were removed from the protocol because of noncompliance. The remaining 21 patients (10 relapsers, 11 non-responders) were evaluated at the end of their 12th week of treatment. Twelve patients (57%) became HCV-RNA negative and nine patients (43%) remain positive at the end of this period.

CONCLUSION: Although further studies on larger patient populations are necessary, our preliminary data suggests that daily IFN alpha 2b and ribavirin treatment is highly effective, especially among patients who have relapsed from previous IFN treatment.

AUTHOR: Karasu Z, et al. Transplantation Institute (NZTI), Oklahoma City, OK 73112, USA.

- SOURCE: J Okla State Med Assoc 1999 Dec;92(12):573-7

  Taken with thanks from the internet email list, HEPV-L.

  [Note, these are the results at only week 12 of a 52 week study that, involving 25 people, is very small in scale. Response to current combo therapy (interferon 3x weekly) is estimated at 40-50% and it would be difficult to say on data from the above report whether daily interferon injections would prove to be a significant improvement.. Ed.]

understanding of HCV and its effect on people's health. To clarify any medical terminology, or for further information, please speak to your doctor or specialist, or phone the Hep C Helpline on 9332 1599 (Sydney callers) or 1800 803 990 (NSW callers).

Getting to know your Hepatitis C Council

Introducing Jennifer Holmes, Vice-President of the Hepatitis C Council of NSW

What was your first involvement with the Council?

I went to a meeting at Royal North Shore Hospital that the Council was running in June 1995. Soon afterwards, I joined the Management committee. Since then I have also been doing the Helpline training.

What is your current involvement?

Vice president, Chairing the meeting when the president is unavailable, Executive officer support and helping out with training for volunteers on the *Hep C Helpline*.

What has been the most difficult part of your work with the Council?

Finding time to do all the reading involved.

What's involved in your current paid job?

Nurse Manager of the Langton Centre, Surry Hills, a comprehensive drug and alcohol treatments centre.

What's been your career highlight?

Falling into the drug and alcohol field in 1987 by accident but it was love at first sight; Helping to organise the first Australasian Hepatitis C conference; Being part of the panel for the Rural Health Education Foundation live satellite telecast on Hepatitis C.

Do you have a particular work philosophy?

An ounce of praise is worth a pound of criticism.

How do you de-stress?

By walking and having at least one people free day most weekends.

Introducing the *Australian Hepatitis Chronicle*

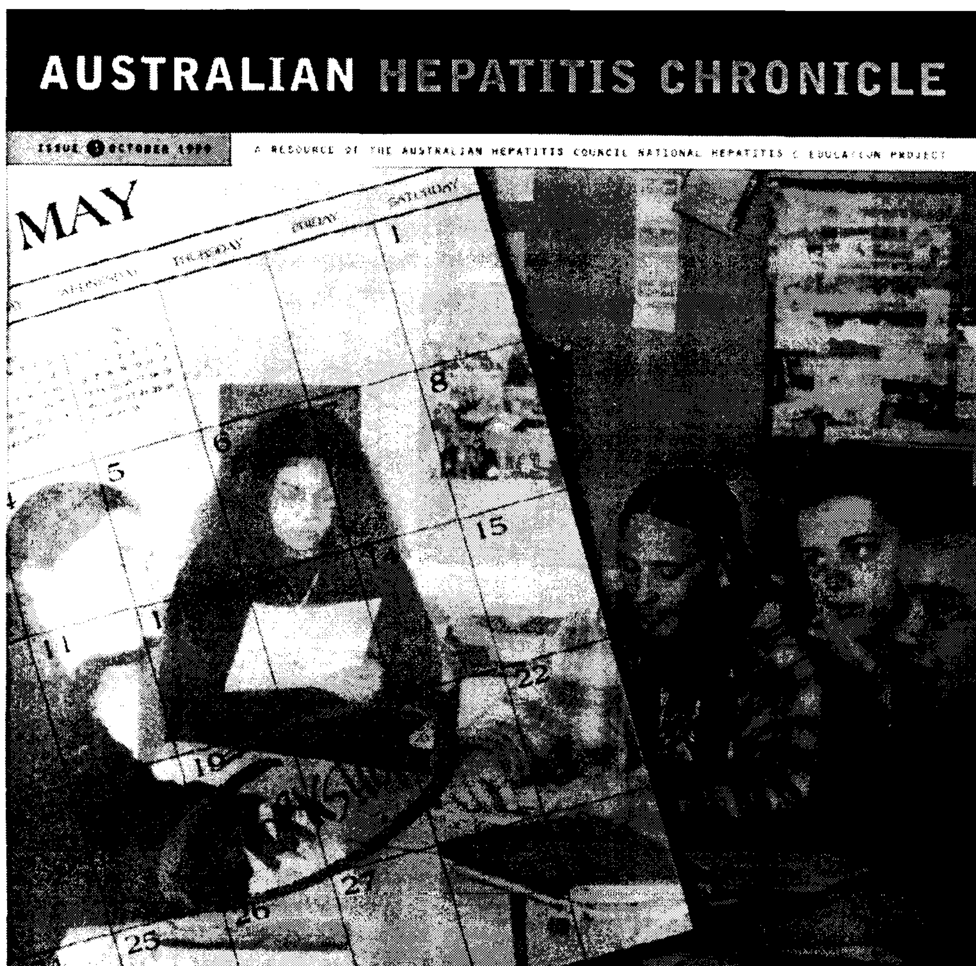
The *Australian Hepatitis Chronicle* is a publication of the Australian Hepatitis Council National Hepatitis C Education Project. The Australian Hepatitis Council is a national peak organisation with its membership comprising state/territory based Hepatitis C Councils.

The objectives of the Australian Hepatitis Council are to:

- Represent at a national level those affected by chronic viral hepatitis and coordinate a national community based response.
- Contribute to the development and implementation of national policies on chronic viral hepatitis.
- Promote awareness of chronic viral hepatitis at a national level.
- Contribute to a national focus for care, treatment and support, and prevention education programs in line with relevant national policies and procedures.
- Develop and coordinate community based national projects.
- Assist member organisations by providing a national network/ link for education and training resources and coordinate the dissemination of state and territory produced resources.
- Address discrimination and promote equitable provision of comprehensive services for people affected by chronic viral hepatitis.
- Represent its members at national and international forums.
- Promote medical, scientific and social research into chronic viral hepatitis.

The *Chronicle* aims to inform members and agencies of the ongoing activity of the Australian Hepatitis Council National Hepatitis C Education Project. It invites contributions from members and non-members who wish to contribute to the Council's goals and objectives.

The *Chronicle* is published four times a year (usually March, June, Sept, Dec). The *Chronicle* is not currently indexed, but will be in time.



SUBSCRIPTIONS

The *Chronicle* is distributed free to hepatitis C project workers and interested others on request. Requests for bulk copies may incur a postage and handling fee.

CORRESPONDENCE

All correspondence about the *Chronicle*, including letters to the editor, contributions etc should be directed to Jack Wallace, Executive Officer, Australian Hepatitis Council National Hepatitis C Education Project, PO Box 357, Curtin ACT 2605, or by email to ahc@hcn.net.au, telephone (02) 6232 4257 or facsimile (02) 6232 4318.

The closing date for receipt of contributions is 6 weeks prior to publication.

Identification and management of dry mouth in hepatitis C

Recent studies (see below) have shown an increased incidence of *xerostomia* (dry mouth) in people with hepatitis C.

The role of saliva includes cleaning, lubrication, chemical protection and antibody and cell mediated immune defence. In essence, saliva acts as the foundation for oral health. Its depletion can lead to rapid and rampant destruction of the *dentition* (character and arrangement of a person's teeth), and have severe impact on a person's quality of life.

Indicators of reduced saliva levels include people's complaints of dry mouth particularly at night; sore oral tissues particularly tongue, gums and cheeks; frothy, foamy and stringy saliva, difficulty talking, eating and swallowing; *halitosis* (bad breath); dental decay and tooth sensitivity.

The management of xerostomia is aimed at prevention of damage to the dentition and involves often simple but effective treatment. Initial management includes the following strategies:

- Saliva stimulation by agents such as chewing gum or sugar free sweets, increased fluid intake to reduce the effects of dehydration, and in severe cases, oral administration of pilocarpine solution (0.5 mg/ml, 51nI qld).

- Preventive dental care such as improving oral hygiene to remove the dental plaque responsible for much of the damage. Diet analysis and advice is important to reduce both the frequency and amount of simple and complex carbohydrate intake. Home fluoride application either as a rinse or gel is essential and changing to a non foaming, dry mouth toothpaste will improve oral comfort.

- Saliva replacement with frequently sipped water or artificial saliva will provide short term relief by lubricating the mouth. However, saliva replacements do not simulate the protective functions of saliva and without the appropriate preventive care, breakdown will continue.

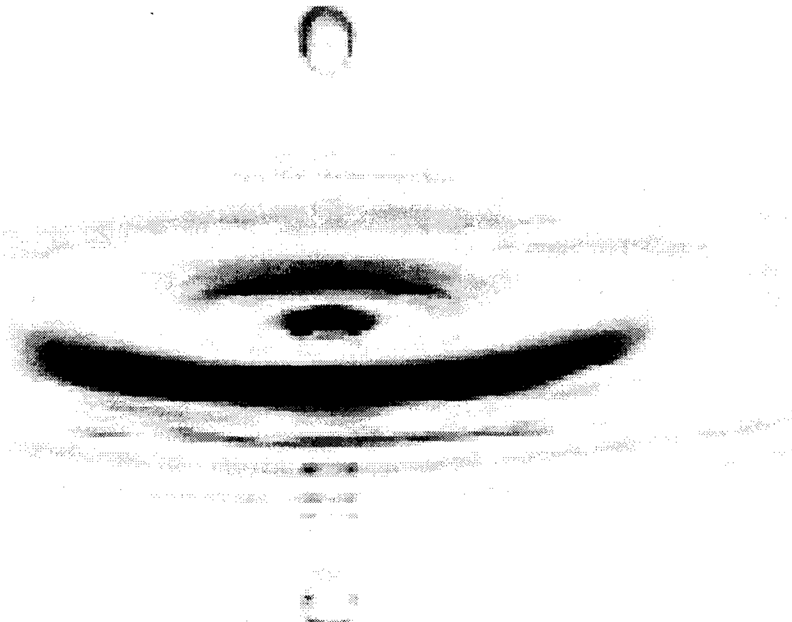
Ideally all patients at risk of xerostomia should have a thorough dental examination and regular dental care to ensure proper diagnosis and management. However, many of these initial management strategies could be implemented by a primary care physician, helping to limit the potential damage to the dentition and its subsequent effects on quality of life.

- Dr Wayne Sherson has a private dental practice in Darlinghurst and is an Honorary Clinical Research Associate at the United Dental Hospital.

Studies mentioned above:

Coates E. et al. Poor oral health - a factor in quality of life of people with Hepatitis C Infection. Paper presented at *The 2nd Australasian Conference on Hepatitis C*, 1999.

Roy KM, Bagg J. Hepatitis C virus and oral disease: A critical review. *Oral Diseases* 5:270-277 1999.



Overloaded with iron

As a result of a motor accident in 1989, I was hospitalised for three and a half months. Of this time I spent three weeks in intensive care with severe bone and lung injuries.

A blood transfusion was required and along with all the broken bones I sustained, my hospital stay was anything but pleasant.

It was only through a routine letter from the Blood Bank in 1998 to my GP requesting I have blood tests done for hepatitis C that I discovered the terrible results - that I was hep C positive.

I was sent to a gastroenterologist at our local hospital and more tests were done that showed my liver had an extraordinary high level of iron.

As a result of this for eight weeks I had to have a weekly 500ml *venesection* [taking of blood] and finally, the level of iron came back to the normal range.

I was then having (fortnightly) venesections and after a few months they were made two monthly and now I'm on three monthly ones to keep my iron level in the normal range. Since this treatment I don't felt as tired as before and have generally felt a lot better.

About midway through 1999 I had a liver biopsy done which showed a heavy amount of fibrosis. Needless to say, this horrified me and the doctor seemed to think the excess iron was speeding up the virus' damage.

I would be interested to know if anyone out there has had this iron overload and, if so, maybe I can read about it in a future *Hep C Review.*

I always read *The Hep C Review* from cover to cover and find the contents most helpful. I can't seem to pass on my bad news to all my family however I have shared it with my husband of course and our children.

Thanks again for the help this magazine gives us and to realise that we're not alone.

Regards, Jean

[Thanks for sharing your story, Jean. Along with possible feedback from other readers and the folk on HEPV-L, we'll see what we can find out from our medical advisors and report back in the next Edition ... Ed.]

Dispelling the diet dilemma

By Simon Sadler

It seems everyday we are constantly being bombarded by nutrition messages. In fact never before have we been exposed to so many different opinions from many so called 'experts' through a large variety of different mediums. Magazines and newspapers tell us the wonders of the latest discoveries in the new area of 'nutritional' medicine, while the television parrots messages of miracle cures and dietary panacaeas.

Meanwhile our families and friends have heard from somewhere that 'Product X' is sure to make us all healthier. It all becomes very confusing, not to mention stressful on our dwindling bank accounts because unfortunately most of these magic bullets 'don't come cheap'. Well not to be left out, I'm going to add another twist to this sordid tale and try to answer this seemingly uncomplicated question. What foods should we be eating to help keep us in good health?

This is a topic where opinions and information are as confusing as politicians around election time. On the surface everybody seems to have our best interest at heart but on closer analysis we enter into a maze of vested interest, broken promises and treachery (please forgive me for being cynical). But what this all means is that we have to be vigilant to avoid getting into trouble. The aim of this article is to give you some basic facts about good nutrition and a healthy lifestyle.

Your diet and lifestyle are important factors in your physical, psychological and spiritual well being and they are important 'health decisions' that you make every day. If you were deciding to commence some experimental drug therapy, wouldn't you want to know all the possible side effects? Your long-term nutritional health is no different.

"serving size variations will be dependent on your age, height and activity level. However, the fact remains that eating a variety of these foods contribute to a healthy balanced diet"

Good nutrition has a number of benefits that are not limited to your physical health. Some of these benefits range from weight maintenance, psychological well being, improved energy levels, optimising immune function and actually reducing risk of hospitalisation.

To help attain some of these benefits, doctors and dietitians for years have been telling us to have a 'balanced diet'. In fact the term has been bantered around so often it is now becoming cliched. But what is a balanced diet and how does it help promote good health?

A balanced diet is a healthy eating plan that incorporates a variety of foods from a number of different sources. When we have a combination of these foods in our diet we are providing our bodies with the essential nutrients it needs for growth and repair, and the building blocks for many of our bodily systems including our immune system. These food groups with recommended serving sizes include:

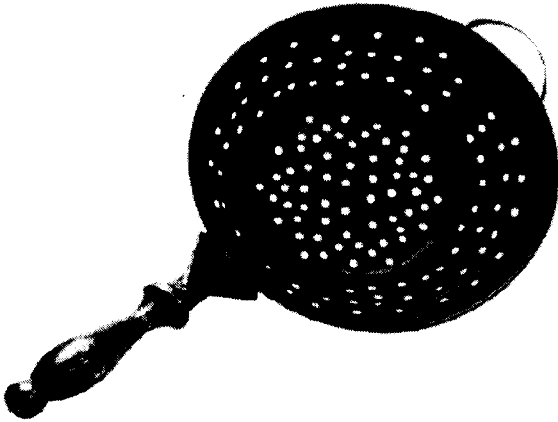
Breads and cereals: (at least five serves a day) which provide a number of the B group vitamins and energy in the form of carbohydrate and also fibre. Foods in this group include rice, pasta, breakfast cereals, Cous cous, and all other grain products such as wheat, rye, and oats.

Fruit and vegetables: (at least 3 serves of fruit and 4 serves of vegetables a day) these are also energy foods and provide a variety of vitamins and minerals, such as vitamin C, B carotene and folate, all of which are essential to help maintain optimal health.

Dairy foods: (at least three serves a day) are an excellent source of calcium, and also contain protein and carbohydrate. If these foods cause you bloating and diarrhoea, soymilk and reduced lactose milk can provide a good alternative. However it is important to consult a doctor or dietitian about your symptoms because eliminating this group of foods may not be necessary and can dramatically reduce the nutrients supplied to your body.

Lean meat, fish and poultry: (two - three serves a day) an excellent source of protein, vitamin B12 and iron.

Legumes, nuts and pulses: (on a regular basis) these include foods such as soy, kidney, and baked beans, lentils, and chickpeas. These foods are an excellent source of protein, carbohydrate, fibre, and zinc.



Fluids: (at least 8 glasses a day) are extremely important in maintaining body hydration and flushing the body of toxins. They include water, juices, cordials and a small amount of soft drink.

Indulgences: (occasionally) These foods are particularly important psychologically as well as nutritionally. They include the foods you treat yourself to everyday such as takeaways, eating out, cakes, biscuits and yes..... CHOCOLATE!

This all sounds very regimented and serving size variations will be dependent on your age, height and activity level. However, the fact remains that eating a variety of these foods contributes to a healthy balanced diet.

As the word 'balanced' suggests, too much of any one of these groups at the cost of another can cause nutritional problems. For example a diet consisting of a large proportion of takeaways, chocolate, soft drink etc is rich in energy but has little in the way of vitamins and minerals - the very nutrients that would strengthen your immune system, improve your energy levels and enhance your feeling of wellbeing. Alternatively a diet consisting only of vegetables and fruit is low in protein and can become very dull and difficult to maintain (both psychologically and from a health perspective). As the old adage says 'Man and Woman cannot live on bread alone'.

Exercise also offers an additional weapon in your pilgrimage for improved health. Exercise is a general term that can be divided into two groups. These two groups are the aerobic and anaerobic or resistive exercise.

Aerobic exercise such as walking, swimming, cycling and dancing improve general fitness and endurance, while resistive or anaerobic exercise such as weights, gym work and exercises such as push-ups and sit ups help improve muscle strength and tone.

Diet and exercise work together to provide many benefits. However, it is extremely important to note that before commencing any form of exercise to consult your doctor, physiotherapist or your dietitian. They will help you develop a program that will not only be of benefit to your health but will be something that you enjoy.

These suggestions often become difficult when you are experiencing one or more symptoms associated with a chronic disease. Side effects such as loss of appetite, nausea, bloating, lack of energy, fatigue and diarrhoea all contribute to a decreased intake and weight loss. If you want to find out more about symptom control, diet and exercise contact a dietitian in your area. They will give you ideas to improve your health that are specific to your situation.

• Simon Sadler is a dietitian at the Albion Street Centre, Surry Hills NSW.

A message from Phil Lesh

Dear Friends, I discovered after a routine physical in 1987 that I had hepatitis C. I am pretty sure that I contracted it during the mid 60's. There was very little information about it back then and in fact there wasn't a definitive test for it until 1990.

My wife Jill and I did learn what there was available about it and I made some healthy lifestyle changes such as quitting drinking, going vegetarian and I started walking daily. I also pursued alternative healing medicine, such as homeopathy and acupuncture.

After our 1998 tour, I discovered that I was anemic and losing muscle mass, and in September, I had two episodes of esophageal bleeding, which led me to the realisation that I needed a liver transplant.

After several months of research and travel to various transplant centres for testing, the transplant took place on December 17 at the Mayo Clinic in Jacksonville, Florida. I was out of the hospital in six days, and home in California after four weeks. I attribute my rapid recovery to the immense amount of healing light and prayer directed toward me by the members of the world's greatest support group, the Deadheads.

However, during the process of preparation, surgery, and recovery, I have become aware that the lives of many, many people are hanging by a thread because of the tremendous shortage of organs (and whole blood) and the general lack of information available, especially to the families of potential donors, who must often make the decision to donate or not at a time of terrific stress and grief.

I intend to do every thing I can, including benefits and interviews, to increase awareness of the issues involved in organ donation and hepatitis C.

Phil Lesh (second from right) alongside fellow members of the rock band *The Grateful Dead* - cornerstones of the hippie culture originating during the mid to late 60's in San-Francisco's Haight-Ashbury district.

If everyone who wishes to donate organs would notify their families of their desire, there would most likely not be any shortage of organs at all, and no one would have to die waiting for an organ.

It is my profound hope that through our community we can bring these issues to a wider public awareness.

- This article originally pritned in the *Grateful Dead's Almanac*, Vol 6, No.2

  Taken with thanks from the *Good Liver*, Summer 99 edition.

Is the treatment good enough?

more about interferon

Those of us who attended the Victorian Hepatitis C Council's AGM in Melbourne on November 25th were gratified to note that keynote speaker Stephen Locarnini (Divisional Head of Molecular Research & Development, Victorian Infectious Diseases Reference Laboratory) has evidently been listening to our pleas for better medical treatment for people with hepatitis C.

As part of his comprehensive and interesting presentation to the AGM, Stephen made two very important points which ought to give pause to medical practitioners who are eagerly offering interferon based treatments to hepatitis C positive people.

Point #1:
Stephen indicated that if he himself had hepatitis C and was otherwise well and was considering therapy he then would choose to wait until better treatments became available unless his liver disease was progressing. This comment reflects both Stephen's informed optimism that better treatments will become available within the next few years and also his acknowledgement that the side-effects of Rebetron (combination Interferon & Ribavirin) can be serious whereas the odds of sustained response are not high unless one has genotype 2 or 3.

Point #2:
Stephen commented on the practice of prescribing interferon in such a way (3x weekly) that the anti-viral concentration waxes and wanes (intermittently dropping below the level that is effective against the virus) saying that "in therapeutics....this is the worst thing to do".

So what does this latter point mean? In medicine for some time now it has been considered a basic rule of thumb to use antibiotic and anti-viral drugs in such a way that there is a constantly active and unremitting concentration of the drug in the blood (or affected organ) during the course of the treatment. The point of this rule is to ensure that the germ (virus or bacteria) does not have a chance to rally and become stronger against the drug.

It seems that (except for the Pegylated version) interferon is currently not being used in this way against hepatitis C.

While I cannot vouch for the benefits or otherwise of the new Pegylated Interferon (currently only available in experimental trials) it does at least have the potential to be used in way which meets this very basic criteria of sustaining a constant therapeutic concentration of anti-viral throughout the treatment.

We are grateful to Stephen for his frank observations on these very important matters, and confident that the International Conference on Viral Hepatitis Treatments (currently underway in Hawaii) will join Stephen in addressing these questions in the interests of better outcomes for people with Hepatitis C (and B?). Watch this space.

Meanwhile back on the interferon treadmill. Tips for punters who are contemplating treatment. Some questions to ask your doctor beforehand.

How badly is my liver damaged right now ?

Is the damage progressing rapidly?

Is treatment urgently necessary or can I afford to wait for better treatment?

What is the genotype of my hep C?

Which treatment is likely to be successful against my type of hep C virus?

What are the odds exactly?

Does the treatment you recommend keep up a constant, unremitting and active concentration of the medicine in my blood throughout the whole course? If not, why not?

What are the side effects which might affect my ability to work and function personally as well on my physical and psychological health?

If you were me, Doc, would you take this treatment?

Good luck punters!!

- *Written by Mary Burns Hepatitis C Helpline Coordinator (Melbourne ,Victoria) with thanx to Suzanne O'Callaghan for moral support, literature search and copies of background reading. Thanx also to Rhonda McCaw and Stephen Locarnini for checking final draft.*

[Current interferon prescribing involves three injections per week for 12 months. This regime is based on optimal results as defined through extensive scientific trials, worldwide - of which a variety of treatment regimes was studied. For info on a small study involving daily dosing, see page 15 ... Ed.]

Your responsibilities when visiting your doctor

Doctors play a key role in ongoing monitoring of a person's hepatitis C and the long-term maintenance of their good health.

This is part two of a four part series outlining the responsibilities and rights of both 'patients' and doctors.

Disclose all information relating to your health to your doctor.

If you withhold information, your doctor can't be expected to make an accurate diagnosis and begin proper treatment. Not telling them everything could even result in potentially dangerous therapy or tests. The information you give your doctor should be confidential and should not be used for any purpose other than to provide for your treatment.

Keep office appointments or cancel well in advance.

Just as it's unfair for your doctor not to keep their appointments promptly, it's unfair for you to be late or to just not show up. If you're going to be late, please call ahead and let them know. If you need to cancel, please try to do so 24 hours in advance so that someone else will be able to make an appointment in your place.

Plan your visit with the doctor.

Think about and write down any questions you may have in advance so that you can refer to them during your visit. Think about your symptoms carefully, so that you can give informed answers to the doctor's questions.

Stop your doctor when you don't understand what they are explaining and ask for a simpler explanation.

The doctor won't know you don't understand unless you tell them. He or she won't think you're stupid if you ask for clarification, and will probably appreciate the fact that you want to be informed about your health. Doctors are used to thinking in obscure medical terms, and tend to forget that not everyone knows what they are talking about. It's okay to slow them down and get the information in terms you understand.

Ask questions.

This is both a right and a responsibility. You need to ask the questions you want answers to. A doctor can't read your mind.

Follow the doctor's advice and report quickly any adverse effects of therapy, complications from tests, or worsening symptoms.

If you don't follow your doctor's advice, why would you be seeing them in the first place? If you disagree with the treatment suggested, you should discuss this with the doctor, rather than just going home and not following the advice. If there are problems with the treatment, the doctor needs to be informed so that changes can be made.

Limit phone calls between visits to adverse effects of therapy, complications or worsening symptoms, or other matters which you have agreed on in advance.

It's important to keep your doctor informed of problems with your treatment. It's also important not to "bug" them. Often doctors will wait several hours to return non-emergency calls so as not to interrupt ward rounds, patient visits, and so on. Don't be too impatient if the secretary has taken a message; the doctor will get it and return your call. If the doctor does not return your call at all, then you have every right to be upset about it and should discuss your concerns about this with them.

◎ Adapted with thanks from a US-based original taken from the internet email list, HEPV-L.

Health Worker Education Strategy

In 1998, fifty health workers from around NSW gathered to discuss current HCV education opportunities. It was recognised on the day that we would see a continued increase in demand for hepatitis C education services; that education for health workers needs to accommodate their diverse roles and experiences; and that education has to be accessible, relevant to particular settings and known to produce positive changes in work practice.

Early in 1999, the Hepatitis C Council NSW secured funding from NSW Health for a six month project to carry forward the work of the previous planning day. In particular, a key objective was to develop an integrated education and learning strategy for NSW health workers who don't specialise in hepatitis C.

Initiated as a collaboration with the Centre for Education and Information on Drugs and Alcohol (CEIDA), the project vision was to develop a user friendly framework that would support action-learning within organisations. The project's approach represents a significant shift from targeting health care workers by their professions to targeting them by the organisations they work in.

A series of tools were developed to assist health worker teams to reflect on what helps and what hinders them in achieving better hepatitis C-related services. Sixteen organisations from around the state participated in structured team processes. The organisations included Needle Syringe Program Outlets, non-government alcohol and other drug agencies, a rural community health centre, and a sector within a rural area health service.

The teams were then involved in mapping their individual and organisational gaps, barriers and opportunities for developing or enhancing hepatitis C services. An organisational action plan was then developed. Most of the organisations were able to develop a broad range of programs and professional development activities. These include interagency program planning workshops, enhanced brief or opportunistic interventions; information loop strategies, client needs assessment strategies and group work skill development.

A key achievement with these action learning processes was that the outcomes were generated by the teams of health workers themselves. The project served as a resource for their activities but in the end, it was their planning and activities that lead to the outcomes.

- For more information, contact the project manager, Rob Wilkins, on 02 9382 8285.

  For a copy of the strategy, call the Hepatitis C Council NSW on 9332 1853 or visit the project website at <www.hepatitisc.org.au/project>

	Aushep 08	Nthn Rivers CH100 trial
Who's it for?	People who've never tried interferon.	A Chinese Herbal Therapy trial - for people who live in the Northern Rivers region of NSW.
What's involved	**(Genotypes 1 or 4)** Group 1: interferon @ 5mu daily for 8 wks, then 3mu 3x wkly for 44 weeks; plus ribavirin, daily for 52 wks. Group 2: interferon @ 3mu 3x wkly for 52 wks; plus ribavirin, daily for 52 wks. **(Genotypes 2 or 3)** Group 1: interferon @ 3mu daily for 4 wks, then 3mu 3x wkly for 20 wks; plus ribavirin, daily for 24 wks. Group 2: interferon @ 3mu 3x wkly for 24 wks; plus ribavirin, daily for 24 wks.	Participants will not know whether they are taking CH100 or placebo. GP visits and health status surveys at 0,1,3,6,9 months. LFTs at 0,1,3,6,9 months. PCR genotyping at beginning of trial. PCR viral detection and viral load tests at beginning and at 24 wks. Group 1: CH100 taken 3x daily for 24 wks. Group 2: Placebo (harmless substitute) taken 3x daily for 24 wks.
Where are treatment centres?	Illawarra, John Hunter, Nepean, Prince of Wales, Royal Nth Shore, Royal Prince Alfred, Westmead, Woden Valley (ACT).	Particular GPs practising in the Nthn Rivers area participating in the trial (although enrolment is closed - see below).
Would anything rule me ineligible?	Having cirrhosis, Previous treatment, Injecting drugs (oral methadone OK), Hep B coinfection, Falling pregnant (women), Conceiving a child (men). People should have already had the following tests done prior to enrolment: 1x PCR viral detection test; 3x LFTs showing elevated ALT; a biopsy result no more than 2 yrs old; a negative HBV test.	People must have 2x positive HCV antibody test results - the 1st done at least 12 months prior - and liver function tests showing ALT levels currently or recently elevated above normal. Other exclusion criteria: current interferon or any herbal treatment, hyper-tension, pregnancy or breastfeeding, psychotic illness, non-HCV liver disease, HIV/AIDS, injecting drugs, alcohol intake of >70g per wk.
Are enrolments still open?	No, enrolments have just recently closed. When available, update reports will be published in this magazine.	Enrolments closed towards the end of August 1999. When available, update reports will be published in this magazine. Nikki Keefe 02 6620 7518 (Thurs), Tim Sladden 02 6620 7509 (other days, Mon-Fri).

The impact of diagnosis of chronic hepatitis C infection on quality of life.

By Alison Rodger

There have been a lot of reports in the medical literature on the fact that people with chronic hepatitis C virus (HCV) infection report disabling fatigue and a reduced sense of well-being. When their 'quality of life' was measured on a variety of scales it is significantly worse than for the populations who do not have hepatitis C. There have been many theories for this;

The effects of the virus itself.

A diagnosis of 'illness' or chronic infection that no-one is quite sure what the outcome of it is and that no-one can guarantee a cure at present, can lead to a large degree of emotional stress.

Such stress can be made worse in the case of hepatitis C because of the discrimination that still exists around the virus.

Many people became infected with hepatitis C as young adults during a time of their life when they were experimenting with drugs. To find out that what seemed harmless experimentation has resulted in an infection like hepatitis C can be difficult to deal with.

Previous studies have not really been able to separate out these factors because all subjects knew they were infected at the time they completed the quality of life scales. In our study about half of people were unaware they were infected when they completed the initial questionnaires. This allowed us to examine the impact of the Hep C virus in those who didn't know they had it, compared to the overall impact on those who knew their diagnosis.

The quality of life tool that we used is called the Short Form (SF) 36 which looks at both physical and emotional health measures. By scoring the questions answered it is possible to see how a person views their quality of life in a number of areas. The SF-26 form is widely used both in Australia and overseas to look at quality of life and was used in the National Health 2000 survey.

We found that the group **that knew that they had hepatitis C** had significantly worse quality of life scores in seven out of eight areas measured when compared to population norms. However, **those who didn't know that they had hepatitis C** scored significantly worse in only three out of 8 areas. In the other five their quality of life was normal.

While those who **didn't know** they had the virus scored worse in areas measuring energy levels, Those who **did know** they had the virus scored badly in many more areas including emotional health, physical health, ability to carry out social and other commitments and psychological health.

The evidence suggests that just being told you have a diagnosis of hepatitis C can affect how a person feels in a number of areas and can significantly affect your life. This is separate to the possible added effects of the virus on energy levels or any increase in liver function tests. We think that communication of the diagnosis should only be done by trained professionals who take an adequate amount of time to discuss <u>all</u> the issues around being diagnosed with hepatitis C and provide adequate ongoing support.

- This information initially presented at the Second Australasian Conference on Hepatitis C, Christchurch NZ, 17-19 August 1999.

  Text abridged from the referenced original: Rodger AJ, Jolley D, Thompson S.C, Thomson J.A, Lanigan A, Crofts N. The Impact Of Diagnosis of Chronic Hepatitis C Infection On Quality Of Life. *Hepatology* 1999;30: 1299-1301

The NSW Health Hepatitis C Public Awareness Campaign

(from page 1)

Background

It is estimated that there are approximately 200,000 people in Australia who have contracted the hepatitis C virus. The rate of new infections is estimated to be 11,000 people annually with NSW accounting for over 40% of all HCV cases, both in terms of prevalence (people already with HCV) and incidence (new cases of HCV infection).

To date, education work to prevent hepatitis C has concentrated on the development of specific education programs targeting high-risk populations and specific measures such as needle and syringe programs. Indeed there has been as yet no hepatitis C information and education mass media campaigns targeting the general community in Australia.

In response to this, NSW Health established in March 1999 a campaign steering group, comprising representatives from the NSW Health Hepatitis Advisory Committee, NSW Health Department, Commonwealth Department of Health and Aged Care and other relevant non-government organisations, researchers and general practitioners to oversee the development and implementation of the campaign.

Process

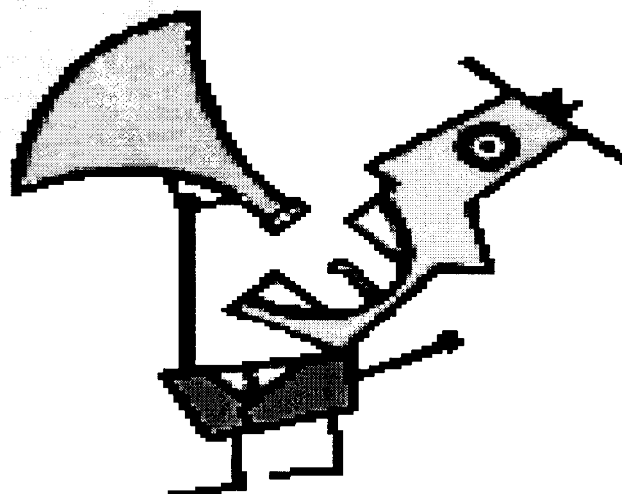
A consultation process involving a broad range of key stakeholders for the campaign was conducted in April and May 1999. The process included focus groups with people with hepatitis C in both rural and urban NSW as well as telephone interviews with a range of key informants. The information collected was used to develop an overall communication strategy and key messages for the campaign, which include:

The general community:

Hepatitis C is a widespread infectious disease that can cause serious health problems. Major risks of infection are through sharing injecting equipment, as well as tattooing and body piecing with unsterile equipment. Transmission, symptoms, effects and the treatments for hepatitis C are different to those of hepatitis A & B. Information and support is available.

People with hepatitis C:

Information, treatment and support is available.



People with hepatitis C who are from a non-English speaking background:

Hepatitis C is a widespread infectious disease that can cause serious health problems. Major risks of infection are through sharing injecting equipment, as well as tattooing and body piecing with unsterile equipment or through medical procedures carried out with unsterile equipment in some overseas countries. Information and support is available.

Health Professionals:

Your attitude towards people with hepatitis C can make a difference.

NSW Health, using the campaign communication strategy, selected and appointed an advertising agency in January 2000 to develop the campaign products. The campaign is presently in the final processes of developing a broad range of campaign material to be launched in late March 2000.

Education components

The NSW Health Hepatitis C Public Awareness Campaign will employ a broad range of education components. These will include:

- Statewide television advertising, broadly based on the key messages of the campaign which will run from late March 2000 until late April 2000.
- Print resources, including posters and pamphlets available from Area Health Services and other relevant health organisations.
- A telephone contact helpline, which will be available throughout the period of the campaign providing information and referrals relating to hepatitis C.
- Local Area Health Service activities will include, local campaign launches, information for general practitioners, needle and syringe programs.
- Information mailout to general practitioners.

NSW Health has also been working with a range of relevant government and non-government organisations including the Hepatitis C Council of NSW, the NSW Users and AIDS Association, CEIDA and the Multi-Cultural HIV/AIDS Project in developing a range of additional support services to deal with the impact of the campaign. These include material targeting specific ethnic groups.

The Hep C Helpline, NSW's statewide telephone information and support service, operated by the Hepatitis C Council of NSW, will be the main advertised number for the general public to call during the campaign.

Websites around the world

If you want to find out more about hepatitis C - and related topics - why not jump on the net and surf some sites?

It's a great way to spend an hour or two but remember that it may be frustrating finding exactly what you want and you may easily find people's personal opinion - dressed up as fact.

Accordingly, other than for our own website, we can't vouch for the accuracy of information you may find on these listed sites. If you have queries, contact the NSW Hep C Helpline.

Hepatitis A Virus (HAV)

[illegible] Infectious Disease (NCID):

[illegible]dod/diseases/hepatitis/a/fact.htm

[illegible]

[illegible]edu/diseases/hepatitis/hav_faq.html

Hepatitis B Virus (HBV)

World Health Organization (WHO):

http://www.who.int/inf-fs/en/fact204.html

CDC: National Center for Infectious Disease (NCID):

http:/www.cdc.gov/ncidod/diseases/hepatitis/b/fact.htm

Johns Hopkins University:

http://www.hopkins-id.edu/diseases/hepatitis/hbv_faq.html

Hepatitis B Foundation (HBF):

http://zippy.trade[illegible]/hepb/home.html

Hepatitis B (Du[illegible]

http://h-devil[illegible]ke.edu/h-devil/stds/htitis.htm

Hepatitis C virus (HCV)

Hepatitis C Council of NSW

www.hepatitisc.org.au

Hepatitis C Council of QLD

www.powerup.com.au/~hepcq

Hepatitis C Council of VIC

www.hepcvic.org.au

Australian Commonwealth Dept Health & Aged Care

www.health.gov.au

NSW Health Department

www.health.nsw.gov.au

American Liver Foundation

http://sadieo.ucsf.edu/alf/alffinal/

Hepatitis C Foundation

http://www.hepcfoundation.org/

Hepatitis Foundation International

http://www.hepfi.org/

Hep-C Alert!

http://www.hep-c-alert.org/

HepCure

http://www.junction.net/hepcure/index.html

HepNet

http://www.hepnet.com/index.html

HepOnline

http://www.heponline.net/

Sapient Health Network

http://www.shn.net/hepatitis_c_1.html

World Health Organisation

http://www.who.int/emc/diseases/hepatiti/index.html

World Health Organization (WHO):

http://www.who.int/inf-fs/en/fact164.html

Hepatitis C, The Virus and the Disease (ALF):

http://gi.ucsf.edu/alf/infohepc.html

The National Digestive Diseases Information Clearinghouse (NIH):

http://www.niddk.nih.gov/health/digest/pubs/chrnhepc/chrnhepc.htm#A

Natural History of Acute HCV Infection, Excellent Graph:

http://www.hopkins-id.edu/diseases/hepatitis/hep_fig8.html

CDC, Hepatitis Branch:

http://www.cdc.gov/ncidod/diseases/hepatitis/c/fact.htm

National Kidney Foundation (NKF):

http://www.kidney.org/general/aboutdisease/index.cfm

Definitions, Glossary:

http://www.hepnet.com/liver/glossary.html

Other Liver Related Web Sites (Columbia):

http://cpmcnet.columbia.edu/dept/gi/other.html

World Map of Hepatitis C Virus around the World:

http://www.epidemic.org/theFacts/theEpidemic/hepC_worldPrevalence.html

U.S. Veterans with Hepatitis:

http://www.geocities.com/Pentagon/Bunker/2704

How to Start a Support Group:

http://www.geocities.com/Pentagon/Bunker/2704/Support.html

Basic Con[illegible]ation, Organizations for Info on Hepatitis:

http://www.[illegible].com/Pentagon/Bunker/2704/Info.html

United States [illegible] Alliance (USHA):

http://members[illegible]2000/

National Hepatitis [illegible]:

http://members.aol[illegible]Home.html

Hepatitis C Foundation [illegible]

http://www.hepcfounda[illegible].html

Hepatitis Foundation inter[illegible]:

www.hepfi.org

Hep C Quilt (USA):

http://www.heponline.net/quilt.h[illegible]

Hepatitis D Virus (HDV)

CDC, National Center for Infectious Disease (NCID):

http://www.cdc.gov/ncidod/diseases/hepatitis/slideset/hep00051.htm

Johns Hopkins University:

http://www.hopkins-id.edu/diseases/hepatitis/hdv_faq.html

Hepatitis E Virus (HEV)

CDC, National Center for Infectious Disease (NCID):

http://www.cdc.gov/ncidod/diseases/hepatitis/slideset/hep00058.htm

Johns Hopkins University:

http://www.hopkins-id.edu/diseases/hepatitis/hev_faq.html

Hepatitis F Virus (HFV)

Johns Hopkins University:

http://www.hopkins-id.edu/diseases/hepatitis/hfv_faq.html

Hepatitis G Virus (HGV)

CDC, National Center for Infectious Disease (NCID):

http://www.cdc.gov/ncidod/diseases/hepatitis/nonanonb/fact_g.htm

Johns Hopkins University:

http://www.hopkins-id.edu/diseases/hepatitis/hgv_faq.html

Over the next couple of editions, we'll provide more lists of interesting websites relating to:

- Blood
- Medical information
- Herbs/Chinese medicine
- Genetics & virology
- Medicine
- Nutrition
- Basic sciences (medicine)

Experience of a hep C support group in Northern NSW

A little less than a year ago, we formed a hep C support group to seek and share information. We meet in a small town in rural northern New South Wales.

The group is organised by a health worker. We meet once a month, in the evening, as some of us work. There aren't any formal rules, other than a group agreement to keep what transpires in the group confidential and not to disclose members' identities.

The group is open to people affected by hepatitis C and their friends and family. Sometimes we view a video or have a guest speaker, often we circulate new information, such as the latest *Hep C Review.* Although the group is still running after almost a year, it is small and it has been difficult to attract new members.

One of the reasons for this is the reluctance to be identified as someone who has hep C, especially in a small town where everyone knows each other, and disclosure may affect your job - or your children. Also, some people just don't have the energy to come to meetings. And where we are, public transport is not readily available, so those without a car are virtually excluded

When asked to discuss why we sought a support group, most of us replied, "information." Information on hepatitis C is hard to come by and we have experience of GP's and specialists who seem to know very little about it.

We want to beat this infection, and we need information to do it. In attending a support group, we feel less alone. We value each other's support. We listen to each other's experiences and problems and share things we've learned along the way. We've taught each other how to relax and meditate, and shared our understanding of test results. We've encouraged each other through liver biopsies and shared experiences with complementary therapies.

Some of us have participated in the Northern Rivers Hepatitis C Chinese Herbal Trial, and we've shared that, too!

We've also shared some ideas for improving the lives of people affected by hepatitis C.

People need to be made aware so they can make lifestyle changes. And, in addition to educating doctors about hepatitis C, we feel

there is a great need to educate the general public, in order to decrease discrimination. Sure, Hep C is a virus, but it's not as contagious as everyone thinks. We need a public campaign to educate people about hep C - to market it as an illness, a liver virus, not HEP C: THE SOCIAL THREAT. We'd like to see funding for grassroots workers and shopfront premises. And, last but not least, we want ideas on how to get funding for things like these.

- Anyone interested in attending a hep C support group in the Tweed/Murwillumbah area, please contact Marilyn on (02) 66720277.

INject
YOurSelF
DON'T
INFecT
YouRSelf

You

Can INject without catching Hep C. If you already have Hep C you can avoid reinfecting yourself.

How?

CHange the way YOU INject.

Avoid Hepatitis C When Injecting - Whenever possible try following this guide to avoiding blood contact.

The amount of blood needed to infect someone else with the Hep C virus can be so small that you can't even see it.

Injecting Gear - have a new fit, spoon, water, filter, swab and tourniquet

Clean Your Act Up wash your hands with warm soapy water and clean your spoon with a fresh swab

clean the fingers you'll use to pull off a filter with a fresh swab

keep all your injecting gear separate from other people's gear

(For example; a shared tourniquet could have been touched with (invisibly) bloody fingers or may rub over someone else's injection site, then over yours, sharing blood and hep C)

Do it Yourself inject yourself - if someone else does inject you, make sure they've washed their hands first

During and After if you get blood on your fingers, go and wash your hands before you touch anything on the table - if someone tells you to pass them something, tell them to wait

if you do touch something by accident, (a cup, fit bin - whatever) let your mates know not to touch it themselves before they hit up.

wash your hands after touching anything that someone else may have touched

dispose of equipment thoughtfully - especially, fits back into fit packs or plastic drink bottles

Remember

- use new equipment every time - Your fit, Your water, Your filter, Your swab, Your tourniquet - *It's Your Life!*
- wash your hands with soap and water
- make sure the bench or table where you're injecting is as clean as possible

Can't be bothered with all that?

If this all seems too hard, remember that many suggestions are common sense - it's all about avoiding even the smallest amount of blood contact. A bit of preparation, having new injecting gear on hand and thinking it through is all it takes. For more information on local needle & syringe programs, contact ADIS - 9361 2111 (Sydney) or 1800 422 599 (NSW).

Above page taken from the Kirketon Road Centre newsletter. Our thanks for permission to reprint.

Mono-interferon

People with significant symptoms, raised ALT levels and chronic persistent hepatitis, and all those with chronic active hepatitis on biopsy, irrespective of symptoms, can be considered for interferon treatment. It involves injections, three times a week, for twelve months. Only around 20% of people, overall, maintain a good long-term response. People who already have cirrhosis don't respond as well to interferon - only around 10% have a good response.

Interferon treatment nearly always involves side effects. Some people report no problems at all while others find the side effects so unpleasant they stop treatment. If considering treatment people should be aware of the possible side effects before making a decision. If concerned, someone may decide to postpone treatment until a particularly demanding work project or other personal commitment is completed.

Interferon side effects can include flu-like symptoms - fevers, chills, lethargy, muscle pain, and depression. Existing depression and mood swings may worsen and need to be monitored closely. Overall, side effects may gradually lessen as a person's body develops a natural tolerance to the drug.

An initial psychological assessment should be given. If someone has a history of psychological problems such as depression, interferon treatment may still be given but will be monitored especially closely as it can worsen such pre-existing conditions. Less common side effects can include mild temporary hair loss, blood disorders, thyroid disorders, skin lesions and worsening of psoriasis (a skin disorder). Overall, most side effects will usually go away once treatment stops.

Mono-interferon eligibility

Interferon is available through the Pharmaceutical Benefits Scheme S100 category for people who meet the criteria listed below. Treatment centres exist in every state and should offer a nurse educator/counsellor for patients, 24 hour patient access to medical advice, a day-stay liver clinic and facilities to do safe liver biopsies. To access subsidised S100 interferon treatment, people need to meet the following requirements:

- have a liver biopsy that shows chronic hepatitis (waived for people with clotting disorders)
- have a repeatedly positive HCV positive test
- have raised ALT levels in conjunction with demonstration of viral infection (HCV antibody positive and/or HCV PCR positive)
- do not have cirrhosis or other liver disease
- are not pregnant or likely to become pregnant during treatment
- have no history of major psychological problems - eg. schizophrenia, major depression
- be able to attend regularly for treatment and follow up
- drink no more than seven standard drinks per week

Combination therapy?

Government subsidised S100 combination therapy is available only to people who have previously had interferon monotherapy (where such treatment would have complied with S100 criteria for PBS subsidy) but relapsed. It consists of interferon and ribavirin, collectively manufactured under the name "Rebetron". It involves a 6 month course of interferon injections (3 times a week) and ribavirin capsules (taken twice a day). People are asked to visit their GP or specialist for follow up visits during and after treatment. S100 subsidised combination therapy is withdrawn after three months of treatment if HCV RNA still remains detectable (ie. if a person remains PCR positive).

Studies have shown that people with hepatitis C are more likely to have a sustained response with combination therapy than with interferon alone. Overall, a person's chance of responding well to combination therapy is related to their hepatitis C genotype and the amount of virus in their blood. To date, genotypes 2 and 3 have been shown to have a higher response rate (60-70%) to combination therapy than genotypes 1 or 4 (20-30%). If people have responded to previous interferon monotherapy but then relapsed, there is still a good chance of response with combination therapy. Those who did not respond to previous interferon have only a low chance of responding to the combination therapy.

Many people who have considered the relative response rates and are interested in combination therapy are holding off interferon monotherapy while awaiting a possible change to S100 guidelines that would allow for combination therapy as a first option for hepatitis C treatment.

Side effects with combination therapy vary for each person and do appear to become less severe as treatment continues. They are similar to those experienced with interferon alone (see left). A potentially serious side effect of ribavirin is anaemia. People's blood counts are monitored very closely, especially in the first few weeks, and doctors may reduce the ribavirin dose if necessary. Ribavirin has also been shown to cause birth defects and combination therapy is not available to women who are pregnant or breastfeeding, or to anyone (women and men) not using adequate contraception during treatment or up to six months afterwards. Treatment centres will be able to provide detailed information about possible side effects and how to manage them.

NSW treatment centres:

Greater Sydney

Bankstown-Lidcombe
Campbelltown
Corrections Health (Long Bay)
Mount Druitt
Prince of Wales
Royal Prince Alfred
St Vincent's
Westmead
Blacktown
Concord
Liverpool
Nepean
Royal North Shore
St George
Sutherland

Regional NSW

Bathurst
Coffs Harbour (Base)
Dubbo (Base)
John Hunter
Orange (Base)
Wagga Wagga (Base)
Bega
Corrections Health (Bathurst)
Illawarra
Lismore (Base)
Port Macquarie (Base)

Complementary therapies

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

Certainly though, many people report positive benefits.

Natural therapists using acupuncture, homoeopathy, herbs or other methods aim to improve the overall health of their patients.

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

Some people choose complementary 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 complementary or 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 reasonable 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 complementary 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 complementary therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well-experienced in working with people who have hepatitis C.

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

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

Researched?

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

A previous Australian trial of one particular Chinese herbal preparation has shown some positive benefits and few side-effects (see Ed 15, p6). A similar trial but on a larger scale has been initiated in the NSW Northern Rivers region (see Ed 24, p8).

Want more information?

For general information about complementary therapies, phone the *NSW Hep C Helpline* (see page 42).

Additionally, contact any of the following organisations:

Organisation	Phone
Association of Remedial Masseurs	9807 4769
Australian Acupuncture Association	1800 025 334
Australian College of Acupuncturists	4677 2358
Australian Homoeopathic Association	9713 2793
Australian Natural Therapists Association	1800 817 577
Australian Traditional Chinese Medicine Assoc.	9699 1090
Australian Traditional Medicine Society	9809 6800
Homoeopathic Association of NSW	9247 8500
National Herbalists Association of Australia	9211 6437
NSW Association of Chinese Medicine	9212 2498
Register of Traditional Chinese Medicine	9660 7708

NSW Hep C Helpline

For free, confidential and non-judgemental information and emotional support you can phone the *NSW Hep C Helpline:*

9332 1599 (Greater Sydney callers)

1800 803 990 (NSW regional callers)

The service gives you the opportunity to chat with trained phone workers and discuss those issues important to you. It also provides referral to local healthcare and support services.

Sexual health clinics

Although hepatitis C is not classified as a sexually transmitted disease, staff at these clinics can offer a range of services including pre- and post-test counselling, antibody blood tests, general counselling and primary healthcare (the type of service that GPs provide). They are listed in your local phone book under 'sexual health clinics'.

If you are concerned about confidentiality, these clinics do not need your surname or Medicare card and keep all medical records private.

Community centres

Community Health and Neighbourhood Centres exist in most towns and suburbs. They provide different services, including counselling, crisis support and information on local health and welfare agencies. Some Neighbourhood Centres run a range of support and discussion groups and activities that may range from archery to yoga.

Community Health Centres can be found by looking in your White Pages under 'Community Health Centres'. Neighbourhood Centres can be found by phoning your Local Council.

Local support services

There are few local hepatitis C specific support services. This isn't because of lack of need but because there have been inadequate resources to develop them, or integrate other appropriate services. So where does this leave you?

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

Local hepatitis C services

Greater Sydney		
Central Sydney	Peter Todaro	9515 3375
Nthn Sydney	Graham Stone	9926 6717
SE Sydney	Lesley Painter	9382 8370
Sth West Sydney	James Mabbutt	9828 5944
Wentworth area	Elizabeth O'Neill	4724 3877
Western Sydney	Chris O'Reilly	9840 4105
Regional NSW		
Central Coast	Karen Nairn	4320 3399
Far West NSW	Darriea Turley	08 8080 1511
Hunter	Marilyn Bliss	4924 6477
Illawarra	Brian O'Neill	4228 8033
Mid Nth Coast	Robert Baldwin	6588 2789
Mid West NSW	Dave Brackenreg	6339 5576
New England	Karin Ficher	6766 2288
Nthn Rivers	Kerry Leitch	6620 7505
South West NSW	Dalton Dupuy	6058 1700
Southern NSW	Geetha Isaac-Toua	6298 9292
Western NSW	Scott Davis	6885 1700

One-to-one counselling

Some people with hepatitis C may want to talk to a specialist counsellor who can provide special support or therapy when they have specific problems they're having difficulty dealing with.

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

To find out more, speak to your GP, or contact your local sexual health clinic, Community Health and Neighbourhood Centres, or the NSW *Hep C Helpline.*

TRAIDS - the Transfusion Related AIDS & Infectious Diseases Service - was originally set up to provide counselling and support to people who contracted HIV through contaminated blood products. *TRAIDS* now also provides services to any people with HCV, including family counselling.

Family counselling

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

To find out more, contact *TRAIDS* (above), speak to your GP, look in the Yellow Pages under 'counselling', contact Family Planning or your local Community Health or Neighbourhood Centre, or phone the NSW *Hep C Helpline* (see above, top left).

Hep C Helpline extends hours during Awareness Campaign

The *NSW Hep C Helpline*, the state-wide telephone information and support service operated by the *Hepatitis C Council of NSW* will be open for extended hours for a six week period beginning Monday 27 March.

During this period, the *Helpline* will be open during the following hours:

Monday to Friday:	**9am - 9pm**
Weekends:	**10am - 6pm**

The majority of our usual callers are people who have hepatitis C and their family members or friends. But we also talk with a great number of other people - healthcare workers included - who often phone seeking clarification of questions around HCV or requesting resources. During the campaign, we expect to take a large additional number of calls from members of the general public.

Do you have a hep C story to tell?

If so, we'd all love to hear it.

Your story can be kept confidential and does not need to carry your name, suburb, etc.

So please send in your stories to us. They are such an important feature of our magazine.

The Council is always looking for people willing to do media work. We'll offer training. Give us a call if you are interested.

Except for videos, these resources are available free of charge.

Videos are borrowed for two weeks at a time and will only cost you the return postage. Phone or write and tell us what you'd like - but please do not send any payment for videos - just pay for the return postage when you post them back to us.

Eds. 1-8 back issue pack - various topics / historical interest

Ed 9 - Chiron's patent / living with grief

Ed 10 - natural therapies

Ed 11 - genome subtypes / life insurance / Terrigal symposium

Ed 12 - drug law reform / HCV fatigue / women & HCV

Ed 13 - HCV & prisons / 94-95 annual report

Ed 14 - discrimination / drug law reform / DSS / clinical trials

Ed 15 - partying safe / informed consent / stress / Nat AIDS strategy

Ed 16 - diet & nutrition / DSP changes / IDU & hep C councils

Ed 17 - study grants / HCV & relationships / Australasian conference

Ed 18 - Parliamentary Inquiry / HCV & IDU / safe disposal

Ed 19 - notifications / diagnosis / understanding research

Ed 20 - PCR / biopsy / treatments / transplant / tattooing

Ed 21 - legal issues / liver function tests / sexual transmission

Ed 22 - living with chronic illness / painkillers & HCV / alcohol & HCV

Ed 23 - The Neglected Epidemic / overseas update / genotypes

Ed 24 - alternative therapies / fatigue / Pegasys interferon trial

Ed 25 - current & evolving drug treatments / interferon side effects

Ed 26 - living better / combo therapy / 2nd Australasian conference

Ed 27 - seeking support / HCV & disclosure / summarising Aust. response

Hepatitis C - a brief introduction - (brochure)

Hepatitis C - what you need to know - (booklet, single copies free)

Hep C Helpline - Poster and calling card (bulk copies available free)

Video 1 - ***Interferon / HCV & women*** - (you pay return postage)

Video 2 - ***homoeopathy / herbalism*** - (you pay return postage)

Video 4 - ***hepatitis C / the liver*** - (you pay return postage)

Look Back Look Forward - video (you pay return postage)

Research Pack 1 - epidemiology / prevention / serology / diagnosis

Research Pack 2 - overview / National Action Plan

Research Pack 3 - 1994 NHMRC Hepatitis C Report

Research Pack 4 - surveillance / post-transfusion HCV / herbalism

Research Pack 5 - AHMAC / NSW Taskforce Report

Research Pack 6 - prisons / treatment / IDU / PCR

membership form

Please complete as much of this form as possible. Our policy is to respect your privacy. All details on this form are treated in the strictest confidence and all communication is carried out discreetly.

Please return this form with your cheque, money order or credit card details to:
Hepatitis C Council of NSW
PO Box 432 DARLINGHURST NSW 1300

Please make cheques out to *Hepatitis C Council of NSW.*

1. Please complete either a, b or c.

a. For people affected by hep C, or other interested people.

Name			
Postal address			
Suburb / Town			
State		Postcode	
hm phone		Wk phone	

b. For individual healthcare or welfare professionals.

Name			
Occupation			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

c. For agencies, companies and organisations.

Organisational name			
Contact person			
Position			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

2. If you can help with any of these activities, please tick the following boxes.

Admin and office work?	
Other?	

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

Renewal		New member	

4. Please circle one membership fee box.

All memberships expire on 1 March each year and should be renewed as soon as possible after this date.

Our range of fees allows for people with no real form of income (eg. prisoners) to pay a zero fee. We suggest people on government benefits could pay the concessional fee.

Waged	$25	Professional healthcare worker	$40
Concession	$10	Community-based organisation	$50
Zero Fee	$0	Public/Private sector organisation	$70

5. Separate donations are gratefully accepted by the Council.

If you make a separate donation, please record the amount here. $

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

Card number

Card type (please circle) MasterCard | Visa | Bankcard

Expiry date month ____ year 19__

Cardholder's full name

Cardholder's signature

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

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

Signed

Dated

Please contact the office if you would like a copy of our Constitution, or visit our website: www.hepatitisc.org.au/constitution.html

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

THE HEP C REVIEW IS GOING TO JAIL

The Hepatitis C Council of NSW and the NSW Department of Corrective Services have combined forces to supply information about hepatitis C (hep C) to inmates and staff in the state's correctional centres.
This is important because about half of all the inmates in NSW jails are already hepatitis C positive, and high-risk behaviours like injecting drugs, tattooing and body piercing are extra risky in jail because there are no needle & syringe programs, and tattooing and piercing equipment is mostly 'home-made' and impossible to keep sterile. With so many inmates already having hepatitis C, accidental cuts from other people's razors and other sharp objects are also riskier in jail.
This edition of *The Hep C Review* is the first to be sent out to the jails, so we are including this brief survey to find out what you think about the magazine, and to hear what else you would like to know about hepatitis C. We are also interested in your opinion about other ways the Hepatitis C Council can help people in jail.
We think it is very important to meet the needs of all our readers, so please fill in the survey, whether you are in jail or not. It is anonymous, so **DO NOT PUT YOUR NAME ON THE FORM.** Just answer the questions or tick the boxes, then fold, seal and return to us - POSTAGE FREE!

ABOUT YOU

How old are you? ....

Are you: ☐ Male ☐ Female ☐ Transgender

What is your home postcode - or your last postcode before coming to jail? ....

If you are answering from a jail, are you: *(Please tick the box that best applies to you)*

- ☐ An inmate
- ☐ A correctional officer
- ☐ Inmate Development Staff
- ☐ Corrections Health Service staff
- ☐ Other *(please give details)* ....

Which jail are you answering from? ....

If you are not answering from a jail: *(Please circle yes or no for each)*

Have you ever been in jail	yes / no
Do you have someone close to you in jail at the moment	yes / no
Have you ever had someone close to you in jail	yes / no

For everyone, are you: *(Please tick as many boxes as apply)*

- ☐ A person with hepatitis C
- ☐ A partner or family member of someone with hepatitis C
- ☐ A friend of someone with hepatitis C
- ☐ A health care worker
- ☐ A social welfare worker
- ☐ Other *(please describe)* ....

....

....

ABOUT HEP C

Are the following statements about hepatitis C true or false? *(Please tick one box for each question)*

	True	False	Don't know
If someone has hep C, they can't get it again			
Hep C is not passed on by sharing cups and plates			
Hep C can be passed on through invisible tiny amounts of blood			
Sharing razors is safe unless you cut yourself badly			
If you don't share needles and syringes, you can't get hep C			
Sexual contact is a high risk for hep C			
There's a small risk that babies can catch hep C from their mother during birth			
There is no medical treatment for hep C			
Most people won't feel ill for many years after catching hep C			
Hep C can lead to cancer of the liver			
Hep C symptoms can be helped by a good diet			
Moderate drinking is good for people with hep C			
Once you have hep C, there is nothing you can do to feel better			

ABOUT *THE HEP C REVIEW*

Do you find *The Hep C Review* easy to read and understand?

☐ Yes ☐ Most of it ☐ Some of it ☐ No

How interesting do you find the following sections? *(Please tick one box for each section)*

	very	fairly	not very	not at all
Editorial page (p.3)				
Letters to the editor (p.4-5)				
News (p.1 & p.6-9)				
Information updates (p.12-15)				
'My Story' (p.11 & p.22)				
Prevention page (p.27)				
Interviews				
Cartoons				

What do you think people with hepatitis C, and their friends and families expect from a magazine such as *The Hep C Review*? ....

....

What do you think prison inmates expect from such a magazine? ....

....

What do you think correctional officers and other prison staff expect from such a magazine? ....

....

....

The Hep C Review can carry more news and research reports that apply specially to jails, and we invite people in jail to send letters to the editor and contributions to 'My Story'.
How should this material be presented? *(Please rank 1, 2, 3, in your order of preference)*

- ☐ mixed in with the regular format of *The Hep C Review*
- ☐ a special prisons issue from time to time
- ☐ a separate 'prisons page' in every issue of the magazine

ABOUT OTHER HEPATITIS C INFORMATION

The Hepatitis C Council of NSW operates the state-wide *Hep C Helpline* which offers free, confidential information and support over the phone for people who are affected in any way by hepatitis C.

If the *Hep C Helpline* was available directly to prisons, how useful do you think this would be:

	very	fairly	not very	not at all
for inmates				
for correctional officers				
for other prison staff				

What would be the best times for a direct *Hep C Helpline* to be available? *(You may tick more than one)*

Days
- ☐ Weekdays (Monday to Friday)
- ☐ Saturdays
- ☐ Sundays
- ☐ Holidays (such as Easter and Xmas)

Times
- ☐ Morning before 9:00 am
- ☐ Morning - 9:00 - 12:00
- ☐ Afternoon - 12:00 - 3:00
- ☐ Afternoon - 3:00 - 6:00
- ☐ Evening - after 6:00pm

Do you have any comments about a *Hep C Helpline* for prisons? ....

....

....

The Hepatitis C Council of NSW also provides other materials about hepatitis C. Which of the following do you think would be most useful in jails? *(Please mark 1 to 4 in order of usefulness)*

- ☐ Pamphlets
- ☐ Brochures
- ☐ Information booklets
- ☐ Videos

Thank you for answering the questions. Are there any comments you would like to make? ....

....

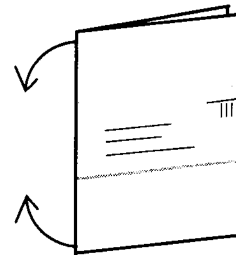
....

....

....

To send ..

1. Gently pull out the centre spread survey form
2. Fold the bottom part of the page backwards
3. Fold the top part backwards
4. Seal the horizontal join with sticky tape (there's no need to seal the ends)
5. Post the survey form in your nearest post box.



Thanks again for your valuable assistance!

No postage stamp required
if posted in Australia

REPLY PAID No 618
PO BOX 432
DARLINGHURST NSW 1300

If you want to make any other comments, please print them clearly in this box.