

The Hep C Review

Autumn Edition April 1997

Issue 17

HEPATITIS C COMES IN FROM THE COLD

The Australian National Council on AIDS and Related Diseases (ANCARD) recently announced its responsibilities had been expanded to take on HCV.

ANCARD is directly responsible to Dr Michael Wooldridge, our Federal Minister for Health. Its chair, Mr Chris Puplick, has made a firm commitment about the coordination and advising on a national response to hepatitis C.

"There is no vaccine, no cure and treatment options are very limited. Related issues of discrimination against hepatitis C positive people are yet to be addressed and ANCARD has made a commitment to deal with this public health crisis" said Mr Puplick.

"Hepatitis C is one of the most underpublicised public health problems in Australia", he said.

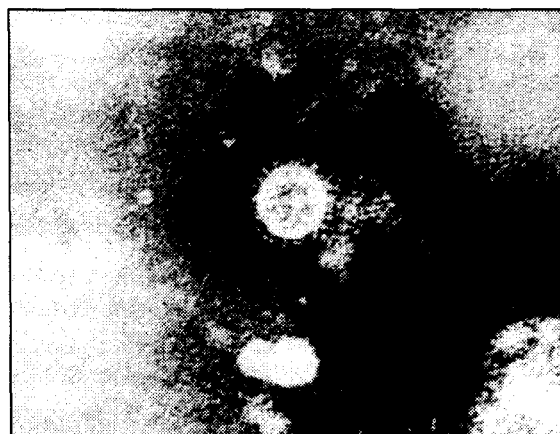
The Hepatitis C Council of NSW welcomes the expansion of ANCARD to take on hepatitis C, fully supporting this timely strategic development. One concern we have, though, is that ANCARD may be limited in its potential for promoting politically sensitive issues due to its makeup - ie. ANCARD may not be able to realise the same cross-parliamentary support as the HIV-related intergovernmental committees and federal parliamentary liaison groups of the mid-1980s.

Responding to our concerns, Chris Puplick, indicated he did not believe our concerns were valid, nor likely to effect the outcomes of ANCARD's deliberations.

"To say that ANCARD is inhibited from dealing with politically sensitive issues is simply not true. Our brief encompasses everything in the Third National Strategy - that includes drug law reform, discrimination issues, federal-state relations, public education and a host of other equally sensitive matters ... as Chair of ANCARD, I am determined to find the extra resources for dealing with hepatitis C issues."

"The decision of Mike Wooldridge to expand ANCARD's brief ensures that the concerns of people in the hepatitis C area will be heard and responded to at a more senior and powerful level than has ever previously been the case in Australia."

Of major significance are the valuable lessons gained from history. Success against HCV will depend on an effective multi-tiered national response. We must all support ANCARD and help it achieve effective coordination of the national response to hepatitis C (also see page 3 editorial). □



A VIRUS EXPOSED?

In what could be a world first, scientists at the Nihon University School of Medicine, Japan, believe they have photographed the hepatitis C virus (centre of photo.)

This remains to be confirmed but if it is the case, it will be the first time HCV has actually been seen.

Until now, scientists have only been able to 'see' HCV through a process of molecular genetic mapping. Hopefully, the next stage will be laboratory culturing of the virus - growing it in the quantities that allow direct scientific experimentation.

Why has it taken so long? The hepatitis C virus is found in our blood in minute quantities compared to other viruses.

Also, HCV is incredibly small, measuring in at around 80 nanometres (a nanometre is one billionth of a metre!)

How can we try to comprehend this type of size?

The above photo shows the virus enlarged many, many times.

If we enlarged a mouse to the same degree it would cover all NSW and tower 1,000 kilometres into the sky! □

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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. Views expressed in this newsletter are therefore not necessarily those of the Hepatitis C Council of NSW.

All hands on deck - a call for greater partnership

by Professor Geoff Farrell and Paul Harvey

Many hands make light work is a common phrase that promotes the benefits of a partnership approach. When facing crisis, such an approach can yield great benefit when it involves the whole community. It is on this basis that Australia has built a world renowned reputation for its HIV/AIDS response.

Since the 1980s, an evolving, comprehensive HIV response has harnessed the motivation and energy of key people - those living with HIV/AIDS, specialists and doctors treating the condition, community-based peer educators, researchers racing to explain the virus and related conditions, health bureaucrats developing strategic responses, and politicians on federal, state and local levels.

Most importantly, the support of the wider community was secured through awareness campaigns headed by media identities such as Ita Buttrose.

Unfortunately, we have not seen the same effective and rapid overall response to the current HCV epidemic. What we have seen is relatively ineffective national leadership that's led to comparatively inadequate approaches by state governments. But although the lack of national leadership, to date, represents a major 'weak link' within an HCV partnership approach, it shouldn't be seen as an excuse for despondency or inaction.

Within a partnership response to HCV, there are plenty of responsibilities to go around, relating to the many HCV needs that remain unaddressed.

We note the current expansion of ANCARD (Australian National Council on AIDS and Related Diseases) which now takes on overall responsibility for advising the Federal Health Minister on implementation of a national HCV response.

Hopefully, this development will lead to better resourcing and more comprehensive leadership from the top-down. Meanwhile we must continue to ensure effective cooperation within our work.

One way of helping to ensure this is the continued promotion and fostering of inter-professional cooperation amongst the wide range of people working in the HCV sector - including, but not limited to

- allied health workers
- Area Health Service management
- community development workers
- community sector project workers and related staff
- medical specialists: gastroenterologists & hepatologists
- epidemiologists
- general practitioners, some with special training
- health bureaucrats and planners
- health educators and trainers
- nursing staff
- public health workers
- medical and scientific researchers
- social workers
- social researchers

Differences of opinion do exist - such as palliative and preventative approaches, allopathic and 'natural' treatment strategies. As workers, planners and decision makers, we must acknowledge these respective yet complementary roles.

Given that the HCV sector currently experiences under-resourcing, it is imperative that within the development of HCV strategies, we must ask "how can we best work together so as to gain maximum use of our available resources?"

We must also harness all our best resources to understand the disease better, how to prevent it, how to cure it and how to lessen its impact on the lives and livers of those who cannot yet be cured.

Particular workers may need to take on additional roles and responsibilities. All workers will need some level of additional and ongoing training. Awareness of specialist and localised hepatitis C services will be essential for referral purposes, and to provide information and support for those with this common disease.

Let us hope that in ten years time it can be said that the Australian hepatitis C response has provided a world renowned model of excellence.

- Prof Geoffrey Farrell is Storr Professor of Hepatic Medicine at the Storr liver Unit, Sydney University at Westmead Hospital, and the founding patron of the Hepatitis C Council of NSW.
- Paul Harvey is Senior Project Officer of the Hepatitis C Council of NSW.

□



DSS support & me

Thanks for your article on the proposed DSS changes.

As though those of us suffering from debilitating and life-threatening diseases haven't enough to cope with, without the added emotional burden of having to survive on even less income.

The sick, the elderly and those demoralised by lack of real employment opportunities have always been easy targets for governments, all too ready to cut spending to reduce the so-called budget deficit.

Money seems to appear out of a hat when it comes to handouts to big business in the form of extra tax dollars and grants, or the proposed \$1 million worth of fireworks for the Olympic Games.

Don't let politicians sit in their ivory towers, oblivious to the havoc they are causing (although I suspect they are only too aware!). Write, phone or fax, not once, but as many times as it takes to stop these changes to the DSS from passing through the Senate.

Let them know just how difficult life can be when you are sick. Just as they feel entitled to their free lunches, trips abroad and chauffeur driven cars etc, at the expense of the taxpayers, so we too, former and present taxpayers, are entitled to support from the Government, during our difficult times.

With thanks.

J.D.



(Carbon Copy)

Dear Senator Newman,

I recently received the latest newsletter of the Hepatitis C Council of NSW. I read with alarm your Government's proposed changes to the Disability Support Pension Impairment Tables.

I am writing you this letter with details of my medical history and daily living costs, in order that it may give you some insight of what it means, financially and emotionally, to live with a life threatening disease on a limited income such as the Disability Support Pension.

I am a 42 year old woman who has suffered from hepatitis B & C since 1980. I have many consequent health problems, including a depressed immune system, an inability to digest most foods. I weigh only 40 kilos and I also have cirrhosis of the liver.

My income consists of a part-disability pension, plus I receive \$150 per fortnight from a part-time job. My total income is \$525 per fortnight, or \$262.50 per week.

Until mid-1994, when my health began to deteriorate rather rapidly, I was working 30 hours a week as a Diversional Therapist in a nursing home - a job I loved. As I steadily became too ill to work this many hours I applied for a pension in November 1995. After passing a stringent medical exam, and filling in numerous questionnaires, I was accepted for a part-pension.

I have been working 12 hours per fortnight for the past 9 months, but I am now finding it very difficult to even keep working this many hours as there are days when I feel too ill and exhausted to keep going. If I am unable to keep working then my income would drop by \$90 a fortnight, or \$45 per week which would leave me with a total weekly income of \$217 per week to live on.

My weekly expenses consist of \$100 per week rent, approximately \$90 per week on grocery and health food items (in an effort to boost my ailing immune system). I also spend \$65 per week on Chinese herbal medicines and acupuncture treatment. My total weekly living expenses therefore amount to \$255 per week. This doesn't include electricity, phone and car running expenses (necessary for work). I don't drink or smoke. I rely on the local library for reading material and I don't (and can't) spend any money on entertainment.

As you can see my living expenses presently outweigh my total income, and will probably get worse if I have to stop work altogether. Without support from my family I don't know where I would end up. Orthodox medicine is totally unable to help me - with an attitude of wait and see. Meanwhile, I continue to lose weight, and feel at times, as though I'm fighting for my life. The emotional toll of the financial and health problems are very great, as you can imagine.

If you make access to the pension more difficult via changes to the Impairment Table or take away the rental assistance allowance from those receiving the Disability Support Pension, I fear you will leave many very sick people in a vulnerable position, unable to pay their rent and meet their daily living expenses.

I have seen examples first hand of a government which turns its back on the most vulnerable members of its society. In 1990 I travelled to San Francisco and saw many AIDS patients, some little more than skin and bone, lying in doorways with pathetic signs scrawled on pieces of cardboard, explaining their plight.

Is this the path Australia is to take? I leave it up to your Government's conscience, until the next election. Thank you for taking the time to read my letter.

Yours, JD



Mt Druitt Support Group

I am writing on behalf of anyone that may be concerned about hepatitis C and would like to be in the company of other people with the condition.

There is a hepatitis C support group (coffee shop style) running every Sunday night from 6.30pm to 8.30pm.

The location of the support group is at the Holy Family Centre, Therry House, 254 Luxford Rd, Ermington, Mount Druitt.

For more information, phone Paulo on 9628 4165.

Many thanks,

Paulo.



Oxygen & HCV

Readers may be interested in the initial results my company has achieved with a hep C patient.

After nearly 10 years of symptoms, he was introduced to hydrogen peroxide stabilised with colloidal silver, which is taken in drinking water.

His first blood test one month after commencing the regime showed a marked improvement in liver function tests. Regular monthly tests for the last six months have shown that his liver enzymes have returned to the normal range - a fact verified by his doctor.

While this anecdotal evidence is encouraging, it obviously cannot be used to say the hydrogen peroxide and colloid silver is a cure. What can be said however is that at the dilutions being used (about 40 parts per million), the product is harmless and approved by the National Health & Medical Research Council as a purifier for drinking water.

It effectively reduces the taste of any chlorine previously added and replaces some of the oxygen removed by chlorination.

It releases a volume of free oxygen into the body and it is this process that we believe assists in dealing with viral illnesses such as hepatitis C.

Readers seeking more information about this

simple treatment of water, can contact me on 02 9674 8284.

Stafford Lowe - Lanco Environmental Services

[It should be noted that by printing this letter, the Hepatitis C Council does not in any way seek to endorse the product.]



“astonishing ignorance?”

How about us having a regular column called ‘Most Astonishing Displays of Ignorance of Hep C’ in our newsletter?

It could sort of be a competition to discover the most appalling things that have happened to us. For example, my two entries would be:

About 18 months ago, I went for a blood test for liver function. When the doctor asked me how I contracted HCV and I replied that my specialist believed I got it when I had a blood transfusion when I was born (and I’m in my 40’s), the doctor told me I couldn’t possibly have gotten it then as it didn’t exist back then. He said that hep C has only existed since 1989. I had to explain the facts to him.

I attend an evening class in which one of my fellow students is a young policeman. He told me very emphatically one evening that you can get hep C from spit. I told him maybe you could get hep B that way but that hep C is transferred by blood. But no way was he having that. He definitely heard of a fellow policeman contracting hep C by spit.

[Great idea! If anyone wants to send in further examples of astonishing ignorance we’ll run a regular column.]



MID NTH COAST SUPPORT

In response to a growing demand for support services for people affected by hepatitis type viruses, the Sexual Health Unit, Coffs Harbour has begun a Hepatitis Support Group. The support group began in March and runs: 9:30am till 11.30am, Wednesdays, Group Room (City entrance), Primary Health Care, Cnr High & Boambee Sts, Coffs Harbour.

This is a free and confidential service that hopes to provide collective support to people who are affected by hepatitis viruses.

Due to high numbers of people with hepatitis C living on the Mid North Coast, the support group will focus on this grouping, however not at the exclusion of people affected by other hepatitis viruses.

The group will constantly be evaluated and is being facilitated by myself, the Sexual Health Counsellor, who will be able to individually support people if needed.

For more information, phone Bernie on 066 59 1424, or come along to the meeting.

LIVEABLE HEP C

It's been many years now since I was diagnosed with "liveable" hep C. Now, the virus places little effect, physically or emotionally on my relationship - but it was very different earlier on.

When I was first diagnosed, my relationship with my husband and family was scrutinised in so many ways that I didn't believe we would survive. Nothing would prepare us for the roller coaster of emotions we faced.

Like most people who are diagnosed with chronic illnesses (that involve social stigma), we experienced a variety of feelings and emotions. Shock, anger, disbelief, sadness, fear, depression, and anxiety all roll through your body without rhyme or rhythm.

Usually your lover and/or family experience similar emotions, though often not at the same time as you. That's if you have the confidence to tell them of your diagnosis when it happens in the first place.

I know of other people with hepatitis C who decided not to tell a soul of their diagnosis, for fear of isolation and negative repercussions. If you have been always open, this kind of secret can eat away at you and your relationships. Anyway, for me the emotions were classic text book stuff.

When I was first diagnosed I could literally feel this virus running around in my system, unsure of how long it had been there or what damage - if any - it had done. For my husband, the thought of me dying (which is what we thought was imminent), was too much to handle.

After the first couple of weeks when we started to realise that life would go on for at least another few years, ongoing problems began to set in.

After only having to use condoms as a method of birth control we started to discuss the options of safe sex practice (as suggested by our un-knowledgeable doctor.) This placed a huge strain on our relationship and our sex life was non existent.

Doubts about our relationship crept in with the rot and the paranoia. Telling the kids who were all adolescents was also a difficult period - How did you get it? How long have you had it? Have you given it to us? Can we tell our friends?

Very difficult questions to answer when you don't know the answers yourself.

Over time, I thought that we had dealt with everything and it wasn't such a big issue. We had done lots of reading and talked to lots of people about hep C.



Our sex life was back on the agenda, and the kids had moved on to their own adolescent crises. But out of the blue, we turned on the telly and "Witness" is running a factual program on hep C and the feelings of confusion and doubt, and all the other emotions come flooding back for us all.

You open the newspaper and some sensational article on the 'killer virus' throws your family back into a whirl of mixed emotion.

But, somewhere along the track, my HCV diagnoses have allowed for a part of my relationship to grow. Grow beyond a richness that most relationships wouldn't unless confronted by this socially unacceptable disease.

I know it sounds crazy, but the sharing and dealing with this crisis has changed my life for ever.

I know it isn't the same for all people diagnosed with hep C because I've spoken to people whose relationships have not survived the pressure. Sadly, this wasn't because they were fragile to start with, but possibly because of the lack of support and the ignorance from community and health professionals - and because the secrets were too great.

My life and that of my husband and family are full of love, commitment and compassion. We have all experienced a dramatic change in our relationships that will affect us in a positive way forever.

Maureen from Tamworth □

interferon - 12 months treatment gets the nod

The Pharmaceutical Benefits Advisory Committee (PBAC) is an independent body that advises the Commonwealth Department of Health & Family Services. It has recently recommended that Commonwealth subsidy for use of interferon alfa for use with hepatitis C be extended from the current six months, to allow for up to twelve months treatment.

The announcement coincides with a recommendation from the National Health & Medical Research Council (NHMRC) and lobbying from industry bodies, hepatitis C clinicians and community-sector organisations.

The industry is confident that Senator Chris Ellison, Parliamentary Secretary with responsibility for the Pharmaceutical Benefits Scheme will fund the twelve months treatment - so much so that they're already supplying the additional 6 months supply of the drug to people currently on the Section 100 treatment.

Response is significantly improved with the 12 months treatment regime which increases the sustained response rate from 15-20% to a possible 20-40%. The term 'sustained response' is regarded as normalisation of liver function and absence of viral RNA in the blood, for at least 12 months following treatment.

Unfortunately, interferon still can't yet be seen as a fully effective treatment or cure, but the twelve months treatment development is certainly good news for anyone considering interferon treatment for hepatitis C.

We now wait to see if good predictors of interferon response can be confirmed. These may include PCR testing for viral genotype or titre (load).

We will report on this in our next edition.



ICI's new research into hepatitis C treatment

Many people associate ICI with industrial gases and chemicals. It therefore came as a surprise to hear that for some time, they have been researching hepatitis C treatments.

ICI Australia which is jointly UK and locally owned has been researching a new liver disease treatment - still at an experimental stage. It is based on increasing the liver's ability to heal itself by increasing the flow of oxygenated blood through it. Specifically, through the hepatic artery.

Proposed by an Australian clinician, it is based on similar treatments for angina and other forms of heart disease (drugs that increase the flow of blood through the heart muscle).

ICI Australia's pharmaceutical division is the ninth largest pharmaceutical company in Australia and is confident the treatment, although not seen as a cure, will benefit many people with hepatitis C. An initial trial of low dose diltiazem by people who had failed to respond to interferon treatment, showed a significant response.

"Of 20 patients in our initial trial, many experienced a significant improvement of liver function," said Dr Howard Smith, Medical Director at ICI Australia Pharmaceuticals.

Calling for caution until results of a current nation-wide trial are known, Dr Smith emphasised the importance of avoiding use of similar heart treatment medications.

"Heart treatments are based on much greater doses and a fast-release tablet. What we are looking at is a greatly reduced dose, delivered through very slow-release tablets." He added that "misuse of heart preparations might actually cause liver damage in people with pre-existing liver disease."

The current trial involves three NSW centres - Concord, Royal Prince Alfred and Westmead hospitals. The trials have only just begun and will involve a total of 200 people. Trial participants are being selected by the treatment centres. All have symptomatic hepatitis C and raised liver function test results.

If the trial confirms ICI's expectations, the treatment should be available within 2-4 years for treatment of hepatitis C. It is possible, but not yet known, that the treatment may also be useful for people with established cirrhosis and other serious liver disease.



BLOOD BANK BLUES

In November 1990 I fractured a bone and had an operation at Royal Newcastle Hospital. I was not really aware of it at the time but was given a blood transfusion.

In February 1993 after donating blood, I received a letter from the Hunter Blood Bank informing me that I was hepatitis C positive. I saw my GP the following day who informed me I had joined the ranks of a growing number of people with HCV.

I contacted a doctor at Sydney University who informed me that many people caught hepatitis C from blood transfusions prior to February 1990.

I then went to see a doctor at the Blood Bank to talk about what had happened. She said that most people with hepatitis C had certain risk factors in their background and that the main ones were unsafe anal sex and injecting drug use.

I told her that these did not apply in my case but that I did have an operation in late 1990, and that I couldn't remember exactly if I'd had a transfusion or not.

She claimed that Australian blood banks started screening all donated blood in February 1990 - eight months before my visit to the hospital. She said that I couldn't have caught hepatitis C through the blood supply.

I was quickly becoming depressed by the thought that I had a potentially life threatening disease for which there is no cure and seemingly no cause.

Time passed until June 1994 when the Blood Bank phoned to say that they had traced my hepatitis C to the transfusion. I contacted a solicitor who advised me to take legal action for damages.

My claim was heard in May 1995 but we wanted an extension of time to gather more evidence. The Blood Bank was represented by a Queens Counsel who cross examined me for several hours. The end result was

that I lost the case and costs were awarded against me. The reason - not enough evidence!

After the court case, I found out more about my situation. I had caught HCV because the initial HCV tests were not as good as those used today. A person who had donated blood had hepatitis C but the screening test did not pick it up - a false negative result.

The QC said that I had been identified through a lookback program and that the blood bank doctor I saw in 1993 did not follow up on my case because she wasn't sure if I'd had a transfusion or not. If I agreed not to pursue the matter, the Blood Bank would agree not to pursue its costs, he said.

So where do I stand?

The Blood Bank now admits they gave me HCV. I am aged in my early forties and I understand that it's possible I'll have major problems down the track. I've heard that one in four people develop cirrhosis of the liver and that one in ten may die from hepatitis C.

I went into hospital with one injury and came out with a possible terminal illness. I get this strong feeling that the Blood Bank feels I should have considered the risks before my initial transfusion. But hey, it's not as if I planned to break my thigh bone, and I thought hospitals were places where you were cared for and cured. And I told them in 1993 I had no idea how I caught hepatitis C but that I'd had an operation in 1990. They didn't follow up on this pretty obvious connection.

Are there other people like me that they ignored? If they could trace back later to who donated the blood that I received, how come they couldn't just follow up my case at the time? Did this lead to any people being unnecessarily infected with the virus after 1993 and not being informed?

Although the Blood Bank had state-of-the-art technology, it appears to me they lacked basic common sense.

I acknowledge that the Blood Bank is pretty insulated from legal action. I certainly can't afford to appeal my case. But what lessons can be learned from the situation?

If any organisation can wash its hands of all responsibility, who is to say that one day it may take liberties with a little cost cutting here and there? Or worse still - become so self righteous, it simply ignores evidence that it can do wrong?

Sincerely - Jeff

□

[nb: Jeff has agreed that it would be useful to have a response from the NSW Blood Bank. This can be found on page 32 - Ed]



HEPATITIS C AND OTHER CHRONIC ILLNESSES - AND THEIR EFFECTS ON RELATIONSHIPS

by Prof Robert Batey

It is most appropriate that *The Hep C Review* consider the topic of chronic illness and its effects on relationships.

As a clinician I feel it important to highlight the fact that any chronic illness does place enormous stresses on personal relationships. Hepatitis C is no exception and it places its own stresses on relationships, not the least because of its infectious nature.

Over 25 years of clinical practice it has always fascinated me that relationships often stand acute and severe traumas only to fall apart when the suffering individual returns to normal health.

I can only presume that the enormous emotional commitment that goes into helping a close friend or partner through an illness, ultimately drains an individual's resources to the point that they are no longer able to see their partner in the same light once health has been restored.

Fortunately, hepatitis C does not fall into this category of acute massive ill health but rather provides a chronic stimulus to stress in a relationship. Again, it is important to highlight the fact that hepatitis C does not differ from many chronic illnesses in many respects.

Anybody suffering from a long term symptomatic disorder will go through phases of depression, anger, frustration and just plain despair. All of these emotions will, from time to time, spill over and affect close friends and partners. Partners can often cope with these inexplicable "outbursts" but

sooner or later repeated demands to cope with poorly explained emotions lead to tensions and ultimately, in many situations, loss of commitment to the relationship.

In the 1990's with its increased focus on individual rights, with less focus on responsibilities, it is not surprising that chronic illnesses have led to breakdowns in relationships and ultimately separations.

Hepatitis C does pose particular problems in a relationship in that it is an infectious disorder, capable of transmission by blood contact and possibly transmissible by sexual contact.

These are concerns which can challenge individuals with hep C on a daily basis, leading to personal tension for that person, and to stresses within their relationships which ultimately can prove fatal to those relationships. To have a partner constantly worried that they might contract an illness, will often lead to inappropriate responses to life experiences that an ordinary couple might cruise through without any problems.

It is imperative in any management situation to talk through some of these issues with the couple in the hope that trauma can be minimised. Effective counselling and information sharing will hopefully minimise the trauma to relationships and allow healthy and constructive means of coping with stress to be developed.

It is most important that we do acknowledge the problems chronic illness presents, particularly in these days of individual rights. I stress this for a second time as I believe that rights have taken precedence over responsibility for many people and relationships do demand a degree of commitment and responsibility through good times and bad times.

In dealing with hepatitis C, those of us involved in the management of patients really do need to recognise that patients do come with partners, family, friends and work mates, and that appropriate and correct information must be provided to patients to allow them to deal effectively with these different contacts.

Where necessary, treatment centres should be able to provide counselling for these other persons should they come with questions and concerns about their own safety with respect to hepatitis C infectivity. We still have a long way to go in developing these appropriate services.

- Prof Robert Batey is head of Gastroenterology at John Hunter Hospital, and a member of the NHMRC Hepatitis C Working Group.

□

HepCare - trialling a new approach to hepatitis C healthcare

Tell us about HepCare

HepCare is a research trial sponsored by NSW Health in partnership with the Commonwealth Government. This trial is one of 12 Coordinated Care trials being undertaken across Australia. The focus of this one is people with hepatitis C.

The aim of the trial is to test a new way of providing health care to people with hep C (called Coordinated Care). The proposed outcomes of Coordinated Care are to improve the health and well being of people on the trial.

What is Coordinated Care?

Coordinated Care is a new model of delivering and funding health and community services which is designed to make sure each person is given the best service. A health professional (or Care Coordinator) will work with all trial participants individually to develop a care plan which addresses all of their health care needs.

The care plan will not look at hepatitis C in isolation from the person's other health care needs, but will consider it in regard to other health matters. For instance, a person may have asthma and this will be incorporated into the care plan. Having a care plan individually worked out should ensure better access to health services and lead to improved health.

The Care Coordinator may be a service provider already known to the person or they may be linked up with a trained coordinator working with the trial.

Tell us about the Trial

The trial is looking for people with hep C who live around or use health services in the Northern suburbs of Sydney. Another arm of the trial is recruiting people with hep C

from the Hunter Region. The trial will proceed for two years, and after that time, will draw conclusions about the results of the new model.

Tell us about the two phases.

Connecting a Care Coordinator with a participant on the trial will take place during Phase 2. Before this can occur, project staff must have an understanding of the types of services people with hepatitis C currently access. This information will provide a picture of the services to include in participants' care plans. Identifying current health service usage takes place during Phase 1.

How will that information be determined?

The information about health service usage, such as visits to the doctor or admissions to hospital is held by the Health Insurance Commission in Canberra. It can be accessed for research purposes by using the number on your Medicare Card. The trial is asking for people's consent to access this information.

The trial is not interested in why a service was used, rather which service and how often. Once again, the purpose of accessing this information is for the trial to gain an understanding of the types of health services being used. This will make planning for Phase 2 more accurate.

Will the information be treated confidentially?

Absolutely! All participant's data will be security coded to ensure that information remains confidential. The information collected during this trial will be used only for the purposes of this study and will be available to project staff only. Trial participants can have access to their own information that the trial has collected about them.

How do I get involved?

Anyone who has hepatitis C and lives in (or uses healthcare services in) either the Northern suburbs of Sydney or the Hunter Region can take part. In order to make the trial representative of the population of people with hep C, we need to speak to a range of people who are living with the virus.

Whether you access a lot of services or none at all, we want to hear from you. Project staff are available to provide further information about the trial and to answer any questions. HepCare is an exciting research trial that should lead to better health care and service for people with hep C. If you or someone you know is hep C positive, you can find out more by calling 9976 9641. Make a difference, get involved!

□

Are you an HCV worker and want to learn more?

The recently extended NSW Study Grants Program for HIV/AIDS, Sexual Health & Hepatitis mirrors the thinking behind the expansion of the 3rd National HIV/AIDS Strategy to include related areas of health. This NSW Study Grants Program provides financial assistance to health care and community workers to undertake study or training for the purpose of developing or upgrading their skills in the prevention and/or management of HCV, HIV or sexually transmitted diseases.

Eligibility criteria:

Workers applying for Study Grants should be working in an HCV/HIV/STD related field. This includes professional care for people in community or inpatient settings; volunteer support; education and prevention services.

Alternatively, workers may require HCV education and training as a component of their generalist non HCV-specific work.

Applicants are required to:

- provide details of the proposed study program, and how this will be of direct benefit to them and/or their organisation in the management or prevention of HCV;
- provide endorsement from their employer or sponsoring organisation.

Study Grants are not to be used:

- as a substitute for training courses or activities normally funded under other programs;
- as a top up for perceived or actual inadequacies in funding from other sources;
- for training courses or activities normally considered part of inservice training or staff development;
- to fund attendances at conferences in Australia or overseas;
- for undergraduate training, or for training towards formal qualifications provided by educational institutions in Australia or overseas;
- to undertake research.

Grant recipients are required to:

- notify the Study Grant Coordinator if from a non-government organisation (NGO) or your regional HIV/Infectious Disease Coordinator if unable to attend the proposed trainings, or if the course is cancelled;
- provide the Study Grant Coordinator or your regional HIV/Infectious Disease Coordinator with a report on the study undertaken within 2 months of completion of the program.

Overseas training:

The Study Grants are normally available only for Australian residents and for training within Australia. Applications for overseas study will be considered in exceptional circumstances where it can be demonstrated that measurable benefit to HCV/HIV/STD services in Australia would result. These applications are subject to approval by the Director General.



How to apply for a Study Grant:

- if you are a government employee or in private practice, complete an application form and return to your regional HIV/Infectious Disease Coordinator.
- if you work in an NGO, complete an application form and return to the Study Grants Coordinator (contact details below).

Payment of Study Grants:

Cheques will be made payable to individuals only on receipt of the original receipt for training fees. When the employer or sponsoring organisation has paid the training fees, cheques will be made out to the employer or sponsoring organisation. Generally, cheques are made payable to the organisation conducting the course.

For Seeding Grants used to establish training programs, a separate application form is available from the Study Grants Coordinator.

For more information, contact the Study Grants Coordinator:

Susan Venables Tel: 02 9382 3697

Fax: 02 9398 8296



SURVEYING THE SURVEY - HCV & RELATIONSHIPS

by Toni Powell

Sixteen months ago my friend Donna and I decided to get off our butts and do something. Seemed like a great idea at the time....Do a survey....write a book!!

With a lot of help and input from the Hep C Council, various kind doctors, interested groups and others we published our 6 page survey in the Hep C review.

Over 100 people responded and we ended up with 90 usable surveys. Now we seem to be drowning in a veritable sea of detailed information.

We now know more than we did. We know what people want in a book, the age and sex of respondents. We know where they were born and if they feel their doctor understands the impact of their symptoms on their lives. We have a list of commonly experienced symptoms and know how many have been treated with Interferon. We also know people's most likely source of infection, where they have travelled and if they drink alcohol.

What we know most about, however, is how difficult it is to quantify a survey. The survey was fairly complex and not limited to simple yes or no answers. Room was given for a sentence (or as it turned out frequently...paragraphs) so answers were not cut, dried or easily assessable.

Take the issue of relationships. Paul rang and asked if I'd do a short article on the subject based on our survey. Wasn't a subject we had really delved into so far but it sounded easy. So I thought I'd just go through the survey looking for relevant questions, report in with impressive statistics and dazzle everyone.

Have you observed any illness related stress in your relationships?

Three left the question blank but fifty five answered YES - get out my calculator...that is 61%. Hey I have a statistic!

Thirty two people answered NO so that's 35.55% - this is great.

I'm speeding along like this only until I look at these thirty two a little closer and notice that some had answered YES to being discriminated against in other questions. Others had written elsewhere in the survey things like -

- * *I am afraid to form any close personal relationships because I have Hep C.*
- * *My boyfriend couldn't cope with the idea of me having it (HCV) so he broke it off with me. I am wondering if I will face rejection in future personal relationships.*
- * *My husband refuses to eat or drink from any utensil that I have used.*
- * *I was asked by friends to drink my coffee out the back.*

If this is not illness-related stress then what is it? Either the ones who said they do not experience illness-related stress have a different idea of stress to me or the question meant different things to different people.



My researcher extraordinaire bubble is burst and I am left wondering how I am supposed to interpret this? Do I include these thirty two NO answers as they read for that question or do I look at the whole picture? Were there 35%

answering NO or, if I were to adjust it, 24%? If I assume 24%, am I fiddling the figures? I realise at this point dazzling is out of the question and decide to forget statistics for now.

Still, it was DEFINITELY definite that people were feeling illness-related stress in their relationships. Some of the respondents seem to have it pretty rough:

- * *My child's father is in and out of our lives. He is a truck driver and doesn't understand the meaning of moral support. He gets angry at me for not feeling well and thinks I should be able to just get off my bum and make out HCV doesn't exist and it should go away. He causes so much stress in our lives but he is the only friend I have in the area and if not for him dropping in I wouldn't see anybody except when I go into town shopping.*
- * *My husband ignores my condition and he can't help me with the house or children and it's very stressful having his dinner on the table and the house clean when he comes home. Category F husbands (like mine) need to be told where to get off.*
- * *I can't see much hope of forming a relationship now I have hep C and genital psoriasis rash! The psoriasis being a gift from Interferon in this case.*

Quite a few respondents answered WHAT RELATIONSHIPS? or expressed despair at ever being able to have a partner as the fear of rejection over hep C was so great.

There were so many, in fact I wondered if I should put them in touch with one another....sort of a hep C dating agency where the trauma of having to disclose to each other would be avoided. Sense prevailed.

There were also quite a few category F partners. A number commented that they were expected to pull themselves together, get well, stop being lazy, stop making excuses and were viewed as using hep C to get out of work. In close relationships these attitudes are pretty poisonous so there were a number of marriage breakdowns directly attributed to hep C.

Many answered just a plain YES to the question and did not elaborate. Of those who went into more detail, frequently mentioned sources of relational stress were:

- * too tired for sex (or now disinterested)
- * fears of passing it on (for some this even meant very restricted hugging and kissing of their own children or grandchildren)
- * low self esteem
- * feeling contaminated
- * having to tell people
- * feeling they were not pulling their share of the load
- * being irritable & moody (most common)
- * having a junkie stigma

For the most part the NOs were just plain no but overall the survey indicated that some people had very supportive people around them:

- * *My wife has accepted it. When we first found out it was very hard, but once we knew what we were dealing with, she was OK. She's been great.*
- * *My husband is very helpful and supportive. He is happy to do anything that needs to be done.*

One survey I read last night amazed me with how parallel it was to my own adventure with hep C. Their answer to the question about stress in relationships echoed my experience.

"Finding out I had hep C actually lessened stress on relationships as I had a reason for feeling like death warmed up and felt less like a hypochondriac bludger. I also began to take care of myself and now feel comparatively well."

I was ecstatic to find they had even used the same alternative treatments with similar results! Maybe I was onto something! It was a major let down to finally realise it was the survey I had anonymously filled out. I did not even recognise my own handwriting!

I had imagined that in this article, with all these statistics at my fingertips, I would be able to cover a heap on relationships ... discrimination, sex, relating to doctors etc etc. I've managed to look only at stress.

People are phoning asking for results of the survey and I can see now that a lot of it can't be confined to mere figures. Maybe that's just as well. We want to write a book to tell about how it really is, to offer some help...and statistics would never do that.

For us the survey is a wonderful source, giving us exactly what we were looking for. Thank you to all who took part.

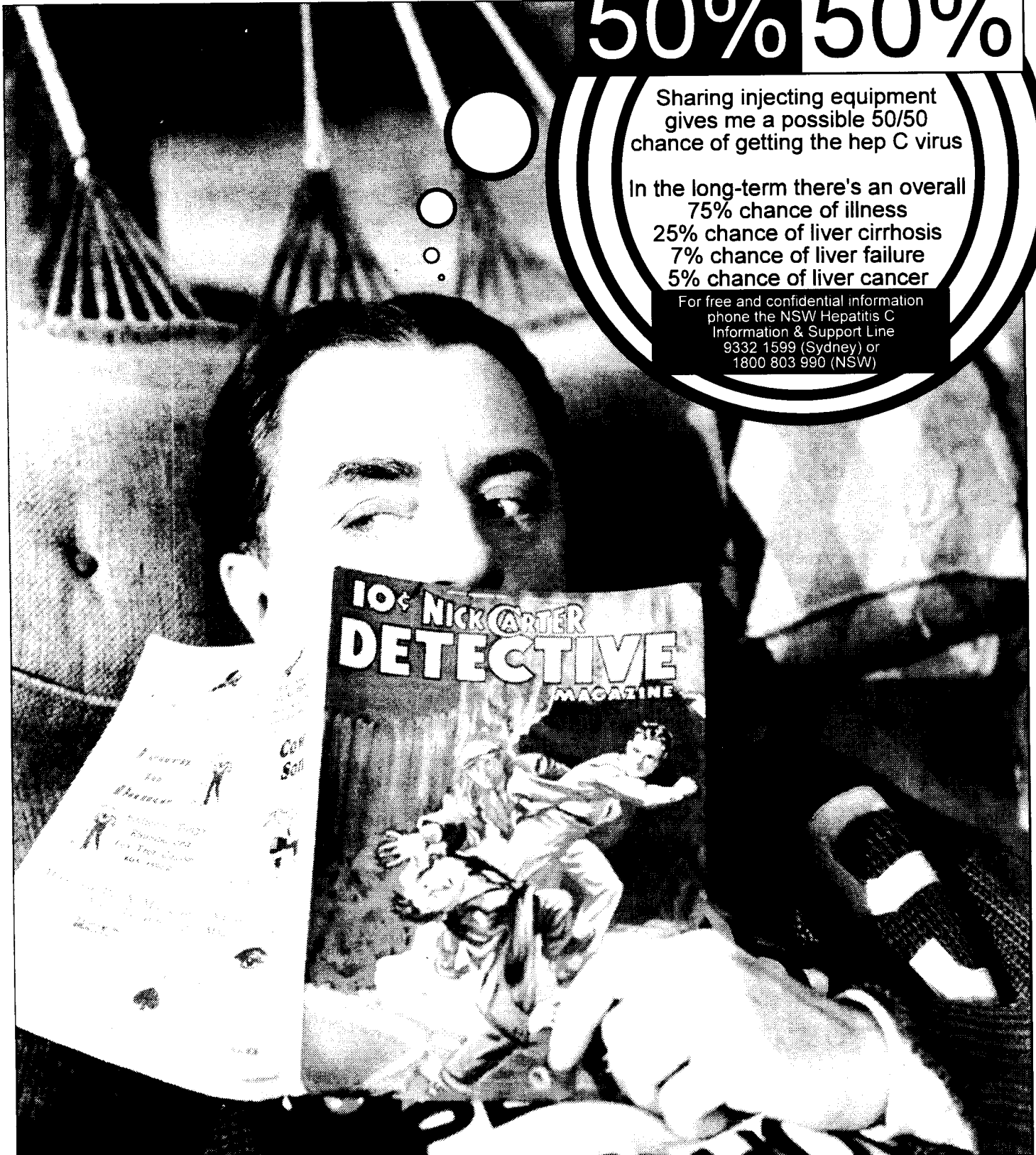
- **Toni Powell & Donna McDermot are co-authoring the book HEAVEN CAN WAIT - Living with hepatitis C.** □

50% 50%

Sharing injecting equipment gives me a possible 50/50 chance of getting the hep C virus

In the long-term there's an overall 75% chance of illness
25% chance of liver cirrhosis
7% chance of liver failure
5% chance of liver cancer

For free and confidential information phone the NSW Hepatitis C Information & Support Line 9332 1599 (Sydney) or 1800 803 990 (NSW)



USE A NEW FIT FOR EVERY HIT is only part of the message I've got to consider the concept of blood awareness - ie.

- All blood can contain HCV and other blood-borne illnesses
- It can only take microscopic amounts of blood with HCV to get into someone else's body for the virus to be transmitted
- So I need to prevent contact with other people's blood - even in amounts too small to be seen

Can a comic book stop hep C?

Of great importance to individuals and our community as a whole, is the prevention of hepatitis C transmission.

Many people say that no one project or approach will stop the spread of such viruses as hepatitis C.

What may work, though, is a combination of specifically targeted strategies, ranging from big-picture issues like drug law reform, down to individual localised education programs.

The Western Sydney HIV Prevention Service and the Hepatitis C Council are working together on one such localised project - an eight page comic book for young people in Sydney's western suburbs. The comic aims to provide key prevention messages as well as general hepatitis C information.

By involving Streetwize Productions - renowned for such comic book projects - we will help make sure the resource is culturally relevant and attractive to young people.

The comic books will specifically target young people who begin injecting drugs, aiming to help them avoid contracting hepatitis C.

A frightening statistic coming out of the recent 1st Australasian Conference on

Hepatitis C related to young people attending the Kirketon Road Centre at Kings Cross. Of their clients under 20 years old who test HCV negative, close to nine out of ten contract the virus within 12 months.

The time gap that exists between when people start to inject and when they might contract HCV is very small. It's usually during this window of opportunity that people first come into contact with needle & syringe exchange program staff and access harm minimisation resources.

What the comic book project hopes to do is provide harm minimisation messages to young people prior to, or during the window of opportunity.

The comic book neither condones nor condemns drug use. It simply provides information that helps people prevent what is a very real health threat.

The comics will be available through a wide range of community outlets, including community centres and youth clubs.

Many regionally based HCV

prevention services across NSW will be able to make use of the books.

By amending the local contact phone numbers contained within the comic books, they'll have an effective localised resource.

We will provide further news on the project, but in the meanwhile, for additional information, workers can contact Tracey McCormack on 02 9893 9522. ☐



A past Streetwize comic that focused on epilepsy and youth

Hunter hep C

**an interview with Tracey Jones - HCV
Clinical Nurse Consultant at John Hunter
Hospital, Newcastle, by Paul Harvey.**



Tracey, what brought you to hepatitis C nursing?

Previously I worked here in Newcastle with HIV patients, Paul. I started way back in the early days and remained there for a period of nearly nine years. When the hepatitis C position was advertised back in 1995 I had already considered that it was time for a change.

What does a Clinical Nurse Consultant actually do?

Well, in the Hunter my work covers the entire Hunter region - from Newcastle to Muswellbrook. As a CNC, I am involved in two outpatients' clinics. Our patients are referred to us by GPs or specialists. Patients can also self refer to me. A majority of our hepatitis C patients come to us for the interferon treatment program. I ensure these people know what is happening and what to expect with the treatment, and also help with their follow-up, ensuring our information is up to date with the National Database.

I do any inservice training that is requested by clinics and other healthcare services here in the Hunter, and this has included within some of the local jails.

On top of this, there is my involvement in local strategic planning. Workers like myself are often invited onto teams involved in developing local HCV strategies and services. Also we are invited onto standing committees working with hepatitis

C. For example, I'm on the Area steering committee for the management of hep C, as well as the NSW HepCare steering committee. I guess I'm involved in most aspects of hep C issues.

I also play a patient advocate role and work to make sure the local community is as well informed as it can possibly be.

Tracey, it sounds like they've put an educator/trainer, social worker, nurse and community development worker in the kitchen wizz?

That's about right. I liaise very closely with a whole range of workers - especially Professor Batey, Kerry Todd and Marilyn Bliss from the Public Health Unit, and Mark Toohey, the clinic's new social worker here at John Hunter hospital.

As a matter of fact, one of the most rewarding aspects of my role is its responsibilities and the fact that it brings me into so much contact with really wonderful people here in the Hunter and across NSW - as one example, there's a state-wide hepatology nurses research group that I'm part of which is currently trying to get an Australia-wide research project off the ground. It is looking at the knowledge and attitudes of nurses in regards to hepatitis C. In fact, I have been involved in several research projects over the past 18 months here at John Hunter Hospital with a specific hep C focus. It's really heartening that we are all ultimately focused on the same thing - improving healthcare services for patients.

What are the current challenges that you face?

Well, aside from my actual workload, I sort of feel like I'm re-living my previous 8 years with HIV all over again at times. What with hep C discrimination issues and prejudice against patients.

But the immediate response to your question has to be education. We have to continually try to make the general community more aware and more accepting of the actual hep C virus.

And getting people to understand the issue of the fatigue associated with this. Too many people are written off as lazy, often because the person is too scared to say what's wrong with themselves.

Another important challenge is to convince the Department of Health of the necessity for increased funding, that can be utilised to increase the number of healthcare workers dealing specifically with hep C issues.

Tracey, if you could have a magic wand for a day, what would you want?

Well, it would be great to have my own office - or maybe one I had to share with only one other worker. (Laughter) That would be good.

I think that everything that's being done is positive and because many of us going through this now have had past experience with HIV issues, we've been able to learn what works well and how to most effectively develop long term projects.

Up here in the Hunter, we want to achieve one thing - an excellent healthcare service for hep C patients. And probably the best way to do this is by listening to our patient's needs and acting accordingly. □

FIRST AUSTRALASIAN CONFERENCE ON HEPATITIS C

by Stuart Loveday

This major conference was held in Sydney from 16 to 18 March. For the first time, a jointly organised Australian and New Zealand meeting of clinicians, the communities affected, researchers, epidemiologists, and other health professionals covered the four subject areas associated with hepatitis C: public health and community support, clinical sciences, basic sciences and epidemiology and social research. Keynote speakers include specialists from Australia, USA, Spain, Italy.

What distinguished this conference from others held in Australia so far is that for the first time, the communities affected, that is people with hepatitis C and the community organisations working on their behalf, were fully involved in the planning, auspicing and running of the conference.

For many, the conference was an exhausting, jam-packed program of presentations, workshops, discussion, debate and, as always, a great networking and lobbying opportunity.

On occasion debate became quite heated, possibly as a result of frustration caused by the painfully slow progress in providing adequate information, prevention, treatment and support services, and probably as a result of the very limited resources the health system and communities have at their disposal to defeat this major personal and public threat that is HCV.

With any health meeting of this size and standing, there's always the expectation that news about better treatments will be there to cheer us up; that announcements of breakthroughs in technology will see a vaccine being developed; that an easy answer to prevention is just around the corner. In short, we hope to hear really good news.

Instead, it's confirmed that there's still no chance of a vaccine against this exceptionally complex virus; that *maybe* interferon and ribavirin combination therapies offer a better chance of eradicating the virus; that yes, the governments of Australia *still* need to provide more effective leadership and funding to stop the spread of HCV and to care for those already affected; that much social research still needs to be carried out to help us develop effective programs that will help reduce transmission. In short, we hear more of the same.

But, and it's a huge but, the fact that 500 people gather for three days, share these ideas and bring this news and these demands once more to

the ears of policy makers and the public, means that little by little, people with hepatitis C and those at risk from it will be better off.

So what were some highlights?

Bad news: a study at the Kirketon Road Centre (KRC) in Sydney's Kings Cross showed that 89% of young people under 20 years old contract hepatitis C within one year after starting to inject - and that's with the best information currently available. Average annual infection incidence rates at KRC are 17%.

Good news: Chris Puplick, Chair of ANCARD, said in an introductory address that hepatitis C is the most significant stated and unstated threat to public health in Australia. Why good news? ANCARD is providing, for the first time, effective leadership through national coordination of the hepatitis C response.

Bad news: needle exchanges in QLD are being closed down and are under attack in NSW. Drug policy reform remains a far-off likelihood. Without regulation, and while the current prohibitionist policy remains, people will be far more likely to remain using drugs unsafely. And if we can't tell the truth about drug education in schools, then how can we teach effective harm reduction?

Good news: Soon we should know whether PCR testing, detecting viral load and genotype, will more accurately determine indicators as to whether anti-viral treatment is more likely to be successful.

Bad news: Interferon treatment for 6 months duration has more limited success than first thought - around 10 to 20%.

Good news: the PBS has recommended to the Federal Government that funding should be made available for 12 months' treatment - where 20 - 40% enjoy success.

Bad news: hepatitis C in prisons and other marginalised communities is a much bigger problem than in the broader community - and there does not seem to be the political will to do much about it.

Good news: no indicators emerged to say that hepatitis C is any more easily sexually transmitted than we already know - but that small element of doubt remains.

Bad news: that at the current estimated rate of 8,000 to 10,000 new HCV transmissions happening in Australia each year, again it was pointed out that this is adding around \$143 million direct medical costs to the health budget each year. And this doesn't take into account the broader social and economic costs.

Good news: a healthy, balanced lifestyle, with good support, stress and nutritional management, coupled with an holistic approach to health while having hepatitis C and with full involvement in our own selfcare, will strongly assist in maintaining our health and wellbeing. Common ground was established between complementary therapists and medical doctors.

In closing the conference, the NSW Health Minister Dr Andrew Refshauge had this to say: "Australia's response to HIV has been the best in the world. One of the plans for the future is to learn from the lessons of the past." If NSW and the rest of Australia *can* learn from the lessons of HIV, and apply those lessons in concrete, visionary terms, then that will be good news indeed.

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

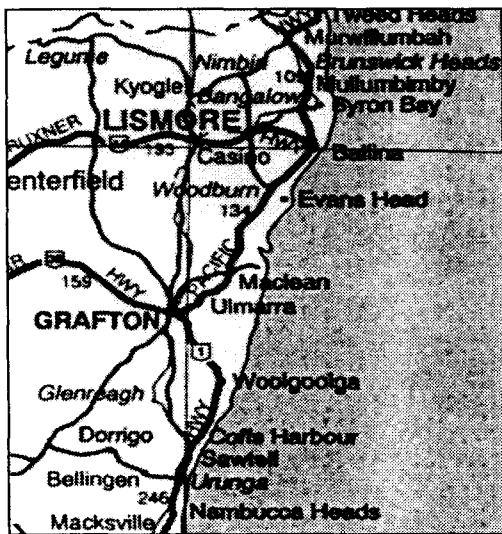


Clarifying how hepatitis C is transmitted should reduce community concern and reassure partners and household contacts of people with the virus.

a report by **Tim Sladden**,

Uncertainty about how hepatitis C virus (hep C) is spread has given rise to community concern and discrimination of people living with the virus.

It is now becoming increasingly clear that hep C is almost entirely spread via direct blood contact. A recent study that we conducted in the North Coast of New South Wales supports this as we found blood exposures for almost all study respondents.



The majority were former or current injecting drug users. Receipt of blood transfusions was the next most common exposure, and tattooing, needle sticks, blood splashes and origin in high risk countries accounted for most other cases.

Knowledge of transmission patterns should reduce community concern about hep C and help reassure family members and other household contacts that there is no risk of infection via casual contact. Getting this message across to the general community will reduce the paranoia associated with blood borne viruses such as hep C.

People living with the virus pose no risk to the general community, or to their workmates or families provided blood exposures are avoided.

Hep C cannot be transmitted via shaking hands, sharing toilets or washing facilities, sharing eating utensils (provided these are not used for injecting drugs eg spoons or cups), sharing towels, linen or washing machines, or by hugging or kissing (people should avoid contact with open wounds, cuts, blisters or cold sores.) Further still, biting insects do not transmit hep C.

To ensure blood exposures do not occur, people with hep C should not share any drug injection equipment or donate blood or organs. They should not share personal items such as toothbrushes, razors or combs that can have minute amounts of blood on them and these items should be kept separate from those of other household members.

People with hep C should cover any cut or wound with a waterproof dressing, wipe up any blood spills with paper towels and bleach and place blood stained items in a plastic bag before disposing of these in the garbage. If people inject, used needles and syringes should be replaced in fit packs and returned to needle and syringe exchanges.

Sexual transmission is very rare, but may increase with menstruation, unprotected anal sex, high viral blood levels (often during early, acute infection), or if other sexually transmissible diseases (STDs) are present.

People having sexual contact with someone other than a long term partner should always practise safe sex and use a condom to protect themselves from a variety of sexually transmissible diseases.

People with hep C in single, stable relationships, where their partner is uninfected should seek medical advice regarding their infectivity to their sexual partner.

Transmission from mother-to-infant is also very rare, the risk again increasing with high viral levels and STDs. Hep C has not been found in breast milk but cracked or bleeding nipples may allow transmission to infants. People who are planning to have a baby should also seek medical advice regarding their infectivity to their baby.

The bottom line is people with hep C can benefit a lot from support from their family and friends, and pose no risk of infection via everyday, casual contact.

Anyone interested in our study may find it in the Medical Journal of Australia vol 166 (6), p290-293, or may contact the North Coast Public Health Unit on (066) 21 7231.

• **Tim Sladden is an epidemiologist at the North Coast Public Health Unit based in Lismore. Public Health Units are part of the NSW Health Department.**

□

You can't always get what you want but you get what you need.

Did my wanting to be healthy stem from having hep C or from wanting better quality relationships?

Six months ago I would have said definitely - healthy relationships.

Now I realise that I want to be healthy for my own sake.

That is - healthy from all angles.

Feeling good Emotionally, Physically, Mentally and Spiritually.

No, I'm not religious. The spirit I talk about is within.

Pretending to be spiritual and feeling rotten inside does not add up. The really big concern for me is to feel emotional well being. Everything flows from that and how I achieve this is by hard work. The cycle of feeling good physically, mental alertness and putting it all together and having so called spirituality. Any part of the cycle that gets lost along the way throws everything into discord and I try again. That's what I said, ..working at it..

How long does all this take? It is taking..... a while.

Pat

□

Growing your own body parts is on the way

by Leigh Dayton

Lizards grow new tails. Cockroaches sprout replacement legs. And now scientists predict that early next century people will toss out their implants and bionic bits and grow their own replacement tissues and organs.

According to biologist Professor David Stocum of Indiana University in Purdue, USA, the fruits of 'regenerative biology' promise to reduce health care costs substantially while improving the quality of life for people whose bodies have been damaged or worn.

"That will be miracle enough," he wrote in an editorial in this week's *Science* journal. Although basic research and technical challenges must be met before people can regenerate their own replacement parts, Professor Stocum said that "the major approaches to solving the problem are in place."

In fact, regeneration is already being applied in some situations, said Geoff McCaughan, an associate professor at the University of Sydney and head of the Liver Immunobiology Laboratory at the Royal Prince Alfred Hospital.

He said that surgeons in Europe, Japan and parts of the US frequently exploit this fact when they transplant pieces of liver from parent to child.

After the procedure, which has been tried out at the Princess Alexandra Hospital in Brisbane, the liver regrows to normal size in both donor and recipient.

This happens, he said, because "you can wipe out two-thirds of the liver and it will regenerate itself in the same way as in the Greek myth of Prometheus, where an eagle nibbles at his liver each night and it regenerates."

Dr George Michalopoulos and Dr Marie DeFrances of the University of Pittsburgh wrote in *Science* that the liver does this because when it is injured, proteins called cytokines and growth factors cause its cells to undergo "partial differentiation", allowing them to divide simultaneously while performing their normal functions.

In some other tissues, such as bone and skeletal muscle, Professor Stocum said that small caches of "precursor" cells known as stem cells are set aside for growth and repair. If damage occurs, these generalised cells are stimulated to "differentiate" into the right kinds of specialised bone and muscle cells needed for repairs.

- Leigh Dayton is Science Writer for the Sydney Morning Herald. This article is taken from the SMH, 5/4/97.

an hcv counselling perspective

by Annie Kia & Kerry Leitch

Counselling Issues and hepatitis C

As counsellors working in a sexual health service in Lismore we have a significant number of people accessing our service in order to deal with issues associated with their hepatitis C.

Our 'clients' include those who have just been given a new diagnosis, people who have been given their diagnosis some time ago and have been given misinformation (generally of the "horror story" variety) and people dealing with chronic ill health.

In addition, clients are presenting who are alcohol and drug dependent, and clients who are wanting to deal with issues about their past injecting drug use. Usually counselling would be over a short period of time but occasionally we provide more in-depth therapy for persons wanting to make a shift in how they cope emotionally with hepatitis C.

People who have been given a hepatitis diagnosis want several things - including answers and reassurance regarding their health. Counsellors can provide information, listening and help with decision-making around disclosure and lifestyle changes.

One of the difficulties about having hep C is the fact that people do not know if they will have mild symptoms or none at all, or if they will go on to develop more serious disease. Everybody with hep C would like to know the answer to this question, but unfortunately this is one of the things that cannot be simply determined.

So while counsellors cannot answer the question "what will happen to me now?", they can sometimes help the client come to terms with living with this kind of uncertainty.

Counselling strategies

At times people find themselves in a situation in which they need to talk about how hep C is affecting them, in particular those who have chronic disease. Their partner or family members may be burnt-out from hearing of what it's like to cope with intermittent or chronic illness. In this case it may be a good idea for the

person to be encouraged to visit a counsellor to explore their feelings in relation to the illness.

At times hepatitis C brings up issues from the past that a person can benefit from talking about in a counselling situation. For example, they may have used injecting drugs in the past and have buried that part of their lives either in their own psyche, or in relation to the information that they have given to others about their history.

It is useful for a client to explore how they feel about that part of their lives as in some cases this lifestyle has been kept secret and may carry some guilt. It is imperative that the counsellor impart a non judgemental attitude to enable clients to feel safe in disclosing past and current behaviours.

Besides issues from the past, there might be some very pressing issues to do with lifestyle changes in the here and now. A client who had previously not taken very good care of their health might want counselling and support in making changes to their diet or those wanting to give up excessive alcohol may need assistance in a referral to drug and alcohol services, or to appropriate self-help groups.



The issues mentioned above are typically dealt with in a small number of sessions, but at times a person might present who is wanting to make a significant change in how they deal with their illness, which may be impacting negatively in their lives.

In such instances we have used cognitive approaches to help the person find a new way of dealing with chronic disease. An example of this would be helping the person to find different thoughts so that they generate different feeling states.

The concepts of rational emotive therapy (RET) are sometimes useful here. The basic concept in RET is that our thoughts tend to create our feelings. If A is the event, B is our thinking about the event, and C is our feeling about the event, it is helpful to acknowledge the power that B (thinking) has in generating C (feeling).

Applying these concepts when working with a person with hep C you might find a scenario in which the person wakes up with

severe fatigue, some unexplained pain and cannot go to work. A bit of time exploring their thinking habits might reveal that they have a tendency to interpret this event catastrophically.

The A-B-C sequence might typically go:

- A Wake up feeling sick
- B Think *"oh no! This probably means I'm going on to be one of those who has liver failure"*
- C Feel *"despair"*

Through exploring this sequence, the client might learn to think different thoughts, for example:

- A Wake up feeling sick
- B Think *"well, this looks like a pattern of intermittent ill health. I need to adjust my life to this"*
- C Feel *"disappointment, perhaps some grief that has to be worked through"*

Clients sometimes benefit from keeping a diary for a while in which they note their habitual thought patterns, and practise running thoughts that lead to more productive feeling states.

In the example above, a feeling of disappointment at not being able to work is much more preferable to feeling despair.

Likewise, if the person needed to work through some grief as they come to terms with the loss of feeling 100% every week, this is an easier feeling to deal with than the despair generated by the "oh no" thought in the first scenario.

The above type of intervention might be appropriate for clients who are having significant problems living with a debilitating illness.

However, most of the hepatitis C counselling that we provide at our Sexual Health Service involves only a few sessions - in which we provide information, brief intervention, and listening.

Above all, in providing hepatitis C counselling, the quality that is most helpful is that of acceptance of the client. Given the stigma that is still unfortunately associated with this illness, acceptance is critical.

- Annie Kia and Kerry Leitch work at the Lismore Sexual Health Service - part of the North Coast Area Health Service. □

DISABILITY SUPPORT PENSION UPDATE

In the last edition of *The Hep C Review* we highlighted proposed Dept of Social Security changes to the Impairment Tables used to assess people's eligibility to receive Disability Support Pension (DSP). The effect of these changes could have been to reduce the number of people with chronic fatigue (the major symptom of hepatitis C illness) currently able to claim DSP through their inability to work more than 30 hours per week.

We made an urgent submission in October 1996 protesting against these changes, and lobbied government and opposition politicians to oppose them as well. In December the Federal Senate rejected this part of the Social Security Legislation Amendment Bill, and called for further changes to be made and for proper community and professional sector consultation to take place.

Under the revised amendments in the second draft, some positive changes had been made, which we welcome and support, but we remain concerned that still too great an emphasis is placed on medical diagnostic criteria. Function based assessment criteria have been introduced in the Impairment Tables, and we welcome this.

The Hepatitis C Council of NSW has made a second submission to the DSS. This is fully endorsed by ANCARD, members of our Medical Advisory Panel and hepatitis C councils from across Australia.

We are also concerned that the proposed tables, excessively emphasising work attendance and work related performance, will disadvantage people who are making concerted efforts to remain independent and motivated though part time employment.

Outside of this, and not being considered in the legislation that will go before Parliament, is the worrying fact that there now appears to be a *double assessment* of eligibility to DSP. The new combined claim package form appears to introduce newly introduced criteria for assessing a continuing inability to work. The standard of these criteria is far more stringent than that used in the Tables and is in our view unnecessarily excessive. We are also disturbed by both the timing of this review, coming in at the end of the submission time for the Impairment Tables, and the short time given to assess the impact of these new criteria.

It is by no means certain that all people eligible under the existing criteria will remain so once the changes are made. We await the DSS reply, and will keep you updated.

- By Stuart Loveday - EO, Hepatitis C Council of NSW □

The Unexpected Diagnosis: normal reactions to an abnormal event

by Mary Sawyer

Reactions to the Diagnosis of Hepatitis C

In Australia and other western countries, the highest incidence of hepatitis C virus (HCV) is found among people who have injected drugs and among past recipients of unscreened blood or blood products - particularly clotting factor concentrates.

A confirmed diagnosis of hepatitis C can be difficult for people to accept, additionally so if they haven't engaged in high risk practices.

Any people receiving an HCV diagnosis can experience a state of turmoil that threatens their biological, psychological, social and spiritual stability.

Sudden unexpected events such as a diagnosis of HCV shatter the assumptions that one has about oneself, eg. that good health will be life long.

Australians have the benefit of a health care system that has generally been reliable and trustworthy. It is understandable that people with HCV who haven't engaged in high risk practices would react with an additional level of anger toward the health care system.

When people are confronted with the diagnosis of an incurable, chronic illness, they experience a range of individual reactions. This paper outlines some of these reactions.

Initial Reactions:

The initial diagnosis of HCV, whatever the route of transmission, can be a stressful life event that tests our coping mechanisms, relationships and emotional health. A person faced with a stressful situation such

as a devastating diagnosis often experiences feelings of frustration, anger and depression. If coping mechanisms fail, frustration makes further attempts to solve the problem futile. Hence there is a loss of emotional equilibrium which may lead to crisis. In order to maintain emotional equilibrium and not experience a crisis, people need to have the following three balancing factors in place:

- a realistic perception of the problem
- available coping mechanisms
- available social supports.



One missing balancing factor can tip a person or family into a crisis situation. When this occurs, the impact phase or the shock of the initial diagnosis characteristically results in emotional upset.

Typically there is a dramatic increase in generalised anxiety, hyperalertness, increased startle response, difficulty separating from family members, poor concentration, anger and un-cooperativeness. Physical symptoms manifest as somatic distress, shortness of breath, weakness, and fatigue. Interpersonal behaviour may be disorganised, docile or hyperactive. A snap shot picture reveals a person who is depressed, withdrawn, crying and perhaps feels guilty.

After the initial impact phase of the diagnosis, the person moves on to the defensive retreat phase, although initially a he/she may fluctuate between the phases of defensive retreat and acknowledgement of reality. During this phase they can still be tense, feel inadequate, apathetic or euphoric, and experience swings of emotion.

Cognitively he/she fantasises about what could have been done, avoids thinking about the event and denies through rationalisation, the cause of the situation. Interpersonally, he/she usually withdraws yet may seek the support of others indirectly.

Temporary retreat is an adaptive response - emotionally, mentally and socially - acting to protect from the perceived stress and loss and overwhelming anxiety. This allows a person time to gradually realise what has happened and avoid the debilitating effects of high anxiety or panic.

Although tension and anxiety may rise, there is a gradual increase in a person's self satisfaction and confidence. Coping skills improve and appropriate plans are made.

The final resolution phase clears the way for a gradual mastery of the situation, and a lowering of anxiety and possible bitterness. Cognitively, problem solving is more successful and thinking and planning are better organised.

Interpersonally, new resources are discovered, support systems are used and there is a resumption of status and roles. On the whole, crises are self-limiting, usually lasting 5-6 weeks before people start to get on with their lives.

Ongoing Reactions:

When the reality of the seriousness of a chronic ongoing disease hits the individual's family members, other, more confronting reactions may arise.

Chronic conditions are characterised by the unpredictability of flare-ups, setbacks, recurrences and exacerbations. Family reactions include

- anger and hostility toward the care giving system if excluded from information and the decision making process
- hostility towards spouse, strained family communication and coping patterns
- shutdown in family communication (common)
- repressed grief, depression, hopelessness

- exacerbations of a person's illness may produce anger and hostility within family members
- ambivalent feelings about the ill family member, followed by guilt
- loss of former family role and the ill person questioning their personal value

Uncertainty and Incurable Disease:

Incurable disease often involve much uncertainty. Chronic conditions are characterised by the unpredictability of flare-ups, set-backs, recurrences and exacerbations. This uncertainty often generates more stress. In the case of a person with HCV, uncertainty may make it difficult to have a clear perception of how they became infected, the diagnosis itself, the progress of the disease and how it will affect their lifestyle. This uncertainty can limit the person's sense of control and increase their sense of hopelessness.

Uncertainty can also make coping more difficult because it interferes with the ability to assess the situation. Hence, mobilising functional coping mechanisms can be difficult. It is more likely that emotion charged coping strategies will be used to cope, such as avoidance, denial, smoking, alcohol consumption, overeating and expressing anger.

Research has found that anger is positively related to the lack of clarity within such a situation. The greater the lack of clarity the more anger a spouse may feel. This anger could flow on to the partner with HCV.

It is also believed that increased uncertainty relates to poor adaptation for cancer patients. As with these patients, people with HCV may also adapt poorly because of the uncertainty of the disease process. The greater the uncertainty, the greater are feelings of dissatisfaction with the health care system, problems in family relations, emotional distress, sexual and work problems.

As there is a dearth of research in emotional social reactions to HCV, it can be predicted that similar problems may occur in the future.

The range of social/emotional experiences for people diagnosed with HCV and their significant others warrants sensitive handling. Fear, anger and uncertainty in coping with hepatitis C is not only stressful in the short term, but goes on over time. Counselling of people before and after diagnosis of HCV infection is highly recommended.

- **Mary Sawyer is a lecturer in the Department of Nursing Practice at the Australian Catholic University in Sydney. Mary is a registered nurse and a registered psychologist. She lectures and researches in psychosocial management of acute and chronically ill patients and their families. □**

RELATIONSHIPS AND CHRONIC ILLNESS

by Pam Shipway

When we think of relationships we have a picture of individuals freely committing to a mutually exclusive emotional connection. When one of these individuals is diagnosed with a chronic illness or condition it adds another dimension to the relationship.

Diabetes, haemophilia, HIV or hepatitis C are some of the conditions that can impact on relationships. Spontaneity and impulsiveness are difficult for a person with diabetes who daily needs to consider medication, insulin injections, strict dietary control, and the possibility of hypo's.

The daily life of someone with haemophilia is often interrupted by 'bleeds' and the need for immediate treatment.

HIV/AIDS has placed limits on people negotiating a new relationship and has been a major factor involved in many broken relationships.

A hepatitis C diagnosis can add a similarly negative dimension to forming a new relationship and the need to disclose when in an existing relationship. I have observed people who have these conditions become frozen in their denial of the unacceptable reality of their situation and experience difficulty in any discussion around this.

Discovering that you or your partner has a serious illness can trigger the same emotions as occur following bereavement. Mourning the *loss* is very legitimate and occurs before you can begin to accept what has happened

and anticipate what is ahead for you both.

There are intense feelings to work through, adjustments to be made and expectations to be reassessed. It is natural to think of what you can no longer do, but to focus on the positive and the good things that remain can be beneficial. Even writing lists of what is possible and achievable can be a useful exercise.

People who have two or sometimes three such medical conditions often avoid seeking close relationships, denying themselves emotional involvement and intimacy. With existing relationships when difficulties exist, the added strains involved due to chronic illness can lead to the end of the relationship.

One of the big things is how to tell others outside your "couple relationship". Family, friends, work mates, all pose questions of when and how much to tell - and maybe whether to tell or not.

The possible transmission of a condition to a partner sexually,



or to children through genetic factors is a consideration when deciding who should be told.

For some people, seeking support or talking to people who have been in a similar situation can be helpful. It can also be useful to obtain as much information and support as is available through organisations with expertise in the particular condition.

- Pam Shipway is the Coordinator of the Transfusion Related AIDS & Infectious Disease Service (TRAIDS) - a service providing counselling and support services to people with medically acquired hepatitis C (ph 02 9843 3143). □

the bitter taste of discrimination

With the body's infection of hep C you usually come across all the discrimination and application that any infectious diseases bring.

In my case, maybe no one can help. I have been told by doctors who would not operate on a leg injury (I had at work), hard luck, you're too high a risk for my surgical team.

Also, I have had doctors wash their hands after shaking my hand while saying hello. They've moved their chairs backwards, and also stood and moved away from me to the furthest corner of the room.

I have also had governmental and private dentists tell me to go away. They say they would not like to take a chance of infection. All they do is pity me, which is not much good for a toothache or cut leg.

Police put rubber gloves on to fingerprint me once. I've never heard of that before.

Discrimination - that's one side to it all.. But also you usually get so damn tired you usually don't want to get out of your own way. But they tell you it's not that bad and send you home to rest - 'big help.'

People just don't want to know unless it affects them. As if having an infectious disease puts them in danger so they say "STAY AWAY".

Sure, it works to a point but knowledge and understanding would be better than ignorance. So to say my life has changed, being hep C positive is an understatement.

Yours TC

A VIEW FROM THE MID NORTH COAST

I first got sick in 1978 when I was 20 years old. I had been using with friends for around 18 months or so and it was common practice back then to share fits - they weren't that easy to get so nearly everyone I knew, shared them.

I got very sick, very quickly. Even after numerous tests by my then GP and liver specialists, they couldn't tell me much except that my liver was swollen and that I didn't have heps A or B.

After being sick on and off for 20 years, and reading about hep C when it was first discovered, I thought back and realised that's probably why I started to get sick all those years ago.

Anyway, of course I tested hep C positive when I had the HCV antibody test.

Since I have been aware of my illness, I have tried to eat healthily and give up drinking. Over the years I've had chronic tiredness - sometimes to the point where it's an effort just to get up. I have also found it takes a little longer to get over little things like colds and other viruses.

Sometimes I have bouts of nausea and burp, bringing up the foulest smell of rotten egg gas. Other days I am fine and have energy to burn. The worst thing is that there's no pattern.

During the last 20 years, I have had a child and found the hep C did not affect my pregnancy (except of course for the tiredness.)

Anyway, I have a healthy 12 year old. I also have a partner who tests positive to a number of heps but he doesn't seem to be affected.

I've found most people are tolerant when I disclose my hep C status, but then again, I only disclose my status when necessary.

I am not embarrassed in any way about being hep C positive and have not been discriminated against by anyone so far. I think that all the latest information should be available to anyone seeking it.

Information should be free and made easily available to all parts of the community. I think the biggest single factor that has been instrumental in stopping or at least containing the spread of hep C has been the fact that needles and other equipment have become relatively easy to obtain.

Yours sincerely,
'Sick of being sick'
Urunga NSW

TRIAL OF A NEW, LOW-DOSE, SUBLINGUAL INTERFERON

"FERIMMUNE™ TABLETS 200 IU"

If you have Hepatitis C and have never had injections of interferon before, you may be eligible to take part in a clinical trial of a new, low-dose, sublingual (under the tongue) interferon product.

If you would like further information, please phone Janice, the study co-ordinator at Royal Prince Alfred Hospital on
9515 8643

This study has been approved by the Royal Prince Alfred Hospital Ethics Committee.

Remember the hepatitis C survey?

Back in September 1995, Edition 12 of the *Review* carried a survey developed by Toni Powell and Donna McDermott. The survey was aimed to guide the development of a book about living with hepatitis C.

The response was very positive with Toni and Donna receiving lots of responses. This response has enabled the authors to start work on the book *Heaven can Wait - Living with Hepatitis C*.

If you didn't know of the survey and want to be involved, phone Toni on 049 50 5585.

Like other hepatitis C books coming onto the market, *Heaven can Wait* will provide a very useful blend of clinical and personal information.

The 250-300 page book, still in development, will be reviewed within the *Hep C Review* upon release. We look forward to this as it will be the first available Australian book on hepatitis C. □

REVIEWED BOOKS

Matthew Dolan's *The Hepatitis C Handbook*, extensively reviewed in these pages, is not yet available in Australia. While arrangements are being made for local distribution, copies can be ordered from Central Books in London:

Tel 0011 44 181 986 4854

Fax 0011 44 181 533 5821

Email: peter@centbks.demon.co.uk

Payment by credit card equivalent 13.00 UK pounds plus post and packaging

Updates and information:

http://ourworld.CompuServe.com./homepages/Matthew_Dolan

ISBN 0 9529509 0 1 Published by Catalyst Press.

Email 106330.3137@CompuServe.com.uk

Living with Hepatitis C by Richard English and Dr Graham Foster will be reviewed in the next edition of *The Hep C Review*. Published by Robinsons of London, this 1997 self-help guide looks at all aspects of hepatitis C and at the full range of treatment options, both conventional and complementary, and is particularly strong on the psychological aspects of coping with hepatitis C.

Available in Australia in July through Random House ISBN 1-85487-913-8. Price \$16.95 □

The Hepatitis C Handbook

Matthew Dolan, Catalyst Press

A review by Peter de Ruyter.

Once I started to review those sections dealing with Traditional Chinese Medicine, Western Herbal Medicine and Homoeopathic treatments I was hooked and really wanted to cover the entire book.

It is indeed a timely and extraordinarily empowering book. One that truly should be read by every person concerned with this virus - especially people living with the challenge of HCV, and their partners, friends and family. It should also be compulsory and urgent reading for every government health official who has anything even remotely to do with this virus and the impact it has on our community.

The book's facts and figures plainly show that we are in the midst of yet another silent epidemic of frightening proportions.

The style is easy to read and understand for the lay-person, yet scientific enough to also appeal to practitioners. The text covers a holistic range of topics to do with hep C, providing information which is balanced and of great practical benefit to the reader.



The ancient Chinese script symbolising *harmony*

At present the medical system has very little to offer people with hep C, yet Dolan offers not only hope, but explores the many useful natural therapies. Such therapies have already proved their value in treating this disease, not just from a theoretical perspective, but from the much more grounded everyday clinical experiences obtained by so many.

Having said all the above, there are two points about which I have reservations. I would strongly endorse Dolan's slight reticence towards fasting, but state categorically that fasting can be quite hazardous to anyone with poor liver function. We live in very toxic times and the body is able to store such toxins for long periods in various body tissues such as fat.

The stimulation of a hard fast (ie. just water and no food at all), can result in a massive release of such stored toxins into the blood stream over a relatively short period of time. In turn this can easily overload an already struggling liver, resulting in further liver damage.

"Healing crisis" symptoms - such as headaches, nausea, tiredness and irritability - in a person with compromised liver function, may indeed be signals of further damage occurring, rather than just an elimination of toxins. I would urge the utmost caution in fasting for anyone who has any form of liver disease.

An alternate form of fasting for people in this situation - if they really want to do it - would be to fast for one to two days only at a time. Here they could minimise stress or harm to the liver yet induce some cleansing of the body by eating only rice, plenty of filtered or spring water plus *freshly made* and diluted vegetable juices.

The best juices would be lettuce, broccoli, capsicum, bok choy, celery as well as small amounts of carrots. My personal view is not to mix fruit and vegetable juices together as there is some indication that this further stresses the digestive system.

The other concern is the use of NAC. I do agree that it is a remarkable supplement to use in a large range of health issues, including hepatitis C. I would recommend it myself in practice; however, from a few snippets I've come across in the literature regarding the use of NAC in those with compromised liver function, I would urge at least some caution until this issue is clarified more through further research. Where true liver function tests are available such as caffeine or sodium benzoate clearance tests, these would be good to use in order to ascertain the exact status of the liver and hence the possibility of potentially compromising immune function.

There is also the interesting snippet regarding long-term use of NAC in regard to the possible induction of copper and zinc deficiencies.

Other than that, I would like to congratulate Matthew Dolan on an absolutely excellent book. I will be sure to highly recommend it to all my hepatitis clients, including those with hep A & B.

Thanks again for the opportunity to review this most important and valuable book.

•• Peter de Ruyter is a renowned herbalist, having been working in the field of Western herbalism and HIV/AIDS for over 10 years. He practises from a holistic medical centre in Bondi Junction, Sydney. □

What do people eat to get themselves in the mood for sex?



By Ruth Ostrow,
Daily Telegraph

I chose this question from our Great Australian Sex and Relationships Survey because the answers gave me a bit of a laugh. Not surprisingly, the statistics reveal that the single most popular food or drink for creating a sexy mood is alcohol, with a staggering 79 per cent using it as an aphrodisiac.

I was interested to find that slightly more women than men nominated this as their favourite option.

Wine was the highest rating alcoholic beverage, followed by champagne, which is more popular with females than males, and beer, which predicably arouses five times more men than women. Spirits rated last.

The next most popular foods of love were sweet things - the most popular sweet food being chocolate.

A recent survey in America found that 98 per cent of women think about having sex while eating chocolate, and 86 per cent think about eating chocolate while having sex. So it is not surprising that after alcohol, this is the top gastronomical turn-on.

I recently researched a story on erotic foods and why certain foods were considered aphrodisiacs. I interviewed several experts who each had a different view.

While the experts continue to argue the facts, I continue to read the impossibly long list of what gastronomical delights get people excited.

My favourite responses were the odd ones. One person named mineral water as an aphrodisiac, another pavlova cake, someone said pain-killers (oh dear!) and many liked chilli and other spices.

But the strangest turn on of all was Mexican food. Must be the beans. Kinda puts a whole new meaning to the phrase "the sex really blew me away", doesn't it? □

Chinese herbs for irritable bowel syndrome

by Alan Bensoussan

Irritable bowel syndrome now affects almost one in five people in Australia, and no reliable treatment is available. Australia's largest clinical trial of Chinese herbal medicine in the treatment of irritable bowel syndrome is currently being conducted by the Macarthur Research Unit for Complementary Medicine (University of Western Sydney.)

I've been investigating irritable bowel syndrome in conjunction with Professor Nick Talley of Nepean Hospital and Dr Meng Ngu of Concord Hospital. I anticipate this study to be one of the world's most fascinating explorations of complementary medicine.

In summary, the trial will:

- test the effectiveness of Chinese herbal medicine, in the treatment of irritable bowel syndrome (IBS).
- be the largest trial of Chinese herbal medicine (CHM) in Australia, and the largest thoroughly controlled trial of CHM in the West.
- be fully controlled and blinded - ie. patients, gastroenterologists and herbalists do not know which patients are taking active medication. All patients will receive active medication at some stage. The placebo has been designed to look, taste and smell like the active Chinese herbs.
- aim to test the true practice of traditional Chinese medicine as much as is possible - ie. to allow the Chinese herbalists to treat patients as individuals and prescribe differently for each patient.
- be the first clinical trial to be performed where patients may be treated individually with Chinese herbs yet remain blinded as to which treatment they are receiving.
- have the collaboration of 2 major teaching hospitals and gastroenterology units in Sydney, as well as a number of private gastroenterologists.

A number of successful trials have already been reported in China on the management of irritable bowel syndrome and its associated symptoms, and so it is important to test traditional herbal therapies in treating the condition in Australia. Traditional Chinese medicine (TCM) includes a wide range of therapies and is best known for the practice of acupuncture and Chinese herbal medicine. TCM has been used for centuries, and is becoming increasingly popular in Australia with an estimated 2.8 million consultations every year.

My colleagues and I are currently recruiting participants for the trial who will be required to take Chinese herbs in capsule form over a four month period. All Chinese medicines and consultations with the Chinese herbalists are free, and all patients are guaranteed active treatment at some stage during the trial period.

Patients with irritable bowel syndrome who are interested in participating in the clinical trial should contact Alan Bensoussan on 02 9772 9363 or Kathryn Taylor on 02 9772 6385.

- Alan Bensoussan is head of Macarthur Research Unit for Complementary Medicine (University of Western Sydney) □

The Hepatitis C Handbook

Matthew Dolan, Catalyst Press, UK

Reviewed by Prof Robert Batey

It is a pleasure to review this handbook produced by Matthew Dolan, a professional I have met in London and who is committed to ensuring that hepatitis C information is available to as many people as possible in a format which is readable and reliable.

The book has been designed with all levels of the community in mind and it has been divided into a number of major sections.

In part 1, the author deals with the background facts, figures and theories relating to hepatitis. This section covers information about the virus, the clinical illness caused by hepatitis C infection and the overlap that has been seen by some as existing between hepatitis C and other medical conditions such as chronic fatigue syndrome. Issues of coinfection with hepatitis B or HIV and a description of the liver itself are included in this first major section. This section of the book has been well researched and is well presented.

In part 2, the issue of a positive diagnosis is dealt with. This section is of major importance

because it raises all of the issues that are part of the life of an individual who has been given an HCV diagnosis. Extracts from individuals who have been given a diagnosis and have had to come to grips with this are included and it is very helpful to read through the experiences of patients as they have worked their way through the health care system.

In part 3, treatment options are canvassed and I believe that this has also been done very fairly. A lot of information about a number of herbal treatments is included and whilst there is a lack of major references confirming the efficacy of many of these compounds, it is important to have them identified so that individuals can consider the use of these alternative therapies in light of information provided.

In parts 4 and 5, issues of lifestyle modifications and their impact on the disease and some recent conclusions are covered.

In showing this book to other members of my own staff I have found their responses included "this is the best summary of hepatitis C we have seen in our professional experience" and "can we have an individual copy for ourselves". Praise enough in itself.

Whilst minor modifications might be made by some who read the book, I think it is appropriate to suggest that this handbook is an invaluable companion for all who are involved in dealing with people with hepatitis C. It comes in a very usable format. It is not excessively expensive and I would recommend that everyone who has anything to do with Hep C purchase a copy of the book.

Robert Batey is Conjoint Professor in Gastroenterology at the University of Newcastle, and Director of Gastroenterology at the John Hunter Hospital, Newcastle. □



healthy & happy

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, our Council has a web page that can be found at:
http://www.span.com.au/hepatitis_c/info.html

Our site will soon feature the winning pics of our graphics competition, recently advertised in *The Hep C Review* (page 27, edition 16.) Entries are still open!



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.

TREATMENT TRIALS

a current update

There are several treatment trials in progress in NSW.

The Aushep 4 trial compares one group of people on a 12 month interferon program against another group on a 6 month program. All trial places are full, but for further information, contact Sue Cromie (03 9276 223).

The Aushep 5 combination treatment trial involves the use of ribavirin and interferon. This trial is for people who have already been on interferon and initially responded, but who relapsed after stopping treatment. This trial is not yet funded but will hopefully start in the second half of 1997. For more information contact Tracey Jones (049 21 4789) or Susan Holdaway (02 9845 7706).

Other upcoming trials at Westmead Hospital for people who didn't respond to interferon are hepazem, and beta interferon.

Hepazem is a drug normally used to treat high blood pressure. It is believed that hepazem will increase the oxygen supply to the liver, increasing the liver's ability to fight hepatitis damage. It is not a cure, but is hoped to improve liver function possibly resulting in reduction of viral load and increase in the body's defence mechanism, thereby improving a person's quality of life.

Beta interferon is newer than the current, alpha interferon, and is still under investigation. Westmead hospital will be involved in a new dose-finding trial. Early trials showed promising results in people who did not respond to alpha interferon. For further information, contact Susan Holdaway (02) 9845 7706.

□

The Hepatitis C Handbook

Matthew Dolan, Catalyst Press

Reviewed by Prof Geoff McCaughan

I read this book with great interest - so much so that I was even taking it to the gym with me!

The first two sections of the book provide a significant and useful range of information including scientific facts on the virus (genotypes, natural history, infectivity, etc).

The book also includes a large section on symptomatology which I found rather difficult.

It is clear that symptoms such as fatigue, right upper quadrant discomfort and nausea are related to HCV. The list of associated conditions such as arthritis, cryoglobulemia arthritis, lymphoma, etc. seemed complete (although I'm not sure about hypertropic cardiomyopathy).

However, the list of suspected or possible clinically linked conditions listed on page 74 seemed a bit tenuous, and overall, many references are totally inadequate (eg. pages 4, 5, 7, 16, 23, 26, 50.) The book is also critical (p 83) of hepatologists, "minimising" symptoms or playing down the long term consequences of HCV infection. At times this criticism is warranted, but not always.

The third section of the book is an excellent reference guide to conventional therapeutics, traditional Chinese medicine, Western herbal medicine and vitamins etc. It does not advocate one form of therapy over another but provides options.

I found the reference to nosodes in the section on homoeopathy a little disturbing. Do some of these remedies really contain human liver infected with HCV? If so, what is the source? The lack of detail in homoeopathic regimes did not impress me with the notion of patient empowerment with respect to this therapy choice.

Overall, I would recommend the book to patients, those who support patients, and to healthcare workers (including hepatologists.)

In particular, I will use the book as reference for herbal therapies (there is a detailed list with ingredients) and also to remind me of the frustration of many HCV patients in their encounters with conventional medicine.

- Prof Geoff McCaughan is Physician In Charge, Transplant Hepatology, AW Morrow Gastroenterology & Liver Centre, Royal Prince Alfred Hospital. □



Australia's National Interferon Database is like a garden of treatment information.

Interferon treatment involves ongoing follow-up every 6 months after treatment ceases.



This information, fed into a confidential database, allows researchers to fine-tune treatment options, determining why different people are more suitable for interferon.

The project needs our support. Try not to drop out during the 5 year follow-up period. And check that your specialist sends on your information to the Interferon Database at John Hunter Hospital - ph 049 21 3794 or fax 049 21 3475.

THE 1ST AUSTRALASIAN HCV CONFERENCE

Organised by a committee of key individuals and organisations, the 1st Australasian Conference on Hepatitis C utilised four major streams - basic sciences, clinical sciences, epidemiology and social research, and public health.

Keynote speakers included Miriam Alter, Blaine Hollinger, Steve Jones, Leonard Seeff, James Shih (all USA), Cheryl Brunton (NZ), Massimo Colombo & Patrizia Farci (Italy), Juan Estaban (Spain), Paul Wells (UK), and Australian speakers, Chris Burrell, Tim Costigan, Linda Selvey, John Kaldor, Stephen Leeder, Wendy Loxley and Richard Smallwood.

Describing all the information covered at the conference would necessitate a separate booklet on its own. We have listed many of the individual papers presented by the range of both keynote and other speakers. If you are interested in any of the topics below, contact our information & support line (details on page 2) and we will send out detailed information.

Such information usually represents discussion on a topic and it may be a mistake to take it as scientific fact. Such fact is arrived at after exhaustive re-trialing and peer scientific review.

- Aboriginal healthcare & HCV
- Alcohol & hepatitis C
- Babies born to HCV IDU mothers
- Blood bank lookback program
- Chinese herbs & hepatitis C
- Complementary therapies & HCV
- Emerging new therapies
- Ethics & Australia's HCV response
- Harm minimisation video resource
- HCV genotyping in Australia
- HCV related liver cancer
- HCV transmission on NSW North Coast
- HCV vertical transmission
- Hepatitis G virus
- Home treatment for blood clotting disorders
- IDU & effect of HCV status on risk behaviour
- IDU discrimination
- IDU in Canada
- IDU peer education strategies
- IDU transmission risk questionnaire
- IDUs in UK
- Improved clinical services for people with HCV
- Interferon response
- National HCV needs assessment
- National interferon database
- Naturopathic approaches to HCV
- NSW prisons & HCV
- Outreach & IDU education
- Patient to patient HCV transmission
- PCR & HCV infectivity
- PCR testing
- Perinatal transmission of HCV
- Post-transfusion hepatitis C
- Quantitative PCR as predictor of interferon treatment
- Quasispecies & hepatitis C
- Risk of sexual transmission of HCV
- Risks for ambulance officers
- Risks in a juvenile justice setting
- Seroconversion within group of NZ IDUs
- Specialist's perceptions of role & availability of support services
- Targeting of interferon therapy
- Thailand & HCV
- Women & HCV social stigma

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NSW BLOOD BANK

A response to Jeff's letter

Thank you for the opportunity to reply to Jeff's letter (page 8).

On behalf of the NSW Red Cross Blood Transfusion Service, I would like to make the following points.

Hepatitis C antibody screening was introduced in NSW in February 1990, as it was around the rest of Australia (we became the second country in the world to introduce universal screening.) This was quite an achievement as we preceded the introduction of screening in the USA where the test was actually developed. We must all accept that the first test was not perfect, but equally accept that the test introduced at that time was the best test available and found the majority of donors affected with Hepatitis C.

Since then, there have been new improved second and third generation tests introduced and the efficacy of the testing has continued to increase so that now the test is exceptionally good. Whilst no biological test system will ever be perfect, the evidence is that the current testing is of an extremely high standard as clinical post transfusion hepatitis has now virtually been eliminated as a clinical entity. Over time, the improvement in testing as better kits became available was demonstrated by the lookback that Red Cross conducted, initially back to 1980 and now extended prior to that date.

Again, I believe Australia is leading the way as few countries have decided to undertake this exercise which State and Commonwealth Governments, as well as Red Cross, believe to be an important initiative.

Dr B. Wylie
Director
NSW Red Cross Blood Transfusion Service

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Heppers on the Net

If like me, you're basically obsessive, the internet can chew up a serious amount of quality time and actually impact on many aspects of your day to day life. This is particularly so when you first go online. But hey, gradually you evolve a more balanced relationship with it. Sort of like you do with hep C.

For a while after I was diagnosed, it was all about consuming. I longed to corner other heppers and talk hep C. You know - compare ALT levels, biopsy results, diets, interferon stories, etc. Great party asset *not!*

After a while having hep C was just sort of 'there', like the other inevitables of death and Christmas and hopeless politicians - and people asking why you don't drink. I learned to just factor my awareness of my hep C into my day to day life. I became aware of the resulting changes in my life, and developed an antenna for what was important for me.

But back to the internet - if we're talking quantity, the net is an information goldmine on hep C. But the world wide web, being what it is, you need to be discriminating about what's important and what's not. Two sites which between them have links to a lot of other information are:

hepatitis haven at

<http://www.tiac.net.users/birdlady/hep.html>

and the *happy heppers homepage* at

<http://www.geocities.com/HotSprings/2630/index.html#links>

Also check out the *American Liver Foundation*, the *Hepatitis Information Network*, and the *Focus on Hep C International* homepages. These will lead to dozens of great information packed destinations.

There are also two 'lists' on which people exchange information and stories. The first is called *HEPV-L*. To sign up on this list, send an email to: LISTSERV@MAELSTROM.STJOHNS.EDU and within your email message, type *SUBSCRIBE HEPV-L*, then type your first name followed by your last name and email address.

The second list is called *HEPC*. To subscribe, send an email to MAJORDOMO@LISTS.VOSSNET.CO.UK and as before, type in your first name, last name and email address.

Both 'lists' tend to have the same info. Some of the 'list' info is fascinating hard core stuff about treatments, new drugs, clinical trials, etc. This is usually obtained from medical professionals or takes the form of abstracts from medical journals or conference papers.

Within the 'lists' you can also share hep stories and other life experiences with many other ordinary people from all over the world. You can contribute or ask questions - but as mentioned above, you need to be discriminating about what is quality stuff. As always, seek informed opinion.

And also, if you feel like shootin' the breeze, drop me a line at PETERN@MAGNA.COM.AU

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SOME READERS GO A LITTLE ODD WAITING FOR THEIR HEP C REVIEW



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BE PART OF OUR AUGUST MAILOUT ON 4 - 8 AUGUST
JUST CALL PAUL ON 02 9332 1853

Artwork by Basil Wolverton (L) and James Montgomery Flagg (R)

Previously we contacted individual volunteers and potential volunteers to recruit mailout workers, whereas we now rely on readers who respond to this advertisement.

The work involves inserting newsletters into envelopes. The envelopes are then labelled and sorted. Yes, it's very interesting

work - so interesting that we spend a lot of time chatting, telling jokes and talking hep C.

With the August mailout, we are planning a wine tasting of de-alcoholised or very low alcohol wines. Primarily this to have a bit of fun, but it will also form the basis of a wine guide 'article' to be featured in Edition 18.

So make sure you mark your social calendar and phone in. Places are limited and will fill quickly. □

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.. but without the work done by our team of phone volunteers, we might as well just pack up and go home.

Volunteers come and go on a natural basis so we have top-up training sessions every four months.

The work is rewarding and can involve learning valuable new skills that are often useful in the paid workforce.

The next training session begins late July 1997.

If you or any of your friends are interested, live in Sydney, and want to find out more, give us a call. Phone Helen on 9332 1853.

Our next edition of *The Hep C Review* will focus on the relationship between hepatitis C and injecting drug use.

For most of us, injecting drug use is the most likely route of contracting HCV, and may be either a current or past behaviour.

For others, injecting drugs has nothing to do with having hepatitis C.

But the portrayal of hepatitis C issues within Australia's electronic and print media ensures that injecting drug use is an issue for everyone affected by the hepatitis C virus.

The next edition will discuss issues such as prevention, law reform, discrimination, media responsibility and access to hepatitis C treatment, care and support services.

We'll be printing articles from health professionals working in the field, and most importantly, your views and stories that we hope you'll share with all our readers.

So please, write in with your personal stories or viewpoints (our contact details can be found on page 2).

The Weekender

The man who put Tamworth on the map
EXOTIC Morocco
More Mercedes for your money

FEATURES P 5 TRAVEL PP 10-11 MOTORING P 14

BOOKS P 6 MUSIC P 7 LETTERS P 8 OUTDOORS P 9 COMICS P 17 TV PP 18-19

HEPATITIS C

Australia's greatest health threat?

HEPATITIS C is Australia's fastest-growing infectious disease - 10 times more prevalent than HIV. It's also a potential time bomb, with symptoms taking about 13 years to show. Hepatitis C is transmitted through contact with blood, and among injecting drug users the disease is now at epidemic proportions. JENNY DENNIS reports on Australia's new health threat and what's being done to control the spread of the disease.

STORY WEEKENDER 2-3

THE WEEKENDER, Saturday, January 18, 1997

The Illawarra Mercury's cover page (above) is an example of media portrayal of hepatitis C and injecting drug use. What are your views on media coverage of this/these issues?

interferon what you may need to know

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).
- One positive antibody test result, then a second test repeated between 4-6 months later.
- Liver function tests (with ALT readings 1.5 times normal upper limit) done three times over a six month period.
- Absence of cirrhosis or other serious liver damage.
- Absence of HIV infection.
- For women - not currently breastfeeding nor any chance of pregnancy while under treatment.
- No history of significant psychological problems.
- Must be able to attend regularly for treatment & follow-up.
- Alcohol use of no more than seven standard drinks a week.
- No history of injecting drug use in the previous 12 months.

The course of treatment involves giving yourself an injection three times a week. Twelve months of treatment is currently recommended.

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 | Bigge Park Centre (Liverpool) |
| 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 |
| 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.

□

Natural therapies

These have been used to treat hepatitis C and its possible symptoms but to date, there have been few research trials in Australia to check the effectiveness of natural therapies.

Certainly though, many people report positive benefits.

Natural therapists using acupuncture, homoeopathy 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 worldwide 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 Homoeopathic 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 |
| Homoeopathic 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 | ☎ | 046 77 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).

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NSW Hepatitis C Information 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 coordinate 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:

- Western NSW: Robert Baldwin, 068 85 8937
- Hunter: Marilyn Bliss, 049 24 6477
- Mid West NSW: Jeanine Buzy, 063 32 8576
- SE Sydney: Colin Clews, 9588 6777
- Mid Nth Coast: Lee Davidson, 065 51 1251
- South West NSW: Dalton Dupuy, 060 58 1700
- Nthn Rivers: Wendi Evans, 066 21 7231
- New England: Margaret Gearin, 067 66 2288
- Sth Wst Sydney: Mark McPherson, 9827 8033
- Lower Mid Nth Coast: Liz Meadley, 065 51 5400
- Central Coast: Karen Nairn, 043 20 3399
- Illawarra: Brian O'Neill, 042 28 8211
- Wentworth area: Elizabeth O'Neill, 047 22 2255
- Western Sydney: Chris O'Rielly, 9843 3118
- Central Sydney: Lesley Painter, 9515 3202
- Nthn Sydney: Anthony Schembri, 9926 8237
- Far West NSW: Darriea Turley, 080 88 5800
- Southern NSW: Greg Usher, 048 27 3148
- SE Sydney: Marlene Veleckey, 9382 3694

One-to-one counselling

Some people with hepatitis C may want to make use of a specialist counsellor. These 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.

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 the postage when you send them back to us. All you will need to pay is the return postage of \$3.00

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

| | | |
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| Hep C - a brief introduction | An A4, two fold brochure giving an overview on hepatitis C | \$5 per 100 |
| Hep C - what you need to know | An overview of hepatitis C, including testing, treatment, biopsies, haemophilia, lifestyle changes, prevention, drug use, women & hep C, prognosis and a hep C glossary. | no cost |
| Newsletter back issue pack | Topics include Social Security, Disability Support Pension, Interferon treatment, natural therapies, history of the Council/Support Group | no cost |
| Video No.1 | Prof Geoff Farrell discussing Interferon treatment, & Jennifer Holmes discussing women & hep C. | \$3.00 return postage |
| Video No.2 | Ken D'Aran discussing homoeopathy, & Raymond Khoury discussing herbalism. | \$3.00 return postage |
| Video No.3 | Women and Hepatitis C Forum - featuring Dr Ingrid van Beek, Ses Salmond and Cheryl Burman. Apologies - this video is temporarily unavailable. | |
| Video No.4 | 2 Quantum episodes: & hepatitis C and the liver | \$3.00 return postage |
| Research Pack No 1 | Hepatitis C research papers - overview, prevention, diagnosis, serology, epidemiology (1993-1995). | no cost |
| Research Pack No 2 | AGI booklet (1994), Fairfield Hospital healthcare provider booklet (1994), & National Hepatitis C Action Plan (1994). | no cost |
| Research Pack No 3 | NHMRC Hepatitis C Report (1994) | no cost |
| Research Pack No 4 | WA Dept Health HCV booklet (1995), & hepatitis C research papers | no cost |
| Research Pack No 5 | AHMAC - The Nationally Coordinated Hepatitis C Education & Prevention Approach (1995), & NSW Health Taskforce Report (1995) | no cost |

Hep C Classifieds - keeping you in touch

For Sale

Microsoft 'Natural' keyboard. As new. Still in box with software and documentation. Yours for \$50 (less than 1/2 price).

Phone Paul (02 9360 7795)

This space is all yours. Just write in with your advertisement or notice.

This space is all yours. Just write in with your advertisement or notice.

This space is all yours. Just write in with your advertisement or notice.



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 | | | |
| Street 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? | <input type="checkbox"/> |
| Other? | <input type="checkbox"/> |

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

| | | | |
|---------|--------------------------|------------|--------------------------|
| Renewal | <input type="checkbox"/> | New member | <input type="checkbox"/> |
|---------|--------------------------|------------|--------------------------|

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.
 These are tax deductible. If you make a separate donation, please record the amount here.

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

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|------------------------|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|---------------------------|--|--|------------|--|--|------|--|--|----------|--|--|
| Card number | | | | | | | | | | | | | | | | Card type (please circle) | | | Mastercard | | | Visa | | | Bankcard | | |
| | | | | | | | | | | | | | | | | 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 for office use only | Date received | \$ received | Receipt no. | Date entered | Member no. | Info pack |
|-------------------------------------|---------------|-------------|-------------|--------------|------------|-----------|
| | | | | | | |
| staff initials | | | | | | |