

The Hep C Review

Spring Edition October 1999

Edition 26



HCV - The Evolving Epidemic 2nd Australasian Conference on Hepatitis C

Christchurch Convention Centre
17 – 19 August 1999
Christchurch, New Zealand

The successful 2nd Australasian Conference on Hepatitis C highlighted the continuing efforts to reduce HCV transmissions and to reduce the impact of hepatitis C infection on the lives of the hundreds of thousands of people affected – living on both sides of the Tasman.

Over 350 Australian, New Zealand and other international delegates filled the Christchurch Convention Centre to report on, discuss and test progress within The Evolving Epidemic, the name given to this keynote conference – a decade on following formal identification of the hepatitis C virus.

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*edition 26 focus:
info update:
updates*

*Hepatitis C and living better
Interferon/Ribavirin combination treatment
Second Australasian Conference on Hepatitis C*

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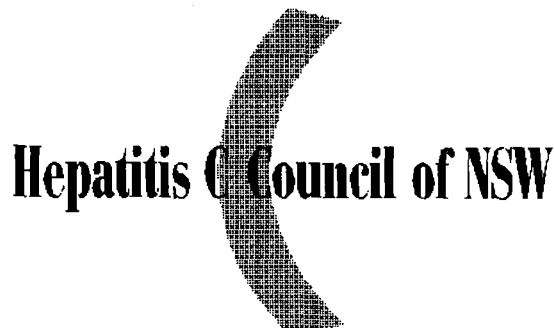
The Hepatitis C Council is an independent, community-based, non-profit membership organisation. We provide information and support to people affected by hepatitis C and assist in preventing further spread of the hepatitis C virus. We are primarily funded by NSW Health.

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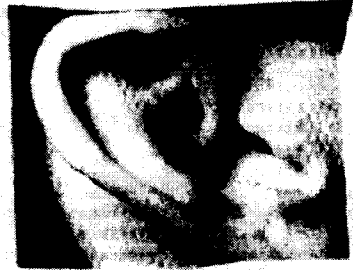
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information

information



support
support
support

support



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free
free

free & confidential

referrals
referrals
referrals

referrals



HEP C

02 9332 1599

FOR LOCAL CALLERS

HELPLINE

1800 803 990

FOR NEW CALLERS

A copy of our recently developed *Hep C Helpline* poster. If you'd like some large, glossy copies to display in your neighbourhood, just phone the *Hep C Helpline* on 02 9332 1599 or 1800 803 990.

An approach to drug treatment and rehabilitation

By Dr Ingrid van Beek

From a public health perspective I think that there are two key components to providing effective drug detox treatment and rehabilitation.

First, people's access to the health system is incredibly important. It is necessary for the health system to have contact with as large a proportion of the injecting drug using population as possible at any one time - at all stages of their injecting drug use, preferably even before they commence but during and also when they are ready for treatment.

Second is that treatment and rehabilitation services should be attractive, appropriate and acceptable to the injecting drug using population and also to the community that must host the programs.

Consultation and involvement of the affected community - the consumers and the community that hosts the programs - are incredibly important for the treatment and rehabilitation programs to be successful.

The Kirketon Road Centre is an example of a comprehensive, integrated community-based program. As a result of the Rogan parliamentary committee report, which was endorsed by the NSW Parliament in 1986, Kirketon Road was established primarily with a view of preventing HIV and other transmissible infections (STDs, hepatitis) among at-risk populations. At the time there was an appreciation that there was a need to go out and make contact with people who were at risk.

I think it would be fair to say that prior to that time most services set up for injecting drug users or other people with drug and alcohol problems took the view: when and if you are ready you can come to us and ask for help, then we will probably have the best outcome.

However, in the mid-eighties, the immediacy of AIDS caused us to shift to a very different approach. It was necessary because not only were the at-risk populations going to be potentially affected by this devastating epidemic but other parts of the population also stood to be affected, and the economic and social costs were recognised to be potentially very large.

So the service was set up under the philosophy of reaching out and being accessible, acceptable and affordable to those populations. It was set out at the time that the service should be non-judgmental in approach and that it should consider that health is a basic right for people

regardless of what population they come from or what other behaviours, criminal or otherwise, they may be involved in.

That philosophy has stood us in good stead. We started out providing medical counselling and social welfare services. In 1988 we added a needle syringe program to the mix. In 1990 we extended to an outreach program and in 1993 we set up a methadone access program particularly targeting people who had difficulty accessing existing mainstream services.

At this stage we provide services in the inner city extending into the Kings Cross area and out to the Redfern area at The Block. Our various aspects of operation make contact with 500 clients a day. We have certainly achieved access to the at-risk population. That is not an end in itself, of course. We have to maximise the opportunity provided by that access.

In this regard I applaud the recent funding of projects to enhance needle syringe programs so that they can use the access that they also have gained over the last decade to perhaps refer people on to treatment and so on.

Particularly in recent times this need has become even more present as there have been increasing pressures particularly on government programs in the AIDS area as a result of stagnant funding levels and the concurrent advent of a hepatitis C epidemic which has put even more pressure on our programs to get clean injecting equipment out there.

Unfortunately, at this stage I would have to say that in our clinical practice, despite having this access to an at-risk population, our counsellors come to me day after day saying that when people now ask for referral into treatment their hearts quake. They know that this is the beginning of a series of telephone calls which can literally take hours. The counsellors have to approach one

treatment centre after another, subject to the vagaries of the focus of each centre, trying to pre-empt the trick questions that inevitably seem to come along.

We are almost at a stage where people have better access to drug detox treatment and rehabilitation programs if they have committed a crime and come through the recently initiated Drug Court scheme. Treatment access through the Drug Courts can only work well within a context of good access to treatment services for all people and while I would applaud the recent initiative of the Drug Court, I believe there is a great need to improve the current state of treatment services, generally.

Treatment and rehabilitation initiatives need to be considered in the light that drug dependence - I underline drug dependence, not all drug use - is a chronic relapsing condition. You may have heard it before but I am going to say it again: It is a chronic relapsing condition, just like many other conditions that people in the health field deal with.

Drug users are individuals. One would be misguided in thinking that there could be one solution for all the individuals who, at different times, have very different needs. We need to consider the chronicity of this condition in our approach. We need to proceed in the same non-judgmental way as with blood pressure, for example, and look firstly at the research evidence. We need to consider which treatments are most effective and then tailor those to an individual at a particular time.

It is an hierarchical approach: you try one thing and if it does not work you try another. If one medication does not bring down a patient's blood pressure another medication is tried. Drug treatment is no different.

"treatment and rehabilitation services should be attractive, appropriate and acceptable to the injecting drug using population and also to the community that must host the programs"

Having said that, it is important that I also say that one could easily become depressed, tempted to throw the baby out with the bathwater and start from scratch. There is no need for this. There are some excellent services in place. We have tried very hard and I am proud of my colleagues in this field; they have done very well under difficult circumstances. Obviously, we need to provide better access to services. I suggest that is most appropriate through integrated community-based services such as Kirketon Road, which, despite the fact that it has been replicated internationally, continues to be one of the very few such services in this country.

Additionally, we need more treatment, more of everything, and that will involve a financial investment. I agree that we should look at how wisely we are spending money. But, trust me, we are extremely efficient now. In the past 10 years we have seen incredible constraints placed on the public health sector and there really is no fat left. We need more money.

The methadone program is a cornerstone of not only drug treatment but also HIV and HCV prevention. Whilst I think that we may want to look at how this program operates we need to be very careful not to malign such a successful program. We have certainly expanded the program very rapidly to meet public health objectives for quantity. A large proportion of the injecting drug-user population accesses this service. However, we now need to turn our attention towards the quality of the treatment.

I suggest that these programs are best integrated into other drug and alcohol services so that we do not have a single mind-set, and so that the availability of other options and treatment is made known to clients on methadone. The methadone program should be run under a case management model. But, again, that would need resources. Currently this treatment is extremely cheap. To run it as a case management model would have huge resource implications.

We also need diversity in treatments including naltrexone, buprenorphine, LAAM, residential programs and therapeutic communities.

We need to support Narcotics Anonymous, and we need inpatient, outpatient, medicated and non-medicated detoxification programs. All this is very costly.

We must also look towards new approaches and not be scared. Fear, of course, underlies a lot of approaches to drug use. Given that this is all associated with great morbidity and mortality it is understandable that the parents of young people are fearful and anxious about what we do and the messages we send out. However, other countries have tried other approaches.

I recommend that we also consider such things on a trial basis and, pending the results of those trials, introduce them into the communities in a limited way. We need to be careful in considering new initiatives and not make the

mistake of applying a test that is completely unrealistic and unachievable. No one initiative will address all the issues associated with illicit drugs. For example, in the Drug Summit it was said that heroin programs, or injecting rooms, are unlikely to stop 16-year-olds from commencing injecting drug use. That is absolutely true, but it should not stop us from considering those programs, certainly in the circumstances under which I work.

We work with people who use drugs heavily and who have been entrenched in that sort of lifestyle for many years. Although they are probably a small proportion of the drug-using population, they are significantly responsible for a lot of the crime associated with drug use. In the drug using population heroin programs may well be a useful strategy to include in the mix of things.

There is a need for further integration and it needs to happen at a micro level between treatment and rehabilitation programs. Many people fall through the middle, after detoxification and before rehabilitation.

We need integration between the government and non-government services, particularly as the government services have been suffering over the past decade. We also need integration between services and the local communities. At a more macro level we need a whole-of-government approach.

We have major training needs, particularly medical training. There is no medical training in Addictions Medicine. Those who work in this area are usually there by accident and have usually come from related areas.

We must stand together and continue the bipartisanship that the Drug Summit has endorsed and embraced. This is not about closing ranks; this is about being open and honest, and working constructively towards a common goal. It is about being a caring society that treats marginalised populations with dignity and respect and, at the same time, makes the community feel safe and secure.

To do that we need to balance public health and public order approaches: not too much of one or the other, but a balance. That can be effected at a local community level. We have made great inroads into doing that in the Kings Cross area. It means that we have to recognise that communities are different: what is good in Kings Cross may not be right in Cabramatta. We need to engender community understanding of the complexity of this issue - and not underestimate the ability of the community to understand those complexities - but at the same time encourage the community to own these things.

I rarely come across communities which say, "Yes, this drug-using problem is our own". Usually it is considered an import. I need to find a community that says "No, it belongs here and we will deal with it here."

All the research, treatment and rehabilitation is fine and well, but it needs to be hosted by communities which support those programs. It is very difficult working with a population experiencing issues that are extremely complex in a community environment which is often hostile. The morale in this sector is very low and we really need the support of communities and politicians. That is where politicians can have a major impact in assuring the community that as difficult as it is sometimes to support these programs they need to do so for the greater good.

- Dr Ingrid van Beek is Director of the Kirketon Road Centre, Kings Cross, NSW, and a member of the HCCNSW Medical and Research Advisory Panel. This editorial is abridged from the speech given as the Introductory Speaker on "Treatment & Rehabilitation" at the NSW Drug Summit, May 1999.

"It is about being a caring society that treats marginalised populations with dignity and respect and, at the same time, makes the community feel safe and secure"



Treatment update

I've just started the interferon Ribavirin treatment. I started last Thursday. So far I've taken it 3 times and at this present time there are no side effects that worry me. All that I can notice is my legs are always itchy and I'm always thirsty like I need to drink water. Even after I've just had a drink my mouth is always dry but besides those two I feel good.

I have to go back and see my Doc next Thursday afternoon. I think he just wants me to go back and check on me just to make sure that I haven't grown another head on my shoulder or something like that and to have another blood test to see if my ALT levels have dropped again, if not I'll have to change my diet again.

See you later, Bob



Inside hep C

Hello! I would just like to say thank you for your information provided in your magazine and the support.

I'm currently serving an 11 year sentence, I always look forward to the *Hep C Review*. I feel bad not being able to make a donation to the *Hep C Review* or even put my hand up as a volunteer but as soon as I'm out of this hole (I hope next year) I will be more than happy to pay for my copy of your top magazine.

Any free time I have I would love to do any work for you that may need doing no matter how big or small. It's all I could do for all the things the *Hep C Review* has done for me and I'm sure a great deal of other inmates.

Best wishes to you all at the *Hep C Review* and Hep C Council of NSW.

Yours sincerely, Teepe



How big is a virus?

How big is a virus? What is apoptosis? How are antibodies produced? What is a cytotoxic T cell? How does penicillin kill a bacterium?

I found a great web site resource for learning about the mechanics of disease and the human immune system. For answers to these questions and many more, see: <http://www.cellsalive.com/>

There are a lot of graphics and QuickTime movies that may slow down your browser but this site is well worth waiting for.

Best Regards, "Uncle" Dave



Partners

I wanted to let you know what it has been like for me as a partner of someone with Hep C. My relationship started 18 months ago & I knew from the start my partner had Hep C (genotype 2b). He contracted the virus through needle stick injury & blood spill at work in Drugs & Alcohol.

My friendship & concern for my friend came first before any personal fears of contracting the virus. I felt very saddened and frustrated watching him attempt to participate in a research study with combined therapy - actually had to make his ALT worse just to get onto the study! Eventually he was accepted. Twelve months of injections (due to cease in 7 more doses!)

I was not prepared for all the side effects he was to experience. The initial 10 million units left him shivering uncontrollably all night long. I froze in bed next to him. What was I in for? A lot of debriefing & honest dialogue! I have 3 children: 10yrs boy, 8yrs boy, and a 3 year old girl. We all participate in the process of his recovery, joining in with morning juices to low fat diet, no alcohol, the ritual injections (which fortunately as a nurse I can help administer) 3 times a week!

The children are wonderful. They talk openly and empathize about Bob's hep C. They have learnt that his well being is all of our family's well being.

This determination to heal his body has been a journey which I am only the richer in experience for having travelled. I am very proud of his perseverance. His hair is more gray & thinner, his once fit body is tired & fatigued, his eye sight has markedly deteriorated - BUT he is overwhelmed at an initial negative PCR and his liver levels are all normal & have been throughout the study.

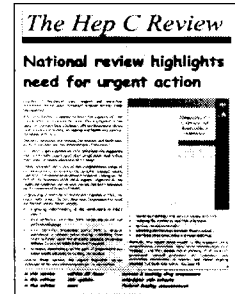
I think hep C is a dreadful virus - I take all necessary precautions with blood to blood spills but basically our life has never been better. My family intends to see the Hep C virus through, no matter what.

I hope everyone out there has hope & determination to be healthy in mind, body & spirit. I believe the greatest asset of all has been support - talking to others; friends, family. Finding a body therapist has been enormous support for Bob, joining a support group via the Hep C Council is fantastic and a wonderful sharing experience, and the children of course are so healing in themselves.

One writer recently wrote her 12 year old daughter was too young to know - I don't think so - speak simply and openly, honestly and lovingly and children are so accepting and thirsty for knowledge. Then you no longer become sick but unwell at times. Hep C is but one part of the whole. For me it is easy to forget at times that Bob even has hep C, because it has been reduced to just another factor in our intricate family life!

God bless, from Louise

Correction & comment from Ed 25



Blood transfusion

We published an error in Edition 25's letter "Just a short hello" (page 5).

We mistakenly printed, "I had a blood transfusion in 1998."

Instead it should have read: "I had a blood transfusion in 1988."

With the blood screening techniques that were adopted in 1990, and an improved test in 1991, the chance of contracting hepatitis C virus through the blood supply is extremely low.

Hepatitis C transmission

Within the above headlined article, taken from *The Age* website, and contained in our Edition 25 (page 7), it was mentioned that: "Hepatitis C is usually transmitted by an injection of an illicit drug or blood transfusion ..."

More correctly, it should have read: "These days, hepatitis C is usually transmitted through shared use of illicit drug injection equipment. Additionally, prior to 1990, around 1 in 10 cases occurred through contaminated blood supplies or blood products."

Mailorder Ribavirin

Within our Edition 25 editorial, we mentioned that Ribavirin can be obtained via mail-order. A healthcare worker has written in expressing concerns that this may be an illegal activity.

Australia's therapeutic goods legislation exists to provide excellent safeguards to ensure the safety, quality and efficacy of medicines approved for use in Australia. Under limited conditions, it also provides access to unapproved medicines.

Although Ribavirin is part of the new combination therapy, by itself it is not authorised in Australia for the treatment of hepatitis C. But because Ribavirin is not included in the Customs (Prohibited Goods) Regulations, healthcare workers are able to access it under the Special Access, Clinical Trial Exemption, and Clinical Trials Notification schemes. Additionally, individuals are able to access Ribavirin under the Personal Import Scheme.

It should be noted that terms and conditions apply with all the above access schemes.

We certainly agree with the healthcare worker in that ANYONE CONSIDERING INTERFERON OR COMBINATION THERAPY SHOULD DO SO WITH THE ASSISTANCE, AND UNDER THE GUIDANCE, OF THEIR GP AND A HEPATITIS C SPECIALIST.



Transplant friends

I am sending this to you as you may be interested or know someone who is.

I am a Moderator in an online email subscription group for transplant support. This includes carers, parents, friends, or associated people that may be interested in giving online support and/or advice about transplants of all descriptions.

It works through a central email setup - Onelist, and the group is called Transplant_Friends. It works like email when you send a message to the group, everyone on that group receives your email.

We talk about all areas of transplant issues and offer support and advice and friendship. I have found it very useful for me and am now a Moderator to help people subscribe and assist manage the group.

I am sending an invitation to you, please disregard if you do not want to. I thought it might be useful for others as well, so please forward to others if you feel it useful to them.

You can join the list by going to the following web page:
http://www.onelist.com/subscribe.cgi/Transplant_Friends

Alternatively, email us on:
Transplant_Friends-owner@onelist.com

Respectfully, Fran.

Hepatitis C and living better

There's not much many of us can do when our car gets a bit 'sick.' We just drop it off at the service station and say "fix it." But by keeping to a responsible maintenance schedule we can help avoid such situations.

Likewise, with our own health, we can take steps to avoid letting ourselves run down. Having a chronic illness - like hepatitis C - may involve bouts of illness and it makes sense to maintain our overall level of health. This relates to both physical and mental health.

This edition of *The Hep C Review* attempts to cover a range of approaches people can take to improve their health and better adapt to living with their hepatitis C.

We hope that our range of articles and news items on hepatitis C and lifestyle meets your information needs. Additionally, we hope that it provides discussion points and signposts where you can find further, more detailed, information.

This edition also includes our first hepatitis C timeline. The end of 1999 will mark the beginning of a new millennium and the end of a decade of HCV development. Our timeline attempts to chart these developments - within the context of a community perspective that is predominantly NSW-focused.

S100 combo therapy

Combination therapy marketed as 'Rebetron' has been authorised for subsidised treatment of hepatitis C. Made available under Section 100 of the Pharmaceutical Benefits Scheme, subsidised combination therapy is available only to people who've already tried interferon monotherapy and relapsed.

Treatment lasts for 6 months. Response is monitored through HCV PCR testing and subsidised combination therapy is withdrawn if a person remains PCR positive 3 months into treatment. Because of its additional side effects, combination therapy is not provided to anyone - women or men - not practicing effective birth control. For more information, see 'Combination therapy', page 26, and 'Interferon combo therapy update', page 40.

Good news studies

Two recently published studies suggest that the long term outcome of hepatitis C may not be so serious as currently believed.

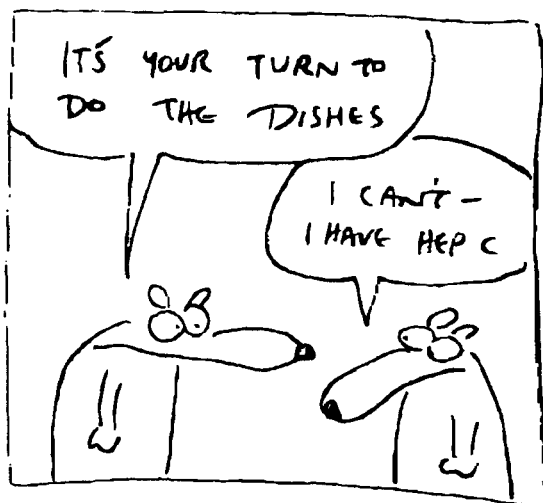
In the first case (see below for details), researchers in Ireland followed up a number of women who contracted HCV via contaminated prenatal injections between 1974 and 1978.

Approximately 700 women tested antibody positive and of these women, 390 tested PCR positive. Three hundred and seventy six of the PCR positive women agreed to take part in the study.

- The most common age of the group of women was 45 and they'd had HCV for around 17 years.
- 81% reported feeling symptoms of illness, most commonly being fatigue.
- 47% showed slightly raised ALT levels (40-99 above norm).
- 8% showed significantly raised ALT levels (99 or more above norm).
- 98% showed liver inflammation on biopsy (but in most cases, the inflammation was either slight or moderate).
- Only 2% (seven women) showed signs of probable or actual cirrhosis.

Although most of these findings do not surprise us, it is heartening to see the low rate of cirrhosis among the Irish women. It will be very useful to see a further follow up after another 5-10 years.

ADVANTAGES OF HEP C



In the second study (see below for details), Australian researchers followed up a number of people for whom the Fairfield Hospital, Melbourne, had stored blood samples dating back to 1971-75.

A complete follow up (PCR, LFTs, biopsy) was done on 35 people shown to be HCV PCR positive, and a sample set of 70 people shown not to have ever had hepatitis C - with the PCR positive group being more likely to report a history of injecting drug use.

Of the group of 35 PCR positive people (who'd had hepatitis C for over 20 years), 6% (two people) were shown to have progressed to cirrhosis.

The researchers concluded that although the PCR positive group face an increased risk of liver-related illness, few had progressed to cirrhosis. This suggests that the *natural history* (long term outcome) of IDU acquired hepatitis C may be less serious than is currently believed.

- Study 1 - Clinical outcomes after hepatitis C infection from contaminated anti-D immune globulin. *New England Journal of Medicine* April 22 1999; Vol 340, No 16.

Study 2 - Assessment of long-term outcome of hepatitis C virus infection in a cohort of patients with acute hepatitis in 1971-1975: results of a pilot study. *Journal of Gastroenterology & Hepatology*. March 1999; 14 (3) : 269-73

NSW Health Minister announces extra money

Increased surveillance and enhanced prevention and treatment services are among a range of new measures being implemented by the State Government in response to the growing impact of hepatitis C on the community.

The Minister for Health, Mr Craig Knowles, announced that recurrent funding for hepatitis C programs would more than double to almost \$1.5 million for 1999/2000.

The new initiatives follow the release, in November 1998, of the report of the NSW Legislative Council Standing Committee on Social Issues, *Hepatitis C - the Neglected Epidemic*. This report contains 132 recommendations to which the Government is currently responding. Among the key initiatives being implemented by NSW Health, are:

- Enhancement of recurrent funding of \$746,000 for treatment, care, support and laboratory services,
- Upgrade of the departmental Hepatitis Advisory Committee to a Ministerial Advisory Committee,
- Increased funding and better integration of the Needle and Syringe Program,
- New education resources and public education campaign.

Clinic to pay over eggs

By Lorna Knowles

A Sydney fertility clinic which destroyed a woman's embryos because she had hepatitis C was ordered to pay her \$15,000 in damages.

The woman and her partner had tried to conceive a child for nine years before seeking help from the Westmead Fertility Centre in 1993.

Initial tests found that the woman had chronic hepatitis and liver disease, primarily from hepatitis C.

She was offered treatment in a program where eggs are removed from the ovaries and inserted into the fallopian tubes with sperm. Normally, any excess eggs not inserted into the fallopian tubes are frozen and stored.

The Clinical Director of the centre was concerned the woman's stored eggs could infect laboratory staff and other embryos stored in 500 straws in the liquid nitrogen tank.

He decided with staff members that the woman would be provided with the initial treatment but not egg storage. But the woman was not told of that decision and signed consent forms which made no reference to the plan not to preserve excess eggs.

"I asked what would happen if there were more than the required amount that they were going to put back and I was told that they would be put into freezing for later use," the woman told the Administrative Decisions Tribunal.

The couple claimed discrimination on the grounds of physical impairment. The Western Sydney Area Health Service, which runs the clinic, was ordered to pay the woman \$15,000 for the hurt and suffering she experienced as a consequence of its discrimination.

- Taken with thanks from the *Daily Telegraph*, 20/7/99.

New virus is missing piece in hepatitis puzzle

Italian researchers, led by Dr Daniele Primi, believe they have found a new hepatitis virus - possibly the last major piece of the puzzle of blood-borne hepatitis.

Using an unusual technique to test nearly 600 stored blood samples, largely from the laboratory of Dr. Harvey Alter at the (United States) National Institutes of Health, Dr. Primi's team linked the newly found virus to cases of hepatitis with unexplained viral causes. They also found it in patients who were infected with known viruses that causes hepatitis and AIDS.

Dr. Primi's team has named the new virus SEN-V after the initials of the man in whose blood it was first detected. The "V" stands for virus, Dr. Primi said. The Italian scientists have determined the virus's complete genetic structure, found five closely related variants and developed tests to detect them.

Dr. Basil Rigas, a professor of medicine at New York Medical College in Valhalla and Rockefeller University in Manhattan, said, "This looks like it is the last chapter in our 30-year quest for agents that cause viral hepatitis." Dr. Rigas, who is a member of Diasorin's medical advisory board, said the results needed to be replicated, but said, "The data are as good as they come."

The scientists noted that the virus did not represent a new threat, but rather explained cases of hepatitis whose cause was not known. "This is not a panic and there is no indication from work so far that the new viral illness is increasing through the world," Dr. Alter said.

Dr. Leon, Dr. Primi and Dr. Alter say there are plans for additional studies to determine:

- what proportion of chronic liver disease the new virus causes.
- whether the virus is spread through sex and routes other than blood and injections.
- whether the new virus can increase the severity of illness from AIDS and other types of hepatitis.
- the number of healthy people who are carriers of the virus.
- what role, if any, the virus plays in other liver diseases, like fatty liver and fulminant hepatitis, which quickly causes death.
- whether effective therapies can be developed.
- whether chimpanzees can be infected to study the course of the viral infection.

The scientists believe they can clarify some issues in a few months, while others will take up to two years. They noted that it took several years for other scientists to show that what was initially called the Australia antigen was in fact the hepatitis B virus. Similarly, it took several years to show that the hepatitis C virus was a common cause of chronic illness.

- By Lawrence Altman of the New York Times.
Taken with thanks from the Internet list, HEPV-L

Tiny US pharmacy takes on drug company

By Edward R. Silverman, Newark Star Ledger

A small specialty pharmacy based in Pittsburgh, USA, is about to challenge the Schering-Plough Corporation for the fast-growing market for treating hepatitis C, and its plan has not only angered the big drug maker, but thrilled patients and surprised regulators.

Fisher's Specialty Pharmacy Services plans to make its own version of a pill called Ribavirin, which the big drug maker licensed from another company and currently sells in its big-selling hepatitis C kit. Fischer's introduction is timed to coincide with the 1999 expiration of a patent on Ribavirin.

In order to make the alternative pill, Fisher's will first import the key ingredient from overseas and then rely on compounding - much like an old-fashioned apothecary. The pharmacy will pack powder into capsules according to a doctor's prescription. They plan to sell their version of Ribavirin for about 80 percent less than the cost of the pill in Schering-Plough's kit, which is sold under the Ribetron name. Their lower price tag is significant, because Ribavirin can't be purchased separately - it was approved to treat hepatitis C only in combination with Schering-Plough's Intron A, or interferon, an injectable medicine.

Since the Ribetron kit was approved in the USA last year, Schering-Plough has come under fire because some people want to combine the Ribavirin pill with another company's

interferon. But the drug maker won't lower the price or unbundle - sell separately - the two drugs in the kit, despite a belated plea by the (US) Food & Drug Administration.

"We're hoping (Fisher's alternative) is leverage because, ideally, we'd like to see a drop in the price and the treatment unbundled," said Brian Klein of Hepatitis C Action & Advocacy Coalition, a patient-advocacy group that brought the issue to the attention of the American Medical Association's Council on Ethical and Judicial Affairs, and has lobbied members of Congress to hold hearings into Schering-Plough's marketing practices.

In the past, Schering-Plough has defended its marketing practices by noting that other companies that sell an interferon haven't offered evidence their products would prove effective when combined with the Ribavirin pill in the Ribetron kit. And the drug maker said it never sought FDA permission to market the pill separately and would be liable for any mishap resulting from the use of the pill with another interferon.

However, Klein noted that Schering-Plough was prevented from bundling the two medicines in Europe, where Ribavirin is sold separately. "They obviously can't be too concerned about safety if they're selling it (separately) over there," he said. "We're not suggesting one pill is better than another, but we're certainly hoping people will consider (Fisher's pill), since Schering-Plough's marketing practices are reprehensible."

- Taken with thanks from the Internet email list, HEPV-L

Centrelink phone service for people with disabilities and carers

Centrelink is pleased to announce a new dedicated 'one-three' phone number for customers with disabilities and carers.

The new 13 27 17 phone number is supported by teams of specialist staff in five Call Centres across the country, who have been trained in disability awareness as well as in the technical aspects of the following payments and services:

- Disability Support Pension Sickness Allowance
- Carer Payment Child Disability Allowance
- Mobility Allowance
- Employment assistance for people with disabilities
- And payments made to the partners of those customers, such as Parenting Payment or Partner Allowance.

A feature of the 13 2717 Disability, Sickness and Carers service is its ease of access. Customers are welcomed to Centrelink by the recorded message, but there is minimal messaging and no action required by the caller to be connected to a Customer Service Officer. In addition, those customers who call Centrelink on the existing one-3 numbers can make a selection in the interactive voice response unit and be automatically transferred to the new number.

This new service is a response to feedback from key Disability and Carer groups, as well as a result of Centrelink striving to improve services for all its customers.

References to 13 2717 in customer forms and letters will be phased in over the next six months. In the meantime, we encourage you to take advantage of the service offered by the 13 2717 number.

New type of artificial liver

By Mark Skertic

An artificial liver that uses human cells to keep a patient alive was used for the first time at the University of Chicago Hospital.

"Assuming this device does what we anticipate it will, it's a big advance," said Dr. Michael Millis, the hospital's director of the liver transplant program.

Sheryl Orlyk, 34, whose liver had begun to fail, was the first patient to use the device. Several artificial livers use pig cells to duplicate the functions of a liver, but the device being tested at the University of Chicago is the first to use human cells.

A mother of three, Orlyk, of Carpentersville, used the device while waiting for a liver transplant. Taking part in clinical testing of the device was his sister's chance at life, Mike McCabe said.

"Right now, she's so bad anything that will buy her time can't hurt," he said.

The extra-corporeal liver assist device - ELAD - uses a cartridge filled with human liver cells genetically engineered to keep dividing. Plasma is separated from a patient's blood and then pumped through the cartridge. The cells mimic the function of a liver, removing toxins and manufacturing proteins. The treated plasma is ultimately re-mixed with the cellular components of the blood and returned to the patient.

Devices that use animal cells can't be used for more than eight hours a day, but the ELAD can be used continuously for 10 days, Millis said.

- Taken with thanks from the Internet email list, HEPV-L

Four-way liver transplant

By MARTIN FACKLER, Associated Press

Four teams of Japanese doctors began a tricky series of liver transplant operations in July that will be the first in the world to simultaneously involve four patients.

The procedure is called a domino transplant because it involves a string of operations conducted one after the other, like a line of falling dominoes.

The transplants are common in Europe, where they are used to help critically ill patients who might not survive the long waits for a healthy liver. But previous domino transplants involved only three patients.

In domino procedures, the first two operations are just like a regular liver transplant. Doctors removed half the liver from a healthy donor and then give it to a recipient who

suffers from an ailment. In this case, the recipient is the donor's younger brother.

The domino effect comes as the ailing liver taken from the first transplant recipient is then given to a third patient with more serious problems.

The operations in Kyoto are unique because the second donated liver was cut in two and given to two women who both have life-threatening liver diseases. Doctors can transplant half a liver because the organ can regenerate and become a healthy organ.

"If it can help people who are suffering ..., then please use my liver," the donor of the second liver was quoted as saying before the operation.

This was the first domino transplant operation in Japan. The first domino liver transplant in the world was conducted four years ago in Portugal.

- Taken with thanks from the Internet email list, HEPV-L

New hep B treatment

Subsidised Lamivudine (Zeffix) is now available for treatment of chronic hepatitis B in Australia. The treatment was added to the Pharmaceutical Benefits Scheme Section 100 highly specialised drugs program, the listing taking effect from 1 July 1999.

Taken in the form of tablets, it is available to people with hepatitis B who meet the following criteria:

- Have evidence of chronic hepatitis on liver biopsy (waived for people with blood clotting disorders).
- E antigen positive and/or HBV DNA positive and having evidence of chronic hepatitis B for at least 6 months.
- Have an ALT greater than twice the upper limit of the laboratory reference range on 3 occasions over a period of 6 months.
- Do not have cirrhosis.
- Are not pregnant, not breastfeeding, or are not practising an adequate form of birth control.
- Would attend regularly for treatment and follow up.
- Have no more than 7 standard drinks per week.

US FDA approves new hepatitis C virus test

WASHINGTON (Reuters) - The United States Food and Drug Administration has approved an improved, more specific test to check blood for the hepatitis C virus.

The test, made by the (US) Chiron Corporation, is more sensitive to antibodies against the virus and can help pick out infected blood that has passed other tests, the FDA said.

The new RIBA HCV 3.0 Strip Immunoblot Assay, looks for five antigens to the virus, compared to earlier tests that find four antigens. Antigens are the proteins that react to antibodies.

"Improved screening tests were put into use in July 1992," the FDA said in a statement. Occasionally, however, these very sensitive blood screens that rarely miss a true infection can give a false positive result - a test result that may not reflect a true infection."

- Taken with thanks from the Internet email list, HEPV-L

Living positive and reducing stress in your life

A diagnosis can be overwhelming and is often accompanied by feelings of helplessness, anger, denial and fear. Adding to this confusion, is the sense of urgency to do something, anything. Additionally, there is a constant stream of new information, conflicting studies and a lot of unknowns. This new world can be very daunting and stressful.

Scientific studies have demonstrated that a high level of stress can be bad for the health, but dealing with stress can seem difficult. It is best to reduce the stress in your life by starting slowly. Imagine a person trying to learn to swim. You wouldn't begin with complicated racing turns and intricate hand movements. You wouldn't be able to do it and would probably just give up.

The same goes for stress reduction. Start slowly with the basics and go from there.

Fear of disclosure is a major stress in the lives of many people with HCV. People may discriminate against you because of their fears and ignorance. Although it is hard to change the attitudes of the world, you can slowly take control over your own reactions to such people.

Nurturing, caring and forgiving yourself and others is a positive step. Living more in the moment, helps you to be more grounded and worry less about the future. Bad things that happen around us are, at best, only partly under our control. But, how you react to bad events is under your control. Your mind, body and spirit are all connected, so taking charge of your

health will dramatically reduce your levels of stress, and taking care of your body will help your mind.

How can you reduce stress? Here are some simple ways that have proven effective for many people.

Journal or Diary

Writing down your feelings and thoughts can help enormously. Keep a journal or diary, or write poems or stories about your feelings and experiences. You may find later, when reading your journal, that you have grown stronger and more confident. Your writing can be a source of strength and allow you to get out pent-up feelings.

If you don't enjoy writing, try drawing or pointing or sculpting with plasticine or paper mache. You may surprise yourself with what happens.

Meditation

Meditation is an effective way of reducing stress and anxiety. Many organisations offer programs in various forms of movement meditations like Yoga and Tai Chi, for meditation through breathing, relaxation and movement. If you are more inclined to an inner meditation (less physical) try Zen or Vipassana. These are relaxation exercises, not religions.

Religion

Many people find sources of comfort, support, strength, and stress-reduction in religion. Whatever your beliefs and practices, religion and prayer can be calming and empowering.

Massage

You may want to have a regular massage by a registered massage therapist. They are experts at reducing stress through massage therapy. Your doctor can usually refer you to a good one.

Go soak yourself

Take a hot relaxing bubble bath, or try a sauna or steam, followed by a cool (not cold!!) shower. Make sure to drink plenty of water. This is

Edition 3	1992	1992	1993
<p>HEPATITIS C SUPPORT GROUP NEWSLETTER NO. 3 187 DECEMBER 1992</p> <p>Happy Christmas and a Healthy New Year to all!</p> <p>The Hepatitis C Support Group has been established to provide information and support for people with Hepatitis C. The group is open to all people with Hepatitis C, regardless of when they were diagnosed. The group will provide information on the latest research, treatment options, and support services. The group will also provide a forum for people to share their experiences and concerns.</p> <p>The group will meet on a regular basis to discuss these issues. The group will also provide a forum for people to share their experiences and concerns. The group will also provide a forum for people to share their experiences and concerns.</p> <p>The group will meet on a regular basis to discuss these issues. The group will also provide a forum for people to share their experiences and concerns. The group will also provide a forum for people to share their experiences and concerns.</p> <p>The group will meet on a regular basis to discuss these issues. The group will also provide a forum for people to share their experiences and concerns. The group will also provide a forum for people to share their experiences and concerns.</p>	<p>newsletter, later to become <i>The C Files</i>.</p> <p>1992 Oct - NSW Health circulates policy document, <i>Hepatitis B & C Management Plan</i>, to Area Health Services encouraging each area of the state "to become more self-sufficient in the provision of healthcare for hepatitis B or hepatitis C."</p> <p>1992 Nov - Hepatitis C Update Seminar organised by the WA Hepatitis C Support Group and the National</p>	<p>Centre into Prevention of Drug Abuse.</p> <p>1992 Nov - Inaugural meeting of the NZ Hepatitis C Support Group.</p> <p>1992 Dec - Inaugural meeting of the Victorian Hepatitis C Support Group.</p> <p>1992 Dec - Interferon approved for treatment of hepatitis C by Therapeutic Goods Administration (but not covered under Medicare</p>	<p>PBS).</p> <p>1993 Jan - NZ Hepatitis C Support Group publishes first edition of their self titled newsletter - later to become <i>The Chronicle</i>.</p> <p>1993 Feb - Hepatitis C Support Group incorporates as the Australian Hepatitis C Support Group.</p> <p>1993 May - Presentation of 4,000 signature petition to Hon Terry Griffiths, NSW</p>

very relaxing and also helps take stress off the liver and kidneys.

Get into nature

Nature biking for the weekend, or even for a few hours walking in the park, or by the water can clear your mind. It's good for your physical health, too. Perhaps you could get some sort of pet or companion animal. Studies have shown pets are good for stress reduction and general improvement to quality of life.

Exercise

A long swim, *isometric exercises* (those involving opposing muscles groups), gardening, half an hour with an axe on the woodpile, or some other physical exercise can be terrific for relieving stress. Check with your doctor about your best options.

Learn to Take things in Stride

Don't take events, or yourself, too seriously. Daily hassles can sometimes be more stressful than major life crises. Laugh and be silly. Rent some funny videos and surround yourself with supportive friends. If you have access to the Internet, find jokes and comic strips. Public libraries have lots of silly and funny books and videos.

Finally, pay more attention to your basic health care. Your diet, sleep patterns, exercise and feelings of self worth have an enormous impact on your stress levels. Go slowly and forgive yourself when you slip. Start each day anew with compassion and understanding, for yourself and for others.

- Adapted from an article, taken with thanks from the (Canadian) website of the British Columbia Persons with AIDS Society: www.bcpwa.org/PLM/chap7.htm

I'm not going to be alienated

First of all, I feel guilty about the fact that I circled "zero fee" on my application form, but after reading a couple of issues of your fantastic newsletter, I felt I just had to be able to access your knowledge and insight regularly - and when I'm less hard up, I hope to become a full-fee paying member.

One of the really appalling things about living here in Tasmania - apart from the fact that everyone knows your business - is our society's judgemental attitude towards the methadone program.

My mother has recently discovered that I am on methadone and intends to use this fact against me, to alienate me - even from my father, her ex-husband, who she phoned with the news after 22 years of their bitter divorce - and to justify an inquiry into my right to custody of my son. She would sooner he lived with his violent, manipulative, drug-dealing father than with me.

As for my ex, he informed me of his hep C status soon after we met in 1991. At that time he'd been advised that it was pretty harmless, and would merely involve regular liver function checks. He then introduced me to I.V. drug use by doing the injecting for me - while I looked away. I don't blame him for this but I do blame him for his response, after we'd seperated, when I discovered in early 1994 that I was hep C positive: "Oh yeah .. there was one time I remember when we shared the same needle .."

Anyhow, thanks for all the support you've provided.

Rachel



(model/s used above)

1993

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Edition 4

Parliament House primarily calling for the NSW Government to, inter alia, initiate an anti discrimination focused community awareness campaign.

1993 May - WA Health Department commits to initial funding of WA Hepatitis C Support Group.

1993 June - Dr Brian Pezutti, MP, facilitates first meeting between Australian Hepatitis C Support Group

and NSW Health Department representatives.

1993 Aug - The booklet, *Hepatitis C: 10 Questions and Answers*, published by the (NSW) Centre for Education and Information on Drugs & Alcohol.

1993 Oct - First National Symposium on Hepatitis C, and annual event held at St Vincent's Hospital, Melbourne. "Virtually all people with acute HCV infection seem

to become chronically infected and .. liver disease .. develops in an average of 67% of cases" M Alter (USA).

1993 Oct - Release of the Joint Report on the Epidemiology, Natural History and Control of Hepatitis C by the National Health & Medical Research Council and Australian Health Ministers' Advisory Council. Report urges, "Comprehensive educational

Australian Hepatitis C Support Group Inc.

Hepatitis C Update Seminar

NEWS

(model/s used above)

Liver pain

Many people with chronic hepatitis C express frustration when it comes to describing and sharing the experience of various abdominal pains and discomforts with their physicians. Frequently, these acute or chronic pains are dismissed as having little or nothing to do with chronic liver disease.

What do physicians know about abdominal pain? Read the following and learn about the mechanisms of abdominal pain in general and the types of pain that result from diseases of some specific organs.



Abdominal organs are unresponsive to many stimuli that normally would elicit severe pain. For example, cutting or crushing of abdominal organs does not result in a recognizable sensation. The pain fibres in the *viscera* (the organs contained in the four main body cavities: skull, thorax, abdomen, pelvis) are generally sensitive only to stretching or increased wall tension. The causes of stretching or tension vary from intense muscular contractions to inflammation or swelling caused by physical damage or infection.

In hollow organs such as the intestine or gallbladder, *nociceptive fibres* (receptors which respond to stimuli intense enough to cause tissue damage: such as burning, crushing or cutting) are located in the muscular wall. In solid organs such as the liver and kidney, such fibres supply the outer 'skin' and react to stretching. An inflammatory reaction to microbes or toxins produces organ pain through the elaboration of tissue hormones or *metabolites* (substances produced by metabolism).

Four different mechanisms give rise to abdominal pain: (1) visceral; (2) referred; (3) parietal peritoneal; and (4) psychogenic.

Visceral Pain

Organ pain resulting from stimulation of the sensory *afferent nerves* (conveying towards centre of body) that serve abdominal organs. The pain is often difficult to describe (usually as cramping or aching), dull in nature, and poorly localized to the midline from the upper to the lower abdominal area. The pain may be accompanied by nausea, vomiting, sweating, pallor, and restlessness. People often move about in bed, occasionally finding relief with a change in position.

Referred Pain

Visceral pain may be referred to a remote area of the body, where it is perceived as *cutaneous pain* (sensation of pain in the skin) in an area supplied by the same spinal cord level as the affected abdominal organ. Referred pain is usually well localized and appears when visceral stimuli become more intense. Thus, swelling of the liver capsule by a *hematoma* (swollen blood vessels) after liver biopsy is first perceived in the abdomen but may be referred to the right shoulder.

Peritoneal Pain

When the *peritoneum* (membrane that encloses the abdomen) becomes stimulated or damaged as a result of abdominal organ disease process, nerves supplying the area are stimulated and generally produce pain that is more intense and more precisely localized than visceral pain. The classic example is the localized pain of acute appendicitis. Peritoneal pain is often

Edition 5	1993	1994	1994
<p>Australian Hepatitis C Support Group Inc.</p> <p>Professor Bob Batey addresses Wyong Support Group</p> <p>NEWS</p> <p>The following news items were reported in the Australian Hepatitis C Support Group Inc. newsletter, Edition 5, 1993.</p> <p>1993 Oct - first meeting of state based hepatitis C support groups, councils and foundations.</p> <p>1993 Dec - First notification of possible patient-to-patient transmission of HCV</p>	<p>programs are necessary to reduce disease transmission, promote rapid, timely and accurate diagnosis, improve clinical management, and allay fears and eliminate prejudice in the general community."</p>	<p>(reported in <i>NSW Public Health Bulletin</i>, Vol. 5, No 5, May 1994 pages 47-51).</p> <p>1993 Dec - Community sector lobbying for Australian Pharmaceutical Benefits Scheme funded interferon treatment.</p> <p>1994 Jan - Australian Gastroenterology Institute publishes the booklet, <i>Hepatitis C: Second Edition</i>.</p>	<p>1994 Feb - The booklet <i>Hepatitis C Information</i> released by the Western Australian Alcohol & Drug Authority.</p> <p>1994 Mar - Australian Hepatitis C Support Group reports that Commonwealth Dept Health has rejected all three project funding applications submitted (total \$125k).</p> <p>1994 April - WA Hepatitis C Support Group changes its name to Hepatitis C Council of WA.</p>

aggravated by movement; hence a person's desire to lie completely still.

Psychogenic Pain

This is obviously abdominal pain that is perceived but without any local cause. Unfortunately, this may be a pain mechanism that some physicians choose to attribute to episodes of pain experienced by some people with chronic hepatitis. However, as cited above, physicians should take the time to explain and concede that there are valid causes for different types and intensities of abdominal pain that arise from our internal organs due to inflammation and toxic conditions.

Furthermore ...

When the hollow structures of the gallbladder and biliary tract dilate due to disease process, pain is experienced in the upper abdomen or right upper abdomen. Pain may also be referred to the back between the shoulder blades. Pain from the pancreas is also felt in the upper abdomen and is often referred to the middle of the back.

In a manner analogous to the liver, gallbladder, and biliary tract on the right, lesions in the tail of the pancreas that involve the diaphragm, may result in referred pain to the left shoulder.

Bacterial or viral infection of any intra-abdominal organ may cause abdominal pain. Interference with venous or arterial blood flow can affect the abdominal organs. Clinically this may present as severe abdominal pain and shock.

- From *Focus on hepatitis C*, the international newsletter published by the Quantum Media Group (Nov 1994 issue).

Alcohol & HCV

The risk of developing cirrhosis appears to be higher for people with HCV if they also drink heavily (see definition below).

A reduction in alcohol intake should be someone's first step in any attempt to reduce the possible risk of serious liver damage. This is also an important step before considering treatment options.

Recommendations

People who have hepatitis C would benefit from cutting out alcohol use altogether - or further reducing it below the recommendations for people in the general community. The recommended alcohol intake for people in the general community (who don't have hepatitis) is:

- * women should drink no more than 2 standard drinks a day (see definition below),
- * men should drink no more than 4 standard drinks a day,
- * everyone who drinks regularly should have at least 2 alcohol free days a week.

Tips

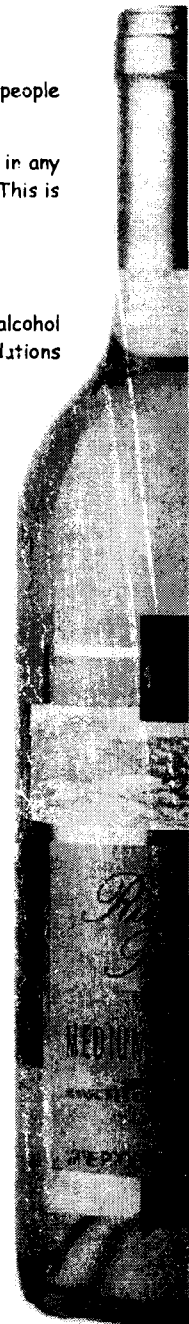
People who find it difficult managing their alcohol intake should seek advice from the Alcohol & Drug Information Service - phone 1800 422 599 or 9361 2111.

People may find the following tips useful:

- * Avoid binge drinking (drinking lots in a short period of time).
- * Try low alcohol drinks.
- * Alternate non-alcoholic drinks with alcoholic ones.
- * Avoid places where you may be pressured to drink heavily.
- * Avoid drinking in 'rounds' by purchasing your own drinks.
- * Finish each drink before the next so you can keep track of how many you've had.

"Heavy drinkers" When we use this term we are referring to people who regularly drink more than 5 standard drinks in a day, and who regularly have less than 2 alcohol free days per week.

"Standard drink" refers to 1 middy of normal strength beer, 1 standard glass of wine or 1 nip of spirits.



1994

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Edition 6

1994 June - CEIDA hosts Hepatitis C Forum at Masonic Centre, Sydney.

1994 July - Australian Hepatitis C Support Group reforms as the Hepatitis C Council of NSW, and the previously established 008 freecall hepatitis C phonenumber refocuses solely as a NSW statewide service.

1994 July - Hepatitis C Train the Trainer manual developed by the Hepatitis C Council of WA as part of its Rural

Education Project.

1994 Aug - Hepatitis C Council of NSW establishes Medical Advisory Panel, made up of 6 eminent NSW clinicians working with HCV.

1994 Sept - Hepatitis C Council of NSW changes the name of its previously self titled newsletter to *The Hep C Review*.

1994 Sept - NSW Health establishes its first HCV advisory body,

the Hepatitis C Taskforce.

1994 Sept - Incorporation of the Hepatitis C Council of SA.

1994 Sept - Victorian Infectious Diseases Reference Laboratory releases the booklet, *Hepatitis C: an information booklet for healthcare providers*.

1994 Oct - The strategic policy document, *National Hepatitis C Action Plan* released by the Australian

Australian Hepatitis C Support Group Inc.

President's Report

(This section contains a detailed report from the President of the Australian Hepatitis C Support Group Inc., including information about group activities, member concerns, and future plans. The text is small and partially illegible due to the image quality.)



Fatigue and hepatitis C

Fatigue can be described as a sense of excessive tiredness, lack of energy or total body give out. The majority of people who have hepatitis C may at some stage experience fatigue although it must be stressed that it is not unusual for many people to experience periods of extreme tiredness which may relate to a busy lifestyle, stress or other factors. The term fatigue is commonly used for any symptom associated with tiredness. Fatigue specific to hepatitis C is not associated with the clinical entity known as Chronic Fatigue Syndrome (CFS).

Fatigue may or may not be associated with over exertion or lack of rest, and may or may not be alleviated by rest. There is a wide clinical spectrum of fatigue. The mildest forms are where fatigue is experienced only through over-exertion or lack of rest, and responds well to rest. In its severe form, fatigue is not the result of either over-exertion or lack of rest, and in turn does not respond to rest.

Factors contributing to fatigue

- Liver dysfunction
- Chronic activation of the immune system
- Impaired liver function through alcohol, poor diet and other toxic substances
- Poor sleep and lack of rest
- Drug use
- Stress, distress and other situational problems
- Medical treatments such as interferon

Management of fatigue

In anyone who has hepatitis C, validation of fatigue symptoms is very important. An explanation as to why fatigue is experienced often relieves the stress caused by it to a certain degree. It is also important to be informed about the detrimental effects of alcohol, drug use, poor rest and poor lifestyle on liver function that will in turn contribute to increased fatigue. All of these lifestyle factors probably have a major impact on the immune system in addition to the virus itself.

As well as adopting changes in behaviour and lifestyle which would maximise individual wellbeing and health, there are a number of tips to best manage the fatigue state so that the normal activities of daily living can be achieved without as much effort.

Experiencing fatigue over a period of time can impact on many areas of life such as relationships, work or other activities. The management of fatigue may

Edition 7	1994	1994	1994
<p>Australian Hepatitis C Support Group Inc.</p> <p>Update from America</p> <p>HEALTHY CARRIER STATE - AN UPDATE</p> <p>Update from America... (text continues)</p>	<p>Health Ministers' Advisory Council; the strategy aims to minimise the transmission of HCV and to minimise the personal and social impact for those already infected.</p> <p>1994 Oct - AHMAC endorses establishment of the AHMAC Hepatitis C Implementation Working Group to oversee implementation of recommendations from the National Action Plan.</p>	<p>1994 Oct - Research paper, <i>Risk factors for hepatitis C infection among injecting drug users in Sydney</i>, published in <i>Genitourinary Medicine</i> (Vol 70, No 5).</p> <p>1994 Oct - Interferon monotherapy (for 6 month) available in Australia through Pharmaceutical Benefits Scheme, following Therapeutic Goods Administration approval for use in Dec 1992.</p>	<p>1994 Oct - National Interferon Database established.</p> <p>1994 Nov - Second National Symposium on Hepatitis C held at St Vincent's Hospital, Melbourne "Hep C might be best considered as an environmental risk for IDUs, not just a classic infectious bloodborne disease" Nick Crofts.</p> <p>1994 Nov - 1st National Meeting on Public Health Aspects of Hepatitis C, held at St Vincent's Hospital, Melb. Dr</p>

require some readjustment and professional help. In some cases it is important to consider some type of counselling support to assist in managing the fatigue which can cause people to feel quite depressed.

Interferon

While most people with hepatitis C are aware of Interferon as a drug treatment for hepatitis C, they may not be aware that this drug has been synthesised to match one of the naturally occurring interferons in the body. These are proteins produced by special cells which are made when the body recognises a foreign substance entering it. It acts as part of the protection mechanism against infection and is stimulated by a viral attack such as the flu virus. Interferon is actually the substance that seems to be the major factor in the flu-like symptoms and fatigue associated with hepatitis C.

So why does hepatitis C cause fatigue?

Fatigue does tend to be intermittent and mild, and in general, patients with more advanced chronic active hepatitis and raised liver function tests, (specifically higher ALT levels), tend to experience more severe symptoms of fatigue. However, this is not the rule and fatigue is not a reliable indicator or measure of disease progression or severity. Many people with hepatitis C experience some sort of fatigue and it is the most common single symptom.

The cause of the fatigue experienced in hepatitis C has not been fully determined. There are probably multiple contributing factors towards this symptom and no one single factor can easily be studied without the influence of other factors. Also, the mechanism of how a disease state causes fatigue is not clearly understood.

There are two possibilities that could be contributing factors to the fatigue experienced in hepatitis C:

1. The Immune System

The major factor in chronic hepatitis C that may contribute significantly to fatigue symptoms is the continuing and long-term response of the immune system to the virus. It is

generally accepted that the virus is both directly damaging to liver cells (the direct effect on other cells of the body has not been established) and indirectly damaging to the cells of the liver via the activity of the body's immune response to the virus.

In other viral conditions such as measles, flu or hepatitis A for example, the response of the immune system rapidly produces antibodies, which eventually defeat the virus. The immune system, after clearing a virus such as measles returns to a less active state. In the majority of patients with hepatitis C (probably up to 75%), the immune system fails to have any impact.

2. The Metabolic Process of the Liver

The liver is the largest organ in the abdomen and is the centre of all metabolic processes that occur in the body. Liver disease of any kind interferes with the normal biochemical processes in the liver. The liver effectively acts as a filter for any toxic and unnecessary substance in the blood that may interfere with metabolic processes. It has a great deal to do with all substances that enter the body and a large proportion of the chemicals that are produced by other organs. This is why alcohol and certain other drugs are thought to have a strong bearing on the rate of disease progression in the liver.

In chronic hepatitis any number of metabolic processes could be interfered with, resulting in the escape of toxic substances into the body. This has not been proven but fatigue symptoms have been seen to respond favourably to diets and herbal treatments which address this sort of toxic overload.

The immune system is an intricate and complex part of the whole individual and is intimately related to individual health. With the continuous and ongoing activity of the immune system and the related activity of certain chemicals and molecules as part of the immune response, there is understandably an ongoing effect on the wellbeing of the individual. The intermittent nature and unpredictability of this system could possibly be reflected by the individual nature of each person's immune response to the virus.

Herbals

Chinese and herbal medicines have been used with some success in the treatment of hepatitis C and the Traditional Chinese Medicine CH100 has been shown to significantly reduce the symptoms associated with hepatitis C including fatigue.

Some formal trials have been done and certain combinations of herbs have been used in China, apparently successfully, for many years. When using herbals and liver tonics, it is recommended that you consult a certified herbalist or naturopath.

- Taken from a factsheet compiled by *HepCare*, the Hepatitis C Case Management Trial. Also see the article, 'Simple ways to help recapture some energy', on page 20 - also taken from the *HepCare* factsheet.

1994	1994	1994-95	Edition 8
Nick Crofts highlights the HCV transmission risks of the drug injecting environment, including injecting equipment other than needles and syringes.	1995 Jan - Interferon trial initiated (involving standard monotherapy among people with haemophilia).	begins at John Hunter Hospital, Newcastle.	<p>Australian Hepatitis C Support Group Inc PO Box 98, Richmond NSW 1513 Telephone: (02) 9439 0000 Fax: (02) 9439 0001 Email: info@hepcare.org.au</p> <p>The group is a not-for-profit organisation that provides support and information to people living with hepatitis C. The group's activities include:</p> <ul style="list-style-type: none"> • Providing a helpline service to answer questions and provide emotional support. • Organising social events and support groups. • Providing information and education about hepatitis C. • Advocating for the needs of people living with hepatitis C. <p>The group is currently seeking members and is open to all people living with hepatitis C, regardless of their stage of disease or whether they are on treatment.</p> <p>If you are interested in joining the group, please contact us on the above details.</p>
1994 Nov - Hepatitis C Council of NSW facilitates Hepatitis C Briefing Forum at NSW Parliament House.	1995 Jan - Hepatitis C Council of VIC publishes first edition of their newsletter, <i>the Good Liver</i> .	1995 Feb - Research paper, <i>Spread of bloodborne viruses among Australian prison entrants</i> , published in the <i>British Medical Journal</i> (Vol. 310, Feb 95).	
1995 Jan - NSW Health finalises <i>Report of the NSW Hepatitis C Taskforce</i> - but it remains unreleased until Nov 1995.	1995 Feb - Inaugural meeting of the Hepatitis C Council of Queensland.	1995 Feb - The booklet, <i>Hepatitis C: A guidebook for health professionals and people with the disease</i> is released by the Communicable Disease Control Unit, Health Department of WA.	
	1995 Feb - Clinical trial of CH100 Chinese herbal preparation		

Homebound website activities

Stuck at home with too much time on your hands? Get on the web and check out these interesting sites.

Online Audio and Video:

<http://webevents.microsoft.com/default.asp>

Mp3 Help for Beginners:

<http://www.mp3pages.com/info/help/>

Mp3 Music downloads:

<http://hello.to/mp3shock>

Greeting Cards On-Line:

<http://www.123greetings.com/>

Funny Cards:

<http://www.ohmygoodness.com/>

Virtual Wonders, Cards:

<http://cards.eesite.com/>

Virtual Flowers:

<http://www.virtualflowers.com/>

The Probert Encyclopedia, General Information:

<http://www.spaceports.com/~mprobert/index.html>

Your Age in History:

<http://member.aol.com/records123/wish.html>

Games, Toons, Puzzles, Music:

<http://www.shockrave.com/sw.html>

Downloadable Games and Programs:

<http://www.jumbo.com/pages/games/>

Earth Cams:

<http://www.earthcam.com/>

Hubbell Space Telescope Images:

<http://www.deepspace.ucsb.edu/images/>

Smithsonian Museums:

<http://www.si.edu/>

Images of Sunsets:

<http://members.aol.com/danglick01/sunset.html>

Butterfly:

<http://members.aol.com/EducAngel/butterfly.html>

Winter's Wolf:

<http://pw1.netcom.com/~lghtman/snow.html>

Simple ideas to help recapture some energy

- Balancing your daily activities is very important. Try to avoid overloading your day, work at the time of the day when you feel your best and arrange to do things then;
- If it takes you a while to get going in the morning, schedule your appointments for a later time so that you don't have to rush;
- Sit down to iron or shower for example, so you are not having to support yourself;
- Use equipment if it helps conserve energy, e.g. use a washing trolley instead of carrying the washing to the clothes line;
- Have the most commonly used items out in the kitchen or at waist height so you don't have to bend or reach which takes more energy;
- Rather than trying to sleep when you are fatigued, rest or do a lighter, easier activity as you will regain more energy from this sort of break;
- Pace yourself, give yourself timeout and regular breaks in your day;
- Prioritise your activities into what you need to do over what you think you have to do;
- Ask someone else to help you if you are too tired;
- Fatigue does not mean you cannot or should not exercise. Exercise can be invigorating and strengthening. Consult with a physiotherapist or GP to assist with an appropriate exercise plan for you;
- Avoid big heavy meals, take smaller meals without rushing and give your body time to concentrate on the digestive process before undertaking any activity;
- Try not to have very hot showers, as this can be tiring. Also make sure the room is well ventilated otherwise the steamy humid environment can contribute to fatigue;
- Use the escalator - every little thing helps;
- Try to establish pre-sleep routine at night. For example, have a quiet time, a warm drink, wind down and prepare your body for sleep;
- Your occupational therapist can help you with more ideas.

Taken from a factsheet compiled by *HepCare*, the Hepatitis C Case Management Trial.



Edition 9	1995	1995	1995
	1995 June - Opening of HCCNSW Hunter Branch office.	1995 Mar - Community sector lobbying initiated against Australian Patent Office granting of 'Chiron' patent.	1995 May - The brochure <i>Hepatitis C: The Facts</i> released by the Victorian Department of Health & Community Services.
	1995 Mar - Hepatitis C Council of SA publishes first edition of its newsletter <i>HCV Newsletter</i> - later to become <i>Hep C Community News</i> .	1995 May - Royal Prince Alfred Hospital shown to be 'tagging' inpatients who have HCV with yellow wristbands.	1995 June - AusHep 4 interferon trial initiated (involving standard monotherapy).
	1995 Mar - Proposal for a National Awareness Week media campaign, sponsored by industry & Commonwealth (later rejected by community sector as inadequate).	1995 May - Victorian Department of Health & Community Services releases the strategic policy document, <i>Management, Control and Prevention of Hepatitis C: A Strategy for Victoria</i> .	1995 Sept - Launch of the <i>NSW Community Policy on Prisons & Bloodborne Communicable Diseases</i> , produced by a coalition of community sector organisations.

Conference highlights and lowdown - a personal perspective

By Stuart Loveday

When you take part in masses of HCV strategic planning sessions, HCV education workshops, HCV advisory committee meetings, an HCV parliamentary inquiry, and, yes, plenty of hepatitis C conferences, and then another hep C conference comes along, you get to think - *here we go again*. Some wag even renamed this one *The Revolving Epidemic*. What could be new? What could we take home that hasn't been said time and time again?

Enter the second big Australasian conference - via Christchurch international airport where the first sign outside in the cold night air is *DANGER: ICE* - and things start to look a little different and exciting again.

For me, conferences are good for three reasons. We get to hear, analyse and question new information that's presented as a result of trials, projects and research. Second, we get to meet new friends, share that information and stories about how hard or easy it might be to implement what we believe is right - *networking* becomes a key activity. Finally, we get time to reflect on our broader direction and approach, and enjoy, in that process, the support of others we don't normally work with.

Christchurch is a friendly and beautiful place - our hosts and organisers welcoming and optimistic. With the snowcapped Southern Alps of Te Waipounamu - South Island - as a backdrop, what better venue than this to encourage the New Zealand health authorities to sit up and take further notice of the huge and complex health, social and economic problem that hepatitis C presents.

A well balanced representative grouping and articulate mix of people with hepatitis C, including current, ex and future drug users, workers from community based organisations, social, clinical and virological researchers, needle and syringe program workers, health bureaucrats, epidemiologists, alcohol and other drug workers, doctors, nurses, dentists, manufacturer's representatives, politicians and journalists gathered to hear the good news and the not-so-good news.

Not at all good, is that prevention initiatives are still hindered by society where the main risk behaviour leading to HCV infection, injecting drug use, remains an illegal and highly stigmatised activity, and where discrimination is rife.

Good, is that a firm re-commitment to scientifically proven harm minimisation principles will remain at the forefront of the public health and political response to hepatitis C.

Adding to this commitment, at the end of the packed program of events, when everyone was tired and conferenced out, New Zealand delegates packed into a large room got their heads down and planned the makings of a detailed strategic national response.

Not so good, was the expected news that a vaccine was nowhere nearer, but brighter news came from papers detailing more effective combination therapies - interferon and ribavirin seems to be the way of the short term future.

Good too was how we heard of the anecdotal progress of some complementary therapies, and with more scientific research planned (but with funding limitations slowing its progress to a crawl), this is clearly an area to watch.

Very good indeed was the general consensus that extremely serious liver disease happens in fewer people than first thought, and takes longer to develop. Still devastating though, is the continuing news some people will inevitably go down that track, and have a hard time of it getting there.

A new area to focus on - HCV and poor oral health - gives cause for concern. Dry mouth, a cause of dental decay, appears to be an effect of HCV infection - and consequent self esteem and health problems add to the social impact.

Perhaps the hardest hitting and most optimistic presentation came in one of the major sessions on the last day - we heard how hepatitis C needs to be *normalised* in the eyes of the wider community, and of ways to achieve this. A woman with hepatitis C said *if more people knew about it, maybe people would start respecting each other more and try to help you know maybe I could feel a bit better about myself. I wouldn't feel like a disease anymore.*

Another conference, another milestone. Thank you to our old and new friends in Aotearoa across the Tasman. We look forward to strengthening the partnership of a truly effective Australasian response to hepatitis C.

- Stuart Loveday is the executive officer of the Hepatitis C Council of NSW.



1995	1995	1995	Edition 10
1995 Sept - HCGNSW publishes first edition of the brochure, <i>Hepatitis C: a brief introduction</i> .	<i>Prevention Approach.</i>	1995 Nov - SA (Health) Hepatitis C Working Party releases the booklet <i>Hepatitis C: Questions & Answers</i> .	
1995 Oct - Hepatitis C Council of QLD publishes first edition of its self titled newsletter - later to become the <i>HepC News</i> .	1995 Oct - Richard Evans, Member for Cowan, states in Federal Parliament, "All in all, the government has been caught napping, particularly the Minister for Human Services and Health. The government has been simply too slow to realise the magnitude of this problem and too slow to realise and respond to community needs."	1995 Nov - Third National Symposium on Hepatitis C held at St Vincent's Hospital, Melbourne. "Vaccine development is slow. Don't expect anything for 12-15 years" Johnson Lau.	
1995 Oct - AHMAC Hepatitis C Education and Prevention Reference Group publishes the policy document, <i>The Nationally Coordinated Hepatitis C Education and</i>		1995 Nov - Community endorsement for establishment of the Australian Hepatitis Council.	

Poor oral health - a factor in quality of life for people with hepatitis C

By Elizabeth Coates, Richard Logan and Bronwyn Scopacasa,

It was assumed from *anecdotal* (non scientific observation) and clinical evidence that people with hepatitis C had poorer oral health than other groups in the community. Several proposed causes for this were the use of methadone medication, poor utilization of dental services, injecting drug use and poor diet.

Several additional questions arose for our research, such as: could people with HCV suffer loss of esteem due to poor oral health; what impact might this have on their lives and were difficulties experienced with eating due to poor oral health?

A specific dental clinic was established in Adelaide to investigate and manage oral health of people with HCV infection. This was funded by the *HIV/AIDS and Related Programs Unit* of the Department of Human Services, South Australia.

Over a period of time, our clinic found that the number of decayed and missing teeth experienced by people with HCV infection was 2-3 times greater than that found in other clients. One explanation suggested for this was that people with HCV infection might not visit their dentist as often as other people. Our research found however that people with HCV infection had gone to the dentist as often as other groups of clients indicating that the dental treatment may need to be more intense in order to save teeth.



Over half of the people attending the clinic had a dry mouth or little saliva. As saliva is extremely important in protecting teeth and gums it is possible this dryness explains some of the decay of teeth. Some medications, such as methadone and antidepressant medication, are noted for causing a dry mouth.

But in this study over half of the clients took no such medications and yet, they had a dry mouth. This suggests that the dry mouth could be caused by a range of factors, including the hepatitis C infection.

People were asked if the health of their mouths and teeth had affected their quality of life. The answers given were compared to previous surveys and the clinic found that the social impact of their dental health was extreme with significant problems in all areas investigated. People with HCV avoided going out as a result of mouth problems, were uncomfortable about their appearance, had toothache and had difficulty relaxing.

Clients were asked if they felt that problems with their mouths had impacted on employment opportunities. Over half felt they had been disadvantaged in gaining employment because of poor appearance or by needing to seek dental treatment instead of attending work.

Conclusions drawn from this study were that there is an urgent need for priority delivery of dental care for people infected with HCV, as their oral health is poor relative to comparable socio-economic groups. Treatment must incorporate a preventative orientated dental program and education on oral health should begin when HCV is diagnosed. People with hepatitis C infection often appear to have dry mouths and this may be the cause of poor oral health. Quality of life is impacted by poor oral health with people often experiencing pain with their teeth and mouths, preventing them from relaxing and going out.

- Drs Coates, Logan and Scopacasa work at the South Australian Dental Service, Adelaide Dental Hospital, Frome Road, Adelaide.

From research presented at the Second Australasian Conference on Hepatitis C, Christchurch NZ, 17-19 August 1999. For a full copy of the research paper, contact the Hepatitis C Council of NSW (see page 2).

(model/s used above)

Edition 13	1996	1996	1997
<p>The Hep C Review</p> <p>NATIONAL epidemic-NATIONAL response</p> <p>PRISONS - what do they mean for HIV?</p>	<p>1996 Nov - Fourth National Symposium on Hepatitis C held at St Vincent's Hospital, Melbourne <i>"Studies show that at time of diagnosis, there is a particular need for pre/past test counselling and basic printed information at diagnosis providing referral contact details for further information and support services"</i> Suzanne O'Callaghan.</p> <p>1996 Nov - Community lobbying initiated towards amending</p>	<p>proposed restrictive changes to DSS Disability Support Pension.</p> <p>1996 Dec - Third edition of the brochure, <i>Hepatitis C: a brief introduction</i>, published by HCCNSW.</p> <p>1996 Dec - Release of <i>Partnerships in Practice, National HIV/AIDS Strategy 1996-97 to 1998-99: A strategy framed in the context of sexual health and related communicable diseases</i>, also known as the Third</p>	<p>National AIDS Strategy.</p> <p>1996 Dec - Expansion of the Australian National Council on AIDS to the Australian National Council on AIDS and Related Diseases.</p> <p>1997 Jan - Beginning of the <i>National Hepatitis C Education Program for General Practitioners</i> project, carried out by the Royal Australasian College of General Practitioners.</p>

Combination therapy

What is combination therapy?

Combination therapy used for the treatment of hepatitis C consists of interferon and ribavirin, collectively manufactured under the name "Rebetron".

Studies have shown that people with hepatitis C are more likely to have a sustained response to the combination therapy of interferon and ribavirin than they would with interferon alone.

How does it work?

Interferon is a natural substance made by the body to help defend itself against infection. Synthetically manufactured interferon in large doses can help to reduce the amount of hepatitis C virus in the body and slow down the disease process. Since November 1994 interferon has been the only government funded treatment for hepatitis C in Australia.

Ribavirin is a drug which helps to cut down the rate of viral replication. With hepatitis C, ribavirin has been shown to work best in combination with interferon rather than as a treatment on its own.

What is the response rate?

Current research suggests that response to combination therapy is related to two factors: a person's hepatitis C genotype and the level of virus in their body. To date, genotypes 2 and 3 have been shown to have a higher response rate (65% or more) to combination therapy than genotype 1 (25-40%).

A sustained response can lead to a reduction in possible long-term complications such as cirrhosis of the liver. New information about how long a sustained response lasts is still being gathered, but current research suggests that if someone responds to treatment for at least 6 months following end of treatment, there's a good chance that their response will last indefinitely.

People should ask their GP or contact their nearest liver clinic to discuss genotype and likely chance of response to combination treatment.

What about side effects?

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: initial fever, chills, muscle aches and headaches. Later, people may experience tiredness, loss of appetite, nausea, vomiting, diarrhoea, or itchy skin. Some people also experience thinning of their hair.

A potentially serious side effect to combination therapy, caused by ribavirin, is *anemia* (a lack of iron in the blood). Doctors will therefore monitor your iron levels very closely, especially in the first few weeks.

Also, ribavirin has been shown to cause birth defects. Combination therapy, therefore, is not available to women who are pregnant and/or breastfeeding, or to anyone (both women and men) who do not use adequate contraception during, and for up to six months after, treatment.

Treatment centres will be able to provide detailed information about possible side effects and how people can manage them.

What's involved in treatment?

'Rebetron' is a 6 month course of interferon injections (3 times a week), and ribavirin capsules (taken twice a day).

People are asked to attend their GP or specialist for follow up visits during and after treatment.

Edition 15	1997	1997	1997
<p>The Hep C Review</p> <p>DOES AN HIV STRATEGY EQUAL AN HCV STRATEGY?</p> <p>New research highlights need for standardised national surveillance system for HCV</p>	<p>1997 Mar - The Weekend Australian newspaper reports: EARLY ACTION ON HEP C AIDS RECOVERY: About one in three patients with hepatitis C receiving interferon were cured if the treatment was given early and over several years, the first large Australian trial has found.</p> <p>1997 Mar - The Age newspaper reports: HEPC OUT OF CONTROL, STUDY SHOWS: Hepatitis C in Australia is spreading out</p>	<p>of control, with 10% of drug users becoming infected every year.</p> <p>1997 Mar - Sydney Morning Herald newspaper reports: JAILS 'A BREEDING GROUND FOR HEP C: Australian prisons are a breeding ground for hepatitis C, with half of all inmates tested having the disease.</p> <p>1997 April - The Hep C Handbook, by Matthew Dolan (UK) becomes available in Australia.</p>	<p>1997 April - Australian Gastroenterology Institute releases 'third editions' of its booklet: <i>What do I Need to Know about Hepatitis C?</i>, and brochure: <i>Hepatitis C: An information leaflet for patients and other interested members of the public.</i></p> <p>1997 May - Hepatitis C Council of SA releases their HCV video, <i>"Hepatitis C, not my whole life"</i>.</p>

How can I get this treatment?

Combination therapy is available through the 'free list' via the Pharmaceutical Benefits Scheme S100 Highly Specialised Drug category, through clinical trials or through the compassionate access program. People may also be able to purchase the treatment privately.

Government funded S100 combination therapy is available only to people who have relapsed following previous treatment with interferon alone - and who continue to meet the interferon monotherapy criteria (see below).

It is important to note also that S100 combination therapy is withdrawn after 3 months of treatment if people remain PCR positive.

People should discuss their treatment options with their GP, liver clinic or specialist.

S100 interferon criteria

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

Where do I get further information?

To find out more about accessing combination therapy, people should contact their GP or local liver clinic/specialist. Some contact numbers are:

- EastHep at Prince of Wales Hospital, Randwick - 9382 3818
- Royal Prince Alfred Hospital, Camperdown - 9515 7268
- Westmead Hospital, Westmead - 9633 6086
- Canberra Hospital, ACT - 6244 2222
- Orange Base Hospital - 6362 1411
- Wagga Wagga Base Hospital - 6921 2711
- John Hunter Hospital, Newcastle - 4921 4473

For further information on treatment options in your area or hepatitis C in general, contact your GP or call the NSW Hep C Helpline on:

9332 1599 (Sydney callers)
1800 803 990 (regional callers)

Notes:

Sustained-response - usually refers to a loss of measurable virus in the blood and normalisation of liver enzymes (liver function tests), that lasts at least 6 months after therapy ends.

Relapse - implies a response of some kind but then a return to abnormal values, both with viral load and liver function tests.

- Produced by the Hepatitis C Council of NSW, October 1999

1997

1997

1997

Edition 16

1997 May - Commonwealth endorses subsidised interferon for 12 months - as opposed to previous 6 month regime.

1997 May - The NSW Legislative Council Standing Committee on Social Issues was asked to carry out an inquiry into hepatitis C in NSW. This was the first time in Australia that a parliamentary committee was asked to formally review hepatitis C.

1997 June - Establishment of the national peak community-based organisation, the Australian Hepatitis Council.

1997 June - Medical Observer journal reports: **BLOOD PRODUCTS AND HEP C - A LEGAL NIGHTMARE: On 14 July a hearing will begin in the Victorian Supreme Court: NJ v Australian Red Cross. It is a test case on behalf of 30 people who are seeking compensation after allegedly contracting the**

incurable hepatitis C virus from blood products.

1997 July - Research paper, **Incidence of bloodborne virus infection and risk behaviours in a cohort of injecting drug users in Victoria, 1990-1995**, published in the Medical Journal of Australia (Vol 167, 7 July 97).

1997 Aug - Inaugural meeting of the ANCARD Hepatitis C Subcommittee.

The Hep C Review

DISABILITY SUPPORT PENSION OUTRAGE AVERTED FOR NOW

12 months Interferon treatment shown to work best

The Hep C Council has been successful in its campaign to ensure that people with hepatitis C can access the Disability Support Pension (DSP) for 12 months of treatment. This is a significant victory for people with hepatitis C, as it allows them to access the DSP for the full 12 months of treatment, rather than the previous 6 months. The DSP is a government benefit that provides financial support to people who are unable to work due to a medical condition. The Hep C Council has been successful in its campaign to ensure that people with hepatitis C can access the DSP for 12 months of treatment. This is a significant victory for people with hepatitis C, as it allows them to access the DSP for the full 12 months of treatment, rather than the previous 6 months. The DSP is a government benefit that provides financial support to people who are unable to work due to a medical condition.

Consensus interferon news from the US

Speaking from the 49th Annual Meeting of the AASLD (American Association for the Study of Liver Disease), Dr Carl Jones reports from the initial stages of his consensus interferon study, that 62% of genotype 1 patients are showing HCV PCR negative. Consensus interferon (Infergen) is a slightly different type of the interferons used for HCV treatment here in Australia.

"We have collected a lot of three month HCV RNA data, and even though the study is in its infancy, we're very excited," says Dr. Jones, gastroenterology fellow at Allegheny General Hospital, Pittsburgh, Pennsylvania. "When you tease out the data and just look at genotype 1 patients who are taking the drug three times a week, 27% are HCV RNA negative, and of those taking the drug five times a week, 62% are HCV RNA negative by the end of month three.

Genotype 1 patients have more resistant disease. Typically, when they are treated with conventional interferon alfa dosing, they show a sustained response rate of only 5-10%. The sustained response rates with genotype 1 patients are very dismal, especially with monotherapy interferons, notes Jones, referring to the standard doses of interferons often used.

"Combination therapy shows a little more promise, but the best genotype 1 data show a 21% sustained response rate in these patients. We were hoping that 15 micrograms of consensus interferon would not behave like 5 or 10 million units of conventional interferon where you see a logarithmic increase in the side effects," Dr. Jones said.

"To our surprise, we found that the 9 microgram and the 15 microgram side effect profiles were similar and that the higher dose of consensus interferon is very tolerable."

"Right now, I think that conventional interferon - three million units three times a week - is pretty much a dinosaur. The two better therapies are combination therapy (ribavirin plus interferon) and the higher dose of consensus interferon," according to Dr. Jones.

Even at this relatively early point in the study, Dr. Jones says he believes the results are clinically important. Other studies have shown that the sooner a person's virus levels come down during treatment, the better are their chances for a sustained response.


"Based on statistics, I'm projecting that we should see a 26 to 30% response rate in genotype 1 patients receiving the drug three times a week and 50 to 55% in the five times a week group. That's much better than what we are seeing with combination therapy, and we should have more reliable data in six to eight months," Dr. Jones says.

- Abridged from an article posted to us by Beth, an Australian internet emailer. Taken with thanks from the Hepatitis Study Centre website: http://members.tripod.com/~gastro_doc/lvl24.html

High virus levels lead to slower viral clearance & increased relapse risk

Sustained responders to HCV treatment clear their infection more slowly; if they start out with higher levels of the virus in their blood. Researchers reported at the Digestive Disease Week conference that this so-called baseline viral concentration closely correlates with the rate at which sustained responders clear the virus from the bodies. It appears that a higher baseline viral load increases the likelihood that a patient who initially responds may relapse in the post-treatment period.

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

Edition 17	1997	1997	1997
<p>The Hep C Review</p> <p>HEPATITIS C COMES IN FROM THE COLD</p>  <p>A VIRUS EXPOSED?</p> <p>1997 Aug - First print run of the HCV Streetwise Comic <i>Hit me with your best shot</i>, for Western Sydney AIDS Prevention Service (NSW). To date, the resource remains undistributed.</p> <p>1997 Aug - Sydney Morning Herald newspaper reports: CALL FOR ACTION TO HALT EPIDEMIC OF HEPATITIS C: The Federal Government had been urged to conduct a far-reaching overhaul of the treatment of hepatitis C, which has reached epidemic proportions among intravenous drug users.</p>	<p>1997 Sept - Haemophilia Foundation Australia releases the booklets Hepatitis C: For people with bleeding disorders and hepatitis C and their families, and Haemophilia/Hepatitis C: A publication for teachers who work with students who have haemophilia.</p> <p>1997 Oct - Hepatitis C Council of QLD launches, Hepatitis C: reduce the risk, a resource manual and video kit for youth workers.</p> <p>1997 Oct - HCCNSW carries out strategic planning exercise. Key</p>	<p>recommendations: expand and improve our existing resources and capacity to encourage development of services in local areas.</p> <p>1997 Nov - Fifth National Symposium on Hepatitis C held at St Vincent's Hospital, Melbourne. Future trends in antiviral therapy seem promising, especially in regard to protease inhibitors. Watch out for the hammer head ribosyme library Stephen Locarnini.</p>	

The study categorized 232 previously untreated patients according to their baseline viral HCV RNA concentrations. They fell into four groups, or "quartiles," from the lowest to the highest viral concentrations. All patients received 9 micrograms of consensus interferon (Infergen) three times a week for 24 weeks, and then were observed for another 24 weeks after treatment.

The percent of all patients who responded (undetectable serum HCV RNA values) by week 12 in each quartile was 71%, 53%, 34%, and 34% in Q1 (lowest virus concentration) through Q4 (highest), respectively. More patients with lower baseline viral concentration responded early compared to patients with the highest starting viral concentrations. By weeks 2-4 of consensus interferon treatment, most sustained responders in the lowest three quartiles had undetectable HCV RNA values. Sustained responders in the highest quartile required treatment for 12 weeks before achieving undetectable HCV RNA levels.

These findings may help predict early in treatment who will benefit from therapy, according to the study's lead researcher, F. Blaine Hollinger, M.D., professor of medicine, virology, and epidemiology at Baylor College of Medicine, Houston, Texas and director of the Eugene B. Casey Hepatitis and HIV Research Center and Diagnostic Laboratory.

A significant proportion of patients in quartiles 1 and 2 (lowest two baseline viral levels) had a transient response to treatment but did not become sustained responders (56% in quartile 1; 41% in quartile 2). Dr. Hollinger suggests that higher and more frequent initial doses of consensus interferon may eliminate HCV in more patients who relapse or fail to respond.

The study should help physicians better predict the success of therapy. "Patients want to know what their probability of success is, and we've looked at a lot of factors: the concentration of virus in the blood stream,

whether or not they have cirrhosis, what their genotype is. If it's genotype 1, they're more resistant to the interferon, if they are genotype 2 or 3, they are more sensitive," Dr. Hollinger says.

"So we try to take all those factors into account to try to make a decision... those that have a very low concentration of virus will lose their virus much more quickly and are more likely to have a sustained response than those who have a higher baseline concentration."

Dr. Hollinger says that the quartile data show that patients with the highest concentrations of virus do respond to treatment, but not as rapidly or as completely as patients with a low baseline viral load. For many of these patients, their viral level declines during therapy, but then increases after treatment stops. "This suggests that what we really need to do is treat them at higher concentrations," he says.

"It would suggest that there is a subset here that if they were treated with so-called induction therapy, which is treating every day for a month or two months at higher dosage, in this case 15 micrograms of the consensus interferon or 5 million units of Intron or Roferon, that perhaps you will pull some of the non responders into the sustained responder group."

"If we learned anything from the HIV data, it was that... you must hit the virus hard and quickly, drive it down so that resistant virus is not generated," Dr. Hollinger says.

He believes that the next step is to take all data from the study and combine it with genotype and other factors to come up with an algorithm to better predict treatment response. "So that if you came up to me as a patient and I did your baseline [viral concentration], I did your genotype, I looked at your liver to see how bad your liver disease was, I might be able to say to you, 'If you wanted to be treated, here's what I think your probabilities of success are.'"

Highlights of these studies and several others from the DDW meeting are available at www.highlights.wellweb.com on the web and in Adobe Acrobat format for printing.

- Distributed by: Patients NewsWire, USA
Contact: Derek Moran at <derek@pond.com>

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).

1997	1998	1998	Edition 18
<p>1997 Nov - 44% of Australian HCV notifications (to end of 1996) shown to have occurred in NSW.</p> <p>1997 Nov - World Health Organisation reports that 3% of world population have been infected with HCV (i.e. more than 170 million people).</p> <p>1998 - International trials (involving Australian sites) show interferon plus ribavirin produces twice to three times better sustained response rates.</p>	<p>1998 - International trial of Pegasys (pegylated interferon) launched (involving several Australian sites); showing very promising results.</p> <p>1998 Jan - Sunday Telegraph newspaper "Doctors column" wrongly implies that transmission via airborne particles is a major HCV risk.</p> <p>1998 Jan - Research report <i>Secondary Students, HIV/AIDS and Sexual Health</i>, published by the Centre for the Study of Sexually Transmissible</p>	<p>Diseases, shows knowledge about hepatitis C to be very poor.</p> <p>1998 Feb - Federal Minister for Health announces a one-off funding allocation for social and behavioural research into hepatitis C.</p> <p>1998 Feb - Weekend Australian newspaper reports: CANBERRA HIT BY HEPATITIS C ROW: The Federal Government has been criticised for blocking trials into a combination drug therapy for hepatitis C</p>	

Medicine information kit

By Helen Hopkins.

People have been campaigning for a number of years to have full information about medicines available to all people. Consumer Medicine Information (CMI) is now available for many medicines, however a lot of people do not know about the information, who to ask for it, or where else they could obtain it if their pharmacist is unable or reluctant to provide it.

Previously called Consumer Product Information, CMI is plain English information about medicines, clearly written for people in a way that we can understand. It is designed to complement, not replace, discussions between people and their health care providers about courses of treatment and medications.

A doctor or pharmacist might provide CMI when discussing medicines with people. CMI also provides a written reference about the medicine for checking later on at home. The aim is to help people use medicines appropriately and encourage them to take a greater responsibility for and interest in managing their medication, whether it is prescribed by a doctor or bought over-the-counter.

The information must be prepared by manufacturers for all new prescription medicines, and must be provided for all prescription medicines by 2002. It is also required for some over-the-counter medicines.

It must be factual, must not contain any advertising. The quality of information in CMIs is monitored by a Quality Assurance Reference Group, which includes representatives of consumers, doctors, nurses, pharmacists, the industry CMI writers and an expert in communication.

A lot of work has been done to make CMIs available for pharmacists to print out from their computer system when they dispense medicines, but this does not always occur. Sometimes the CMI is included as a leaflet in the medicine pack. Sometimes you might have to request it from the manufacturer.

- Rob Kirkby is Visiting Professor at the School of Psychology, University of New South Wales.
- Helen Hopkins is Senior Project Officer Pharmaceuticals Project, at the Consumer Health Forum, Canberra, ACT.

- choose a physical activity that is pleasing and enjoyable,
- exercise in a situation where interpersonal competition is absent,
- exercise in an environment that is known and predictable and in which you feel comfortable and secure,
- if possible, select an activity that encourages rhythmical breathing.

Some people have found that medication prescribed for their condition has produced negative consequences, such as irritability and difficulties in concentration. It is noteworthy that investigators using the Profile of Mood States (POMS) - a well-established *psychometric test* (medical questionnaire) - have shown that not only is anger and irritability lessened by involvement in physical activities but, as well, individuals who exercise report reduced confusion and clearer thinking.

Finally, exercise can help to strengthen a person's sense of "hardiness" and assist him or her to cope with adversity, change, and stress. Involvement in exercise has been linked with increased feelings of control over external events, a sense of involvement and purpose in life, and the ability to accept challenges and adapt to life changes.

To conclude, from the evidence briefly outlined above, it can be seen that while exercise is an important contributor to quality of life for everyone, it has particular benefits for those affected by hepatitis C.

Remember, regular, moderate exercise is the aim. Walking and swimming (with appropriate stretching and warm-up) are excellent exercises, however, any physical activity is better than none! At the other extreme, don't overdo it, and check with your physician before you start.

- Rob Kirkby is Visiting Professor at the School of Psychology, University of New South Wales.

1998	1998	1998	Edition 20
State funded 'Public Health Outcomes Funding Agreement' project.	1998 July - Hepatitis C Council of WA release HCV pamphlet for people who inject drugs, co-produced by Western Australian Substance Users Assoc.	information resource, the brochure, <i>Hepatitis C: Information for all Australians</i> .	
1998 July - AusHep 7 interferon trial initiated (loading dose v. standard monotherapy); later prematurely terminated due to insufficient enrolments.	1998 July - Commonwealth announces Medicare funding for PCR Viral Detection testing (in limited circumstances).	1998 Aug - ANCARD Hepatitis C Virus Projections Working Group publishes the report, <i>Estimates and Projections of the Hepatitis C Virus Epidemic in Australia</i> .	
1998 July - Hepatitis C Council of WA launches its community education package: "Could you have hepatitis C?", featuring brochures, posters and video.	1998 Aug - Commonwealth Department of Health & Family Services releases its first national hepatitis C	1998 Aug - Research paper, <i>Infection with HIV and hepatitis C virus among injecting drug users in a prevention</i>	

Hepatitis C and food

Healthy eating is important for everyone as people generally feel better when they eat well. If you have hepatitis C, you may need to think about what you eat.

The role of the liver

The liver is one of the most important organs of the body and has an ability to repair itself. It is the 'factory' that converts 'raw materials' from the digestive system into substances the body needs. It detoxifies harmful substances such as alcohol and helps to remove waste products.

What HCV does to your liver

Many people with the hepatitis C virus (HCV) remain quite well. However, HCV can cause damage to liver cells. Even if the liver is not significantly damaged, some people may feel quite ill. This is due to the way the body fights the hepatitis C virus.

Healthy eating

Healthy eating involves choosing a variety of foods. In the right balance, these foods will meet your body's need for energy, growth and repair.

To get a good daily intake of vitamins and minerals you need to eat some food from all the groups every day. Vary your choices from day to day.

Fats & HCV

You don't need to cut out all fats and oils just because you have hepatitis C. You do need to eat some fats to make hormones and to allow body cells to function properly. Eating too much fat is very common in Australia and is a risk factor for heart disease, diabetes and becoming overweight. People in Australia are advised to eat less fat.

Your liver makes bile that helps you to digest and absorb fats. Your liver is able to do this even when it is damaged.

Some people with hepatitis C may have trouble coping with fats. The hepatitis C virus may make you feel sick or nauseous even if your liver is not damaged. When you feel sick or nauseous for any reason you may find that fatty food doesn't agree with you. Then you may want to change your fat intake.

Nausea & loss of appetite

Here are some tips to help when you have lost your appetite or feel nauseous:

- eat small amounts often,
- eat most when you feel hungry (often at breakfast),
- choose foods that contain lots of vitamins and minerals. You can meet your requirements in a smaller amount of food by eating foods like cheese, yoghurt, nuts, tofu, dried fruit, soy drinks, flavoured milk, milkshakes or smoothies,
- try different tastes to stimulate your appetite, eg. bitter, sour, salty or sweet.

Special nutritional supplements may be useful if you are not eating well or if you are losing too much weight. Discuss these with a dietitian.

Vitamin & mineral supplements

Illness can cause your body to need more vitamins and minerals but if you are eating well you should be getting enough from your food. Vitamin and mineral supplements may be useful if your appetite is poor. Be careful not to exceed the recommended dose as this may be harmful.

Salt

All people in Australia are advised to eat less salt whether or not they have hepatitis C. You can do this by using less salt in cooking and reducing salt use at the table. Many manufactured (processed) foods are high in salt and it is worth trying low salt or salt reduced varieties of these foods.

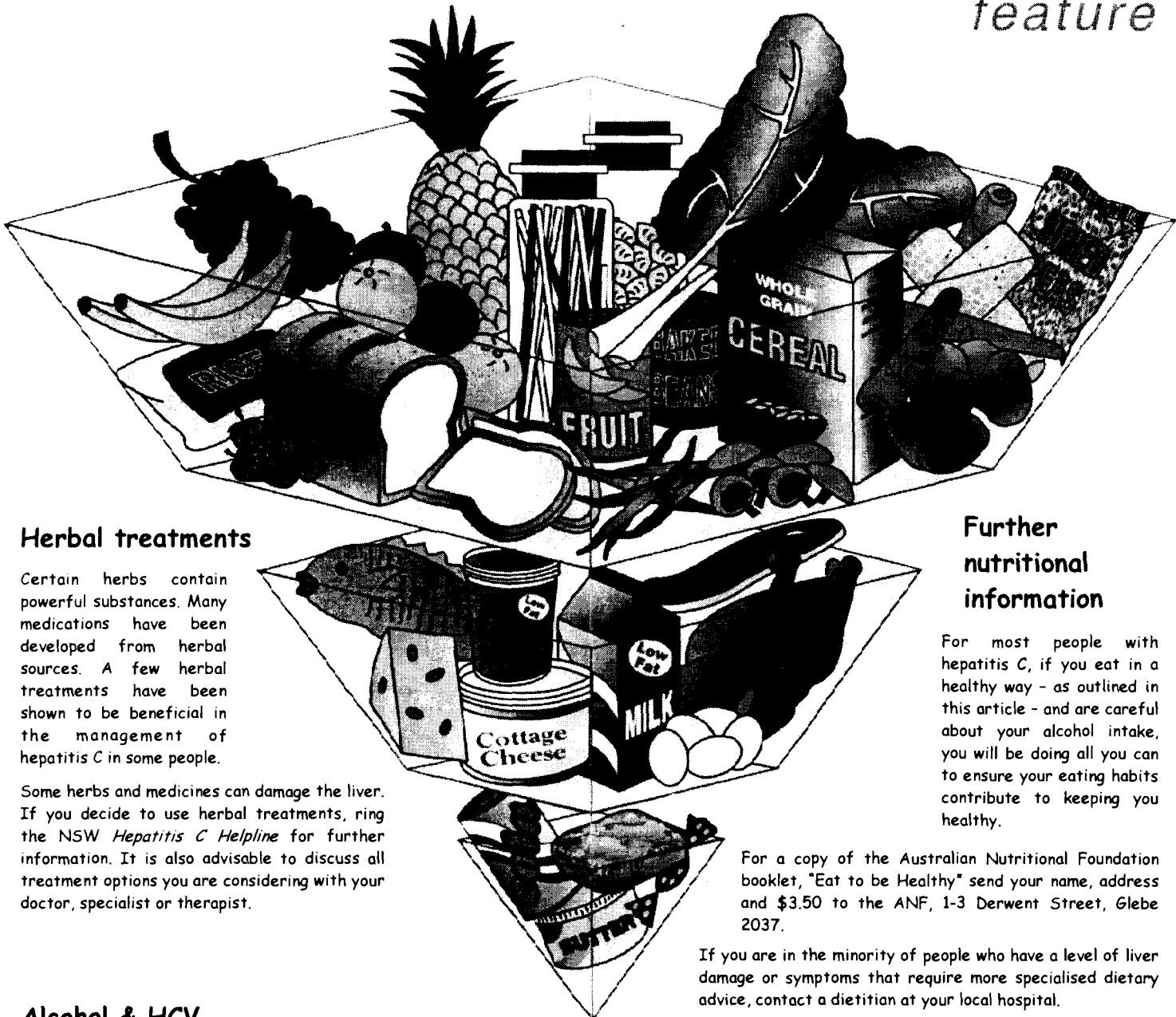
Lifestyle & food

Eating is a pleasure and a social event. Take the time to eat properly by eating slowly and chewing your food well.

For many reasons exercise may make you feel better. Exercise may improve your appetite. You don't have to take it seriously, only regularly. If you feel tired you should rest. Don't wear yourself out.

Drinking and using other drugs affects your health. Consider other ways to have fun and enjoy yourself.

Edition 21	1998	1998	1998
<p>The Hep C Review</p> <p>HCV media hype leads to misery</p> <p>Sexual disease a risk for 20 years</p>	<p><i>setting: retrospective cohort study, published in the British Medical Journal (1998; Aug 15, 317:433-7).</i></p> <p>1998 Aug - Sydney Morning Herald newspaper reports: FEAR OF RAMPANT HEP C EPIDEMIC: The often fatal hepatitis C virus is running rampant through some sections of the community, presenting Australia with one of its most significant public health concerns of recent years.</p>	<p>1998 Sept - Sydney Morning Herald newspaper reports: HEPATITIS C EPIDEMIC TO COST \$1BN, EXPERTS WARN: Australia faces a \$1 billion health care bill over the next 10 years because of the hepatitis C epidemic, new studies warn.</p> <p>1998 Sept - Commonwealth provides limited HCV funding allocation to some States under the Public Health Outcomes Incentives Projects Scheme.</p>	<p>1998 Sept - The Bulletin magazine sensationalises hepatitis C, reporting it as "often fatal... a plague unleashed by intravenous drug use with infected needles."</p> <p>1998 Sept - Launch of ARCHI, the Australian Reference Centre for HCV Information, providing detailed clinical information and referral for healthcare workers.</p> <p>1998 Sept - Sun Herald newspaper reports: BARBER</p>



Herbal treatments

Certain herbs contain powerful substances. Many medications have been developed from herbal sources. A few herbal treatments have been shown to be beneficial in the management of hepatitis C in some people.

Some herbs and medicines can damage the liver. If you decide to use herbal treatments, ring the NSW Hepatitis C Helpline for further information. It is also advisable to discuss all treatment options you are considering with your doctor, specialist or therapist.

Further nutritional information

For most people with hepatitis C, if you eat in a healthy way - as outlined in this article - and are careful about your alcohol intake, you will be doing all you can to ensure your eating habits contribute to keeping you healthy.

For a copy of the Australian Nutritional Foundation booklet, "Eat to be Healthy" send your name, address and \$3.50 to the ANF, 1-3 Derwent Street, Glebe 2037.

If you are in the minority of people who have a level of liver damage or symptoms that require more specialised dietary advice, contact a dietitian at your local hospital.

Alcohol & HCV

Alcohol can cause damage to the liver. Having hepatitis C and drinking alcohol increases the risk of liver damage. If you have HCV, ideally, it's better not to drink. If you choose to drink, consume low alcohol beverages, have several alcohol-free days each week and avoid binge drinking as this is especially damaging.

Other useful contacts

Speak to your GP or for information on alcohol and other drugs, phone the Alcohol & Drug Information Service (ADIS) on 02 9361 2111 or 1800 422 599. Additionally, phone the NSW Hepatitis C Helpline for information about other referrals - 02 9332 1599 or 1800 803 990.

1998	1998	1998	Edition 22
<p><i>HEPATITIS RISK: Doctors believe a big jump in the numbers of people with hepatitis C... may be linked to practices at some barbers shops.</i></p> <p>1998 Oct - Hepatitis C Council of QLD publishes the booklet, <i>Women and Hepatitis C.</i></p> <p>1998 Oct - A W Morrow Gastroenterology and Liver Centre publishes the brochure, <i>Hepatitis C and Pregnancy: Hepatitis C and Children: a brief guide.</i></p>	<p>1998 Nov - Sixth National Symposium on Hepatitis C held at St Vincent's Hospital, Melbourne. "Our cross sectional survey of people on the Mid North Coast of NSW showed approximately 50% being dissatisfied with their GP or specialist. The main reasons being perceived lack of caring, understanding, professional advice and knowledge of HCV" Sarah Thackway.</p> <p>1998 Nov - Parliament of NSW Standing Committee on</p>	<p>Social Issues publishes the report, <i>Hepatitis C: The Neglected Epidemic</i>, with a key conclusion: "Strategies to prevent further transmission of hepatitis C must be broad and multi-faceted. The Committee fully supports the concept of harm minimisation and considers it to be the most effective underlying principle for strategies to prevent the transmission of hepatitis C amongst injecting drug users."</p>	<p><i>The Hep C Review</i></p> <p>PCR given - yet kept - by Commonwealth</p>

Medicines & hepatitis C

By Geoff Farrell

The main concerns around prescribing medications for people who have hepatitis C are:

- a) whether the liver disease would lead to accumulation of the drug in the body, causing further illness, or
- b) whether the drug could worsen existing hepatitis or cause liver damage because of toxic interaction with hepatitis.

For doctors, difficulties are posed by commonly found packaging inserts which can state that a particular agent is *contraindicated* (not recommended, implying it is dangerous to use) in people with liver disease. Thus a common error for doctors is to advise against medicines for other illnesses a person may have - such as high blood pressure, lipid disorders such as high cholesterol, depression or metabolic bone disease such as osteoporosis - because of unwarranted fears about adverse drug effects.

Alternatively, self-prescribing of vitamins and complementary (alternative) medicines, and recreational drug use and drug dependence are issues that need to be considered by medical prescribers.

In general, only people with very severe liver disease would have problems with their liver's ability to process and eliminate drugs and medications.

Severe liver disease means cirrhosis or acute liver failure, usually with abnormalities of key measurements such serum albumin concentration and prothrombin time, or presence of ascites or hepatic encephalopathy.

On a more technical level, prescribing medications for people with severe liver disease needs to take into account the pathways of metabolism and elimination pertinent to the drug under consideration, i.e. hepatic versus extrahepatic; cytochrome P450 versus conjugation and biliary secretion - this is where a liver expert can help in difficult cases.

Fortunately, the vast majority of people with hepatitis C do not have liver failure and prescribed drugs will not accumulate in the body.

In regard to the majority of people who have hepatitis C but with only mild liver impairment, the following classes of medicines have been specifically researched:

- Pain killers including opiates, paracetamol & non-steroidal anti-inflammatory drugs (NSAIDs, which are usually used for arthritis or period pain);
- Oestrogens; antibiotics including anti-tuberculosis chemotherapy;
- Anti-depressants;
- Lipid-lowering drugs;
- Vitamins & alternative therapies;
- Recreational agents & drugs of addiction.

Although there are few pitfalls:

- * Dosage of paracetamol used regularly may need to be reduced in some individuals. A good guide is never more than 4 tablets (i.e. 2 grams) each day if used regularly, or if the person is not eating, or with people who drink more than 4 standard drinks a day, or if the person is taking some other particular types of medication - like anti-convulsants for epilepsy.
- * NSAIDs possibly should be avoided, including ibuprofen (which can be bought without a prescription).
- * Possible damage to liver cells with anti-tuberculosis drugs is probably increased in chronic viral hepatitis and HIV.
- * Some Chinese Herbal Medicines and vitamin A are potentially damaging to liver cells.
- * Use of lipid-lowering drugs, anti-depressants and oestrogens is reasonable in cases of uncomplicated hepatitis C and should not be denied if a person's medical condition warrants it (closer monitoring of ALT may be useful to reassure patient and doctor).
- * There are problems in long-term methadone prescribing for people with severe hepatitis C who may eventually be deemed unsuitable for liver transplantation because of on-going dependence issues.
- * The safety and efficacy of other treatments for opiate dependence, particularly naltrexone (which can damage liver cells) require more rigorous assessment for people with hepatitis C, although studies so far have not shown this to be a major problem.

- Prof Geoff Farrell is Director of the Storr Liver Unit, Department of Medicine, University of Sydney at Westmead Hospital, NSW.



Edition 23	1998	1998	1998
<p>The Hep C Review</p> <p>HEPATITIS C REPORT CALLS FOR URGENT GOVERNMENT ACTION</p>	<p>1998 Nov - Following a poorly worded Commonwealth press release and promotion of the clumsy term "HCV as an HIV related disease", Channel 10 primetime news carries as its main feature, the false warning that <i>those at most risk were prisoners and young people who don't use condoms.</i></p> <p>1998 Nov - Sydney Morning Herald newspaper runs headline: 200,000 STRICKEN AS HEPATITIS C SWEEPS NATION.</p>	<p>1998 Nov - Weekend Australian newspaper reports: <i>"HIDDEN EPIDEMIC: Every hour of every day one Australian will contract hepatitis C, yet experts say this potentially fatal virus is still misunderstood."</i></p> <p>1998 Nov - HCCNSW launches information resource, <i>Hepatitis C & food.</i></p> <p>1998 Dec - Release of the hepatitis C video, <i>Look back, look forward.</i></p>	<p>1998 Dec - Clinical trial of CH100 Chinese herbal preparation begins in the Northern Rivers Area Health Service (NSW).</p> <p>1998 Dec - United States Food & Drug Administration approves Rebetrin Combination therapy for people, previously untreated.</p> <p>1999 Jan - Following media reports of children as young as 12 or 13 injecting heroin, NSW Minister for Health moves</p>

My exposure to hepatitis C

I have been a nurse for the past 22 years. Two years ago I learned that I was positive for hep C. I would like to share with you my own personal experience in contracting HCV, no doubt as a result of one of the many needlesticks I received in my career.

During the summer of 1996 I felt very fatigued. I realized that it was time to have my 6 month post needlestick lab work done, so I went to the employee health dept. I did not know if my fatigue could be attributed to my 2 jobs and academic work or if it might be the result of something more serious.

Because I did not hear anything from employee health I assumed it was the former.

A few months passed and I slipped and fell at work and had to fill out more paperwork which was forwarded to employee health. A few days later I received a call to come and talk to a nurse there. They had just discovered that positive results of my test for HCV had come back a few months earlier.

I knew that I had contacted this bloodborne pathogen at work. Because I had been at the same place of employment since the beginning of my career I filed for Workers Compensation.

I was discouraged from filing a claim by the employee health dept. The nurse there told me that I just needed to get more rest. As the reality of my situation set in and I researched the disease further, I realized that serious consequences could occur. I wanted to do everything in my power to minimize these side effects and went to a hepatologist.

Luckily, my liver enzymes were not elevated and thus I did not meet the criteria for interferon treatments. Through a long diagnostic process that included a liver biopsy, it was concluded that I had HCV for about 10

years, which coincided with the time when our medical centre became a trauma centre and we became exposed to more trauma patients.

I still am able to continue to live life to its fullest but I am also leaning towards a part time career in occupational nursing. I see my doctor every 3 months to ensure my enzymes remain normal. I live with the constant fear that they might become elevated and I will have to start treatment with interferon.

A colleague was also exposed at work and is currently receiving interferon and is so sick he is unable to work. For now, workers comp is picking up my case and reimbursing my related health care expenses. I hope to have medical coverage for the rest of my life, which I've been told is how long I will have HCV.

HCV is communicable but also preventable. As health care dollars are stretched further and further, protecting ourselves from any preventable disease is vital. Equally important is our responsibility as health care providers to protect each other from disease by practising the principles we teach.

As a health care worker who harbours HCV I hope that an HCV vaccine will be developed as well as a more promising treatment and ultimately a cure.

'Lyn'

- A case study, taken with thanks from the US *Journal of Emergency Nursing*, April 99.

Editorial comment: Within Lyn's case study, she mentions monitoring of liver function tests as being her deciding factor for interferon treatment. These tests do provide a rough gauge of liver condition but a liver biopsy is a much more accurate tool for treatment assessment.

PCR viral genotype testing is also emerging as a useful treatment assessment tool.



(model/s used above)

1999	1999	1999	Edition 24
to shut down needle & syringe program in Carolyn Lane, Redfern. This coincides with several local government councils moving to close similar services.	1999 Jan - Central Sydney Area Health Service become the first NSW Area Health Service to develop and adopt a localised HCV strategy <i>Hepatitis C Business Plan</i> .	million.	<p>The Hep C Review</p> <p>Combination therapy approved as standard treatment in USA</p> <p>The Hep C Review has been published in the 24th edition of the journal. This issue contains the latest information on the new combination therapy for HCV. The review is available in both print and audio CD format. It is a valuable resource for health care workers and patients alike. The review is available for purchase or can be downloaded from the website.</p> <p>The review is available in both print and audio CD format. It is a valuable resource for health care workers and patients alike. The review is available for purchase or can be downloaded from the website.</p>
1999 Jan - Commonwealth Dept Health publishes the report, <i>Hepatitis C: A Review of Australia's Response</i> . Contains <i>Gaining control of Hepatitis C Virus epidemic in Australia</i> ; the first Australian overview of HCV prevention.	1999 Jan - The research report, <i>Economic analysis for hepatitis C: Australia's response</i> , published on the Commonwealth Department of Health website, suggests extrapolated HCV costs of \$10 billion with an additional annual \$550	1999 Mar - First edition of <i>Australian Hepatitis Chronicle</i> , a resource of the Commonwealth sponsored, Australian Hepatitis Council's National Education Project.	
		1999 Mar - Hepatitis C Council of WA launches the audio CD, "Living with Hepatitis C", aimed at providing support for people living in WA's isolated rural regions.	

Living with serious illness: building a support team

Adapted from a transcript of Susan Belgard's internet chat room forum on chronic illness.

Susan recently discussed the building of support teams. Following are some bullet points coming from the discussion. If they appear disjointed, it's because they represent the comments of either Susan or individual forum participants.

- The beneficial effect of strong social ties is well-documented in medical literature, yet hasn't been firmly established as a routine part of medical treatment. The medical evidence shows that people do better on a physical level if they are in regular contact with others.
- Some of the statistics can help motivate you. People who had open heart surgery, for example, had seven times better survival rate if they had close relationships than if they were alone!
- Living with a serious illness can involve several different responses: building and deepening social relationships, ways to spread care giving tasks, including as many people as possible, encouraging people to ask for help, or friendly cards, phone calls and having as much fun and recreation as possible.
- Chronic illness is something others don't understand well. It's important to be as frank as possible - this is what disease I have and these are my limitations right now.



- It is hard to lose independence. One part of asking for help is that our upbringing doesn't train us to do that - we are trained to be independent. We live in a highly mobile society, as well, where people often are not near their families. When someone says, how are you? our programmed response is "fine" but we need to learn to say we are "not fine."
- Many people need to learn to ask for help - and one important thing is to determine what you want. The important part is being able to say to people it would be great to have them help support you.
- "I think it's important to realise that having help doesn't mean losing independence. Every CEO has a ton of help to get their company profitable, and they don't lose control. So you're the CEO of your life - you can ask for help and not lose independence!"
- "One thing I ask people to do is to be sure that their friends and family communicate with them - send cards, phone, write, email - no matter where they live."
- It helps to actually have a list or chart where you write down what you want. And then begin to find out who can help you with a particular thing - maybe bring a meal once a week, watch a video, etc.
- Another suggestion is to have people who can't visit say a prayer or affirmation for you - there is a scientist who is doing some research on the effectiveness of prayer in helping people who are ill feel better - it is all positive energy.
- I want to encourage you to build a list of little things that people can help with. And always end a call by asking for something specific - even if it's just "please give a call next Monday."
- Also, encourage your friends to send you funny stories, jokes, favorite photos of you and them and display them - keep them visible.
- The idea of building a support team follows the idea of getting the very best medical care possible - it's about you being your own advocate for your best shot at being healthy.
- The important thing is to have a sense that people do care and are willing. You have to believe that, you have to convince yourself that is true, in order to reach out.

Susan Belgard is the founder of the Safety Net Project <<http://www.safetynetproject.org>> It is a nonprofit organisation helping people who are ill develop their own support team of family and friends.

Edition 25	1999	1999	1999
<p>The Hep C Review</p> <p>National review highlights need for urgent action</p>	<p>1999 Mar - Canada approves combination therapy for hepatitis C.</p> <p>1999 April - Beginning of the <i>NESB Hep B & C Project</i>, at the NSW Multicultural HIV/AIDS Service, funded under the (Commonwealth & State) Public Health Outcomes Funding Agreement grant scheme.</p> <p>1999 May - NSW Premier's Drug Summit held. Recommendations supported HCV prevention initiatives:</p>	<p>including trials of limited drug law reform and community based injecting facilities.</p> <p>1999 May - European Commission approves combination therapy for hepatitis C.</p> <p>1999 May - Beginning of the <i>NSW HCW Hepatitis C Education Strategy project</i>, carried out by HCCNSW, funded under the (Commonwealth & State) Public Health Outcomes Funding Agreement grant scheme.</p>	<p>1999 May - First National HCV Educators Forum held in Canberra as a joint project between Australian Hepatitis Council and Australian Intravenous Association, sponsored by the Commonwealth.</p> <p>1999 June - Federal Health Minister announces \$12.4 million in new hepatitis C funding (with a strong community focus) over 4 years.</p> <p>1999 July - Australian Hepatitis</p>

Update of hep C treatment trials				
	Aushep 06	Aushep 07	Aushep 08	Nthn Rivers CH100 trial
Who's it for?	People who've already been on interferon but didn't experience a sustained response.	People who've never tried interferon.	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>Group 1: interferon @ 10mu daily for 4 wks, then 5mu 3x weekly for 48 wks. Ribavirin given twice daily.</p> <p>Group 2: interferon @ 10mu daily for 4 wks, then 5mu 3x weekly for 48 wks. Placebo capsules given twice daily.</p>	<p>Group 1: interferon @ 9mu daily for 1 mth, then 3mu 3x weekly for > 1 year.</p> <p>Group 2: interferon @ 6mu daily for 1 mth, then 3mu 3x weekly for > 1 year.</p> <p>Group 3: interferon @ 3mu 3x weekly for > 1 year.</p>	<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. LFTs at 0,1,3,6,9 months. 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?	Not applicable as enrolments closed.	Nepean, Wollongong, Concord, St Vincent's, Lismore, RPAH, RNSH, Prince of Wales, Campbelltown	Not yet finalised but will probably include most major hospitals See Aushep 7 (left) for a guide.	Particular GPs practising in the Nthn Rivers area participating in the trial.
Would anything rule me ineligible?	See Aushep 8 (right).	Having cirrhosis, Previous treatment, Injecting drugs (oral methadone OK), Hep B coinfection.	<p>Having cirrhosis, Previous treatment, Injecting drugs (oral methadone OK), Hep B coinfection, Falling pregnant (women), 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</p>
Enrolments still open? (ph contacts)	Enrolments have closed and Aushep 6 is now in progress.	No, enrolments are now closed.	<p>Enrolment 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.</p> <p>Nikki Keefe 02 6620 7518 (Thurs),</p> <p>Tim Sladden 02 6620 7509 (other days, Mon-Fri).</p>

**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 who has just injected may have touched

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.

interferon / combo therapy update

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:

Bankstown-Lidcombe	Bathurst	Bega
Blacktown	Campbelltown	
Coffs Harbour (Base)	Concord	
Corrections Health (Bathurst)		
Corrections Health (Long Bay)		
Dubbo (Base)	Illawarra	John Hunter
Lismore (Base)	Liverpool	Mount Druitt
Nepean	Orange (Base)	Port Macquarie (Base)
Prince of Wales	Royal North Shore	Royal Prince Alfred
St George	St Vincent's	Sutherland
Wagga Wagga (Base)	Westmead	



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*:
9332 1599 for Sydney callers or 1800 803 990 for NSW callers.

Additionally, contact any of the following organisations:

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

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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 (Sydney callers)

1800 803 990 (NSW 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.

Following is a list of healthcare workers in your local region who can possibly refer you to local hepatitis C services, including support groups:

Mid Nth Coast	Robert Baldwin	02 6588 2789
Western NSW	Scott Davis	02 6881 2215
Hunter	Marilyn Bliss	02 4924 6477
Mid West NSW	Dave Brackenreg	02 6332 8576
Southern NSW	Geetha Isaac-Toua	02 4827 3328
South West NSW	Dalton Dupuy	02 6058 1700
Nthn Rivers	Kerry Leitch	02 6620 7505
New England	Karin Ficher	02 6766 2288
Central Coast	Karen Nairn	02 4320 3399
Illawarra	Brian O'Neill	02 4228 8211
Wentworth area	Elizabeth O'Neill	02 4724 3877
Western Sydney	Chris O'Reilly	9840 4105
Nthn Sydney	Bernie Coates	9926 6717
Central Sydney	Peter Todaro	9515 9600
	Jan Pritchard-Jones	9515 8643
Far West NSW	Darriea Turley	08 8080 1511
SE Sydney	David Willock	9382 8370
Sth West Sydney	James Mabbutt	9827 8033
	Laura Baird	9828 5944

One-to-one counselling

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

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

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

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

Family counselling

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

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

Hep C Helpline extends hours

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

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

Monday to Friday: 10am - 5pm

Monday evenings: 5pm - 8pm

These changes mean that we will be 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*.

Memorial Service

There will be a memorial service for those who have lost their lives to illicit drugs on Sunday, 24 October at 7.30pm at the United Church, 160 Liverpool Road, Ashfield.

The Revs Bill Crews and Ray Richmond will take part in the service along with other ministers including Buddhist, Jewish and Islamic priests.

The highlight of the service will be a candle lighting ceremony for those who have died whilst names are read from a memorial book.

On the same weekend another ceremony is expected in Canberra - and future services are expected in Brisbane, Melbourne, Perth and on the Gold Coast.

For more information, contact Tony Trimmingham of Family Drug Support on:

Ph: 02 9818 6166 or 1300 368 186

Email: trimmo@tig.com.au

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

Hepatitis C - a brief introduction - (brochure)

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

Hep C Helpline - Posters 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

