

The Hep C Review

Winter Edition September 1998

Edition 22

PCR given - yet kept - by Commonwealth

In partnership with the federal Ministerial advisory body ANCARD (*Australian National Council on AIDS & Related Diseases*), hepatitis C councils and specialist clinicians have lobbied for greater access to Medicare covered PCR tests.

In welcome response to ANCARD's formal submission, the Commonwealth Department of Health and Family Services recently announced that people with hepatitis C can now have PCR tests done that will be covered under Medicare Benefits Schedule.

Consequently, people with hepatitis C can request a PCR test from their doctor and they won't be charged for it.

Limitations have been applied and before people rush out to request their test, they'd need to know that:

1 Medicare covers the basic PCR HCV viral detection test - as opposed to viral load or genotype tests (*see Ed 20 for more info*).

2 Medicare covers only one PCR test each year for any one person.

1 Medicare covered PCR tests are available only in limited situations - including:

- * those people who have had a positive HCV antibody test and who have normal liver function test results on two occasions six months apart, or
- * people who have inconclusive HCV antibody test results, or
- * people who have weakened immune systems (eg. HIV/AIDS) and want to confirm whether or not they are hepatitis C positive, or
- * people who have experienced a risk exposure (eg. needlestick injury) and want to confirm during the 'window period' whether they have contracted HCV.

The Commonwealth has funded PCR for use in a limited set of situations although our recent ANCARD submission urged a much wider usage. We had hoped for PCR access that would greatly assist people considering or undergoing treatment, and people considering whether to proceed with pregnancy.

We don't expect unlimited access to PCR for all people with hepatitis C, but we do expect that in the immediate future, the Commonwealth must consider the current and evolving scientific evidence that supports the following applications:

* PCR viral genotype testing to help assess which people have a better chance of responding to interferon treatment.

* PCR viral load testing to monitor, in the early stages of interferon treatment, which people will not respond - thus saving months of side effects.

* PCR viral load testing to predict the relative risk of vertical transmission during pregnancy.



The Commonwealth is certainly to be congratulated for the current initiative. The next step is to resubmit the submission for funding that allows wider Medicare coverage of PCR testing - which is being done by CTTAC (the Clinical Trials & Treatments Committee within ANCARD).

The Diagnostics and Technology Branch of the Commonwealth Department of Health and Family Services will consider the evidence and will make a recommendation in due course.

We believe the evidence to support funding for PCR viral load and genotype testing is overwhelming.

Individual hepatitis C councils and the Australian Hepatitis Council will be providing strong support to have this submission approved as a matter of urgent priority.

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

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Parliamentary committee considers hepatitis C

By Jan Burnswoods, MLC

In 1997 the NSW Minister for Health, Dr Andrew Refshauge, requested the *Standing Committee on Social Issues* inquire into hepatitis C in New South Wales. This is the first time an Australian Parliamentary Committee has been asked to examine this issue which impacts upon such a significant proportion of the community.

We were asked to comment on the social and economic impact of the disease; the extent and epidemiology of the virus; the adequacy of policies relating to diagnosis, treatment and prevention; and specific "at risk" groups including health care workers.

Throughout 1997 and 1998 we received written submissions and took formal evidence. Over 100 submissions were received - the majority from people with hepatitis C or their family members. A very wide range of people made submissions including current and past injecting drug users, prisoners and people who received HCV infected blood/blood products. The perspectives brought to the inquiry by each of these groups have been invaluable in informing us of the day to day reality of living with the disease and the all pervasive impact it has upon people's lives.

During the course of evidence, we heard from some of Australia's most eminent hepatitis C specialists: Professors Farrell, Batey, McCaughan, Crofts, and Wodak in addition to experts in drug and alcohol, epidemiology, virology and public health. Representatives from a number of agencies providing a range of services to those with hepatitis C also gave evidence: the Hepatitis C Council of NSW, NUAA, TRAIDS, and the Haemophilia Foundation.

Some of the most poignant and moving evidence came from those with HCV as they recounted their first hand experience of dealing with hepatitis C - the side effects of interferon therapy, the difficulties in accessing information and understanding general practitioners, the overwhelming sense of helplessness as their health deteriorated.

The Committee has come to appreciate that hepatitis C impacts upon the lives of people in a myriad of ways. The debilitating fatigue, for example, that limits relationships, work, and interactions with children - even simple household tasks. Many spoke of the fear they have of neighbours, work colleagues, even family members finding out their HCV status and the prejudices and stigma that would come with that knowledge. Stories were shared of blatant discrimination, and misunderstanding from community members, even health care workers, who fear a disease they know so little about.

"Stories were shared of blatant discrimination and misunderstanding from community members, even health care workers, who fear a disease they know so little about."

A number of issues were raised by witnesses during the course of the Inquiry including access to interferon therapy (the current criteria, location of prescribing centres), funding for PCR testing, availability of care and support services, prevention strategies, dedicated HCV funding, along with issues faced by specific groups such as prisoners, injecting drug users and those living in rural communities.

Preparation of the final report is almost complete and it is anticipated the Committee will finalise it when Parliament resumes in September. We hope to table its findings in October/November. Once tabled, copies of the final report will be available to anyone interested. People who made a submission or gave evidence will automatically receive a copy. However, if you did not make a submission yet would like a copy of the

final report, please contact the Standing Committee and leave your details. We can be contacted by phone on 02 9230 3435, by fax on 02 9230 2981 or by email on cknight@parliament.nsw.gov.au

Once again, we would like to thank those who made a submission to this inquiry. I can assure you that the contribution made was important and played a part in helping us understand this disease and its debilitating consequences.

- Jan Burnswoods, MLC is chair of the NSW Parliamentary Standing Committee on Social Issues.



More on legals

Thanks for the articles on legal issues - they were interesting.

What is of greater interest to me, though, is the question of where people who are already in employment stand in regard to their hepatitis C.

My current employer does not know that I have hepatitis C and this is no problem as it doesn't impact on my health and I feel quite well.

I'm thinking of the future and I'd like to know what will happen if I do become ill and have to take time off. Will my employer be able to sack me?

Many thanks if you can answer my query.

Regards - Olly

We've contacted the Anti-Discrimination Board and put together a detailed response. See page 31 - Ed.



In Defence of Kombucha

In your November '97 issue you ran a brief report referring to the possible harmful effects of Kombucha tea on the liver.

Since I am not aware of anyone else having leapt to its defence, I feel compelled to write to say that, as someone who has struggled for 10 years with the symptoms of hepatitis C, I attribute the improvement in my health over the past 2 years directly to Kombucha. Over the years I have tried a range of remedies, as we all tend to do, but it is only since I started drinking Kombucha in May 1996 that I have felt consistently better. I know it sounds like an advertising spiel, but it is very easy to make the stuff oneself, so no one stands to make a quid out of it.

I drink it first thing each morning on an empty stomach, usually with a teaspoon of Livatone powder mixed in, and I am convinced that it is beneficial.

I would not want to suggest that Kombucha alone is the key to coping with hepatitis C. For me there have been other strategies as well, such as:

- * a great reduction in work stress (I now work from home as a consultant rather than as a nine-to-fiver)
- * considerable attention to diet (simple food, an absolute minimum of fat and sugar, and NO grog)
- * plenty of rest
- * regular exercise
- * Guarana to rev me up a bit when I need something to get me through the day's activities
- * a close relationship with the Almighty and liberal doses of prayer

I recommend all of the above. I had a negative reaction to Interferon (my ALT went through the roof), whereas others have been greatly helped by it. Conversely other people have, according to your report, had a bad reaction to Kombucha, and I feel for them.

But my own reaction to it has been entirely positive and I believe it is worth a try, as part of a comprehensive lifestyle response.

Chris Marshall

Our initial comments on Kombucha were contained in Edition 19 - Ed.



Anne's letter

I would like to comment on the letter from Edition 21 of the *Hep C Review* written by Anne. I took great offence to her classification of some people with HCV being "the innocent ones".

What does this mean? To me it is laden with judgement and I am exceedingly saddened to read such moralistic dogma.

Anne wrote that her daughter got hep C "through no fault of hers". Again, what does this mean? Is someone to blame if they have stuck a needle in their arm? What if they only used once? What if they used for years but are now clean and living a life in which they abide by laws and pay their taxes? What if they have used for years and are still struggling with the horrible disease of addiction?

And, what if they contracted HCV through sharing a razor with an HCV+ person who is unaware of their status? I am sure that the morals of each of us would come into play and many of us would feel uncomfortable about this issue.

However, I do not believe that people want to get this condition and therefore there is no distinction between an "innocent" person with HCV and anyone else who is positive. Whether you stick a needle in your arm is beyond the point.

The "stigma and frustration" as Anne calls it, which many people with HCV feel, I believe is directly due to close-minded, moralistic statements such as those made by Anne. If Anne's daughter wishes to read about people who are "like her" maybe she should take an active role and write in to tell her story. I gather that is what this Review is all about.

Yours truly - Genn.

Consider the approach of your medical advisor. He saw me for just over 20 minutes, mainly asking general questions about my name, address and whether I still drive or do my own shopping.

Okay, my answer is yes - I'm still driving my car. But am I supposed to walk to the shops and carry my shopping home?

If these types of questions formed the basis of his evaluation of my condition, your system is very wrong. Especially in regard to illnesses such as hepatitis C. Your whole definition of 'disability' seems to be limited to visible outward signs such as missing limbs, blindness, etc.

You've seen my doctors' notes and you feel that I can compete in the job market with everyone else. I feel your attitude is very insensitive and ignorant. You really need to educate yourselves on this condition. Surely you can consult with Australia's hep C specialists and find out what are the realities for this illness.

When we are healthy and working, we pay our taxes to society. Our belief is that we will be cared for if we unfortunately develop health problems - especially life threatening ones.

My experience of the Department of Social Security is far from this ideal. I urge you to reconsider my case. I ask this not just for my sake, but for the sake of all of us who are affected by diseases of the 21st century.

I have contacted the Welfare Rights Centre and they have been very helpful. The above letter highlights the sense of injustice that I feel and I hope for all of us that my appeal is successful. I wonder how many of us with hep C have faced the same injustice.

Regards, Michael



Social Security Blues

I've attached a shortened down version of a letter I recently sent to the Department of Social Security following their rejection of my application for Disability Support Pension.

To the Delegate of Secretary of the Department of Social Security.

I am disappointed with your formal decision about my case.

In your letter responding to my application, you simply state that my impairment rating is less than 20% and that because of this I am ineligible for the Disability Support Pension.

In support of my application, I submitted letters from my GP and specialist. Both of these people gave professional, clinical opinion that supports my case.

My GP highlighted that I have a "severe problem with fatigue," and that for many days, I am confined to my home, relying on assistance from my teenage sons.

Meanwhile, my specialist outlined the condition of my liver: "fairly severe lymphocytic hepatitis due to hepatitis C [with] mild piecemeal necrosis and early fibrosis."

My specialist also performed a PCR viral load test which showed high level of viremia (2.0×10^6).

Both my GP and specialist have treated my condition for almost two years and my GP is of the opinion that I should be considered as unable to work.



Positivity power

Within Edition 21 I had an article titled 'Creativity and interferon'. If anyone out there is trying to contact me in regard to my article, please email me at <smfoster@ion.com.au>

Also, in response to JE's letter titled 'Diet Feedback', I too had good results including lowered ALTs after trying Sandra Cabot's *Liver Cleaning Diet*. Of course it is not a cure, but it helps.

In response to Valerie's 'The Good News', it's nice to see folks coping from love and understanding. It is a shame that so many have been scared by diagnosis and the use of such terms as 'incurable and life threatening illness' (see Ed 21 feature article 'Hepatitis C and Depression').

After all, there is a treatment with a one in three chance of sustained cure, and it is my understanding that less than 10% of

letters

people die as a result of having hepatitis C - and who knows what their diets and drinking habits were.

We all need to focus on the positive. Having hepatitis C isn't so bad and there are a lot of worse things out there.

Sincerely yours, **Marty**

Reviews of Sandra Cabot's 'Liver Cleansing Diet' can be found in Editions 15 & 16 - Ed.



The meaning of love

After having received my HCV diagnosis, I've discovered a new found appreciation for life. I've penned the following poem written for my girlfriend and hope you can find space to print it.

The first moment I laid eyes on you it was like I just walked through heavens gates, the sparkle in your eyes told a thousand stories.

At this time I knew that you were the only woman that I would ever truly love forever, it was like all my wildest dreams came at once. I feel like nothing in the world could stop me from being with you.

When we walked along the sands of the beach the sun sparkled on your face catching every inch of your beauty making you look like an angel from above.

Ever since I met you my life has changed for the better, I now know that there is a God, and he has sent me the most special gift in the world.

You are the princess of my dreams and the woman of my heart, you have made me everything that I am, without you my heart would stop beating and my life would be over.

I hope that we can spend the rest of our lives together and take our love for each other to new heights.

I know now that I will never need for anything again because I have you, I know that I can give you everything that you have been wishing for and much more, and my love will always be strong for you and never die.

I love you and I always will even when I die, my love for you will come to the grave and comfort me always and forever.

by Glenn Smith, in love of Natalie Bennett

(I would be really keen to get feedback on my poem above. Please write to me at: PO Box 197, Parklane, JUNEE NSW 2663)

AT THE PUB



Chronic illness - an introduction

Unlike many other viral illnesses, hepatitis C poses a range of often challenging issues for those people contracting it:

- It is a 'sleeper' illness - entering the body, it usually gives no hint of its presence and illness, if it develops, usually takes more than 10 years.
- It is 'long-term' in nature - probably 'life long' in cases where it remains untreated
- It will have different long term effects on people - with no current effective means of predicting individual outcomes.
- Currently, treatments are not overly effective.
- Currently, preventative vaccines do not exist.
- It is assumed there is a worrying level of ignorance towards hepatitis C amongst the general public - leading to perceptions of possible discrimination, and in many cases, actual proven discrimination.

Given the above, many people's experience of hepatitis C is much more than just medical or clinical - it has personal, social and even political aspects of illness.

Having hepatitis C will involve responses other than just visiting the doctor, taking a pill or having a shot and taking it easy for a while. Invariably, it will involve adapting to living with actual or potential chronic illness.

In this edition, we explore what hep C's chronic nature may mean for people.

As usual, we emphasise that our magazine is unable to address all issues. If you can suggest additional articles on chronic illness for Edition 23, please write in with your suggestions.



ACT first to announce hepatitis C compensation payout scheme

As reported in the Canberra Times, 19 August, the ACT government has agreed to compensate people who contracted hepatitis C via contaminated blood in ACT hospitals between 1985 and 1990.

The proposal will soon be put to the ACT Legislative Assembly for approval.

Individuals will be eligible for a payout up to \$100,000. It is believed the complete package will amount to \$3.7 million over a period of two years.

ACT politicians are now involved in an inquiry to determine why such action was not undertaken sooner. Current health minister, Michael Moore, is considering setting up a vigorous investigation.

Although the matter was discussed at a national meeting of health bureaucrats in 1994, former ACT health minister, Kate Carnell, claimed she was not briefed on the issue.

It is believed the Commonwealth government will cover 40% of the overall cost of ACT's package - although they have refused to compensate people who contracted HCV through blood-products used for clotting disorders.

New therapy packs powerful, one-two punch

'Rebetron' consists of a 6-month course of interferon injections combined with ribavirin capsules. It was approved for use in the United States by the FDA in June for adults with hepatitis C who initially respond but later relapse with standard treatment (interferon alone).

Interferon alone eliminates the virus in only 10%-20% of patients. Another 25%-40% respond but subsequently relapse.

In patients for whom the FDA approved the therapy [people who had previously relapsed on interferon alone] nearly half experienced a sustained remission (6 months or more) when administered the interferon/ribavirin combination in trials held in both the United States and Europe - roughly 10-fold better than the patients who received interferon alone.

Although the FDA approved the therapy specifically for the subgroup of patients who relapse after responding to interferon alone, physicians will be able to prescribe the treatment for patients as a first course. While the FDA has not yet reviewed the data, Willis C. Maddrey of the University of Texas South-western Medical Centre in Dallas notes that published results out of Europe suggest that previously untreated patients respond better to the combination.

Of course, the new treatment won't be for everyone. The side effects of the combination therapy are potentially serious because ribavirin causes a non-immune haemolytic anaemia, with an average drop in haemoglobin of about 2g.

"It's important for physicians to plan for that, to test patients' haemoglobin levels before treatment and at 2 and 4 weeks, and not to use this drug in anyone who couldn't stand a moderate drop in haemoglobin," says Maddrey.

As for the people who don't respond to the Rebetrone, Maddrey predicts that the next breakthrough will come with the addition, not substitution, of another antiviral drug, possibly a protease inhibitor, to the combination treatment. "It's similar to what occurred in AIDS, where we did well with AZT for awhile, but the real breakthrough came when we added a protease inhibitor to the AZT," he says. "We feel that multi-drug therapy is the wave of the future, and that hitting this virus in two or three sites gives us a much better chance of eradication."

- Taken from the international journal, *Gastroenterology* 1998; 115: 255-256.

Plan to slow GPs who speed through patients

By Marion Downey

Five-minute medicine - when some GPs see three times as many patients and earn three times as much as the average doctor - could be wiped out if doctors are paid in alternative ways being investigated by the Federal Government and the medical profession.

The Government's response to two reviews of general practice, presented by the Federal Minister for Health, Dr Michael Wooldridge, backs proposals to change the general practice fee structure to "minimise perverse incentives and maximise incentives for good-quality care".

Dr Wooldridge explained after the launch of the response that fast-turnover medicine was sometimes appropriate, "but clearly there are a small number of GPs that are seeing an extraordinary number of patients without improving patient outcomes".

A new professional standard, defining the level of GP services that can be carried out without endangering patient care, also received full government backing.

Dr Wooldridge also confirmed yesterday that the profession and Government would hold discussions over the next six months to finalise a five-year financing agreement.

The Government also wants the profession to debate alternatives to fees for service, such as a flat payment to cover GPs' practice costs combined with a rebate for consultations, at a lower rate than at present.

Dr Wooldridge said a General Practice Advisory Council would be set up to negotiate GP financing and new professional partnerships would focus on improving general practice in six areas, including improving access to medical services in rural areas.

The Australian Medical Association's federal president, Dr David Brand, said he backed moves to pay GPs to practise quality medicine but flat payments to cover expenses would pave the way to nationalised medicine.

But he said the profession was prepared to consider setting a standard for the number of hours GPs should work.

"We may need to look at ways of looking at inappropriate servicing and defining the hours worked by doctors. We are running a safe hours campaign for junior doctors. We could also do the same thing for general practice."

- Marion Downey is Health Writer with the Sydney Morning Herald. Article taken from SMH, 11/6/98

United States will discharge HCV soldiers

As reported by overseas news sources, US officials plan to discharge Armed Forces recruits found to be ill with hepatitis C.

The Deputy Assistant Defence Secretary for Health Affairs, Dr John Mazzuchi, recently secured funding for research that will explore how many of the two million US armed forces personnel are ill with hepatitis C. There is growing debate, however, over just how many personnel may be HCV positive and whether epidemiological research should be done at all.

The estimated prevalence in the US general population is 1.8%. Should the US military have the same prevalence, around 36,000 soldiers would carry HCV.

Some years ago, US military services began discharging new recruits who were found to be HCV positive through blood donations. At the moment, the only soldiers HCV screened are those who donate blood.

An overall policy is soon to be adopted by all US Armed Forces, reflects that of the Air Force - combat ready personnel with HCV will be allowed to remain in the service as long as they can do their jobs, then will qualify for government disability benefits.

Former United States Surgeon General, K Everett Koop, and other US medical and health experts said that if military authorities failed to adopt widespread HCV testing, several serious issues would later haunt them:

HCV positive personnel with bleeding wounds or cuts could transmit the virus to other soldiers who have skin abrasions.

HCV positive personnel who remain unidentified could be called upon to act as "walking blood banks" - not an uncommon responsibility within the armed services - and unknowingly transmit HCV to wounded comrades.

HCV positive personnel who are chronically ill with the virus but remain undiagnosed, might benefit from current and emerging drug therapies.

HCV positive personnel who drink alcohol but remain undiagnosed could benefit from knowledge of their infection given that alcohol exacerbates possible liver damage caused by HCV.

product labels. The amount of silver required to produce argyria is unknown. However, the FDA has concluded that the risk of using silver products exceeds any unsubstantiated benefit (1).

In October 1996, the FDA proposed to ban the use of colloidal silver or silver salts in over-the-counter products (2). To access the full text of this announcement, search the Federal Register for "colloidal silver."

Above references

(1) Fung MC, Bowen DL. Silver products for medical indications: risk-benefit assessment. *Journal of Toxicology and Clinical Toxicology* 34:119-26, 1996.

(2) US Federal Register 61:53685-53688, 1996.

- Stephen Barrett, MD works with 'Quackwatch' which can be found at: <http://www.quackwatch.com>

Taken from the international email list:
HEPV-L@MAELSTROM.STJOHNS.EDU

Colloidal silver: risk without benefit

By Stephen Barrett, M.D.

[Within Edition 17, we printed a 'Letter to the Editor' titled "Oxygen & HCV" in which a reader proposed colloidal silver as an effective although untested treatment for hepatitis C - Ed.]

In recent years, silver-containing products have been marketed with unsubstantiated claims that they are effective against AIDS, cancer, infectious diseases, parasites, chronic fatigue, acne, warts, haemorrhoids, enlarged prostate, and many other diseases and conditions. Some marketers claim that colloidal silver is effective against 650 diseases.

Colloidal silver is a suspension of sub-microscopic metallic silver particles in a colloidal base. Long-term use of silver preparations can lead to argyria, a condition in which silver salts deposit in the skin, eyes, and internal organs, and the skin turns ashen-grey.

Many cases of argyria occurred during the pre-antibiotic era when silver was a common ingredient in nose drops. When the cause became apparent, doctors stopped recommending their use, and reputable manufacturers stopped producing them. The official drug guidebooks (United States Pharmacopeia and National Formulary) have not listed colloidal silver products since 1975.

FDA laboratory studies have found that the amount of silver in some product samples purchased has varied from 15.2% to 124% of the amount listed on the

Despite liver failures, diabetes drug kept on market

As reported via the internet, Rezulin, a new diabetes treatment (also known generically as troglitazone) has shown bad effects on the liver.

Within a small minority of people using the drug, liver function tests show abnormal elevation of particular enzymes.

Manufactured by Parke-Davis, Rezulin went on the market internationally in 1997. It is the first new diabetes drug developed for some time.

Internationally, over 12 people have died from liver failure while on the treatment - although a US consumer's group claims this figure may be twice as high and that the drug should be pulled off the market.

Parke-Davis have responded claiming that liver problems associated with Rezulin will be avoided by more careful prescribing by GPs. Consequently, detailed information concerning possible contra-indications will be made available.

Rezulin is not yet available for use within Australia although it is currently under evaluation by the Therapeutic Drugs Administration. The treatment is expected to be on the market here in Australia, early in 1998.

To be prescribed under more rigorous guidelines than when initially implemented in the USA, it is believed Australians need not be overly alarmed about risks associated with Rezulin.

Certainly, this case highlights the need for people with hepatitis C to fully disclose and discuss their hepatitis C status with doctors and specialists - especially when medications are prescribed or given.

Indulge yourself

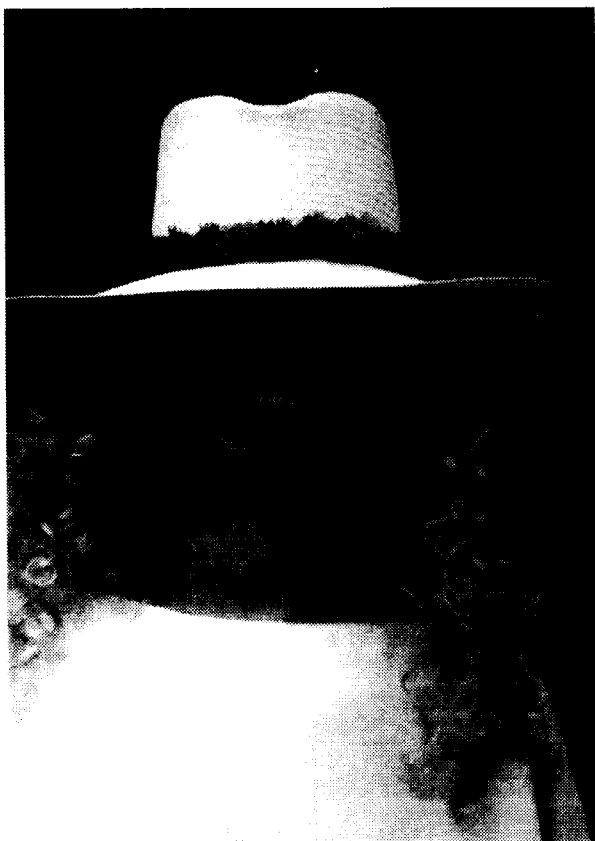
Hi. My name is Marty. I am currently participating in an interferon dosage trial and thought perhaps sharing my experience might be of some value to others out there currently on, or considering the interferon program.

The study I'm in has over 2,000 participants from around the globe. It is a blind study trying out four different doses, using Type A and pegalated interferon. I was lucky enough to draw the pegalated form, which means one injection per week instead of three with the type A.

It is the drug company's intention to find a more user-friendly drug, and determine effective dosage.

I am a 50 year old female, menopausal and on HRT, and in good health other than the hep C which I have had for more than 20 years. Before deciding to go for the cure, I was feeling some mild symptoms of the virus, and a biopsy showed mild to moderate scarring of the liver. This I feel was caused by heavy social drinking for 10 or 12 years.

The interferon has really slowed my life down, something I now feel I needed to allow my liver to heal. If you can, I suggest you take the year off while under treatment. Your body will need the rest as it is working very hard to fight the virus. I am now at week 30, with 18 more to go. The worse part of the treatment for me thus far was and is:



- My highly activated immune system attacked my thyroid. It is now necessary to take thyroid medication, perhaps for life. Some others have been affected in the same way. The doctors say this may have surfaced later in life anyway, but was probably propagated by the interferon.
- I have lost about half the volume of my hair. They assure me I won't go bald, and will thicken back up when I go off the medication.
- Headaches, fatigue, and muscle weakness have been prevalent throughout, however there are more days now where I feel almost normal.
- Dry eyes, mouth, and bladder all through the night interrupt my sleep.
- Regarding libido, I now know why they call it interferin!

These symptoms may sound pretty bad, but they are tolerable. I feel they are worth enduring for the chance of sustained cure. My blood tests show that I am responding well to treatment.

Here is a list of the other therapies I am trying. I feel they help me tolerate the medication and help promote healing. I am open to most methods of healing and figure I have nothing to lose and everything to gain by trying them.

- * Acupuncture twice a month to support the body. The style of acupuncture I receive is also geared to enhance awareness.
- * Massage once a month really feels good to those sore muscles. Touch is very relaxing and healing. The style I receive is Esalen Style, with the long firm smooth strokes.
- * I do a relaxation and visualisation everyday. I receive audio tapes through the mail from the Relaxation Centre of Brisbane tape library.
- * Crystal healing and meditation. I was invited by 2 different friends to attend this free group which meets at the Eagle Heights Centre on Mt Tamborine once a week. I find the group very supportive and loving, and I always feel better afterwards.

I am lucky to have a very understanding and supportive husband who has taken so much of the stress out of my life by assuming most of the chores like cooking and cleaning. My friends and family are also very caring and encouraging. Hep C support groups are around if you need them and if you find someone who has undergone treatment and received the cure, it is great to have a phone buddy to encourage you to hang in there and talk with about how you're feeling.

Just a couple of last suggestions:

Try not to focus too much on the physical. Keep the quality of your life high, laugh as much as you can. Don't push yourself to do too much, take life slow and easy, rest as much as you can, reserve your energy for your healing. Use your quiet time to meditate - healing occurs in that quiet space.

Remember, no alcohol, and a low fat-high fibre diet helps as do vitamins and minerals. If you need someone to correspond with, feel free to write me at smfoster@ion.com.au

Love Marty



Chronic illness and its 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.

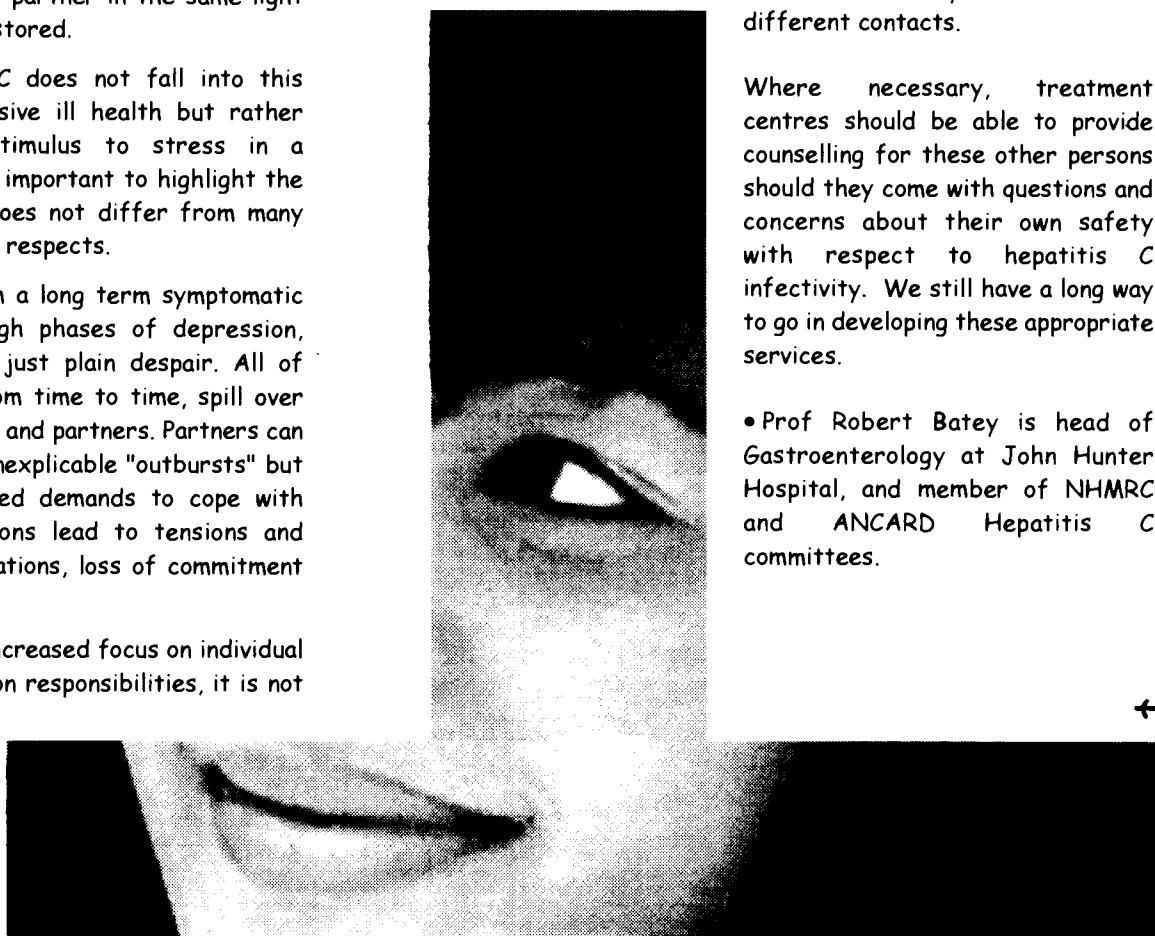
It is imperative in any management situation to talk through some of these issues with the couple in the hope that trauma can be minimised. Effective counselling and information sharing will hopefully minimise the trauma to relationships and allow healthy and constructive means of coping with stress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

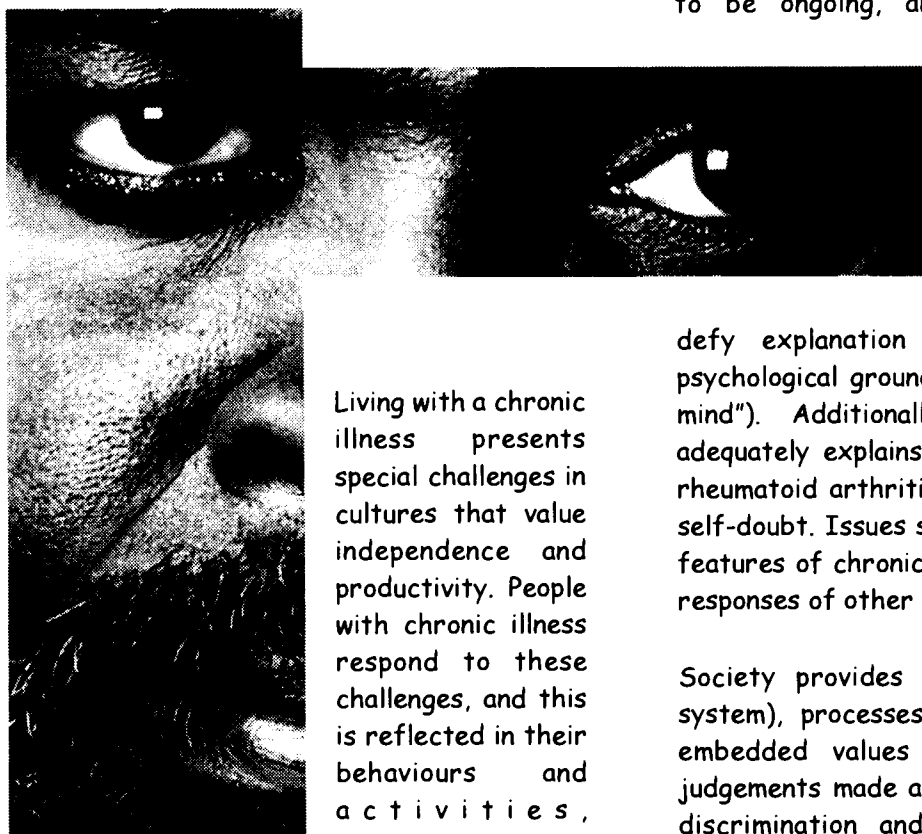
• Prof Robert Batey is head of Gastroenterology at John Hunter Hospital, and member of NHMRC and ANCARD Hepatitis C committees.



(model/s used above)

Social aspects of living with a chronic illness

By Michele Travers.



Living with a chronic illness presents special challenges in cultures that value independence and productivity. People with chronic illness respond to these challenges, and this is reflected in their behaviours and activities, encounters with

other people, and feelings about themselves and others.

For many, coping with a chronic illness requires a revision of one's life, and affects all aspects - from the functional to the deeply personal. Chronic illness is always present, even when not visible or "active", and in that sense, chronically disrupts the person's life. Research has shown that many experiences are related to the chronic nature of the condition, and the ways in which a society judges and manages chronic illness.

This article will discuss some of the important aspects of the social world that affect the experiences of people with ongoing conditions.

Society is better equipped to deal with acute illness. These illnesses are generally of a short timeframe, present with clear symptoms, involve standard treatments, predictable outcomes, and effects considered to be temporary.

Chronic illness is not a temporary disruption - it may involve many patterns such as a gradual deterioration or periods of better health interspersed with relapses, but there is usually no end to the condition or return to the previous level of health. Unlike acute illness, management and support needs to be ongoing, and involves adaptation and constant negotiation of the environment rather than a period of recovery or rehabilitation.

Many chronic illnesses are difficult to diagnose with vague and unpredictable symptoms, and in the period prior to diagnosis patients whose symptoms

defy explanation may find themselves dismissed on psychological grounds ("too much stress", or "it's all in the mind"). Additionally the absence of a medical label that adequately explains the person's illness to others ("I have rheumatoid arthritis") commonly contributes to feelings of self-doubt. Issues such as these may arise from the clinical features of chronic illness, but they are complicated by the responses of other people.

Society provides structures (such as the health care system), processes and codes of behaviour that reflect embedded values and beliefs, and these affect the judgements made about people with chronic illness. Stigma, discrimination and invalidation are examples of these judgements in action, and are commonly reported. Some conditions are more stigmatising than others - often these conditions are those that challenge deeply held social beliefs.

Examples of such conditions include psychiatric illness, conditions for which the physical basis remains unclear (such as Chronic Fatigue Syndrome), and sexually transmitted diseases (which in the case of HIV/AIDS has also reflected society's homophobia);

Even with the same condition different degrees or sources of stigma may exist. For example, the person who contracted HCV or HIV from the use of needles encounter quite different responses to those people with a medically acquired route of infection, because their behaviour more directly challenges those socially held values of decision-making, free will, and personal responsibility.

(model/s used above)

This difference is seen in the notion of 'innocent and guilty victims', based on the perceived source of infection, and introduces another layer of stigma - the chronically ill person is already marginalised - some of these illnesses are more stigmatised than others, and among these further marginalisation occurs.

Therefore, the social context influences experiences of illness, and threats to feelings of positive self-worth frequently arise from the social environment. Isolation is commonly reported, and is influenced by many factors such as stigma and unpredictable symptoms that make it difficult to plan, complete or attend activities.

A person's world begins to restrict as time becomes filled with health-related activities. At different times, feelings of shame, guilt, depression and anger related to the chronic condition and its impact on the person's life are likely to arise. Losses also need to be addressed and include those readily identifiable (for example, decrease in energy, loss of employment) but also those not so apparent to others (for example, loss of spontaneity, valued social roles, dreams and hopes).

The ill person may find themselves dismissed in subtle ways, such as when emotions that other people find troublesome become discounted as being part of the illness. It is difficult to feel good about oneself in the face of such social pressures.

An awareness of the influences of society on chronic illness helps to provide a reality check about social encounters that may potentially threaten a person's sense of value. It is important to recognise that many difficulties are related to society's limitations in providing non-judgemental support, rather than resulting from the person's inadequacies in coping with the condition.

- Michele Travers, RN, BA, MA, FRCNA, is a Senior Lecturer in the Department of Behavioural & Social Sciences in Nursing, University of Sydney.



Love and light

Hi, my name is Marianne and I am HCV positive. Thank you for all the information you have sent - my gratitude cannot be expressed in words.



I am a mother of two children, a single parent and I estimate that I came into contact with HCV in 1988. My status was confirmed in 1992 and I am seven years into recovery from drug dependency.

My ex-partner was diagnosed as having nonA-nonB in 1988 and he was the only person who I shared with.

I have experienced much discrimination and prejudice, coming from an ignorant and fear-based position from many people. These have included the general population, friends, doctors and government departments. I have felt diseased, isolated, alone, angry and frustrated.

Recently my ALTs have risen and many symptoms have become severe. Although these affect me greatly I refuse to let it beat me.

I know there are many others who experience what I have and my heart goes out to all.

I feel there needs to be a rise in planetary consciousness and I have decided to go with my heart to contribute to this rise.

I am studying at TAFE and in my second year. As part of my course - Certificate in Alcohol & Other Drug Studies - one of the requirements is field work placement.

In this light, I am passionate about setting up support and education groups for people in the Lower Blue Mountains area. On reading and researching this topic, I've discovered there is only one such group in Katoomba which is a support group.

In response to people like "Bobby" of Blacktown (Ed 20, P 5), I agree that there aren't enough support groups. I've experienced his frustrations and discrimination and I wish to be able to share and offer support to people with those burdens.

Maybe something I have researched, be it diet, info, self management, etc, will be helpful. My overall desire is to be an effective worker and human being.

Love and light to all who have HCV and to humanity as a whole.

Marianne



(model/s used above)

Treat the person, not the disease

Finding out I was Hepatitis C positive was a shock.. I was planning to travel and I was going through the normal preparatory travel vaccinations. A blood test to check if I had hepatitis B immunity came back with a surprise. It came back showing hepatitis B immunity and hepatitis C positive.

The doctor, a woman I had been seeing at the time for health matters related to my menopause, delivered the news of this test result in the gravest manner, so different from her usual upbeat, light hearted and reassuring approach I'd been used to.

Hepatitis C - not me! Oh yes, you, and you better have an AIDS test too, she said. Had I had any blood transfusions? No.

How did I get it, I asked? I knew very little about hepatitis C but I knew I suddenly felt 'dirty'. I'd had some boyfriends who had been injecting drug users. Could I have picked it up there? No. By this time I was crying. Don't worry she said .. and we can do a liver biopsy .. cancer.

The doctor was going through the stages of treatment. By now I was sobbing deeply and felt all the energy for my life slipping away and I wondered how I would be able to keep going - to carry on with my positive plans towards many goals. I felt like I wanted to die. I cried as if I'd just lost my life.

"Now you'll have to tell your sexual partner", she said in her deeply concerned doctor's voice.

"I can't .. he won't want to make love to me any more," I managed to reply through gasping sobs. Thoughts of a very changed sexual life again reinforced the 'dirty' feeling I now had about myself.

Finally, after my sobbing had subsided, I admitted to injecting heroin 25 years ago - the first and last time



I ever injected drugs. I was under a certain amount of peer pressure, with acquaintances who were long time users.

It wasn't until sometime later when my thinking became clearer that I realised her consultation didn't add up. Why the urging for an AIDS test? Why the discounting of drug using sexual partners as the possible means of contracting hepatitis C and why the insistence I tell my then sex partner if I hadn't contracted it sexually?

The doctor gave me the number of the Hep C infoline and said I should call them. Her only other advice was to start coming for regular vitamin B injections.

I managed to pull together and left the consulting room. I went to the front desk, hiding my face, my shame, and blindly handed over my Visa card to pay for the consultation - no bulk billing here.

(Only after when claiming at Medibank did I notice I'd been charged a double consultation fee or \$60. I'd had to pay for my crying time.)

During the consultation I also received results from a hormone test. It showed I was well into menopause, but that was only briefly mentioned in the consultation. Gone were my hopes to have a child.

For some time I'd been trying, hoping, to fall pregnant. The doctor knew this, she'd even prescribed some fertility herbs to help in my final stages of fertility. No time was spent in dealing with this. And now I was expected to tell my partner I was hepatitis C positive. What a day it was turning into!

After getting out of the doctor's rooms it felt good to be out in the fresh air - to be able to breathe and to open up into my own space. From a feeling of the deepest despair, I gained my composure and inner strength and began to think for myself. A voice from my inner body wisdom told me I was well and that I was no different than I was an hour ago, before I was diagnosed so gravely.

My inner voice grew stronger and I felt a mighty power within me giving me the strength to deal with it and overcome it - giving me the will to continue my life, to enjoy my life, to look forward to my life.

When I got home I called the Hep C Infoline. It was certainly a helpline - a lifeline at the time. I called that number a few times over the following days and slowly began getting up-to-date facts and piecing together information. I found the process reassuring and felt I was coming to terms with being hepatitis C positive.

Some people come into contact with the hepatitis C virus but their immune system is able to knock it out. I'm a healthy person and I was surprised that mine didn't. The way I feel about it now is that I have the virus cruising in my blood but not affecting me. I remind myself that I didn't go for tests because I had symptoms of ill health.

"Treat the person, not the disease" is the philosophy at the core of eastern medicine, Ayurvedic and Chinese. Funny I thought, the diagnosing doctor I'd seen also prescribed an alternative approach to medicine. But that doctor with all her good intentions was unnecessarily alarmist and with all her well meaning concern, she neglected to tell me about the good liver function test also contained in the report. I found that out for myself later when I went back for copies of the test report.

(model/s used above)

Through my research and inquiry I have become better informed about hepatitis C. I'm able to understand and accept my hep C status but I wonder about other people. So I don't tell them. I keep it secret.

Now that I have ascertained that hep C is not a sexually transmitted disease I don't feel at all obligated to tell any sexual partner, particularly if safe sex practices are being followed. I've told my sister, a couple of friends and dental professionals.

My last visit to the dentist was for intensive gum cleaning which caused bleeding. As I left the surgery I glanced back to see the dental assistant, gloved and masked, spraying the basin and surrounds with some disinfectant. But I didn't feel 'dirty' or 'ashamed'. I could see that precautions needed to be taken to avoid the spread of the virus, no matter how unlikely it seemed in the circumstances.

"My inner voice grew stronger ... giving me the strength to deal with it ... to continue my life, to enjoy my life, to look forward to my life"

Most of the time now I don't think about being hepatitis C positive. Sometimes days go by and I forget about it altogether because I'm not sick, I look well, and I continue to think well. I know the odds and I believe they're in my favour. My life is a healthy one and I am involved in so many things that hep C status doesn't affect.

Sometimes I'd prefer I'd never found out and then again I think it's better that I know so I can take especially good care of myself with a liver friendly diet and lifestyle. But this was a path I was on before I found out so I don't feel the virus is imposing these changes on me. I'm being healthy because I want to.

I never went back for the vitamin B injections and have since found a doctor who is well informed about hepatitis C and supports me in a non-alarmist approach to dealing with my positive status. I'm trusting in my own body wisdom and I'm getting on with living my life to the full, free of fear or anxiety about what may or may not happen, healthwise, in the future.

Yours in good health - Louise

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Books for pain sufferers & those with a chronic illness

By Laurie Grant

I was at the hospital today and found a pamphlet from the Arthritis Society that had reviewed some books. I found two of them that might be useful reading for those of you who suffer from pain or have trouble adapting to living with a chronic illness.

Chronic Muscle Pain Syndrome

Author: Paul Davidson, MD

Published by: Villard Books Inc, Random House of Canada, 1265 Aerowood Drive, Mississauga, Ontario, L4W 1B9 (1990)

Comments: Informative and well referenced. Provides accurate information on the diagnostic features of the syndrome. Easy to understand, and could be quite profitably read by most fibromyalgia patients. Helpful glossary. Therapeutic advice is practical and useful, however, some questions raised about suggestions regarding aerobic exercise. Some concerns about the author's opinions and theories in the 3rd and 4th chapters.

We Are Not Alone: Learning to Live With Chronic Illness

Author: Sefra Kobrin Pitzele

Published by: Workman Publishing, 1 West 39th Street, New York, New York, USA 10018 (1986)

Comments: Comprehensive and inspirational. While the author is a lupus sufferer, information is universal in theme and application. Guides the reader through earliest symptoms, diagnosis and initial reaction, through to eventual acceptance and adaptation to chronic disease. Helpful in discussing adjustment as extended to spouse, family and friends and deals sensitively with sexuality. Provides information to effectively communicate with care givers and access support agencies. A large section is dedicated to adaptive strategies at all levels of physical, psychological and emotional limitation. Has useful glossary of medical terms. Effectively conveys patient's full range of emotions.

- Be Well, Be Happy
Laurie, The SnakeFighter
Toronto, Canada
<http://www.geocities.com/HotSprings/Villa/2630>

Taken from the international email list
HEPV-L@MAELSTROM.STJOHNS.EDU

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Painkillers and the liver

People phoning the NSW Hepatitis C Telephone Information & Support Service often ask whether over-the-counter pain killers (or analgesics) are harmful to the liver.

Generally speaking, when taken according to directions, the answer is no - but there are exceptions.

PARACETAMOL

Paracetamol is used to relieve mild to moderate pain. It also lowers body temperature in patients with fever.

Paracetamol is generally regarded as safe with relatively few side effects when used in its normal dose.

Adult dose: 1 to 2 tablets every four to six hours when required up to a maximum of 8 tablets in 24 hours.

However, continued use over a long period can be harmful as paracetamol can cause acute liver damage especially in people with excessive alcohol intake or people with liver or kidney disease.

ASPIRIN

Aspirin is used to relieve mild to moderate pain as well as treating fever. It also has an anti-inflammatory effect in that it reduces swelling and inflammation.

Adult dose: 1 to 3 tablets (300 to 900mg) every four hours when required up to a maximum of 12 tablets (3600mg) in 24 hours.

Aspirin can disrupt blood coagulation by increasing bleeding time. This effect continues after the aspirin has been stopped for approximately 4 to 7 days. Although there is no actual drug interaction between aspirin and interferon, both can disrupt blood coagulation processes and hence should be used with caution together.

Care is also needed when using aspirin in the later stages of liver disease if blood coagulation is abnormal.

Aspirin can cause liver injury especially in high doses - hepatotoxicity has occurred in doses higher than 2000 mg per day.

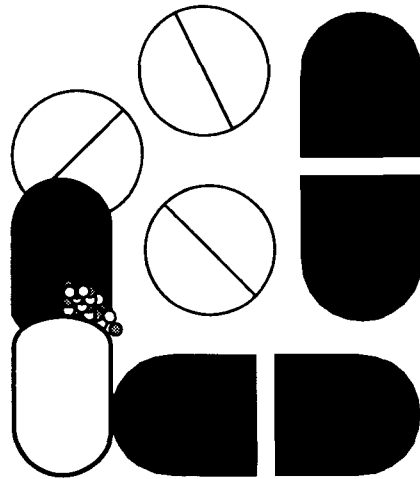
IBUPROFEN

Ibuprofen is a non-steroidal anti-inflammatory drug used to treat pain, fever and inflammation.

Adult Dose: 1 to 2 tablets three to four times a day when required to a maximum of 1200 to 1800 mg per day.

As with aspirin, ibuprofen prolongs bleeding time and therefore should be used with caution in the later stages of liver disease and with people on interferon. This effect on blood coagulation is reversible and only lasts as long as the drug is circulating in the bloodstream.

Hepatotoxicity is a rare side effect of non steroidal anti-inflammatory drugs and can occur early on in treatment when ibuprofen is used regularly.



CODEINE

Codeine is available in combination with other medicines such as paracetamol. These are classified as restricted medicines and are only sold in pharmacies under the supervision of a pharmacist.

In people with liver impairment, the effects of codeine can be prolonged and hence caution is advised.

SUMMARY

Aspirin, codeine, ibuprofen and other non steroidal anti-inflammatory drugs should only be used after consulting with your doctor.

Paracetamol is probably the safest pain killer for people with hepatitis. However, it should only be taken at normal dosages for short-term pain relief and not with large amounts of alcohol.

If you require pain medication rather than something for the occasional headache etc, consult your doctor.

- This article is from the NZ Hepatitis C Support Group newsletter *The Chronicle* (May/June 1998). Information came from the Medical Information Pharmacist at Auckland Hospital. The article was reviewed here by Dr Jacob George, Senior Lecturer in Hepatology, University of Sydney at Westmead Hospital.



Wellbeing of people with chronic illness

Most patients with cancer and other serious illnesses want more information than their physicians offer, which frequently leads to unnecessary distress and feelings of hopelessness, an Australian research team reports.

In one cancer program, for example, 75 percent of elderly patients said their doctors created undue worry by not providing them with sufficient information, while 40 percent of cancer patients in another study felt they were not fully informed about their diagnosis, prognosis, and treatment.

"Health professionals believe that breaking bad news is an important task, but they feel inadequately trained to do it effectively," write Dr. Rob Sanson-Fisher and colleagues at the NSW Cancer Council Education Research Program, writing in a series of articles in the summer issue of *Behavioural Medicine*.

Although some physicians believe that hearing bad news can be sufficiently upsetting to harm a patient's health, the evidence points in the opposite direction, Dr. Sanson-Fisher and his colleagues said.

Patients may be seriously upset after learning a diagnosis of cancer, but most adjust well in the long term. "In fact, uncertainty is a major cause of emotional distress for patients," they write. "Relief from this uncertainty can, in itself, be therapeutic."

Studies do show that the way patients are told bad news can exacerbate the distress they feel. Breaking bad news abruptly, over the telephone, or in the recovery room can prove especially distressing, they write.

Many patients also react negatively when they feel physicians have withheld information or have not told them about other sources of help. Findings such as these have led to medical school courses in how to break bad news and development of guidelines.

Among the essential steps outlined by the Australian team:

- * Give the patient the diagnosis honestly but not bluntly.
- * Encourage patients to express their feelings.
- * Offer a broad but realistic time frame for the prognosis.
- * Discuss the treatment options.
- * Avoid the notion that nothing more can be done.
- * Arrange another time to review the situation.
- * Provide information about support services.

While guidelines help establish the minimum level of care that patients can expect to receive, the challenge remains to design effective programs to convey bad news, the researchers said. Programs studied in 10 randomised controlled trials had little effect on psychological adjustment and inconsistent effects on patient knowledge and satisfaction with their care, they added. Another challenge is to persuade physicians to abandon old habits and adopt new techniques.

"Given the difficulty in altering

clinical behaviour, it is not reasonable to expect that widespread adoption will be achieved by simply producing best-practice guidelines," the researchers write.

- From *The Doctor's Guide to Medical & Other News*, a fortnightly newsletter that can be accessed at: <http://www.pslgroup.com/dg/90b7e.htm>



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(model/s used above)

Adaptation to chronic illness

by M Bennett & Dr L Bennett

Adaptation to a chronic illness can be challenging for people and may include handling changes, developing new roles, and dealing with social isolation.

Handling Changes

Developing an understanding of the impact of chronic illness on your psychological well being is often very difficult. Medical appointments, fatigue and daily commitments all mask our ability to really pay attention to how well we are coping.

By keeping good diary notes of the day's activities, a number of practical benefits can be achieved. Diaries are useful tools when trying to identify the events that are causing difficulty. Careful review of your notes can assist you to identify specific stressors that lead to an overload situation and help you to plan strategies that will avoid emotional exhaustion.

Anticipating how activities will impact upon your health can allow you to devise a plan to deal effectively with your week. At times many will cope very well with major crises, only to find the smallest challenge overwhelming. For many who have gone from feeling well and in control of their lives, it is difficult to let go of the normal patterns or ways of behaving.

The internal dialogue that we conduct with ourselves can either improve psychological well being or increase our distress. It is helpful to monitor the cognitive messages that we are constantly giving ourselves. Being conscious of the messages allows us to be in control and focus on positive messages.

The key is to diarize, anticipate stressors and develop strategies to deal with these where possible.

Developing new roles

If current roles at work are too difficult it may at times be necessary to talk with your employer / colleagues about job sharing or reduction in hours. Partners or colleagues may feel overburdened and resentful of the changes in your role if these changes are not discussed and negotiated in a carefully considered way.

As your role changes, due to your inability to do all of the things you previously did, it may cause a negative impact on your level of self esteem. Rather than allowing yourself to feel hopeless and negative, focus on the things that you are still able to do well and discuss sharing the load with others. Sometimes role swapping may suit a partner, for example you may not be able to cope with driving through peak hour traffic but preparing the evening meal at your own pace may be possible.

Avoiding Isolation

Stay involved in the decision making processes in your home and at work and let people know the ways that you can still contribute. It may be necessary to be assertive about your rights and needs if you are to stay involved in activities.

Talk with your friends about the need for flexibility in social arrangements. Alert them ahead of time that you may not always be able to meet social engagements due to unpredictable fluctuations in your health and how you are feeling.

At times you may experience feelings of anger and frustration and you will need to acknowledge that these are normal given the changes in your health. Counselling with a health professional who understands your illness, can often be useful to develop appropriate strategies for coping better.

Communication with the key people in your life is important to let them know the impact of your health on you at the time and to discuss how you can work on problems and strategies together. A lot of give and take is involved. Regular meeting times to discuss progress plans and changes can be helpful.

Conclusion

The adaptation to chronic illness can be improved by developing an understanding that some changes will be necessary and actively handling the changes. Developing new roles will allow greater control over the impact of the illness on your psychological well being and may even provide new opportunities. In addition, social isolation can be reduced significantly by assertively pursuing your rights and needs.

- M Bennett & Dr L Bennett are practising psychologists. They can be contacted via PO Box 1062 HUNTERS HILL NSW 2110.


(model/s used above)

Doctors who make mistakes

by Melissa Sweet

Everybody is fallible, even doctors, particularly when they work under pressure in a less than perfect system.

Mark Ragg [author of a recent article in the Sydney Morning Herald] revealed how his inexperience as a junior hospital doctor coupled with a lack of appropriate support and poor working conditions, led to mistakes and patients' deaths.

What is remarkable about Ragg's story is not that he may have "killed" patients - many doctors could tell a similar story - but that he admitted especially in such a public forum (on the front page of *The Weekend Australian* of April 11, no less).

As a species, doctors are not generally known for admitting mistakes, much less saying sorry. Fiona Tito, the former chair of the Federal Professional Indemnity Review, sums this up in a joke: What is the difference between doctors and God? Answer: God doesn't think he is a doctor. That she still gets a laugh, even in these times of increased scepticism about modern medicine, is a reflection of the persistence of the culture of perfectionism in medicine.

The Australian Medical Association latched onto Ragg's story as an illustration of funding problems, but Ragg, who now works as a freelance journalist, says his aim was not to bag the health system. Rather, he wanted to encourage awareness, among doctors and the public generally, about medical fallibility.

"If there was a greater recognition of fallibility, doctors would listen better to patients; patients would ask more questions of doctors; there'd be a much better flow of information both ways, with much better results."

A good theory, but not so easy to translate into medical practice. Dr John Quinn, the director of clinical training at St Vincent's Hospital, says he could have written a story such as Ragg's.

"When I was [an intern] at Liverpool Hospital, the nursing staff used to save lives regularly," he says, "by telling me what to do." Quinn who now counsels medical graduates, says many find it difficult to admit mistakes because they "come from a school and university system that rewards perfectionism."

Ms Marilyn Walton, the director of the NSW Healthcare Complaints Commission, will release a book later this year, called *The Trouble with Medicine*, arguing that doctors at all levels have difficulty recognising the limitations of their skills and knowledge.

The hierarchical nature of medicine also discourages questioning of the system, she adds, as does the tradition for doctors to view themselves as autonomous clinicians rather than members of a team.

Many doctors are reluctant to acknowledge mistakes for fear of being sued. But surely many patients would be less likely to think of litigation, if they felt they had received an open and frank explanation of what had gone wrong. Not to mention an apology. And if health professionals were less defensive, it would be easier to get on with the complicated business of identifying problem areas and developing systems to help reduce mistakes.

As Tito says: "There's this whole notion that if you're a doctor and you make a mistake, it's a moral failing on your part, rather than you're a human working in a complicated system. There needs to be more openness and accountability within the system about what goes wrong; accountability, not in terms of punishing people, but in saying what can we do better."

Information technology is expected to boost efforts to improve quality of our healthcare; for example, the intensive care unit at the New Children's Hospital plans to introduce an electronic drug ordering system with the aim of reducing medication errors. Dr David Schell, a specialist in the unit, notes that ICU nurses are using technology as complex as that in a light aeroplane yet they haven't had anything like the backup safety systems available to pilots.

Which helps explain the applause for Ragg's confession: he has drawn attention to the fallibility not only of health professionals, but also of the system in which they work.

- Reprinted with thanks from the *Sydney Morning Herald*, 17 April 1998.

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Alcohol, HCV and liver disease

Following is a report on the research project, *Role of Alcohol in the Progression of Liver Disease Caused by Hepatitis C Virus Infection*, published in the international journal, *Hepatology* (Vol 27, No 6, June/ 1998).

The study was carried out by George Ostapowicz, Katrina Watson, Stephen Locarnini and Paul Desmond at the St Vincent's Hospital, Melbourne.

Following is an outline of the study. If you want to read a full copy of the original paper, contact your local library - or better still, a university library.

Introduction

For some time doctors have believed that when people have hepatitis C liver disease, the consumption of alcohol will help hasten their liver disease. Many international studies have supported this while others have not.

This study is the most recent Australian research attempting to shed light on the above belief. Specifically, it aimed to "examine the association between alcohol use and the severity of liver disease" and to "identify other factors related to the development of cirrhosis."

Methods

Over a two year period, 234 people's biopsy results were studied. Additionally, all had PCR viral load tests (measuring amount of virus in their blood) and most had PCR viral genotype tests (determining the subtype of their HCV).

Researchers interviewed each person and asked basic questions that included age, gender, country of birth, racial background and occupation (both present and past).

People were also asked about risk factors for their HCV infection. This included information about past blood transfusions, operations, injecting drug use, tattoos, needlestick injuries and anything else that could involve breaking the skin.

What was of primary interest to the researchers was each person's drinking history and patterns. A separate detailed questionnaire was used - already proven within other prior research studies to provide detailed, accurate information about alcohol use.

The researchers separated all people into two groups - one group including people with cirrhosis - the other made up of those not having cirrhosis.

These groups were then compared to each other with the researchers hoping to discover any major differences in regard to the variables mentioned earlier (age, gender, genotype, viral load, alcohol consumption, etc.) The research team utilised a computer program especially designed to do this - quickly and in great detail.

Results

- * The average age for the 234 people studied was 40.8 years.
- * Twenty nine percent were female, 71% were male.
- * A majority were Australian born (68%). Others came from Italy, Egypt, Vietnam, United Kingdom and New Zealand.
- * ALT scores (taken as an average of 3 readings) were raised for 97% of people.
- * Fifty people had developed cirrhosis (21% of total group).
- * Although levels of daily alcohol consumption varied greatly, nearly everyone (96%) had consumed alcohol on a regular basis.
- * Two hundred and sixteen people had PCR viral genotype tests. Of these, 34% were type 3a, 22% were 1b, 15% were 1b, another 15% were a subtype of type 1 but it couldn't be determined. The remainder were made up of subtype 2 (7%), subtype 4 (4%), subtype 6 (1.5%). Three people (1.5%) had both subtypes 3a/1b.

Associations

- There was no proven link between gender and cirrhosis.
- It was shown that people with cirrhosis were older (this would be expected).
- It was shown that on average, people with cirrhosis had contracted HCV later in life than the non-cirrhotic group, and their HCV infection had been for a longer period of time.
- There was no proven link between viral load and cirrhosis.
- A loose trend existed for people with subtype 1b having cirrhosis more frequently than people with 1a or 3a. This trend was not enough to prove a linkage.
- There was no proven link between daily level of alcohol consumption and cirrhosis.
- It was shown though that people with cirrhosis had a greater total level of alcohol consumption during both their lifetime and their HCV infection.

Discussion

The research team concluded that "total lifetime alcohol consumption is a risk factor for the progression of liver disease caused by HCV."

They highlighted the fact that 20% or more of people with hepatitis C develop cirrhosis and emphasised the need for people to be better able to predict whether they may develop cirrhosis or not - this information playing a useful role in any decisions around treatment of hepatitis C.

Certainly the above research adds weight to the argument for all people with hepatitis C to decrease their level of alcohol consumption. Ideally, those of us with HCV should abstain from alcohol altogether.



The last rites - not!

At the end of 1990 I was being woken at night with strong pain in my upper abdomen. This went on for a few weeks around the same time I noticed that I became violently ill after one or two alcoholic drinks (which I had a lot) I also had an itch that seemed to come from inside that nothing could relieve. Finally when I noticed my skin was yellow, I went to the doctor.

He suggested blood tests for either hepatitis or an ulcer. He sent me to the Hospital as the blood tests could be done and interpreted quicker. On the drive over I knew what the outcome would be. I had been an IV drug user for the past 5 years and had shared needles often. Call it a death wish or more I just didn't care.

Five hours after my first blood test I was seen by a young doctor who classed me along with all other junkies (understandably) and it was decided to admit me and put me on antibiotics.

I was told I had hep but it would take a few days to identify which type. In the meantime he'd need to put a drip in my hand, that was if I had a decent vein left to use. He then offered to put the drip in without using a local anaesthetic first. His way of showing his disgust I think, I got the message.

I spent five days in hospital, three of those hooked up to the drip. On the second day a Priest (Catholic) came in and delivered the last rites!

I had no idea of what was happening and I was too scared to ask. I was not given any counselling or reading matter or information of any sort. All I knew was I had given myself a death sentence.

I have not touched drugs since that day and am now happily married with 5 children (3 of those born since hep C, my last in January this year). I suffer constantly from tiredness and mental fatigue. Occasionally I have a good day and it feels like the sun's out in my life.

My husband is an extremely understanding and caring man but like the few doctors I've seen he believes too much is blamed on the hep C.

So most of the time I suffer in silence or deny my disease, scared of ridicule saying things to myself like I'm just getting old or the kids have kept me busy or just because I'm pregnant at such an age (36 yrs) or the baby's been up through the night, justifying my symptoms to myself as well as everyone else.

It's not until I read my copy of the Hep C Review and read about other peoples stories that I allow myself to believe my symptoms and disease are real.

Thank you for the greatest and only source of information I have and the opportunity to tell my story. Keep up the good work.

Karen.



(model/s used above)

1998 readership survey results

Congratulations and thanks to everyone who was able to assist with our membership survey in Ed 20.

Two hundred people returned the survey form - which was a wonderful response as we were initially aiming for only 150.

Jane, our volunteer admin assistant, quickly entered the survey data onto the SPSS computer program. Thanks to Jane, we can present this report so quickly.

Response

Of the 200 people who responded:

- 57% were female, 42.5% were male, and one person identified as transgender.
- Fig 1 (below) shows that 74% of people were aged between 30-50.
- Fig 2 (above right) shows that 78% of people had achieved the higher school certificate or better.
- 50% of all people came from the Sydney metro region, 44% came from regional NSW, and 6% lived interstate.
- 11% were born in a non-English speaking country, of whom 6.5% said a non-English language was spoken in their home.
- Eighty percent of all people identified as having hepatitis C, of whom 56% were female and 44% male.
- 26% of respondents identified as healthcare workers (52), of whom, 35% said they were hepatitis C positive (18).

Fig 1 Age of respondents

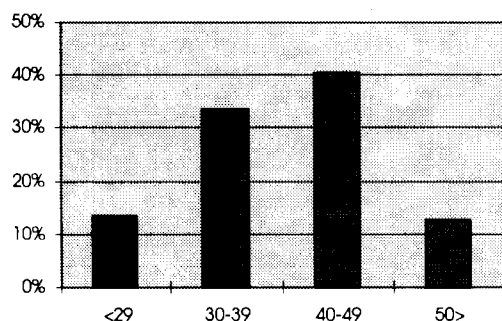
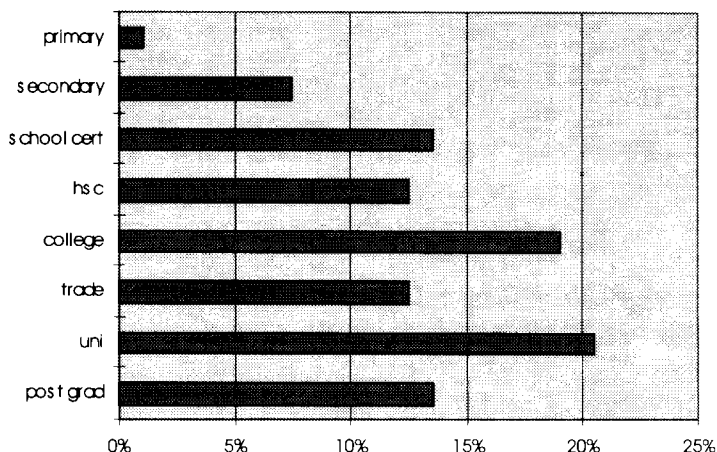


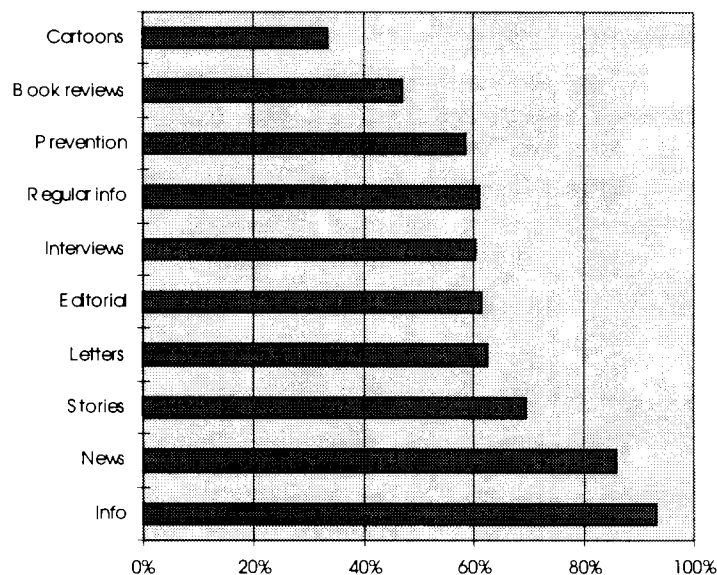
Fig 2 Respondent's education background



Because comparatively few healthcare workers responded to the survey we can't say that our sample represents our overall readership.

Given, though, that hepatitis C positive people in our sample represent 20% of our overall hepatitis C positive readership, we can say that our results are valid in regard to people with hep C.

Fig 3. Interest in Magazine Features



Results

Although 90.5% of all people said the magazine fully or mostly meets their expectations (Q24), the most useful comments relate to individual features of the magazine (Q15).

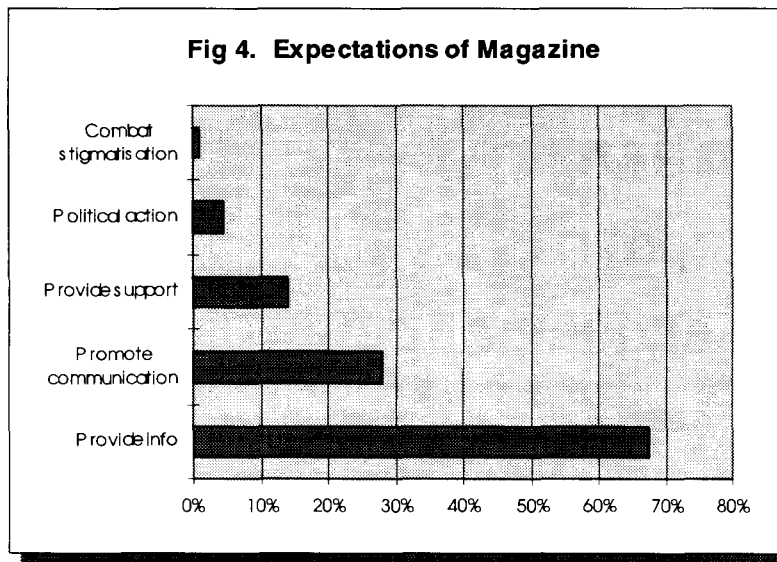
Figure 3 (above) shows that 93% of respondents were very interested in information updates, 84% were very interested in news, and 67% were very interested in reading other peoples' personal stories.

Supporting the above comments were the responses to question 23: *What are your expectations of a magazine for people affected by HCV?*

Seventy nine percent of all respondents replied to this question. Their comments were coded into several themes: provide information, promote communication, provide support, undertake political action and combat stigmatisation.

As shown in figure 4 (right), most people had high expectations for information and promotion of communication.

Although not shown in these tables, it was interesting to note that many people expected the magazine to help portray their lived experience to doctors and other healthcare workers (Q24).



Hepatitis C 'community'

One of the Council's aims is to foster within our sphere of influence, a sense of belonging amongst people. One that promotes communication between people affected by hepatitis C and reduces the isolation that many may experience. Our use of the term 'hepatitis C community' relates to this aim.

Of the 153 people who responded to question 25, *What do you understand by the term hepatitis C Community?*

- 81 felt it meant "all those affected (people with HCV, their friends & families, healthcare workers, etc).
- 53 felt it was limited to "just those people who are HCV positive".
- 19 mentioned other themes including: "doesn't really exist" (7), "a shared situation" (4), and "injecting drug users" (2).

Of the 190 people who responded to question 26, *Is the term a useful way of describing people affected by HCV?*

- 65% said yes; 35% said it was not a useful term.

Interestingly, of the 119 people who wrote comments elaborating on their yes/no response to Q26,

- 69 made negative comments, while 14 made positive comments. The remaining 36 were neutral.

Fig 5 (right), shows that of the 83 people who offered positive or negative comments to Q26,

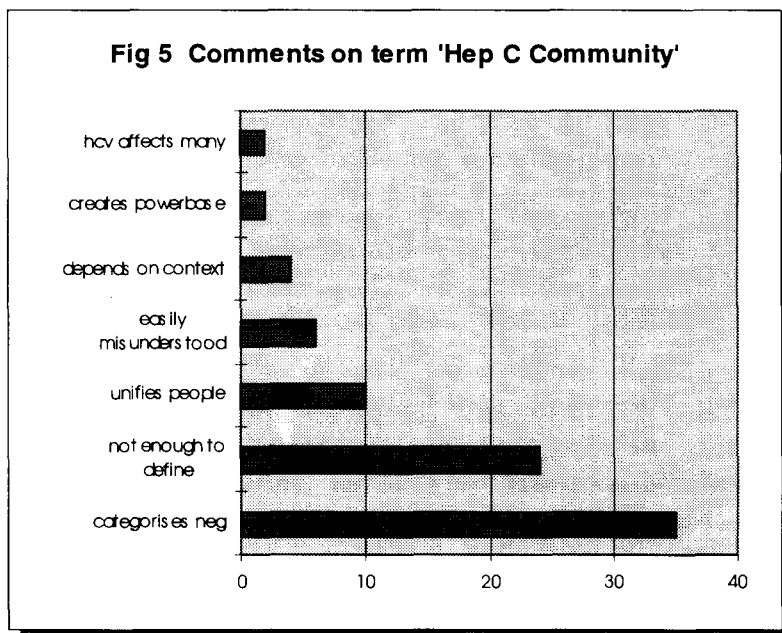
- 35 felt it negatively categorised people
- 24 felt that people just having HCV wasn't enough to define a 'community'

- 10 felt the term unifies people
- 6 felt it was too easily misunderstood
- 4 felt the meaning depended too much on the context in which it's used
- 2 felt it creates a useful power base
- 2 felt it useful as it highlights that HCV affects many people.

Discussion

The survey showed that particular features of *The Hep C Review* were well regarded and that these coincided with readers' expectations of the magazine. Although some people showed little interest in some features, there was no evidence that would support dropping particular features of the magazine.

While many readers felt the term "Hepatitis C Community" is useful, there was a significant level of reservation about its use. Further work should be done to explore whether the term is inherently problematic or whether more effort should be put into promoting its use.



The doctor/ patient role in hepatitis C management

By Dr David Brand

One of the greatest pleasures of being a family doctor is the opportunity to take care of a patient and their family over a long period of time.

The Australian health system is extremely fragmented, usually due to the different funding sources for particular services. This results in some services being supplied by the states, usually through hospitals and other services being supplied by the Commonwealth through the private sector.

One of the major roles that a general practitioner can play is to help coordinate the care of a patient and advocate on behalf of a patient, especially those with chronic medical problems.

General practitioners provide out-of-normal-hours care and usually provide access for their patients for health care 24 hours a day.

Just as there is an enormous diversity in the problems that a general practitioner deals with, there is also a large diversity in the types of practice of general practitioners.

General practitioners are subject to enormous competition both from within their own ranks and from other health care providers. As such, they have learnt to rapidly adopt their practice to the needs of the community which they serve.

Increasingly, patients complain about the problems associated with having a different doctor each time they go to the hospital. General practitioners are often the only constant medical adviser in the care of a patient.



AMA

The Royal Australian College of General Practitioners has developed guidelines for the management of hepatitis C in general practice. This reflects the treatment of hepatitis C from hospital to community setting.

For those patients with hepatitis C often there are many other non-medical issues that need to be dealt with. General practice provides a holistic approach to not treating the patient as a disease but rather as a person. The person often requires psychological as well as medical support.

While many patients with hepatitis C prefer to see general practitioners or specialists that deal with this problem on a regular basis, many other people with hepatitis C enjoy the anonymity and close bond with their own general practitioner.

Successive governments have promoted the rhetoric regarding the importance of the primary care general practitioner in the care of patients with chronic illness, but their interests seem to be financial.

However, patients with chronic illnesses prefer to be seen in the community in which they live and being treated by someone who knows their whole condition (for Aboriginal and Torres Strait islanders, general practitioners are often the only doctors available to provide care).

General practitioners will remain the principal carers of patients with chronic illnesses.

- Dr David Brand is President of the Australian Medical Association.



Better value for our health dollar

By Dr Con Costa

The elderly, the chronically ill, women, children and their GPs are all short-changed by the present way we pay our doctors: the "piecemeal" fee-for-service, system.

Recently, health minister Michael Wooldridge announced that all new young doctors entering general practice would be paid under a salaried scheme for their training years (* see below).

These young doctors will no longer be able to access Medicare bulk billing. More importantly they will no longer be on the piecemeal or fee-for-service treadmill.

Although this may have been done for the wrong reasons ie. to save the treasury some money, it is a bold new experiment which will prove an extraordinary opportunity for those with chronic illness. For the first time ever in Australia there will be hundreds if not thousands of young doctors employed in General Practice under a salaried system - just as they were in the hospital system. These doctors will be able to spend as much time with patients, including the chronically ill or the elderly with multiple complaints, as the patient may require.

Better management of chronic illness

In treating chronic illness it is important to maintain, as far as possible, continuity with the same GP or at the very least, continuity of the patient's notes. Unfortunately, with the health landscape quickly changing in Australia, both patient and doctor are finding that this is not always possible.

Continuity of care means the doctor has the benefit of a prior knowledge of the patient and also a good therapeutic relationship has probably been established. This translates into more holistic care with more appropriate investigations and higher patient satisfaction.

Continuity of patient notes - where continuity of care by the one doctor is not possible - is still better than a situation where the patient is being

DRS

Doctors Reform Society

seen by a different doctor on most visits ie. where a patient is "doctor hopping" for medical needs.

Interestingly, many young people and males go for the convenience of seeing the closest doctor when they are sick. They do not value or understand the many benefits of seeing a regular GP. In contrast elderly people, those with chronic illness and women prefer to see the same doctor at most visits.

In England continuity of care is highly valued. All patients must sign up with a GP who is usually paid on a salaried basis by the government - the higher the patient numbers on their books, the higher the salary. In Australia patients prefer the "freedom" to shop around for health care and our doctors are paid on a private, fee for service basis. As a result, continuity of care suffers.

How can we best cope in a changing landscape?

In Australia continuity of care is best found in a group practice situation, ie. where there are two, three, four or even more doctors working together. This gives flexibility for both patient and doctor, as even the best therapeutic relationships sometimes may fatigue or breakdown. Also doctors working in group practice have support from their colleagues, which is very important when dealing with chronic illness or "difficult" patients.

If a relationship is not working out, the patient can easily transfer to another doctor in the practice without unnecessary confrontation or alternatively the doctor can suggest the patient sees another doctor in the practice. Continuity of the notes is also better assured.

This is not to say that there are probably not a lot of very good solo GP's. However, group practice encourages high quality of work and all the doctors are under daily scrutiny from their peers through shared notes or shared patients. This peer review is essential for maintaining standards although not always an inevitable outcome of group practice.

Additionally group practice has the economy of scale which may allow for the employment of other allied health professionals such as a nurse to assist the patients. This assistance can often be crucial - say for weighing and measuring patients, recalling high-risk patients or explaining to an elderly, hard-of-hearing patient the correct way to take their medications.

What hinders GP teamwork and continuity of care?

The problem in bigger Medical Centres where there is a guaranteed large pool of patients on hand, is the tendency to "cream skim" the "quick and easy" patients with simple problems such as coughs and colds or cuts and bruises, and to discourage the chronically ill, the elderly or those with complex problems that will take up large amounts of the doctor's time.

This brings us to the most important point. The biggest single thing that militates against good care for the chronically ill is the fact that Australia's doctors are in the majority paid under a private, "piecework" system which we can compare to taxi drivers.

Taxi drivers make a lot of money by doing a lot of small, quick trips. Some taxi drivers would be loathe to drive a passenger from the city to the outer suburbs as their overall income would fall dramatically. (This is not to demean taxi drivers as most do a great job).

Similarly doctors are paid in a way which makes them watch the clock. Under the present system of fee for service they can be very highly rewarded by doing "six-minute" consultations rather than two or three long consultations per hour. Spend more than three quarters of an hour with a patient and GPs are working for "free"!

The way we pay our doctors thus gives the totally wrong incentives for good health care. Those that most need the care and the professional abilities of the doctor are the least likely to get it.

To take the taxi analogy further - the customer wants to get to Penrith but fee-for-service payment encourages us to let them down at the perimeter of the CBD! This means that the chronically ill and elderly are often not getting anywhere near where they need to go.

No wonder many with chronic illness turn to alternative practitioners. Without buying into the question of the validity of many of the alternative therapies, patients often know they will at least get time, a good hearing and plenty of support. And all of the above are important factors in good health outcomes.

Yet with all the technological development of western medicine, the way we commodify the doctor service under fee-for-service means that time is the thing most doctors are least able to give.

Thus the health system gets more expensive, and inconvenient for the patient, as doctors try to apply expensive technological quick fixes to human problems.

Blood test, x-rays, CT Scanners, MRI, nuclear scanners, ultrasounds become the catchcry of a profession that cannot afford to spend time with patients. Increasingly the technology is used, not for the benefit that can be gained from the test, but as a substitute to proper history taking, full examination and the important art of listening to the patient.

Fee-for-service disincentives professionalism and the doctor spending time with the patient. It also encourages them to work in isolation from other allied health professionals.

For example, if the nurse changes the dressing, gives the immunisation or checks how the diabetic is using their home blood sugar machine - the doctor cannot charge a fee. The result is that the doctor persists in doing more and more of the perfunctory work - because it attracts a fee.

The way forward

We need to build on the health access that Medicare has provided Australians by encouraging health professionals to fulfil their major role as diagnosticians and healers. We need to encourage them into teamwork situations - with other doctors as well as other health professionals - where they can spend more time with the elderly and the chronically ill, women and children.

To do this we need to change the way in which we are paying our doctors and this is why Dr Wooldridge's largely unnoticed step of salarising trainee GPs is such a monumental one.

We need a doctor pay system which encourages doctors to spend time with patients and not to grab for the nearest technological fix for the purpose of quickly terminating a consultation. We need a system of payment that encourages the professionalism of doctors and not perfunctory behaviour.

Hopefully, Dr Wooldridge will not bow to the enormous pressure which will be put on him by the Royal Australian College of GPs (RACGP) and the GP supervisors prior to the start-up date at the beginning of January, 1999.

If he stands firm, it will prove a great natural and open experiment in which the benefits of non piecework system of remuneration for our GPs and our patients will become clearly apparent.

It will also ensure the further strengthening and survival of Medicare by providing even better value for our health dollar.

- Dr Con Costa is president of the Doctors Reform Society.

[It was reported within *The Australian* newspaper on Fri 21 Aug, that the Federal Government had bowed to pressure and backed down on the salaried-GP training scheme - Ed.]

A plea for change to ignorant and unacceptable funeral practices

I am writing as I lost my brother last October, 1997 from a drug overdose. He died so suddenly that our family didn't identify him but we planned to have a viewing with him at the funeral.

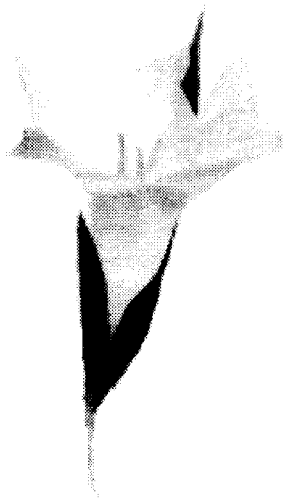
With one day's notice from the funeral, the funeral directors made a phone call to my family stating in that call, "We have some good news and some bad news."

"The good news is that we have your son's body back on the coast so the funeral is right to go ahead tomorrow as planned."

"But the bad news is that your son had hepatitis C and it is a highly contagious disease. Because you're not allowed to view a person with hepatitis C there can't be a viewing."

It wasn't until months later when I found out that we as a family had every right to view my brother.

I'd written to the Minister for Health, Andrew Refshauge, and he sent a letter back explaining our rights - but it is too late, my brother is buried.



STOP THE DISCRIMINATION

Mathew's situation (below) is not simply a mistake - it is a tragedy.

This is not the first time this type of situation has occurred (see letters within Ed 13 & 14) and without concerted efforts, such unacceptable workplace practices will continue to occur within the funeral industry.

The Hepatitis C Council has initiated discussion with NSW Health and the funeral industry union aimed at developing an industry-wide briefing campaign that will help ensure that such unacceptable practices do not occur.

Cheryl Burman
President

My mother and I have suffered extra grief because of the inappropriate and incorrect actions of the funeral directors. I have a case right now with them as they were negligent in their handling of this whole affair.

The reason I'm writing this letter to readers of *The Hep C Review* is because I feel I owe this to my brother because all my mother wanted to do was see her son of 28 years for her last time in her life. This right was taken away.

I would hate to think that this is going to happen to someone else's family. The thought that this may have been occurring for some time is also hard to swallow.

I believe that until a funeral company is taken to court and punished for their behaviour, this type of ignorant and disgusting action will continue within the funeral industry. It is in this regard that I decided to take legal action against the funeral company.

On behalf of my brother that passed away, thank you for taking time to read my letter.

Mathew M.

Living with a chronic illness: does the route of transmission make a difference?

By Claire Booth

Hepatitis C is unfortunately too often associated with a 'lifestyle' of drug use. This prejudiced view of what 'kind of people' have HCV is distressing for anyone living with the illness, and their supporters. Many people living with hepatitis C do not fit the stereotype that is associated with this route of transmission.

So what difference, if any, does the way a person catches HCV make?

There are thought to be differences in terms of disease progression. People with blood clotting disorders often have had many doses of different genomes (subtypes) of the virus over periods of time and this can increase the seriousness of the disease. In the same light, the more frequently someone has shared injecting equipment, the more possibility of getting different genotypes of the virus.

Disease progression is also dependent on dose. It is thought that a larger transmission dose of the virus can increase the seriousness of the illness in some people. This mainly affects people who have received HCV through blood or blood products.

There are also unique psychological and social dilemmas faced by people with different transmission routes. For those people who do associate with IDU culture, there is the problem that other people's knowledge of their HCV status immediately reveals this aspect of their life - knowledge which they may prefer to keep to friends within their cultural group.

However there are many people who contracted hepatitis C from sharing injecting equipment many years ago. They have changed lifestyles, moved into different areas of life, and now no longer think of themselves as 'drug users'. For these people, finding out they have HCV can bring up feelings of regret about past behaviour. Hepatitis C can

sometimes even be associated with some sort of punishment for past wrongdoing - the sins of the past catching up with them, or a kind of karmic retribution. Negative attitudes from health care workers can feed into these feelings making them more persistent.

For people who don't know how they contracted the virus the dilemmas can also be great. They may receive prejudicial treatment from health care workers who don't believe their story. "He must have done something to get this", or "all junkies tell lies anyway" attitudes are unfortunately still common.

This can exacerbate feelings, confusion and questioning, and create a powerful quest to find the 'truth' about the source of the transmission. This quest can sometimes threaten to overtake peoples lives, especially with intensive questioning from inquisitive others.

For people who contracted HCV from an improperly sterilised piercing or tattoo needle, a harmless fashion statement has suddenly turned into a potentially serious illness. To some, the piercing or tattoo becomes a visible scar or reminder of the virus. There may be feelings of regret at having bothered to get it done, or anger at the practitioner for having wrongly reassured them of the procedure's harmlessness.

These kinds of feelings are often magnified for people who contracted the virus through a medical procedure or blood transfusion. The original operation or medical procedure was, in many cases, lifesaving and the recovery, long and challenging. The knowledge of the virus can have the effect of bringing that trauma back to vivid memory. A sense of betrayal and injustice at the health care system that inadvertently gave them the virus is sometimes one of the legacies carried by people living with medically acquired HCV.

Each mode of transmission has its own associated problems but the commonalties of all people managing their illness, I believe, outweigh any differences. Everyone faces similar problems in negotiating intimate, social and family relationships. All face the same problems in keeping their diagnosis private to minimise discrimination, and in facing the challenges in their working lives. Everyone needs to reassess priorities based on possibly limited energy and in the advocating for high quality health services.

For all people living with hepatitis C, coping with symptoms and the prejudice of ignorant others is challenging. To focus on the differences of the 'other' (ways of contracting HCV), only increases the feelings of discrimination all people living with hep C have to contend with.

Focusing on the common things that people share creates an environment in which people can feel supported and builds a strong base from which to advocate for improved services.

- Claire Booth is the Coordinator of TRAIDS, a counselling information and resource centre for people living with medically acquired HIV and people with HCV. You can contact her on 02 9843 3143 weekdays for more information.

Naturopathic care and chronic illness

By Justine Lovelock

What is a naturopath

Naturopaths are therapists who assess all facets of a person's health, encouraging them to care for their own health.

Naturopaths use holistic methods such as:

Herbal medicine - utilising not only empirical knowledge, but the latest scientific research.

Naturopathic nutrition - using food and dietary regulation medicinally is of the utmost importance not only when people are sick, but when they are in continuing good health. In life, we are what we eat (and drink).

Homeopathy - using homeopathic remedies which stimulate the body's own natural defence mechanisms.

Remedial therapies - including therapeutic massage, lymphatic drainage and other complementary methods of hands-on healing.

Philosophy

The key to treating any illness whether acute or chronic is found in the philosophy of all healing professions. The naturopathic philosophy is simply to locate and remove the actual cause, to support the person both physically, mentally and emotionally, and to examine systems of natural cleansing within the body, the person's vitality and their spiritual well-being, lifestyle, etc.

Prevention of illness, rather than waiting for someone's wheel of life to come to a grinding halt is in many ways, the key to health and the major difference between the general practitioner and naturopathic practitioner.

Naturopathic practitioners treat more than just the so called disease picture in front of us, but the total person, warts and all.

The initial consultation

Initial consultation with a naturopath may take from 30 to 90 minutes. The extra time that a naturopath spends with a client helps the

practitioner not only to build an accurate case history but to get a feel for the person's physical component of ill-health and their equally important mental and emotional health.

Being given the time and space to talk is one of the corner stones of the practitioner/client relationship. This aspect of consultation also gives the client time to assess the practitioner.

A good case history would include such things as current diet, family history of illness, childhood illnesses, occupation, prescribed medicines, alcohol and other drugs, allergies, systems review as well as presenting symptoms and other relative areas of interest.

These case-taking procedures, along with other diagnostic tools such as iridology, observation techniques (eg. postural analysis) and kinesiology, help the naturopathic practitioner in providing a treatment regime suitable for each person.

Addressing chronic illness

In helping people with chronic illness the disease process needs to be considered - how it moves from acute through to sub acute and finally to chronic disease. Progressing back through these stages is often the key to reducing chronic symptoms and signs and returning a person back to a better state of health.

In regard to chronic illness, a homeopathic consultation would take into account such things as, presenting symptoms; the person's nature (fears, trauma, etc); food and beverage cravings, aversions or aggravations; sleep quality; weather; other acute or chronic conditions; and family health history of significant illnesses.

The right therapist

is someone who looks at YOU, not just as a clinical problem, but as an individual who does and should have a say in their own health and well-being. This is the holistic approach.

A good therapist is someone who encourages people to ask questions regarding their health and gives accurate information explaining the medical jargon.

He or she should keep abreast of the latest information regarding health and encourage you to do the same - health is not a spectator sport. They should be willing to network and consult with other practitioners, referring you for complementary treatment where necessary - to chiropractors, osteopaths, massage therapists, physiotherapists, general practitioners and specialists.

To locate an ANTA (Australian Natural Therapists Association) practitioner in your area, phone tollfree 1800 817 577. These practitioners are qualified in basic sciences, along with naturopathic sciences and supported by government accredited courses.

- Justine Lovelock, ND, is a member of the Australian Natural Therapies Association.

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Hepatitis C and life insurance

By Dr John McKeand

Infection with the hepatitis C virus is now relatively common in Australia. The clinical course of the infection varies widely however. In some cases there are no symptoms and no illness develops. In other cases the infection may result in cancer or severe liver disease and ultimately liver failure. Fatigue is an occasional symptom and can be a prominent side effect of certain treatments of hepatitis C infection.

In many instances life insurance will be available to persons with hepatitis C but a higher premium rate will usually apply. Disability insurance will only be available in a small minority of cases.

The insurance terms available will depend on the individual circumstances. In order to clarify the circumstances it would be usual practice for the insurance company to seek medical reports from the doctors that have attended the insurance applicant. This can only be done with the written authority of the person concerned however.

Are you obliged to inform the insurance company that you have hepatitis C?

Because of the serious consequences of hepatitis C, the presence of the infection is something that is of vital interest to life insurance companies. Life insurance contracts are contracts of "utmost good faith" implying a duty on both parties to the contract to act fairly.

Further, the Insurance Contracts Acts 1994 imposes a duty on persons applying for insurance to disclose to the insurer all matters known to the applicant that could impact on the risk the company is insuring. A failure to disclose relevant information may entitle the insurer to avoid the contract and therefore not pay any claims that may occur.

The effect of the above is that it is essential for an infected individual to disclose their infection to insurers in order to have confidence that the insurance contract will indeed provide the cover required.

- John McKeand is Chief Medical Officer at National Mutual Financial Services.

Chronic HCV causes a significant reduction in quality of life in the absence of cirrhosis.

The effects of chronic hepatitis C virus (HCV) infection, in the absence of cirrhosis, on peoples' quality of life was assessed using the short form 36 (SF36) symptomatology questionnaire.

Seventy two people with chronic hepatitis C were polysymptomatic and had significant reductions in their SF36 scores for all of the modalities tested.

Thirty people with chronic hepatitis B virus (HBV) infection showed a reduction in the SF36 scores that assessed mental functions, but they had no decrease in the scores that measured physical symptoms, indicating that the symptoms associated with chronic HCV infection are qualitatively different from those associated with chronic HBV infection.

People with chronic HCV infection who had used intravenous drugs in the past had the greatest impairment in quality-of-life scores, but the reduction in quality-of-life scores was still found in patients who had never used drugs.

The reduction in quality of life could not be attributed to the degree of liver inflammation or to the mode of acquisition of the infection.

Hence, chronic infection with HCV per se gives rise to physical symptoms that reduce the quality of life of infected patients.

AUTHOR: Foster GR, Goldin RD, Thomas HC, Liver Unit, Imperial College School of Medicine at St Mary's, St Mary's Hospital, London, England, UK.

SOURCE: Hepatology 1998 Jan;27(1):209-212

- Taken from the international email list: HEPV-L@MAELSTROM.STJOHNS.EDU

Hepatitis C and employment

People with hepatitis C may have concerns about illness and work.

If you have hepatitis C your status should not in itself lead to negative consequences at work. This is because employers are obligated to ensure that their workplace and work practices don't discriminate against people with disabilities - and infection with hepatitis C is classified as a disability.

This obligation applies equally if you apply for an advertised position (see *pre-employment medicals*, Ed 21 p15), or if you are already working but become ill through hepatitis C.

In some cases where there is a public health concern or occupational health and safety considerations, an employer may discriminate. For example, where an employee is involved in invasive medical procedures or where an employee is to be deployed in combat or combat related duties for the Australian Defence Forces.

Discriminatory workplaces or practices may include long work shifts, expectations to work double-up shifts or the lifting of heavy loads.

If you do need to take time off because of illness this would be taken as sick leave. If the amount of time off taken exceeded allowable limits, you would most likely need to enter into negotiations with your employer.

If an employer wanted to sack or retrench all employees who took excessive sick leave, this could be seen as discriminating against people with disabilities.

For people who experience chronic lethargy and tiredness, options may include working on a part-time basis. Perhaps a 'flexitime' arrangement would suit people who generally feel well but on odd occasions may feel unable to work.

Within such negotiations it may be necessary to disclose your hepatitis C status. Your employer should not discriminate against you if this is the case. Any negotiation should centre around your current level of work ability and not involve the fact that you have hepatitis C.

- For more information, contact the NSW Anti-Discrimination Board on: 02 9318 5444 or 1800 670 812.



Office of the

**Minister for Defence Industry,
Science and Personnel**

ADF policy towards hepatitis C

Following our request, the Australian Defence Force provided us with the following information.

The ADF policy on Hepatitis C is contained in the Surgeon General Australian Defence Force Health Policy Directive No 217 - *Hepatitis C Virus Infection*. This policy contains information on the structure, transmission of, and methods of diagnosis for hepatitis C. The policy also details ADF requirements for HCV screening and the management of members diagnosed with hepatitis C.

Routine screening for anti-HCV is performed on all new entrants to the ADF and whenever screening for other blood borne diseases (HIV and Hepatitis B) is performed, either on clinical grounds or in accordance with operational policy.

Any member who has a positive anti-HCV test then also has a polymerase chain reaction (PCR-HCV) test performed. The PCR-HCV test is used to determine whether individuals are infectious with HCV. Australian Defence Force members with positive PCR-HCV test results are determined to be infectious with HCV. Management of ADF members in this situation is as follows:

- new entrants are discharged from the Service, and
- serving members are referred to an appropriate specialist medical practitioner for further clinical management and counselling on lifestyle modifications and precautions.

All ADF personnel are required to be in a state of 'battle readiness'. The particular problem with members diagnosed with an infectious blood borne disease is that they constitute a risk to other ADF members who may have to render 'buddy aid' in the operational field environment. Members diagnosed as being infectious with HCV are classed as 'not operationally deployable'.

This status is reviewed after one year, and if the individual remains infectious with HCV, their non deployable status is confirmed as permanent. Members who have a permanent non-deployable status confirmed are then referred for an employment standard review to determine their fitness to continue serving in the ADF.

Any entrant, or member, who is diagnosed with HCV and then discharged as a result, may re-apply for entry to the ADF. However, such re-entry is only permitted if serial PCR testing, and specialist medical opinion, indicates that they are no longer infectious.

next edition

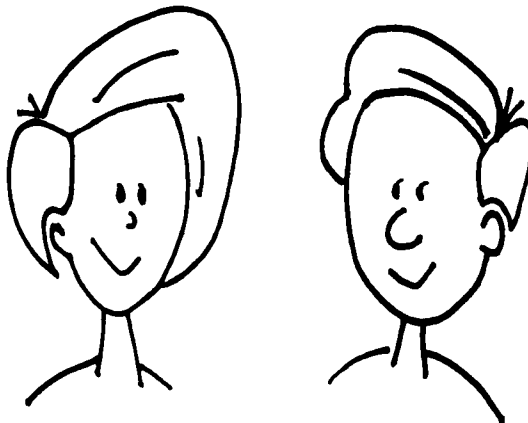


What has been happening overseas with HCV?

Our next edition will focus on overseas news, including -
treatments
political action
support services
& research

Hey, I just moved from Queensland and my new GP is sending my 3 year follow up report

I stopped interferon treatment after 3 months but I still attend for regular check-ups



If you've had interferon and don't attend for follow up checks, they won't find out how to improve the treatment. Make sure your treatment centre or GP forward your follow up reports to the Hepatitis C National Database
ph. 02 4921 7431 fx. 02 4921 7432



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

Our site contains general information taken from *Hepatitis C: what you need to know*.

Seminar: Spanning Identities

Access Plus is a community-based organisation encouraging access and equity for all gay, lesbian, bisexual and transgender people with a disability.

They have organised the above seminar which aims to identify barriers in accessing services, and to provide a forum in which people can share experiences of living with a disability. It will take place in October 1998.

For more info, phone Ian Archer-Wright on 02 9360 6687.

IS HEPATITIS C TAKING YOUR MIND OFF THE JOB?

call the
NSW HEP C TELEPHONE INFO & SUPPORT SERVICE

9332 1599 for Sydney callers
1800 803 990 for NSW callers



Lewis Hine: *The Empire State Building Photographs* - courtesy of Avery Architectural and Fine Arts Library, Columbia University in the State of New York ©

Look before you leap - advice on superannuation payouts.

by Paul Garde

Are you concerned about being retrenched or considering resigning on health grounds?

Make sure you get your superannuation. Leaving work for good is a very important event, particularly in legal terms. The way you approach the end of your employment can have a big impact on your access to benefits which you could be entitled to. This is especially the case if you want to claim a Total and Permanent Disablement (TPD) Benefit.

The HIV/AIDS Legal Centre NSW Inc (HALC) has acted for clients in relation to a number of TPD claims and recommends:

Don't just leave work on the spur of the moment.

Even if your fund does provide TPD cover, that cover may cease at the moment you resign or are

retrenched, or soon after at a time specified by the fund - eg. 30 days after resignation or termination.

Preserving your eligibility is vital - it may even be preferable in the long term to take unpaid sick leave while you seek legal advice on your entitlements.

Find out if you're covered.

Not all funds provide members with TPD cover. Whether or not TPD benefits are available to you is important information, which you need to know before you finish work.

You should try to get all information possible about TPD cover in your fund, from pamphlets to your annual member's benefit statements. Quite often member's benefit statements go astray if the fund does not have your current address.

Information can be obtained by the fund, or from your employer (who makes compulsory contributions under the Commonwealth Superannuation legislation).

Take legal advice before acting.

Because the decision to leave is so important, HALC recommends that you seek legal advice before resigning from work. Again, it may be preferable to take unpaid sick leave before ending your employment permanently.

Taking legal advice before you resign avoids many of the problems which can arise in pursuing TPD claims, especially the time limit for applications. Even where late applications are allowed, HALC's experience suggests that succeeding in a TPD claim made after the time limit is more difficult.

To prove "total and permanent disablement", fund members have to get certificates from two medical practitioners stating that they are unlikely ever to be able to work again in a job for which they are reasonably qualified by education, training or experience.

Getting this documentation and proving disablement to the satisfaction of the fund, becomes harder the longer a person waits after the end of employment. With proper legal advice you should be able to access all the appropriate benefits which your fund provides.

- This article abridged with thanks from the original which appeared in *Talkabout* Sept 1997.

Paul Garde is Co-ordinator of the HIV/AIDS Legal Centre NSW Inc - Ph 02 9206 2060



**INject
YOurSelf
DON'T
INFECT
YouRSelf**

You

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

How?

CHange the way YOU INject.

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

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

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

Clean Your Act Up - wash your hands with warm soapy water and clean your spoon with a fresh swab
clean the fingers you'll use to pull off a filter with a fresh swab
keep all your injecting gear separate from other people's gear

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

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

During and After - if you get blood on your fingers, go and wash your hands before you touch anything on the table - if someone tells you to pass them something, tell them to wait
if you do touch something by accident, (a cup, fit bin - whatever) let your mates know not to touch it themselves before they hit up.
wash your hands after touching anything that someone else who has just injected may have touched

Remember

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

Can't be bothered with all that?

If this all seems too hard, remember that many suggestions are common sense - it's all about avoiding even the smallest amount of blood contact. A bit of preparation, having new injecting gear on hand and thinking it through is all it takes. For more information on local needle & syringe programs, contact ADIS - 9331 2111 (Sydney) or 1800 422 599 (NSW).

Above page taken from the Kirketon Road Centre newsletter, No 5. Our thanks to KRC for permission to reprint.

regular feature - interferon update

Interferon

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

- Chronic hepatitis proven by liver biopsy (except patients with blood clotting problems).
- A repeatedly positive antibody test.
- Liver function tests (see page 16) with elevated ALT readings, three times over a six month period.
- Absence of cirrhosis or other liver disease.
- For women - not currently breastfeeding nor any chance of pregnancy while under treatment.
- No history of significant psychiatric illness.
- Must be able to attend regularly for treatment & follow-up.
- Alcohol use of no more than seven standard drinks a week.

The course of treatment involves giving yourself an injection three times a week for up to twelve months.

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

If your ALT readings (see page 16) don't come down after three months on interferon, 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 centres

Interferon is classified as a potentially hazardous drug with possible serious side effects, and accordingly, the 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.

Interferon treatment centres for hepatitis C exist across NSW (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.

Current treatment centres:

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

Side-effects

Interferon makes most people feel ill and some side-effects can be serious. If you are thinking about interferon treatment, seek information about side-effects from doctors who are up to date on hepatitis C, read the Council booklet, *Hepatitis C - what you need to know*, and phone the NSW Hepatitis C Telephone Information & Support Service on 1800 803 990 (NSW callers) or 9332 1599 (Sydney callers).

Benefits

With twelve months of interferon treatment, it is believed that up to one in three people achieve what is called a 'long-term remission'. This means that the virus seems to be cleared from the person's blood and their liver function returns to normal. Symptoms related to the hepatitis C disappear as well.

[This information is routinely validated by the Commonwealth Department of Health & Family Services, Pharmaceutical Benefits Branch]

Complementary therapies

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

Certainly though, many people report positive benefits.

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

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

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

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

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

Costs

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

Choosing a practitioner

If you decide to use complementary therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well-experienced in working with people who have hepatitis C.

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

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

Healthy herbs?

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

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

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

Want more information?

Contact any of the following organisations:

Australian Acupuncture Association	1800 025 334
Australian Homeopathic Association	02 9879 0049
Australian Natural Therapists Association	1800 817 577
Australian Traditional Medicine Society	02 9809 6800
Association of Remedial Masseurs	02 9807 4769
Homeopathic Association of NSW	02 9247 8500
National Herbalists Association of Australia	02 9211 6437
Register of Traditional Chinese Medicine	02 9660 7708
Australian College of Acupuncturists	02 4677 2358
NSW Association of Chinese Medicine	02 9212 2498
Australian Traditional Chinese Medicine Assoc.	02 9699 1090

regular feature - support services

NSW Hep C Telephone Info and Support Service

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

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

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

Sexual health clinics

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

They are listed in your local phone book under 'sexual health clinics'. If you are concerned about confidentiality, these clinics do not need your surname and keep all medical records strictly private.

Community centres

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

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

Local support services

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

For particular assistance, whether it's help with the kids, housing, finances or home shopping, look in

the White Pages telephone book. In the front, you'll find a whole range of services that are mostly aimed at the general community.

Following is a list of healthcare workers in your local region who can possibly refer you to local services:

Mid Nth Coast	Robert Baldwin	02 6583 0750
Western NSW	Chris Bourne	02 6882 9858
Hunter	Marilyn Bliss	02 4924 6477
Mid West NSW	Dave Brackenreg	02 6332 8576
Southern NSW	Geetha Isaac-Toua	02 4827 3413
South West NSW	Dalton Dupuy	02 6058 1700
Nthn Rivers	Wendi Evans	02 6620 7505
New England	Karin Ficher	02 6766 2288
Central Coast	Karen Nairn	02 4320 3399
Illawarra	Brian O'Neill	02 4228 8211
Wentworth area	Elizabeth O'Neill	02 4724 3877
Western Sydney	Chris O'Reilly	9840 4105
Nthn Sydney	Anthony Schembri	9926 8237
Central Sydney	Peter Todaro	9515 9600
Far West NSW	Darriea Turley	08 8080 1511
SE Sydney	David Willock	9382 8370
Sth Wst Sydney	Ken Wong	9827 8033

One-to-one counselling

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

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

To find out more, speak to your GP, or contact your local sexual health clinic, Community Health and Neighbourhood Centres, or the NSW Hepatitis C Telephone Information & Support Service.

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

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'; contact Family Planning or your local Community Health or Neighbourhood Centre; or phone the NSW Hepatitis C Telephone Information & Support Service (see above, top left).



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

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

Description

Newsletters 1-8 back issue pack - various topics / historical interest

Ed 9 - Chiron's patent / living with grief

Ed 10 - natural therapies

Ed 11 - genome subtypes / life insurance / Terrigal symposium

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

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

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

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

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

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

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

Ed 19 - notifications / diagnosis / understanding research

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

We have an abridged version of our booklet on our website. Look for it at .. http://www.span.com.au/hepatitis_c/info.html

Description

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

Hepatitis C - a brief introduction - (brochure @ \$5 per 100)

Hepatitis C - what you need to know - (booklet)

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

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

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

Research Pack 1 - epidemiology / prevention / serology / diagnosis

Research Pack 2 - overview / National Action Plan

Research Pack 3 - 1994 NHMRC Hepatitis C Report

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

Research Pack 5 - AHMAC / NSW Taskforce Report

Research Pack 6 - prisons / treatment / IDU / PCR

STOP PRESS . STOP PRESS . STOP PRESS

Second Greater Western Sydney Drug & Alcohol Conference.

Dates: 10 & 11 December 1998 (with evening session on 10th)

Venue: Westmead Hospital

Invited speakers include:

Dr Jon Currie, Director - D&A Services, Western Sydney Area Health Service.

Renee Bittoun, Director - Smoking Research Unit, Dept of

Psychological Medicine, University of Sydney.

Dr Alison Ritter, Deputy Director - Turning Point Alcohol & Drug Centre, Melbourne.

Dr Martin Weltman, Staff Specialist - Drug & Alcohol Services, Wentworth Area Health Service.

Tony Trimmingham, Damien Trimmingham Foundation.

Dr Lisa Maher, Research Fellow - School of Community Medicine, University of NSW & National Drug & Alcohol Research Centre.

For more information, contact Nichole Rhodes on

02 9840 3888.



Hep C Classifieds

FOR SALE

Add a bit of excitement to your life with this well maintained Yamaha Sidecar outfit.

The bike: Yamaha XS750SF, triple cylinder, shaft drive - v good cond.

The chair: HRD sidecar purchased 1997 fits two kids or one adult.

Extras: spare tank & sidecovers, some electrics and instrumentation,

two new & one used helmets, canvass covers for bike and chair.

The price: all up, \$3,500.

Contact: Paul on 02 9332 1853.

Registration: YGQ650 (expired Aug 98 but has current pink slip).

"With the kids in the chair and your partner behind you, motorcycling can now be a real family affair."

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

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

1. Please complete either a, b or c.

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

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

b. For individual healthcare or welfare professionals.

Name			
Occupation			
Postal address			
Wk phone		Wk fax	
Mobile phone		Email	

c. For agencies, companies and organisations.

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

2. If you can help with any of 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.

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

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

<input type="checkbox"/> Mastercard	<input type="checkbox"/> Visa	<input type="checkbox"/> Bankcard				
<table border="1"> <tr> <td>month</td> <td></td> <td>year</td> <td>19</td> </tr> </table>		month		year	19	Expiry date
month		year	19			
Card number						
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 _____

Please contact the office if you would like a copy of our Constitution

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