



# NO SHAME ON ME

A REPORT ON HEPATITIS C FOR THE  
VICTORIAN ABORIGINAL COMMUNITY



VACCHO

**ABOUT 16,000  
ABORIGINAL AND  
TORRES STRAIT  
ISLANDERS ARE LIVING  
WITH HEPATITIS C.**

**"WE WANT THOSE WHO ARE ALREADY  
INFECTED TO UNDERTAKE THE  
JOURNEY, STARTING BY LOOKING AT  
THE BLOKE OR THE WOMAN IN THE  
MIRROR AND ASKING THEMSELVES  
IF THEY GENUINELY WANT TO GO  
FORWARD. THERE ARE TREATMENTS  
AVAILABLE, THERE ARE CULTURALLY  
RESPECTFUL PROGRAMS AVAILABLE IF  
THEY ARE READY TO STEP UP."**

Uncle Jack

## COMMON QUESTIONS

This booklet is about hepatitis C and Aboriginal people in Victoria. It started as a research project where we interviewed Aboriginal people with hep C. We also spoke to Aboriginal health workers and a few doctors. We started by asking questions about ways of improving access to hep C treatment in the Aboriginal community, but we learned a lot more about what hep C means for Aboriginal people. The quotes in this booklet come from the interviews we did for the research.

This report would not have been possible without the people who talked to us about how having hepatitis C affects their lives. We would also like to acknowledge the contribution of the Koori Hospital Liaison Officers, Aboriginal Liaison Officers, Community Health workers, Aboriginal Community Controlled Health Organisations and GPs who shared their knowledge with us.

The research team thanks the reference committee for making this report possible.



### **So, what is hep C?**

Hep C is a virus that can make the liver sick.

### **How do you get hep C?**

Hep C lives in blood. Anytime that there is blood around, there is a risk that hep C is in that blood. Blood with hep C in it must get under your skin and into your bloodstream. This can happen by sharing needles, as well as unsterile tattooing and body piercing..

### **What does hep C do?**

Some people are lucky and naturally get rid of hep C. But most people get chronic hep C, and they are infected for life unless they get treatment.

Hep C doesn't make people sick straight away, so they might not know they've got it. Hep C can cause stomach pains, digestive troubles, and itchy skin. It can make people tired and sometimes depressed. A small number of people can get more serious liver disease.

### **So, can you get rid of hep C?**

There is a treatment for hep C that cures most people. The medications are quite strong, though, so treatment isn't easy!

### **If you have hep C, how can you stay healthy?**

The best thing you can do is reduce or quit alcohol. Also, try and eat less fat and more vegetables. Smoking and other drugs can also make you sicker.

### **How do you know if you have hep C?**

You have to visit a doctor or health service for a blood test. You can't tell by looking at someone if they have hep C.

### **OK, so how can you avoid hep C?**

Remember that hep C lives in blood. Don't share needles, spoons and other injecting gear, and don't share tattooing or piercing gear either.

### **What about sex?**

It's very unusual for hep C to be transmitted from sex. This only happens if blood is there during sex. Be careful of blood (or sex that might cause bleeding).

### **Is that all? Can't you get it from sharing food?**

No way! You can't get it from sharing cups or smokes, or from kissing, mozzies or toilet seats!

## THE MORE WE TALK ABOUT HEPATITIS C, THE LESS SHAME AND STIGMA THERE WILL BE FOR PEOPLE WITH HEPATITIS C.

### **There are many reasons that people don't like to talk about hep C.**

The shame and stigma of hep C is not always about the disease itself. One person said that if they talk about hep C, people will think, 'what might I have been doing to have caught hep C?'

*"I don't like telling people I have hep C, because I'm embarrassed what they'll think...I was too embarrassed to ask questions."*

### **Shame job?**

Every single person in this study talked about shame. This really shows just how much shame can create silence around hep C. People said that communities are too shame to talk about it, and people with hep C are too shame to learn more or ask questions.

*"Cultural Shame is always there, so sometimes people do not want to mix with their community, because they are "shamed up" by their lifestyle."*

People told us that shame has stopped health workers talking about hep C. Shame can stop people from asking questions about hep C, and finding out more about the treatment. Some people can be cured of hep C, but they might be too shame to find out more!

One health worker said *"a lot of them will talk with me about their other issues, but they never, ever bring up hep C, and I avoid it too, because I'm there to support them, not alienate them."*

**Does it really have to be this way?** One person with hep C said this:

*"There are that many diseases in this country now, and there weren't when our people come, so it's no shame on me, it's a shame on white fellas!"*

### **Talking about it!**

*"How I found out that there's medication for hep C is through my neighbour. We were talking about hepatitis and that, she said 'I'm on medication for that' and I was just shocked! I said 'what? I didn't know there was such a thing', you know."*

*"It's more about being ashamed of the unknown, you don't know what it is, and so you don't go talkin' about it. I've been diagnosed 13 years ago, it's only in the past couple of years, that I've been openly able to talk and enquire about it."*

One person suggested that if you bring people together to educate and support them about hep C, it needs to be done in a much broader way than just addressing hep C. There are lots of ways that people come together such as women's groups, youth groups and elders groups. *"There's the danger of getting labelled if you turn up to a lecture about hep C. But all of those groups, they could be the vehicle to disseminate educational information about hep C."*

## WE NEED MORE TRAINING ABOUT HEPATITIS C FOR ABORIGINAL HEALTH AND COMMUNITY WORKERS.

*"It wouldn't hurt for us to have more education about hep C ... I'm aware of all that sort of stuff about transmission, but treatment, I'm way behind. Obviously when people get sick I liaise with the doctor but I don't know a lot myself. It wouldn't hurt to read up more."* (Aboriginal Health Worker)

Some health care workers did not know how hep C is transmitted or what hep C does to the body. Very few health workers knew that hep C treatment is available. They also said that people in the community don't know very much about hep C.

### **Training about confidentiality**

*"Confidentiality is a huge issue."* One big worry for many Aboriginal people with hep C is the fear that other people will find out. Worrying about privacy stops some people from going to the health service to get their hep C checkups.

Even though 'confidentiality' is promised, lots of people talked about how this is sometimes impossible. After all, *"we have Aunties and Uncles working in some of our services."* Which means that sometimes, *"the whole family finds out."* Because of this, some people choose to go to a service where they don't know anyone.

### **Even doctors don't know everything**

*"I used to think that there was just no treatment for hepatitis C, and that you have to avoid toxins to your liver."* (Doctor)



I think it's people's responsibility to take their medication BUT... it's our responsibility to make it possible for them to do so.

Treatment for hep C has been available for over 10 years, but not all doctors have learned about it. One doctor in the study said that she'd learned out about the hep C treatment from one of her patients!

### Health information

*"I was diagnosed with hep C six years ago. And I've just found out that I can go and get treatment from the liver clinic; I didn't know that before today. I think there just needs to be more awareness and places where I can go to find out research about it, because I'd like to know more about it, and what it's doing to my body and what I can do to help it."*

**The people that were interviewed said that they wanted health care workers to give them more information about hep C.**

A health worker said, *"I had once someone with hep C, who didn't really realise how they got it. They thought they got hepatitis because their house wasn't clean."*

## WE NEED TO GET THE LATEST HEPATITIS C INFORMATION OUT THERE TO PEOPLE WORKING IN ABORIGINAL HEALTH SERVICES.

After talking with lots of Aboriginal health workers and people with hepatitis C, it is clear that many people don't understand hep C very well. More information needs to be provided to health services, so that it can be passed on to people with hep C in the community. Lots of people with hep C want to find out more about the hep C treatment, and how they might be able to get rid of the hep C virus.

Some people said they felt let down by health services because they felt that hep C wasn't talked about enough. The more information health workers have, the more they can pass on to communities.

There are times when information about hepatitis C makes a huge difference to people, especially when they have just been told about having hepatitis C.

One person said, *"The doctor didn't even let me know what it does, like when he told me I've got hep C. I just sat there in his office and I just cried. He didn't tell me, 'do you know about your hep C, do you know what it does, do you know how you can control it, and you can get rid of it'"*

Others had the same experience. *"They didn't tell me nothing, absolutely nothing. Just 'You've got hep C' and that's it."*



Can I help you?

Yes we'd like more knowledge on hep C and what it does to our bodies and how we can help prevent it getting worse and treatment and...

## DID YOU KNOW?

For people with hepatitis C, the 3 best ways to stay healthy are:

### 1. DRINKING LESS ALCOHOL

Drinking alcohol can increase the amount of damage that hep C does to the liver. This means that alcohol can make people with hep C get sicker, quicker.

### 2. EATING WELL

The liver is sensitive to what we eat and drink. Avoiding fast food like burgers and chips is a good start. Eating more vegies and fruit, and less sugary drinks can really help the liver.

### 3. HEPATITIS B VACCINATION

The vaccine protects people from getting hepatitis B. Hep B is another type of liver disease. Having both hep B and hep C is dangerous for the liver.

And...

### FIND OUT IF TREATMENT MIGHT WORK FOR YOU?

Treatment for hep C is not easy, but it might mean that you can get rid of hep C once and for all. With the right support and preparation, would hep C treatment work for you?

**Want to know more? Use one of the phone numbers at the end of this booklet.**

## THERE ARE LOTS OF DIFFERENT WAYS THAT HEALTH SERVICES CAN LOOK AFTER ABORIGINAL PEOPLE WITH HEPATITIS C.

Some people said that the only place they get their hep C check-ups are Aboriginal community health services. Other people said the opposite: that because they worry a lot about people finding out about their hep C, they prefer to see a hep C doctor in a mainstream health service. There is no right or wrong – just **different** ways of doing things!

### Hospitals

People with hep C are often told to visit a special hep C doctor at the hospital. The hospital clinic is an excellent way to get a check up, and to find out about treatment for hep C.

Some other people talked about how they were scared of going into hospitals. Hospitals are seen as places where people die, so unless it is an emergency, people will often put off going to the hospital. This is why people sometimes make appointments but don't show up.

One health worker who works in a hospital said, "the larger hospital setting provides a cover. There is also the option to say that they are just visiting someone. They can walk past and say hi, I've just come to visit so and so, or I'm just passing though, I'm going to an outpatients clinic, it could be for their heart, it could be for their lungs."

### Hep C peer support

*"Someone who's been living with hep C for ten years has got a lot of information to give someone that's just been diagnosed. They're just going through all that guilt and shame, and what ifs. Someone who's been living with it for 10 or 20 years can go, 'mate, it's not the end of the world'."*

Most people said that counselling and support groups would be a good idea. They would allow people to share their different experiences of living with hep C, and also to talk about shame. Of course, people worry about their privacy, so it's important for support groups to be safe places to talk openly.

*"When I first found out about hep C, there were so many people I didn't want to share it with, and then I find out there are so many out there that have it. So how lonely are they? And they can't speak to no one."*

## BRIGHT IDEAS FOR HEALTH SERVICES:

- HEALTH WORKERS COULD HELP OUT WITH APPOINTMENT REMINDERS, AND DRIVE PEOPLE TO APPOINTMENTS AND HOME AGAIN
- YOUNG PEOPLE COULD DEVELOP THE WEBSITE OF THE ACCHO SERVICE, WITH LINKS TO OTHER SITES, SO THEY CAN LEARN MORE ABOUT HEP C WITHOUT TELLING ANYBODY
- HEALTH SERVICES COULD HAVE FIXED APPOINTMENTS BUT ALSO LEAVE 'WALK IN' APPOINTMENT TIMES FOR PEOPLE WHO HAVE TROUBLE WITH APPOINTMENTS.
- SERVICES COULD HAVE A CALL BACK SERVICE FOR PEOPLE WITH MOBILE PHONES WHO DON'T HAVE MUCH CREDIT
- HEP C COULD BE INCLUDED IN GENERAL HEALTH EDUCATION AND COMMUNITY ACTIVITIES, NOT JUST 'HEP C ONLY' EVENTS.

## IS GROUP TREATMENT FOR HEPATITIS C A GOOD IDEA FOR ABORIGINAL COMMUNITIES?

Treatment for hep C is not easy. But the fact is, if you finish the treatment, the odds are that you will be cured. That's about a 60% chance.

In mainstream health services, people do hep C treatment by themselves.

What would it be like if few people all started treatment at the same? Would this make a difference for Aboriginal people that were thinking about treatment?

### **This is what one person told us about doing the hep C treatment:**

*"It brings up everything, all the childhood stuff, all your colonisation stuff, it brings up everything, it's all out on the table...It's pretty hard to take responsibility for your health in this society when you are not accepted as anyone that's worthwhile. Being a drug addict, being an Aboriginal man or woman, or being anything, you can find a thousand excuses for not partaking in this society and getting out of it."*

### **One GP talked about support groups for people doing the hepatitis C treatment.**

*"We had this hep C support group going, and that was really useful. People met every week, and some people, not everyone, started at the same time. There was a bunch of people who were starting, and a bunch of people who were sort of in the middle and a bunch of people who were coming to the end. So, it was really useful for people to see where people were at different stages, and people who had come to the end you know, they come and give the people who were just starting some advice. It was really useful."*

### **Another doctor thought the idea of small groups of people going on treatment at the same time was a good idea. "**

*As long as it was done respectfully and each person was invited. Like, would you like to meet other people? Because I think there is so much shame around having hep C."* Of course, it would be important to have someone to keep the group together, make reminder calls, organise child care and transport. This GP even thought that the whole group could have their appointments at the same time to make the hospital visit easier.

## FOR MORE INFORMATION ABOUT HEPATITIS C AND THE TREATMENT CALL

### **VACCHO**

(Victorian Aboriginal Community Controlled Health Organisation)  
Sexual and Reproductive Health Team  
03 9419 3350

### **VAHS**

(Victorian Aboriginal Health Service)  
STI/ BBV Nurse  
03 9419 3000

Drug and Alcohol Worker  
03 9403 3300

### **Hepatitis C Victoria**

Aboriginal Program Worker  
03 9380 4644

### **Hep C Infoline**

1800 703 003

## FOR FREE HEPATITIS C TRAINING FOR HEALTH WORKERS CONTACT

### **Hepatitis C Victoria**

03 9380 4644

### **The Victorian Viral Hepatitis Educator @ St Vincent's**

03 9288 3586

### **VACCHO**

Sexual and Reproductive Health Team  
03 9419 3350

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