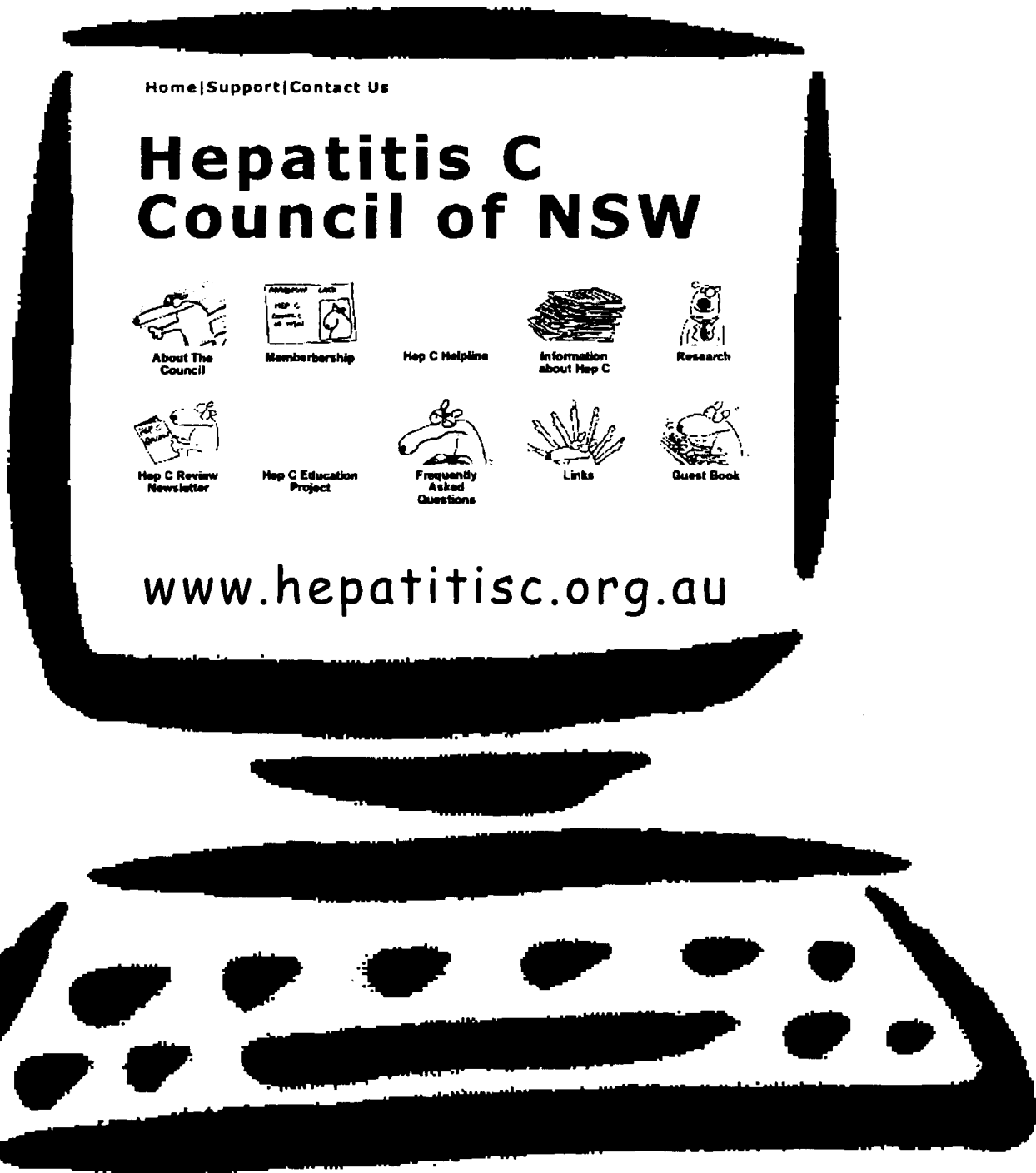


The Hep C Review

Summer Edition December 1999

Edition 27



We're proud to announce the launch of our own website - one that replaces our previous 'page' on the SPAN site. Our new site provides a wide range of information and enables communication amongst us, here in New South Wales, and with others around Australia and across the globe.

*in this edition
in this edition
in this edition*

*edition 27 focus: seeking support
info update: hepatitis C and disclosure
feature: summarising the national and NSW responses*

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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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Maintaining the momentum

By Stuart Loveday

We are in an exciting phase of the public health response to hepatitis C in Australia generally, and in New South Wales in particular.

Five current, closely interrelated developments are of special importance as 1999 draws to a close.

- ⊙ NSW Health is developing the 1st Hepatitis C Strategy for the state.
- ⊙ The Commonwealth Department of Health and Aged Care plans to launch the 1st National Hepatitis C Strategy in March 2000.
- ⊙ Following its completed review, NSW Health will shortly produce a comprehensive Hepatitis C Care and Treatment Services Plan.
- ⊙ A major Hepatitis C Public Awareness Campaign will begin in NSW in March 2000.
- ⊙ Underlying all of this is the NSW Government's keenly awaited response - now imminent - to the inquiry report of the Legislative Council's Standing Committee on Social Issues - *Hepatitis C: The Neglected Epidemic*.

The Hepatitis C Council welcomes the strategic intent of these new policy and service developments. However, there are some key areas of evidenced need that must be clearly addressed in the responses.

The hepatitis C strategies need to distinguish between the additional support needs of people considering or undergoing treatment, and the psychosocial needs of the many thousands more who are ineligible, unable or who do not want to undergo what is without doubt a difficult regime of pharmaceutical treatment.

Depression, a feature in the lives of around half the people living with hepatitis C, often goes hand in hand with the other common aspects of many people's lives - unemployment, poverty, relationship difficulties, discrimination, loneliness and the stigma of living with hepatitis C.

Many existing providers of psychosocial support are non-specialist health care workers working in a broad range of organisations. All health care workers are well placed to provide basic levels of information and to give this much needed support. But both health care workers, and the organisations they work in, are also in need of support, as another health "issue" is added to their ever increasing workloads.

By providing appropriate learning opportunities for health care workers, the capacity of health care organisations and workers to take on hepatitis C as part of their core business is enhanced. Improved services result. Ultimately, this can support the capacity of people living with HCV to manage their own health better.

An existing and very welcome initiative, the *NSW Health Care Worker Hepatitis C Education Strategy Project*, funded by the Commonwealth Dept of Health and Aged Care in partnership with NSW Health, is now at its conclusion. We urgently need to maintain the momentum of its first phase and implement the well evaluated findings and the resultant strategy. Fortunately, the implementation of this strategy will not require significant additional sums of money.

Another essential inclusion is the need for these new strategies to explore how people living with HCV can best use complementary therapies. So many people are already investing large amounts of faith and money - sometimes with anecdotally reported good results, sometimes with no discernable benefit - on unproven therapies. Rigorous, scientific research trials of herbal and other therapies - either to reduce the symptoms of HCV illness, the side effects of pharmaceutical treatment, or to treat HCV itself - are needed. We need to have proof so that people can make informed choices - as they can now with the improving drug treatments available.

In August, NSW Health Minister Craig Knowles announced a welcome doubling of recurrent hepatitis C-specific funding in NSW to almost \$1.5 million in 1999/2000. While this sum is additional to the funding for the essential harm minimisation

activities carried out by needle and syringe programs in NSW, it still needs to cover other hepatitis C prevention initiatives, care, treatment and support activities and to enhance HCV surveillance systems. There are estimated to be 90,000 people in NSW living with hepatitis C, across all 17 Area Health Service regions.

We applaud this strategy development. The real challenge remains for the NSW Government to provide the necessary commitment and resourcing to meet fully the objectives contained in the plans.

- ⊙ Stuart Loveday is Executive Officer of the Hepatitis C Council of NSW

"The Hepatitis C Council welcomes the strategic intent of these new policy and service developments"



Great report

Thanks for the report on HCV and dental health!

My teeth were always very good until my hep C became symptomatic, then my incisors started dropping out of sockets and I lost one. My gums started to recede and other teeth started falling apart.

I don't drink or even smoke and I'm not on methadone. Man, I say it was the hep - and I've talked to other people who've experienced similar.

Thanks for the good work.

Dennis in Seattle, USA

[NB: our conference summaries in this edition and our last have been posted on the internet email list HEPV-L (see Ed 24, p 30) - Ed.]



Congratz

Firstly, let me congratulate you on your very informative magazine. I have been positive for a few years now as a result of dangerous injecting practices.

When I read *The Hep C Review* for the first time I got angry that there is so much my doctors have not told me.

I was hoping you could explain a few things to me: firstly could you tell me about genotypes? What their uses are, how they are decided and what implications they have? Also, as I read I keep coming across references to PCR. Could you explain what this is please?

I'm going to tell my partner that I have HCV and I'm not sure how he will react. If his feelings for me are true, he will see HCV as a part of our life together and not be threatened by it.

Deep down, I'd much rather not tell him, ever. Yet I believe it is his right to know.

My family have been extremely supportive, although ignorance has bred fear in some of my family and

friends. They are either too scared or too sure of themselves to ask questions.

At one point the question was raised that if my cat scratched me and drew blood, then scratched someone else, could they become infected? We sought medical advice and found that it is a highly unlikely possibility, yet it showed me just how scared some people are of contracting HCV.

Perhaps if people knew more about HCV these fears would not be as widespread.

Keep up the good work on *The Hep C Review* because you've given me more relevant information in one edition than two doctors and an HIV/AIDS counsellor has been able to in over two years.

Thanks, Tarz

[Tarz, we'll arrange for a Hep C Helpline worker to call you back. For more information on the areas you've mentioned, also see below - Ed.]

Genotypes: 'HCV genotypes' Ed23, p11; 'Treatment of hepatitis C' Ed25, p32; 'What is a cure' Ed25, p30; 'Combination therapy' Ed26, p40;

PCR: Coverstory Ed22; 'Predicting response' Ed25, p11; 'Combination therapy' Ed26, p26;



Seeking consensus

My copy of *The Hep C Review* arrived yesterday and I read the article on consensus interferon with some interest. I started investigating consensus interferon about 5 months ago and got very excited by what I read - I will try and explain why.

The preliminary results show outcomes far superior to combination treatment i.e. Genotype 1 - 30% sustained remission on combination and 50% (projected) sustained remission on consensus. My excitement was not so much with consensus interferon per se but what the outcomes might be if you manufacture it in slow release form (like pegylated interferon) and add ribavirin to it e.g. the difference in sustained outcomes with Genotype 1 patients increases from 11% with interferon alone to 30% when you add ribavirin to it.

About a month prior to the Christchurch Conference (August 1999) I spoke with a drug company rep here in Adelaide - whom I trust and respect. He told me that he did not think consensus was any better than combination therapy and more importantly that the manufacturers of consensus interferon, a company called Amagen, will never market the drug in Australia as the market is too small.

When I was at the Conference I asked Stephen Locarnini about it and he said it was no better than interferon. I also asked Greg Dore - same

response - and finally I spoke to a drug company rep whom Stuart introduced me to. She also said consensus was no better than combination therapy and that Amagen will never release it in Australia.

I am not sure why these four people are so sure about the efficacy of a drug which has not yet completed clinical trials and I will personally take a "wait and see" stance on this one. My reason for writing to you is to alert people who may want to try consensus interferon that the only way of getting it would be to import it.

My specialist has told me that Thailand is a good place to buy pharmaceuticals at reasonable prices.

Thanks once again for an excellent publication - it's an inspiration.

Regards to everyone, Doug

[Anyone who is considering interferon-based therapies should do so with the assistance and under the guidance of their GP and a hepatitis C specialist. Also see, 'Mailorder Ribavirin', Ed26, pg7 - ED.]



Depression - it's treatable

As a GP, I find *The Hep C Review* of great value. I was especially interested in the emphasis in the recent edition on nutrition and lifestyle factors as a means to fight fatigue (Ed26, pgs 18, 20).

However, I was surprised to find no mention of depression in your article on fatigue. Depression is common: one in ten Australians suffer it as some stage. It can have serious effects on the immune system, can be the cause of pain and can lead to other physical illnesses. That's the bad news. The good news is that it is treatable.

It is true that fatigue caused by mild depression will respond to the lifestyle changes mentioned on page 20 in the latest edition, but I am concerned that some of your readers may not be aware how debilitating more severe depression can be. People can be troubled by a level of fatigue that just doesn't lift no matter what they have tried.

May I urge anyone with significant fatigue to attend their doctor with the question: might this feeling be depression (or indeed some other coexistent illness)?

I have a number of patients with hep C who have become symptom-free since their depression was treated. On the other hand, others have undergone a year of antiviral therapy, cleared the virus yet remained fatigued. It's worth a look.

Regards, (Dr) Gillian Deakin

[Thanks for bringing our attention to this aspect of addressing probable symptoms relating to hepatitis C. Readers can find more information on this subject in Ed21, p20 and Ed24, p18 - Ed.]



Down to earth

Having been a member of the NSW Council since being diagnosed, I wish to express my appreciation to all involved in your *Hep C Helpline* and the publication of your quarterly review *The Hep C Review*. I very much appreciate the wealth of information, human, down to earth approach as well as for the discretion in it's diffusion.

Your request in last issue for personal contributions prompted me to submit "my story." Feel free to use it if you think this can be of some help to anyone.

Thanks, Jean

[See page 11 - Ed.]



A pill a day?

I've been on the CH100 herbal tablets for some time now and am feeling better than before.

I'm wondering, though, if the Council can help out with organising a bulk buyer's club or something? This would help to bring the price down a bit and that's where my problem is - currently I'm having trouble affording the tablets.

Regards, Ken

[Thanks for the suggestion Ken. A Council staff member has recently developed a discussion paper on this idea to put to the Council's Management Committee. We'll report back in Ed28 - Ed.]

Seeking support

Reaching out for support is something we all do on a regular basis to varying degrees, either formally or informally.

The range of possible support mechanisms includes quite obvious things like visiting counsellors or psychologists if necessary. Most importantly, it also includes many everyday options: regularly talking to others and keeping in touch with family and friends; maintaining a sense of humor; or simply finding a good pet.

A key problem for many people with hepatitis C may be the personal disclosure that is usually involved in seeking support around their health.

This edition of *The Hep C Review* attempts to cover how people can identify their range of support sources and how to tap into them.

We hope that Edition 27's range of articles and news items on hepatitis C and seeking support meets your information needs. If not, we hope that it provides discussion points and signposts where you can find further, more detailed information.



COMING TO TERMS WITH HEPATITIS C

LOOK BACK LOOK FORWARD

a film by KATHY SPORT

Copies of this excellent video can be borrowed from the Council office. See page 43 for more information.

Government acts to rename its national advisory committee

The Federal Government has re-appointed Mr Chris Puplick as chairman of the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD), the Federal Minister for Health and Aged Care, Dr Michael Wooldridge announced recently.

Dr Wooldridge said he was delighted to re-appoint Mr Puplick who has served as chairman of the Council so professionally over the past three years.

"I am particularly pleased that Chris has managed to lift the profile of hepatitis C. The Council has made considerable progress in developing nationally focused policies and programs for hepatitis C education and research, without diminishing the importance of HIV/AIDS," he said.

It is with this in mind that the previously named Australian National Council on AIDS and Related Diseases (ANCARD) has been renamed the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD).

"During the last three years the Council has supported the formation of the Australian Hepatitis Council to provide advocacy and education about hepatitis C and the government has responded with research grants of more than \$1 million to assist the process.

"At the same time, Chris has overseen the development of strong links between Government and clinicians, researchers and community groups and has helped with the increased awareness of research, education and treatment developments."

Dr Wooldridge said he expects ANCAHRD will continue to be an effective, accountable and innovative body under the chairmanship of Mr Puplick and was pleased to see him at the helm again as Australia embarks on its first National Hepatitis C Strategy.



UK hepatitis C scare

Around 1,700 women and children are being contacted by four different hospitals following a hepatitis C scare in the UK. The women had been treated by a gynaecologist who has since been found to have hepatitis C.

Letters to the women and their children have gone out offering blood tests and counselling. It follows the news that hepatitis C was transmitted to a female patient by the surgeon at a hospital in Lincolnshire. Special telephone hotlines have been set up to offer advice.

Dr Martin Wale, a consultant epidemiologist said: "The chances of transmission are very, very low. We may well not find any more patients but we are asking patients to please come forward to be reassured."

The doctor and the patient he infected are not being named and have both been treated for the disease.

© ITN News Online: <<http://www.itn.co.uk/Britain/brit19991026/102611.htm>>

Taken with thanks from the internet email list: HEPV-L

New drug effective against an HCV model

Researchers at Jefferson Medical College (USA) may have found a promising drug against the hepatitis C virus. While they are quick to point out that the drug, N-nonyl-DNJ, stopped only a *surragate* (similar) virus from reproducing in the laboratory - and not the actual HCV - they believe the findings, which build on their earlier success against hepatitis B virus, may someday lead to a single drug against both viruses.

Timothy Block, Ph.D., professor of biochemistry and molecular pharmacology and medicine at Thomas Jefferson University in Philadelphia, USA, and colleagues at Oxford University in Oxford, UK, used the drug to inhibit the activity of an important cellular enzyme, glucosidase.

This in turn prevented the bovine diarrhoea virus (BVDV) from making more virus (because HCV cannot be grown in the lab, researchers use BVDV as a testing model). Dr. Block believes glucosidase inhibitors have a "reasonable likelihood" of working against HCV therapeutically.

"This is the first drug since alpha-interferon to my knowledge for which there is published experimental evidence against HCV - in the form of BVDV inhibition," says Dr Block. The next step, he says, is to experimentally test the drug against HCV and to determine why the virus is so sensitive.

© Taken with thanks from the internet email list: HEPV-L

Charges against Wayside Chapel minister dropped

By Sally MacMillan

Wayside Chapel pastor Ray Richmond is thankful to be a free man again. The Kings Cross clergyman was facing a possible jail term for operating a drug injecting room.

But the 61 year old Uniting Church minister vowed he would stand up to be counted and run such a room again should the situation arise anew.

"This is a win for commonsense. A win for compassion and tolerance," he told *The Daily Telegraph* after police withdrew the charges.

Police did not have to offer an explanation for the withdrawal. Sources, however, said the decision not to prosecute was made using discretionary powers. Consideration was also given to legislative changes to approve NSW's first legal drug injecting facility to be run within Sydney.

© Abridged with thanks from *The Sunday Telegraph*, 31/10/99.

[Although initially proposed to run out of St Vincent's Hospital, it is currently believed that the drug injecting facility will be operated by the University of NSW - Ed.]

Texas changes provider of prison ribavirin

By Mike Snyder, Houston Chronicle, USA.

In a move that could save millions of dollars, health-care contractors for the Texas prison system are purchasing Ribavirin from Fisher's Specialty Pharmacy Services in Pittsburgh, a small Pennsylvania pharmacy, rather than from Schering-Plough, a pharmaceutical company whose marketing of the drug has been controversial.

Prison system health-care officials decided in June to begin treating prisoners with the combination therapy after a study showed that 29 percent of the state's inmates, or about 42,000 prisoners, were infected with HCV. Although many of those prisoners would not be candidates for treatment for various reasons, officials have expressed concern that the high costs of the two drugs could have a serious impact on the prison health-care budget.

Until recently, Ribavirin was available for treatment of hepatitis C only as part of a kit marketed by Schering-Plough Corp., a drug manufacturer based in Madison, N.J. The other drug in the kit is Schering-Plough's brand of alpha interferon. For a standard one-year course of treatment, the retail cost of the two drugs is almost \$18,000 per patient, although Calhoun said the prison system was purchasing Rebetrone for about \$14,700. By obtaining the Ribavirin from Fisher's and the interferon from another supplier, the prison system will reduce the cost of the combination therapy to about \$5,000 per patient, Calhoun said.

Don Kerrish, a co-owner of Fisher's, said the pharmacy began looking for alternative ways to supply patients with Ribavirin after realizing that many patients, including some with health insurance, were unable to afford the Rebetrone kit. After the patent for Ribavirin expired recently, he said, the pharmacy's lawyers did some research and concluded that compounding the drug would be legal.

© Taken with thanks from the internet email list: HEPV-L

Researchers discover key to liver damage from alcohol

Investigators have identified a key process by which alcohol is likely to damage the liver in people who drink heavily, according to results from a study in the September 15th issue of the *Journal of Clinical Investigation*. They also showed that high doses of vitamin C could partially reverse this process, which may open up new therapeutic opportunities to treat alcohol-induced liver disease.

Dr. Emma A. Meagher and colleagues from the University of Pennsylvania, Philadelphia, measured the amount of so-called oxidant stress in a number of people who had been exposed either experimentally to alcohol or who had used alcohol excessively in their past. In the first study, 10 healthy volunteers were asked on a number of occasions to drink an alcohol-containing beverage with increasing amounts of alcohol.

"Even at blood alcohol levels that are attained socially, alcohol turns out to be a pro-oxidant," Dr. Garret A. Fitzgerald, senior author of the study, told Reuters Health in an interview.

For example, at a blood alcohol level of 0.08 - the legal limit for driving in most (US) states - the biochemical markers measured by the team and which reflect the degree to which volatile forms of oxygen in the body attack fat went up as much as 345%.

The team next demonstrated that patients who had developed cirrhosis of the liver after many years of excessive alcohol use also had significant elevations in the same biochemical markers of oxidant stress.

Tests carried out in a third group of patients who had been admitted to hospital with acute alcohol poisoning also revealed "astronomical" levels of oxidant stress, he added.

When investigators then introduced high-dose antioxidant therapy in the form of 2,500 mg a day of vitamin C for 10 days, biochemical markers of oxidant stress in patients with alcohol-induced liver disease decreased by approximately 50%. "We know that oxidant stress is important in other diseases such as cancer and heart disease and this study gives us a chance to now ask, how important is oxidant stress in mediating the adverse effects of alcohol on tissues like the liver," commented Fitzgerald.

If vitamin C and perhaps more potent antioxidants are found to help control or even reverse the damage induced by alcohol, there may be "new therapeutic opportunities" to treat alcohol-induced liver damage, Fitzgerald suggested.

© SOURCE: The *Journal of Clinical Investigation*, 1999;104:805-813.

Taken with thanks from the internet email list: HEPV-L

New internet database for medical & health information

by Harvey S. Bartnof, MD

PubMed Central, a new controversial free web project, will change forever the dissemination of life sciences research information. NIH (US National Institutes of Health) Director and Nobel Prize laureate Harold Varmus, MD, believes that several aspects of the internet can be exploited to provide quick, easy and worldwide access to biomedical research information as it becomes available. In particular, the *layering* of information with *intrafile hyperlinks* allows for an almost infinite amount of detail to be available for those who were interested (this means you can go to different levels of detail on a topic, depending on what suits you). Also, references would be *hyperlinked* (this means clicking on a button in one website will automatically take you to relevant information in another website) so that one would not have to go visit a library to find the journal in question.

The scope of the database includes all life sciences. In addition to biomedical research, plant and agricultural research will also be included. The main function of PubMed Central will be to archive, organize and distribute peer-reviewed reports from journals in addition to reports that have been screened but not formally peer-reviewed.

Some of the expenses for this new website will be borne by submitting authors. This will shift the cost away from readers who, in the past, may have had to pay subscription or single reprint fees.

Dr. Varmus and the NIH extended an invitation, "We now invite the scientific community to engage in this exciting new venture. We plan to be ready to make reports accessible through PubMed Central by January 2000. Publishers, societies, editorial boards and other organisations interested in depositing content in PubMed Central are urged to contact us at PubMedCentral@nih.gov

Comments concerning this new development may be sent to the NIH at execsec1@od.nih.gov

The website that has complete information about PubMed Central, including the original proposal and a subsequent addendum is www.nih.gov/welcome/director/pubmedcentral/pmcprint.htm

© Taken with thanks from the internet email list: HEPV-L

Vaccine could prevent hep B liver cancer

Levels of hepatitis B related liver cancer could be dramatically reduced by using the already available vaccine to prevent chronic hepatitis B infection and by vaccinating people who are already infected.

Studying hepatitis B in the *woodchuck* (a small possum-like animal found in North America), in which the disease is virtually identical to that in humans, Georgetown University researcher John Gerin said today that even when an animal is already infected with hepatitis B, drug treatment for hepatitis dramatically cuts the viral load and delays the onset of the cancer beyond the carrier's natural lifetime.

"The cancer is called hepatocellular carcinoma and researchers estimate 60 percent of all liver cancers are caused by hepatitis B," Gerin said, adding that

there are "more than 350 million carriers of hepatitis B worldwide."

Gerin said the research team chose the woodchuck for study not only because of the similarity with hepatitis B in humans but also because studies had already shown that the lifetime risk of liver cancer in woodchucks with experimentally induced chronic hepatitis B is virtually 100 percent.

Because the animal lives an average of 10 years, studying the progression of the infection and the onset of cancer can be accomplished within a feasible period.

In making his announcement, Gerin cited two animal studies, conducted jointly with Cornell University and the National Institutes of Health. In one, the researchers found that when woodchucks are vaccinated against hepatitis B, they show a fourfold reduction in chronic infection and an eightfold reduction in liver cancer - the results of both studies showed delayed onset and slowed progression.

Gerin said, "This research shows that with a combination of vaccination and treatment it is possible to prevent liver cancer in perhaps an entire generation of people with hepatitis B."

© By Glenn Garelik, UPI Science News

Taken with thanks from the internet email list: HEPV-L

[This news is particularly relevant for readers who have hepatitis B or hepatitis B & C coinfection. For more information, speak to your doctor or specialist - Ed.]

Alcoholics good candidates for liver transplants

Alcoholics do as well after liver transplantation as other transplant patients, researchers report, and should be eligible for available organs.

Overall, about a third (32%) of alcoholic liver transplant recipients resumed drinking after their procedure, but this "did not affect survival and compliance with the immunosuppressive (drug) regimen necessary to prevent rejection of the transplanted organ," write Dr. Georges Pageaux and colleagues at the Hospital Saint Eloi in Montpellier, France. The findings are published in the September issue of the journal *Gut* - see below.

Liver transplantation in alcoholic patients remains controversial. According to the French team, some experts worry that alcoholics who resume drinking after transplant will fail to comply with necessary immunosuppressive drug therapies, endangering their health and 'wasting' the donated liver.

The study authors also believe that there is also a "moral discrimination against alcoholics" which keeps them off organ waiting lists.

Investigating further, Pageaux's team compared the outcomes of 53 patients with alcoholic cirrhosis who received liver transplants between 1989 and 1994 with the outcomes of 48 patients without cirrhosis who received liver transplants during the same time period.

They found that survival rates and compliance with immunosuppressant drug regimens were roughly similar in the two groups - even though about a third of the alcoholic patients began drinking again after their procedure. In the vast majority of cases a return to drinking did not affect the patients' survival.

But the researchers note that relapse "may have a disastrous impact" on the public's opinion with respect to liver transplant in alcoholic patients. For this reason, they say, "we need to explain to the public that alcoholism is not a vice but a disease."

In an accompanying editorial, Drs. M. R. Lucey and R. M. Weinrieb of the University of Pennsylvania School of Medicine in Philadelphia comment on the relapse rate among the alcoholics in Pageaux's study.

"Like the cliché about the glass being half full or half empty, the data on alcohol relapse after liver transplantation can be viewed as surprisingly good or disappointingly bad," they say.

"Many alcoholic patients return to alcohol use after liver transplantation despite the devastating effects of alcohol on their lives, and despite evidence of continuing alcoholic injury."

"Our goal should be to reduce further the frequency of relapses to excessive, harmful drinking."

© SOURCE: *Gut* 1999;45:421-426.

Taken with thanks from the internet email list: HEPV-L

Scientists show how viruses co-opt cell defences

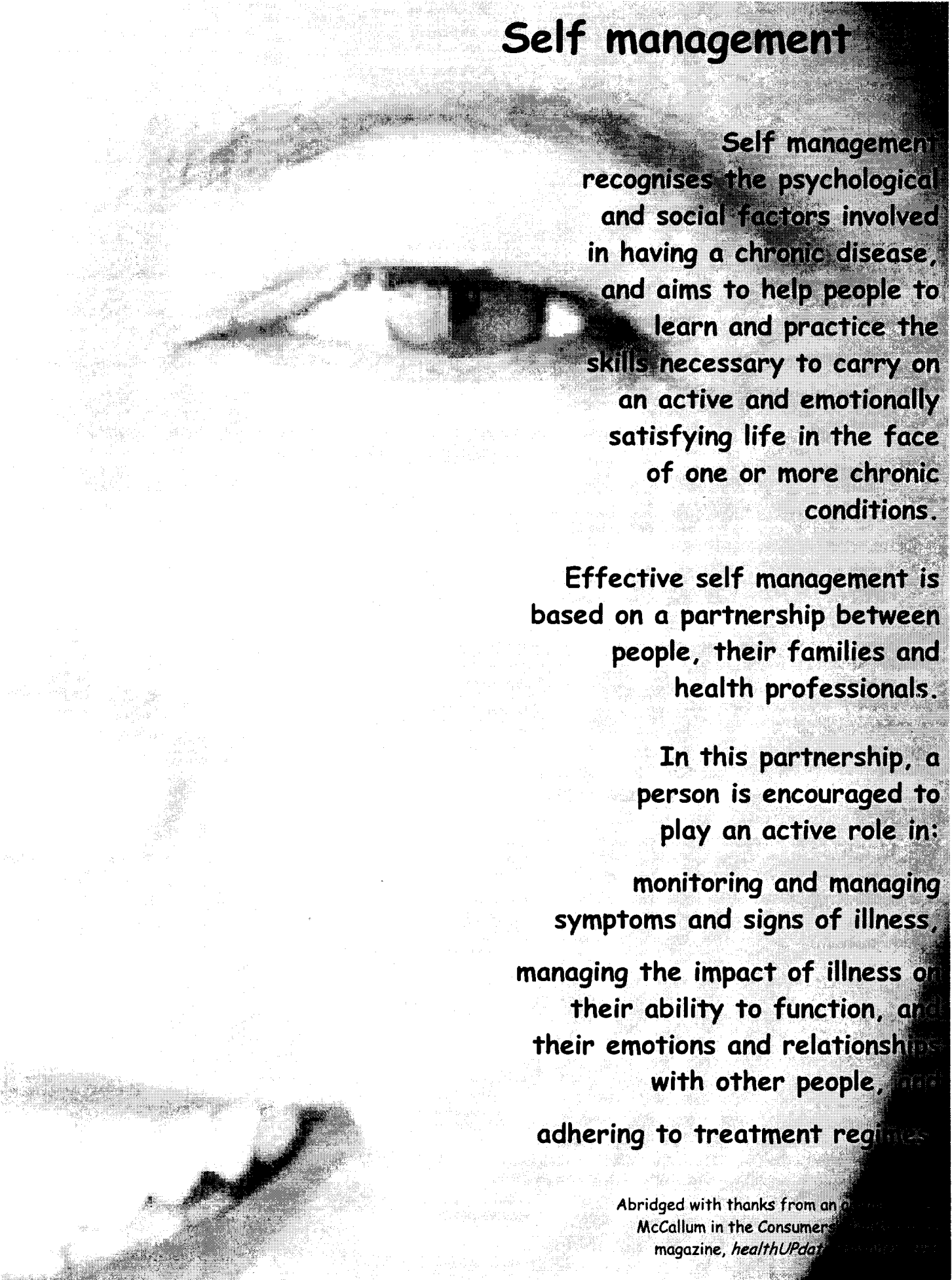
Scientists at the University of California, San Francisco and the San Francisco General Medical Center have developed a model to study how viruses like hepatitis B and C evade and co-opt the defence strategies of the cells they invade to cause chronic infections.

In a study reported in the *Proceedings of the National Academy of Sciences*, a group led by Allan Lau and Michael Yeung has shown that a virus can establish a persistent infection if it can overcome cell suicide, an important host defence. And they have shown that once the virus establishes a lasting presence in the host's cells, physiological changes begin. The cells grow more slowly and the virus becomes less infectious over time - evidence of co-evolution for the virus and its host.

The discovery could lead to methods to find new antiviral agents, to boost the effectiveness of antiviral drugs and possibly to end hepatitis C and other persistent viral infections.

© Taken with thanks from the internet email list: HEPV-L

Self management



Self management recognises the psychological and social factors involved in having a chronic disease, and aims to help people to learn and practice the skills necessary to carry on an active and emotionally satisfying life in the face of one or more chronic conditions.

Effective self management is based on a partnership between people, their families and health professionals.

In this partnership, a person is encouraged to play an active role in:

monitoring and managing symptoms and signs of illness, managing the impact of illness on their ability to function, and their emotions and relationships with other people, and adhering to treatment regimes.

Abridged with thanks from an article by McCallum in the Consumers Health Council of Australia magazine, *healthUPdate*, November 1998.

I was hep C positive

My story is off the beaten tracks. I am 71 years old and I was diagnosed only 2 years ago. My condition had been left latent for years. When cracks started to become evident in my own family structure, I then accepted to move and went to see my GP.

Following my complaint of persistent general apathy, first comment was "you are depressed" and I was offered the help of one of the supposed wonders of this century SERAPAX, VALIUM, MOGADON and the like. My immediate answer was NON (no in French!).

In 1963 I had been the victim of the previous wonder weapon easy prey to neurologists; Deep Sleep Therapy with intensive usage of the then wonder drugs. First intramuscular injections were ordered; then, when my blood pressure went alarmingly low, tablets in massive doses followed.

Valium, Librium, Largactyl, you name it, they tried it on me. I was not given a chance to voice my consent (honestly I was not even able to reason after what they had done with my poor soul).

I'm still today paying for it! Not in cash but in left over side effects.

So my advice to anyone: stay well away from all these products. At risk are permanent changes of your own personality! And what about your family? She married you for what you were. Then, after the wonder treatment she finds a different person. What about your children, "something has changed in my dad!"

Next line of investigation straight serology. The first blood test revealed a lack of assimilation of iron by my body. A following test revealed the real cause of my problems: I was hep C positive.

The possible origin of my condition is tentatively assumed to be the result of my participation in collective vaccination programs (Typhus, Typhoid, Yellow Fever, etc). A row of participants were lined up in groups of 10 or so, with a nurse inserting a needle in the shoulder of each one of us followed by another nurse dispensing the required amount of vaccine from a large syringe. Lastly, a cotton ball dipped in 90° alcohol - was it one ball per person? (I'll never know, the action was taking place behind us!)

That was common practice in quite a few European countries in late 40's early 50's, in particular, with army recruits. I tentatively consider January 1950 to be the correct time.

Following a visit to Canberra Liver Clinic I was prescribed complete abstinence of alcoholic beverages. Being born French that was the most difficult aspect of the treatment.

I obliged and it was followed by an immediate disappearance of the discomfort felt on my right side. I had been living with the problem for so long that, in fact, I failed to mention it to any of the doctors I met through my ordeal; to me this discomfort was part of the normal aging process.

The next two years were uneventful until the day, living on a farm, I decided to dose myself against round worms with COMBANTRIN. Let it be known this product and hep C do not agree. Your liver readings go skyrocketing! VERMOX is the only worm treatment acceptable.

Same applies to people with Osteoarthritis. In periods of crisis use minimal doses of Prednisolone. It took me 2 month to get back to manageable levels of ALS/ALT.

Throughout my personal ordeal, everyone - GP, specialist, laboratory personnel, Hep C Helpline staff, drug companies information service, not to forget my own family - has been extremely supportive.

Regards, Jean

←



(model/s used above)

Summarising the Australian national and NSW HCV responses

Since the hepatitis C virus was first identified in 1990, the Commonwealth and State governments have developed national approaches to hepatitis C education and prevention, and coordinated treatment and care services, particularly in the form of community-based supports. Working in collaboration with healthcare workers, affected communities and the private sector, initiatives have included:

- ⊙ Making the blood supply safe following the availability of a diagnostic test for hepatitis C;
- ⊙ Subsidisation of Interferon & Combination treatment for people with hepatitis C who meet treatment criteria;
- ⊙ Ensuring access to the highest quality diagnostic testing through the introduction of more stringent requirements for pre-market evaluation and registration of hepatitis C test kits under the Therapeutic Goods Act;
- ⊙ Development of a nationally coordinated approach to education and prevention, working with affected communities to develop and implement a range of national education initiatives consistent with this approach;
- ⊙ A twelve month pilot surveillance study with States and Territories. The results of this study informed the development of a National Hepatitis C Surveillance Strategy, recently endorsed by the Communicable Diseases Network of Australia and New Zealand;
- ⊙ Commissioning research into the epidemiology of hepatitis C in Australia, and social and behavioural research which would guide the development of the national response;
- ⊙ Developing National Health and Medical Research Council (NHMRC) guidelines on the detection and management of hepatitis C, endorsed by the NHMRC in March 1997;
- ⊙ Facilitation of a report developed by the Hepatitis C Councils titled 'Meeting the Needs of People in Australia Living With Hepatitis C'. This report was funded and is distributed by the Commonwealth Department of Health & Aged Care (CDHAC);
- ⊙ Production of a range of materials for the general community, people at risk of infection and people already affected by hepatitis C;
- ⊙ The Commonwealth worked with State and Territory-based hepatitis C councils to establish and

fund the Australian Hepatitis Council to develop education and prevention and health management and monitoring programs for people affected by the hepatitis C virus;

- ⊙ The Commonwealth funded the Australian IV League to develop an education strategy to address the issue of hepatitis C prevention amongst people who use drugs illicitly;
- ⊙ A hepatitis C/HIV co-infection program for people with haemophilia conducted by the Haemophilia Foundation of Australia;
- ⊙ A two year education program for general practitioners developed by the Royal Australian College of General Practitioners;
- ⊙ Conducting and publishing a national needs assessment for health care workers;
- ⊙ Interactive satellite broadcasts for rural/remote GPs and other healthcare workers.
- ⊙ Education materials addressing infection control for the tattooing industry have been produced and distributed to State and Territory health authorities and members of the Professional Tattooing Association of Australia;
- ⊙ The development and production of education resources for the Australian Vietnamese injecting drug user community about safer injecting and overdoses;
- ⊙ Facilitation of the report by the *Australian National Council on AIDS Hepatitis C and Related Diseases* Hepatitis C Subcommittee "Estimates and Projections of the Hepatitis C Virus Epidemic in Australia";
- ⊙ A blood borne virus education program in high schools to produce a parent information resource and a national secondary education framework document;
- ⊙ A review of better practice in injecting drug user education and evaluation by the Australian Research Centre in Sex, Health and Society at La Trobe University with outcomes of this review presented to the inaugural National Hepatitis C Educators' Forum held in Canberra in May 1999;
- ⊙ Two Hepatitis C Information, Support and Referral Services for Health Care Workers: the Australian Reference Centre for Hepatitis Information toll-free phone line and web page, providing technical information on hepatitis C; and the National Needlestick Injury and Other Exposures Hotline, providing twenty-four hour referral and support following occupational exposure to blood products;
- ⊙ National Hepatitis C Prevention Initiatives - identification and modification of a range of resources and development of a range of targeted resources to reduce hepatitis C transmission amongst current injecting drug users; including those from culturally and linguistically diverse backgrounds (in progress);
- ⊙ Development of a media guide on hepatitis C to provide journalists and other media personnel with accurate information and promote balanced reporting of hepatitis C (to be developed);
- ⊙ Healthcare Worker Education - publication of a supplement in nursing journals to raise nurses' awareness and training of hepatitis C;
- ⊙ Social Research - priority areas for social research include injecting drug user initiate studies, reducing the impact of a diagnosis of hepatitis C, hepatitis C and gay injecting drug users, and information and counselling needs of the general community in relation to hepatitis C;
- ⊙ First National Indigenous Injecting Drug Use Forum held in Brisbane, September 1999.

- ⊙ Sports and bloodborne viruses video, in production.
- ⊙ Epidemiology/Data Collection - National Hepatitis C Treatment Database to be managed by the University of Newcastle (finished in October 1999) and a Hepatitis C Incident Case Register to collect information and track progress on newly acquired infections;
- ⊙ Prisons - sponsorship of a Public Health Association of Australia conference entitled *Minimising the Harm: Health in Prisons*.
- ⊙ The 1999/2000 federal budget also provided \$12.4 million (over 4 years) to lower the current rate of transmission of hepatitis C in Australia and provide support for those already affected by hepatitis C. This will be facilitated by the provision of improved education, prevention and health maintenance initiatives for those currently infected and those at risk of becoming infected. This measure also provides for commissioned research to guide the design of the national response in key operational areas, and provides for the enhancement of existing interventions with proven success in reducing transmission of hepatitis C.
- ⊙ Production of a Needle & Syringe Program PR information kit.
- ⊙ Research funding for twelve projects:
 - 1 An intervention to improve compliance with skin penetration guidelines in tattooists, beauty therapists and hairdressers. Jill Cockburn, et al. University of Newcastle, NSW.
 - 2 A pilot peer-based hepatitis C counselling and testing service at a needle & syringe program. Nick Crofts, et al. Centre for Harm Reduction, Macfarlane Burnett Centre, VIC.
 - 3 Prevention of hepatitis C infection amongst injecting drug users of Vietnamese ethnicity. Nick Crofts, et al. Centre for Harm Reduction, Macfarlane Burnett Centre, VIC.
 - 4 Quality of life among people living with chronic hepatitis C infection. Michael Dunne, et al. Queensland University of Technology.
 - 5 Identifying the social, personal and health needs of women living with hepatitis C. Sandra Gifford, et al. Deakin University, VIC.
 - 6 National survey of GPs about needs, outcomes and patterns of care. Leena Gupta, et al. Central Sydney Area Health Service, NSW.
 - 7 Risks for hepatitis C: transition and initiation to injecting drug use among youth in a range of drug user networks. Susan Kippax, et al. National Centre in HIV Social Research, NSW.
 - 8 Exploring testing injecting drug users for hepatitis C and HIV/AIDS. Wendy Loxley, et al. Curtin University of Technology, WA.
 - 9 National survey of hepatitis C risk practices among injecting drug users: an overview of risk practices and their context. Greg Rumbold, et al. Turning Point Alcohol & Drug Centre, VIC.
- 10 Reducing transmission of hepatitis C in high risk young people: a peer education strategy. Susan Sawyer. Royal Children's Hospital Research Institute, VIC.
- 11 Feasibility study of non-injecting routes of administration among intravenous drug users. Alex Wodak, et al. National Drug & Alcohol Research Centre, NSW.
- 12 Gay men, drug culture and hepatitis C prevention. Gary Dowsett. Australian Research Centre in Sex, Health & Society, VIC.
- ⊙ NSW Health are collaboratively developing the first NSW Hepatitis C Strategy. It will provide a framework to direct NSW's response and is being developed alongside the 1st National Hepatitis C Strategy.
- ⊙ Other Commonwealth sponsored non-research hepatitis C projects (not connected to the above funding grant scheme) have been initiated here in NSW. These are funded through a joint Commonwealth/State scheme called Public Health Outcome Funding Agreements Incentive Projects and include:
 - 1 *Review of care & treatment needs of people with HCV*. NSW Health Department.
 - 2 *NSW healthcare worker education strategy project*. Hepatitis C Council of NSW.
 - 3 *Non-English speaking information & support project*. Multicultural HIV/AIDS Service.
 - 4 *NSW Public Awareness Campaign*. NSW Health Department.
 - 5 *NSW school-based education project*. Consultant to be confirmed.
 - 6 *Review/development of HCV education resources project*. Centre for Education & Information on Drugs & Alcohol.
- ⊙ A NSW survey of hepatitis C information and education resources (1999) listed close to 90 different resources. Of this wide range, the most commonly utilised resources are:

1 <i>Hepatitis C: What You Need To Know</i>	(booklet)
2 <i>The Hep C Review</i>	(magazine)
3 <i>Hepatitis C: A Brief Introduction</i> ,	(brochure)
4 <i>Hepatitis C & Food</i>	(brochure)
5 <i>Contact</i>	(booklet)
6 <i>Hepatitis C: Information for All Australians</i>	(brochure)
- ⊙ In NSW we have also seen several localised projects aiming to improve access to and quality of clinical services. These include HepCare - based in Northern Sydney, Central Coast & Hunter Area Health Services (AHS), Rural Demonstration Project (Northern Rivers AHS) and metro Demonstration Projects based in Central & South East Sydney AHSs, and Western Sydney & South West Sydney AHSs.
- ⊙ Additionally, some NSW Area Health Services have put in place or are developing local business or strategic plans. Some AHSs are employing project and health promotion officers in order to develop local responses to hepatitis needs.

The SIC project:

A peer driven hepatitis C intervention for under 25 year old injecting drug users

By Patricia Preston and Felicity Sheaves

The Safe Injecting Cwiz (Quiz) Project is a hepatitis C prevention project, carried out in the Wentworth Area Health Service - an outer western region of Sydney that includes Penrith and areas of the Blue Mountains and Hawkesbury.

An initial investigation centered on research done into injecting drug use and behaviour change, theories and actual projects dealing with bloodborne virus prevention, and the experience and views of workers in the field (eg. youth & NSP workers).

This investigation suggested that a successful program would need to be low-key and delivered through the existing grapevine and networks. It would also need to be empathic and sensitive to the young people involved.

The diverse nature of the young people targeted - including age, injecting experience, confidence and literary skills - meant the project had to avoid any type of 'classroom' approach. Consequently, the project adopted an interactive style, engaging young people through a catchy hep C quiz and drawing on their experiences and existing knowledge. In this way, participants' shortcomings in knowledge and practice around hep C were more able to be successfully addressed.

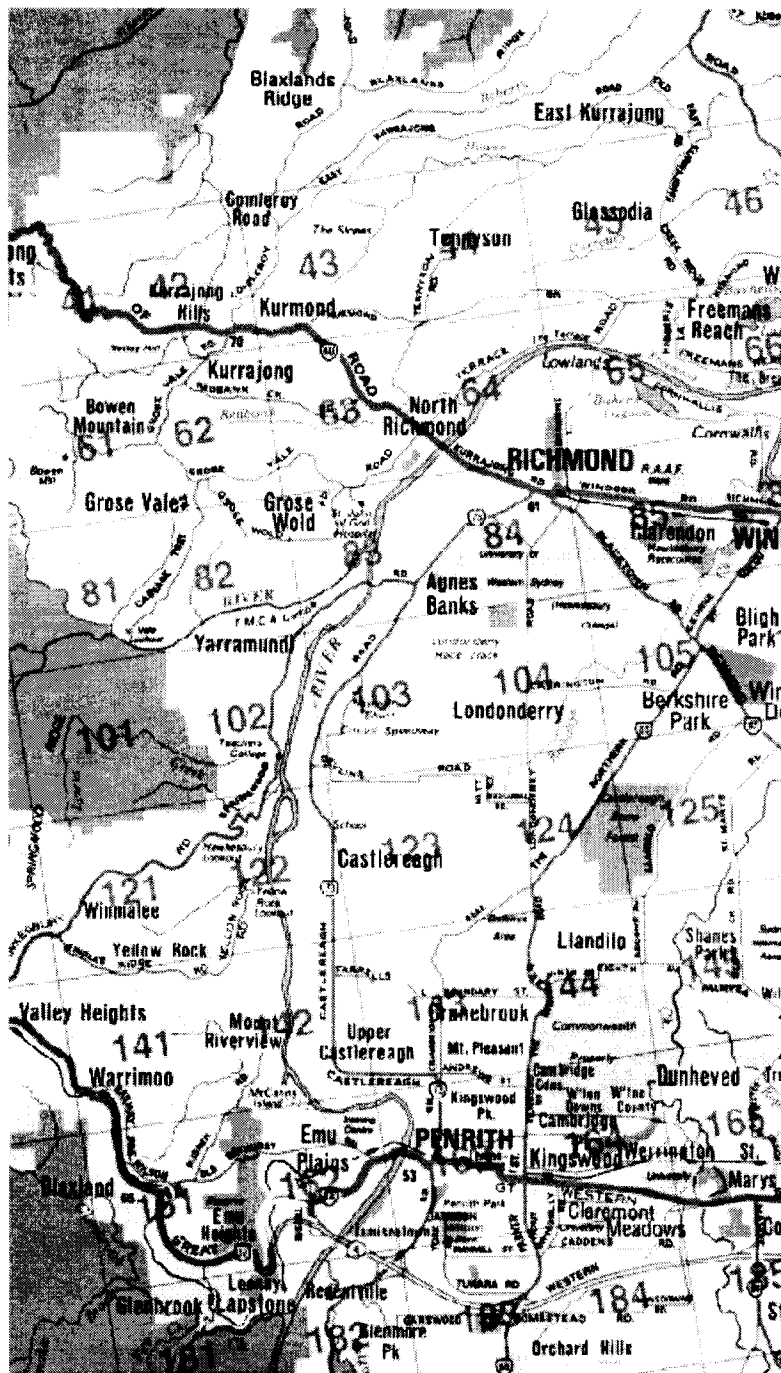
Developing the SIC Project

A six month timeframe for the project and the desire to reach as many young people as possible meant that the educational intervention could not be substantial. However we had to address the tension between having a minimal intervention - such as a short quiz - yet being still able to achieve behaviour change within our participants.

To help ensure that our quiz had some impact, we developed a strategy that involved adult learning principles, and also drew on theories of memory, learning and behaviour change. The quiz information was broken down into 3 key chunks: What is it?; How do you get it?; How do you avoid it? These chunks were further broken down into several (maximum 5) related messages.

A series of physical props were developed and used within the learning process. These included a liver sample (professionally mounted in resin and obtained from a teaching hospital), used dressings, pads, tampons and other items - all of which facilitated discussion and promoted interest in the quiz information.

Individual intervention sessions included a) a project introduction and overview (including payment details), b) demographic and HCV risk questionnaires, c) the SIC quiz, and d) a survey around injecting, social and support networks (for research purposes).



Peer driven model

The SIC project design was adapted from a successful peer-driven HIV prevention project carried out in the United States by Broadhead (and others) - known as the 'Connecticut Model.'

This model uses peer based networks among target groups and provides monetary incentives that draw people along through the project's various stages - a type of 'pyramid selling' of health promotion that has also been previously used by the Central Coast Area Health Service (NSW).

Advantages of the 'Connecticut Model' are that:

- ⊙ Participants are identified and recruited by others who possess inside knowledge that healthcare workers may not have - enabling more effective recruitment.
- ⊙ Peer recruitment allows for penetration of social networks, better reaching the more 'invisible' and hard to reach participants.

- ⊙ Peers help to translate health messages into a meaningful form for those who are less literate.
- ⊙ Payment that's tied to involvement and performance provides incentive and can be linked to quality control measures.

Results

Links built up with youth services providers and drug/alcohol workers provided the main route of initial contact with young injecting drug users.

As at mid October 1999, we had 87 people participating in the project. Although we have only been able to follow up 31 participants, there was a distinct decrease in the level of transmission risk occurrence (sharing fits, sharing other equipment, number of sharing partners) during a 3 month follow up period, following the SIC intervention.

Feedback from participants validates the quiz design. Usefulness, practicality, clarity and visual elements have been highlighted as strengths of the project.

"I really liked the hands on stuff ... now I've seen it, I'll remember it and I wouldn't have remembered it if she had of just told me. We went to the supermarket and checked it out. Out of 15 bleaches, there were only 3 bleaches with the right amount of stuff."

Interim findings

The interim findings suggest that the project is able to impact on HCV risk behaviour but there are significant barriers to change that were identified by participants - mirroring those found in other research. In order to address these barriers, wide scale and ongoing education and structural reform is required. Some practices such as sharing with sexual partners are resistant to change despite educational and structural measures.

At this stage, the main strength of the project seems to be the design of the education session. It is able to cater to a wide range of education levels, personal styles and educational needs. The project has been able to deliver second level messages - which we found the participants ready for. These included messages around reinfection, coinfection, secondary injecting equipment (other than fits) and general blood awareness.

The project went some way towards helping address other health issues of some participants - an important additional outcome given their level of marginalisation and under utilisation of general healthcare services.

- ⊙ Patricia Preston and Felicity Sheaves are SIC project officers at the Wentworth Sexual Health & HIV Services, Health Promotion Unit, Wentworth Area Health Service.

From research presented at the Second Australasian Conference on Hepatitis C, Christchurch NZ, 17-19 August 1999.

Quiet pleasures

Having had a bout of hepatitis A several years ago, I still had no idea there was such a thing as hepatitis C until about three years ago when I was first diagnosed. I had been feeling tired all the time and begun to suspect that possibly chronic fatigue syndrome did exist and I had it. I also had a lot of mysterious numbness in my hands and feet. I had long been a "party person" and was accustomed to assorted unexplained cuts and bruises. But the bruises became more frequent and they didn't seem to come from blows. I just disregarded them.

Finally my right foot went numb for no reason. I could stand it no longer and went for check up. As part of a routine blood test they called me back and told me I was positive for hepatitis C.

"What's C?" I asked. "I had A and got over it ok and I've heard of B but what's C? Who do I see to get cured?"

"It's not that simple," the nurse told me. Perhaps I should come in and talk with the doctor.

The doctor was rather grave and laid it out to me. I was stunned. I had no idea ... and just as my life was coming back together after a long terrible period. I got on the internet and couldn't believe what I was reading. This sort of thing didn't happen to me. I could always weasel my way out of anything more or less, but this stuff was just there and there seemed to be not much to be done about it.

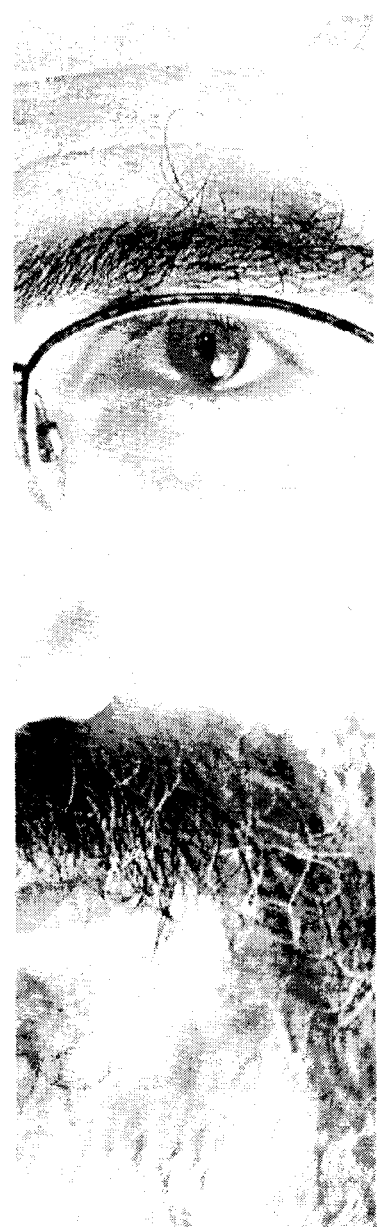
That fact was confirmed by a specialist. Eventually I spent a year of hell on interferon and ribavirin. But after six months I was "undetected."

People my age with cirrhosis at that time were considered poor candidates for such therapy but it worked. Of course in the meantime it almost destroyed my life but I stuck with it. I am off it now for a month. I feel better than when I began but still tire easily. No bruises though. I gave up booze and a lot of other things I used to like to do. You might say I grew up.

My life is very different now. I no longer have boundless energy. I stay at home mostly - but there are quiet pleasures in that. I am very glad I still have my own liver, although that was open to discussion for a while.

A friend went to Australia a few years ago and brought me back some kangaroo paw seed and other things (I'm a great gardener). I almost got them to bloom before they died. I think I over-watered them. That's the extent of my direct contact with your country, but I'm sure I'd love the place.

Warm regards, Carl
Cookeville TN USA
blueboy@iname.com



(models used above)

Hepatitis C and disclosure

So the time has come when you are considering telling someone you have hepatitis C. They may be a friend, family, your employer, a healthcare worker, a partner or potential partner who you are worried about telling.

At the moment you're probably worried about what to say, how to tell them, and what their reaction will be. These feelings are perfectly normal and are experienced by many people when they are preparing to tell someone they care about that they have hepatitis C.

It is important to remember that you have control over who you choose to tell. You may choose *not* to tell some people about your hepatitis C, and this is your right. Your choice *not* to tell others is your own and should be respected.

Who do I have to tell?

Generally speaking you don't have to tell anybody that you have hepatitis C, except the Blood Bank. You should not donate blood, blood products, semen or organs.

Most people do not have to tell their employer that they have hepatitis C. If you are a healthcare worker involved in 'exposure prone procedures', then you may be legally obliged to inform your employer of your positive status. If this is the case, you should refer to guidelines from NSW Health (or your state or territory health authority) on the performance of exposure prone procedures.

Health authorities recommend that you inform healthcare workers if have hepatitis C as this may be necessary for good health care. If healthcare workers, including dentists, are possibly going to come into contact with any persons blood, they should be using *standard infection control precautions* (see p25).

Some people have experienced discrimination from healthcare workers after telling them that they have hepatitis C. Think about which healthcare workers you choose to tell.

Telling someone you have hepatitis C

How you decide to tell another person, what you say, and when you tell them, will depend completely on your own personality and style. There are however some things that you can do to make it easier for both you and the person you are telling.

When should I tell someone that I have hepatitis C ?

If you have only recently found out that you have hepatitis C it may be worth waiting a while before you tell many people about it. It may take you some time to adjust to the new diagnosis and to decide who you do and don't want to tell.

Many people worry about telling a new or potential partner, and in particular how long they should wait before telling them. Some people choose to let the person know before the relationship begins. That way, if the outcome is unfavourable it seems easier to leave the relationship. Others choose to wait until the relationship has developed a little, when there is a certain level of comfort and trust.

Some healthcare workers - such as your GP or surgeon - may need to know about your hepatitis C so they can provide you with better healthcare treatment for any accident or ailment you may have (e.g. providing medicines that may be less harmful for the liver).

Where and when ?

There are better times than others to raise the topic. It is important that you have the discussion when both of you are able to give the subject plenty of time and attention. Also, try to choose a place where you feel comfortable and safe. Some people take the phone off the



hook and talk about it over a quiet dinner. Others like to choose a more public place such as a restaurant or park so the person can feel free to go and think about things alone.

What should I say ?

First of all, remember that this is not a confession. You are simply sharing with someone some new information about yourself.

It is a good idea to practice the situation with a person you have already told. If you have not told anyone yet, you may want to practice with a counsellor or even in front of the mirror. Having practiced it out loud can make the world of difference when it comes to the real situation.

When you practice, plan what you are going to say and how you are going to say it. You might want to write down some points that you don't want to forget. Try to be natural and spontaneous, and speak calmly and clearly. If you do practice with a friend don't let the response always be calm and understanding. It is important that you are prepared for all situations.



(models used above)

Conversation starters

Here are some ideas about how to raise the subject. Remember these are only ideas to get you started. Make sure you say what feels comfortable and right for you.

"I have something I'd like to discuss with you, last year I found out that I have hepatitis C. Can we talk about it now?"

"I feel as though we are really starting to get to know each other and I would like to tell you something personal. I have a virus called hepatitis C, do you know much about it?"

"I feel our relationship is strong and that I can tell you anything. I found out recently that I have hepatitis C."

Hepatitis C - basic facts

When you decide to tell someone that you have hepatitis C, they are likely to ask you questions about it. It is important that you are able to answer these questions yourself, or to have some literature on hand that can help you give the answers. This will make it easier for both of you. Contact the *NSW Hep C Helpline* (see p42) for information resources that will cover most aspects of hepatitis C.

It might be useful to have handy the phone number of the *NSW Hep C Helpline* so the person you're telling can phone for telephone information and support.

Outcomes

People will react differently when you tell them you have hepatitis C. Some people may be very concerned for you. Some may find your news perfectly normal and offer you support. Others, however, may respond fearfully or belittle you.

If the outcome is a negative one, it is not a reflection on you and you are not responsible for their reaction. People may have a misunderstanding about what hepatitis C is, or their views might be based on misconceptions about hepatitis C. This is why it is a good idea to have up to date and accurate information on hand. You might want to encourage them to phone the *NSW Hep C Helpline* or a counsellor.

It may take some people a little time to take in the information you have just shared with them. Remember that you also may have had many different thoughts, feelings and questions when you found out that you had hepatitis C.

Whatever the outcome, give yourself a pat on the back because you have achieved a task that many people find difficult.

For more free, confidential, and non judgemental information and support call the *NSW Hep C Helpline*.

Look under H in the *White Pages* telephone directories for hepatitis C information and support services in other state and territories.



Hepatitis C infection in children

By Maureen Jonas, USA.

Transfusion-associated HCV infection has become rare since blood-donor screening was initiated in 1990 [in the USA and Australia]. Nonetheless, many people were infected through transfusion, and some were infants or young children at the time of infection.

In adults, HCV infection acquired through transfusion persists in up to 70 to 80 percent of cases. A proportion of these people will subsequently have severe liver disease, such as cirrhosis, within 20 years after infection. It is uncertain whether the long-term outcome of HCV infection in children is similar to that in adults.

The course of HCV infection in adults is influenced by several factors. Older age at infection is associated with a more rapid evolution of liver disease. Coinfection with hepatitis B or the human immunodeficiency virus increases the morbidity associated with liver disease. Even moderate long-term intake of alcohol is associated with a higher likelihood of cirrhosis, *decompensated cirrhosis* (see endnote), and *hepatocellular carcinoma* (liver cancer).

HCV genotype 1, especially type 1b, is more likely than other genotypes to be associated with advanced liver disease and to respond less favourably to therapy.

Children have become infected with HCV primarily through the transfusion of blood or blood products or through *perinatal transmission* (from their mothers at birth). The usual factors that might predict outcome of illness in adults - age at acquisition and mode of acquisition - are difficult to separate as predictors in *pediatrics* (health and medicine of children).

The course of transfusion-associated HCV infection may vary according to the underlying disease for which transfusion is required.

Chemotherapy-induced changes in the immune system reactivity in children with leukemia may be associated with milder hepatitis. Conversely, iron overload in those with *thalassaemia* (a type of blood disorder) may increase the risk of liver disease.

Research by M. Vogt, et al (see study quoted below) has provided valuable new information about the outcome of transfusion-associated HCV infection in children. The authors studied 458 children who had received blood transfusions when they underwent cardiac surgery early in life, before the implementation of blood-donor screening.

When examined about 20 years later, 67 of the children (14.6 percent) were positive for HCV antibodies. This risk of infection is similar to that reported in other cohorts of patients who had a single, large-volume exposure to blood, including a Japanese study of children who had undergone cardiac surgery. The risk is less than that in children who have ongoing transfusion requirements, such as those with *thalassaemia* or *haemophilia* (a blood clotting disorder), or those undergoing *haemodialysis* (having the blood filtered by machine).

Two of the findings of Vogt et al. are particularly noteworthy. First, only 55 percent of the anti-HCV-positive patients (37 of 67) had *detectable HCV RNA in their blood* (PCR positive) at the time of reevaluation. This percentage is lower than that reported in analyses of patients who were infected through transfusion as adults. The reasons for the relatively high rate of spontaneous clearance are uncertain.

The second important finding was that the clinical course of hepatitis C in the children who were still infected was more benign than would be expected in people infected as adults. All but 1 of the 37 patients with *detectable HCV RNA* (PCR positive) had normal levels of *alanine aminotransferase* (ALT).

But there was another explanation for the one child's elevated levels of liver enzymes: severe right-sided congestive heart failure.

Of 17 children who underwent liver biopsies, only 3 had signs of progressive liver damage. Two of the three had congestive heart failure and the other had serologic evidence of past infection with hepatitis B. That infection, however, had resolved. Thus, HCV infection could be implicated as a cause of cirrhosis in this patient.

With the implementation of blood-donor screening, new HCV infections in children will be acquired primarily through mother-to-infant transmission. The risk of perinatal transmission from mothers [who are PCR positive] may be as high as 5 to 10 percent.

Given the number of women of childbearing age with chronic HCV infection in the United States, there may be a considerable number of infections by this route in newborns. There are currently no recommendations in the US to screen women for HCV infection either before or during pregnancy. One reason is that no effective means has been identified to decrease the likelihood of perinatal HCV transmission from women with the virus.

The infants of women known to be infected with HCV should be evaluated at 12 to 15 months of age (in Australia, the recommended age is 18 months), when the mother's HCV antibodies transferred through the placenta will no longer confound the results of antibody testing.

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

Industrial liver disease

Non alcoholic steatohepatitis: a toxic liver disease in industrial workers.

Cotrim HP, Andrade ZA, Parana R, Portugal M, Lyra LG, Freitas LA Division the Gastroenterology, Department of Medicine, Universidade Federal da Bahia, Brazil.

Aims:

Occupational and environmental exposure to *hepatotoxins* (substances toxic to the liver) has recently been implicated in non alcoholic *steatohepatitis* (a particular form of liver illness).

The aims of this study were to determine the presence and frequency of non alcoholic *steatohepatitis* (NASH) in a large group of workers chronically exposed to several volatile petrochemical products in an industrial area in north-east Brazil and to observe its course in workers removed from the work environment.

Methods:

1500 asymptomatic workers were screened with standard liver blood tests during 1994-5. Those with elevated *transaminases* (liver function test readings) on 3 occasions were evaluated further both clinically and with *HBSAg* (hep B), HCV antibody, ferritin, lipids and autoantibody testing.

Patients with no *etiological diagnosis* (observable cause for their illness), and who weren't positive for heps B or C, nor were heavy alcohol drinkers underwent liver biopsy. Additionally, those with obesity, diabetes or an isolated abnormal *GGT* (liver function test reading) were excluded. Of workers diagnosed as having NASH, with compatible *histology* (cellular damage as studied by biopsy) and no excess alcohol intake, a proportion were removed from the work environment and evaluated monthly with liver blood tests and a repeat liver biopsy 8-14 months later.

Results:

112 workers had abnormal *transaminases* and 32 fulfilled the criteria for liver biopsy. 20 of these were classified as NASH, the remainder had viral hepatitis (6 people), alcoholic liver disease (5) or portal vein thrombosis (1).

In all of the 10/20 who were removed from the work environment, their aminotransferases and *GGT* gradually decreased and their histology improved.

Conclusions:

These results demonstrate that NASH can occur following chronic exposure to volatile petrochemical substances in the workplace.

Exposed workers should be regularly screened for the presence of liver damage and ideally removed from the work environment where possible.

© Taken with thanks from the internet email list: HEPV-L.
Full article in *Liver* 1999 Aug;19(4):299-304

NB: Compared to Brazil, where the above study was carried out, Australian workplaces have better Occupational Health and Safety Standards. But the above information may be relevant to some workers here in Australia, eg, some Australian farm workers do experience abnormal liver function results as a result of ongoing contact with fertilisers and pesticides. For more information about industrial liver damage and your health, speak to your doctor or specialist - Ed.

The findings of Vogt et al. and other studies suggest that HCV infection acquired by transfusion in early childhood may resolve without treatment more commonly than infection acquired later in life. With the children in whom infection does persist, hepatic injury seems to progress slowly and is typically mild within the first 20 years after infection.

Does this mean that early-onset HCV infection is always a benign disease? *Histologic studies* (tissue studies using microscope) of children with HCV confirm that some have fibrosis; the fibrosis progresses with increasing age and duration of infection.

Even in the prospective studies of adults in which few symptoms and limited *morbidity* (illness) were noted for up to two decades after initial infection, some patients eventually had substantial morbidity. We do not know whether more serious manifestations of liver disease will appear 30 or 40 years after infection. Thus, it is important to screen and follow patients who are at risk for hepatitis C and to do more than simply reassure infected children and their families.

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Taken with thanks from the internet email list: HEPV-L

Research study: *Prevalence & clinical outcome of hepatitis C infection in children who underwent cardiac surgery before the implementation of blood-donor screening.* New England Journal of Medicine 1999, Sept 16; 341 (12) : 866-70

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).



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).

Hepatitis C: global scope of the problem

Hepatitis C is a global health problem caused by infection with the HCV. Although *representative prevalence data* (numbers of people infected) are not available in many countries, available data indicate that approximately 3% of the world's population is infected with HCV.

Most¹ populations in Africa, the Americas, Europe and southeast Asia have HCV antibody prevalence rates under 2.5%. Prevalence rates for the Western Pacific regions average 2.5 - 4.9%. In the Middle East, the prevalence ranges from 1% to more than 12%. Thus it is estimated that as many as 170 million persons worldwide may be infected with HCV.

Well designed prevalence studies of the general population are needed in many of these regions to arrive at a more accurate estimate of infection and disease burden.

In developing countries, the primary sources of HCV infection include transfusion of blood or blood products from unscreened donors; transfusion of blood products that have not undergone viral inactivation; *parenteral exposure to blood* (ie. blood entering someone's body anywhere other than the mouth/gastro tract) through the use of contaminated or inadequately sterilised instruments and needles used in medical and dental procedures; the use of unsterilised objects for rituals (eg. circumcision, scarification), traditional medicine (eg. blood letting) or other activities that break the skin (eg. tattooing or body piercing); and intravenous drug use.

Of specific concern in developing countries is the delivery of injections outside the medical and dental settings, often by other than medically trained personnel. There appears to be an overuse of injections to deliver medications that could otherwise be delivered orally.

In developed countries, there does not appear to be a high risk for occupationally acquired HCV infection, such as found for hepatitis B infection. Follow-up studies of needlestick injuries from HCV positive sources indicate a 0-10% seroconversion rate (average 2-5%). Transmission from infected healthcare worker to patients is a rare event.

© Abridged from the World Health Organisation report, Global surveillance and control of hepatitis C, *Journal of Viral Hepatitis*, 1999, 6, 35-47.



Optimal treatment strategy for chronic hepatitis C in 1999

W Ray Kim, John J Poterucha, E Rolland Dickson, John B Gross Jr, Mayo Clinic, Rochester, MN

Aims:

The addition of ribavirin (RBV) to a 12 month course of interferon (IFN) increases sustained response. In patients with non-1 genotypes, the efficacy of 6 month of combination therapy is equivalent to 12 months of interferon monotherapy. We compared the cost and quality of life outcomes of different strategies using IFN and RBV.

Methods:

We constructed a computer simulation model, based on our previously published pharmaco-economic model (Ann I Med '97). Three therapeutic strategies for *treatment-naive people* (those who've never had treatment) were compared:

- 1 Sequential: All people were first treated with interferon for 12 months, and all non-responders and relapsers were subsequently treated with combination therapy for 12 months;
- 2 Combination: All people were treated with combination therapy for 12 months; and
- 3 Customized: Genotype 1 people were treated with combination therapy for 12 months; those with other genotypes were treated with combination therapy for 6 months.

Results:

All three strategies eventually led to an identical rate of sustained response (38%). The average cost per response achieved for the sequential, combination, and customised strategies was \$54,500, \$43,600, and \$38,100 respectively.

The customized approach was associated with the least decrease in the quality of life as a result of treatment (2.7% decline from baseline, compared 3.6% for combination and 6.1% for sequential strategies).

The customized approach remained the best strategy when the estimates used in the analysis were varied over a wide range, including the costs of combination therapy and genotyping.

Discontinuing interferon at 3 months in non-responders improved the sequential strategy modestly but did not affect our conclusion.

Conclusion:

The optimal therapeutic strategy for treatment-naive patients with chronic hepatitis C in 1999 is to start with interferon / ribavirin combination therapy, treating genotype 1 patients for 12 months and non-genotype 1 patients for 6 months. This strategy appears to be most cost effective and best tolerated.

© Research presented at the Digestive Diseases Week (DDW), Orlando, Florida, USA, 16-21 May 1999.



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

Milk thistle (*Silybum marianum*) as a therapy for liver disease

By K Flora, M Hahn, H Rosen & K Benner at the Division of Gastroenterology, Oregon Health Sciences University, Portland, USA.

Silymarin, derived from the milk thistle plant, *Silybum marianum*, has been used for centuries as a natural remedy for diseases of the liver and biliary tract.

As interest in alternative therapy has emerged in the United States, gastroenterologists have encountered increasing numbers of patients taking silymarin with little understanding of its purported properties.

Silymarin and its active constituent, silybin, have been reported to work as antioxidants, scavenging free radicals and inhibiting lipid peroxidation.

Studies also suggest that they protect against genomic injury, increase hepatocyte protein synthesis, decrease the activity of tumor promoters, stabilize mast cells, chelate iron, and slow calcium metabolism.

In our article (see below) we review silymarin's history, pharmacology, and properties, and the clinical trials pertaining to patients with acute and chronic liver disease.

© Article in *Am J Gastroenterology* 1999 Feb;94(2):545-6. For full article, go to PubMed Central database: www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?db=m_s and search for the following numbers - PMID: 9468229, UI: 98127747.

(Also see page 8, "New internet database..")

Above article from the internet email list, HEPV-L

Disinfecting against HCV?

Recent tests at the University of Trieste have confirmed the value of two phenol-based disinfectants in surgical instrument decontamination and environmental disinfection against the hepatitis C virus. However, a chlorine (bleach) compound was found in the same study to be an ineffective decontaminator.

Lysol and Intrepid are two of many phenolic disinfectants in the USA, but the article did not mention the brand name of the products used. Phenolic compounds may contain phenol, cresols, hexylresorcinol and/or hexachlorophene.

The purpose of the study was to evaluate the inhibitory activity of the phenolic disinfectants and a chlorine compound (NaDCC) on hepatitis C virus (HCV) binding and infectivity.

In this study, *VERO cells* (see below) and the *competitive reverse transcription technique* (a type of PCR) were chosen as the preferred method for testing antiviral activity (*VERO cells* are a continuous cell line derived from kidney cells and suitable for analyzing HCV binding and replication).

The phenolic disinfectants inhibited HCV binding and replication at their recommended use dilutions. The chlorine compound was ineffective probably because of its low concentration in the presence of protein substances in *VERO cell* cultures.

© By Will Lawson and Joan King-Diemecke

Original study "Effect of Chlorine and Phenolic Disinfectants Against Hepatitis C Virus" from *Am J Infect Control* 1999 Jun;27(3):236-239

For more information about sterilisation and disinfection, visit the following website: <http://biology.rwc.uc.edu/HomePage/micro/CONTROL.out>

This article, taken with thanks from the internet email list: HEPV-L

NB: Until clear Australian guidelines emerge for effective chemical de-contamination of blood contaminated medical equipment, heat sterilisation through autoclaving is recommended. Everyone who encounters blood spills - whether in a medical setting, at work or at home - should carry out *Standard Infection Control Precautions*. For more information, see page 25 - 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).

NSW Isolated Patients Travel & Accommodation Assistance Scheme (IPTAAS)

Background

The Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS) was established in the 1970s to provide financial assistance to people in isolated and remote rural areas of Australia who needed to travel more than 200kms to access specialist medical treatment. The Scheme was transferred to each of the States in 1987 and apart from some minor changes, the eligibility criteria and levels of support established by the Commonwealth were largely retained in New South Wales.

NSW IPTAAS

The target population for IPTAAS in New South Wales is defined as people living in isolated and remote areas of the State who:

- ⊙ are permanent residents of NSW;
- ⊙ need to travel more than 200kms one way to access specialist medical treatment or specialist oral health services not available at a local level;
- ⊙ have not received, or claimed by way of compensation, damages or other payment (e.g. Third Party) in respect of the illness or injury;
- ⊙ have not received benefits or claimed from a registered benefits organisation, such as private health funds; and/or
- ⊙ need to travel interstate to receive specialist medical treatment or specialist oral health service not available in NSW.

To be eligible for financial assistance individuals must be referred by their GP to the nearest specialist in a particular speciality and live at least 200km one way from the nearest specialist. Assistance will not be granted where the medical service is available locally unless a valid medical reason is provided (Section A, Question 4).

Air and/or upgraded travel arrangements

Prior approval for air travel must be obtained by the referring GP or treating specialist from the IPTAAS office located within the Area Health Service in which a person lives before they travel. Medical reasons are the primary reason for approval of air travel. For example where the individual's medical condition would be exacerbated by any other form of transport. Certification of the need for air travel and/or upgraded travel arrangements should be provided by the referring practitioner or treating specialist (in Part 6 of Section A of the IPTAAS claim form).

Accommodation benefits

Benefits of up to \$30 per night are available towards commercial accommodation only, when overnight stays are required during a period of treatment.

Escorts

Benefits may be paid in respect of an approved escort for patients who meet the conditions of eligibility for assistance under IPTAAS. Patients under 17 years of age are eligible for an escort. Where a patient is over 17 years of age, benefits for an escort will only be paid if the referring practitioner or treating specialist determines that it is medically necessary for an escort.

Mandatory patient contribution

IPTAAS is not a full reimbursement scheme. A mandatory patient contribution fee of up to \$40 is deducted from travel costs per claim. The mandatory contribution reflects the fact that other people living within the 200km limit also incur travelling, meal and accommodation expenses in accessing specialist medical treatment, especially where frequent access is required.

Veterans

Veterans, war widows and their carers may be eligible for assistance with travel expenses for treatment through the *Repatriation Transport Scheme* (Department of Veterans Affairs). If a veteran or war widow is eligible for and has claimed travelling expenses under the *Repatriation Transport Scheme*, they cannot also claim financial assistance for travel or accommodation expenses under IPTAAS.

If such a person is ineligible for attendant expenses under the *Repatriation Transport Scheme*, they cannot claim financial assistance for attendant travel or accommodation expenses under IPTAAS.

A veteran or war widow will not be considered eligible for assistance under IPTAAS unless they have checked their eligibility for assistance under the *Repatriation Transport Scheme* first. If a veteran or war widow is not eligible for any assistance under the *Repatriation Transport Scheme*, they may be eligible to claim financial assistance under IPTAAS. To accurately establish eligibility to claim financial assistance through IPTAAS, veterans, war widows or their carers should telephone the nearest IPTAAS office (contact details below) before making a claim.

Review of IPTAAS

A review of IPTAAS was undertaken in 1998 and a discussion paper on the review was issued for community comment in January 1999. After extensive consultation with peak professional and community groups, the recommendations of the review have been finalised and submitted to the NSW Minister for Health for his consideration.

How to apply and making a claim

Claims for assistance under IPTAAS are processed by the Health Service in the area where the patient resides. People interested in the scheme should contact their nearest IPTAAS Office (see details below) to check their eligibility for financial assistance under IPTAAS before making travel arrangements.

An IPTAAS application form has three sections; one must be completed by the referring practitioner, another by the treating specialist, and the other by the applicant. Application forms can be obtained from IPTAAS Offices as well as General Practitioners, specialists and social work departments.

Claims for financial assistance under IPTAAS must be lodged within three months of treatment. Completed application forms should be sent to the nearest IPTAAS Office where the person permanently resides.

IPTAAS - Albury
Greater Murray Health Service
PO Box 326
ALBURY NSW 2640
Ph: (02) 6058 4455
(02) 6058 4498
Fax: (02) 6058 4528

IPTAAS - Bathurst
Mid Western Area Health Service
Bathurst Base Hospital
Howick Street
BATHURST NSW 2795
Ph: (02) 6339 5312
Fax: (02) 6339 5357

IPTAAS - Broken Hill
Far West Area Health Service
PO Box 457
BROKEN HILL NSW 2880
Ph: (08) 8080 1432
Fax: (08) 8087 8627

IPTAAS - Dubbo
Macquarie Health Service
PO Box M61
EAST DUBBO NSW 2830
Ph: (02) 6881 2264
Fax: (02) 6881 2225

IPTAAS - Goulburn
Southern Area Health Service
PO Box 274
GOULBURN NSW 2580
Ph: (02) 4823 7805
Fax: (02) 4823 7929

IPTAAS - Lismore
Northern Rivers Health Service
Locked Mail Bag 11
LISMORE NSW 2480
Ph: (02) 6620 2168
Fax: (02) 6621 7088

IPTAAS - Tamworth
New England Health Service
PO Box 83
TAMWORTH NSW 2340
Ph: (02) 6766 3946
Fax: (02) 6766 4576

IPTAAS - Taree*
Mid North Coast Health Service
PO Box 35
TAREE NSW 2430
Ph: (02) 6551 1229
Fax: (02) 6551 2087

* People on the Mid North Coast who live outside of the postcodes 2440 or 2443-2459 should contact: Tamworth for those in the Lower North Coast; and Lismore for those in the Macleay-Hastings region.

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Respecting Madame Joy

By Jeff Moss

In an unusual, in-your-face new book, two Perth drug workers examine the human desire for the pleasures of using mind-altering drugs and how that desire has been regulated and manipulated throughout history.

Madame Joy is outrageous and courageous, both in content and writing style. It is wild and daring; racy even. It has some rough edges and is unashamedly cheeky. But its essential message creeps under your skin and packs a provocative punch.

The authors are psychologist, Monique Berkhout, and social worker, Francesca Robertson. Berkhout has worked in drug-related counselling and information services in Western Australia since the mid-1980s, predominantly in the government sector. She emphasises that the ideas expressed in Madame Joy are her personal views. Robinson heads a non-government agency assisting women with addiction-related problems.

Madame Joy is an archetypal character who became part of the book comparatively late in the writing process. She was created to personify "the human desire to feel different and experience pleasure by using mind-altering substances" - be they caffeine, alcohol, heroin, nicotine, cannabis, ecstasy or psychoactive mushrooms.

"As we walk the human journey through time," says the book's introduction, "we will come to recognise Madame Joy, smiling to herself behind her many masks."

"As the angel of mercy, she soothes us in our hour of need. As the stout-hearted friend, she is a devoted and life-long companion. As the demon lover, she strips away our inhibitions and has us dancing naked with delight. As the keeper of the keys, she can unlock the gates to set free the libido of the soul. And as the siren, she has the power to sing home-yearning sailors to their doom."

Everybody uses drugs

Subtitled "the story of human drug use and the politics of its regulation", Madame Joy traces the history of human drug use from prehistoric eras to the present with an emphasis on Western culture and tradition.

The story is divided into four consecutive "landscapes" or periods of history - each with its distinct and dominant *paradigm* (belief system) about mood or mind altering drugs and prescriptions for using them. It looks at how the "truth" about drugs changed significantly in each landscape and how "potent lies" about drugs were invented to override users' experiences and impose alternative explanations.

Berkhout and Robinson focus on the pleasures and benefits of mood and mind altering drugs, be they legal or illegal.

"Everybody uses drugs, with a few minor exceptions," Berkhout says. "A lot of people use illicit drugs and the majority do it to the advantage of their lives."

"With that came the other central concept that most of us use our drugs well, some don't use at all, and some use badly."

No academic text

Berkhout and Robinson met in 1992 and soon became friends. They shared "a passion for social justice, and interest in politics, and a mistrust of authority in general and governments in particular."

Many of their discussions focused on ideas that eventually flowered as Madame Joy, following four years of research and writing. An early decision was to steer clear of writing a scholarly, academic text. Their target audience was the general public. "What we wanted," said Berkhout, "was a book that my mum could read and enjoy and give to her mates who were worried about their grandchildren."

Pro drug?

Despite the emphasis on the pleasures or benefits of mind-altering chemicals, the authors refuse to accept the label of being "pro-drug".

During the book's promotional phase, their publisher advised that "certain of the major newspapers are not going to run anything on Madame Joy because they object to the pro-drug view of the book."

This, Berkhout and Robinson say, misses the point they are making. They do not see themselves in black-and-white terms as either pro-drug or anti-drug, but as pragmatists who accept that most people do use drugs to alter their state of consciousness and that most people will continue to do so.

This, they stress, needs to be accepted as the starting point for helpful responses to drugs and drug use - and the starting point for any regulation.

Seven central concepts of Madame Joy

- We have always used drugs and we always will
- Regulation of drug use is a matter of survival
- Regulation needs to be drug specific and locally determined
- Prohibition increases the demand for drugs
- Drug use satisfies social, spiritual and medical needs
- Drugs induce pleasure which is not the same as happiness
- Like any human activity, most people get the hang of it, some do it badly, and a few don't do it at all.

Both women are staunch advocates for the regulation of drugs and drug use. "We are certainly not looking for a free-for-all out there," Berkhout told one interviewer, "but regulation needs to be drug specific and locally determined. What might be appropriate for a remote Aboriginal community may not be appropriate for an urban population."

They are not impressed by one-size-fits-all global prescriptions such as prohibition that override the experiences of local communities.

For Berkhout and Robinson there is only one basic reason for telling this story of human drug use and the politics of its regulation. It is "to find clues for the construction of a wiser future."

As their synopsis of the book puts it, "to dance with Madame Joy is to be soothed, entertained, stimulated and spiritually enriched and it is also dangerous. Respect, caution and regulation of that desire is always a fundamental issue of survival."

Madame Joy is published by HarperCollins (Australia) and is available through major bookstores.

© This article abridged with thanks from *Connexions* 1999 Vol 19, No 5 - produced by CEIDA (the Centre for Education and Information on Drugs and Alcohol).

Standard infection control precautions

There's a growing awareness of the risks of bloodborne illnesses transmitted through blood to blood contact.

But being "blood aware" doesn't mean being fanatical about avoiding contact with other people's blood. It simply means adopting reasonable steps that reduce the overall chance of catching diseases.

Principles for Standard Infection Control Precautions

- ⊙ Your skin is your first line of defence. Make sure you have no uncovered cuts, abrasions or dermatitis.
- ⊙ Wear single-use, disposable rubber gloves when dealing with any body fluids.
- ⊙ Disposable materials (eg. paper towel) should be used when cleaning up body fluid spills or splashes.
- ⊙ Any surfaces which have had body fluid spills or splashes should be cleaned with detergent and water.

If contact with body fluids does occur:

- ⊙ Wash the body fluid away as soon as possible, preferably with soap and water.
- ⊙ Rinse away any body fluids from the eyes, nose and mouth with plenty of water.
- ⊙ Injuries such as cuts and needlesticks should be washed with normal saline or soapy water, encouraged to bleed, treated with antiseptic (optional) and then covered using a waterproof dressing.
- ⊙ In the workplace, any accidental exposure should be reported accordingly to the relevant workplace policy.

Standard first aid precautions

Before first aid

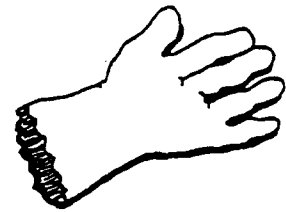
1. Wash hands (using soap & water)



2. Cover any cuts or abrasions on your own skin (using waterproof dressing if possible)



3. Wear single-use, disposable latex or rubber gloves (these are not essential but should be worn if available - especially if you have cuts or abrasions on your own hands).



After first aid

1. Wash hands immediately (using soap & water) if they have been in contact with blood or other body fluids without the protection of disposable gloves.



2. Mop up and wash blood splashed surfaces with detergent and water.



3. Discard materials used to wipe up body fluid in a plastic bag.



4. Remove clothing splashed with blood or other body fluids and wash as normal.



5. Wash hands (after removal of disposable gloves).



Responding to illicit drugs effectively:

a history of the St Vincent's Alcohol & Drug Service

by Dr Alex Wodak

The *Alcohol and Drug Service* at St Vincent's Hospital was established in the early 1980s after the Wran Government recognised that continuing to incarcerate people intoxicated in public was expensive, ineffective and counterproductive.

The decriminalisation of public drunkenness in New South Wales led to the establishment of a network of hospital based alcohol and drug departments and proclaimed places. This new policy recognised that it was better for the community and the individuals concerned if people found intoxicated in public were taken to health services rather than be locked up in police cells.

Perhaps because of its history, the Alcohol and Drug Service at St Vincent's Hospital has always taken a keen interest in the "big picture" and in aiming to provide an evidence-based, cost-effective service which is attractive, appropriate and acceptable to people who consume alcohol and other drugs in a high risk manner.

In addition to providing comprehensive, holistic and integrated programs, our location within a leading university teaching hospital has enabled us to contribute substantially to a number of major initiatives in the alcohol and drug field since the service was established in 1982.

Gorman House, our non-medical detoxification service, was (with Basement 82 at Royal Prince Alfred Hospital) the first non-medical detoxification service in the country. Gorman House now has over 3,000 admissions a year. Unfortunately, Gorman House is only able to accommodate about one third of the people seeking admission because of the high demand for this service.

In a non-medical detoxification centre, carefully selected, trained and supervised staff are used in preference to high-cost medical and nursing staff. Only medication for symptom relief is used but the environment (including the staff) acts as a tranquilliser. About half the admissions these days are people detoxifying from illicit drugs (mainly heroin).

The *Alcohol and Drug Information Service* was established in November 1982. It was the first telephone service of its kind in the country and acted as a model for other services subsequently established in other states.

The *Rankin Court Methadone Stabilisation Clinic* opened in September 1984. This methadone unit was built to serve as a model for other methadone units being established elsewhere in NSW (and other states). For many years, health professionals setting up new methadone units made the pilgrimage to Rankin Court to find out how the new style service had been established.

The philosophy has changed a little over the years with greater emphasis these days on stabilising street drug users and people emerging from prison so that their care can be continued on a shared care basis with a willing general practitioner and a community pharmacy. This methadone unit was one of the first in the country to have a major involvement in the management of HIV infected injecting drug users.

The Service was very involved from 1984 in advocacy for the establishment of a National Centre for Alcohol and Drug Research. Together with colleagues (Associate Professor Robyn Richmond, Professor Ian Webster), we contributed substantially to the advocacy process, successfully tendered and then subsequently established what is now called the *National Drug and Alcohol Research Centre* at the University of New South Wales.

"Although temporarily delayed by inclement political circumstances, most now accept that a heroin prescription trial in Australia is both inevitable and highly desirable"

Recognising the need for developing a standardised instrument for measuring outcomes from treatment, the Service also conceived the project which ultimately became the Opiate Treatment Index developed at NDARC. This instrument is now also being used overseas.

The Alcohol and Drug Service at St Vincent's Hospital was successful ten years ago in obtaining funding from the NSW Department of Health to establish an organisation of drug users. This interest grew out of early involvement to control the spread of HIV among injecting drug users and the recognition that this would not be possible without a strong and effective user based

organisation. This led to the initial establishment of the *AIDS and Drugs Information Collective (ADIC)* and subsequently the *New South Wales Users & AIDS Association (NUAA)*.

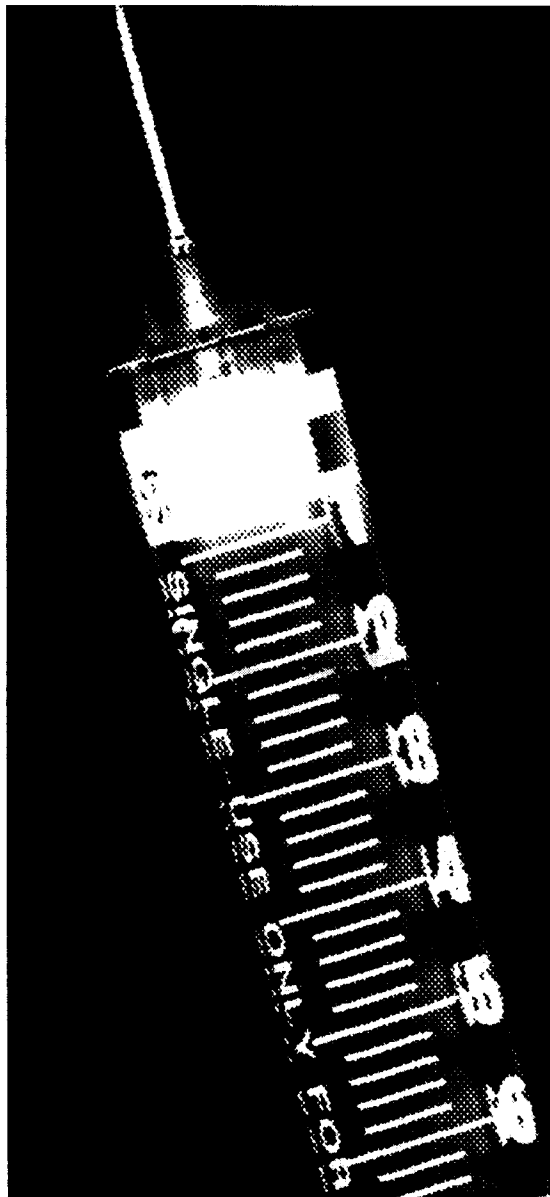
The Alcohol & Drug Service also took an active role in the establishment of the *Australian Society of HIV Medicine*. Recognising the importance of collaboration and mutual support for doctors working in the difficult alcohol and drug field, and anticipating similar problems in another possibly low status area, an organisation for doctors working in the HIV area was established. None of the originators foresaw what has been achieved by the *Australian Society of HIV Medicine (ASHM)* in a such short period.

In November 1986, we started Australia's first needle syringe program. This was initially not sanctioned by authorities or legislation but the act of establishing this service helped to concentrate the minds of authorities on this obvious need.

In 1990, evidence was given to a Parliamentary Committee from the ACT Legislative Assembly which led to a recommendation for a scientific evaluation of heroin prescription. The Service was involved in some of the committees established to consider the trial. Although temporarily delayed by inclement political circumstances, most now accept that a heroin prescription trial in Australia is both inevitable and highly desirable.

Involvement in this work led to increasing interest in an advocacy for drug law reform. The Director of the Alcohol & Drug Service is the current President of the *Australian Drug Law Reform Foundation* and also President of the *International Harm Reduction Association*.

The annual national survey of people attending needle syringe programs also had its origins in work done by us. This survey has led to the development of a low-cost, high-yield instrument for monitoring



demographic characteristics, changing patterns of drug use and changing patterns of blood borne viral infections among injecting drug users cross the country.

We have followed the development of responses to hepatitis C in Australia with keen interest. A modest public clinical service has been provided (recognising the high cost and major limitations of first generation treatment).

Advocacy for consideration of non-injecting routes of administration as a way of obtaining control of hepatitis C among injecting drug users met initially with some resistance from organisations of drug users (and support from many individual drug users). This opposition has diminished over time.

The Service has also contributed to the development of a strategy to gain control of hepatitis C among injecting drug users in Australia.

We have been very fortunate to have had consistent and strong support from the Sisters of Charity Health Service, the organisation responsible for St Vincent's Hospital. This is one of those rare health service organisations with a genuine commitment to serving the poor and disadvantaged and supporting public health.

That St Vincent's Hospital was initially selected as the site for a NSW trial of a medically supervised injecting room came as no surprise considering its long history of "low threshold" service provision to people with alcohol and drug problems, research, teaching, public health advocacy, commitment to innovation and an equally strong commitment to serving poor and disadvantaged members of the community with dignity and compassion.

Although a specific directive has precluded establishment of the safe injecting facility here by St Vincent's Hospital, we are confident that establishment of such a facility elsewhere will proceed under others and will contribute to a reduction in transmission of hepatitis C (and other blood borne viral infections).

Many look forward to the establishment of this service - including most of the local Kings Cross community.

- Dr Alex Wodak is Director of the Alcohol and Drug Service, St Vincent's Hospital, Darlinghurst, NSW.



Is your GP part of your support team?

By Claire Booth

Have you ever gone to the doctor and come out feeling worse? Do you find it hard to ask questions of your doctor? If your doctor explains something and you don't understand, do you stay silent?



For many people living with hep C, trying to find a way through the medical system can feel like a losing battle, or at best, a frustrating experience. But it doesn't have to be that way.

General practitioners are highly trained, hard working people who are at the front line of medical care. Because of their many years of training and long working hours, they are highly respected in the general community. They are also often extremely busy.

The combination of 'busy-ness', training and respect can have a strong effect on us when we consult them. It may be harder to explain clearly

(model/s used above)

what we need under these circumstances. It may even have the effect of masking or minimising the depths of our concerns. How do you stand up to minimising?.. By affirming that you are important.

Your GP is there to help you, not the other way around. Remember you do not have to minimise your feelings or concerns about ill health in order to make the GP feel better - that's their job.

Thinking quietly beforehand about what you specifically want your doctor to understand, will make it easier. Why not go with a shopping list of your concerns?

Your shopping list of issues should be focused on things you want your GP to know about how you are feeling. For example, if you say "I feel tired", what will the doctor make of that? Well everybody feels tired sometimes, so what is different for you?

Instead, consider what will your doctor understand if you say, "I feel tired in the morning after 10 hours sleep, I feel tired just walking up the six steps to my house."

The second statement is specific; it has time, place, amount of activity and context. The GP will have a much clearer understanding of what is wrong if you can be as detailed as possible.

If you have three or more concerns on your shopping list, ask for a long appointment. This can usually be done with the receptionist at the time of making your booking. Long appointments are a great help to your doctor. After all, no-one can do much in 10 minutes!

A busy GP will appreciate you doing this and have more time for your concerns. If your GP does not bulk bill and paying is a problem, ask to pay the gap payment, and/or take the invoice to Medicare. If your doctor doesn't offer long appointments or you cannot afford them, see your doctor more often. Perhaps go once a week until you have worked through your list of concerns.

Confusion about the GP's role can also result in frustration or poor communication. If you have a clear understanding of what you can expect your GP to do for you, then neither of you waste time and effort.

What is a GP's role?

Your GP is one of your primary health care providers - primary health care is front line care. You don't need a referral from somebody else to see a GP. A useful way to think about it is that your GP is your health care professional 'handyman', or the GP surgery as a 'one stop shop'.

A general practitioner is good at preventing, identifying and treating 'ordinary' health problems and knowing when you need the expert 'plumber' or 'electrician', that is, a specialist.

Your GP is expected to have knowledge about an enormous range of medical problems. They play a proactive role; that is, they help you identify problems at an early stage and assist you to prevent serious disease developing.

The role of a GP is to spot early warning signs, help maintain good health, provide timely referrals to specialist care, and participate in shared care with your specialist. Participating in shared care really means assisting you to make informed decisions about managing your health and helping you maintain your quality of life.

A GP does this by helping you understand the meaning of test results and their implications for your health, working with you to reduce or avoid medication that is toxic to the liver, and if necessary, supporting strategies of harm minimisation. They may also help you to support your self care by use of diet or lifestyle changes.

Finally the GP should encourage you to seek other forms of support if needed, for example counselling, support groups, nutritional advice or use of complementary therapies.

Sounds wonderful! But does it match your experience? If it doesn't, don't despair. You may want to consider asking your GP some questions about their role. Are they comfortable with the level and timeliness of correspondence between themselves and specialist? Can they help you work out a better strategy to get this information?

Perhaps your GP can do the routine blood tests and you take the results to the specialist? Some other questions you may want to consider asking your GP: have they attended any hepatitis C training for GPs? Do they have other patients with hep C? If you use vitamin or herbal supplementation - what do they think? Are they tolerant of people using complementary therapies?

If you can already answer these questions positively then your GP is probably well involved as

part of your support team. If you haven't asked these questions yet give it a go! You will quickly find out if this is the doctor for you. Remember, there is nothing wrong or disrespectful in asking these questions. Some doctors may be initially surprised, but most will quickly understand you are interested in and committed to your own health, and will support you as much as they can.

If you get a negative reaction, which can happen sometimes, perhaps consider these questions to yourself: Does the GP have discriminatory practices against people living with hep C, or against people who inject illicit drugs or have done so in the past? Is the GP uninterested in hep C care and treatment? Is this why you haven't had a good experience? Or perhaps the GP is not yet very knowledgeable about hepatitis C? If not, then your GP may be interested in training in order to help you more effectively. Each division of general practice offers some training about hep C that your GP can take advantage of. There are GP management guidelines available from the *Royal Australian College of General Practitioners*, and the *National Health and Medical Research Council*. The Hepatitis C Council can also provide these.

Of course you can also take your questions and concerns to another doctor (*see my note, below*). The nurse at your specialist treatment centre may have a list of GPs who have completed hep C training. The *NSW Hep C Helpline* (*see page 42*) also keeps lists of interested GPs and will help if you are nervous about how to approach your GP. Your present doctor may also be happy to refer you to another GP with more interest and or a higher case load in hepatitis C.

Your GP can be an invaluable member of your support team, helping you maintain the highest possible quality of life. You have the right to have your concerns taken seriously, and to involve the medical expertise of healthcare workers to your best advantage.

© Claire Booth is a counsellor and the Coordinator of TRAIDS: medically acquired HIV and Hepatitis C Counselling, Information and Resource Centre - phone (02) 9843 3143 or email at Claire_Booth@wsahs.nsw.gov.au

Note: I realise that in rural and regional areas of NSW this may not be possible. In these regions, GPs play a vital role and by necessity, have a greater responsibility for all aspects of health care.

[Also see article on page 31, "Your rights when visiting a healthcare worker" - Ed.]

"Your GP can be an invaluable member of your support team, helping you maintain the highest possible quality of life. You have the right to have your concerns taken seriously, and to involve others' medical expertise to your best advantage."

Not disheartened

Friends, I have just tried (and failed!) interferon treatment and I thought my experiences might be useful to others.

The process of undertaking interferon treatment was initially quite frightening, however the wonderful staff at Canberra hospital helped me overcome my initial fears.

Starting on 6 million units per day, I experienced one horrific night, but otherwise the side effects were manageable. I did not miss a single day at work, and with family support I was able to 'compartmentalise' my treatment as part of any daily routine.

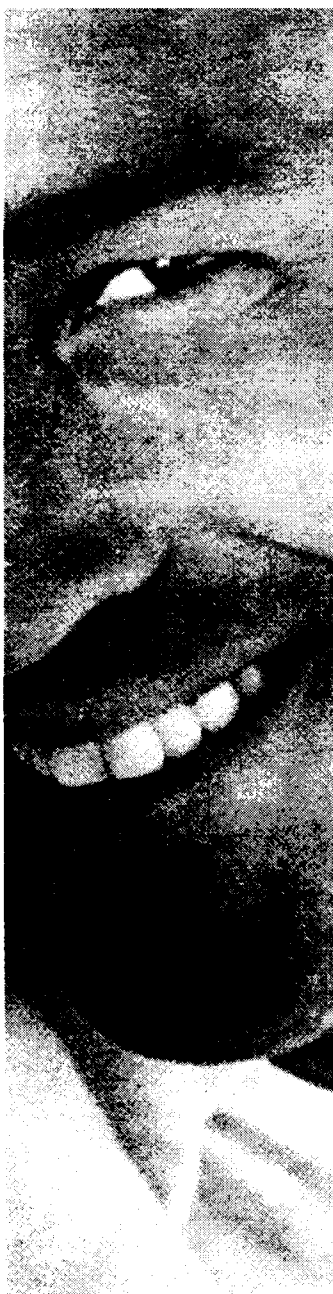
Unfortunately, I was a non-responder and the interferon program did not work. So much mental anguish and stress was involved in being on the treatment program that I was actually relieved by this. Even though interferon is not my answer, I am not disheartened or dispirited - quite the opposite.

Having failed to respond to this treatment, I have decided to be positive, live as healthily and enjoyably as possible (I even have the occasional light beer) and wait for further developments.

The interferon program, at least in my case, was not a horrid experience and even being a non-responder was not the nightmare I initially envisaged.

Certainly, the *Hep C Review* has been a big help with information and support.

Regards,
Simon



(model/s used above)

Easthep clinical services

Easthep is an initiative of the Prince of Wales Hospital, offering hepatitis clinics at both the Prince of Wales Hospital and Albion Street Centre. Our multi-disciplinary team is a dedicated group of Hepatologists, Research Scientists, Registered Nurses, counsellors and a dietician.

The Easthep team of professionals provide:

- ⊙ assessment, management and treatment of viral hepatitis
- ⊙ facilitation of patient education
- ⊙ counselling
- ⊙ infection control
- ⊙ nutritional services
- ⊙ information systems and services
- ⊙ research

Easthep is involved in many research projects, including the international and "AusHep" hepatitis C treatment trials. This enables people access to the latest treatments and diagnostic tests free of charge. In addition, people have access to Ribavirin under the Special Access Scheme. Nursing staff are available 24 hours to assist people with difficulties relating to treatment.

In collaboration with the Royal Hospital for Women, our team of professionals aim to assist in patient management for pregnant women who have viral hepatitis. Our focus is to provide holistic care, facilitate patient education and provide current information to minimise the risk of vertical transmission. Continuity of care is offered following delivery. Referrals to Paediatrician Specialists are available.

The staff are friendly and available through appointments, and on a mobile service, 24 hours a day, 7 days a week. There is a Psychologist available at the Prince of Wales Hospital, dedicated to people with viral hepatitis. This has proven to be a service in high demand, with approximately 50% of people visiting the clinics accessing the service at some time.

The team also runs clinics at the Albion Street Centre, Surry Hills. This service facilitates access to viral hepatitis assessments (including liver biopsies and HCV RNA PCR), counselling, dietician advice and combination treatment. People's confidentiality is maintained with the "first name only" system being adopted by the Albion Street Centre.

- ⊙ For more information about Easthep, contact Melissa Bagatella on 0413 746 291, Sue Polis on 0414 993 502, or the Easthep Clinic office on 9382 2750.

Your rights when visiting a healthcare worker

Doctors play a key role in ongoing monitoring of a person's hepatitis C and the long-term maintenance of their good health. Increasingly, doctors work in partnership with specialist clinicians and other healthcare workers.

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

To have as much information as you wish about the illness

You see the doctor in order to gain an understanding of your health. It is a service you pay for. You have the right to know about your diagnosis, prognosis, alternate forms of treatment, what your doctor recommends and why they believe their recommendations are the best course of action. If you continue to have problems with your health and a diagnosis has not been reached, you should have an explanation of why not. Also, if further tests are needed they should be explained to you. It's your body and your health that are at stake here. You wouldn't take your car in to a mechanic and let them begin tinkering around in the engine without first telling you what they were doing and why. You shouldn't allow a doctor to do the equivalent with your body without being informed of what's going on.

To be allowed enough time for questions and concerns about problems

When we first hear our diagnosis or have new medical terms thrown at us, we are often taken off guard. We tend to forget some of the information we are told, or don't think of the questions we want to ask until later. You should have an opportunity both at the initial visit and at subsequent times to discuss your problems. It is helpful to write your questions down as you think of them, and take them with you to refer to, and as a reminder, on your next visit.

Be seen within a reasonable time of the scheduled appointment

Sometimes unexpected problems and emergencies come up with other patients that may cause a delay in your appointment time. These situations can't be helped and aren't the doctor's fault. A half-hour wait probably isn't unreasonable as long as you are informed of the delay. If your doctor is chronically late you should decide if this is just too much of a waste of time or annoyance to you, and if so, choose another doctor who is able to keep their appointments within a reasonable amount of time.

To have reasonable access to your doctor

You and your doctor should agree on what you consider "reasonable access" in advance. Your idea of what constitutes reasonable access may widely differ from theirs. If so, you may be able to reach a compromise. If not, it's good to find this out early so that you can find another doctor.

To participate in major decisions in your care

Participation is not only the right but also the responsibility of the patient. It is important to be well educated about your illness and you must ask questions so your decisions are as informed as possible. You and your family are the main persons affected by your illness, not your doctor.

Know your doctor's non office hour availability and provisions for coverage of patients during these times

Emergencies, accidents, and crises don't always occur during office hours. Who is available to cover for your own doctor during nights, weekends, and holidays? It is a good idea to meet the covering doctors so you can decide whether you can work with them. If there are special conditions, treatments, adverse reactions, preferences, be sure to have your own doctor write them clearly in your chart so that the covering doctor can refer to them. Remember the substitute may be your doctor during your most vulnerable and neediest times.

Determine who other than your doctor shall have access to information about your health

The relationship of doctor and patient is confidential. In some cases, people may be asked to sign a release form authorising your files to be released to your insurance companies, or in special instances to compensation boards.

Know in advance the approximate amount of charges and possible arrangements for payment

It is necessary to determine if you can afford the charges and to find out if Medicare or private health insurance will cover them. It is not poor taste to ask about charges in advance. If you cannot afford the charges, ask your doctor if they will work out a sliding scale based on your ability to pay (many will). Determine exactly what the charges include, and whether things such as laboratory tests and x-rays are included in them. Also, check in advance what Medicare or private insurance will cover as well as any possible gaps in cover.

Change physicians if a breakdown in your relationship occurs and have your records transferred to your new doctor

Sometimes things happen. As in any other relationship there can be personality conflicts, or perhaps you don't agree on how your case should be treated - or maybe the needed confidence just isn't there. If this happens, do not allow it to continue. Find another doctor who you can trust and get along with.

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

[Because this article was developed in the United States, some information may not relate directly to Australian healthcare settings - Ed.]



Visible attitudes

I have an illness, the hepatitis C virus, which isn't going away. My virus and I have an intimate relationship with each other, we co-exist in one body, and I now find the biology of my disease exciting rather than repulsive. But it wasn't always that way.

I've known about my hep C for 7 years now, and it has been a long process of coming to terms with it - deciding on treatment options, (I have chosen the alternate pathway), dealing with revelations to prospective partners, changing my life style to take into account my exhaustion and giving up alcohol, and trying to learn to take better care of myself and accept my disease.

In this period I have noticed that society in general often views illness as a moral issue rather than a health issue, where the carrier of an illness is seen to be some how morally inferior, and therefore different and often treated badly.

The other view that I have widely encountered is that the person and the illness are seen as being completely detached from each other. My body is spoken about by the medical profession as an almost strategic military defence system, rather than the space in which I exist in the world, and

my illness likened to an alien invader, as if it were a terrorist or a computer virus bent on my destruction.

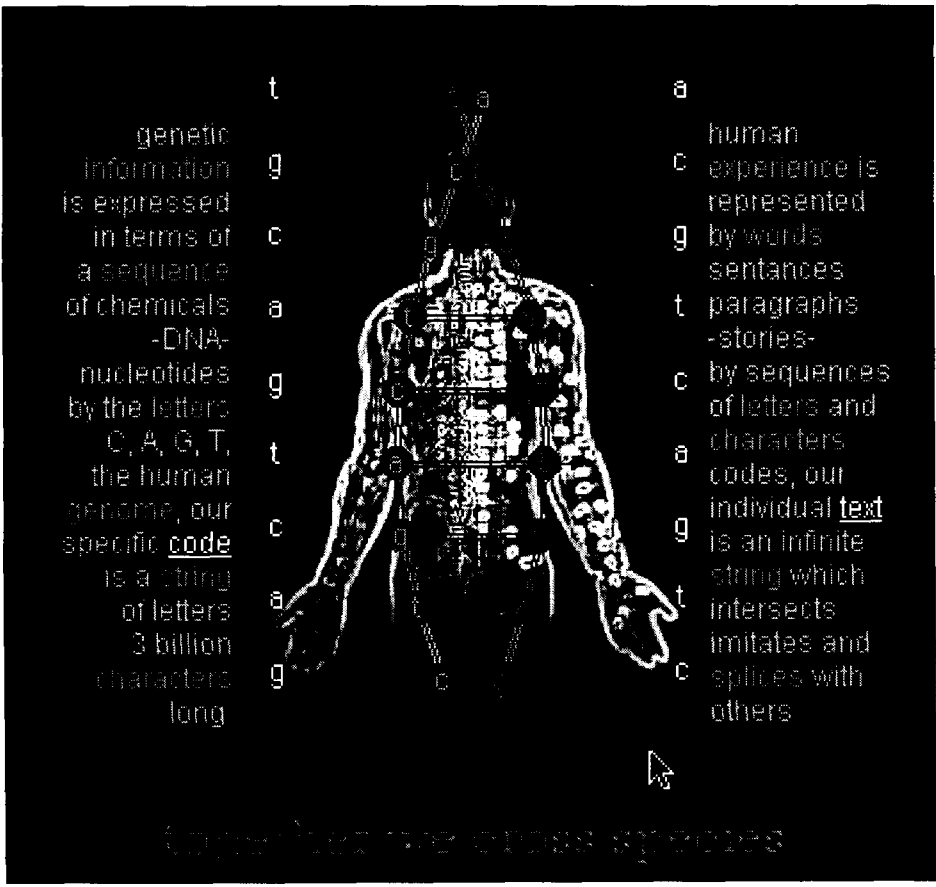
I believe that both these societal attitudes makes us sicker, as we are not considered as a whole individual, not approved of, and not supported, often having to lie about our illness especially in small communities for fear of subtle and not so subtle discrimination. I was attending a local community group when I told another member that I had hep C, and even though I explained the most likely paths of transmission she expressed a deep concern about catching the illness from me. The following week all the ceramic cups that we regularly drank tea and coffee from were replaced with disposable plastic cups, which was a direct and misinformed result of my disclosure. This is a minor example from many experiences of exclusion, difference and sometimes outright bigotry.

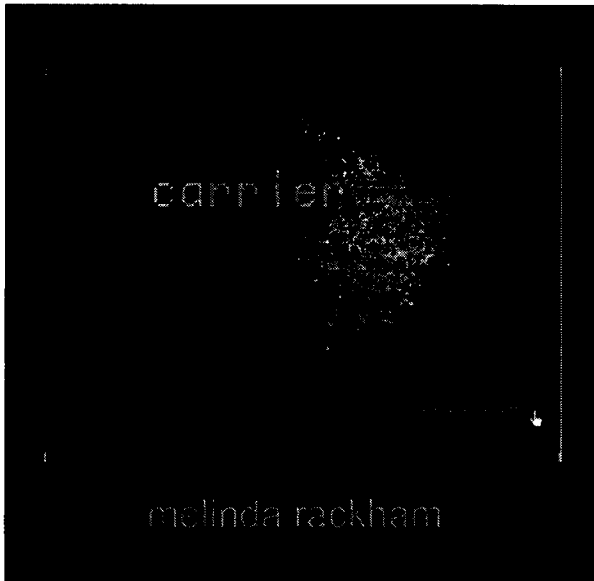
But the general community can't really be blamed for their lack of knowledge. Most television and newspaper reports focus on the more sensational causes and effects of HCV, while leaving the realities of day to day living with hep C as not newsworthy.

Because I was living in a small rural community with little understanding of Hep C for a number of years, I turned to the Internet for the majority of my information and support. This was great but it didn't replace having a local community, and I believe we will continue to live less comfortable and satisfying lives, despite advances in treatment options, while hepatitis C remains invisible, and those who are HCV positive remain isolated, in the general community.

I wanted HCV to be visible, and in 1997 I decided to make the CARRIER Internet site, which after two years has just been released. CARRIER is a combination of poetic and artistic interpretations of living with a virus; of computer rendered visualisations of viral interactions; of support and information both on and off the Internet , with links to Internet mailing lists, support groups, even a singles site for those with HCV. CARRIER also contains personal stories about living with the virus that have been contributed from the Internet, some after a call for participation in *The Hep C Review* some time ago, and some from mailing lists overseas.

As everyone's computer is different there are 3 viewing options for CARRIER, one is for text only , for older computers or slower modems; one is a self navigation option where you can choose which part of the site to look at, for the average home computer; and the third option is to be guided by "infectious agent" a *java applet* (function that asks questions and guides you through sections of the site). For those with new computers and fast





modems. CARRIER is open to further input which can be done from the anonymous response form in the information section, or by email to me directly.

CARRIER was initially researched at Wollongong University, and produced with New Media funding from the Australia Council for the Arts. John Tonkin and Damien Everett worked on the java and sound for the site, and it was finished with contributions from many people including Jerry Z's 3d computer rendering of the virus, and Horst Keikle's assistance with VRML at Vislab Sydney. Audrey, former president of the Hepatitis C Council of NSW also provided much appreciated support in the end stages of production.

The site I hope will bring some other understanding of living with HCV to the arts and more general community, as it is available on the Internet and in galleries both in Australia and Internationally. I have recently shown CARRIER at several conferences including Contagion at the University of Sydney, and Invencao in San Paulo, Brazil; and at galleries in Germany, and Japan.

More locally, CARRIER will be showing in public galleries in Sydney mid 2000 and is currently at the Institute of Modern Art in Brisbane where it has just won 2nd Prize at the National Digital Art Awards.

Visibility is I believe a huge step towards changing attitudes in society, and I have received some great feedback from viewers of the site, some of whom had no previous knowledge of what HCV is. Please visit CARRIER on the Internet or if it is shown at a gallery near you.

Regards, Melinda Rackham

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	Aushep 08	Nthn Rivers CH100 trial
Who's it for?	People who've never tried interferon & have genotypes 1 or 4, or, 2 or 3.	A Chinese Herbal Therapy trial - for people who live in the Northern Rivers region of NSW.
What's involved	<p>(Genotypes 1 or 4)</p> <p>Group 1: interferon @ 5mu daily for 8 wks, then 3mu 3x wkly for 44 weeks; plus ribavirin, daily for 52 wks.</p> <p>Group 2: interferon @ 3mu 3x wkly for 52 wks; plus ribavirin, daily for 52 wks.</p> <p>(Genotypes 2 or 3)</p> <p>Group 1: interferon @ 3mu daily for 4 wks, then 3mu 3x wkly for 20 wks; plus ribavirin, daily for 24 wks.</p> <p>Group 2: interferon @ 3mu 3x wkly for 24 wks; plus ribavirin, daily for 24 wks.</p>	<p>Participants will not know whether they are taking CH100 or placebo.</p> <p>GP visits and health status surveys at 0,1,3,6,9 months.</p> <p>LFTs at 0,1,3,6,9 months.</p> <p>PCR genotyping at beginning of trial.</p> <p>PCR viral detection and viral load tests at beginning and at 24 wks.</p> <p>Group 1: CH100 taken 3x daily for 24 wks.</p> <p>Group 2: Placebo (harmless substitute) taken 3x daily for 24 wks.</p>
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?	<p>Having cirrhosis,</p> <p>Previous treatment,</p> <p>Injecting drugs (oral methadone OK),</p> <p>Hep B coinfection,</p> <p>Falling pregnant (women),</p> <p>Conceiving a child (men).</p> <p>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.</p>	<p>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.</p> <p>Other exclusion criteria: current interferon or any herbal treatment, hypertension, pregnancy or breastfeeding, psychotic illness, non-HCV liver disease, HIV/AIDS, injecting drugs, alcohol intake of >70g per wk.</p>
Enrolments still open? (ph contacts)	<p>Enrolments are now open.</p> <p>People interested should contact the 'liver clinic' at their nearest major hospital.</p>	<p>Enrolments closed towards the end of August 1999.</p> <p>Nikki Keefe 02 6620 7518 (Thurs),</p> <p>Tim Sladden 02 6620 7509 (other days, Mon-Fri).</p>

support than ever before to cope with everything. Either way both scenarios place unbelievable pressure on partners and families. Not only do they have to watch their love one trying to cope with the new rules Hep C has laid down but also having to take on much more responsibility than ever before. Partners and families also find themselves worrying about what is ahead of the family as a group and if they can survive this roller coaster of mixed emotions and mood swings.

Inability to do what we like and enjoy - socially

Isolation is very evident in this area of our lives as our Companion restricts our stamina to get out to mix and participate socially eg. dancing, parties and entertaining.

Coping with our doctor's 'bed side manners'

Most medical practitioners are pleasant and understanding. However, some of us experienced attitudes of negativity, bluntness in opinions and felt dismissed. We all expressed concern over the lack of knowledge about hep C within the medical profession. This has disturbed us greatly in our battle with our Companion. In fact most of us agreed that there were times when we could exchange seats with the doctor. It is as if the patient is training the doctor which instantly brings up another barrier for us to breakdown. The following choices were considered as an aid in riding the medical merry-go-round.

- Be assertive or take someone with you to the doctor. We were surprised how differently patients are treated when they have a support person in the room with them.
- Make sure your doctor explains everything at your level not his/hers. If you don't understand or are confused challenge them and ask questions until you get an answer.

- Write questions down at home when you think of them and go with a shopping list. Ten minutes in a surgery is not enough time to identify things that are bothering you especially if he/she has given you bad news. It is hard enough to concentrate when you are already in a confused state with your hep C symptoms.
- Try to keep a copy of any reports, blood tests and some of us found it useful to use a diary to record how we were feeling as it is difficult to remember what you did a few hours ago not to mention 2 weeks. This could also help in research at some stage.

Disclosure discrimination

This topic generated quite a lot of discussion. Most of us were reluctant to tell others about our Companion. It appeared to be something we avoided getting into. In fact at one stage it was suggested that we rename the virus, as the word hepatitis straight away rang warning bells to others of a contagious disease. Some of us found it much easier and less complicated to just tell people we had chronic fatigue, which did not pose a threat to anybody.

If disclosure was done in an environment where we already had formed working relationships and friendships, it was more accepted and dealt with in an understanding manner. However, in a new environment the response was not so supportive and generated enormous problems that affected people both emotionally and in their ability to mix with others. One of the participants in the group experienced this first hand and it hit him very hard.

We are all told discrimination can be dealt with from a legal point of view. This is fine to know that this type of support is there, but it takes so much energy to deal it. Our energy levels are already depleted and part of self-care is to reduce stress not create it. Group work helped tremendously with this issue as we all realised that the network we had formed would help us tackle issues of discrimination.

Treatments experienced by the group

At least four of us had tried alternative therapies such as herbalism, naturopathy, homeopathy, kinesiology or acupuncture at some stage during our path with some good results in temporarily improving our quality of life.



(models used above)

My buddy & reluctant companion:

hepatitis C from a support group member's point of view

This article was compiled following an 8 week support group conducted by the TRAIDS Counselling Information & Resource Centre.

Nine people attended the group - all were there for similar reasons: To make the personal contact with other people that is so lacking in the services available to date; to find out how to cope physically and emotionally with their Reluctant Companion (hep C); and to find out how to help keep their Buddy (immune system) strong.

The first icebreaking session

Very early in the initial session it became clear that each and every one of us had a story to tell, a frustration to overcome and a simple need for friendship in this often isolating illness. This made the attendance of two facilitators valuable in containing everyone's emotions. It was like letting a cat out of the bag. We had all been locking so many feelings and emotions away and had never had the opportunity to release them before that day. The response was overwhelming.

Issues to talk about

As a group, we brainstormed areas of discussion. The following topics - reflecting people's need to find space and to cope with everyday feelings - were clearly identified as the most important issues to discuss:

- ⊙ Telling our stories and personal experiences of diagnosis.
- ⊙ Effects of hep C on our lives
- ⊙ Treatments experienced by everyone in the group.
- ⊙ Developing strategies for positive self care.

An interesting outcome of setting themes was that even though it is important to be aware of how this virus is transmitted to protect our families and others in the community, it was not an issue that we regarded as highly important.

Telling our stories & personal experiences of diagnosis

As mentioned earlier all of us had things bottled up inside. None of us had been in a position with the possibility of openly and thoroughly communicating to others what was happening to us and how we really felt.

Individual feedback from some members of the group about telling their stories was obtained by asking the following questions.

⊙ What was it like for you to tell your story?

"I found it unlike me to be so confident in front of strangers who were as confused as myself and unable to find any help."

"I found it to be a big relief to confide with other people who were in similar circumstances."

"I found it comforting to find that I am not alone, that others could relate to my story."

"It was as if a heavy weight was lifted from my shoulders. To have the opportunity to talk freely about my condition in a safe environment was wonderful and has given me a lot more strength emotionally."

⊙ What was it like to hear other peoples stories?

"Probably, it was the first time, I or anyone there, really unwound completely and often were in tears (all of us) and told of their deepest feelings without being self conscious."

"I was surprised to find out other people were experiencing very similar situations as myself "

"I am thankful that my condition isn't as bad as some other people in the group."

"It completely removed the feeling of isolation and loneliness that I have experienced with this sickness."

"It helped validate how I was feeling."

Effects of hepatitis C on our lives

There was agreement that Hep C is a very isolating illness and creates barriers in many aspects of our daily lives. The issues basically came down to what type of restrictions and frustration our Companion puts on our every day life.

Inability to do what we like and enjoy - physically

Unfortunately, most of us expressed a concern that we can no longer be a participant in sports and have reluctantly become spectators. Many of us had to leave work or reduce our workload. To a certain extent, it's like turning your back on your life; especially when you have the skills and knowledge to carry on but your medical condition and energy levels restrict your ability to develop and progress in your profession and socially.

Inability to do what we like and enjoy - emotionally

Every participant explained how their concentration and ability to do simple things was extremely limited by the confusion and disorientation that comes with hep C. This frustration in fact evolved through group discussions as one of the most common frustration's we all experienced from our debilitating Companion. All of us were quite relieved after comparing our experiences. Until then we had related these symptoms to aging processes, being absent minded or being a mum etc. Several people in the group expressed the anger and frustration of not knowing what was ahead of them wondering if it was worth living. Everyone identified at some time they had considered either giving up, or were plain scared of dying.

(Self care issues later in this paper discuss outcomes of dealing with these feelings)

Inability to do what we like and enjoy - diet

Hep C puts restrictions on our ability to eat and drink what we would like. We were all very conscious of the fact that too many fatty foods and excessive alcohol intake etc do not make us feel very well the next day. "What you eat and drink today controls how you function the next day."

Inability to do what we like and enjoy - relationships

We discussed different ways of being in relationships and how most people fall into one of two categories; followers or leaders. Leaders with Hep C tend not to be able to cope with every day things any more like banking, planning and organising the way they used to. Followers with Hep C tend to need more

feature

One person who has two strains of hep C has been having Vitamin B12 injections for over 7 years. She has found her quality of life has been maintained enough to work part time and just plain keep her "head above water", which is a major improvement since beginning these injections.

Two of our group were currently taking CH100 tablets - the Chinese herbal formula trialed at John Hunter Hospital - which appeared to be helping reduce symptoms in one person. The other person had to stop taking because it did not agree with her.

Three people in the group were long term diagnosed with hep C and had tried interferon treatment. One started but had to stop the treatment because of other medical complications. She went 9 months with absolutely wonderful response (and very few side effects for the first 5 months). She was PCR negative and on top of the world but her thyroid became affected and her PCR went positive again after 8 months so she had to stop.

The second person had to stop within 3 months because of side effect to the medication, and has been unable to try interferon in combination with Ribavirin due to another medical condition.

The third person had to stop interferon the first time because of a flu infection but has since started again with a combination of naturopathic herbs, interferon & ribavirin. He was 4 months into the 12-month course with a PCR negative result which was very encouraging. Taking naturopathic herbs with the combination treatment is against medical advice, however everyone expressed the feeling that one should be allowed to make one's own informed decisions. If naturopathic herbs make us feel better, why not use them? Not much else improves our quality of life.

The two group members who got a fair way into the treatment stated that the emotional effects increased dramatically as they progressed through it.



Developing strategies for positive self care

Acknowledging your condition

Trying to be too positive and simply ignoring a diagnosis of hep C can do more damage than we realise. Hep C is a quiet achiever and this Companion takes its own path regardless of outward appearances of its host (us). We agreed that it is best to come to terms with the diagnosis, put as much anger as possible behind us and get on with taking control

(model/s used above)

and using the time and space we have to improve as best we can our quality of life. The following self-care strategies were discussed as a way of doing this.

Preventative care

Listen to the warning signs. Chronic fatigue can continue until you have crossed the line and come to a dead stop - hit by a bus syndrome. A preventative approach is kinder to both the individual & the progression of your Companion. You must work with your BUDDY (immune system). It's a two way street. Your BUDDY can only help you if you are kind to your system and don't overload it with extra demands.

Self Care Strategies

Finding a balance between you, your BUDDY & COMPANION drives self-care. Sometime you may have to walk away from things that are obviously too much for you to handle, along with managing hep C. The group identified that the following strategies are the best medicine for re-charging your battery to help keep your Buddy strong.

Diet

Most of us have adopted a regular diet, reduced fat intake and lots of water to help our systems eliminate toxins. All of us were also supplementing our diet in some way with vitamins or herbs to help improve our well being.

Emotional

Reduce emotional stress. Find a support person. Talk about your feelings and don't lock them away because you could risk locking away your life. Talk freely with other patients through clinics, doctors and support groups. Try not to overload family and friends so much that they are scared and worry so much about you that it puts another strain on yourself. Walk away from emotional unrest. Put yourself first, then consider other people's needs. Realise that you are on a long road: As mentioned earlier, Hep C is a SLOW achiever so you do have lots of time to consider your options. Don't panic. Put any anger about how you contacted the virus behind you. It's too late to go back and change things and besides it takes too much energy that you need for other challenges. Get a phone buddy.

Physical

Adequate rest/daily cat naps. Remove things in your life that create physical stress: For example instead of carrying a wet basket of washing, get a trolley. Avoid bending as much as possible. Avoid excessive physical strain. Find a substitute for sport like remedial type aqua aerobics, tai chi, yoga and controlled swimming regimes. Reduce excessive workloads if they are wearing you out too much. Make plenty of relaxation time doing things you enjoy.

Spiritual

Some of us have found that a strong sense of spirituality has been very important to help come to terms with the demands, stresses and challenges that our COMPANION continually throws our way.

Support for family members

Quite often the whole family gets caught up with this fast moving roller coaster of hep C. You can't always be there for them as sometimes you are too sick to control your own feelings. Most hospitals and doctors have information about support services available for your family to help them deal with your illness. Ideal times for help for the family would be when you are first diagnosed and after about 3 months to either reinforce information that was too overwhelming in the first meeting or to answer other issues that have appeared for you and your family since diagnosis.

Group feedback on self-care strategies

Individual feedback from some members of the group about self-care was obtained by asking the following questions.

1. What strategies of self-care did you learn from the group?

"I heard about several treatments that I was unable to get much detail about and had been very wary of the treatment and side effects. I understood more



easily than anything I had read in any printed literature that I had been able to obtain."

"Good Diet, explore natural therapies and check current treatment centres."

"I have learnt how to change my style of eating and now eat the right kind of food & drink."

"I have learnt how to help my GP with a lot of information about Hep C."

2. How have these strategies changed your ability to live with this Companion?

"Knowing how others have suffered and have been able to overcome many personal and deep frightening experiences and how they have tried to find ways around their problems & treatment has given me the strength to soldier on."

"Learning about self care strategies has given me some peace of mind."

"I am learning to live Hep C, without thinking about it everyday now."

"Given me more autonomy in dealing with Hep C and I am now able to advocate for myself and others."

Benefits of group togetherness

As a group we identified that the amount of literature that is available is useful but our mental retention and ability to concentrate hindered us in absorbing all the finer details of most documents.

The group found comfort in being able to talk freely to facilitators who could explain any grey areas of diagnosis, services, and simply provide support, understanding and guidance in this debilitating illness. Having a safe and comfortable place to meet and plenty of time to chat about our problems was a vast contrast to the amount of time a patient has to discuss matters with their busy GPs or medical staff.

There was absolutely no pressure to discuss any matters that we did not want to address. One to one counselling was there if patients needed this as a back up to the group environment. Participants found this a wonderful substitute when there were personal things we could not quite come to terms with talking about in a group situation.

Recently diagnosed people in the group gained a great deal of first hand knowledge from the others who had already tried treatment options available.

Overall the group environment gave us all the strength to deal with our situations and more importantly helped us build a support network with other people experiencing the same lifestyle.

"Contact with others who have had the same daunting experiences was the most precious thing we can take away with us from this group."

Overall feedback

As a group we asked the facilitators to identify things we had alerted them to about our tug-of-war with our COMPANION. They identified 3 areas they had not realised impacted so dramatically on our lives:

- * Confusion - memory loss and inability to perform simple tasks
- * Energy levels - (there is tired & there is T-I-R-E-D)
- * Isolation associated with this virus and related problems with personal relationships

Hopefully this information will carry through to other groups.

My personal observations

Overall the group seemed to agree that the support and sense of peace we have gained in a group situation is irreplaceable.

It was my observation that group support would be invaluable through the following stages of diagnosis, treatment and progression of our COMPANION.

- * Initial diagnosis Pre/Post test
- * Anytime a medical person leaves you up in the air or when you receive negative results over the phone.
- * Before any scans, biopsies or commencing long term or varied treatment.
- * When you feel like a lab rat (only filling a hospital quota)
- * Anytime you feel the doctor is not listening to you or you are getting conflicting information.
- * If treatment is unsuccessful and you need more time to consider your options.

Conclusion

Each and every one of us valued the communication and learned so much more from others experiences of living with Hep C. Basically we decided that if we could find a way to make our Reluctant Companion lay dormant and improve our lifestyle we would all be happier people.

The overall success of this group was attributed to the fact that we all had been seeking this type of help and communication with others. Our individual strength and ability to be so frank shone through on numerous occasions and has led to continuing friendship and get togetherness that none of us want to lose. We have formed these friendships to support and help each other travel whatever path is ahead of us and have a few laughs along the way.

"We learned things from each other, that no book or doctor could tell us."

- Julie Graham, on behalf of a successful Hep C support group (1998) conducted through TRAIDS: 02 9843 3143

**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.

Hepatitis C forum

Free access to complementary therapies (and funded research into their effectiveness) were identified as key needs at a public forum into hepatitis C, hosted recently by the Hepatitis C Council of NSW.

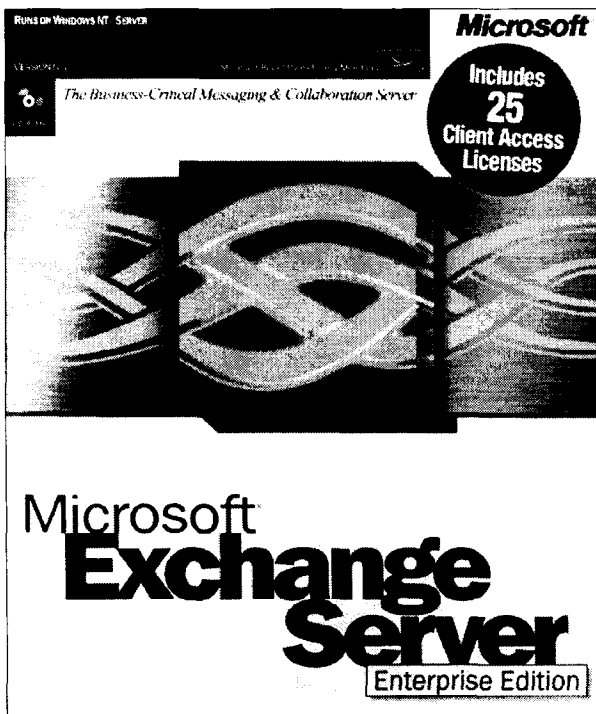
Packing a meeting room and overflowing into an adjacent corridor, forum participants debated what hepatitis C related needs they felt remained unaddressed.

Additionally, many people felt there was a need to address discrimination within the wider community; with a worrying level of confusion about hepatitis C being seen by some participants as a key problem.

Thanks, Microsoft!

Our thanks go to *Microsoft Australia* who have been able to step in and offer direct assistance within the HCV response here in NSW.

Their generous support - through the donation of various software products - enables the expansion of our computer network and communication capabilities. It has been warmly welcomed by Council staff and management.



Microsoft Exchange Server Enterprise Edition. Includes 25 Client Access Licenses. The Business-Critical Messaging & Collaboration Server.

A new man

Many things have changed since I was first directed to you in early 1996.

The original diagnosis had a devastating effect on my life. After being away from heroin for more than 20 years, a hep C positive result brought back many memories - good and bad - from that brief experience.

The devastation encouraged me to wallow in self-pity. "Why did this happen to me?"

About the same time I became re-acquainted with Denise, a Christian lady from the Seventh Day Adventist Church, whom I had met in 1995. Denise and I shared an interest in good, healthy food and nutrition - and its relation to physical well being. She was able to enlighten me on Christian lifestyle and spiritual well being.

We got together often and talked about the relationship between spiritual and physical health. I attended her church often and also visited other churches.

In early 1997 I experienced the spiritual healing of a neck injury that for several years had caused me much pain. This happened in a small Pentecostal Church in Penrith.

I checked out other churches and in early 1998 started attending Penrith Christian Life Centre, making it my own church. There is a healing service every Thursday - except for Christmas school holidays - and I go along as often as possible. The 6pm service on Sundays is also extended into time for healing.

Having my neck healed increased my faith and belief in God. The physical, emotional and spiritual healing that I have received has made me a new man (I feel born again). With the good health and positive attitude that I now have, often I simply forget that I have hepatitis C.

The people at my church accept me as a new Christian and are always encouraging me to keep on growing in a positive way. Just over a year ago, I met a beautiful woman of God who has accepted me with my past and my hep C status. We are engaged to be married.

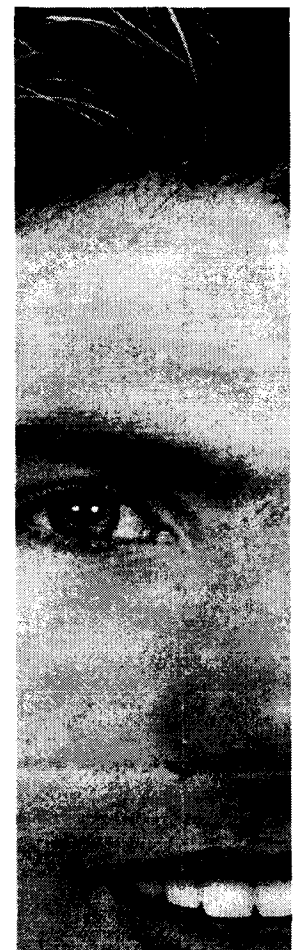
I don't know where I would be if the Hepatitis C Council was not there when I needed you. I thank God for you good people and for all the other good people and events that have brought me to where I am today. I am grateful for the Grace and the Mercy that God has extended to me.

There are many people who would not think of going to church to be healed; three years ago I wouldn't have thought it possible.

There are many good Pentecostal Churches and not all religions teach or accept divine healing. I would encourage all people to investigate Pentecostal Churches - and some conservative Churches - for their healing ministries. I know it has worked in my case.

Many thanks for your help and support

Regards, Allan



(models used above)

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.

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

Regional NSW

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

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

support services

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 9600
	Jan Pritchard-Jones	9515 8643
Nthn Sydney	Graham Stone	9926 6717
SE Sydney	Lesley Painter	9382 8370
Sth West Sydney	James Mabbutt	9827 8033
	Laura Baird	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	Darrieta Turley	08 8080 1511
Hunter	Marilyn Bliss	4924 6477
Illawarra	Brian O'Neill	4228 8211
Mid Nth Coast	Robert Baldwin	6588 2789
Mid West NSW	Dave Brackenreg	6332 8576
New England	Karin Ficher	6766 2288
Nthn Rivers	Kerry Leitch	6620 7505
South West NSW	Dalton Dupuy	6058 1700
Southern NSW	Geetha Isaac-Toua	4827 3328
Western NSW	Scott Davis	6881 2215

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).



stop press

Hep C Helpline extends hours

The *NSW Hep C Helpline*, the state-wide telephone information and support service operated by the *Hepatitis C Council of NSW* has extended its hours by 38%.

From the 1st September, the *Helpline* is open during the following hours:

Monday to Friday: 10am - 5pm
Monday evenings: 5pm - 8pm

These changes mean that we are able to offer greater access to HCV information and support for everyone affected by hepatitis C - and as is always the case, a friendly chat if that's what you want.

The majority of our 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.

All callers are always very welcome - including the students and employers who frequently phone in.

All callers who use our service are offered a free HCV information resource pack that, if requested, can include specific information about particular aspects of HCV.

We trust that our extended hours of opening will provide you with increased opportunity to access YOUR *Hep C Helpline*.

Look back, look forward video now available

Copies of the *Look back, look forward* video are available for borrowing from the Council (see page 2).

Describing individual people's experiences with HCV, and including several interviews with expert clinicians, the video is a must for anyone wanting to find out more about hepatitis C - and how other people deal with it.

It's been proven a useful resource for individuals and groups, and particularly good for healthcare worker education sessions.

classifieds

For sale

1977 Holden Torana. 3300 6 cylinder. Good motor and tyres. Good interior finish. No rust, some body damage. Rego to 12/99 (GH 801) \$500 ono.

Phone Paul on 9558 9550 - Marrickville

more information

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

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

