

GOOD LIVER

NEWSLETTER OF THE HEPATITIS C COUNCIL OF VICTORIA



**"SELF MANAGEMENT:
WHAT'S IN IT FOR ME?"**

CHRONIC HEALTH CONDITIONS, SUCH AS HEPATITIS C, AFFECT PEOPLE BOTH PHYSICALLY AND EMOTIONALLY. THE SEVERITY OF SYMPTOMS MAY VARY ON A DAILY BASIS. IN ORDER TO MANAGE THIS VARIABILITY EFFECTIVELY, PEOPLE WITH CHRONIC CONDITIONS NEED TO BECOME ADAPTABLE TO CHANGE. THIS IS COMPLICATED FURTHER BY THE ELEMENT OF UNCERTAINTY ABOUT THE SEVERITY OF SYMPTOMS TOMORROW AND IN THE FUTURE.

Learning ways to manage change and the challenges associated with a chronic condition can help people avoid life in the "vicious cycle". When people with a chronic condition like hepatitis C are in this cycle they often move from doctor to doctor, experiment with treatments, and have negative emotions. They experience financial impact from expensive treatments, depression, perhaps more doctors and so forth. But by taking an active role in the self management of their condition, people with hepatitis C and other chronic conditions can avoid this vicious cycle.

Self management includes managing not only the physical problems such as pain and fatigue but also dealing with difficult emotions such as anger, fear and frustration, and the impact the condition has on

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HEPATITIS C COUNCIL OF VICTORIA INC

Suite 5, 200 Sydney Road,
Brunswick, Victoria 3056
Telephone: 03) 9380 4644
Country Callers: 1800 703 003
Facsimile: 03) 9380 4688
Email: hepcvic@vicnet.net.au
Web: www.hepcvic.org.au

CONTACT THE COUNCIL:

Helen McNeill
Executive Officer
helen@hepcvic.org.au

Genevieve Dickson
Office Coordinator
gen@hepcvic.org.au

Venetia Brissenden
Project Coordinator
Project Blood Oath
venetia@hepcvic.org.au

David Clements
Project Coordinator
Workforce Development Initiative
david@hepcvic.org.au

Linda Connor
Community Development
and Education - Rural
linda@hepcvic.org.au

Barb Healy
Community Development
and Education - Rural
barb@hepcvic.org.au

Piergiorgio Moro
Community Development
and Education - Metro
pier@hepcvic.org.au

David Samson
Community Development
and Education - Custodial Settings
davids@hepcvic.org.au

Heather Smith
Communications and Publications
heather@hepcvic.org.au

The Good Liver is produced by the Hepatitis C Council of Victoria. The opinions and language expressed in this newsletter are not necessarily those of the Council.

Reader Response

Your comments or experiences in regard to any articles in the Good Liver are welcome. Call, write or email: heathers@vicnet.net.au

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vic council news:



A NEW PROJECT AT THE COUNCIL

The Hepatitis C Council of Victoria is heading up an exciting new pilot project aimed at increasing the awareness of hepatitis C prevention among young people experiencing homelessness. The project is called **Project Blood Oath** and is coordinated by Venetia Brissenden, who has been seconded from her previous role as the Custodial Settings Officer to this 10-month pilot project.

There is a real need for creative and sophisticated hepatitis C prevention initiatives targeted at homeless young people. One in five new hepatitis C infections occur in young people aged 15 to 19 years and research shows that young people who are homeless are at greater risk than their home based peers. They are also an incredibly difficult group to reach with prevention messages, particularly as they are dealing with a variety of issues and often leading very chaotic lives. Hepatitis C is only one of a number of hazards experienced by people who are young, homeless and using drugs.

Project Blood Oath is auspiced by a consortium made up of the Hepatitis C Council of Victoria, Open Family Australia, Melbourne Citymission and the University of Melbourne. The Project will have both an education and an outreach component. If any one has any questions about the project, please feel free to contact Venetia on 03 9380 4644.

NEW EMAIL ADDRESSES

The Council is in the process of changing its internet provider. All staff now have new email addresses which are printed in the left hand column on this page. We will be able to receive emails sent to the old addresses until December 2004. Please update your address books - we'd hate to lose contact with you!

MEDIA REPORT

IMMUNITY FIND RAISES HOPE FOR HEP C VACCINE.

A vaccine for hepatitis C could be available within a decade after landmark Australian research found that people repeatedly contracting the virus can develop a natural immunity to infection.

The discovery was made during a study of 160 prisoners, considered at high risk of contracting the virus through intravenous drug use. Four prisoners who contracted the virus later cleared it without developing any anti bodies or traces of infection. Significantly, two of them showed signs that their white blood cells had formed an immunity against the virus.

Clinical trials are under way on two possible vaccines, with treatment likely to be ready for distribution within 10 years.

*Excerpt of article courtesy of
The Australian. 23 August 2004*

OUR NEW CUSTODIAL WORKER

Towards the end of the financial year we welcomed David Samson to the position of Community Development and Education Officer - Custodial Settings. David temporarily replaces Venetia Brissenden who has been seconded within Council to Project Blood Oath.

David comes to us with a long history of working in education and training around blood borne viruses. Prior to taking up his position with the Council he was the Hepatitis Educator with Royal District Nursing Service, and before that was Manager of the AIDS, Hepatitis and Sexual Health Line.

David sees it as a priority that every prison in Victoria accesses the Custodial Settings project as an education and training resource for prisoners and prison staff. Building on the existing good relationships with prison authorities and other partner organisations working in prisons, he will be working to keep a high profile for hepatitis C education in this high risk environment.

Annual General Meeting

TREATMENT HAS BEEN AN AREA OF IMPORTANT CHANGE IN THE LAST 12 MONTHS.

Dr Katrina Watson, Gastroenterologist will give one of two presentations on the treatment of hepatitis C.

**Tuesday 12 October 2004
5 to 7pm**

**The Terrace
Royal Botanic Gardens, South Yarra**

Come along and be informed about your options.

RSVP: 6 OCTOBER: 9380 4644



THE AUSTRALIAN HEPATITIS COUNCIL NEEDS YOU!!

The Australian Hepatitis Council is committed to providing a national voice for people with hepatitis C. To better achieve this, we've added to our Board by introducing two dedicated positions for people with hepatitis C.

For more information see the enclosed flyer in this issue or contact Helen McNeill at the Victorian Hepatitis Council on 03 9380 4644 who will be able to send you an information pack.

NOMINATIONS CLOSE 29 OCT 2004.

MEMBERS ADVISORY GROUP

- Would you like to know more about the Council?
- Do you have ideas about how the Council could work better for you?
- Would you like to have your say about how the Council works?

If so, then the Members Advisory Group (MAG) is the forum for you. MAG is the Council's forum where members can have a voice. Come along to the next meeting - **Sunday 10 October from 12.30 to 1.30** at the Council offices, in Sydney Road Brunswick. For more details call Pier on 9380 4644.

Welcome to the spring edition of Good Liver. Spring is my favourite time of year - I suddenly seem to feel newly energised, focussed and optimistic despite some of the confronting and distressing images of our world that we see on a daily basis. I hope you are enjoying spring too.

In this edition of Good Liver there are several articles outlining different aspects of the self management of chronic conditions such as hepatitis C. Although hepatitis C treatments are greatly improved and an increasing number of people have the opportunity to clear the virus, many continue to live with hepatitis C in the long term. Everyone with hepatitis C self manages in some way, however some people are what could be called active self managers whilst others are passive self managers. Which do you think you are?

In the last 10 years I have worked with people with a wide range of chronic conditions, such as migraine, arthritis, chronic fatigue syndrome and Crohn's disease. I have witnessed some amazing outcomes from people increasing control of their chronic condition and improving their general health through active self management. I would encourage you to take the time to read the articles and think about the way that you manage your hepatitis C. Are you doing ok, or is there a

possibility that a more active role could be helpful?

Our Annual General Meeting is fast approaching and we have chosen a subject for the presentation that we believe will interest a large number of our members. There will be two presentations on treatment of hepatitis C. This has been an area of important change in the last 12 months and we would like members to be fully informed about it. Even if you are not seriously considering treatment at this stage this is an opportunity for you to be an active self manager by being informed about your options in managing your hepatitis C. You can find out more about the event on your invitation mailed with this issue of Good Liver. But why not put the details (5 to 7pm, Tuesday 12 October) in your diary now. We would love to see you there.

Please don't hesitate to contact me if you have any thoughts about our work that you would like to share - I love the opportunity to hear what is important for people with hepatitis C from those who really know our members.

Best wishes

Helen
helen@hepcvic.org.au

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SELF MANAGEMENT CONTINUED

lifestyle and on others. At times, this seems like a huge burden. Knowing you can take some control in managing your health can lighten this burden.

How can you become an active self manager?

- Get involved in activities that promote your health eg. healthy eating, being physically active
- Monitor signs and symptoms of your chronic condition
- Deal with the effects of the condition on your personal health and relationships with others. For example learn ways to conserve energy and manage fatigue
- Work with health care professionals and share decisions about treatment
- Follow a treatment plan

Self management is not an alternative to medical care; rather it encourages a partnership with health care providers. This does not mean that you have to manage everything alone. Seeking information and support from others is very important.

SELF MANAGEMENT EDUCATION

There are a number of education programs designed to assist people to develop the skills and confidence to manage their chronic health problem. Some of these programs are disease specific such as the six-step asthma program, the arthritis self management course and the living with cancer program. The Chronic Disease Self Management Course, also known as the Better Health Self Management Course, was designed for people with one or more different chronic conditions. Whilst people who attend this course may have a variety of different conditions, they often find they have many concerns and problems in common. The sharing of ideas, through small group discussion, goal setting and positive feedback is integral to the structure of the course. Whilst the course is generally delivered to a group of people with different conditions, it is also suitable for a condition specific group like hepatitis C.

The course was developed by the Stanford University Patient Education Research Centre and has been available in Australia since 1996. It is delivered weekly for 2 1/2 hours, over six weeks. Course leaders attend a pre course training program. Leaders may be either health professionals or people who have a chronic condition. These leaders contribute significantly to the course as role models.

Content of the Better Health Self-Management Course includes:

- How to manage pain and fatigue
- The benefits of physical activity
- Understanding medication use
- Managing anger, fear and frustration
- Solving health-related problems
- Better communication with doctors

There is growing research evidence for the benefits of self management education programs. According to Lorig (2001), people who participated in the better health self management course, when compared to those who did not, demonstrated significant improvements in frequency of physical activity, cognitive symptom management (eg. relaxation techniques), communication with doctors, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. There were also health care cost savings due to fewer days spent in hospital, and a trend toward fewer outpatients visits.

The value of chronic disease self management programs in Australia is increasingly being recognised and supported. The Federal Government has funded the development and implementation of a variety of chronic disease self-management education models. The Sharing Health Care Initiative, which is part of the Enhanced Primary Care (EPC) package, will be completed during 2004 and will provide research evidence on the applicability of a range of models in a variety of Australian settings and health conditions. Further funding was provided by the Federal Government in the

IF YOU THINK YOU MIGHT BE INTERESTED IN PARTICIPATING IN A SELF MANAGEMENT COURSE OR WOULD LIKE TO KNOW MORE, PHONE THE HEPATITIS C COUNCIL AND HAVE A CHAT WITH HELEN. IF THERE ARE ENOUGH PEOPLE INTERESTED WE MAY BE ABLE TO ARRANGE TO RUN A BETTER HEALTH SELF MANAGEMENT COURSE SPECIFICALLY FOR PEOPLE WITH HEPATITIS C.

2003-2004 budget to further integrate chronic condition self-management into the Australian health care system.

Being actively involved in the management of your hepatitis C can help you to feel a greater sense of control over your health and help you avoid the "vicious cycle". Self management education courses can help those who want to learn more about how to best manage the physical and emotional challenges of living with a chronic condition, in a friendly and supportive environment.

Liz Bongetti
Nurse, Health Educator.

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BENEFITS OF PHYSICAL ACTIVITY & EXERCISE

There can be no doubt that exercise plays a critical role in helping us to maintain good health. Health and fitness professionals have been aware of and promoting the benefits of physical activity for many years. However, it wasn't until a report was released by the USA Surgeon General in 1996 which documented the relationship between physical activity and health, that these benefits became common knowledge.

The Surgeon General's report was not only significant in confirming the role of exercise in maintaining good health and preventing disease, it also highlighted the importance of physical activity in managing chronic illness. Exercise was shown to play a part in reducing high blood pressure, reducing feelings of anxiety and depression, and reducing body weight. Further research has demonstrated that appropriate physical activity can prevent the progression of atherosclerosis (hardening of the arteries), reduce the effects of type II diabetes and improve bone density. An important addition to these findings is that regular participation in physical activity can reduce the amount of money people spend on various treatments and alternative therapies in an attempt to manage or "cure" their condition.

To date there has been little research conducted into exercise and hepatitis C, however the findings of research into some other chronic illnesses can be applied. For example, regular appropriate exercise can help with:

- Fatigue - regular exercise can help reduce fatigue by improving general

fitness, muscle strength and sleep patterns. Appropriate exercise can also help reduce muscle aches and pains experienced by some people with HCV by relieving tension in tight and stiff muscles.

- Stress - physical activity causes the release of "feel good" hormones called endorphins and has been shown to reduce symptoms of stress, as well as anxiety and depression, which are commonly experienced by people with a chronic illness.
- Body weight - regular exercise along with a balanced diet is essential in reducing body fat and maintaining a healthy body weight. Obesity is a known risk factor for the progression of cirrhosis in people with chronic liver diseases like hepatitis C so maintaining healthy weight is critical for long term health. (*Hickman IJ et al (2004). Gut. Mar 53(3): 413-9*).

Many people living with a chronic illness find the idea of exercise quite daunting, but physical activity doesn't have to be overly strenuous to be effective. If you're not used to exercising or you suffer from fatigue, start slowly and only exercise for short periods at a time. Starting a regular exercise program may be as simple as walking around the block! The key is to add a little more activity to your daily routine than you would normally undertake (eg. walking to the local shop instead of driving) and gradually working up from there. Here are some helpful hints:

- If you're not used to exercising start with short sessions (ie. 15 mins) a couple of times a week, then gradually increase the length of time you exercise for as well as the number of times a week you do it.

- If you are able to participate in exercise that is a little more vigorous, always ensure you spend at least 5 minutes warming up and cooling down. For example if going for a walk start at a very slow pace for the first few minutes, then speed up the pace. A few minutes from the end slow the pace right down again.
- Always listen to your body. Sometimes you do just need to rest so try to exercise when you have the most energy. On days when you are feeling only so-so, try something a little less active like going for a leisurely stroll. Exercise should not cause you any pain so stop immediately if you experience any unusual pain. Always stop if you feel nauseous, light headed or dizzy.
- Appropriate types of exercise include walking, swimming, hydrotherapy, golf, tai chi, lawn bowls, dancing, gentle resistance training, chair based exercise classes, individualised exercise program prescribed by a health or fitness professional, among others.

If you are not used to exercising then it is important you consult your doctor or specialist before commencing a program. Some medications can reduce tolerance to exercise so it's important to get professional advice. If you are a regular exerciser but are thinking about increasing the intensity of your program or trying something new, it's also a good idea to talk to your doctor. Happy exercising!

Jane Barnes
Physiotherapist

PROBLEM SOLVING

Being an effective self-manager relies on being able to identify and solve problems and make decisions. Most of us solve all sorts of problems every day, often without even realising that is what we are doing. When the car breaks down and we call a friend for a lift, for example, we have solved the problem of how to get to our destination without a working car. Of course, not all problems are this easy to solve.

When problem solving happens effortlessly and is successful, we tend not to notice it. All of us would be familiar however, with problems that just don't seem to go away (no matter how much we ignore them) and issues, obstacles and decisions we mentally tuck away in the 'too hard' basket. These are often problems that require a change in behaviour to solve, such as giving up smoking, increasing our exercise or eating a healthier diet. As most of us know, good intentions, no matter how sincere, often crumble at the first hint of a problem.

DEFINING THE PROBLEM

Problem solving has two distinct phases: a problem definition phase and a problem solution phase. It is important to properly define the problem before seeking a solution. Techniques such as writing the problem down, or explaining it to a friend, force us to be specific and concrete about what we are experiencing. It can also help to ask yourself the following series of questions:

- What can you see or feel that causes you to think there's a problem?
- Where is the problem happening?
- How is it happening?
- When is it happening?
- With whom is it happening? (Be careful not to jump to "Who is causing the problem?" no matter how tempting this may be. Blaming someone else actually leaves you powerless to sort the problem out yourself.)
- Why is it happening? (This last one can help to ensure that you are working on the right problem. For example, if the problem you initially identify is feeling tired during the day, asking 'why' may

lead you to identify the underlying problem of having trouble getting to sleep at night.)

Try and write down a brief description of the problem using the flowing prompts "The following should be happening, but isn't..." or "The following isn't happening and should be..." Be as specific, as concrete and as descriptive as possible.

Once you have defined the problem there are a few different techniques you can employ to get you thinking creatively about possible solutions. These are just a few of the many techniques available on the web and in the library. Some techniques will be better suited to some problems than others, and some problems, of course will not be able to be resolved this way. This will certainly be true of those problems which involve strong feelings such as fear, anxiety, dependency or self doubt. Strong feelings are likely to set up barriers to any decision making process and may require a different approach to sort through.

All of these techniques can be done individually or with others that you trust. Using more than one mind to address the problem has the benefit of widening the list of possible solutions and coming up with strategies that you yourself might never have thought of.

BRAINSTORMING.

This is a simple process with the goal of getting past the obvious and generating some creative solutions. Generally the point is to come up with as many ideas as quickly as possible, leaving the critiquing, culling and judging until later. During the brainstorm there should be no criticism. Turn your inner critic off! The idea is to get outside the parameters of your normal thinking and become as creative as possible in the search for a solution to the problem. Many of the solutions thought of during a brainstorm may be impractical or undesirable, but this technique can also produce some creative and workable solutions that may not have been immediately apparent.



BEGINNING AT THE END.

A problem can often be more easily solved by starting with the solution and working backwards toward the problem, filling in the necessary steps along the way. When solving a problem, we typically wish to do more than simply rid ourselves of some unacceptable situation. More often than not we are trying also to achieve some other, more desirable state of affairs. Theoretically speaking, we're trying to move from the problem state to the solved state. Ask yourself questions like these: "How will I know the problem has been solved? What will I accept as evidence? What does the solved state look like?" Then ask yourself "what do I need to happen to get to that solved state?"

CLARIFYING THE GOALS

If we don't want something that already exists, our goal is typically one of eliminating something. If we want something that doesn't exist, our goal is ordinarily one of achieving something. For any problem situation, it is useful to ask the following questions as a way of clarifying all your goals and objectives:

- What are we trying to achieve?
- What are we trying to preserve?
- What are we trying to avoid?
- What are we trying to eliminate?

Once these questions are clarified, moving on to the how can be a lot easier.

IMPLEMENT SOLUTION

Once a solution or number of solutions has been identified it is important that an action plan is formulated and implemented.

HEPATITIS C AND ALCOHOL

Problems are never solved without action. Hopefully you will have used one or two of the techniques described above and will have a list of possible solutions to try out. Some solutions may require some planning, and it may help to detail the plan on paper. It may also be useful to impose a time limit or a review date to check whether the solution is working.

MONITOR PROGRESS AND TRYING AGAIN

If the problem hasn't been solved, take the time to identify why. Was the solution you picked not right for the problem? Has the problem changed? Does the solution need more time? If you identify that it was the wrong solution, pick another one from your original list and try that instead. Remember though that change can be difficult and be sure to give your solution a fair chance before discarding it.

Some problems will not be solvable at this point in time. However, many of those things that irritate, annoy and frustrate us about how we manage our lives can be changed if we put our minds to it. Using problem solving techniques can become second nature and the good news is that we get better at it the more often we do it.

Finally, if your solution works remember to pat yourself on the back!

Venetia Brissenden
Coordinator - Project Blood Oath

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Alcohol is a potent poison to the liver and in combination with hep C, may increase damage to the liver.

Chronic excessive alcohol intake can greatly accelerate the rate of fibrotic progression of hepatitis C. There also appears to be a strong link between the development of cirrhosis, hepatocellular carcinoma and people who consume chronic excessive amounts of alcohol. There is little evidence to be certain whether small amounts of alcohol does significant damage to the liver.

Moderating alcohol intake may be the most effective health maintenance strategy for people with chronic hepatitis C infection. Evidence shows that people with hepatitis C related cirrhosis should avoid alcohol.

ASSESSING YOUR ALCOHOL INTAKE

Although chronic excessive alcohol intake accelerates the rate of fibrotic progression in chronic hep C, most studies have found that lesser (small) degrees of alcohol intake do not worsen the disease.

RECOMMENDATIONS FOR ALCOHOL CONSUMPTION

Alcohol should be minimised to not more than one standard drink per day. If you have hepatitis C and wish to drink then it is important to limit your alcohol intake to well below the NHMRC alcohol guidelines, to about 7 standard drinks (for men) or 4 standard drinks (for women) per week, with at least two alcohol free days per week.

People with hepatitis C related cirrhosis are advised to abstain from alcohol use entirely.

For people having difficulties limiting their alcohol consumption referral to a drug and alcohol agency and ongoing support may be beneficial. Phone DIRECTLINE, the Alcohol and Drug information service on 03 9416 1818 or freecall 1800 136 385.

ALCOHOL AND HEPATITIS C TREATMENT

People who drink alcohol and are preparing for or considering antiviral therapy should limit their drinking to less than 7 standard

drinks per week 6 months prior (during the 'work-up' period) as well as during treatment. Referral to a drug and alcohol agency and ongoing support may be beneficial.

WAYS TO MANAGE ALCOHOL INTAKE

It is important to remember that alcohol causes liver inflammation and think about whether or not you wish to start or continue to drink alcohol. The advice of your specialist, doctor or treatment centre also needs to be considered. Try experimenting with different strategies that may help you to reduce your alcohol intake. Some simple strategies include:

- avoid binge drinking (consuming hazardous or harmful levels of alcohol in a relatively short period of time) - this places a heavy strain on the liver to detoxify and metabolise the alcohol;
- try not to drink in rounds, always finish a drink before pouring another and avoid situations where you may feel obliged to or pressured to drink;
- start with a non alcoholic drink or alternate alcoholic drinks with non-alcoholic drinks or low alcoholic drinks - this will help reduce the amount of alcohol being processed by your liver over a short period of time;
- switch to low alcohol drinks altogether;
- have at least two alcohol free days a week;
- do not save your weekly ration of drinks to be consumed in the one session;

If cutting out alcohol entirely is not an option for you, consider reducing the amount of alcohol you drink or trying one week without alcohol. Then measure how you felt in the week you reduced/or gave up your alcohol intake compared to the week when you drank. The change in your health state may be noticeable enough for you to consider longer-term strategies for reducing or giving up alcohol.

Thanks to the QLD Hepatitis C Council for this information reprinted from 'The C-Factor' Issue 6, 2004.

DRUG PROHIBITION AND HEPATITIS C IN AUSTRALIA

In May 1953, over half a century ago, the Commonwealth government over rode objections from the states and the medical profession and banned the importation and production of heroin. The Director-General of Health in New South Wales, the British Medical Association (later to become the Australian Medical Association), the Royal Australasian College of Physicians and the Royal College of Obstetricians and Gynaecologists were among those to declare that 'the use of heroin should not be prohibited'. Nevertheless, the Commonwealth advised the State Premiers in May 1953 that the importation of heroin was to be absolutely prohibited. Until the states and territories subsequently ran out of stock, heroin continued to be lawfully prescribed by doctors and dispensed by pharmacists under careful controls, much as it had for many previous decades and much as other drugs derived from the opium poppy are still used medicinally today.

The ban was introduced largely due to external pressure from the Permanent Central Opium Board, the forerunner of the International Narcotics Control Board. The involvement of the United States in this intervention has long been suspected but never confirmed.

Before heroin was prohibited, very few people used illicit heroin in Australia. Significant illicit heroin use in this country began a decade and a half after heroin was prohibited in the late 1960s when US servicemen, briefly visiting on leave from the Vietnam War, introduced the drug and the practice of injecting to young Australians. Once introduced, heroin injecting, and then later other illicit drug use, increased rapidly. Drug arrests in New South Wales grew five fold from 173 in 1972 to 909 in 1977 while overdose deaths increased three fold from 14 in 1974 to 49 in 1976. Every few years, a new crisis occurred with the community shocked to discover that the illicit drug problem was growing alarmingly. Almost every year for the last quarter

century, one or other Australian jurisdiction has launched a parliamentary enquiry or Royal Commission into the drug problem. The result of these reviews in the early years was always the same: expand the police drug squads and increase the severity of the penalties.

Draconian responses to drugs soon became a spectacular political magic pudding capable of electing even the otherwise unelectable. But illicit drug problems continued to deteriorate steadily. The numbers of drug users, the range of drug types the quantities of drugs consumed, the number of casualties and crimes all increased inexorably. As the price of street drugs fell, their purity and availability continued to increase. Faced with these consistent findings, most politicians and many community members called repeatedly for more of the same. If all the King's horses and all the King's men had not succeeded, perhaps a few more horses and men might do the trick.

However, the growing cost, limited effectiveness and serious unintended negative consequences of prohibition slowly began to concern an ever-increasing number of commentators. Drug overdose deaths in Australia soared from only six in 1964 to 958 in 1999. The search began for alternatives to banning substances whose demand seems largely irrepressible and whose supply seems largely uncontrollable.

Australia's experience with illicit drugs during the twentieth century was common to most industrialised and later many

developing countries. Global drug prohibition had started slowly at the beginning of the twentieth century but included virtually all nations by the end of the century. The international community gathered at the United Nations in New York in 1998 to take stock of global drug prohibition and contemplate a new slogan ("a drug free world, we can do it"). This was denial on an impressively global scale and took place at the very time that AIDS, the worst international public health threat since the Black Death, was quickly gathering pace. In most continents, sharing of needles and syringes was either the major or the second most important risk factor for HIV infection. In many countries, a deeply entrenched commitment to solving the drug problem by law enforcement had tragically prevented or delayed the introduction of effective means of controlling HIV infection, such as needle syringe programmes.

In April 2003, the half term review of the 1998 UN commitment to eliminating or significantly reducing heroin, cocaine and cannabis use by 2008 was held at the United Nations in Vienna. The United Nations Office on Drugs and Crime declared improbably that "encouraging progress had been made to still distant goals," even though global drug production and consumption showed no overall reduction from 1998 and even though problems had deteriorated substantially in many parts of the world.

The extent to which domestic law enforcement has contributed to the recent heroin shortage in Australia is still debated. While the dramatic reduction in overdose deaths is welcomed, there have also been some concerning negatives. The

This editorial by Dr Alex Wodak was written for the Australian Hepatitis Chronicle, the magazine of the Australian Hepatitis Council. The Australian Hepatitis Council was notified by the funders of the Chronicle, the Australian Government Department of Health and Ageing, that "it is now the Department's progressive approach to ensure consistency across policy areas. (The) Chronicle includes articles contrary to the Australian Government's "Tough on Drugs" policy." Accordingly, Dr Wodak's editorial was cut from that edition of The Chronicle.

The Australian Hepatitis Council, like the Hepatitis C Council of Victoria, is an independent organisation funded to be part of the partnership approach to address hepatitis C. This includes representing the differing views of members of this partnership and exploring all evidence based approaches to addressing the hepatitis C epidemic.

A NEW FACE TO SUPPORT GROUPS

sustainability of any benefits is also in doubt. Heroin availability has increased from its post 2000 nadir but has not yet returned to pre-shortage levels.

Nor is support for Draconian supply control the political magic pudding it once was. For example, the Greens Party almost doubled their vote at the 2003 NSW elections even though their liberal drug policy was widely criticised during the campaign. In the USA since 1996, majorities have supported drug policy reform in 19 of 23 state based ballot initiatives. In Switzerland in 1997, 71% of voters in a national referendum supported retaining the option of heroin prescription for treatment refractory, severely dependent heroin users.

Change in social policy often takes a long time. But after fifty years of heroin prohibition in Australia the winds of change are now well and truly blowing. If demand is constant, the more successful prohibition is in reducing supply, the higher drug prices rise. The higher prices and therefore profits rise, the more attractive drug trafficking becomes to the desperate or ruthless. This economic flaw remains the Achilles heel of prohibition. Australia will not see another fifty years of heroin prohibition. What will follow heroin prohibition is still not clear. In 1992, the most recent figures available, 84% of commonwealth and state government expenditure on illicit drugs was allocated to supply control. Government spin doctors refer to this as 'the balanced approach'. While drug policy continues to rely so heavily on law enforcement, illicit drugs such as heroin and increasingly amphetamine, will continue to be administered almost entirely by injection. While these drugs continue to be injected by a large and growing army of drug users, the number of hepatitis C infections and other injecting-related health problems will continue to soar.

**Dr. Alex Wodak,
St. Vincent's Hospital,
Darlinghurst, NSW 2010**

From diagnosis to specialist's appointments, to treatment and beyond, living with a chronic illness presents a wide range of psychological and emotional challenges. Many people struggle with fear of being treated unfairly, with feelings of isolation, of being out of control, of confusion about who they are now and a loss of hope.

The emotional benefits of participating in support groups are widely reported. In recognition of the pressures of living with a chronic illness service organisations regularly respond by offering a support group. At other times individuals have gathered together to provide mutual support and over time this has grown into a support group.

With the development of cyberspace the notion 'support group' now encompasses a range of forms beyond the traditional 'face to face' groups. These can be:

- Online communities
- Real time chats
- Virtual support groups
- Mailing lists

It is common practice for these groups to request adherence to a set of guidelines that ask members to respect each other's right to confidentiality by agreeing to non disclosure of information about members or private matters that are discussed in the group.

Whether a group has a structured format varies and opinions about the value of structure in the group also vary. One belief is that having the group unstructured leaves space for it to decide what will be discussed. However many facilitators feel that an unstructured group can lead to people feeling unsafe, pressured and frustrated, and that a focused agenda or activity provides a direction for discussion about issues in which all may participate safely at the desired comfort level.

Whether it is face to face, or online, giving people an opportunity to share their experiences has been a constant feature of what happens in a support group.

Support groups are not for everyone but if what happened when people were there was different, perhaps more people might find them appealing. Certainly there is a feeling of a need for change that is

currently influencing the way some support groups are run.

Discussion currently centres around the value of restricting support group activity to sharing of personal stories. Some suggest that if groups focus on what's wrong this may contribute to keeping the participants stuck in the idea that there is something wrong with them.

At the moment there is a focus on a wellness model in the literature about support groups. The idea of wellness and living well with a chronic condition is being taken up with some enthusiasm by a range of groups and it doesn't matter which experience in life people are sharing.

Carmen Freeman, an experienced group facilitator in Colorado proposes that a support group could be more effective if it was experiential in nature.

In addition to the more traditional activities of social and emotional support and information sharing, she suggests that a support group run by a trained facilitator could provide the opportunity for shared experiences that are in themselves life giving e.g. art, theatre and meditation. She proposes that involvement in the activities as a group helps participants to integrate the knowledge and wisdom gained from exploring experiences and also facilitates the phenomena of wellness.

There are numerable support groups for a wide range of health issues. Those that report successful outcomes have some key features in common.

- A skilled facilitator
- Structure
- Belief that wellness and fulfillment can coexist with diminished physical, mental or emotional capacity.
- A safe inclusive welcoming atmosphere.

Perhaps you have some thoughts on support groups or an experience you would like to share. If so drop us a line whichever way you prefer...cyberspace or snail mail is fine with us.

**Barb Healy
Community Development and Education
- Rural. Email: barb@hepcvic.org.au**

THE RELATIONSHIP BETWEEN BODY MASS INDEX AND THE PROGRESSION OF CHRONIC HEPATITIS C

Although the drug treatment of chronic HCV has improved substantially during the last decade, around 50% of our patients do not have a sustained response to antiviral therapy. For those patients who are ineligible for, unable to tolerate or are non-responsive to antiviral treatment, strategies to minimise liver injury and decrease the progression of fibrosis are very important.

A number of host factors have been shown to influence the severity of liver disease in chronic HCV such as age, gender, alcohol abuse, increased body mass index (BMI) and fatty liver disease. While most patients seem to be aware of the detrimental effect of alcohol, the effect of an elevated BMI and physical inactivity are perhaps not as widely appreciated.

WHAT IS BMI AND HOW DO I CALCULATE IT?

As BMI increases above the healthy weight range, the risk of morbidity and mortality from chronic disease increases (Table 1). BMI is calculated by dividing the weight of the patient in kilograms by the patients height in centimetres squared.

$$\text{BMI} = \frac{\text{weight (kg)}}{\text{Height (m)}^2}$$

TABLE 1: BMI CLASSIFICATION

BMI (kg/m ²)	Classification
< 18.5	Underweight
18.5 - 24.9	Healthy Weight
25.0 - 29.9	Overweight
> 30.0	Obese

BMI AND STEATOSIS

Fatty liver or steatosis is common in patients with chronic HCV and occurs in more than 50% of liver biopsies. It is more common and more severe in patients with genotype 3. However, an elevated BMI is

also an important co-factor in the development of steatosis. BMI is associated with more severe steatosis in both HCV genotype 1 and 3¹. Severity of steatosis is important in patients with chronic HCV because it is associated with acceleration of fibrosis progression².

BMI AND FIBROSIS

The mechanisms whereby steatosis contributes to increased fibrosis are still unclear. Many of the patients with steatosis will have metabolic abnormalities similar to that of non-alcoholic fatty liver disease and type 2 diabetes. Abdominal obesity (pot belly), increased serum insulin levels and abnormal blood lipids are strongly associated with obesity and may link BMI and disease progression. This is worrying for countries such as Australia where the prevalence of obesity is reaching epidemic proportions.

OVERWEIGHT AND OBESITY IN AUSTRALIA

Australia is second only to the United States as the heaviest population in the world. Twenty-one percent of Australian adults are obese and a further 39% are overweight. This means 60% of the adult population are above the healthy weight range³.

CAN WEIGHT LOSS IN OVERWEIGHT PATIENTS WITH HCV PROVIDE ANY BENEFIT?

The impact of BMI on disease outcomes has important implications for treatment of patients with chronic HCV. A reduction in excess body weight in overweight patients with HCV and steatosis may improve biochemical features of liver disease and slow the progression of disease.

A study conducted at the Princess Alexandra Hospital, Brisbane, looked at the effect of a weight reduction and physical activity program in overweight patients with HCV and steatosis. After a mean

weight loss of 5.5kg (6% body weight) and a decrease in waist circumference of 8.5cm there was a significant reduction in ALT levels. Patients who underwent a repeat biopsy after weight loss demonstrated a striking improvement in the severity of steatosis. In some patients there was also a significant improvement in the severity of fibrosis⁴.

WHAT ROLE DO HEALTH PROFESSIONALS PLAY IN PROMOTING GOOD NUTRITION?

Clinicians are often asked about diet and lifestyle choices that may help reduce liver injury. There are a number of simple things that can be adopted into everyday clinical practice to help patients make positive lifestyle choices.

MEASURE AND DIAGNOSE OVERWEIGHT AND OBESITY

Be confident with height and weight measurements and know the BMI cut-off points. Place BMI charts up on the wall where patients are weighed or in waiting rooms so they can see a visual example of where their weight falls relative to the healthy range.

Self reported height and weight is not reliable especially from overweight patients. Therefore it is not appropriate to simply ask patients for their height and weight. Easily accessible height measures and accurate scales are vital. It is also important to be consistent with measurements such as taking shoes and heavy jackets off every time the patient is weighed.

DIET AND EXERCISE EDUCATION - QUANTITY OR QUALITY?

Calorie restriction is the first goal for weight reduction. Patients need to decrease serving sizes in order to reduce overall energy intake. We recommend patients follow an individualised calorie restricted diet which includes all food groups, has <30% of energy from total fat and <10% of energy from saturated fat and



approximately 30g of fibre. There are many misconceptions about diet for chronic HCV. One of the most common myths is that patients need to follow a "no fat" diet. Including some sources of monounsaturated and polyunsaturated fats is important and a "no fat" diet is not recommended. The effect of different dietary compositions on disease progression requires further investigation.

Increasing physical activity should be gradual with a goal of 30 minutes of aerobic exercise five times per week.

In overweight patients, weight reduction of at least 4-5% of body weight at a modest rate of 0.5-1.0kg weight loss per week should be recommended. Patients do not need to reach the healthy weight range for benefits to be seen⁴. Excessive and rapid weight loss should be avoided.

Referring overweight patients to a Dietitian is important although, if this service is not available, the "Guide to healthy eating for people with HCV" provides the patient with detailed information on maintaining a healthy balanced diet. This resource can be obtained from the Australian Hepatitis Council free of charge.

HOW DO WE PREVENT REBOUND?

People who continue to self-monitor behaviour and weight are more likely to maintain weight loss long term⁵. You can encourage this by always weighing patients during clinic and making comment on any weight changes. Encourage patients to weigh themselves once per week and to monitor physical activity levels.

ALWAYS GIVE ENCOURAGEMENT!

Many overweight and obese patients have low self-esteem and believe weight loss is too difficult. Health professionals play an important role in providing patients with the confidence that weight reduction is achievable. Sometimes the smallest comment from someone they hold in high regard can be enough to keep them motivated.

CONCLUSION

Obesity is common in Australia and plays a significant role in the progression of chronic HCV. A modest weight reduction and increase in physical activity in overweight patients with HCV results in an improvement in ALT, a reduction in steatosis and in some patients an improvement in the severity of fibrosis. Identification and treatment of overweight and obesity should form an important component of management of patients with chronic HCV.

**Ingrid Hickman BHSoc (Nut&Diet) PhD,
Dietitian-Nutritionist, University of
Queensland, Brisbane**

*Reprinted courtesy of HCC of WA,
from The C Files, Autumn Issue 2004.*

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THINKING TRAPS - SHOULDING & MUSTING

How many times have you said to yourself "I should do more exercise"? It is the statement of every new year's resolution isn't it, or every Sunday night when we think about the week to come.

Or how about thinking "I must get everything done today at work", do you tend to say that to yourself? The question is how do you feel when you say these "shoulds" or "musts" to yourself?

Chances are you feel under pressure and stressed. People often use shoulds and musts as a way of whipping themselves into action and motivating themselves.

The trouble is, that using these terms makes us feel more stressed, and then we're probably less likely to do the thing we are intending to. We usually put high expectations on ourselves to do things, and often they are so high we can't meet them all. Putting this sort of pressure on yourself often ends up in feeling stressed and down. We need to think of being a bit kinder to ourselves, and use terms like "I would like to"...or "I would prefer to" instead. Seeing a clinical psychologist can be helpful to learn to challenge your habitual thinking styles such as saying "should", through a process called cognitive-behaviour therapy (CBT). It can help you to feel less stressed, and help you in the future to avoid the negative thinking traps which trigger you to feel bad.

**By Sarah Egan, Clinical psychologist,
Clinic Co-ordinator, Curtin University
Psychology Clinic**

*Reprinted courtesy of HCC of WA,
from The C Files, Autumn Issue 2004.*

TUNE IN TO HEPCHAT

Hep Chat, the radio program of the Council can be heard every Thursday from 10.30 to 11.00am on 3CR Radio 855AM.





A rabbit vs snail view of life...

THE EFFECT OF A CHRONIC ILLNESS THROUGH A PERSONS LIFE IS OFTEN LIKE A PATH. SOMETIMES IT'S FLAT AND SMOOTH AND SOMETIMES IT'S HILLY AND ROUGH. BY GETTING TO KNOW HER ILLNESS AND BY LEARNING SKILLS TO HELP HER NEGOTIATE ITS PATH, FERN HAS BEEN ABLE TO TAKE BACK CONTROL OF HER LIFE.

Sandy How did you find out that you had Hep C?

Fern A friend contacted me and said that she thought I should get checked out for hep. Ages ago we went to a party and that's where I think I got hep C. I think a whole lot of us did - 20 people, and we all shared a needle back in very early 70's. You couldn't get needles then.

Sandy Who told you about the hep C?

Fern I went to a doctor in the early 90's and had a blood test. I was told that I was hep C positive, that my ALT's were normal and that my hep C was not active. I didn't feel tired. I felt fine, so I didn't take it on or think about it much.

Sandy And what about emotionally - how did you react when you first found out about it?

Fern I was fairly blasé about it. We had just got to know about AIDS and had come to terms with all of that. I felt quite comfortable about my years of using. I didn't have any regrets or any moral judgements, or feel that I had been a bad person for using heroin a long time ago for a short period of time. I had no addiction problems, so I didn't see hep C as an issue. When you start blabbing about it, you soon find out that people have different opinions.

Sandy Did you do anything in terms of self management, after you found out about the hep C?

Fern No, I didn't do anything, I didn't see myself as ill. I just had this virus and it wasn't affecting me. My ALT's were normal and I didn't think twice about it.

Sandy What about later on?

Fern A few years later I got a rash across my stomach and I was getting tired. I was working as a shop assistant, where I was on my feet all the time and I found I wasn't managing standing up for long periods of time. I thought maybe I was getting a bit older - my early 40's and

needed my holidays. I was tired. I would go home and sleep inordinate amounts of time. During my annual leave it was like my body let go and I just slept for 18 hours a day, which I thought this was a bit unusual.

I think I went to a naturopath first. Then I saw a doctor, who said it was nothing, because my ALT's were normal. He thought it was psychological because I had been diagnosed with hep C and said that getting sick was a normal response after finding out you have the virus. I didn't abide by that opinion.

Then I went to a Chinese doctor and realised I was quite ill.

I also kept going back to the GP, as I felt there was definitely something wrong.

About a year after my hep C diagnosis, it was found that I had a hydatid cyst on my liver as well. I felt so tired that I just did not want to get up. I would sit in a chair fall asleep. I would ride my bike and fall off. I was nauseous, I had headaches and the soles of my feet were sore. Getting out of bed was like standing on glass.

I later went to a liver specialist, who didn't know whether it was the hep C or the hydatid cyst that was making me feel so bad. Then in '96 I had the operation to get rid of the hydatid in the liver. I thought I would get better, but I didn't. Again doctors didn't believe there was anything wrong.

Sandy Did you find any benefit from going to the naturopath or the Chinese doctor?

Fern The Chinese doctor helped with my energy levels in the sense that I could get up for half the week. When I went back to work after being on annual leave, I negotiated with my boss to do part time work, as I just wasn't coping.

Sandy What other strategies did you use to manage how you felt?

Fern I didn't know how to manage. I think I was in a state of total anxiety and fear. I thought it must be diet or something, but because I didn't have any direction and no one believed me I would do really odd things, like buy a box of beetroot and get really sick because I had had too much.

WHEN THE DOCTORS DIDN'T BELIEVE ME AND TOLD ME THERE WAS NOTHING WRONG, I HAD TO LEARN HOW TO MANAGE MY LIFE MYSELF.

My biopsy results shocked me into submission. I then found a GP who was also a naturopath and from that moment I learnt management strategies and he put me on a really strict diet. He told me to rest my liver and not eat too much. I could eat rice, steamed vegetables and pears, so it was a very minimal diet. I'm a big eater. If I didn't eat enough I would want to vomit and if I ate the wrong things I would vomit. After about 6 months my stomach settled and my bowels and whole body started to calm down. Also, once I heard I was not going to get any better, I started to do intense meditation and relaxation.

About two years had passed and I felt I was managing my life reasonably well. I did a 2 year course in electronic design and interactive media, so that I could work part time. I got a job at \$55 an hour. I was great, but three weeks into it I bombed out again, due to stress and time lines. I got really vague, my bowels went all askew and my muscles were getting really bad again.

Sandy What did you do to cope?

Fern I looked for a Counsellor, because I thought I needed to work out some way of managing my life. I felt like I had lost everything in a sense. It really helped talking to a Counsellor.

Sandy What was it about talking to a Counsellor that helped you?

Fern It was more like having a sounding board actually. When doctors didn't believe me and told me there was nothing wrong, I had to learn how to manage my life myself.

Sandy What did you learn?

Fern Not to feel bad about who I am. I learnt how I feel and to accept how I felt. Because I felt that nobody believed me, I tried not to be sick. Then there was a point in the counselling where I could let go and relax and express how I felt. I also learnt what my capabilities were.

I put parameters around my work, which gave me a safety net. Then I started up a dialogue with friends and family. Once people understood my boundaries and limitations, they came on board. Before they knew what was going on, I felt guilty and felt like a tear bucket, I just felt like crying the whole time.

I also learnt to pace myself. I started doing things in bite-sized pieces, like exercising for ten minutes in the morning and ten minutes in the evening. I realised that I didn't have to feel guilty if I needed to lie down.

Sandy You were actually starting to rest as a preventative measure.

Fern I didn't necessarily have a choice about resting, although I did feel bad about it. Having counselling took the guilt away. I think guilt is a really big hurdle and I didn't realise how much guilt or feeling like I couldn't manage the normal 20th century lifestyle affected me.

Sandy Is there anything else you can think of that has worked well for you in terms of self management?

Fern Well, another thing with counselling was learning how to work with GP's. I learnt how to document everything and I learnt how to talk to doctors. I have got a good relationship with a doctor now. Working out the parameters with friends and family, not feeling guilty about resting, meditating when I feel like it, exercising when I need to and diet have all helped. Now that I am not as fearful about any new aches, and the guilt has gone, it's great. I think they are big things.

Sandy What was the most useful thing of all the things you tried, or was it a combination?

Fern I think it was a combination. I don't think anything can be isolated. I couldn't have just done diet or I couldn't have just done doctor management. All the little bits worked together and it was a whole lot of managing my life really. It has been a process of years. It's long and it's slow. I can only do things in bite sizes and that's ok. It's like I had to learn to be a snail and from that I could move a little bit faster. I had lost all hope. I was nowhere; I couldn't see my future in any aspect of my life. I didn't know how to proceed; it was like learning how to walk again.

Sandy By pacing yourself, you actually managed to achieve some things that you didn't think you could do.

Fern Yes, yes, I think our society is a bit manic. Before, I had exhibitions, work, socialising and when I look back on it now it looks quite crazy. But that is looking through a snail's eyes rather than through Peter Rabbit's eyes.

Fern Smith is interviewed by Sandy Breit, Hepatitis C Counsellor at The Alfred

BACK TO BASICS ON DIET AND HEPATITIS C

Good nutrition for people living with hepatitis C has a number of benefits that are not limited to an improvement in physical health. The benefits of better eating include weight maintenance, enhanced mental well being, and improved energy levels, optimizing immune function and actually reducing risk of hospitalisation.

In fact, recent evidence suggests that eating well and maintaining a healthy weight may actually prevent or delay progressive liver inflammation and damage.

Basically, if you are eating a variety of food from the five groups regularly this is a great start to giving your body all of the building blocks it needs (Table 1).

The problem for many of us is that for one reason or another we are not able to eat a good variety of foods regularly from these groups. One of the good things about nutrition is that eating well does not necessarily have to be an 'all or nothing' situation.

Small improvements to your diet over a period of time can lead to a number of significant health benefits.

The most important issue with any type of dietary change is consistency. One of the most common situations that occur to people making a dietary change is that they can manage the change for a week or two and then relapse into their old habits (skipping meals etc). People then feel guilty and feel as though all of their effort has been wasted.

This is definitely not the case! If you can recommence the dietary change after a relapse, you will still notice a change in your overall health.

BUDGETARY BLUES

One major problem experienced by many people living with hepatitis C is limited finances. If you are dependent on a pension or only have a limited amount of money to spend on food, before you get your next

pay, plan out 6-8 nonperishable food items that will keep for a long time in your cupboard.

These might include UHT milk and custard, milk powder, tins of salmon/tuna, canned soups/stews, baked beans and other beans (try other beans like refried beans and '3 bean mix') and spaghetti, tinned fruit and vegetables, milo/ovaltine, dried fruit and nuts.

FINAL WORD

It often becomes difficult to eat well when you are feeling sick. People with hepatitis C can experience side effects such as loss of appetite, nausea, bloating, lack of energy, fatigue and diarrhoea. If you want to find out more about symptom control, diet and exercise contact a Dietitian in your area. They will give you ideas to improve your health that are specific to your situation.

TIPS ON BETTER EATING

Seven tips to enhance the quality of the meals and snacks you are (or are not) eating.

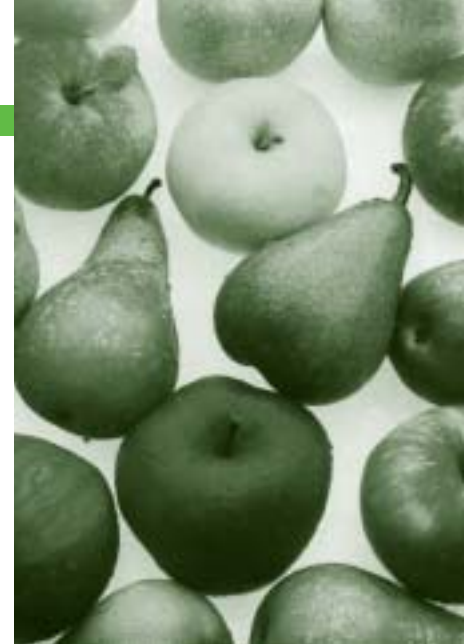
TABLE 1: FIVE FOOD GROUPS

Bread, grains, and Cereals
Fruit
Vegetables
Meat, poultry, fish, eggs and meat alternatives (eg beans and lentils)
Dairy foods, milk, yoghurt, cheese and soy milk

- If you regularly skip meals, try to get into the habit of eating every 3-4 hours during the day. The regularity will gradually enhance your appetite and over a number of weeks you may see a significant improvement in your energy levels.

- Try wholemeal or whole grain bread rather than plain white bread.

- Similarly, try other foods you may not eat regularly such as pasta, rice, and cous cous.



- If you don't usually eat fruit, set yourself a goal of having 1-2 pieces of fruit each day. It doesn't sound like much but it can lead to a change in other aspects of your diet (such as snack foods).

- If you currently drink alcohol, stopping or reducing your alcohol intake will take a lot of excess stress off your liver.

- If you eat meat, choose the leanest cuts available. Good options are skin-less chicken breasts and fillets, trim lamb, and beef, with a minimum amount of marbled and selvage fat. Another excellent food choice from this group is fish. Try to include fish in your diet three times a week.

- Try to include a number of vegetables as part of your daily meals. Try a variety of cooking methods such as steamed, grilled and roasted, and as ingredients in salads. Vegetables are a major source of many of our dietary vitamins and fibre.

Simon Sadler (Nutritionist/Dietitian)
Nutrition Development Centre,
Surry Hills, NSW.

For more information you could visit the Albion St Centre Online at:
<http://www.sesahs.nsw.gov.au/albionstcentre/> and follow the links to "hepatitis C" and "nutrition"

This article has been abridged from the Roche Products Pty. Ltd publication "HepatoCare - Issue 8 April 2004" with the kind permission of the author, Simon Sadler.

A WORKING RELATIONSHIP WITH YOUR...DOCTOR

HAVING A GOOD RELATIONSHIP WITH YOUR DOCTOR IS A VERY IMPORTANT PART OF MANAGING YOUR HEPATITIS C WELL.

QUESTIONS TO ASK ABOUT TESTS AND PROCEDURES:

1. How will this test aid in the diagnosis or therapy of my illness?
2. Will I need to be hospitalised?
3. Will other tests need to be done?
4. Are there simpler or less risky ways to evaluate my symptoms?
5. Will my insurance cover the costs of tests done either inside or outside of the hospital?
6. Please explain to me exactly what you are going to do during this test before you start.
7. How long will it take?
8. Can I expect any unusual feelings, pain, or sensations?
9. Will I need someone to drive me home after the procedure is over, or will it be safe to drive myself?

ABOUT MEDICATION:

1. Why are you choosing these particular drugs for me?
3. What are the chances that the drugs I am receiving will "cure" me?
4. If the drugs do not cure my illness, what effect should I expect from them?
5. How long will I have to take medication?
8. Are there any special instructions for taking the drugs?
9. Are there interactions with other drugs, foods, sunlight, alcohol?
10. What are the side effects of this drug and how often do they occur?
11. If someone accidentally takes my drug, or I accidentally take too much, what is the best course of action?
12. What if I become pregnant while taking this drug?
13. Does this drug interfere with sex in any way?
14. What should I do if I suffer a side-effect or a drug?

KNOW YOUR RIGHTS:

1. To have as much information as you wish about the illness.

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

2. To be allowed enough time for questions and concerns about problems.

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

3. To have reasonable access to your doctor.

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

4. To participate in major decisions in your care.

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

6. Determine whom other than the doctor shall have access to information about your health.

The relationship of the physician and the patient is confidential. Normally you will be asked to sign a release form authorizing your files to be released to your insurance companies, or in special instances to compensation boards, or other physicians. In some cases where a disease is infectious or otherwise might affect the health of others (e.g. hepatitis), the doctor is legally obligated to report the condition to governmental authorities.

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

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

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

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

feedback

A RECENT LETTER TO THE COUNCIL:

I have been an inmate here at Ararat Prison for over 2 years, and in that time have met, worked with and lived with many fellow inmates who suffer the consequences of contracting hepatitis C.

While not a carrier myself, I recognised a need for education about hepatitis C and related issues within the prison system. So when an opportunity presented itself in the form of a role as peer educator, I presented my application and was accepted.

Since then I have attended courses relating to hepatitis C and other viruses, their transmission and control, the additional risks within the prison environment, the myths and the facts, the stigma and the discrimination that quite often go hand in hand with these diseases. We learned about blood spills and how to deal with them, proper sterilisation procedures and personal hygiene, psychological and physical symptoms as well as diet and alternative therapies. We also attended a course in communication to aid us in our roles as educators.

We have put together a presentation program utilising your "This is Bloody Serious" hepatitis C training manual for prison peer educators, which has been attended by almost every inmate here and is now part of the regular induction of new inmates and it's beginning to make a difference! Inmates are beginning to ask questions, they want to know.

I was initially shocked to learn that almost 60% of inmates carry the hepatitis C virus, but after living here for so long, now I understand why.

I live in the hope that together, the Hepatitis C Council of Victoria and our small force of educators here at Ararat prison, can continue to make inroads into the war that is hepatitis C in Victorian prisons. Thank you for making this program a reality.

Peer Educator, HM Prison - Ararat.

This letter was reproduced with permission from the writer. Do you have an issue you would like to write to us about?

FREE COUNCIL MEMBERSHIP FOR INDIVIDUALS (WAGED/UNWAGED) & PRISON INMATES

The Committee of Management of the Hepatitis C Council of Victoria has made a decision to make Council membership FREE to all individuals (waged or unwaged) as well as prison inmates.

WARRNAMBOOL BBV CLINIC

A comprehensive medical service for people affected by blood borne viruses in South West Victoria

We are specialist providers of health care and other support relating to BBV.

For enquires or an appointment contact:

The WRAD Centre
26 Fairy Street, Warrnambool
or telephone 03 5560 3222

TREATMENT STUDY

A Treatment Study for people with hepatitis C who have failed to clear the virus after treatment with Interferon and Ribavirin.

The Alfred Hospital and Monash Medical Centre are involved in a new study using PEG-Intron and Ribavirin to treat people who have had previous Interferon and Ribavirin for at least 12 weeks and still have the hepatitis C virus detectable in their blood.

The duration of treatment will depend on response, but could be for up to 5 years.

For more information or to see if you would be eligible for this treatment program please call either Jo Mitchell (The Alfred Hospital) on 9276 2223 or Sherryne Warner (Monash Medical Centre) on 9594 5545.

diary:

**TUESDAY 12 OCTOBER 2004
HEPATITIS C COUNCIL AGM**

Put this date in your diary now. We look forward to seeing you all!

**15 - 17 NOVEMBER 2004
FUTURES III**

VICTORIAN RURAL HEALTH FORUM

Organised by Country Aids Network (CAN), this forum will be looking at the future directions of BBV and STI support, care and prevention services in rural Victoria. For more information call 03 5443 8355 or email: can@can.org.au

**SATURDAY 20 NOVEMBER 2004
TWELFTH NATIONAL SYMPOSIUM ON
HEP B & C**

St Vincent's Hospital, Melbourne. Contact Ms Eleanor Belot on 03 9288 3580 or email: eleanor.belot@svhm.org.au

TUNE IN TO HEPCHAT

Hep Chat, the radio program of the Council can be heard every Thursday from 10.30 to 11.00am on 3CR Radio 855AM.



DAY TIME TELEPHONE COUNSELLING TRAINING COURSE VOLUNTEERS WANTED

We are seeking mature minded people to train as volunteers to staff our confidential telephone counselling services.

We hold selection days periodically over the year. If you are interested in finding out more call 9347 6133



helpline

all for the
best...

BEFORE HEPATITIS C

I'M NOT SURE WHEN I ACTUALLY DECIDED THAT I'D NEVER HAVE SEX AGAIN BUT IT MUST HAVE BEEN AT LEAST 5 YEARS AGO. NOT THAT I'D PLANNED IT OR ANYTHING - IT JUST KIND OF HAPPENED.

I know that might sound pretty drastic and don't get me wrong I'd love to be in love with someone and share that part of my life but really it's not worth the stress. Well not for me anyway. Since being diagnosed with hepatitis C nearly 7 years ago personal relationships have been a bit of a disaster, you know what I mean? When I say personal relationships I mean ones that involve having sex and all that type of intimacy stuff...for me it's just been too hard.

I guess when I think about it you could divide my life into two stages like BHC (before hepatitis C) and after AHC. (after hepatitis C)

Before I knew I would have considered myself just like everyone else. I had quite a good job and was paying off a mortgage. I suppose if I'm honest, I would've liked to have been in a 'serious' relationship and maybe get married, have kids etc - you know the whole package. At the time I had recently broken up with my long term partner and had been single for over a year.

AFTER HEPATITIS C

When I first found out I had hepatitis C I became hell bent on finding out all there was to know about it and what it meant for my life and well being.

I suppose looking back I was like someone who had received a terrible shock. I felt a bit out of control or kind of 'spun out'. I became completely 'obsessed' about my health. All my focus was on me me me. And how my life would be affected. It was as if part of me, the 'feeling core part' of me had changed and I was no longer just plain old Paula - now I was Paula with the virus.

I found out a lot about the hepatitis C, read articles, and scoured the Internet. I wanted to be really informed. During that time I became a bit of a health nut! God I even stopped drinking! I looked into complimentary therapies and decided to take up exercise.

Wow, if you knew me then you'd know that was a pretty major step.

During this time I occasionally met guys but nothing serious. I actually only had sex once and that time I didn't tell him about my status and we had safe sex anyway. But I found the whole experience really stressful.

I had found out all about sexual transmission and knew that it was a very very minimal risk but even so it was a real worry to me.

I was 36 when I found out being positive and the 'old biological clock was ticking even then, but hey I thought I had plenty of time...maybe not plenty...but enough anyway.

Then a couple of years later I did meet up with a really great guy and we had a lot of things in common but truly when it came to disclosing to him about my hepatitis C status I just clammed up. He had said a couple of thing about 'drugs', nothing bad but I got the impression rightly or wrongly that he was pretty negative about the whole thing. Anyway it never seemed the right time.

It was like how do I tell him without him judging me. Do I bring it up before we have sex or after? What if he felt disgusted? These thoughts just went round and round in my head. I actually ended up getting panic attacks. Yes I know I could have done safe sex first, but what if he felt betrayed when I did tell him because I should have told him before?

Utter madness but I couldn't stop those thoughts creeping in. Lets face it, intimacy needs spontaneity and I felt that was something I was unable to do. So I just stopped seeing him and rationalised it as him not really being the right person for me.

Coping with the knowledge that I could potentially hurt someone took its toll on my emotions. The logical part of me says 'get a grip' but the feeling part gives me no rest.

After that experience I decided I'd just put those feelings aside.

I'm in my early forties now and life is pretty good. I'm very busy with work and have been thinking of moving house, maybe down the coast. I also do volunteer work with an organisation involved with blood born viruses - so yeah, all that knowledge I accumulated over the years has paid off. Although sometimes I feel a bit sad about not having a truly intimate relationship, but I've done what's best for my well-being.

I'm happy with my life choices but sometimes I dream of what might have been...

This scenario does not relate to any particular individual but is compiled from the many calls the Hepatitis Line receives.

TWO LARGE AND LONG TERM RESEARCH STUDIES REPORTED IN RECENT MEDICAL JOURNALS HAVE CONCLUDED THAT THE RISK OF SEXUAL TRANSMISSION OF HEPATITIS C BETWEEN HETROSEXUAL MONOGAMOUS COUPLES IS EXTREMELY LOW OR EVEN NON EXISTENT. FOR MORE INFORMATION ABOUT THESE RESEARCH STUDIES CALL THE COUNCIL ON 03 9380 4644 OR 1800 703 003.

LIVER CLINICS

Albury/Wodonga

Telephone: 02 6024 5255

Alfred Hospital

Telephone: 9276 2223

Austin/Repatriation Medical Centre

Telephone: 9496 2787

Ballarat - Dr Jon Watson

Telephone: 5331 8289

Bayside Hepatitis Clinic

(through the Alfred Liver Clinic)

Telephone: 9276 2223

Box Hill Hospital

Telephone: 9895 3333

Epping - Northern Hospital

Liver Clinic

Telephone: 9219 8335

Footscray - Western Hospital

Telephone: 8345 6490

Geelong Liver Clinic

Telephone: 5226 7111

Knox Private Hospital

(St Vincent's Hepatitis Clinic)

Telephone: 9210 7300

Maroondah Hospital

Telephone: 9871 3371

Monash Medical Centre

Telephone: 9594 5545

Peninsula Liver Clinic

Telephone: 9781 4434

Royal Melbourne Hospital

Telephone: 9342 7212

Sale - Fitzpatrick House

Telephone: 5144 4555

Springvale Liver Clinic

Telephone: 8558 9000

St Kilda - Barkly Street

Medical Centre

(St Vincent's Hepatitis Clinic)

Telephone: 9534 0531

St Vincent's Hospital

Liver Clinic: 9288 2898

Hepatitis Clinic: 9288 3580

Werribee Mercy Hospital

(St Vincent's Hepatitis Clinic)

Telephone: 9216 8633

SERVICES DIRECTORY

METRO AND/OR STATEWIDE

Access Information Centre at the Alfred

Telephone: (03) 9276 6993

Fax: (03) 9533 6324

Email: access@alfred.org.au

Web: www.accessinfo.org.au

ANEX

(Association of Needle Exchanges)

Telephone: (03) 9417 4838

Email: info@anex.org.au

Australian Complementary Health Association

Telephone: (03) 9650 5327

Web: www.diversity.org.au

Body Art

Piercing Urge, Prahran

Telephone: (03) 9530 2244

Web: www.thepiercingurge.com.au

Chinese Herbalist

Lisa McPherson

Telephone: (03) 9481 8514

Chinese Medicine Practitioner

Catherine Riva

Telephone: (03) 9844 0459 (Warrandyte)

Telephone: (03) 9596 2468 (Brighton)

Counselling

Positive Counselling HIV/Hep C Inc.

at The Bouverie Centre, Flemington

Telephone: 9376 9844

www.positivecounselling.org.au

Dentist

Martin Hall, Richmond

Telephone: (03) 9420 1302

Direct Line

Drug & alcohol counselling and NSP info

Telephone: (03) 9416 1818

Free call: 1800 136 385

Employment

Westgate Community Initiatives Group

(formerly Options Enterprises), South Yarra

Telephone: (03) 9824 2330

Equal Opportunity Commission Victoria

Telephone: (03) 9281 7111

Toll Free: 1800 134 142

Email: eoc@vicnet.net.au

Web: www.eoc.vic.gov.au

Haemophilia Foundation Victoria

Telephone: (03) 9555 7595

Hepatitis C Helpline (Counselling)

Telephone: (03) 9349 1111

Freecall: 1800 800 241

Infoshare

Self Help Addition Resource Centre,
Glenhuntly

Telephone: (03) 9572 1151

Email: info@share.org.au

Medical

Barkly Street Clinic, St Kilda

Telephone: (03) 9534 0531

Melbourne Sexual Health Centre

Telephone: (03) 9347 0244

Free call: 1800 032 017

Narcotics Anonymous - Victoria

Statewide service and meeting most areas.

Telephone: 03 9525 2833

Geelong: 03 5221 0803

Gippsland: 0405 378 513

Naturopaths

George Campbell

Telephone: (03) 9646 5455

Andrew Green

Telephone: (03) 9819 6680

Ondine Spitzer

Telephone: (03) 9372 0499

Gill Stannard

Telephone: (03) 9650 3419

Nawala Willumbong Co op Limited

Indigenous drug & alcohol service (St Kilda)

Telephone: 9510 3233

Email: info@ngwala.org

Office of the Health Services Commissioner

Telephone: (03) 8601 5222

Complaints: (03) 8601 5200

Freecall: 1800 136 066

Royal District Nursing Service

Telephone: (03) 9536 5222

Fax: (03) 9536 5333

Email: getinfo@rdns.com.au

Victorian Aboriginal Community Controlled Health Organisation

Telephone: 03 9419 3350

Fax: 03 9417 3871

Victorian Aboriginal Health Service

Telephone: (03) 9419 3000

Fax: (03) 9417 3897

Victorian hepatitis C Educator
Jacqui Richmond
Telephone: 03) 9288 3586
Fax: 03) 9288 3590
Email: richmoj@svhm.org.au

VIVAIDS
Telephone: 03) 9419 3633
Fax 03) 9415 7055
Email: vivaids@vivaids.org.au

RURAL AND REGIONAL

These contacts are able to provide information about local hepatitis C related services as well as active support groups (SG).

Ballarat Community Health
Contact: Carmel
Telephone: 03) 5333 1635

Bendigo - Rural Hep C Network (CAN)
Contact: Ian Comben
Telephone: 03) 5443 2299
Email: rhcn@can.org.au

Bendigo Health Care Group
Contact: Rosie Girvan, Jane Hellstan
or Pauline Woodburn
Telephone: 03) 5454 8416

Camperdown hep C Support Group
Contact: Brian Hinchcliffe
Telephone: 03) 5593 3415

Corio Community Health
Contact: Rochelle Hamilton
Telephone: 03) 5273 2200

Drysdale Community Health
Contact: Sally McMahon
Telephone: 03) 5251 2291

Gippsland - Mobile Drug Safety
Steve Theoclitou
Mobile: 0438 128 919

Horsham - Wimmera Hep C Support Group
Contact: Jan Spencer
Telephone: 03) 5381 9378

East Wimmera Region
(Birchip, Wycheproof, St Arnaud)
Naturopath/Psychologist
Phil Blackwood
Mobile telephone: 0403 625 526

Moe Community Health Centre (SG)
Contact: Catherine Ashford
Telephone: 03) 5127 5555

**Portland - Glenelg Southern Grampians
Drug Treatment Service**
Contact: Bev McIlroy
Telephone: 03) 5521 0350

Shepparton Community Health
Contact: Merri Blair
Telephone: 03) 58 233 200

Torquay - Surf Coast Hepatitis C
Telephone: 03) 5261 3001

Wangaratta - Ovens and King CHC
Contact: Diane Hourigan
Telephone: 03) 5722 2355

**Warrnambool - Western Region Alcohol
and Drug Centre**
Telephone: 03) 5560 3222

Wodonga Community Health
Contact: Jenny Horan/Anita
Telephone: 02) 6022 8888

Yarrawonga Community Health
Contact: Cherie McQualter Whyte
Telephone: 03) 5744 1324

SUPPORT GROUP BREAKING THE CHAINS

HIV | HEP C SUPPORT & EDUCATION GROUP - WARRNAMBOOL

Breaking the chains is a Warrnambool and district group of HIV or Hepatitis C positive people and their friends, families and supporters.

We meet on the 2nd and 4th
Thursdays of every month.

For further information or meeting details, please contact **Jeffrey on 5562 8216** or **Glen on 5561 6257** or **0401240167** or email: breakingthechains@hotmail.com

INFORMATION & SUPPORT GROUPS

Learning about your rights, dealing with discrimination and discussing the issues that impact on you - all these things can happen in the safe environment of a Support Group.

METRO

HEPATITIS C COUNCIL OF VICTORIA:
Contact: Pier Moro 9380 4644

Brunswick Drop In & Information Sessions - open to family, partners and friends.

ALL WELCOME

When: Second Sunday of every month

Time: 2 - 4pm

Next: 12 Sept; 10 Oct; 14 Nov; 12 Dec.

Venue: Hepatitis C Council Offices,
5/200 Sydney Rd, Brunswick

THE ALFRED HOSPITAL:

Contact: Sandy Breit 93276 3061

The support group now meets every second month. You must RSVP to Sandy Breit by 12 noon the day before the scheduled meeting

When: Last Thursday of the month.

Time: 1.30 to 3pm

Next: 28 October; 16 December.

Venue: Hepatitis C Clinic,
4th floor, Alfred Hospital.
Commercial Road, Prahran

ST VINCENT'S HOSPITAL:

Contact: Kate Mellor on 9288 2259

For anyone with hep C - not just those on treatment. This group runs 3 times a year, being 6 sessions over 12 weeks. With guest speakers on particular topics with time for questions and discussions.

When: Next one starts from first Thursday
(the 3rd) in February, 2005

Time: 5 - 6.30pm

Venue: 4th Floor, Daly Wing,
St Vincent's Hospital.
35 Victoria Parade, Fitzroy

RURAL

SALE:

Contact Lauren 5143 8800 or
Catherine 5127 5555

WARRNAMBOOL:

Contact Jeffrey on 5562 8216 or
Glen 5561 6257

INTERNET

If you prefer you can always go to the
NSW community forum at:
<http://hepatitisc.communityzero.com/>

AN INVITATION TO JOIN US

FOR THE HEPATITIS C COUNCIL OF VICTORIA TO BE TRULY REPRESENTATIVE OF THE HEPATITIS C COMMUNITY, A STRONG MEMBERSHIP OF PEOPLE AFFECTED BY THE VIRUS IS ESSENTIAL.

There are 4 types of membership. All include all resources distributed by the Council.

- 1 Individual: Entitles you to one copy of Good Liver per quarter and one vote at the AGM.
- 2 Zero Fee: (For people in Victoria experiencing severe financial hardship and Victorian prison inmates). Entitles you to one copy of Good Liver per quarter and one vote at the AGM.
- 3 Healthcare Professional: As for individual - but includes 3 copies of Good Liver.
- 4 Organisation: As for individual - but includes 5 copies of Good Liver.

COMPLETE THE FORM BELOW AND MAIL TO THE COUNCIL.

TAX INVOICE ABN 48 656 812 701
Please ensure you retain a copy for tax purposes

Are you a new or renewing member?

Title Name

Occupation

Organisation (if applicable)

Mailing Address

Postcode

Local Government Area (ie Banyule, Stonnington, Casey:)

Telephone

Fax

Email

Tick one membership box. (Includes GST)

- | | |
|-------------------------------|-------------------------------|
| Individual (waged) | <input type="checkbox"/> \$0 |
| Individual (unwaged) | <input type="checkbox"/> \$0 |
| Zero Fee (Vic prison inmates) | <input type="checkbox"/> \$0 |
| Professional | <input type="checkbox"/> \$33 |
| Organisational | <input type="checkbox"/> \$77 |

Donations are gratefully received by the Council \$

(All donations over \$2 are tax deductible)

Total \$

Are you interested in becoming a volunteer with the Council?

HAVE YOU CONSIDERED WRITING ABOUT YOUR EXPERIENCES OF LIVING WITH HEPATITIS C.

We get a lot of feedback from people saying they find it really useful to read about how someone else is dealing with hepatitis C. You may have hep C or your life may include a person with hep C. Everyone has a different story to tell and we'd love to hear yours.

It is not necessary to have your name published with your story.