



# Hepatitis C related Stigma & Discrimination – origins, impacts and responses

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# Overview of Today's Discussion

- Hepatitis in context – globally and locally
- Origins of stigma & discrimination
- Personal views of the impact of stigma & discrimination
- What has been done and what can be done to redress stigma & discrimination

# HEPATITIS – Globally and locally

## Worldwide

- 400 million people have chronic hepatitis B
- 170 million have chronic hepatitis C



That means.....**1 in 12 people** in the world  
have chronic viral hepatitis

## Australia

- 90 - 160,000 have chronic hepatitis B
- 197,000 have chronic hepatitis C



# ORIGINS OF STIGMA & DISCRIMINATION

- Erving Goffman defines stigma as **“an attribute which is deeply discrediting”**
- A stigmatised person is someone who embodies **“an undesired difference”**
- Communities defend themselves against threats to their culture by marginalising people who don't conform
- **“acceptable behaviour”** is a social construct

# Origins of Stigma & Discrimination

- The association with injecting drug use drives much of the hepatitis C related stigma
- Criminal activity is the ultimate “**unacceptable behaviour**”
- This leads to people who inject drugs being portrayed as the “**villains**” or “**guilty**” victims of the hepatitis C epidemic

# Social constructs

Have drug users always been stigmatised?

*Some famous drug users.....*

**William Gladstone, William Wilberforce,  
Robert Louis Stevenson, Sarah Bernhardt,  
Elizabeth Barrett Browning, Charles Dickens,  
Sir Walter Scott, George Washington,  
Pope Leo XIII**

# Origins of Stigma & Discrimination

- Relative weight of “**fear of contagion**” in hepatitis C related stigma
- **Discrimination is the enactment of stigma**
- **Rules or sanctions** directed towards affected people, these may be:
  - Carried out by individuals or institutions
  - Intentional or unintentional
  - Covert or overt
  - Routine or episodic
  - Legal or illegal

# Impacts of Stigma & Discrimination - overview

- Hepatitis is unlike heart disease, diabetes or arthritis, it is not a socially acceptable disease
- Sometimes viewed as a sentence rather than a diagnosis – the social impact may be as great as the physical impact of the virus itself
- Hepatitis C is covered in a veil of secrecy, shame and silence
- Are people with medically acquired hepatitis immune to the stigma?
- Healthcare followed by employment are the most common settings for discrimination

# Impacts of Stigma - Disclosure

**“ I disclosed my hep C status to him (partner) in a pretty blasé fashion, thinking it was no big deal. He was taken aback & would use it against me, refusing to kiss me and saying things like he would go & see my friend because she didn't have hep C. It made me realise that disclosure was something to be managed carefully.”**

Member of the Hepatitis Australia  
Community Reference Group

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## Impact of Stigma - Disclosure

**“I just tell them I’ve got chronic fatigue. I think that’s simpler, it’s very acceptable.”**

Interviewee – The 3D Project

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## Impact of Stigma - Disclosure

“Self imposed prejudice is the worst kind of all. I live a lie. To deny the truth to others becomes harder every day. Sadly, I’m unwilling to take the risk... I feel the impact on both myself & my family would most likely be detrimental, therefore living a lie remains the only course of action... I’ve had counselling, I guess that helps.”

Member of the Hepatitis Australia  
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## Impact of Stigma - Disclosure

Jane agreed to tell her story to a major Australian newspaper. The article itself was very well written, informative and balanced. It told Jane's story in a non-discriminatory way..... However a picture of a giant syringe was superimposed over the photo of Jane and her two sons. It had dire effects...Jane was severely discriminated against and her two sons were harassed and vilified at school... she vowed never to go public with her HCV status again.

Case Study – C Change Enquiry

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## Impact of Stigma – access to appropriate care

“I sought a Gastro some distance from where I lived. Upon meeting him, he virtually accused me of previously using drugs. The appointment was unpleasant and by no means friendly. I explained to the Gastro that his knowledge was poor and attitude unacceptable. I then angrily walked out & refused to pay for his lack of service. To my own detriment, I never went near a Gastro for seven years.”

Member of Hepatitis Australia  
Community Reference Group

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# Impact of Stigma – access to appropriate care

“I’d rather pay out of hours costs to see my GP than attend the local hospital emergency department again.”

Member of Hepatitis Australia Community Reference Group

Delia lives in a rural community and experiences severe migraines. She revealed her HCV status the first time she attended the rural hospital. When seeking pain relief she was told “you don’t know what pain is” and “have you come in for the Saturday night special?”

Case Study – C Change Enquiry

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## Impact of Stigma – family and friends

**“My efforts to be honest with family and friends have cost me dearly. Some friends who I’ve known for years have turned their back on me. My marriage failed as my husband saw me as ‘contaminated’ and would not touch me.”**

**Member of Hepatitis Australia  
Community Reference Group**

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## Impact of Stigma – family and friends

“For a long time I was ill at ease with my hep C status and did tend to isolate myself”.

“Currently I have a strong (but small) band of true friends who stuck by me all the way...I am still wary of new friendships and leave the subject of hep C to be discussed with people I know and trust.”

Member of Hepatitis Australia  
Community Reference Group

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# Impact of Stigma - employment

“ I made a WorkCover claim... during the investigation the company legally obtained my medical records and were going to use my hepatitis C status as a case against my claim... My claim was upheld, but two years later I am still treated with distain and was isolated by my manager and some work colleagues.”

Member of Hepatitis Australia  
Community Reference Group

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# Impact of Stigma - employment

Mary was employed as a chef in a busy restaurant and was experiencing intense fatigue. She was confident she was a valued employee and disclosed her HCV status to her manager so they were aware of her circumstances. She was subsequently sacked, the reason given was because they were quiet over January. A friend later told her other staff were informed she had been sacked because she was a drug addict “For the first time in my life I became very paranoid about my illness and have not disclosed to anyone in my new job”

Case Study – C Change Enquiry

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# Responses

- Legislative Remedies
  - Discrimination and Privacy Legislation
  - Complaint mechanisms
  - Onus is on the individual to enforce their rights

**“Anti-discrimination laws cannot change the hearts of men but can restrain the behaviour of the heartless.”**

Martin Luther King

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# Responses

**“There has been little achieved in reducing the stigma associated with hepatitis C any many people still experience discrimination when disclosing their status both in social settings and while accessing health care and other services.”**

Australian Hepatitis Council  
Needs Assessment 2003

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# Responses – Ottawa Charter Framework

- Building healthy public policy
  - Hepatitis C Strategies - national and state levels
  - Drug policy - health framework or legal framework?
- Creating supportive environments
  - Community awareness & attitudes
  - Health professional attitudes
  - The media

# Response – Ottawa Charter Framework

- Strengthening community action
  - Advocacy
  - Public disclosure
  - Get involved
- Developing Personal Skills
  - Know your rights
  - Learn how to make effective complaints
  - Understand the origins of stigma and challenge it

# Responses – Ottawa Charter Framework

- Re-orientating services
  - Healthcare & treatment in different settings
    - Alcohol and Other Drug Clinics
    - Prisons
    - GP prescribers

## Summary

- Relationship between stigma & social order
- Hepatitis related stigma and discrimination is an epidemic in its own right
- Legislative remedies are essential but insufficient to redress discrimination & stigma
- All efforts to deal with stigma are founded on general community awareness and attitudes

**“never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”**

Margaret Mead

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