Sorry, What?!!

CREATING OUTRAGE AT STIGMA AND DISCRIMINATION IN THE HEALTH SETTING

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Why does it matter?

Because

People

Matter

#StrategyGoals

Section 8:

Addressing Stigma and creating an enabling environment

Addressing Stigma in Hepatitis C Care:
Insights from the NSW Hepatitis C Strategy 2022–2025

Stigma Remains a Core Barrier to Elimination

- Many people living with hepatitis C report **discrimination in healthcare settings**—often tied to assumptions about drug use.
- This stigma **delays or deters engagement** with testing, treatment, and ongoing care.

Despite clinical advances (DAAs, high cure rates), stigma remains one of the **biggest barriers to access and engagement**.

Stigma is Both Personal and Structural

- Disrespectful attitudes, invasive questioning, or assumptions about lifestyle are **personal-level stigma**.
- Lack of flexible care models, inflexible prescribing rules, and exclusionary policies represent **structural stigma**.

These systemic barriers reinforce inequity—even when staff have good intentions.

Assumptive Judgments Based on Diagnosis

"You must be using drugs again if your hep C came back."

Actually, no, I haven't used since I was in my 20's

He thinks I'm still injecting
That reinforces the self stigma and shame I already feel

Labelling and Segregation in Medical Notes – using medical language

Clinical notes like:
“Known IVDU. Hep C positive. Seek security if agitated.”

“So, I see you have Hep C. Just so you know, we don’t prescribe S8’s in this practice.”

I’m here for my birth control script how does he know I have Hep C?!! And what's an S8?

Blaming or Moralising language

"You did this to yourself. We're here to help people who want to help themselves"

Does that mean that I don't DESERVE to get treated?
Maybe hes right – maybe I am not worthy of expensive treatments

Certain Groups Are Disproportionately Affected

- **Aboriginal people**, **people who inject drugs**, and those with a history of incarceration face multiple layers of stigma.
  - Pulling people aside at pharmacy to speak privately – can be seen as treating differently for their HCV status
- This **compounds distrust** and drives health avoidance.
  - Will avoid speaking to medical professional due to feeling judged and discriminated against

Peer Involvement is a Proven Enabler

- Inclusion of peer workers improves trust, normalises testing, and **makes services feel safer**.
- Peer-led models are **key enablers** identified in the strategy.

Peer workers help reduce self-stigma by offering non-judgmental support, sharing lived experience, and showing that recovery and wellness are possible—creating trust, normalising care, and restoring dignity.

Inadequate Integration of Peer Support

While peer support is recognized as a valuable component in addressing stigma, its integration into healthcare services remains inconsistent.

The limited involvement of peer workers:

- Reduces opportunities for individuals with lived or living experience (LLE) to contribute to service design and delivery.
- May perpetuate a clinical environment less attuned to the needs and perspectives of people living with hepatitis C or people who use drugs.

Co-Design & Cultural Safety Matter

- Services must be **designed with and for** people with lived and living experience.
- Cultural safety, trauma-informed practice, and low-threshold access are **not optional extras**—they are core to reducing stigma.

Stigma Must Be Measured & Addressed Ongoing

- The strategy calls for:
  - **Tracking stigma** across service settings
  - Embedding stigma-reduction in workforce development
  - **Embedding change** at policy and practice levels

The Systemic Layer

It’s Not Just Individuals – It’s Systems

- Policies requiring abstinence for treatment eligibility.
- Service designs that are hard to navigate or culturally unsafe.
- Lack of peer support integration.
- Lack of NSP access in prisons
- Signage stating no S8’s or Opiates prescribed here
- BBV disclosure for health workers
- ICE epidemic posters in waiting rooms

THE TRUTH ABOUT
CRYSTAL METH
and Methamphetamine
Ice
Tina
Chrissy
Speed
Tweak
Meth
Glass
drugfreeworld.org

ICE TEARS YOUR LIFE APART.
Don't let ice destroy you

alamy

Emphasis on Abstinence in Treatment Access

...implicitly or explicitly...

- Contradicts clinical guidelines recommending treatment regardless of ongoing drug use.
- Creates barriers for people who inject drugs, a key population affected by hepatitis C.
- Reinforces stigma by linking treatment eligibility to behavioural compliance.

Lack of Needle and Syringe Programs in Prisons

•**Exclusion from NSPs reinforces stigma**: Denying sterile injecting equipment to people in custody implies they are less deserving of evidence-based care — reinforcing harmful stereotypes about people who inject drugs.

•**Health care should not be conditional on public judgment**: When harm reduction is withheld in prisons, a message is sent that health rights are contingent on moral approval — *a clear form of systemic discrimination*.

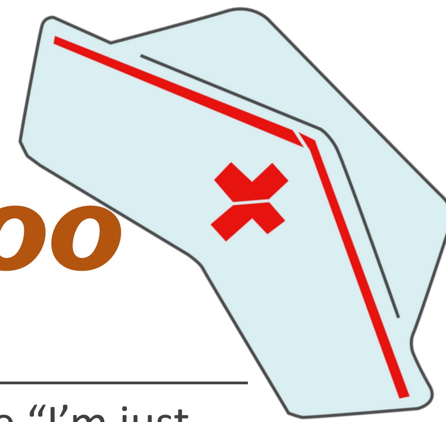
•**Stigma drives risk**: Fear of judgement and punishment leads to covert injecting and equipment sharing, escalating the risk of hepatitis C reinfection and serious injecting injuries.

•**Double punishment**: People in prison are already serving a sentence — denying them tools to protect their health is a second, silent punishment rooted in discrimination.

•**Break the stigma cycle**: Implementing NSPs in prisons acknowledges people who use drugs as full citizens entitled to dignity, safety, and standard health care — *as required under the UN Standard Minimum Rules for the Treatment of Prisoners (Mandela Rules)*.

Thompson AJ & Levy MH. *The potential benefits of a needle and syringe program in Australian prisons. Med J Aust. 2025 Apr 21. doi:10.5694/mja2.52644*

Stigma Wears a Uniform Too



- Looks like professionalism … ***but it's not***… dismissive tone, lack of eye contact, comments like "I'm just following policy" "I wouldn't say it in front of the client" "that's not the way things are done around here"

- Refusal to offer testing or treatment due to assumptions about adherence.

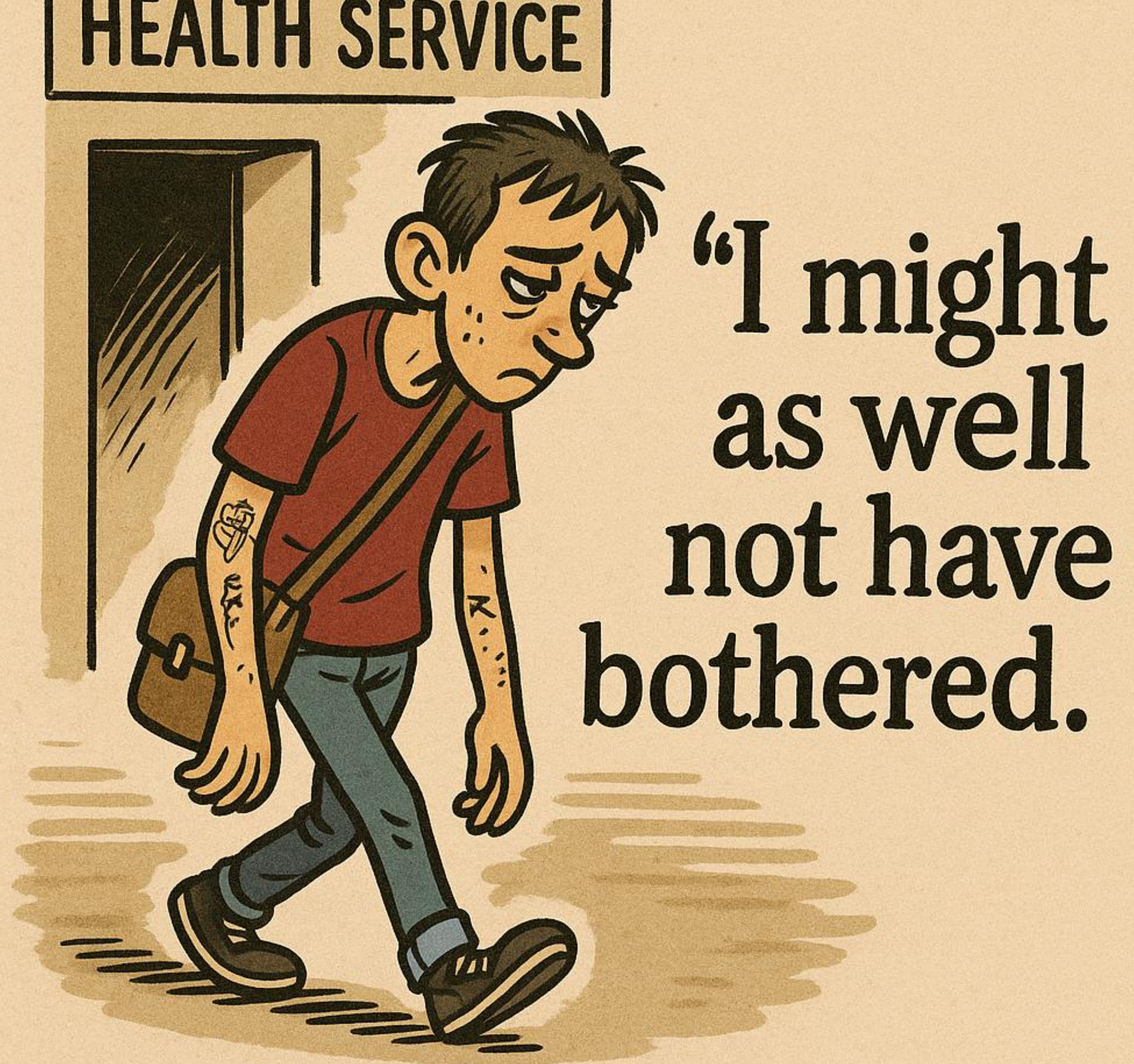
- Speaks in clinical Jargon: Notes in records like "non-compliant" or "drug-seeking" or "HEP C POS", "known IDVU", "difficult historian" = ***bias handed down in scrubs and stethoscopes.***

- Hidden in "Safety" Policies: Extra 'infection control - excessive glove use – or double gloving – or limiting therapeutic touch – driven by fear, misinformation or moral judgement – not evidence.

- Profiling patients according to how they look and their previous medical notes

- It doesn't know it wears the uniform – hiding behind 'good intentions', busy rosters or lack of training. Staff may be unaware their behaviours cause harm … ***but impact matters more than intent!***

Results of Stigma in health care



Anecdotes ‘real-life, real-people’

- Paul needed surgery and whilst she was having a canula inserted by Anesthetist there was blood spilling out – he stated he was HCV positive – and was abused for not telling them earlier!
- Ringo attended ED for acute on chronic cellulitis in legs in pain and doctor prescribing endone for pain but nurse see’s patient is on methadone so withholds endone *“he's already got pain relief in his methadone – don’t want to overdose him”*
- John’s knee surgery was cancelled until he was cleared of HCV
- George was put last on surgical list for scope for variceal screening for cirrhosis as noted patient had cirrhosis on background of HCV

Moving Toward Compassionate Care

To balance safety and patient dignity:

Review Signage Language: Ensure that messages do not generalize or stigmatize but instead communicate a commitment to safe and individualized care.

Educate Staff: Provide training on the importance of language and attitudes in patient interactions.

Engage Patients: Involve individuals with lived experience in developing policies and practices to ensure they are patient-centered.

By fostering an environment of understanding and respect, healthcare services can better support all patients, including those managing hepatitis C or substance use disorders.

What’s Working

Bright Spots and Real Change

Peer-led models reducing fear and increasing uptake.

- **Language audits** in services — changing “dirty/clean” to “positive/negative”.
- **Embedded liver clinics** in sexual health or AOD services — care without judgment.
- **Trauma-informed care** training for all staff.

#LanguageMatters Hepatitis B Hepatitis C

Reducing stigma by using preferred language

In your verbal or written communications relating to **viral hepatitis generally**:

Try this:	Instead of this:	Why?
✔ Person living with hepatitis B/C ✔ Person who has hepatitis B/C	✘ Carrier, infected, diseased, contaminated	These terms are considered offensive and encourage stigma.
	✘ Victim, sufferer	While viral hepatitis can have a significant impact on a person, these terms are disempowering and implies they have no control over their lives.
✔ Contract, acquire*... ✔ Exposed to... ✔ Diagnosed with... ...hepatitis B/C	✘ Catch it ✘ Became infected with	These terms suggest something that is contagious and should be avoided or feared. **Avoid asking how a person acquired viral hepatitis as it can be stigmatising and irrelevant.*
✔ Transmit/transmission	✘ Spread ✘ Give/gave	Transmission is the correct term when referring to the virus passing from one person to another.
✔ Chooses to/chooses not to	✘ Compliant/non-compliant ✘ Adherent/non-adherent	These terms characterise the individual as cooperative or uncooperative, and regard the person as a passive and submissive recipient of care.
✔ Positive/negative blood screen ✔ Blood containing hepatitis B/C	✘ Dirty/clean blood ✘ Tainted blood	Referring to someone who tests negative as clean suggests that people who test positive are dirty.

In your verbal or written communications relating to **hepatitis B**:

Try this:	Instead of this:	Why?
✔ Perinatal transmission ✔ Vertical transmission ✔ Child/infant exposed to hepatitis B	✘ Mother-to-child transmission	Mother-to-child transmission can be perceived to have an accusatory tone that blames the mother for transmitting the virus to her child. This simple change in term turns the focus away from mothers being the 'vectors' of transmission.
✔ Bodily fluids responsible for transmission of hepatitis B (e.g blood, semen, or vaginal fluid)	✘ Bodily fluids	Be specific - hepatitis B cannot be spread through saliva, breast milk, or sweat.
✔ Sexual contact, Sexual transmission	✘ Spread ✘ Give/gave	Sexual contact/transmission are the correct terms when referring to the virus passing from one person to another.

In your verbal or written communications relating to **hepatitis C**:

Try this:	Instead of this:	Why?
✔ Contract, acquire ... ✔ Exposed to... ✔ Diagnosed with... ...hepatitis C	✘ Reinfected	When speaking to someone who has cured hepatitis C and acquires it again, using the term 'reinfected' may be incorrectly perceived by the person that their initial treatment was a failure and a waste.
✔ Sterile/contaminated... ✔ Used/unused... ✔ New/old... ...needle/injecting equipment	✘ Clean/dirty needle ✘ Dirties	The comparison between 'clean' and 'dirty' separates into two groups: 'good' and 'bad'.
✔ Person who uses drugs/alcohol ✔ Person who injects drugs ✔ Person who is recovering from... ✔ Person who is no longer using...	✘ Junkie, druggie, addict, alcoholic ✘ Former addict, recovered, clean	Using clear and non-judgemental language towards substance use minimizes stigma and stereotypes.

Language matters

Version 2

Language is powerful—especially when discussing alcohol and other drugs and the people who have or do use them. While there isn't a one-size-fits-all approach, this resource provides guidelines for using language in a person-centred way. It's important to recognise that language will vary depending on personal, service delivery, and systemic contexts. What matters most is that the language we use reduces stigma and demonstrates respect.

When working with people who have or do use alcohol and other drugs...

Try this	Instead of this
substance use, non-prescribed use	abuse, misuse, problem use, non-compliant use
person who uses/injects drugs	drug user/abuser
person with a dependence on...	junkie, druggie, alcoholic, **addict**
person experiencing drug dependence	suffering from addiction, has a drug habit
person who has stopped using drugs	**clean**, **sober**, drug-free
person with lived experience of drug dependence	**ex-addict**, former addict, used to be a...
person disagrees	lacks insight, in denial, resistant, unmotivated
treatment has not been suitable	not engaged, non-compliant, chooses not to
person's needs are not being met	drug seeking, manipulative, splitting
currently using drugs	using again, fallen off the wagon, had a setback
no longer using drugs	**stayed clean**, **maintained recovery**
drug detected/drug not detected	dirty/clean urine
used/unused syringe	dirty/clean needle
pharmacotherapy is treatment	replacing one drug for another

In certain contexts, such as 12-step programs, people may use identity-first language and refer to themselves using terms like '**addict**', '**sober**', '**clean**', and '**in recovery**'. The choice to use these terms is personal and reflects individual experiences. This guide recognises the importance of embracing and using these terms in a way that feels right for the person. However, it is not recommended for AOD workers to use these terms when describing another person's experiences.

Adapted from Language Matters from the National Council for Behavioural Health, United States (2015) and Matua Raki, New Zealand (2016).

Tips to help you reduce stigma

- Person-first Language is more than just the words we use – body language, tone of voice, and eye contact are all important in conveying respect and dignity to a person

- Use language that conveys optimism and positivity

- Use language that is accessible: free from jargon, technical words, and confusing data

- **Call out stigma:** if someone uses stigmatising language, address it by explaining why it's a problem and suggest a preferred term

Be aware of the context of language:

- Some terms may be appropriately used by people identifying within a certain group but would be stigmatising when used by people outside the group – i.e alcoholic or addict

- Sometimes using and enabling informal, inappropriate, or slang words in conversation is important in establishing rapport. However, it is also important to keep in mind that appropriate language used with one person may be offensive when used with others.

BE THE CHANGE Your colleagues are always watching and listening to you – acknowledge mistakes

Stigma Is Not a One-Off Topic

Stigma must be addressed **at every level**: clinical, structural, and cultural.

- Token conversations don’t create change — ongoing, embedded focus does.
- Patients deserve a health system that’s safe and welcoming, not selective and punitive.
- Pick your battles – make them count – be brave and accountable

One-off sessions or policies are **not enough**
—it requires sustained, embedded action

Final Message

“People are more than their diagnosis or their history. They are their hopes and aspirations too. Our job is to meet them there free from our own value judgements.”

Lets Talk about Hep C: Liver Well short video about stigma

https://youtu.be/pB4a8LLFjP0?list=PL1Vvv0Ay33YQCcFZ34TpwyzgnOI_uwf1v

As a CNC, I can give people medication, education, referrals — but without dignity and trust, it goes nowhere. Reducing stigma is not extra work — it *is* the work

85% of people living with

viral hepatitis reported

experiencing stigma and discrimination

vh2025

KEY ACTIONS & TAKEAWAYS

- Key Action 1: Stigma and Discrimination reduction in healthcare is Everybody's Business
- Key Action 2: This isn't just about attitudes—**it's about systems, models of care, and shared accountability.**

  Key Action 3: Eliminating hepatitis C depends on **removing the fear and shame** from health settings and placing the person before the diagnosis.

Language matters – body language matters – policy matters – humanity matters