

hepatitis^{wa}

Newsletter

Issue 09 | Sept 2014

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Diet for advanced liver disease*

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LETTER FROM THE EDITOR

Thank you for picking up a copy of the September issue of the HepatitisWA Newsletter! A lot has happened this last quarter, including acknowledging and participating in **World Hepatitis Day** (28th July), the official launch of the 'C the person not the disease' campaign, along with the facilitation of numerous community workshops and the coordination of HepatitisWA's Community Grants program. We also say farewell to our longtime Chairperson Dr Susan Carruthers, and say thank you to our Treasurer Maria Kroon, as they both step down from their positions after many years of service. In this issue, we feature an excerpt from the 'Liver Danger Zone' report, released by Hepatitis Australia, which explains what the 'Liver Danger Zone' is, and presents a 'Blueprint for action' on regular liver check-ups. Other features include an article on the unfunded viral hepatitis crisis and an article on the move to establish a prison NSP program at the Alexander Maconochie Centre. The personal perspective in this issue is written by hepatitis C hero Wayne Thacker. Our 'Going Viral' section features a round-up of viral hepatitis articles, and our health and lifestyle section features an article about high protein, high energy diets for advanced liver disease. Last but not least, WASUA talks about celebrating Hepatitis Awareness Week.

Felicia Bradley

Editor

ON THE COVER

Blueprint for Action
Feature

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HepatitisWA (Inc).

HepatitisWA is a community based organisation which provides a range of services to the community in response to viral hepatitis, particularly hepatitis A, B and C.

Please contact us for more information, or make an appointment to call by and talk with an appropriate member of our staff.

Two Brothers

WAYNE HAD SHARED HIS STORY "BANISHING THE MONSTER" WITH HEPATITISWA IN 2012. THE STORY WAS ABOUT HIS EXPERIENCE OF LIVING WITH HEPATITIS C AND UNDERGOING TREATMENT. THE STORY "TWO BROTHERS" IS THE PREDECESSOR OF "BANISHING THE MONSTER"...

I know not everyone has a brother, and some have more than one. Well I was one of five, number two in line. This tale concerns number three and me. He was the younger bro, always over your shoulder, wanting to be involved in everything. We learnt a lot together, from how to play sick to get off school, and how to fight, both dirty and fair. And (of course) the ins and outs of girls. By the time he left school he had a year's insight into the way it worked in the real world, as I couldn't get rid of him once I had a car and wage. He talked me into some very interesting ways to spend that wage, and we shared many adventures.

Mike was a little less inhibited and more likely to get into serious trouble than I was, and more than once I had to bail him out. We started drinking together, but he was the first one to try dope, as well as a few other recreational drugs. Even if we were together now he would take the lead and have the first toke, then pass it to me. This worked for me, as when he passed out I knew to stop. Well, one thing leads to another and we ended up in deeper waters with bigger stakes at play. As the drugs and life in general got harder, we made a pact to keep an eye on each other. We would listen to the other if they demanded it. This of course didn't stop us coming to blows on more than one occasion. That was the way of things when personality and opinions clashed.

So as we set out on this phase of life, we had good intentions. Time passed, habits changed, and we lost our way a little. I realised the path I was on was a dead end, so I changed tack. I tried hard to convince my brother the drugs were winning but he was having none of it. He was in control. Well, I never gave up on him, as much as I wanted to at times, but I realised he had to do it for himself. He ended up on the good old methadone program for a while. About 20 years I think it was. One of the things we did still share was hepatitis C and that didn't help.

I only found out I had the bloody virus when I went to donate blood, and then received a letter a few days later telling me to go see my doc for a confirmation blood test. Guess I wasn't as careful as I'd thought I'd been for all those years. My brother never would tell me what genotype he had, so I don't know if we contracted it together or not. Not that it matters, as I can only blame myself for the situation I found myself in. My biggest fear at this point was, had I given it to anyone else? Not being able to tell how long I had carried it meant I could only start from the present and work back. I figured if my partner of over five years now was clear I could be confident I had gotten lucky and kept it to myself. For once in my life I was lucky. Unlike my brother.

When I realized the virus was here to stay (no cure back then), I listened to the advice given and made some changes to my lifestyle. Mainly dietary and the like as I had already said goodbye to hard drugs by then. The changes did make a difference as my general health was better than it had been for a while. Silver linings eh. I was still trying to encourage my brother get his act together, but as I've said, he had to get there himself.



The main difference between us was still attitude. He thought he was in control and stronger than the drugs, whilst I could see the danger and felt the fear. This arrogance has cost my brother dearly, as for most of his adult life he has ignored his considerable artistic talent and lost more than he knows. He has left behind a beautiful daughter and a small band of real friends, but he has lost the rest of his life, and the chance to see his little girl grow into the fine woman she is becoming.

I can't tell you that drug abuse or hep C caused his cancer, but I can tell you they didn't help his body fight the fight of its life. Even though he had always told me he would never make old bones, his love for his daughter has shown him the value of life, so he fought hard. But he still couldn't put old habits completely to bed, even near the end. The sad thing is, it wasn't the cancer that killed him. The treatment that killed the cancer also killed him. He lost the fight when his heart gave out, but he died clear of cancer. I hope when his

heart stopped it was at peace, but I know that even now it will be breaking because he can't be there for his girl.

Fear of loss is very powerful, if you can see what it is you stand to lose. I thank my stars every day that way back then, I found the courage to be afraid. He was proud in his way, and lived his life with a sense of honour and the friends he made will long cherish his memory, but he is gone from this life.

Make the most of your choices as you never know what the last one will be. Most of his were made in the moment and I know he died with regret, whilst most of mine were made with an eye to the future and I still have one. We are the architects of our own destiny, so plan yours wisely.

W. Thacker.

Photo (L to R): Wayne, Donna, Mary and Mike.



GOING VIRAL



A ROUND-UP OF ARTICLES ON VIRAL HEPATITIS

VERTEX TO END

SALES OF HEPATITIS C

DRUG INCIVEK

Vertex Pharmaceuticals Inc is stopping U.S. sales and distribution of its Incivek hepatitis C treatment, which use has been largely supplanted by the new Sovaldi drug from Gilead Sciences Inc.

On Monday, Vertex sent a letter to doctors who treat patients with liver wasting disease to inform them that it would not be available after October 14, a company spokesman confirmed on Wednesday.

Vertex said in May during a conference call with analysts that it would withdraw from the hepatitis C market but had not said when it would stop making the drug.

Incivek was approved in 2011 and quickly rose to annual sales of more than \$1 billion. Sales began to decline at the end of 2012 as patients began to wait for promising new drugs from competitors, which hit the market at the end of 2013.

The spokesman said the move was due to dwindling patients for the drug and the new treatments that are available. In the first half of the year, Gilead sold about \$6 billion of Sovaldi, which has a high cure rate without the risk of the side effects older treatments carried.

Johnson & Johnson markets the Vertex hepatitis C treatment outside of the United States.

BY CAROLINE HUMER

Aug 13, 2014 Reuters.
tinyurl.com/incivek-drug

THAT HOLIDAY

PEDICURE MAY LEAVE

YOU WITH HEPATITIS C

Getting a tattoo, a bellybutton ring or even a pedicure can seem a great idea while on holiday, but you may end up bringing home something more sinister than just some body ink or brightly coloured nails. Experts working in the area of hepatitis B (HBV) and C (HCV) are predicting a jump in the number of people contracting the viruses overseas because of the types of activities Australians are enjoying abroad.

While there's a vaccine for HBV, there's none for its hardy and virulent cousin HCV, which is often referred to as "the silent killer" because people can have no symptoms for years, even decades, until their liver has suffered severe, life-threatening damage, and even become cancerous.

"What we want all Australians to know before they head off on their overseas holiday is that any activity in which the skin is pierced can lead to infection with hepatitis – and, yes, that can include pedicures, tattoos and piercings, and even getting dental work done abroad," Hepatitis Australia's CEO Helen Tyrell says.

All that's needed for the disease

to be transmitted is for a microscopic amount of infected blood to be left on an instrument that pierces the skin or comes into contact with an open wound, she explains, adding the following warning: "Don't engage in activities in which the skin may be pierced unless you're sure the instruments have been fully sterilised."

While it's important to be vigilant on home soil, it becomes vital when abroad, particularly in the holiday destinations that are popular among Australians, such as the Asia-Pacific region.

"In places like Bali, Thailand, Vietnam and the Philippines, hepatitis C can be nine or 10 times more prevalent than at home, and this coupled with generally lower standards of equipment sterilisation in the average tattoo parlour or where you get pedicures can greatly increase the risk of infection," Tyrell says.

"People on holiday can be more likely to make a spur-of-the-moment decision to take part in more risky activities, like getting a tattoo, so what we're urging Australians to do is pre-plan. If you want to get a tattoo or a piercing while you're away, do your research so you can better know your risk. Ask yourself, does the place sterilise its equipment properly? Does the benefit really outweigh the risk?"

Research has shown that Australians have become increasingly likely to participate in activities abroad that heighten their risk of contracting hepatitis B and C, with almost half having taken part in at least one high-risk pursuit while overseas. Tyrell believes this is because many Australian travellers are unaware of the hepatitis B and C risks associated with what are now considered normal holiday activities.

BY **NEWS.COM.AU**

*Sept 1, 2014 for News.com.au.
tinyurl.com/hep-c-pedicure*

NYC COUNCIL

CONTINUES PUSH ON

HEPATITIS AWARENESS,

TESTING, TREATMENT

Three City Council members who have focused particular attention on the risks of hepatitis B and C have joined city health officials and leading healthcare providers in marking the start of New York's first Hepatitis B Awareness Week.

The July 21 gathering on the steps of City Hall included Health Committee Chair Corey Johnson, an out gay councilman from Manhattan's West Side, on Flushing.

According to the Centers for Disease Control and Prevention, although Asian and Pacific Islanders (APIs) make up less than five percent of the US population, they account for half of all Americans living with chronic hepatitis B. More than two-thirds of the API population were born or have parents born in countries with high prevalence of hepatitis B, and most of those infected had exposure as a young child. An estimated one in 12 APIs has chronic hepatitis B infection.

Among gay and bisexual men, hepatitis B is typically a sexually transmitted disease, and men who have sex with men make up about one fifth of new hepatitis B infections, according to the CDC. Hepatitis C has, in recent years, been identified as a co-infection among people who are HIV-positive.

Hepatitis is associated with a variety of severe liver diseases including cancer.

In June, the Council passed and Mayor Bill de Blasio signed legislation that provided \$750,000 in new funding for community-based groups that do outreach and testing for hepatitis B and C. Grant recipients included a

variety of service providers in communities particularly affected, such as the API and African immigrant population, and also LGBT and AIDS groups, including Harlem United, AIDS Center of Queens County, Housing Works, and VOCAL-NY, and a variety of harm reduction programs that work with injecting drug users.

In February, Chin, Johnson and Koo introduced legislation that would require the health department to report annually to the Council and the mayor on its efforts to stop the spread of hepatitis B and C, which affects an estimated 250,000 to 500,000 city residents. Johnson's Health Committee held hearings on the bill in June, with strong support from its members, though the health department testified that complying with such a law could cost between \$1 million and \$1.5 million annually.

The measure's advocates believe that the de Blasio administration's support for the \$750,000 testing initiative indicates a likelihood that the mayor and the Council can see eye to eye on moving the reporting bill this Autumn.

BY **PAUL SCHINDLER**

*Aug 14, 2014 for Chelsea Now
tinyurl.com/NYC-Council-Hep-Awareness*

Farewell SUSAN

HepatitisWA says farewell to our Chairperson.

After over 20 years of involvement with HepatitisWA, and two extended terms as Chairperson, (the most recent which was 10 years) — Dr Susan Carruthers has stepped down. Our new Chairperson is Ms Ursula Swan.

On September 11th, HepatitisWA held a farewell party for Susan at 'Frisk' in Northbridge, where the staff and board members joined to acknowledge and celebrate Susan's time as Chairperson. Ursula Swan gave a touching speech and presented Susan with a fountain pen. Susan joked that the story behind that was that she never had a pen when she needed one and would always have to borrow the ED's fountain pen.

Our Finance and Administration Manager Vivianne Brown then gave a short speech and presented Susan with a certificate of acknowledgement for her overall commitment to HepatitisWA throughout the years.



I have thoroughly enjoyed my time as Chair and have been ably supported by all staff and other members of the Board. I wish all members, Board members and staff all the best for the future and I am confident that HepatitisWA will continue to provide essential support services, prevention education and workforce development in the years to come.

- Dr Susan Carruthers

Thank you **MARIA**

After 13 years, Maria Kroon has resigned as Treasurer of HepatitisWA.

Maria, HepatitisWA thanks you for your dedication and service over many years. We look forward to working with you, as you continue your commitment as a volunteer for HepatitisWA.



Viral hepatitis more deadly than HIV, but unfunded

Hong Kong

In what has become a cruel public health irony, not being HIV positive is a lethal disadvantage experienced by millions of people with chronic hepatitis and no access to life-saving drugs.

On Global Hepatitis Day last week (July 28), viral hepatitis surpassed HIV, malaria and tuberculosis as a leading cause of death from infectious disease. [1]

Asia bears the brunt of the burden with over one million viral hepatitis-related deaths each year and 70 per cent of the global death toll. In Asia, viral hepatitis is three times more deadly than HIV and nine times more so than malaria.

“For years, viral hepatitis has been largely neglected,” Margaret Chan, WHO director-general, acknowledged recently.

Charles Gore, president of the World Hepatitis Alliance, says viral hepatitis has been so chronically under-prioritised that there is little funding available in domestic budgets and none from international funders.

“The failure to include hepatitis in the Millennium Development Goals (MDGs) has been calamitous in this regard and this mistake is likely to be compounded by the failure to include hepatitis in the post-2015 Sustainable Development Agenda,” Gore says.

A Fatal Error

On 22 July, medical journal The Lancet reported on the triumph of MDG 6, which has seen the HIV death toll fall by almost one third, from a peak of 1.7 million in 2005 to 1.3 million in 2013. Mortality rates for tuberculosis have fallen

to 1.4 million (or 1.3 million, if those who are also HIV-positive are excluded). Annual malaria deaths peaked at 1.2 million in 2004, falling to about 855,000 in 2013. [2]

However, the WHO Global Burden of Disease 2010 study, published in December 2012 by The Lancet, put annual viral hepatitis related deaths at 1.44 million. [3] Experts suggest there has been no reduction since then.

Stephen Locarnini, director of the WHO Regional Reference Laboratory for Hepatitis B, says the decision to exclude hepatitis from MDG 6 was an epidemiological oversight based on flawed data.

Back in 2000, when governments worldwide adopted MDG 6, experts profoundly underestimated the hepatitis disease burden, he says. They only included mortality figures for acute hepatitis and left out those for hepatitis B and C related liver cancer and cirrhosis deaths — which actually account for about 80 per cent of the viral hepatitis mortality burden. The error persisted until the WHO Global Burden of Disease figures came out in December 2012.

Ben Cowie, an Australian infectious diseases physician and epidemiologist, and spokesperson for the Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP), tells SciDev.Net the legacy error has led to a public health agenda that is terribly distorted and far from evidence based.

“Only looking at acute hepatitis mortality was clearly insane. It’s a bit like saying we’re only going to count HIV/AIDS deaths from seroconversion illness and not immune deficiency,” he says.



Haves and have nots

Existing hepatitis B drugs suppress viral replication, which stops progressive liver disease, allowing the liver to recover. The antiviral drugs can reverse cirrhosis, and reduce the incidence of liver cancer by 50-70 per cent. But the vast majority of the 350 million people worldwide with chronic hepatitis B do not receive treatment.

One of the antiviral drugs, tenofovir, is also used in the treatment of HIV, and funding support from international financing organisations such as the Global Fund and the US President's Emergency Plan for AIDS Relief has made it available for people living with HIV in extremely resource-challenged settings in the Asia-Pacific region.

"But the tragedy is that tenofovir is not made available for people living with hepatitis B. So, you can have the dichotomy whereby someone living with HIV is readily able to access free tenofovir for the treatment of their HIV, but his next-door neighbour who is dying of cirrhosis or has progressive liver disease and is at significant risk of liver cancer is unable to access the drug," Cowie says.

India makes tenofovir generically for US\$15-20 per month, but this is still well

beyond the reach of most people living in the Asia-Pacific region, Cowie adds. Licensing deals further restrict the availability of generics.

"This inequitable situation can't be allowed to continue. We really need to broaden the MDGs to include viral hepatitis as a matter of equity, and, especially in the Asia-Pacific region, as an urgent public health initiative," he stresses.

Although the WHO is making inroads in responding to the hepatitis burden, Cowie says the international funding response continues to be woefully inadequate. He accuses the Global Fund of burying its head in the sand.

"We have the data, we've shifted the evidence base, but this is not going to translate into outcomes for people's lives until we have a funding response," he argues.

In reply, a Global Fund spokesperson tells SciDevNet: "The Global Fund has a clear mandate to support programmes that prevent, treat and care for people affected by AIDS, TB and malaria. We are committed to that mandate and do not plan to change it."

Continued over the page

Learning from HIV

There is no hepatitis C vaccine, and vaccine candidates are a long way off. Meanwhile, there are 185 million people living with chronic hepatitis C infection worldwide. But new oral drug treatments for hepatitis C promise greater than 90 per cent cure rates in 12 weeks — even in people with severe liver disease.

However, the revolutionary drug therapies are prohibitively expensive, costing US\$84,000 for sofosbuvir and US\$66,000 for simeprevir per person for a full course of treatment, according to an article published in *Science* last month.

But the authors' analysis demonstrated that the drugs could be manufactured for as little as US\$78 to US\$166 per person, if the same methods used for mass-producing generic drugs for HIV/AIDS were applied. [4]

The US patents for the new hepatitis C drugs do not expire until the mid-to-late 2020s. To avoid an estimated 7.5 million hepatitis C deaths between now and then, the authors called on pharmaceutical companies to allow low-cost mass production of generics, with a small royalty paid back to them.

Prevention is better than cure

The WHA president urges governments not to let the new hepatitis C drugs distract them from the task of prevention.

"The new drugs could be game-changing, but we must see governments and the WHO emphasising prevention as a key part of healthcare systems if the drugs are going to make the global impact we're hoping for," he says.

Although hepatitis C infection rates are tapering off in some parts of the world, they continue to rise in Asia, where many hospitals use contaminated syringes, surgical instruments and blood products; and where harm reduction measures for people who inject drug are often inadequate. A person who has been cured of hepatitis C can easily become reinfected, because natural infection with hepatitis C does not induce immunity.

The single most important preventive strategy for mother-to-child transmission of hepatitis B is a dose of hepatitis B vaccine given in the first 24 hours of life. Without it, exposed newborns have a 90 per cent chance of going on to develop chronic infection. Most people with chronic hepatitis B were infected at birth. But coverage of the birth dose remains low in much of South-East Asia and in remote areas of the Western Pacific.

The GAVI Alliance, a global vaccines partnership, funds a three-dose course of hepatitis B vaccine for many Asian countries, commencing in six week old newborns. But the birth dose remains largely unfunded. Last month, the Médecins Sans Frontières Access Campaign wrote to GAVI, expressing their concern about the missed opportunity and urging GAVI to scale up birth dosing. [5]

While a new development agenda is currently being set in place of the MDGs, the question of who will pay for lifesaving viral hepatitis prevention and treatment remains unanswered. In the meantime, those with chronic infection continue to needlessly die.

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- [1] World Hepatitis Alliance Viral hepatitis now kills more people than HIV/AIDS (July 2014)
- [2] C. Murray and others Global, regional, and national incidence and mortality for HIV, tuberculosis, and malaria during 1990–2013: A systematic analysis for the Global Burden of Disease Study 2013 (Summary) (*The Lancet*, 2014)
- [3] R. Lozano and others Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: A systematic analysis for the Global Burden of Disease Study 2010 (Abstract) (*The Lancet*, 2012)
- [4] A. Hill and G. Cooke Hepatitis C can be cured globally, but at what cost? (*Science*, 2014)
- [5] Médecins Sans Frontières Access Campaign Letter to GAVI Alliance (13 June 2014)

BY **GABRIELLE BABBINGTON**

*Article published on Sept 8, 2014 for
SciDev.Net's South-East Asia & Pacific desk.
tinyurl.com/hep-unfunded-asia*

hepatitis australia

EXPRESSIONS OF INTEREST

Hepatitis Australia Community Board Members

We are seeking applications from people interested in joining the Hepatitis Australia Board as a Community Board Member from the beginning of 2015 for a two year term.

To be eligible for one of these positions you must be a financial member of one of the eight member organisations of Hepatitis Australia, and be living with or previously living with hepatitis B or hepatitis C or be a member of a priority population for hepatitis B or hepatitis C.

New board members will be offered a comprehensive board induction process, mentoring and opportunities for governance training.

If you are interested in joining the Hepatitis Australia Board, please contact Frank Farmer at HepatitisWA on (08) 9227 9805 or at manager@hepatitiswa.com.au to discuss the position further and obtain a copy of the application pack. **Applications close 30 September 2014.**

For general information about Hepatitis Australia please visit www.hepatitisaustralia.com

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Blueprint for action

“If Australia is serious about averting a liver disease crisis, regular liver check-ups must be part of the standard of care for the half a million Australians living with chronic hepatitis B and C.”

Australia's leading hepatitis organisations urge Federal and State Governments to put in place the funding and resources to support the following blueprint for action.

Regular liver check-ups must become the standard of care for all people living with viral hepatitis.

This is possible if Australia:

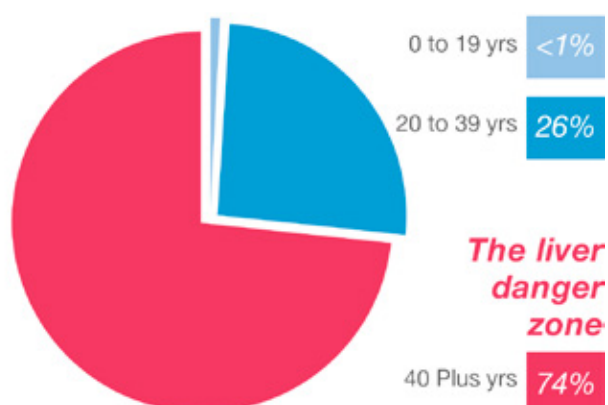
- Invest in services, equipment and training needed to provide access to high quality and regular liver check-ups for all Australians with chronic hepatitis B and C each year.
- Educates and empowers primary healthcare providers to ensure that people with chronic viral hepatitis receive regular liver check-ups.
- Increases efforts to diagnose people with chronic hepatitis B and C and improve their awareness of the importance of regular liver check-ups.

Ensuring all Australians with chronic hepatitis B and C are diagnosed and undergo regular liver health checks to track their liver health is critical in preventing nearly 1,000 deaths occurring each year due to viral hepatitis. This is the first step to avert a liver disease crisis in Australia.

WHAT IS THE LIVER DANGER ZONE?

- Put simply, the *liver danger zone* is the point where a person's risk of serious and life-threatening liver disease caused by hepatitis B or C significantly increases due to age.
- People with hepatitis B or hepatitis C who are over 40 years of age experience an accelerated rate of liver damage which increases their risk of developing liver cirrhosis, liver cancer or liver failure.
- Australia's ageing population and the age demographics of people living with chronic hepatitis B and hepatitis C are combining to place an ever-increasing number of Australians in the *liver danger zone* and one step closer to serious liver disease.
- The most common form of advanced liver disease is liver cirrhosis (extensive scarring). As liver cirrhosis occurs, healthy liver cells are replaced with damaged cells. Left untreated, extensive liver damage may occur and lead to liver failure, which is known as 'decompensated liver disease'. In the case of liver failure, a liver transplant is the only treatment option considered, however, in many circumstances may not be available.
- Liver cancer is the fastest increasing cause of cancer death in Australia and has a poor prognosis. Many people die within the first month after a diagnosis of liver cancer.

Australians with hepatitis C



164,128 people (74%) with chronic hepatitis C are in the **liver danger zone**.

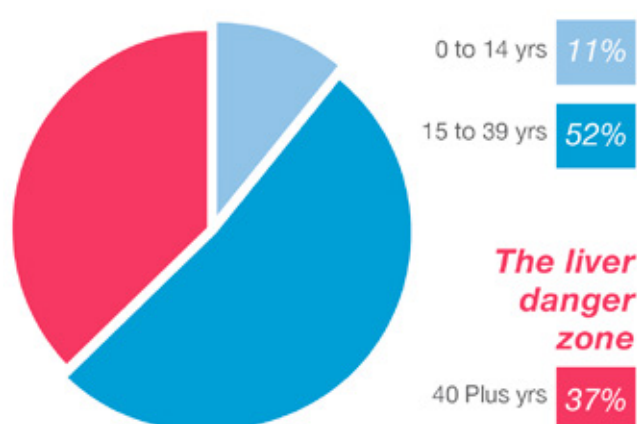
- People with chronic hepatitis who are at risk of developing liver cirrhosis or liver cancer may have very few symptoms (or none at all) until the liver becomes severely damaged.

Health outcomes can be vastly improved through regular liver health check-ups.

- In the final stages of liver disease, where the liver is no longer able to function, waste products build up which affect many organs and can cause multiple organ failure. Where a number of organs are affected, death is likely to follow.



Australians with hepatitis B



83,250 people (37%) of people living with hepatitis B are in the **liver danger zone**.

"We shouldn't be waiting for people to progress to liver cirrhosis, liver failure, or liver cancer. We need to take action to ensure all people living with viral hepatitis receive appropriate care to prevent life-threatening liver disease. The critical first step is to establish regular liver check-ups as a routine part of care for all Australians with hepatitis B or hepatitis C."

The proportion of people in the liver danger zone is lower for hepatitis B (37%) than it is for hepatitis C (74%). This is related to the younger age profile of migrants to Australia compared to the general Australian population. Migrants from countries with a high prevalence of hepatitis B are a significant proportion of all people living with hepatitis B in Australia.

"Successful antiviral therapy has the opportunity to reverse the trend, turning high danger into low danger, but only if people with hepatitis have access to appropriate treatment through regular liver checks."

For more information, visit www.liverdangerzone.com.au

HIGH PROTEIN, HIGH ENERGY DIET

For advanced liver disease

Rationale:

In chronic liver disease, there are additional considerations you will need to make in your diet to support your liver and health.

It is common for people with advanced liver disease to develop 'protein-energy' malnutrition.

Advanced liver disease stops the liver working properly and affects its ability to store and release glycogen, a chemical that is used to provide energy when the body needs it. When this happens, the body uses up its fat stores and breaks down its own muscle tissue for energy.

This can lead to muscle wasting, a loss of strength and unhealthy weight loss. If left untreated, it can result in serious health complications.

To counteract this, people with advanced liver disease need to take in more energy (kcal) and almost double the amount of protein compared to healthy people of the same weight.

The symptoms may be easy to miss. The bathroom scales may not pick up any muscle loss because of fluid retention. Sometimes the loss of weight around the face, upper body, arms and thighs may be noticeable.

All people with advanced liver disease should consult with an accredited practising dietitian (APD) to create a personal high protein, high energy eating plan.





HEALTH BENEFITS

A high protein, high energy diet is important for people with chronic liver disease as the protein and fat is used to maintain muscle and body tissue (including the liver) and to keep the body working normally.

Research shows a high protein, high energy eating plan may improve health outcomes, and help reduce the number of times people with chronic liver disease develop an infection or have to go to hospital.

WHAT IS A HIGH PROTEIN, HIGH ENERGY DIET?

A high protein, high energy diet provides 1.2-1.5 grams of protein/kilogram of body weight/day and adequate energy to maintain fat stores (35-40 kcals/kg body weight/day).

It is important to have a well-balanced diet to ensure you are getting enough carbohydrate, protein, fat, vitamins and minerals.

To increase your protein and energy intake, include atleast one food from each of the following columns at each meal or snack. Also see the sample eating plan.

YUMMY TIPS



| Protein Foods | Energy Foods |
|---|---|
| <ul style="list-style-type: none"> • Milk and milk powder • Yoghurt • Cheese • Custard • Meat, fish, chicken • Eggs • Nuts and seeds (including pastes) • Legumes (baked beans, lentils, chickpeas) • Tofu | <ul style="list-style-type: none"> • Bread and bread products • Breakfast cereals • Pasta, rice, noodles • Cakes, biscuits • Potato, sweet potato, corn • Butter/margarine, oil • Cream/mayonnaise • Jam, honey, golden syrup |
| <p>Some of these foods may be high in salt. If you have been advised to follow a low-salt diet, refer to the low-salt information on the following page.</p> | |

ADDITIONAL CONSIDERATIONS

Overweight

Your doctor may recommend a high protein, reduced fat, moderate carbohydrate diet. Try to limit fatty and sweet foods. Talk to your dietitian about your eating plan.

Diabetes and glucose intolerance

Follow a high protein, high energy diet and include a moderate amount of carbohydrate sources to assist in controlling blood sugar levels. If the restricted diet is leading to muscle wasting and/or weight loss, consult a dietitian for additional advice on meeting your individual protein and energy needs in advanced liver disease.

Vegetarian or lactose intolerance

Adequate protein can be obtained from legumes, nuts and seeds and foods made from these. Soy milk and soy products are a suitable high protein substitute for cow's milk and milk products if dairy product tolerance is a concern.

Changes in sense of taste

Many people with advanced liver disease describe an altered sense of taste and a heightened sense of smell that can reduce their ability to eat. Mineral deficiencies can lead to a changed sense of taste. This can be easily identified by a blood test and corrected with oral supplements. Discuss this with your doctor and dietitian.

Additional stress

Symptoms such as diarrhoea, vomiting, dehydration, constipation, infection or bleeding can place additional stress on the liver. Treatment includes tackling the underlying medical problem and paying careful attention to diet, particularly to eating enough protein.

Eat small meals often and have a snack of energy protein-rich food before bed. This is very helpful for people with liver disease. If you are awake during the night try to have a high protein drink or snack to reduce the time you spend fasting overnight.

Eat frequently

Eat six to eight smaller meals and snacks throughout the day. Aim to eat every two to three hours. Small, frequent meals can boost your nutrition intake and can be useful if you feel full quickly or if your appetite has decreased.

Vitamins and minerals

The changes that occur in chronic liver disease can lead to vitamin and/or mineral deficiencies. Problems such as excessive bleeding, osteoporosis, anaemia, and night blindness can result if vitamin and/or mineral levels are too low.

Common vitamin deficiencies include the fat soluble vitamins – A and D. Identification and correction of these deficiencies is essential in patients with chronic liver disease. Eating a variety of foods can help to avoid the issue of vitamin deficiencies.

Supplements

A number of special nutrition supplements may be able to help increase your calorie, protein, energy, vitamin and mineral intake. Avoid taking any supplements or following diets that are not recommended by your doctor or an accredited practising dietitian (APD).

Fluid reduction

As liver disease progresses, a build-up of fluid in the stomach area (ascites) and swelling of the feet and legs (oedema) may occur. You may also be asked to limit the amount of fluids you drink through the day. This includes all beverages and watery foods such as soup. Half of your fluid intake should be high in protein (e.g. milk).

No added salt

If you have fluid retention, your doctor and dietitian will recommend you follow a no added salt, high protein diet. Salt acts like a sponge with fluid in your body. By reducing the amount of salt you eat and increasing your protein intake you can limit the amount of fluid that stays in your body.

Other ways to add flavours besides salt:

- Freshly ground black pepper
- Lemon, lime and citrus fruits, vinegar
- Oil or butter
- Fresh herbs
- Chillies
- Ginger, garlic, shallots and spring onions
- Spices such as mustard powder, nutmeg, cinnamon, cardamom, ginger, cumin
- Toasted and ground sesame seeds

Hints to reduce salt intake:

- Eat fresh whole foods
- Avoid salty canned or processed foods
- Use low-salt or no added salt versions
 - frozen vegetables have less salt than canned vegetables
- Do not add salt to your meal at the table
- Make your own stock and do not add salt – stock cubes, bouillon cubes and gravy granules can be high in salt
- Eat cold, cooked fresh meat, poultry or eggs instead of deli meats or cured foods
- Choose unsalted butter
- Certain bottled waters are high in sodium – check the labels carefully



HIGH PROTEIN, HIGH ENERGY EATING PLAN

BREAKKIE

- Cereal and full-cream milk/or porridge
- Eggs (cooked to your liking) with unsalted butter and toast (or reduced salt spread)
- 1 cup yoghurt or custard with fruit
- Hot chocolate or coffee made with milk, or a glass of milk

SNACKS

- Ricotta or Swiss cream cheese on toast
- Cheese and crackers
- Milkshake made with full-cream milk

LUNCH

- Sandwich with roast meat, chicken, fish, egg or cheese
- Baked beans (low-salt variety), eggs or grilled cheese on buttered toast
- Meat, fish or poultry with buttered vegetables or salad
- Dessert if desired
- Glass of full-cream milk

SNACKS

- Custard or yoghurt with fruit
- Hard-boiled egg
- Handful of unsalted nuts, or dried fruit and nut mix (low-salt version)
- Custard tart
- Yoghurt
- Milo
- Omelette
- Teacake, muesli bars or fruit bread and a glass of milk

DINNER

- Meat, fish or poultry with buttered vegetables or salad
- Pasta with meat sauce and salad
- Toasted cheese sandwich



BEDTIME SNACKS

- Milkshake or hot milk with honey or other flavourings
- 1 cup yoghurt or custard with fruit
- Hot chocolate made with milk
- Crackers and cheese

hepatitis*wa*

is facilitating a peer
support service for
people living with hepatitis.



The peer support group assists people to achieve better health and well being through discussions and activities. The monthly meetings are confidential, free and provide opportunities to share experiences and thoughts with peers in a friendly and non-judgemental way.

Healthy and tasty snacks will be provided.

For more information, please contact Amineh
on 9328 8538 or support@hepatitiswa.com.au

TIME TO GRASP PRISON NEEDLES

THE tragedy of the AIDS epidemic has been with us since the early 1980s when the Nobel Laureate Prof Francoise Barre-Sinoussi and her team at the Pasteur Institute in Paris isolated the human immunodeficiency virus (HIV).

In Canberra, in the lead up to the 20th World AIDS Conference being held in Melbourne, the professor paid tribute to those who died in Malaysian Flight MH17.

Some of the 298 people on board were heading to Melbourne to share their knowledge about the battle against this insidious virus.

Speaking at the National Press Club, the professor of microbiology emphasised the role that marginalisation and prejudice played in retarding the fight against HIV/AIDS.

On the same platform was former Secretary of Health in the Conservative Thatcher government who added his voice to the challenge that was faced in the early 1980s because of the marginalised groups such as gay men, sex workers and injecting drug users.

The marginalisation continues. The least powerful in our community are those most at risk. This was recognised by governments in Australia and elsewhere. Federal Health Minister Neal Blewett (Labor) and Shadow Minister Peter Baume (Liberal) had the courage to put politics aside to stand up and support gay men, injecting drug users and prostitutes. The results speak for themselves. Australia still has one of the lowest rates of spread of infection in the world.

However, the challenge continues. The third speaker at the Press Club, Australian Prof Sharon Lewin, warned about complacency, revealing: "This year, again, we had the highest numbers of new infections".

The three also discussed the parallel issue of the spread of hepatitis C infection and the importance of tackling marginalisation, bigotry and prejudice.

There is no cure for HIV/AIDS although treatment has come a long way. There has been more success with hepatitis C but the expense puts it out of reach of ordinary people. Prevention is still the most important approach to both infections.

The opportunity to take on the issue of increasing infection of AIDS and hep C in Canberra remains. Chief Minister Katy Gallagher has made public that she is prepared to introduce a needle and syringe program in the Alexander Maconochie Centre.

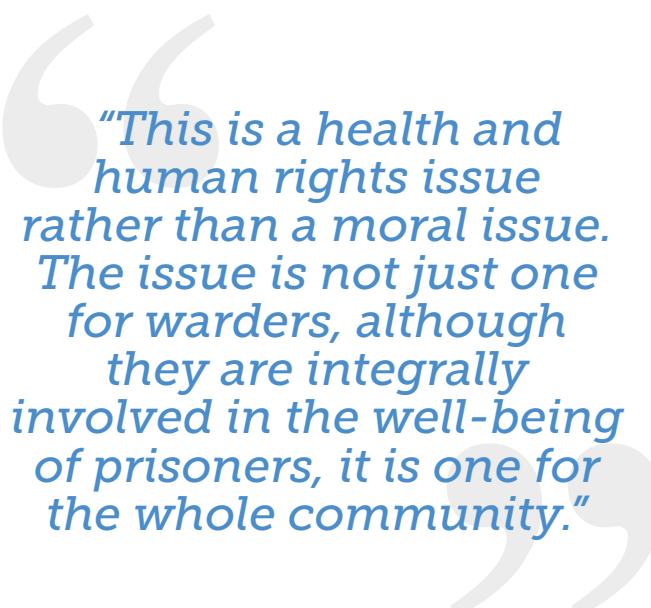
Prisoners often fit into the marginalised groups already mentioned with the additional impact of being incarcerated. And yet the very people who are looking after these prisoners resist the introduction of the needle and syringe program.

Prison officers do not have to participate. A series of methods have been demonstrated that will allow this preventive approach without engaging the warders.

This is a health and human rights issue rather than a moral issue. The issue is not just one for warders, although they are integrally involved in the well-being of prisoners, it is one for the whole community.

Joep Lange, along with his partner and more than 100 AIDS researchers, scientists, medical practitioners and activists, died in the crash of MH17 on his way to the Melbourne AIDS Conference.

Prof Lange was a former president of the International AIDS Society who, amongst other things, worked tirelessly and was not one to shun marginalised groups. He was one of the key leaders in ensuring treatment reached the poorest people on earth and was founder of the PharmAccess Foundation.



"This is a health and human rights issue rather than a moral issue. The issue is not just one for warders, although they are integrally involved in the well-being of prisoners, it is one for the whole community."

The common factor amongst the scientists and activists was a sense of commitment and compassion for those around them, for those less fortunate than themselves. Rather than being judgemental they were compassionate, rather than letting things go on they were innovators, rather than giving up they persisted in looking for cures, in summoning the courage to speak out and to care for those not able to care for themselves.

If the same principles of persistence, courage and caring are applied in the fight against HIV and hepatitis C in Canberra, the establishment of the needle and syringe program in the Alexander Maconochie Centre would be imminent.

Michael Moore was an independent member of the ACT Legislative Assembly (1989 to 2001) and was minister for health.

As CEO of the Public Health Association of Australia, he was responsible for a report on an NSP in the Alexander Maconochie Centre in 2011.

BY MICHAEL MOORE

*Jul 24, 2014 for Canberra City News.
tinyurl.com/grasp-prison-needles*

HEPATidings

hepatitisWA Community Activities

A SNAPSHOT OF HEPATITISWA EVENTS

Hepatitis Awareness Week 2014

HepatitisWA celebrated Hepatitis Awareness Week this year during the week of 28th of July to 3rd of August. Below is a snapshot of each project's activities and events during that week.

HepatitisWA embarked on a number of different activities this year, during Hepatitis Awareness Week (28th July to 3rd August, 2014).

HepatitisWA's Marketing and Resources Officer focused on promoting the "C the person not the disease" campaign during Hepatitis Awareness Week, which was used by permission and adapted from Hepatitis NSW's original campaign.

HepatitisWA commissioned direct marketing through billboards, train stations, metro buses, print media, community television and social media outlets to promote the campaign.

The entire campaign ran from July through August, with a particular focus during awareness week. It has been estimated that this campaign has been sighted over 4 million times (which includes multiple sightings by individuals).

On World Hepatitis Day, HepatitisWA hosted an open house at our premise, where we did a soft launch of the "C the person not the disease" campaign and had over 50 attendees from partner agencies, including the WA Health Department. During the event, Max and Glenn (who had been living with and successfully treated hepatitis C), gave a personal perspective of their journey. Later, HepatitisWA hosted a statewide webinar presented by Dr Nick Kontorinis to WA GPs on hepatitis C.



HepatitisWA disseminated Hepatitis Australia's 'Love Your Liver' Posters to 215 agencies, and mailed out the 'Liver Danger Zone' reports to all the politicians in WA, in time for World Hepatitis Day.

Overall, HepatitisWA had disseminated over 7,000 physical resources during Hepatitis Awareness Week and had reached over 7,000 Facebook users on World Hepatitis Day.

Our Community Engagement Hepatitis B Officer was involved in two interactive workshops. The first was at the Langford Community Center, with 26 attendees from Arabic, Burmese, Mandarin, Malay and Sudanese speaking backgrounds. There was also interpreters for all languages, and the main questions asked were about transmission. The second event was a 'Liver Healthy Life' workshop at ISHA Mirrabooka with 34 women attending. This included a pictorial presentation on hepatitis B and a good liver diet followed by a practical health class on juicing, making raw salad and raw bliss balls. Cultural groups included Arabic, Afghani, Iranian, African, Turkish and Sudanese. Interpreters were available for all groups.

HepatitisWA's Health Promotions Officer had four informational workshops with youth at the Leederville TAFE, Mandurah Baptist College, Southern River College, and at the Stratton Youth Centre.

A range of Workforce Development opportunities were conducted within the Albany region in preparation for Hepatitis Awareness Week. Our Workforce Development Officer conducted a community health worker educational workshop in Albany, which attracted participants from a wide range of workforce groups including Population Health, the Department of Corrective Services, Aboriginal Health, and other health services. This

workshop was well received and generated a lot of discussion. The Workforce Development Officer also provided educational workshops to hospital clinical staff and drug and alcohol workers, both of which resulted in a Hepatitis Awareness Week informational health promotion stall. Lastly, we provided education to prison officers and pharmacy staff. Overall this regional trip was very successful at disseminating information throughout the Great Southern region.

Our Support and Information Officer spent a significant amount of time delivering resources to different agencies in preparation for Hepatitis Awareness Week and also developed and organised health promotion stalls at various locations including Fremantle Hospital, Next Step (AOD Agency), and Royal Perth Hospital.

HepatitisWA was also able to provide our Support Group with the opportunity to enjoy a 'Healthy Liver Lunch' during Hepatitis Awareness Week at VeggieMama in Mount Lawley. This lunch sparked discussion around healthy eating while providing an outlet to share personal stories and experiences.

To celebrate and raise awareness of Hepatitis Awareness Week, the Needle Syringe Program (NSP) displayed informational resources, promotional goodies, and healthy food platters with fresh fruit, and yummy banana bread for NSP clients. We also held a raffle with clients having the opportunity to go into the draw to win one of two raffle baskets containing food and clothing for practical help during the winter period. ■

Photos (Clock-wise): C the person not the disease campaign, Frank Farmer (Executive Director), Charles Watson (Patron), Maria (volunteer), Max and Glenn (guest speakers).

Hepatidings Contributors: Felicia, Amanda, Brenna, Matt, Amineh and Nadia. **Photographs by:** Felicia.



Celebrating Hepatitis Awareness Week

WASUA was one of many agencies that was awarded a **Hepatitis Awareness Week Community Grant** from **HepatitisWA**. HepatitisWA offers community grants to support and resource community organisations in the Perth metropolitan and regional areas to undertake activities to raise awareness of viral hepatitis by hosting a community event, healthy lunch, educational workshop, display stall or create an electronic health promotion message with the aim of increasing awareness of viral hepatitis within the community.

Once again, Hepatitis Awareness Week was a successful time where many people received the opportunity to be educated with the latest facts on viral hepatitis, get access to new resources and have access to a friendly chat with peers who were able to educate and inform people about hepatitis C. There was a keen approach to WASUA's events this year. Thank you to HepatitisWA for helping to make it successful by supplying many various resources, which were both informative and eye-catching.

Lunches were served each day from the WASUA site with healthy liver tips as well as hepatitis A, B and C resources all on display and available to take. WASUA catered for twenty people each day with food served in the boardroom along with arranged information and education on viral hepatitis. We engaged with many peers, who also took part in a survey developed by WASUA's Hepatitis C Educator.



Passages (Northbridge Youth Centre) was another place where WASUA had presented a lunch, with the theme again promoting Hepatitis Awareness Week. WASUA's Youth Worker Fiona was able to introduce WASUA's presence and help facilitate with disseminating of information within the group of youth. Twenty youth presented and became involved by either conversation or by taking resources and filling out surveys. A healthy cooked meal with plenty of various salads, drinks and soups was provided.

WASUA's nurse Jo was available and managed to get six of the youth tested for BBV's as well as administer hepatitis A and B vaccinations. There were a number of people who said they would follow-up on any hepatitis issues they may have, with some of these people already taking advantage of ongoing services such as testing, diagnosis and referral for treatment.

The survey comprised of seven questions;

1. What is hepatitis?
2. Which organ of the body does it affect?
3. What is a blood borne virus?
4. Can you name the types?
5. You can catch hepatitis C by...
6. Is there a vaccine for hepatitis C?
7. Do you know about any treatments available?

Out of 36 people, when asked "What is hepatitis?" over half said the word "blood borne virus" in their answer while less

than half identified it was associated with the liver. Some mentioned other viruses such as hepatitis A, B and HIV, but when coming to name the types of hepatitis C most were unaware. When talking about vaccines for viral hepatitis, two-thirds knew, there was not a hepatitis C vaccine, with the remaining one-third stating they did not know. Only a third of those spoken to knew about Interferon, with all but only a small proportion actually aware of hepatitis C treatments. It was encouraging to see that the youth at Passages who were questioned, all were aware about how hepatitis C is transmitted, as prevention being the main cursor with youth. There still needs to be a lot more education if we want people to have at least a basic education surrounding viral hepatitis.

Hepatitis C remains a big part of many users' lives and with such a low intake on treatment (around 2%), there looks to be a great surge in liver disease in the near future. Only with correct education, (reaching people who need to know about hepatitis) – will people be in a better position to make management decisions. With the greater community involved in hepatitis awareness, there can only be more positive outcomes. WASUA looks forward in continuing to help educate those who need it through Hepatitis Awareness Week again next year. ■

Written by Mikayla-Jay McGinley
Hepatitis C Educator, WASUA.

PERTH
(08) 9321 2877
www.wasua.com.au



WASUA
WA'S DRUG USER ORGANISATION
"if you would judge, understand" L.A. Seneca

SOUTH WEST
Van Phone 0417 973 089
Office (08) 9791 6699

Perth NSEP
Mon - Weds: 10am-4pm
Thurs - Fri: 10am-8pm
Sat & Sun: 10am-12pm

Clinic Hours
Tues & Thurs: 10am-4pm
Closed Public Holidays

South West Mobile provides a mobile Needle Syringe Exchange Program (NSEP) at the following locations and times:

WASUA provides a number of services on premises at 519 Murray Street, West Perth, including:

- NSEP (Needle and Syringe Exchange Program)
- Free hep A and B vaccinations for hepatitis C positive people
- Free blood testing in a friendly confidential environment
- Drug treatment support and referral
- Peer education and training
- Street-based outreach
- Advocacy and support for users
- Safe injecting and safe disposal education and resources
- Hepatitis C/blood borne virus information and resources

Margaret River
Busselton
Jaycee Park, Bunbury
Hudson Road, Bunbury
Bunbury Hospital
Manjimup
Harvey
Donnybrook
Collie

Tues: 1pm-2pm
Tues: 5pm-7pm
Wed: 4:30pm-5:30pm
Wed: 5:45pm-6:45pm
Wed: 7pm-8pm
Thurs: 5pm-6pm
Thurs: 6pm-7pm
Fri: 4pm-5pm
Fri: 6pm-7pm

Hospital Carpark
Kevin Cullen Community Health
JC Park
WA Country Health Service
Dental Clinic Carpark
Hospital Carpark
Hospital Carpark
Hospital Carpark
Ngalang Boodja
(Corner Forrest St & Atkinson St)

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