

The Hep C Review

Spring Edition November 1997

Issue 19

ALARMING HCV TRENDS

Since HCV was made notifiable in NSW (in 1990) our state has recorded over 42,000 notifications. Figures highlighted by the Hepatitis C Council show that close to half of Australia's total HCV notifications are found in NSW alone.

We were able to obtain these figures from individual States/Territories and the National Centre for Disease Control - a unit of the Commonwealth Department of Health & Family Services.

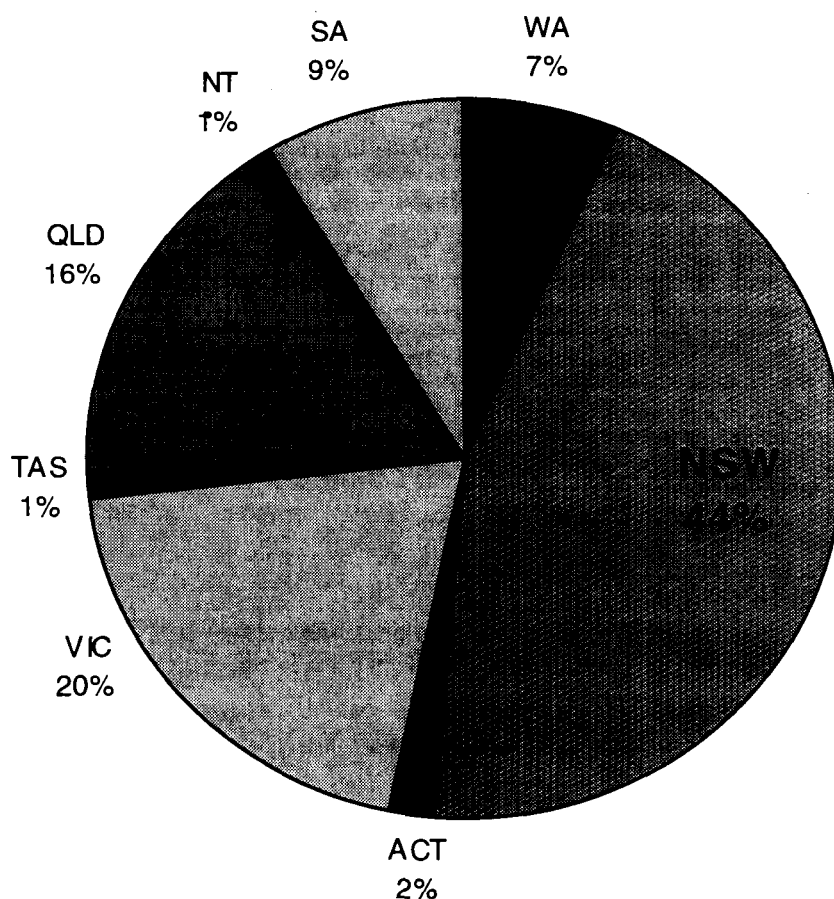
There are problems associated with the figures. Annual totals of HCV notifications have only been gathered by all States/Territories since 1993 and some notifications will represent the second or third time someone had an HCV antibody test. Some notifications might also represent false positive test results - though not many, as most of these occurred prior to 1992 when the HCV antibody tests were less sensitive and specific.

For the 4 year period, 1993-96, there were over 75,000 HCV notifications nationally. Considering the previously mentioned problems, these figures must be considered as approximates - but because the margin of error (estimated at 5%) applies equally across all states, the figures do highlight a useful comparison between States and Territories.

HCV Notifications 1993-96	
NSW	33,766
VIC	15,285
QLD	12,030
SA	6,609
WA	5,090
ACT	1,313
NT	1,039
TAS	773
Total	75,905

Implying that over 40% of Australia's possible 200,000 HCV cases occur in NSW, the figures will sound alarm bells for NSW Health. Considering that each HCV infection is estimated to involve \$14,000 in medical and health costs alone, NSW could be in for a bill of \$1.23 billion. This potential bill doesn't even take into account other economic costs such as lost production (paid/unpaid worker's time off) or support services (respite care, Meals on Wheels, etc).

In 1995, NSW Health released a report on HCV, but we are yet to see a clear and funded strategic plan for the state. Given what is now known about Australia's HCV epidemic, the spotlight of attention must be turned on our politicians and health bureaucrats. How do our political leaders plan to address this crisis? (See our page 3 editorial)



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The 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 (HCV).

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Contributions from Council members and the public are welcomed. Other than for editorial comment, views expressed in this magazine are therefore not necessarily those of the Hepatitis C Council of NSW.

Our thanks to the Avery Architectural & Fine Arts Library, Columbia University in the City of New York for use of the graphic on page 28.

Time to act?

The hepatitis C virus (HCV) has become a critical personal and public health problem in Australia - with more than 40,000 people known to be infected in New South Wales alone.

Given our evolving awareness of the HCV epidemic, especially in regard to the health and social problems involved and the scope of ongoing transmissions, few people believe that the NSW or Federal Governments have made anything approaching an adequate response.

Both in NSW and nationally, a vacuum has existed in regard to leadership that would guide HCV prevention programs and initiatives.

Despite awareness since the early 1990s of the alarming rate of ongoing new infections, no programs are yet in place that are having any impact whatsoever on reducing the spread of HCV.

Treatment, care and support initiatives exist on the back of already overburdened and under-resourced general clinical services, with precious little psychosocial support for those diagnosed with HCV.

The biggest hurdle to a better response is State and Federal commitment to funding.

In comparison to best standard models (such as Australia's HIV/AIDS response), the amount of money allocated to meet hepatitis C needs is grossly inadequate. There may be practical reasons why this is so, but it does not make the lack of an adequate response any more acceptable.

The current NSW Parliament Standing Committee on Social Affairs Inquiry into Hepatitis C will explore and highlight the key issues associated with HCV and

draw to attention the enormous personal, social and economic costs of HCV infection.

Like many of the submissions coming before it, the Standing Committee should also make strong recommendations about initiatives that should be implemented in order to address this epidemic.

It's important to remember, though, that like other governmental committees, it can only make recommendations. Such recommendations would be debated within parliament and possible action would depend on the resolve and agreement of individual MPs.

It's therefore vital that you obtain a copy of our submission, contact your local State MP and highlight the urgent need for action. Will there be another Parliamentary Inquiry into HCV? It's very unlikely. You'd have to agree, **now is the time to act.**

So make two phone calls today - the first to find out what we said in our submission, the second to your local MP requesting an appointment. //

Speaking to your MP

Your local state Member of Parliament is your personal representative within our parliamentary system. Every day, he/she is approached by people just like you - seeking help with individual problems ranging from immigration to irrigation.

Your MP would be happy to hear from you about HCV - your experiences and how it has impacted on you, and your views on how you'd like to see things improved.

All you have to do is phone your MP and make an appointment. If you're unsure of how to contact your MP, just call the state Electoral Office on ..

9209 5999 (Sydney)

1800 043 188 (NSW)

The current Parliamentary Inquiry will table its report early next year. If you contact your local MP now, you'll be helping greatly to improve the chance that our politicians will take notice of the report and implement its recommendations. //



Edition 18

Thanks for compiling yet another excellent Hep C Review. Of particular interest to me were two articles.

The first being the article 'Doctors and IV Drug Users'. I thought the views expressed by Dr Steve Flecknoe-Brown accurate and applaud his integrity in speaking out from his perspective.

Having 'used' for nearly 14 years - from age 14 to age 28 - I think in retrospect of all the abuse hurled towards health professionals and cringe. Especially now that as I've worked in healthcare for many years and experienced the games people play. Poetic justice maybe!

Even my empathy and compassion have been stretched to breaking point. Whilst some addicts express pride and say they are happy with using, for me it was a living hell. Years eaten away with self denigration, self deception, and of course, feeding a habit which could never get enough.

Which leads me to the other article 'My race against time' - an article written from a mother's perspective of witnessing her daughter's active addiction.

Reading it made me envious that two parents cared so much. I'd count that 20 year old addict as privileged in that respect.

My hope would be for every suffering addict to break free but I know from years of losing friends to ODs and suicides that the odds are slim, but always possible ...

Like many of the people who've written in, I too have anguished over who to tell. I have experienced judgmental attitudes and felt like a leper. Ultimately, does it matter how one contracts a disease? Should not the emphasis be on preventative measures and support for those afflicted?

I also think the time has come to do massive media coverage on hep C.

Thanks MM



Contact

I'm sorry that I've taken so long to renew my membership. I have been having some financial problems for the last few months.

I look forward to my copy of the Hep C Review, to read about the latest developments and treatments. I also like to hear other people's stories. It helps me to identify and cope with what's happening to me. Keep up the great work.

Sincerely, BP

[Thanks for the positive feedback. We do have to delete lapsed memberships after 6 months. So please remember, if anyone does have financial problems, just tick the zero fee membership option and send our form back. You'll then be guaranteed another 12 months' membership - Ed]



Naturally speaking

First of all thanks for an increasingly informative newsletter - I've been meaning to write to you for ages but today I also feel compelled to reply to DS's assertion in the last newsletter that 'the listing of natural therapy organisations whose treatment of HCV is at best ineffective, at worst quackery'. Also the phrase 'turning of a blind eye to illegal practises such as injecting drug abuse disturbs me'.

I am one of many HCV positive people who have successfully sent the virus into remission with natural therapies. The advice and information I've received from some orthodox practitioners of western medicine has been mere quackery.

The Hep C Council of NSW, as reflected in this newsletter, does not turn a blind eye to the injection of illegal drugs. It offers a forum in which impartial, informative discussion of IV drug use can take place.

In every newsletter it explains safety procedures. Considering IV drug use is the main way in which the virus is transmitted in this population, surely that's the most appropriate and responsible approach? The blind eye must be DS's.

Keep up the good work - FM



Postal support

My daughter brought me up her copy of *The Hep C Review*, Edition 18 and I was very impressed by it. I felt it has a fair coverage of all aspects of hep C. So many people think that the only way you can get this disease is if you inject drugs.

I felt the warning about tattooists was rather mild - however it was there. My own family doctor holds all skin penetration procedures under investigation.

My 36 year old son has hepatitis C which has been traced back to when he had a tattoo done. He works in a stressful position and gets very tired and seems to have a very 'short fuse'.

A letter I found very empathetic was called 'Loss of Health' (page 5). It is so true. My son could not tolerate interferon at all. He could hardly get out of bed when using it. Until reading *The Hep C Review*, I felt lost.

Regards Ms DG



Tagging

One doctor came to my house when I was sick. He walked in the front door and didn't touch me. From about 8 feet away, he told me I was hep C positive. And when my 20 mth old daughter was in hospital her files were marked in large letters "MOTHER HEP C POSITIVE". My daughter doesn't have the virus.

Thanks, Sharon

[In Edition 11, we covered a similar situation at Royal Prince Alfred Hospital. At the time, senior health bureaucrats stepped in quickly to discourage the practice and to encourage adherence to standard infection control guidelines. These guidelines help prevent infection and ensure that no one is discriminated against in healthcare settings. If people still experience this type of treatment, call the NSW hep C info and support line. Contact details can be found on page 2 - Ed]



A risky holiday

I recently heard that in some overseas countries there is a lot of hepatitis E. Because I have HCV, my doctor says I should avoid other types of hepatitis and I'm wondering if I should steer clear of travelling overseas.

Regards, Daniella

[Hepatitis E is an infection that's rare in Australia but common in many developing countries. Like hepatitis A, it is spread by consuming water or food contaminated with faeces (shit). Sometimes it runs in epidemics; at other times it occurs in isolated cases. It seems to affect adolescents and younger adults, involving a possibly debilitating illness lasting from 2-12 weeks. It is rarely fatal except for pregnant women who have a 20% chance of dying from the illness. If you are worried about overseas travel, you can get more info from your doctor or the Travellers Medical and Vaccination Centre - ph 02 9411 4464 and ask for your nearest branch - Ed]



Less injecting

I really enjoy reading *The Hep C Review*, but was not that impressed with the last issue, No 18. I felt as though you were mainly catering for active intravenous drug users. Articles about how some people were out buying drugs and they had to use them in their car and the dealer got busted.

I suppose you could read about that sort of thing in the magazines that injecting drug users have. IDU people have their own magazine, just like people with HIV/AIDS, gays, lesbians, surfers and bikers, etc. People living with hepatitis C have *The Hep C Review*.

I realise that the majority of hepatitis C is transmitted by IDU, so maybe a page or two should be devoted to issues for current users. *The Review* could also carry phone number references for people needing IDU information.

Please keep the rest of the magazine for people with HCV, and their family and friends.

Regards Pat

[We try to make the Hep C Review relevant to everyone who has the virus or works with it. There's such a wide range of people with HCV - some of whom do inject drugs - that we'll never be able to please everyone; but we hope we'll find a good balance]



Inquiry thanks you

The Inquiry into Hepatitis C has been overwhelmed with the number of submissions received from people affected by HCV. Most people requested their submission be treated in confidence. Also, we are conscious that family members or even the postie in a small country town may wonder when an envelop bearing the Parliamentary logo arrives. To respect the privacy of those who have sent submissions, we have decided not to send personal acknowledgements.

We do want to thank everyone who did respond. The time you took to write to us and your contribution and comments are appreciated and valued. If you want to check that we received your submission, please phone me (my direct line is 02 9230 3435 and my e-mail address is cknight@parliament.nsw.gov.au)

Everyone who has made a written submission will receive a copy of the final report which we will post out in plain envelopes.

Regards Dr Jennifer Knight
Standing Committee on Social Issues
Parliament of NSW



Coff mixture

We thought you might be interested in *LIVA-A*, a brew that lots of people I know here in Coffs Harbour are taking. It seems to provide remarkable results. Many people report higher energy levels within two weeks.

The capsules cost about \$20 for 100. They are taken 3 times daily, and there've been no reported ill effects other than a bit of indigestion if not taken with meals.

Does anyone have information on the ingredients?

eta vulgaris, Taracaxum officinale, Petroselinum crispum, Equisetum arvense, Rumex crispus, Betula alba, Cimicifuga racemosa, Cnicus benedictus, Angelica archangelica, Gentiana lutea, Solidago virgaurea.

Thanks - Lloyd

[See page 8 for news on a recently established research unit - we'll make sure they get your letter. We make suggestions about complementary therapies on page 37. This important information may assist if you are considering these options - Ed.]



Mt Druitt support

In a previous edition of the Hep C Review, I spoke about a support group, here in Mt Druitt. Starting 22 November, we'll be changing our meeting times to: 7-9pm, Saturday nights.

If you need more information, contact me on 02 9628 4165.

Regards, Paulo



The ego has landed

They say that ignorance breeds prejudice. It is sad when an obviously educated person in a position of power sets out to clear the air between injecting drug users and doctors and ends up encouraging harmful stereotypes and providing disinformation. (*Drs & IV drug users*, Edition 18, p30)

The doctor-patient relationship is an unequal one. In our society, doctors act in a position of trust and responsibility - facilitating our access to healthcare options including medications. The redressing of this imbalance is not furthered here by this doctor's quite arrogant tone, lecturing and finger wagging. Dr Flecknoe-Brown's own obvious stereotypes and prejudices need addressing.

The GP: IDUs come from many backgrounds - the medical profession itself has a statistically disproportionate amount of

drug users. Some people who inject do have complex healthcare needs that can be time consuming and some do use Medicare to pay for their visits. On both these issues, so do many people who don't inject drugs. If doctors are not getting enough money from Medicare, the AMA should address this problem, not take it out on people who inject. As for "come off it, I have an idea how much your habit costs", I'd have to reply that most people don't rate doctors among the poor of this country, and many well-off people who don't inject use Medicare too. As is their right.

The hospital resident: Regarding your point people who inject have "exercised choice in getting into IV drugs", this is in itself debatable. Are those others who "have no choice in the misfortune visited upon them" the innocent victims of assault, or would you include those people who've smoked or drunk themselves into ill health, or perhaps those who eat unhealthy food, or those who choose not to exercise? Once you start on this angle, it's hard to stop. Where do you draw the line?

The specialist: Some people who inject, like any other members of our society may have problems with compliance to medications or attending appointments. Maybe some people are too overawed by specialists to ask questions. Perhaps people in a medical crisis might be fearful and intimidated. If specialists considered their patient's frame of mind and chatted informally, maybe you'd find your clients would open up and "show an interest" too.

Perhaps Dr Flecknoe-Brown would be better occupied tackling those doctors who over prescribe Benzodiazapine drugs (far more prevalent a problem and far more damaging than say heroin), or perhaps those doctors who over prescribe antibiotics. No, it seems the AMA has more important issues to deal with, such as furthering prejudice against people who inject and have "complex problems".

If Dr Flecknoe-Brown was just another GP, I'd be less disturbed. As chair of the Council of the AMA he should know better. Maybe he is happy to represent the fears and prejudices of the ignorant, but I somehow doubt that on his advice doctors will be "doing our best".

Regards TB

///

HCV - the first 100 days

Amongst other articles, this edition focuses on people's initial experience of HCV. You could call it 'HCV - the first hundred days'. Consequently, many of our stories are about people who've been through hard and worrying times. If you are new to HCV, don't be unduly alarmed about our personal stories. As a reader, please remember that

- Not all people with HCV get seriously ill. For example, did you know that around 90% of people with HCV won't ever develop liver cancer or liver failure, and that 75% will never develop cirrhosis?
- Our stories and articles often relate to people's sadder experiences. We don't generally hear from the many people who have little problem with their HCV.

Receiving an HCV diagnosis usually triggers some level of shock. This is understandable given the threat to wellbeing and the common misconceptions that HCV equates to a death sentence; or is related to HIV; or that it means you must be a 'junkie' - a term loaded with negative stereotypes for people who do inject.

Consequently, a diagnosis can also raise other powerful emotions. Concern about the possibility of infecting others. Concern about your wellbeing and that of others - your family, friends and dependants.

You and those close to you may also experience much anxiety about change. Will our close intimacy continue? Can we have children? Will I become a burden on our family? Who will want me now?

Such concerns may initially dominate everything after receiving a diagnosis - they are a natural response. Within a short period of time, though, you'll probably seek out the information you'd hope will answer your concerns.

Getting your hands on factual relevant information is of great importance. Of equal importance is talking and sharing any concerns with the people that count. Some people who don't have much family support often contact phone support lines or other support services.

Hopefully, this promotes your 'processing' the shock and allows an acceptance of what has happened. This leads in turn to getting on with life - a life that encompasses living with a chronic illness, but is not dominated by it.

When the above steps don't happen, you may not see HCV as a big issue, or you may be in a state of denial. Denial in itself is not a problem - it's a way of putting something uncomfortable on hold. Eventually though, you'd need to accept the reality of diagnosis and deal with it.

This edition is about "dealing with it".

///

Herbal research centre opens in Sydney

The new *Herbal Medicines Research and Education Centre*, the first of its kind in Australia, will investigate the benefits of herbal treatments such as Chinese medicines.

The centre's director, Professor Basil Roufogalis, said herbal medicines had an important role in health care.

"We are hoping to provide a balanced and scientific view of herbal medicines that will help to address misconceptions, as well as ensuring quality herbal products," he said.

Professor Roufogalis said he was keen to explore the benefits of herbal remedies for illnesses such as hepatitis C.

Abridged from SMH, 22/7/97.

Europe's safe injecting rooms hailed

Politicians who saw first-hand Europe's injecting rooms for heroin users have returned with a mainly positive view of the facilities.

But despite their enthusiasm, a similar system will not go ahead in NSW following fierce opposition from the Liberal and National parties since the delegation returned.

An Upper House ALP backbencher, Ms Ann Symonds, who paid her own way to join the select committee's tour of Switzerland, Germany and Netherlands, said she was shattered that the conservative parties had "taken an axe" to the proposal.

She said the European experience showed that safe injecting rooms resulted in lower crime rates and increased rehabilitation of drug users, and removed the risk of death by overdose for participants.

The involvement of police also resulted in improved intelligence on drug distribution and a much improved clear-up rate of drug-related crime.

But the Premier, Mr Carr, has said his Government will not introduce safe injecting rooms unless there is bipartisan support. This is despite the recommendation of the Police Royal Commissioner, Justice Wood, that the plan be given a trial.

"The Opposition simply can't justify the expenditure of \$100 million of taxpayers' money to have Justice Wood make this respectable, moderate suggestion on managing the drug problem then simply not endeavour to do something about it," said Ms Symonds.

By Mark Riley, abridged from SMH, 11/9/97.

[A NSW cross-party parliamentary inquiry into whether safe injecting rooms should be trialled is currently underway]

Kombucha tea under spotlight

Kombucha tea has been claimed to have a large number of beneficial effects - including the prevention of cancer, relief of arthritis, treatment of insomnia, stimulation of the immune system, and even the regrowth of hair.

The tea is brewed from the Kombucha mushroom. The mushrooms are sold or distributed by naturopaths and other practitioners.

In the last 12 months, the Adverse Drug Reactions Advisory Committee (ADRAC) has received two reports of liver damage in association with Kombucha tea.

In one case, a woman developed rash, fever, rigors, nausea and vomiting after drinking Kombucha tea for a month. Investigations revealed abnormalities in liver function tests, white blood cells, and ESR. She recovered following treatment with steroids.

In the other case, a 35 year old woman developed severe hepatitis following prolonged use of the tea.

ADRAC is concerned that these reports suggest that Kombucha tea may be toxic and is keen to learn of the extent of the problem.

Any person who develops unexplained liver damage should consider whether Kombucha tea is being used, or has been recently used.

For further information, or to pass on any feedback, please phone ADRAC on 02 6232 8382.

Hepatitis C cases soar

An alarming increase in hepatitis C infections is detracting from Australia's spectacular success in controlling the rise of infectious diseases such as HIV/AIDS. Cases of hepatitis C are soaring at 40 times the rate of HIV infection, with little sign of improvement.

Drug and alcohol experts have warned that hepatitis C is potentially the epidemic AIDS could have become. Many cases of hepatitis C acquired by injecting drug users more than 20 years ago are only now coming to light.

Professor John Kaldor, deputy director of the University of NSW's National Centre in HIV Epidemiology and Clinical Research, which edited the report: *Annual Surveillance Report 1997 of HIV/AIDS, and Related Disease in Australia*, said hepatitis C was going to represent a major cause of illness and mortality in Australia for many years.

Dr Alex Wodak, director of the Alcohol and Drug Service at St Vincent's Hospital, said the figures on hepatitis C were alarming.

By Marion Downey, abridged from SMH, 9/8/97.

Call for action on hep C

At the recent launch of the National Health and Medical Research Council (NHMRC) report, 'A Strategy for the detection and management of hepatitis C in Australia', key speakers urged a far-reaching overhaul of the prevention and treatment of hepatitis C.

Professor Geoff Farrell, of the Gastroenterological Society of Australia,

said hepatitis C was the most common reason for people requiring liver transplants, accounting for about 25 per cent of transplants. More than 6,000 new infections occur in Australia each year.

Launching the report, Mr Chris Puplick, chairman of the Australian National Council on AIDS and Related Disease (ANCARD), said that in light of the "idiot behaviour of a large number of politicians", including the "woeful, regrettable and utterly wrong" decision of the Federal Government not to proceed with the ACT heroin trial, the Government had a moral responsibility to find the extra money required to reduce the health impacts of hepatitis C.

A key recommendation was for interferon treatment to be given for 12 months in treating people with liver damage. The NHMRC working party chairman, Professor Bill Reed of the University of Western Australia, said it could permanently rid the virus from about 12 per cent of people who had HCV. When used with the more expensive drug Ribavirin - not currently used in Australia - the clearance rate doubled. The cost of the dual treatment would be about \$16,000 per person.

Professor Reed also said restrictions on interferon had to be reconsidered as people on methadone treatment, or who had injected during the previous 12 months, are currently ineligible. "This is not based on scientific evidence, it's based on people's prejudices," he said.

Professor Farrell said preventing transmission of virus was a huge concern.

"The needle exchange program is critical. We know it has kept HIV/AIDS out of our IDU [intravenous drug user] population, but a lot of people don't realise that other aspects of IDU behaviour, such as some friendly person putting their finger on your vein to stop it bleeding, or sharing a swab, can transmit the virus," he said.

"This is why the behaviour is so dangerous, and while harm reduction is important, I think strategies to prevent IDU behaviour are probably more fundamentally important."

By Leonie Lamont, abridged from SMH 27/8/97.

Amrad joins hepatitis C drugs hunt

US based Amrad Corp says it stands to earn up to \$50 million by collaborating with US company Chiron Corp in searching for a hepatitis C treatment.

The venture, to last an initial period of two years, will use Amrad's research findings to develop potential new

medicines. Amrad managing director John Grace put a conservative estimate of \$50 million on the amount the company could earn through payments if its research was to beat the odds and find an effective treatment for the virus.

He said Amrad would need to contribute to a discovery to be eligible for the payments, and would commit all its existing research on hepatitis C to the new collaborative study.

An estimated 400 million people around the world have HCV, including 160,000 in Australia.

Abridged from Daily Telegraph 20/9/97.

Responding to hepatitis C

Central Sydney Area Health Service (CSAHS) covers a large part of Sydney stretching from Newtown to Canterbury. If you live in this region, CSAHS looks after much of your healthcare services. Perhaps you're wondering about how we are planning to address hepatitis C?

A Hepatitis C Advisory Committee has recently been formed. This committee is made up of directors of services directly involved in hepatitis C and a representative from the Hepatitis C Council. The Committee's primary role is to oversee the development of an Area wide Action Plan. The Action Plan will describe gaps in current services and identify strategies to improve services.

Many gaps have already been recognised, including aspects of prevention and treatment services. The Action Plan will take at least one year to develop.

The Area is now ready to embark on a Hepatitis C Demonstration Project. This is a joint project with South Eastern Sydney Area Health Service. The main

components of this project will be GP and other healthcare worker education; and the instigation and evaluation of community based clinics.

It is hoped that the community clinics will improve people's access to specialist services. A doctor specialising in HCV and a clinical nurse consultant will attend these clinics. The first clinic will be held in either December this year or January next year.

The Area is also establishing patient management guidelines so that people living with HCV receive high quality and consistent information. This will involve wide consultation involving paediatricians, hepatologists, infectious disease specialists and obstetricians. One of the management guidelines that is currently being developed involves the testing of children and the management of positive children.

By Janice Pritchard-Jones, Coordinator of hepatitis C services, CSAHS.

Expensive new detox being trialled

A new heroin detoxification method could be introduced in NSW, Health Minister Andrew Refshauge said yesterday.

The drug used in the program, naltrexone, was already being used in NSW but only to help addicts already weaned off heroin, not for detoxification.

However, several leading Australian medical practitioners have serious concerns about the program. They say there is no proof the treatment works, and warn the medication may even be dangerous if not administered correctly.

Called ultra rapid opiate detoxification, the method involves a five day treatment with naltrexone - which is said to counteract the craving for heroin or alcohol. The initial several hours are spent under deep sedation. Approximate cost of the initial treatment is Aust \$11,000.

The recovering addicts are then given an indefinite course of naltrexone as a maintenance therapy.

"We have a responsibility to ensure naltrexone is safe, is effective and free of harmful effects," Dr Refshauge told State Parliament yesterday.

"As a result I've commissioned an immediate clinical assessment of the use of naltrexone."

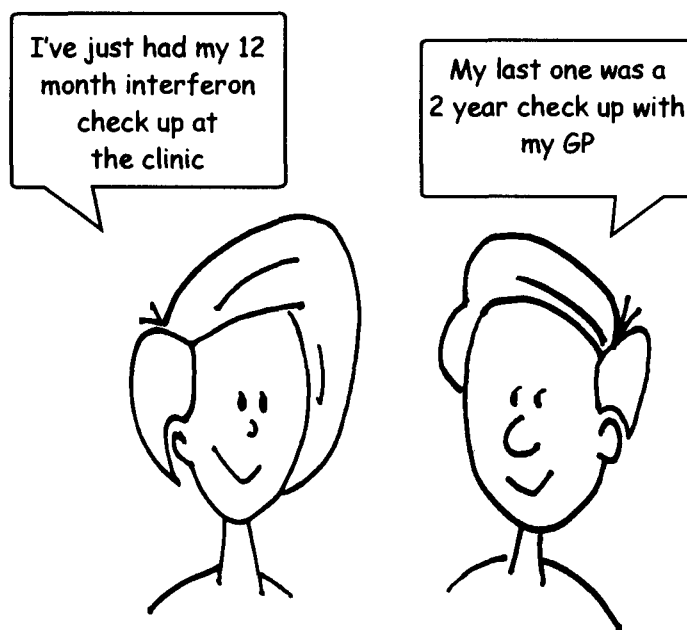
It differs from other therapies in that it is neither addictive nor mood altering.

Dr Refshauge revealed that naltrexone is already on clinical trial in NSW as a maintenance therapy, similar to methadone.

The first trial in the Hunter region involving 40 addicts has just been completed and the results are expected within weeks. Two other trials currently being conducted in the Sydney metropolitan area will be completed later this year.

"These are new treatments and they do offer hope but our job is to ensure that they are indeed effective and they don't encourage false expectations," Dr Refshauge said.

Based on an article by Rachel Morris, abridged from Daily Telegraph 24/9/97



If you've had interferon and don't attend for follow up checks, they won't find out how to improve the treatment. And make sure your treatment clinic or GP forwards your follow up reports to the National Interferon Database (02 4921 3794)

Pre-packaged interferon available

A new method of packaging will make life easier for patients undergoing interferon treatment.

The treatment is currently provided in parts. Patients are required to dissolve a certain amount of powder into sterile water. The solution is then injected just below the skin, into body muscle, three times a week for a period up to 12 months.

The new treatment involves pre-mixed, ready to use, interferon syringes, which come in sealed, sterile packs. The new style interferon became available from 1 August. For more information, contact your treatment centre.

ANCARD WORKPLAN UPDATE

A comprehensive workplan covering work of the Australian National Council on AIDS & Related Diseases over the period 1997-99 has been developed and recently distributed.

Advising the Federal Minister for Health, ANCARD will attempt to solve Australia's hepatitis C public health crisis. Its workplan will guide Australia's response to HCV in a wide range of fields - prevention, treatment, care, research, legal/ethical and monitoring.

ANCARD's workplan will be evaluated on an annual basis. It outlines many specific initiatives including:

- development of a strategic plan to prevent HCV transmission;
- review of National Action Plan treatment and care recommendations;
- compiling inventory of HCV virology, immunology, epidemiology, clinical and social research; identifying priority research needs;
- implementing HCV specific anti-discrimination strategies.

TISS GETS THUMBS UP

Callers have given the NSW Hepatitis C Telephone Information and Support Service (TISS) an overwhelming thumbs up in an evaluation that took place earlier this year.

96% of callers were very happy with the service and would feel comfortable calling again. The majority felt both their information and support needs were satisfied.

"The evaluation indicated that the service has a positive impact in a range of areas. Callers felt that the areas of greatest improvement were access to information, decision making, and attitude to self. Other aspects related to lifestyle and self management", manager of TISS, Helen Mann said.

"We will continue structuring the service to increase the telephone worker's skills in supporting callers in these areas, as well as continuing to offer relevant, comprehensive information".

Hunter support group

A new support group has started in the Hunter region, providing support to people affected by HCV. The group is facilitated by the John Hunter Hospital's HCV/HIV Social Worker.

If you are a person affected by HCV or a healthcare service provider and want more information, please phone Mark on 02 4921 4763. You'll be able to discuss whether the group may be of benefit to you.



HUNTER
HCV
SUPPORT GROUP

The NHMRC Report

The National Hepatitis C Action Plan was developed in October 1994. It recommended a series of major initiatives to be undertaken, one of which was for the National Health & Medical Research Council (NHMRC) to develop guidelines on detection and management of HCV.

These guidelines are contained in the recently released report, *A strategy for the detection and management of HCV in Australia*, which provides an updated commentary on issues such as the transmission of HCV, and makes recommendations on: protocols for laboratory testing, including polymerase chain reaction tests (PCR) and ribonucleic (RNA) tests; public health screening; clinical indications for testing; treatment protocols and options; and guidelines for general practitioners.

Considering the urgent need for guidelines for the management of people affected by HCV, the NHMRC sought the most up-to-date and accurate information to provide to healthcare workers, carers and people affected by HCV (knowledge and understanding about HCV is developing rapidly, and this should be borne in mind by readers of this document).

In preparing the report, the NHMRC addressed several contentious issues, particularly the availability of interferon - the only specific treatment for use in Australia for chronic hepatitis C. The long-term benefits and side effects of interferon for the treatment of hepatitis C have yet to be established and the short-term side effects can be significant for some patients. The efficacy of interferon is still being assessed through the National Interferon Data Base which began in October 1994. Nevertheless the NHMRC acknowledges the restrictions on access to current treatment and, on the basis of scientific evidence, has recommended that the criteria for interferon treatment under section 100 of the National Health Act 1953, be revised and broadened.

The guidelines in this report should lead to more effective pre- and post-test counselling and appropriate referrals to specialist services.

- The Recommended Retail Price (RRP) is \$17.95 and it is available from Australian Government Bookshops. For more information, phone 13 2447 or fax 02 9262 1219. //

Antibodies & Antibody tests?

What are antibodies?

Apart from skin, our antibodies are our main form of defence. They are a form of protein that we produce in response to anything foreign that gets into our bloodstream - things like viruses, bacteria, or vaccines.

Antibodies are pretty well limited to the *humeral spaces* - an almost medieval term for our body fluids which are outside the cells of our body. These include blood, milk & other body fluids.

What do antibodies do?

Basically they stick to things. This alone can disrupt many functions of a virus. The processes involved in a virus entering one of our body cells can be pretty delicate.

Having big globs of protein (antibody) hanging off a virus can be enough to block this fine-tuned procedure.

This is particularly true if there are a lot of antibodies around - and if they recognise different parts of a virus. That way, you can get lots of antibodies covering the surface of the virus, which can pretty effectively prevent it from doing anything.

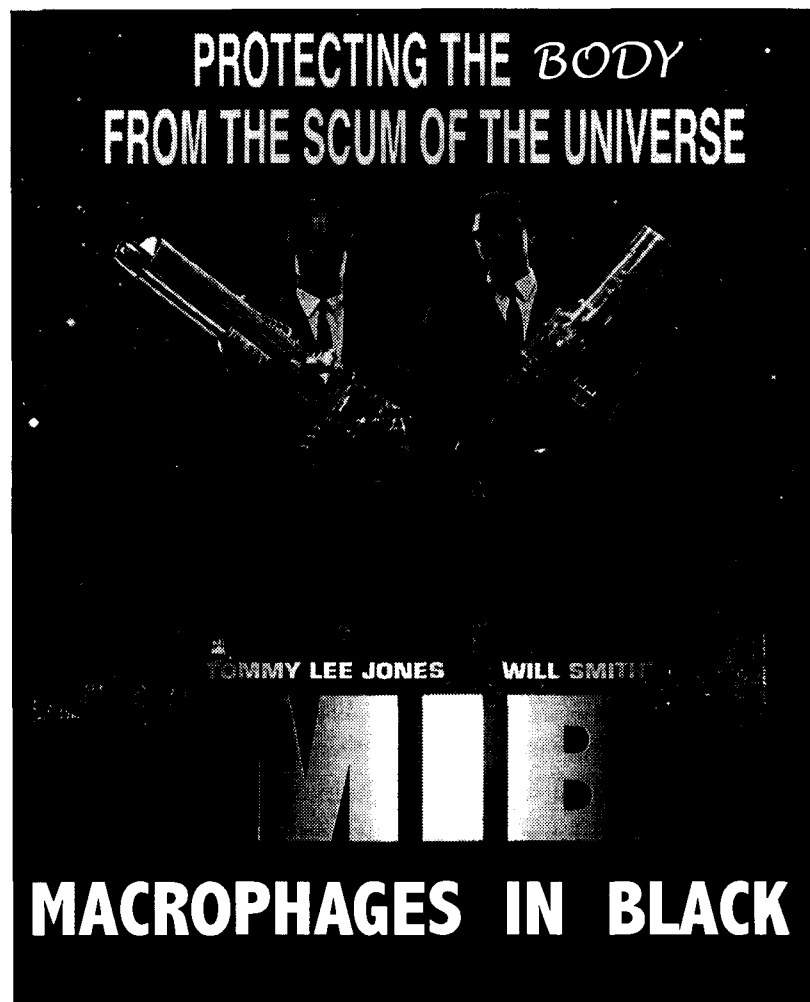
As well as this rather passive function, some antibodies trigger a series of events which result in inflammation of the local area, making it generally inhospitable to bacteria and viruses.

Are antibodies killer cells?

No, but cruising around in our bloodstream, are 'killer' cells called *macrophages*. When they bump into anything, they need some kind of signal to show whether they should engulf and destroy the thing - or whether it's a part of our own body. When anything has antibodies stuck to it, the killer cells take it as a signal that it is something to be destroyed.

Why don't macrophages destroy HCV?

HCV is a master of disguise. As it reproduces, it often changes its appearance ever so slightly. It's a process called *mutating* and means the virus



confuses our antibodies and macrophages, remaining one step ahead of them. Although we quickly eradicate lots of hepatitis C viruses once they're identified, there are always others who've mutated and disguised themselves.

How do the antibody tests work?

Antibody tests are used to see if someone has HCV. they are also used by blood banks to screen donated blood.

The tests look for different 'parts' of HCV antibody in a sample of our blood. The early tests just looked for a couple of parts and sometimes got it wrong. The latest tests look for many different parts of the virus and are much more reliable.

If the test comes back positive, it means that HCV antibodies were found - proof that the virus must have entered our body at some point in time.

If people are able to clear the virus, they still keep their antibodies for some time. A positive antibody test doesn't always mean someone has the virus, although in most cases the person does have it. Until better tests are more widely available, people who are HCV antibody positive should assume they have an ongoing infection and that their blood is potentially infectious.

- Many thanks to Columbia TriStar Films for use of their *Men In Black* graphic. //

A mind/body issue

This article, abridged from the newsletter, *Positive Living*, originally focused on HIV/AIDS but provides useful information about living with chronic illness.

A special program developed at Beth Israel Deaconess Medical Centre, Harvard Medical School, Boston, USA, proposes that there is a link between stress and anxiety reduction, and better health.

The Mind-Body Clinic deals with the unique complexities of HIV disease, factors associated with maintaining good health and compliance with treatment - as well as the overwhelming need to maintain hope.

We teach a combination of relaxation techniques, positive thinking, yoga exercise, nutrition, and training in communication skills that enable people to continue to lead meaningful lives.

Mind/Body Connections

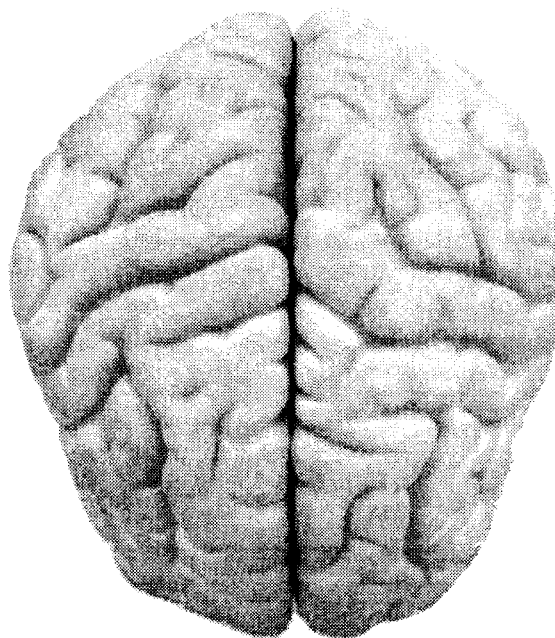
Initially, we present a mind/body model, meaning that health is considered to be the result of interactions between physical symptoms, attitudes, and behaviours.

Participants are taught to recognise the physical, emotional, thinking, behavioural and spiritual warning signs of stress.

Characteristics of Long-Term Survivors

Research has investigated how the mind and emotions impact on health and have identified these characteristics among long-term survivors of HIV:

- They are realistic, accepting their diagnosis but not taking it as a death sentence.
- They have a fighting spirit and refuse to be helpless/hopeless.
- They have changed lifestyles.
- They are assertive and have the ability to get out of stressful and unproductive situations.
- They are tuned in to their own psychological and physical needs, and they take care of them.
- They are able to talk openly about their illness.
- They have a sense of personal responsibility for their health, and they look at the treating physician as a collaborator.
- They are altruistically involved with other persons with HIV.



The Relaxation Response

The program teaches various techniques that produce the Relaxation Response (RR), a psychological state of deep rest that is the opposite of a stress response. Several techniques such as meditation, progressive muscle relaxation, and visualisation are described. Participants practise a relaxation technique at each session. They are provided with an audio tape and are expected to listen to it daily. With practice, participants' physical and emotional symptoms improve, we see decreased anxiety headaches, neuropathy pain, and nausea, for example, and improved sleep and appetite.

Relaxation Response

Techniques

Sit in a comfortable place but try not to lie down. If you lie down on your bed, chances are you will fall asleep. You may sit in a chair, on the floor with a cushion against the wall, or on the bed with a pillow behind you. If you must lie down, then the floor is recommended.

It is much easier to elicit the Relaxation Response (RR) in the same place each day. Try reserving that place for your relaxation; you will find that you will start to relax simply by sitting there. Make sure that the phone is unplugged, the door is closed, and your pets are absent (pets are strangely attracted to a relaxed person!).

It is also easier to elicit the RR, at the same time(s) each day. This helps make it a habit.

If you are eliciting the RR on your own (ie, not using a relaxation tape), do not set a timer. Sit opposite a clock and when you think that the time is up, slowly get up. If the time is not up, simply close your eyes and go back to what you were focusing on.

If you regularly exercise, try eliciting the RR immediately after you exercise; the sense of deep relaxation should come more easily.

Try not to elicit the RR when you are very hungry or when you are full. Try having a glass of juice or a piece of fruit if you are hungry before sitting down. Wait a couple of hours after a full meal.

We generally advise eliciting the RR twice a day for 20 minutes each session. If you simply cannot fit in a session, try focusing on your breath for even five minutes. The only bad RR is one not done.

Mini Relaxation Exercises

Mini relaxation exercises are focused breathing techniques which help reduce anxiety and tension immediately!

You can do them with your eyes open or closed. You can do them any time, no one will know that you are doing them.

Ways to do a mini

Switch over to diaphragmatic breathing; if you are having trouble, try breathing in through your nose and out through your mouth, or take a deep breath. You should feel your stomach rising about an inch as you breathe in, and falling about an inch as you breathe out. If this is still difficult for you, lie on your back or on your stomach; you will be more aware of your breathing pattern. Remember, it is impossible to breathe diaphragmatically if you are holding your stomach in! Relax your stomach muscles.

Mini Version 1

Count very slowly to yourself from ten down to zero, one number for each breath. Thus, with the first diaphragmatic breath, you say "ten" to yourself, with the next breath, you say "nine", etc. If you start feeling light-headed or dizzy, slow down the counting. When you get to "zero", see how you are feeling. If you are feeling better, great! If not, try doing it again.

Good times to do a mini ...

While being stuck in traffic ... when put on "hold" during an important phone call ... while waiting in your doctor's waiting room ... when someone says something which bothers you ... at all red lights ... when waiting for a phone call ... in the dentist's chair ... when you feel overwhelmed by what you need to accomplish in the near future ... while standing in line ... when in pain ... etc.

The only time that mini's do not work is when you forget to do them!!! So go do a mini ...

Creating Passion in Your Life

Because a diagnosis of serious illness can lead to a serious reappraisal of one's life and of what gives it meaning, coping well requires looking at one's goals and commitments, then setting clear priorities and pursuing

feature

them. This keeps you focused on the future and helps you develop resistance to the stressors associated with your illness. We guide participants through an experimental exercise in clarifying commitments and creating passion in their lives. We ask people to focus on eight areas of their lives, and ask themselves what they want in each category.

Creating Passion in Your Life

Career/Education; Relationships; Creative Things; Play; Health; Material Objects; Spirituality.

Close your eyes and just focus on these categories - and let things come into your mind without critical judgement or editing. When you feel you have received enough information about your goals, plans and dreams, open your eyes and commit them to paper, taking your time to enjoy this process.

Yoga Exercise

Body awareness and stretching exercises are important tools for influencing health and well-being. Many people with HIV disease experience loss of energy and fatigue; for them, simple yoga exercises provide a safe and easy way to stretch the muscles and maintain flexibility. Several yoga exercises practised in the program increase lung capacity, massage gastrointestinal organs, and reduce pain by releasing tension.

How Thoughts Can Affect Your Health

Behavioural Medicine recognises the interaction between mind and body and the fact that stress affects us physically, emotionally, cognitively, and in terms of our behaviours.

Our thoughts, beliefs and attitudes about a stressful situation affect us in many ways.

In the program, we teach cognitive restructuring, a technique that enables you to see that your stress does not always come from an outside event or situation - it may have very much to do with how you perceive or think about the situation. While people may be unable to alter the stressful event, they can change how they feel about that stress, and their thoughts and attitudes about it.

We learn to recognise our negative thoughts and how they can become distorted or illogical. We can then challenge those negative thoughts and replace them with more positive statements. For more information on this technique, refer to *The Wellness Book*, Chapter 11 (Simon & Schuster, 1992).

- Abridged from an HIV/AIDS focused article in the magazine, *Positive Living*.

Full article available at <http://www.thebody.com/mb/mindbody.html>



HCV - from the very beginning

I was 28 when I was diagnosed with HCV and HBV and had injected drugs off and on for ten years - though I'd rarely been a sharer of needles.

I had been sick the previous twelve months with constant lethargy, stomach and bowel dysfunction, flues and a protracted chest infection, recurring cystitis and depression, ear infection, sore eyes and occasional severe abdominal pains.

Until my diagnosis I'd assumed my ailments were the result of heavy drinking and had been trying to cut down. I remember laughing incredulously when given the results, partly out of relief it wasn't HIV, partly because I didn't know much about hep C.

The physician at the medical centre didn't either. She just looked terrified and I couldn't work out what the drama was about.

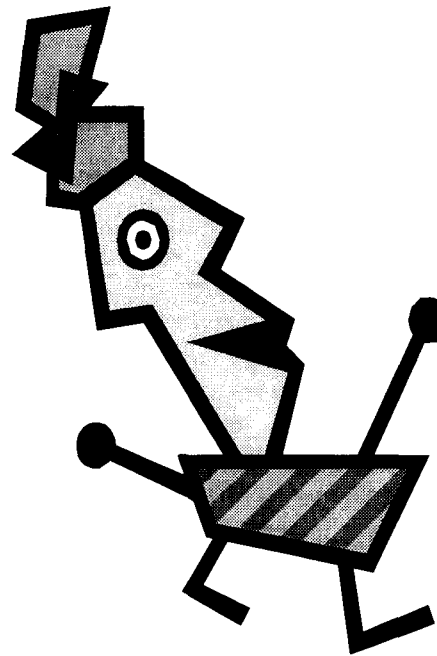
I was sent on a round of doctors and specialists. They all told me I was infectious and that HCV was sexually transmittable. I had shared needles once by accident a year before with an HCV+ friend and assumed this is when I caught it.

I dutifully got on the phone to everyone I'd had sex with in that year and told them that I'd possibly given them a life threatening virus, a virus that could never be eradicated from the body.

Pretty embarrassing. My current lover didn't care though - our experience belied sexual transmission as she was negative. Not only had we had a lot of unsafe sex, sometimes involving blood, her previous lover of over a year had been HCV positive too. I remain completely unconvinced the virus is sexually transmittable.

Unable to get any information from doctors, I educated myself - any literature I could get my hands on. I also talked to friends, many of whom were being diagnosed at that time as well.

I had moments of feeling devastated; that my life would never be the same again but the immediate effect of diagnosis was positive in that it made me get serious about my health, alcohol and drug use.



HCV has changed my life. It has made me very conscious of my own life forces, mortality and health. Everything now revolves around my liver. My Chinese medicine is liver focussed which probably explains its success.

I hope my story will persuade the government to fund more Chinese herbal trials.

I rarely drink and the thought of getting drunk makes me feel sick. I continue to use heroin and other drugs recreationally but never take them for granted. I have also noticed consistent pot smoking can fatigue me so I do relatively little of that too. I can't stress enough the importance of good food, herbal teas, filtered water.

A good diet was easy as I was brought up on excellent food, am a good cook and I know a lot about food and its nutrients. Giving up alcohol and coffee was a total nightmare, but I did it.

From the very beginning doctors I saw were hopeless. Most considered me just another infected 'junkie'. I had a routine check of a congenital heart defect and remember the cardiologist doing the routine "flirt" then backing away when learning I was positive, telling me with disgust how skinny I was.

But at that time my HIV+ friends were dying or encountering far more ominous ignorance and disgust, so it all seemed par for the course - and mild in comparison.

I've always been completely out about having HCV. If people have been freaked out I've calmly explained things to them they didn't previously know. If people are disgusted I don't hang around. I'm really appalled and saddened by some of the stories of stigmatisation I still come across in the *Hep C Review*. I guess being in a mostly urban gay & lesbian environment means most of the people I associate with are pretty savvy about viruses and all things generally considered shocking by the conservative mainstream.

Good luck and regards, Fiona

///

When there's no other way

BLEACHING FITS

- a user's safety guide

The original 2x2x2 bleach message was developed in response to HIV. It was originally thought that it would also be effective for HCV as well.

Only after several years, have we discovered that although 2x2x2 bleach cleaning works well against HIV and hep B virus, its effectiveness against HCV is unknown.

It is difficult to test this as HCV can't yet be grown in a

laboratory and researched properly.

In terms of HCV, **nothing is guaranteed except for using new equipment for every hit**, and avoiding the transfer of blood from one person to another. This means not sharing anything - swabs, water, filters, spoons, cups, tourniquets, bench tops or any other equipment used for injecting. It also means washing your hands before and after preparing and hitting up.

1. **Always rinse your fits (syringes) by flushing them with FRESH cold water as soon as you've used them - whether you think you'll use them again or not.**

This will:

- get rid of blood before it clots making it easier to clean later if you have to
- remove traces of illegal drugs
- reduce the risk to others in the case of needle stick injuries

2. **If you don't have a new fit, use one that you and only you have used before. You should clean it before you reuse it. Ideally, you'll have rinsed it after you previously used it (see above).**

3. **If you must use a fit that anyone else has used (this includes partners, and friends), attempt to disinfect it:**

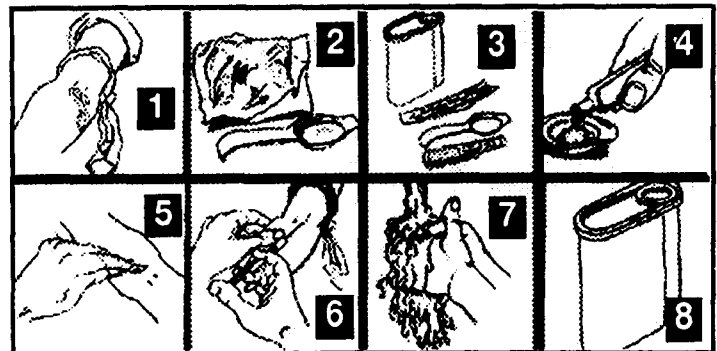
- a. Rinse the fit in fresh cold water.
- b. Take the rinsed fit apart.
- c. Soak it in bleach for at least 2 minutes. Make sure all parts of the fit are covered in bleach. Your bleach must be full strength (5.25% hydrochloride) and not be past its use-by-date. Some of the cheaper brands aren't strong enough and sometimes bottles of bleach can remain on supermarket shelves or in your cupboard past the use-by date. This makes them less effective.
- d. Rinse thoroughly by flushing with fresh cold water at least twice.

4. **If you can't soak the fit:**

- a. Flush the fit out at least twice in cold water (the more times, the better). Make sure you get rid of any visible blood before bleaching.
- b. Fill the fit with with full strength bleach and shake it for at least 30 seconds (the longer you shake after 30 seconds, the better). Do this at least twice, remembering to shake the fit with bleach for at least 30 seconds each time.
- c. Flush the fit out at least twice using a separate cup of fresh cold water. Don't use one you may have used in any previous steps as it will already be contaminated.

SAFETY TIPS

- 1 *Look for blood on tourniquets, clothes & benches*
- 2 *Use sterile cotton wool to filter drugs*
- 3 *Always use new injecting equipment, never share or re-use*
- 4 *Use sterile water for mixing up*
- 5 *Swab injection site before injecting with sterile swab - use sterile cotton wool to cover injection site after withdrawing the fit.*
- 6 *Wash hands before & after injecting others*
- 7 *Wash hands before & after injecting yourself*
- 8 *Dispose equipment in a puncture proof sealed container*



Article abridged with thanks from NAAA News, Spring Edition 1997

My hep C

I suffer from haemophilia and have contracted hepatitis C through transferred blood products over a period of years.

My working life is impacted as the effects of HCV prevent me from working full time. Some of the symptoms I feel are acute tiredness from time to time but I'm unable to know when this will occur.

Being a small business owner, when I feel tired I am sometimes able to have the occasional afternoon sleep.

Other symptoms are lack of concentration which has affected me greatly.

My symptoms come and go and I can't plan ahead as I don't know how I'll feel. My relationship has changed with my family from the time I was diagnosed.

We are fearful that my children and grandchildren may be infected. Overnight stays for my grandchildren place us all on alert so that the kids don't share my toothbrush, etc.

My leisure life is practically zero. If I participate in any activity like lawn mowing, gardening or kicking a ball around, I get very tired.

Healthcare workers can and do treat one like a leper, even when they should be using universal infection control procedures, and most have a lack of knowledge about hep C.

I believe there is a lack of adequate prevention, education and treatment services - and living in the country is even worse. The powers that be forget all about us.

Yours faithfully LB

by Joey

Ever The Optimist

Yes, today I'm feeling great, despite
The news that I'll get no respite
From this nagging pain beneath my rib,
That greets me as I leave my crib,
I've slept all night, I can't deny,
So why am I feeling like I could die
from lack of sleep, and this feeling sick,
How the hell will I eat my weet-bix?
But I'll push them down, at least I'll try,
And hopefully they'll get me by
Till lunchtime, when,
I'll try to eat some food again!
So every day is not so bad
I haven't the time for feeling sad.
There's other things that need to be done
For I am not the only one,
That makes my little family tick,
I just wish I didn't feel so sick.
And still I know that every time,
I hear the news on Channel Nine,
'Look, we've found a cure for some obscure
disease!!'
'SENSATIONAL,' I shout, thinking 'next
time .. HEP C'

annual report 1996 / 97

This snapshot gives an overview of our work in the financial year from July 1996 to June 1997.

It is an abridged version of our full Annual Report. For a copy of the Annual Report or Financial Statements as at 30 June 1997, please telephone the Hepatitis C Council of NSW office on 02 9332 1853.

- 3,069 calls were received by the NSW Hepatitis C Telephone Information and Support Service (TISS) - an increase of 30% over the previous year's 2,358. In the year we ran 3 intensive starter training courses and 3 in-service courses for our TISS volunteers.
- NSW Health endorsed and distributed 65,000 copies of our booklet *Hepatitis C: what you need to know* to medical practitioners and other health professionals in NSW and other states. The booklet was adopted by hepatitis C councils in all other states and territories, by NT and ACT health departments, and by some IDU groups.
- 4,600 information packs were distributed (4,500 in 1995/96). These comprise an information brochure, booklet and membership information as well as the latest edition of *The Hep C Review*.
- 65,000 copies of the brochure *Hepatitis C: a brief introduction* were distributed by the Council (113,000 in 1995/96).
- 16,000 copies of our quarterly newsletter *The Hep C Review* were distributed to members, callers, health and welfare professionals and key agencies and politicians.
- Two support groups were established and run by volunteer psychologists: an ongoing therapeutic support group in Sydney and a group for prisoners in the NSW Dept of Corrective Services.
- At 30 June 1997, 1,300 individuals and organisations were members of the Council, with a further 1,000 key contacts on our mailing list. Extensive networking enabled us to continue to use professional and peer support from other services and key individuals.
- Around 300 internet visits a month to our site at http://www.span.com.au/hepatitis_c/info/html
- 22 education and in-service training sessions for mainly health professionals, but also welfare workers, skin penetration practitioners and employers, reaching 580 participants in all.

fig 1. Common topics discussed by TISS callers
(no. of calls)

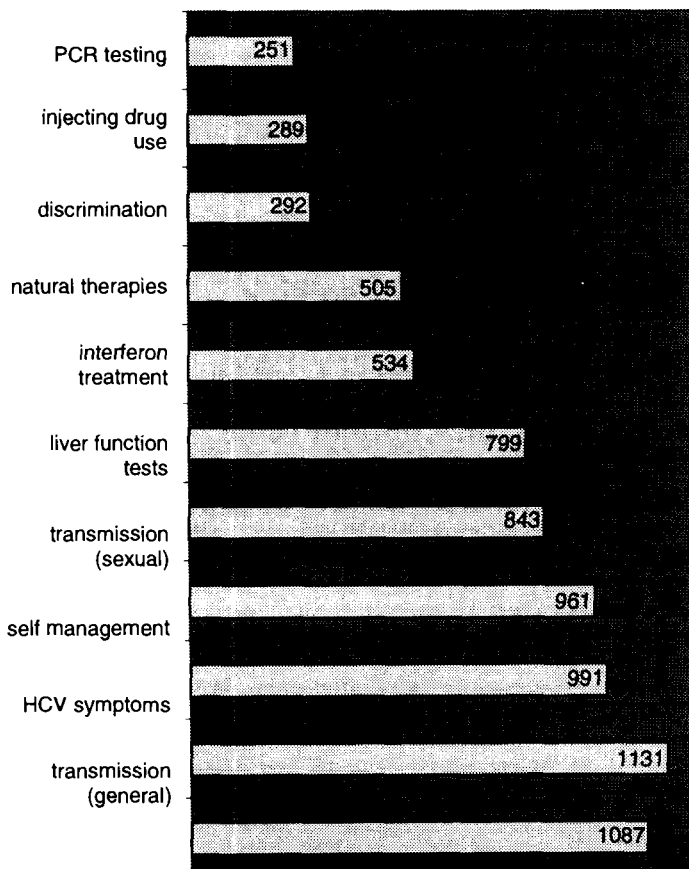


fig 2. Geo area of TISS callers
(no. of calls)

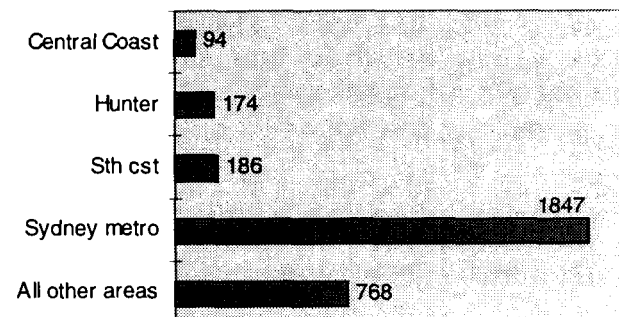
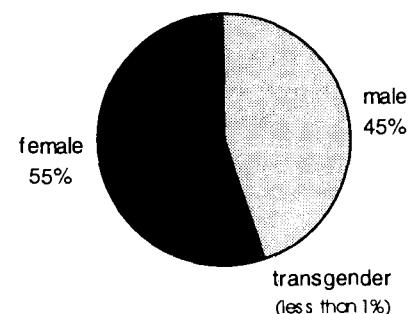


fig 3. Gender of HCV+ TISS callers



Ongoing community representation on 19 separate steering and planning committees, and 27 one-off meetings and consultation events where we represented the communities affected by hepatitis C in meetings with NSW and Federal health departments, general practitioners other health workers and pharmaceutical companies.

- We made 7 submissions on a range of topics, detailing the community view on matters such as HCV detection, management and prevention, NSW and national policy and projects, welfare benefits, anti-discrimination in health services and in employment policy and practice.
- We attended 10 and presented at 5 conferences, seminars and public meetings, ensuring our information is as accurate, up to date and as widely spread as possible.

22 media contacts often led to greater public awareness, education and advocacy for the rights and needs of people affected by HCV.

- Unfortunately, funding difficulties forced the Hunter Branch of the Council to close in October 1996, after almost 2 years' hard work by the team of local volunteers. Our sincere thanks go to them.
- Total income of \$220,800 was set off by expenditure of \$242,200, leaving a deficit of \$21,400. We planned this outcome in order to spend previous years' surpluses brought forward, and it enabled most staff to continue working full time.
- Staff costs for our four full time equivalent salary posts accounted for 63% of total expenditure, while office overheads were kept to a low 14%.
- Our primary funder, NSW Health, increased our annual grant to \$178,000 (\$148,000 in 1995/96), and membership fee income increased by 87% to almost \$19,700. Overall, our income increased by 25% over the previous period. Our thanks to all our funders, especially those individual and corporate donors who contributed to our work.
- Our sincere thanks go to our team of 56 volunteers, both those who staff the TISS lines and those who tirelessly carry out administrative tasks, our Medical Advisory Panel, our Management Committee members and our team of 5 (4 full-time equivalent posts) dedicated and hard working staff.



fig 4. Geo area of Council members

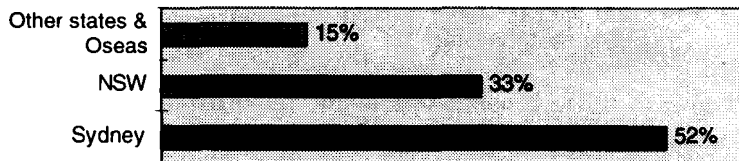


fig 5. Financial income 96/97

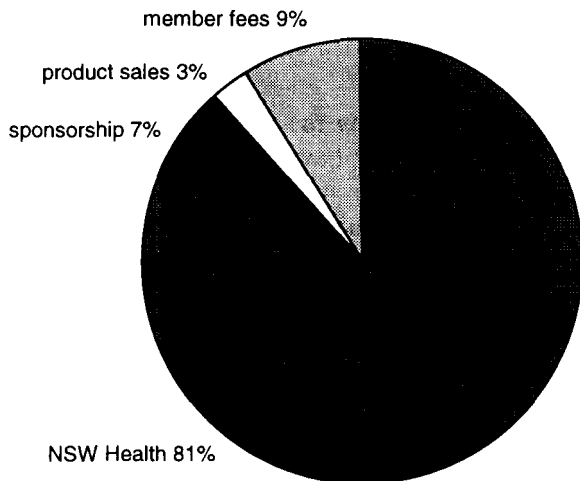
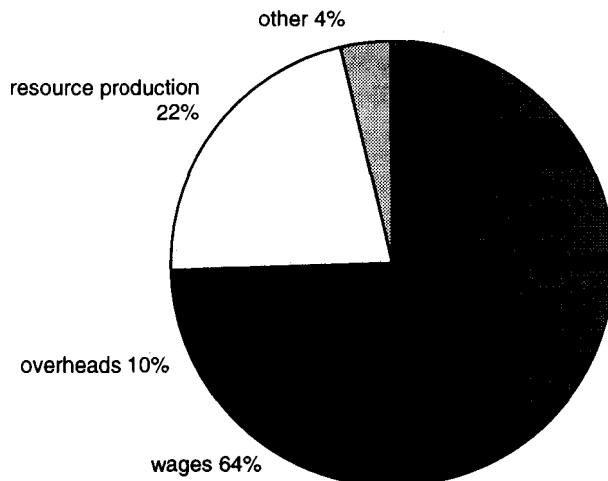


fig 6. Financial expenditure 96/97



Diagnosis - a doctor's view

By Alex Wodak

Most newly diagnosed patients with HCV know very little about their condition. When I encounter such a patient, I try to cover four main areas:

- 1 What can the virus do to health?
- 2 How can damage from HCV be reduced?
- 3 How can the risk of infecting others be reduced?
- 4 What support is available?

What can HCV do to health?

I always try to explain the difficulties in explaining HCV's possible health complications. Most current knowledge has been acquired in less than a decade and during that time, testing for HCV has improved. Shifting the goal posts has made our knowledge base a little confused. So I always emphasise to my patients that they may get a different story from different doctors and they may get a different story from me in twelve months time.

I always try to emphasise that the majority of patients will have a normal life expectancy with normal quality. The commonest symptom undoubtedly is severe fatigue. The most common serious complication is cirrhosis. I usually spend some time trying to explain what cirrhosis means. I then discuss the complications of cirrhosis and give some statistical estimates of the risks of developing some of these complications. Usually by this stage, most patients will have asked many, many questions. It is most important that doctors try to answer these questions.

How can health damage from HCV be reduced?

I try to stress the importance of reducing alcohol consumption as this is something almost everyone can do. I also emphasise the fact that although we know that less is better, we do not

know that total abstinence is essential. I then usually discuss the advantages and disadvantages of interferon emphasising how difficult I would find making the decision if I had to.

These days, I also talk about the possibility of better treatments emerging within a few years. I also discuss, if there is time, the fact that alternative treatments exist, that little information exists about their effectiveness and that some treatments can have side effects.

How can the risk of infecting others be reduced ?

In my experience, all patients are very keen to learn how to protect those near and dear to them. I explain how HCV is spread by blood to blood contact. I then go on to explain how important it is to avoid sharing of needles and syringes, razor blades, toothbrushes, or any other blood containing implements. I also do try to put the low risk of sexual transmission into some kind of context.

What support is available?

I try to assess how the person is reacting to their diagnosis. This may lead to a follow-up appointment or avenues of gaining further help. All of my patients get written information and a very vigorous recommendation to join the Hepatitis C Council. Where appropriate, I refer some patients to other health or welfare organisations.

All of this is done from a liver clinic. In my opinion, these matters should all be discussed by general practitioners who generally know their patients much better than any consultant could ever hope to do in a hospital clinic.

Based on this experience, I am very pleased to be working with a number of colleagues to try and develop a process where patients are given much of this information at their first attendance at a general practitioner so that the liver clinics can do the job they are really meant to.

It is never an easy job striking the right balance with somebody who has just learnt that they have a potentially life threatening illness. Somehow, the doctor has to try and explain that most patients with hepatitis C will live a normal life although some will slowly develop quite serious health complications and some might even die from their condition.

- Dr Alex Wodak is Director of Alcohol & Drug Services at St Vincents Hospital, Sydney; Director of the NSW Alcohol & Drug Information Service (ADIS); and honorary senior lecturer in community medicine at the University of NSW. //

Test counselling

When requesting an HCV test or receiving the results of one, your GP should brief you on hepatitis C and explain how the test works. Your GP should also explore how you'd respond to the result - whether it comes back positive or negative.

Delivering bad news can be a delicate situation. Pre- and post-test counselling makes really good sense, and should always be carried out.



Pre-test counselling should be tailored to each person and must be conducted in private, in an understandable level of language. It should not be rushed.

Pre-test counselling aims to assess whether the person is, or was ever at risk of contracting HCV;

explain any possible clinical signs and symptoms which may have led the GP to suspect HCV;

provide information on testing benefits;

provide information about the test and possible consequences of a negative or positive result;

provide information about testing, including notification and confidentiality of results;

ensure the person can make the best possible decision about whether to have the test or not (informed consent); and

identify possible avenues of support for the person should they have the test and it comes back positive.

Information that should be discussed in pre-test counselling includes:

- brief information about the virus and its history;
- routes of transmission of HCV and strategies to prevent transmission;
- the antibody test and its limitations;
- the meaning of a positive, negative or equivocal test result;
- explanation of the range of outcomes of HCV infection - including advice that in many cases, HCV infection does not have a serious outcome and that if the test is positive, monitoring may be the only action that is required;
- explanation of treatment with interferon, including access through Section 100 PBS;
- explanation of other treatment options and trials, including Chinese herbal preparations;
- discussion on the social impact of having HCV, including the impact that different cultural beliefs and practices may have;
- implications of a positive test result for life assurance;
- discussion on confidentiality, in particular a clear and full explanation of the legal requirements for disclosing HCV status; and
- an assessment by the GP on how the person may react to the knowledge of his/her HCV status.

A written summary of the above information should be provided to the patient, preferably in their native language.

Arrangement for a post-test appointment should be made during pre-test counselling.

Post-test counselling (giving test results)

The result of an HCV test should always be given to the patient in person no matter what the reason for the test or whether the result is negative or positive.

Post-test counselling enables the GP to follow up and ensure that the person understood their pre-test counselling.

If the person's test comes back positive, the GP should again explain the meaning and implications of the test results. The GP has the responsibility to provide or arrange for immediate counselling and support. Sufficient time in the consultation should be allowed for this process.

If the test comes back negative, the GP should provide counselling and information that helps enable the person to remain HCV negative.

- **Abridged from the NHMRC report "A Strategy for the detection and management of hepatitis C in Australia" - see page 12. //**

Help beat it

I was diagnosed hep C positive 4 years ago. I experimented with IV drugs a couple of times nearly 25 years ago, like many of my generation in the 60s and early 70s. Drugs didn't change my life I'm pleased to say, but hep C has. There's the possibility that I'll die prematurely in the next few years.

It's never been completely clear how I contracted the virus. Perhaps it was the couple of times in my youth when I innocently shared needles; perhaps it was from non-sterile minor surgery ... who knows! Anyhow, it's not really important how.

I haven't used IV drugs in 25 years, but I have an overwhelming empathy for the poor individuals who remain addicted to heroin and the equally unfortunate people on methadone programs around the country, the majority of whom are HCV positive.

I abhor the attitude taken by the Federal Government on proposed heroin trials and dread their head in the sand approach. We will all pay dearly for Howard's feeble response - an attitude indicative of ... *junkies just don't count.*

It'd be a sure bet that if North Shore matrons were in danger of contracting a similar disease by their dependence on prescription pills, we would have a very different reaction from the powers that be.

I've been a lecturer in tertiary education, a professional playwright and a freelance actor in theatre, film and television. I'm a grandfather; a devoted father of three adult children. I don't think I'm particularly different. I just happen to have HCV.

Lets all help beat it. PS //

Country Blues

I live in North West NSW.

In 1994, I got to move into a good housing commission place and met a nice guy. We got on really great but those days were when I first noticed getting tired. I knew then that something was not quite right. I used to cry about how tired I was becoming and at the end of 1994, I became pregnant with my 3rd child.

I then watched the shorts for Jana Wendt's *Witness* that talked about a killer virus that was sweeping the country and after 10 years people would be dead.

I could not believe that I was hearing them talk about tiredness. The next day I was tested for HCV.

After what seemed like ages, I was sitting with a friend at home when I got a phone call - it was the surgery letting me know that there was an abnormal blood test and could I 'come in' to discuss it.

Only people who've been through it would understand the shock wave that went through my body.

Back then when I was diagnosed, I used to get the most horrible pains that would run through my liver. I thought I had already developed cirrhosis. The first six months were sheer hell. I sure put my children and boyfriend through the wringer. I was a mess.

I got most of my support through the phone. I'd phoned the Hep C Council and got to speak to a couple of people in Tamworth. Margaret and Raisa were just lifesavers. If I didn't have their support, and the Council, I'm sure I wouldn't have survived.

My boyfriend was tested. He is negative. He didn't know what to think. We didn't have sex for a long time. But everything is fine now. I'm so grateful he didn't catch it.

So I have had the virus for five years. I've now been on interferon for three months and my ALTs have come down to the mid-twenties (they were up to 200 at one stage).

Thank you Margaret and Raisa for being there and helping me through the most difficult time of my whole life. And thanks for keeping it under your hat!

With love, Name Withheld //

HCV & the Steel City

An interview with Chris Lawrence, HCV project worker at Illawarra HIV Prevention Service.

What's your involvement at the service, Chris?

The service is a needle exchange service primarily aimed at preventing bloodborne illnesses such as HIV or HCV.

I have a short three month post to help guide an HCV strategic planning exercise. We'll soon be circulating a needs assessment that builds on a similar survey carried out in 1995/96. Following that we'll be holding an HCV planning workshop.

Ultimately, we're trying to prevent further transmission and to improve information, treatment and support services for people already affected. We want to develop a detailed strategic plan that guides the Illawarra response to HCV. One that addresses needs and fills gaps.

What brought you to this post?

I moved down from Sydney to the Illawarra about three years ago and over that time I've been studying towards a Degree in Welfare Studies at the University of Western Sydney.

Through my study I've been involved in work at the HIV Prevention Service in Wollongong. My current position is a result of this work.

I also have a lot of passion for working with HCV. I've been a member of the Council for ages and even attended a few management committee meetings.

How will the planning workshop work?

Like in other Area Health Services, we'll be inviting a range of people - healthcare professionals, health planners and bureaucrats, people affected and representatives from relevant services.

We will spend time overviewing HCV in the Illawarra, identifying gaps in healthcare services and determining the best strategies to address those gaps.



Want to find out more? Give Chris a call.

You mentioned a previous survey. Were there any interesting findings?

Well, quite a few healthcare providers wanted more information about the range of services they could call on for assistance, or refer people to for additional services.

And many existing services didn't feel they were geared up to handle the expected demands.

Many people with HCV cried out for additional services - medical/clinical, information, counselling and emotional support.

Given these comments, I guess you have some challenges ahead?

You're not wrong. The challenges are enormous. But it's exciting that we're moving in this direction. I've got good support from my colleagues here at the HIV Prevention Service, and from the Area Health Service.

With so many people working together, drawing on professional, and in some cases, personal experience, we hope to meet those challenges.

How can others get involved, Chris?

We are keen to have as many individual people or services as possible involved in the whole process. For more information, people can contact me on (ph) 02 4228 8211. //

The call

Our real life transplant story, continued from edition 18. After months of waiting, following a late night phone call, Sharon has been rushed to her liver transplant centre. She arrives and enters a world of uncertainty, trepidation and hope ...

I was shown to a room and given a gown. It was now almost 4am. The troops waited outside as I undressed. Then I was told to take a shower and scrub from chest to feet. So, I got to take a shower much sooner than I thought.

By 5am, my friends Dede, John, Breezy and Larry had motored to San Francisco. We had quite a crowd in the halls of the sixth floor, in the middle of the night. At 6am, my hepatologist, Dr Gish, came in with several other doctors. Dr Gish had been seeing me for years; we'd done the Interferon route in 1990. He'd kept me patched together with syrup, pills and powders for four years.

"You're going to be eating hamburgers and french fries soon," he stated.

"Why?" I asked, not understanding what he was referring to.

"The donor, he was sixteen."

Again, I was happy for myself. I knew at sixteen, it was probably a good organ. But, as a parent whose own son was killed by a drunk driver when he was eleven - I knew there was a family in the most horrible pain imaginable.

Dr Gish also explained that if they opened me up and found any cancer, the transplant would be aborted. I told him I understood.

An IV was put in my left arm and blood was taken. I was told the actual surgery would be around 10am. It wasn't until eleven that I was taken to the third floor. The surgical floor. The entire entourage of my husband, mother and friends accompanied me. Then we came to a set of double doors. I was kissed by all and we said a prayer. Then I was taken into a room that appeared more like a huge storage closet. The attendant put a green hat and booties on me. He told me the anaesthesiologist would be in to see me. They still had not given me any sedation.

I lay on the trolley in that room alone. Alone for the first time since getting the 'call.' A couple of posters were on the wall, one of mountains, another of water. I knew others had lain in this same room. At one point I thought, this is really stupid. What am I doing here? I could just get up and walk out. But the reality was I knew if I didn't get a new liver I would die. I also knew that I might die in surgery.

The anaesthesiologist came in. I don't remember his name and I wanted to because he was a very calming man. He explained the preparation for surgery. Then he rolled the gurney into the operating room. As we passed a large, very sturdy looking box, the doctor stated that it held the donor liver. I told him I thought they travelled in a cooler.

He said this was much thicker and less chance of the graft getting warm. An odd chill went through my body.

The operating room was very bright, very crowded and cold. It held an array of equipment and enough people for a large party. I got on the table and pieces of foam were placed under my arms and feet. At this time, I guess my nervousness came out. I started interviewing the staff. How long had they been doing transplants? Where did they train? Almost all of them had trained with Dr Starzi in Pittsburgh, PA.

Dr Starzi performed the first liver transplant. I remember saying something about hoping God was on their team.

Then an overwhelming calmness came over me. I felt completely at peace, and I still had not had any drugs. I then KNEW I was going to be okay.

The doctor started the drip and I counted backward, I think.

I woke up to the sound of my husband's voice, then I heard my daughter, Debbie. I couldn't comprehend how she could be here so fast. Debbie was saying something about covering me up, people were coming in. Later, I found out I was completely naked. Not exactly a sexy picture with multiple tubes, IVs, bandages, and machines connected to my body. I heard, rather than felt, the swish of something covering me.

A nurse was telling them I was okay. The surgery had gone very well. I didn't even have to have blood.

As I lay there, I couldn't move any part of my body, couldn't open my eyes, couldn't communicate with my family or friends. Dede kept saying how well my hair looked after twelve hours of surgery. I thought, "twelve hours, I was in surgery twelve hours!"

Sharon's story will be continued in edition 20, which will also feature an article on liver transplantation.

Please remember - more than 90% of people with HCV will never require a liver transplant. //

Living with Hepatitis C

By Richard English & Dr Graham Foster.

Reviewed by Robert Batey

This is the second book I have reviewed on Hepatitis C. Like the first book (The Hepatitis C Handbook), this one is written for the general population and it contains a considerable amount of very valuable and relevant information.

It is not a text book on hepatitis C but it is a resource for people who are concerned about this virus, the infection it causes and the effect that that infection may have on lifestyle in general. The book does omit important information relating to the exact relevance of viral infections, the effects of viruses on liver cell function and even on liver function itself. As a hepatologist, I am dismayed to read that the liver function can be reduced to that of filtering and storing. In fact, the liver carries out more than 1500 functions and it is thus not only the largest organ in the body but the most complex in terms of biochemical functions.

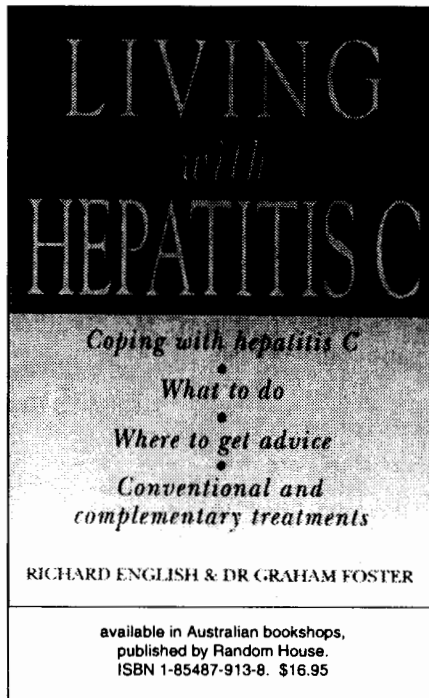
With all of that said, it is important to stress that this book is well written for the purpose for which it was designed. The authors' style is conversational, easy to read and the facts provided are correct and up to the minute.

The book is divided into 10 chapters which deal with all aspects of the complex issue of hepatitis C virus and the infection it causes. The authors deal with what is hepatitis C, how it is detected, how to stop

the virus from spreading, day-to-day coping, treatment issues and there are two chapters on complementary and traditional medicine approaches.

The book also deals with end stage liver disease and transplant, special cases which relate to issues such as prisoners, former intravenous drug users, current drug users, etc. and the final chapter has some personal stories of living with chronic hepatitis C.

The book is a useful resource but I would need to stress that the market can only cope with a couple of books of this type. The previous book was an excellent resource and whilst this book does have some different issues raised, it only contributes a little extra information about hepatitis C than the other book.



Personal preferences may dictate that this is the book that many choose and I would certainly recommend that any library and hepatitis C support group has a copy of this book available for informing their own staff and also for providing information to others.

I can recommend this book as a most useful one with the personal touch at the end being a most important one.

One does need to bear in mind, though, that hepatitis C is one of a multitude of severe diseases affecting the community and some of the comments relating to poor management can equally be applied to many other diseases. This applies pressure to the helping professions in getting their act together in understanding diseases and how they impact on individuals and on a community. It was a pleasure to review this book.

• Robert G Batey is Professor of Medicine at University of Newcastle, and director of the Dept of Gastroenterology at John Hunter Hospital, Newcastle. //

Snakes & ladders

In December 1990, age 62 yrs, I was bitten by a snake and during the course of the drama that followed, I received massive blood transfusions.

I returned home at the end of January 1991 and allowed myself another month to regain some strength before going back to see the kidney specialist who had watched over me in the early part of my hospitalisation. He was the one who first mentioned HCV, saying "you're sure to have it."

Having never heard of it before, but assuming it was something like the hepatitis I had known about for many years, imagine my shock to hear him explain it all. Things like liver damage, cirrhosis, liver cancer; long term progression; no treatment; regular blood tests; blood and saliva contact to be avoided; no alcohol; condoms, after 40 years of marriage!

I could see my whole way of life changing before my eyes. I thought that I would have to give up kissing people, including my grandchildren and husband, and just brush cheeks with them.

I was hungry for information on this demon I had acquired through no fault of my own, and my needs were supplied when I came into contact with the Hep C Support Group in Sydney - now the Hepatitis C Council of NSW.

I encountered a lot of ignorance about hep C at first, even amongst doctors, hospital staff, etc. Some doctors were quite blasé in their total disregard of infection guidelines. Friends and family just carried on as before - no discrimination or fear from them at all.

I have never hidden the fact that I have HCV. I tell anyone who is interested or who should be told - such as dentists, pathology employees, nurses, doctors, coach tour operators etc. because I could not live with myself if someone else picked up this scourge because of my negligence. And that's about my story so far.

With love to you all, SR



My story's not pretty

Twelve months I've known I have HCV. I have other medical problems (a particular bone disorder). I didn't think HCV was much of a problem because at the time, my back seemed to be my worst problem.

Recently, I've had a liver biopsy which has shown I've chronic, active hepatitis C. For the last 12 months, I've expected this but the news still hit me hard. It's like yes, you have a bad liver.

Time for a big change in my life. I've got to face the uphill again. I didn't think these hills could get any higher or rougher again. Again, I was wrong.

I thought I could ignore my problems. Maybe they would disappear. Maybe I could hide my woes behind alcohol and drugs again. Wrong, wrong and wrong again.

Don't know if good things go away but I know that bad things certainly don't.

My thoughts about HCV were "oh yes, just another disease they have come up with - I don't need to worry, things will sort themselves out."

I've been getting the *Hep C Review* booklets for nearly twelve months now. I've looked at these and they have given me some ideas and some answers.

I've not really sat down and read them through - I don't like reading much or writing but I hope my story helps others.

It don't matter how big or tough we think we are. There are things in life none of us can get through on our own.

Thanks, Stephen.



HCV - the first hundred days

By Pam Shipway

In 1994 the Transfusion Related AIDS & Infectious Diseases Service (TRAIDS) was given responsibility for providing counselling, support and referral to people in NSW found to be HCV positive after a blood transfusion. Most had recovered from the condition for which the transfusion was necessary. The diagnosis of another condition was an unexpected shock and one that caused great anxiety about the future.

A major difficulty for the newly diagnosed can be lack of information available on what to expect in regard to health, treatments and lifestyle. For some it provides an explanation for their vague feelings of being unwell, tiredness, mild nausea and an aversion to some foods previously enjoyed.

When diagnosed most have limited knowledge about HCV and may identify with their knowledge of hepatitis A, an illness which is time limited.

Pre test counselling allows information to be given to prepare for a positive result. However, many people receive the diagnosis without prior counselling. Counselling at time of test result and the availability of follow up are an important aspect of care.

Limited information is retained when faced with such a diagnosis. A follow up counselling appointment will allow clarification of what has been discussed and give an opportunity to identify major concerns.

Given the uncertainty that surrounds

hepatitis C and its progression, initial response to the diagnosis is varied. Individuals have stated they felt they had been given a death sentence.

Their fears of passing on the condition are a major concern. One stated that the worry of having hepatitis C was almost worse than the disease due to loss of control over one's life. Others use denial for a time. The dilemma of disclosure - who to tell, who not to tell - adds to the anxiety. Isolation occurs when there is a secret, people become guarded about contact with friends, family, for fear of rejection if that information is shared. The loss of contact with people can be nearly as traumatic as the loss of good health.

Many newly diagnosed with hepatitis C ask to have contact with others in similar situations. Support groups can be beneficial in providing the opportunity of a safe and supportive environment where experiences can be shared and issues that are causing difficulty can be discussed. Some sessions may have a specific focus such as treatments, others a social focus, just to feel accepted and safe among a new group of people. There is a place for both short and long term groups where members can address therapeutic, prevention and treatment issues as well as having the benefit of peer support.

The effect on the extended family varies from total support and acceptance to denial and blame. It has been our experience that partners, family and friends may need as much education and support as the one who has hepatitis C to be able to provide for the needs of their loved one.

Living with a chronic illness will place long term stress on any individual. When that illness is infectious as well as debilitating, the adjustments to one's life will be great. Living with uncertainty, increased and changing information on management of the condition can lead to phases of depression and frustration. Sometimes it is difficult to identify what symptoms are due to the illness and which are emotional stresses.

Support from the 'care team' is vital during these first few months and hopefully will bring about a return to equilibrium as past coping skills slowly return.

- Pam Shipway is coordinator of TRAIDS a counselling and support service - ph 02 9843 3143.

STATISTICS AND RISK - OR MAKING SENSE OF RESEARCH

By Jan Cregan

In my experience as an information and support group facilitator, two of the most difficult issues to deal with in relation to HCV are people's desire for accurate information about the levels of transmission risk in various situations, and their desire for some clear guidance to help them decide on strategies to avoid contracting the virus or, if they are positive, to avoid passing it on to others.

I hear a large amount of distrust and confusion about the official statistics. This usually results from being given conflicting advice by health educators, and this in turn is probably based on apparently conflicting research findings.

To try and clear up some of this confusion, I recently looked at over 500 articles about HCV that had been published in scientific and medical journals. I found infection rates in this literature that ranged from around 0.2% to around 90%, depending on which group of people were being researched. I found articles that appeared to contradict each other, either because they came up with different findings or because the authors came to different conclusions about similar findings. It is no wonder people feel frustrated when they look to the research for guidance.

The first step in untangling this mass of contradiction is to ask who any particular set of results relate to. Has the researcher surveyed or tested the general population, gay men, gay men with HIV or STDs, haemophiliacs, new mothers, drug users, former drug users, drug users in treatment, prisoners or drug users in prison? Or perhaps, some combination of these well-known and supposedly identifiable 'risk groups'?

Knowing this, and knowing the actual ways that HCV can pass among people, is a start in making sense of the statistics.

Below are just a few of the interesting research findings that I found in my search of the literature. It is important to remember when reading them, that there is no such thing as an absolute certainty regarding infection rates. They are based on testing or surveying a number of people who belong to the category that the researcher is interested in, then statistically estimating how those results would most likely apply to all people in the category.

There are a number of reasons why these estimates cannot be absolutely exact. For instance, tests may return false negatives or false positives, or some people may have been tested in the 'window period', the time between a person coming into contact with the virus and the virus multiplying in their body enough to give a reliable test result. People may forget, or choose not to reveal personal details on questionnaires. As a general rule, the more people who are tested, the better the estimate is likely to be.

General populations:

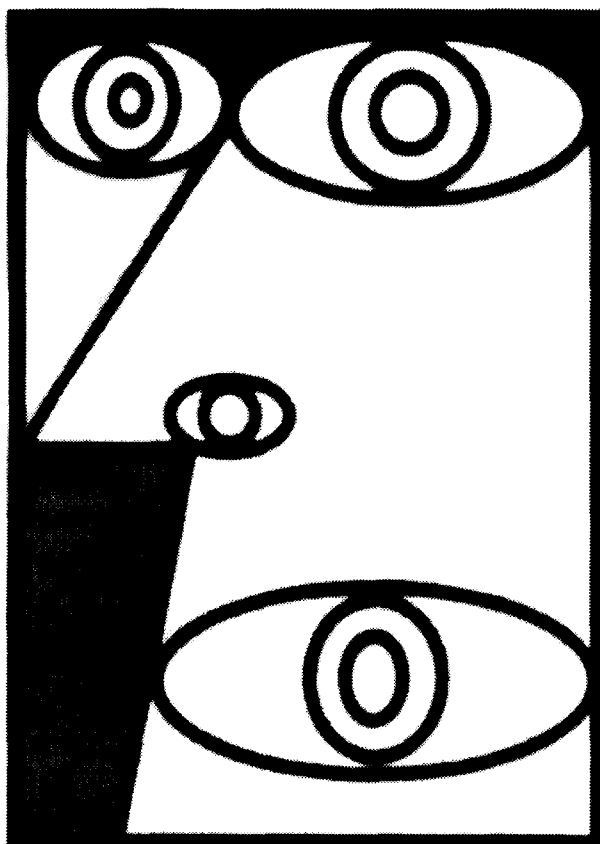
Infection rates vary from 0.2% (2 people in every 1,000) to 2.4% (24 in 1,000), depending on which country the research came from. The figures are mainly derived from blood bank samples taken from potential blood donors. They are assumed to represent the normal population, in terms of their likelihood of contracting HCV. In Australia, 1.5% (15 in 1,000) seems to be the upper estimate for the general population.

STD clinic clients:

HCV infection rates vary from a low of about 2% (20 in 1,000 or 2 in 100 - similar to general population rates), for people who have no history of high risk events such as exposure to contaminated blood products, tattoos or body piercing, or sharing drug injecting equipment. Some researchers found infection rates as high as 61% (61 in 100) among STD clinic clients who inject drugs. While the researchers could not say whether it was due to lifestyle or viral and bacterial factors, HCV infections were higher among people who also had HIV, syphilis, gonorrhoea, herpes, or other STDs. The very highest HCV infection rates were among people who injected drugs as well as having other STD conditions.

Methadone and other drug treatment centres:

Among past and/or current injecting drug users, HCV infection rates vary from about 50% to around 90%. It is worth noting that people who attend drug treatment centres are people who have found their drug use to be a problem in some way - to their physical health, their social and working lives, or their personal relationships - and to be a problem to such an extent that they have decided to seek treatment.



This may also mean that they have had maximum exposure to HCV, through higher rates of injecting and sharing than other users for whom injecting is not such a disruption to their lives. Of course, time is also a factor. Many people who injected on a casual basis in the past were not aware that they were risking health problems and viral diseases like HCV.

Prisons:

About 40% of all people entering prisons in Australia's eastern states are HCV positive. For those who have injected drugs, the infection rate is higher, at about 66% (2 out of every 3 people). Since more than half of all prisoners have a history of injecting, and since the rate of HCV infection among injectors can be as high as 90%, these figures do actually make sense.

Partners and family members:

The first thing that worries all the HCV positive people I have spoken to is whether they are likely to pass on the virus to their families and sexual partners. In some studies, where the researchers knew of no high risk

practices such as sharing injecting equipment among family members, infection rates vary from as low as 0.2% (general population rates) to about 10%.

Transmission routes among family members are not known with any certainty, but are likely to be through sharing any sort of implements, such as razors, toothbrushes, hairbrushes and combs, etc., where even very small amounts of blood can be passed from the HCV-positive person to others.

There is evidence of a low rate of sexual transmission, but the degree of risk is not known. Viral DNA has been found in the semen of men who had high levels of the virus in their blood at the time of testing, and HCV antibodies have been found in the menstrual blood of chronically infected women. The risk of passing on HCV during pregnancy appears to depend on the stage of pregnancy when the mother was infected (the last three months being the high risk period), and on there being a very high level of virus in the mother's blood.

Conclusions?

What do statistics such as these mean in terms of assessing risk and deciding on prevention strategies? It is clear that research offers no clear cut answers about who is infected or what the exact chance might be of transmitting HCV from an infected person to others. Nor can it tell us how to judge which particular occasion of risky behaviour is going to be the one that transmits the virus. At best, the research findings identify practices that carry a degree of risk, and that should be avoided by everyone who is concerned about transmission, whether they are negative and want to remain that way, or positive and don't want to pass HCV on to others they are close to.

One thing that is crystal clear, however, is that sharing injecting equipment carries the highest risk of transmitting HCV. Blood passed from person to person via needles, syringes and other gear is simply a very efficient way of carrying the virus from one person to another. Add to that the high level of HCV infection already present among people who inject drugs, and it is clear that anyone who shares injecting equipment, at any time, stands a very high chance of becoming HCV positive.

There is absolutely no way of knowing which of the people you inject with has HCV - you may even have it without being aware of it - so there is no way of calculating a reasonable level of risk. The only safe strategy is never to share anything that might carry even a tiny amount of blood from one user to another. A new fit for every hit - and new swabs and water etc as well.

- **Jan Cregan facilitates HCV support groups at Long Bay Gaol, Sydney, and is a researcher at the National Centre in HIV Social Research, Macquarie University.** //

What's happening with PCR testing in your local region? Here's a snapshot of the Central Sydney Area Health Service (CSAHS) region.

Three molecular tests are available:

Qualitative HCV Analysis

Determines the presence or absence of HCV in the bloodstream.

Quantitative HCV Analysis

Determines the viral load, or level of HCV in the bloodstream. The results are reported as HCV RNA 'copies' per ml of blood.

HCV Genotyping

Determines the genotypes or 'strains' of HCV in the bloodstream. The test can distinguish the six major types of HCV, and in most cases, the particular sub-types.

Charges

The tests are free to RPAH and CSAHS patients. For other people, the tests cost:

Qualitative	\$50
Quantitative	\$100
HCV Genotyping	\$75

Turnaround times

Approx. 1 week for qualitative; 1 fortnight for quantitative; and 1 month for genotyping.

Requirements

Serum or plasma, red cells separated within two hours of collection, serum stored at -20° C, samples sent on dry ice or ice, no freeze thawing.

CLINICAL HEPATOLOGY RESEARCH NURSES ASSOCIATION OF NSW

NOTICEBOARD

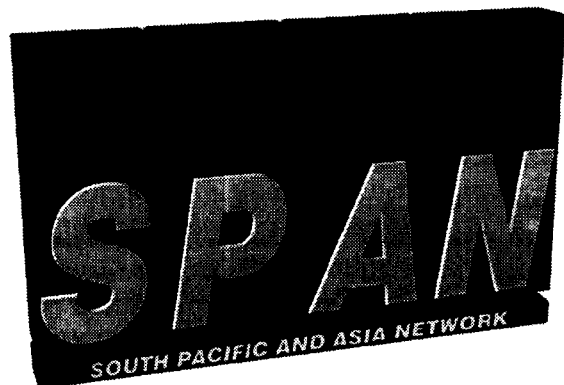
Our guest speaker at the next CHRNA (NSW) meeting will be nutritionist, Raye Squires, from Westmead Hospital, Sydney.

Raye will discuss diets and nutritional factors in relation to HCV.

All healthcare workers associated with HCV are welcomed to the meeting which will be held:

at Conference Room 2 at Concord Hospital, on Fri, 14 November 1997, starting at 6pm.

For more information, contact Tracey Jones on 02 4921 4789 or Sue Huntley on 02 9767 5000.



SPAN's web site, *HEALTHY & HAPPY* aims at promoting information networking within the Asia-Pacific region, and can be found at: <http://www.span.com.au>

Within SPAN, the Hepatitis C Council has a web page at: http://www.span.com.au/hepatitis_c/info.html

Our site contains general information taken from *Hepatitis C: what you need to know*, and will soon feature the Council's new graphics.



looking after your health



when you need help



for health professionals

A veritable smorgasbord of information about diet and nutrition, fitness and exercise, relaxation, healthy recipes and a whole lot more.

A wonderfully information-rich area providing a huge database about condition groups and medical resources. The most definitive site of its type in the southern hemisphere.

A great research tool for the medical professional. Find links to professional groups, research projects and grants, medical and allied health journals.

Moving on

I've been pretty healthy, the life of the party, the joker and vital, but twelve months ago I decided to have a tubal ligation. Since then I've had nothing but problems.

I experienced excessive pain, debilitating headaches and a lot of stress. We then moved to the Mid North Coast region of NSW to be around my family and better healthcare services.

I became increasingly tired, depressed, nauseous, suffered abdominal pain, and intermittent diarrhoea. I also developed severe allergic reactions to several foods and irritants to the extent of not being able to use coloured pencils because the smells sometimes made me feel sick.

Hot oils were probably the worst, sending me down like a ton of bricks with nausea and dizziness.

Finally I was sent to an allergist who has me on a diet free of yeast, moulds, cocoa and all milk products. Although much has improved (breathing difficulties and excess mucus), I still experienced feeling sick most of the time - very drained, diarrhoea and abdominal pain.

Then I got the positive hepatitis C test result and even though my LFT were normal, I could not be pacified.

I've now spent a lot of time anguishing over where this virus came from because I was an injecting drug user 20 years ago - but also, I believe the tubal ligation was not performed under sterile conditions.

But does it matter? I ask myself. I'm still battling with denial of the whole thing.

My doctor was not much help, continually putting my symptoms down to anxiety and depression. Yes I've been depressed, but going from a 'go-for-it' sort of woman to a person who often feels too sick just to go for a ride in the car, is it any wonder?

I'm really terrified about having a liver biopsy from stories I've heard, so I'm not sure what to do yet.

I think the work you're doing is great. I can't tell family or rely on them for support, but my partner is terrific and it's made a very difficult time a lot easier knowing I can always call the support line.

Thank you TS

///

Human nature

I have had a lot of bad treatment towards me by both friends and health professionals. I now no longer disclose to friends and dentists, etc, my condition through fear of rejection and stigmatisation.

This could be potentially dangerous considering some practitioners may not always thoroughly sterilise their equipment.

I have had my gynaecologist of six years no longer want to treat me. He told me there is more to this disease than is being disclosed.

Here on the Upper North shore, I have had friends tell me to stay away until I am better as they fear I may infect their children.

When I inform people, I totally resent the instant reaction of my being infected through injecting drugs - which I have never done.

I have no logical explanation as to how I was infected. None of the means of infection currently discussed are possible in my case - which makes me think, there must be more ways the virus is transmitted.

Did I get infected by a beautician? I have become very aware of what I see around me now.

At my last facial, I noticed the beautician using a cleaning sponge on me then simply rinsed it out for her next client. She also used a thin needle to prick a whitehead and then simply put it back in her tray. WE ARE ALL AT RISK!!

Dentists don't always sterilise their tubes attached to their equipment and there has already been a proven case in hospital where the virus has been passed on to the next patient via tubes that have had faulty sterilisation equipment attached.

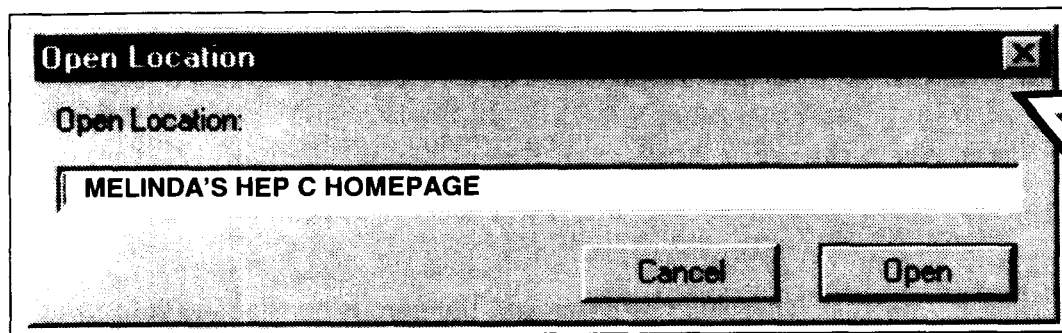
This disease has had a major impact on my life from the day I knew I had it. My doctor was unable to tell me anything about it. She informed me I had contracted it either sexually or via injecting drugs.

As I have never used drugs, I blamed my husband. In my anger, believing he had given me a potentially fatal disease, I accused him of being unfaithful. Needless to say, I am now a single mother with two very young children.

I don't want my name put to this story as I fear by doing so, it may lead to more problems in the future as I now have a lack of trust in human nature.

Regards CW

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Hi, my name is Melinda. I am 38 and have probably had HCV since my early 20s. I didn't really take it all that seriously at first when I was diagnosed about 5 years ago as I didn't have any apparent symptoms, and my life style was healthy - I didn't drink, smoke, or take drugs, and I swam every day.

However, about a year later I started to feel tired all the time and I didn't have the energy to do my work as a sculptor. I had to cancel exhibitions, virtually terminating my career in that field. Realising that it was my HCV, I moved to the country and searched for alternate ways of healing.

Over a period of a year I radically altered my diet and with alternate medical treatment I started to regain my energy. Feeling "cured", I went back to University studying digital art, part-time.

Since then my energy levels have been up and down. I am used to being an energetic, involved and socially active person, but now have recurring liver pain, fatigue, and depression, and often feel overwhelmed about my future health and the impact of HCV on my life.

I'm waiting for a local support group to start up, which may be a long time as I live in a small coastal town in NSW. At the moment I get most of my support from an Internet mailing list of people living with hepatitis, which has been invaluable, and where I have met wonderful people with the virus from all over the world.

HCV is invisible in my local community and there is stigma attached. I have experienced rejection in my personal life through other people's lack of understanding of HCV and their fear of catching it, and the issues associated with

having a chronic illness were a major factor in the break-up of my last relationship.

Because of my own situation I've decided to put together an internet site which will help raise awareness of, and help change negative perceptions of HCV.

As I'm an artist, it will be primarily an art site, but will also contain information on hepatitis resources and medical information on the Internet, links to personal home pages, and support group contacts.

I'd also like part of the site to contain personal stories and I was hoping that some *Hep C Review* readers would contribute their stories on a strictly anonymous basis to this site. Sharing personal stories will make this disease easier for others to understand. Stories provide support and a feeling of togetherness for people who have HCV, especially those knowing no one else with it, or living in isolated areas.

Your story could be about any aspects of HCV, eg. waiting for test results, rejection or stigmatisation, great support you have received, the constant medical rounds, fatigue and/or depression, carers' experiences, death of loved ones, cures, experience of drug trials, complementary therapies, treatment response and regaining energy, liver transplants, biopsies, pregnancy, and positive things HCV has brought into your life like working out priorities, and knowing who your friends really are, changes in lifestyle or career due to HCV.

The list is endless really; please write about whatever is important to you. Your experiences will be anonymous and I've set up a submission form at:

<http://www.subtle.net/Cplus/hep.html>

where you can send an anonymous story over the internet or alternately email me at: melinda@subtle.net or write to me via the *Hep C Review* (sending it on disk would be easiest.)

If you have a personal home page about HCV that you'd like linked to this site please email me. I will publish the address of the completed site in the next *Hep C Review*.

Thank you in advance and take care everyone - Melinda.

melinda@subtle.net

<http://www.subtle.net/line>

<http://www.zip.com.au/~melt>

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AGM

Our 1997 Annual General Meeting was held recently.

AGMs provide the opportunity for Council management to formally report back to the members.

As well as routine legal requirements, reports from the President, Executive Officer and Treasurer were tabled.

The previous Management Committee was re-elected unopposed.

IMPORTANT NOTICE

For people who have diabetes:

If you use a finger prick tester for blood sugar levels, don't let other people use it.

Sharing anything that breaks the skin or draws blood, poses a serious risk of passing on HCV and other viruses.

For info, contact Diabetes Australia by phoning:

02 9552 9900 (Sydney)

1800 451 737 (NSW)

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Sure, for Christmas, we'd all like a 100% effective treatment for HCV - a single dose one, that comes in a variety of flavours! But hey, the reality is we're all going to have to wait a long time before old Santa delivers that one.

Its been a while since we've talked about treatments, so our next edition will focus on them (or lack of them).

If you have a story or view that relates to drug trials, complementary therapies or interferon treatment, please write in.

Stories should be 300 or 400 words. Deadline is 19 Dec 1997.

Interferon

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

- Chronic hepatitis proven by liver biopsy (except patients with blood clotting problems).
- A repeatedly positive antibody test.
- Liver function tests (with elevated ALT readings) three times over a six month period.
- Absence of cirrhosis or other liver disease.
- Absence of HIV infection.
- For women - not currently breast feeding nor any chance of pregnancy while under treatment.
- No history of significant psychiatric illness.
- Must be able to attend regularly for treatment & follow-up.
- Alcohol use of no more than seven standard drinks a week.
- No history of injecting drug use in the previous 12 months.

The course of treatment involves giving yourself an injection three times a week. As from 1st August, six or twelve months of treatment has been available.

The course of treatment must be continuous and excludes re-treatment of non-responders or people who relapsed. Consequently, people eligible for the 12 months course will be new patients. Treatment subsidy is also extended to patients who after the completion of 6 months therapy, chose to continue a further 6 months at their own expense. If their treatment has been continuous, the Commonwealth will subsidise the remainder of the second 6 month period.

If your ALT readings don't come down after three months, the treatment ceases to become available under the PBS. To continue at your own expense for the remaining nine months, the interferon would cost about \$4,500.

Treatment centre facilities

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

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

- A nurse educator / counsellor for patients.
- 24-hour access to medical advice for patients.
- An established outpatient liver clinic.
- Facilities to perform safe liver biopsy.

Treatment centres for hepatitis C exist across the state (see below). You should make sure your centre has the minimum facilities listed above.

If you're eligible and have decided on interferon treatment, you'll then need to go to a treatment centre where you will again be briefed on the treatment and its side effects.

After clinical assessment which may take a couple of weeks, you will be given take home supplies of the drug.

You'll have to return for regular monitoring and further supplies. After treatment, your condition will be further monitored to determine how successful it was.

Treatment centres

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

Side effects

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

Benefits

Currently, up to one in five people with hepatitis C who undertake interferon treatment achieve what is called a long-term remission.

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

[This information routinely validated by Commonwealth Dept Health & Family Services, Pharmaceutical Benefits Branch] //

Natural 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, homeopathy and/or herbs aim to improve the overall health of their patients.

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

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

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

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

Costs

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

Choosing a practitioner

If you decide to use natural therapies, it's vital that you see a practitioner who is properly qualified, 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, *consider changing your natural therapist.*

Healthy herbs?

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

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 recent Australian trial of one particular Chinese herbal preparation has shown positive benefits and few side effects (see edition 15.)

Want more information?

Contact any of the following organisations:

Australian Acupuncture Assoc.	☎	1800 025 334
Australian Homeopathic Assoc.	☎	02 9415 3928
Australian Natural Therapists Assoc.	☎	1800 817 577
Australian Traditional Medicine Society	☎	02 9809 6800
Assoc. of Remedial Masseurs	☎	02 9807 4769
Homeopathic Assoc. of NSW	☎	02 9231 3322
National Herbalists Assoc. of Australia	☎	02 9211 6437
Register of Trad. Chinese Medicine	☎	02 9660 7708
Australian College of Acupuncturists	☎	02 4677 2358
NSW Assoc. of Chinese Medicine	☎	02 9212 2498
Australian Trad. Chinese Medicine Assoc.	☎	02 9699 1090

Referral?

We are in the process of putting together a referral database for various healthcare workers - natural therapists included. This remains an ongoing task. Callers would need to phone the NSW Hepatitis C Info & Support Line (see page 2 for contact details).

regular feature - support services

NSW Hep C Info and Support Line

For confidential and anonymous information and emotional support you can phone the NSW Hepatitis C Information and Support Line.

The service gives you the opportunity to chat with trained phone workers and discuss those issues important to you.

The service also provides referral to local healthcare and support services.

- ① 9332 1599 (Sydney callers)
- ① 1800 803 990 (NSW callers)

Sexual health clinics

Although hepatitis C is not classified as a sexually transmitted disease, the staff at these clinics can offer a wide range of services including pre- and post-test counselling, antibody blood tests, counselling and primary healthcare (the type of service that GPs provide).

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 and keep all medical records strictly private.

Community health / neighbourhood centres

These centres exist in most towns and suburbs, providing many different services, including counselling and information on local health and welfare agencies. Some neighbourhood centres run a range of support and discussion groups. Activities ranging from archery to yoga are sometimes offered as well.

Centres can be found by looking in your *White* or *Yellow Pages* - under 'community centres' - or by phoning the NSW Hepatitis C Information & Support Line. Also look up your local council in the phone book for a listing of its community services.

Local support services

There are few hepatitis C specific support services. This isn't because of lack of need but because there have been inadequate resources to help co-ordinate or develop them. 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 infectious disease Coordinators. These people work within local Area Health Services and can possibly refer you to local services:

Mid Nth Coast	Robert Baldwin	02 6583 0750
Western NSW	Chris Bourne	02 6885 8947
Hunter	Marilyn Bliss	02 4924 6477
Mid West NSW	Jeanine Buzy	02 6332 8576
SE Sydney	Colin Clews	9382 3694
South West NSW	Dalton Dupuy	02 6058 1700
Nthn Rivers	Wendi Evans	02 6621 7231
New England	Karin Ficher	02 6766 2288
Sth Wst Sydney	Ken Wong	9827 8033
Central Coast	Karen Nairn	02 4320 3399
Illawarra	Brian O'Neill	02 4228 8211
Wentworth area	Elizabeth O'Neill	02 4722 2255
Western Sydney	Chris O'Rielly	9843 3118
Central Sydney		
Nthn Sydney	Anthony Schembri	9926 8237
Far West NSW	Darriea Turley	02 8088 5800
Southern NSW	Greg Usher	02 4827 3148

One-to-one counselling

Some people with hepatitis C may want to make use of a specialist counsellor. Such professionals can provide special support or therapy when people have specific problems they find difficult to deal 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 and neighbourhood centres, or the NSW Hepatitis C Information & Support Line.

For one-to-one counselling, also contact TRAIDS, the Transfusion Related AIDS & Infectious Diseases Service. Originally set up to provide counselling and support to people who contracted HIV through contaminated blood products, TRAIDS now also provides services to people with HCV.

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, speak to your GP, look in the *Yellow Pages* under 'counselling' or contact Family Planning, your local community and neighbourhood centres, or the Hepatitis C Information & Support Line. //

regular feature - available information

These resources are available free of charge, or for a low cost that covers cost or postage.

Videos are borrowed for two weeks at a time. Please do not send payment for videos.
Just pay for the return postage when you post them back to us.

Phone or write and tell us what you'd like. See page 2 for our contact details.

Description

Newsletter back issue pack - Editions 1-8
various topics / historical interest

The Hep C Review - Edition 9
Chiron's patent / living with grief

The Hep C Review - Edition 10
natural therapies

The Hep C Review - Edition 11
genome subtypes / life insurance / Terrigal symposium

The Hep C Review - Edition 12
drug law reform / HCV fatigue / women & HCV

The Hep C Review - Edition 13
HCV & prisons / 94-95 annual report

The Hep C Review - Edition 14
HCV discrimination / drug law reform / DSS / clinical trials

The Hep C Review - Edition 15
partying safe / informed consent / stress / Nat AIDS strategy

The Hep C Review - Edition 16
diet & nutrition / DSP changes / IDU & hep C Councils

The Hep C Review - Edition 17
study grants / HCV & relationships / Australasian conference

Description

Hepatitis C - a brief introduction
(brochure @ \$5 for 100, \$50 for 1,000)

Hepatitis C - what you need to know
(booklet @ \$1 each; free to members)

Video No.1 - Interferon / HCV & women
Prof. Geoff Farrell / Jennifer Holmes

Video No. 2 - homeopathy / herbalism
Ken D'Aran / Raymond Khoury

Video No. 4 - Quantum episodes
hepatitis C / the human liver

Research Pack 1 - research papers
HCV / epidemiology / prevention / serology / diagnosis

Research Pack 2 - HCW booklets & strategy document
AGI & Fairfield Hospital booklets / National Action Plan

Research Pack 3 - 1994 NHMRC Hepatitis C Report

Research Pack 4 - HCW booklet / research papers
WA Health booklet / HCV notifications / post-transfusion HCV

Research Pack 5 - HCV policy documents
AHMAC Education for Prevention / NSW HCV Taskforce Report

Chasing up changed addresses is a time consuming task. If you are planning to move in the near future, please don't forget to phone or write and let us know of your new address (our contact details: page 2)

To everyone who responded to the info/support questionnaire (sent to 250 randomly chosen members), thank you very much.

To those who have offered individual information - thank you for your generosity. Unfortunately, I'll not be able to respond to you all. Hopefully, I'll be able to report on the outcome in Edition 20.
Thanks again, from Sandra.

Hep C Classifieds

FOR SALE

Accessories suit Nokia 101 Mobile
Phone:

Battery, Desktop Charger and
Travel Charger

\$20 or any reasonable offer

Phone Prue 10-1 or 2-5 pm
weekdays on 02 9332 1853

MEMBERSHIP FORM

Please complete as much of this form as possible. Our policy is to respect your privacy. All details on this form are treated in the strictest confidence and all communication is carried out discreetly. Please return this form with your cheque, money order or credit card details to:

Hepatitis C Council of NSW
 PO Box 432 DARLINGHURST NSW 2010
 Make cheques out to *Hepatitis C Council of NSW*.

1. Please complete either a, b or c.

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

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

b. For individual healthcare or welfare professionals.

Name			
Occupation			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

c. For agencies, companies and organisations.

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

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

Admin and office work?	
Other?	

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

Renewal		New member	
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4. Please circle one membership fee box.

Membership fees are due annually on 1 March. We welcome a full year's payment but would not want financial hardship to prevent you from becoming a Council member. If this is the case, please circle the concession or zero fee box.

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

5. Separate donations are gratefully accepted by the Council.

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

6. If paying by credit card, please complete this section. Card type (please circle)

<input type="checkbox"/> Mastercard	<input type="checkbox"/> Visa	<input type="checkbox"/> Bankcard		
Card number	Expiry date	month	year	19
Cardholder's signature	Cardholder's full name			

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

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

Signed _____ Dated _____

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