

# HEP C U Later

*Stigma Toolkit*

This toolkit has been developed with the intention of aiding anyone who is working with people affected by hepatitis, to gain a better understanding of how widespread stigma is in the hepatitis C arena and to provide some resources to combat stigma.

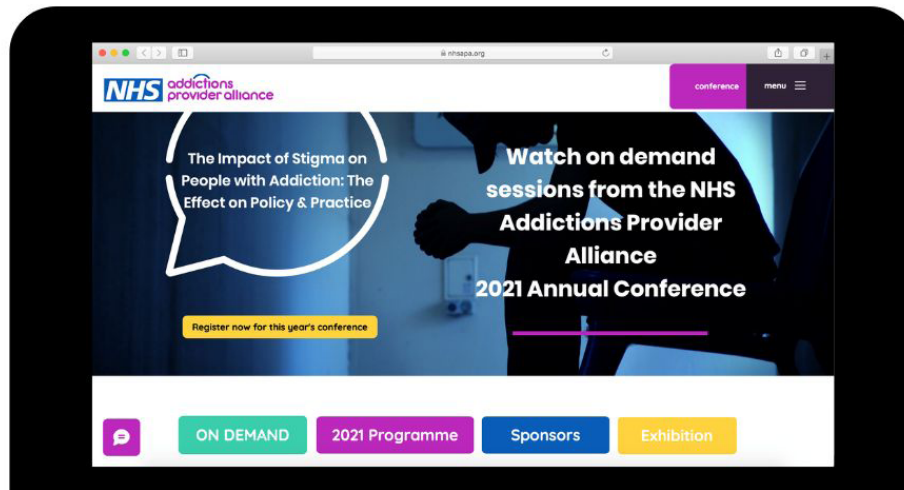
Historically, people affected by the hepatitis C virus have been left feeling marginalised and ultimately isolated because of their viral status, this is due the stigma attached to having been exposed to the hepatitis C virus.

### *Why is hepatitis C stigmatised?*

This is commonly due to and irrational fear of infection, lack of staff training and understanding or the culture within a service where people may be judged or discriminated against due to characteristics or having a lifestyle that is deemed undesirable.

### *Where is a person most likely to experience stigma?*

Click on the link below to view this video from the NHS Addictions Provider Alliance from 2021 conference - [Hep C U Later: Annual Conference 2021 | NHS APA](#)



*"I was given my Hep C + results in a van on the way to a meeting while I was in rehab, I felt terrible in front of my peers."*

*"I was in A&E in London, I told the Dr I had Hep C in the past, straight away I felt judged, The Dr said he needed bloods but he wasn't willing to take them due to my Hep C status, 2 nurses came to take my blood in gowns, masks and visors, I felt dirty even though I completed treatment 12 months ago."*

People affected by hepatitis C experience stigma from many areas, often in healthcare settings where they may experience negative attitudes from staff and may be treated differently due to their Hep C status.

This attitude from staff will often be due to lack of knowledge of how blood borne viruses (BBVs) are transmitted, what the results mean or possibly due to the lifestyle of the service user group who present at their service. People affected by hepatitis C are often people who have used drugs via the intravenous route or are people who currently use drugs, this may carry a stigma of its own.

Discriminatory treatment in healthcare settings where people are made to feel less worthy of treatment than others is a major factor for people with hepatitis C being reluctant to engage with treatment.

Other places where people may face stigma are in custodial settings such as police stations and prison estates. In these settings it is not uncommon for derogatory and stigma heavy language to be used by staff toward hepatitis C affected people.

Peer reporting also informs us that often the persons own peer group and sometimes their family treat them differently once their HCV status is discovered. This again can lead to feelings of rejection and will lead to isolation for the person affected.




*"When I found out I had Hep C I didn't want anyone to know especially my mates, I had seen how friends had been excluded in the past once people found out they were Hep C positive."*

### *Top stigma busting tips*

- Educate yourself about substance use and associated issues.
- Educate your peers.
- Be aware of the language you use and challenge yourself.
- Focus on the positive, celebrate the successes.
- Be inclusive – co-production will help services to challenge stigma.

## *How do we reduce the impact of stigma?*

- Inform people that they are not required to disclose their hepatitis C status except in special circumstances. At the point of a positive test, disclosure support and advice should be given regarding when it may or not be appropriate. While there is no legal requirement to disclose your viral hepatitis status it is recommended that you inform your GP and treatment provider.
- Make testing and treatment easy to access in a non-judgemental setting. Always consider how rigid pathways and appointments may deter a person from attending for treatment.
- Think about how much support is available for people, link them to support groups if available. Visibility is a great way to combat stigma and having people with lived experience of hepatitis supporting people in the service will have a positive impact.
- Peers from the Hepatitis C Trust can support people through all parts of the hepatitis C pathway. Direct service users to their website: [Home | Hepatitis C Trust \(hepctrust.org.uk\)](https://www.hepctrust.org.uk) and free confidential helpline: **020 7089 6221**.
- Look for ways to audit your services against **national hepatitis C standards** and aim for improvement. 
- Education, Education, Education! We recommend the free online hepatitis C training provided by INHSU for professionals: [Hepatitis C online learning modules - INHSU](#).
- Take time to consider the language you use! Remember a person is not defined by their drug use or their viral status, so we refer to the person first. We move away from outdated stigma heavy language such as “drug user”, “IV user”, “substance miss-use”, “substance misuser” and the term “clean”. Please see this useful document from the [Scottish Drugs Forum \(2020\): Moving-Beyond-People-First-Language.pdf \(sdf.org.uk\)](#).
- The same would go for a person’s viral status, it does not define them. We must avoid statements such as “He is a hepatitis C carrier”. A much kinder term would be “a person living with hepatitis C”.
- Start to systematically address any out-dated or stigmatising language used in internal organisational policies, training materials and resources within your service.
- Appropriately challenge the use of stigma heavy language amongst our peers, colleagues and our service users.
- Keep hepatitis C at the core of what we do as drug and alcohol treatment providers. It is essential that we retain a harm reduction focus. It saves lives and can lead to better health and recovery outcomes in later years.

## *Questions to ask in your service*

- Do you discuss reinfection risks with people who have cleared the hepatitis C virus?
- Link to the Hepatitis C Trust's Reframing Reinfections document: [Reframing Reinfection.pdf \(hepctrust.org.uk\)](https://www.hepctrust.org.uk).
- Do you champion de-stigmatising language and are you comfortable challenging both colleagues and service users?
- Do you have BBV testing kits to hand in needle and syringe programme (NSP) rooms so you can opportunistically test people?
- How flexible is your service when it comes to testing for BBVs?
- Does your service offer flexible or late opening appointment slots?
- Do you offer drop in appointment slots?
- How do you celebrate successes and an individual and service level?
- How do you raise awareness of hepatitis C in other areas of healthcare?
- What types of materials do people have to access information about hep C? Do you have leaflets, videos, FAQs?
- How can you actively dispel myths?
- How can you communicate the risks of hepatitis C?

## *How do we keep hepatitis C at the core of what we do in drug and alcohol treatment services?*

- Through services continually raising awareness amongst staff through regular Hepatitis C/BBV training.
- By changing the job descriptions to include knowledge around prevention, harm reduction and safer injecting knowledge and to ensure BBV screening is a part of each role.
- We can keep hepatitis C elimination and sustainability on our services agenda by having a specific slot at teams meetings to discuss hepatitis, testing, new infections and referrals to treatment services.
- Continue the discussion in supervision sessions with staff members by adding it as an agenda item on the supervision template.
- Celebrate progress and keep staff updated.

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