

# DDN

## HEPATITIS C AND HEALTH

Hepatitis C represents a major public health challenge but patients now have the opportunity to be completely free of the virus through a short course of treatment. This guide will help you to recognise stages and symptoms and offer people the targeted help they need.

# HEPATITIS C

## BREAKING THE SILENCE

### FINDING THOSE IN NEED OF HELP

*Although recent medical advances have made hepatitis C treatment much more effective – and far less unpleasant – the condition still represents a major public health challenge, with around half of the UK’s injecting drug users thought to be infected*

**K**nown as ‘the silent killer’ because a person can live with it for years without developing symptoms, hepatitis C is a blood-borne virus that predominantly affects the liver. According to Public Health England’s (PHE) most recent update, around 200,000 people in the UK are chronically infected with the hepatitis C virus (HCV), ‘the majority of whom are from marginalised and underserved groups in society.’<sup>1</sup> It is also estimated that around half of the people living with the virus are unaware that they have it.

According to the World Health Organization (WHO), viral hepatitis is now ‘a major public health problem’<sup>3</sup>, with the number of people living with hepatitis C worldwide topping 71m.<sup>3</sup> The most common route of infection is through small quantities of blood, which can happen via unsafe medical practices, transfusion of unscreened blood, sharing items such as razors or toothbrushes, or sharing needles or other drug-injecting equipment. There is also a risk of infection via straws or banknotes used to snort drugs such as cocaine, MDMA or amphetamines.

PHE states that injecting drug use ‘continues to be the biggest risk factor for HCV infection’, and in the UK around half of people who inject, or who have previously injected, drugs will be infected with the virus – a figure that has ‘remained mostly unchanged over the past ten years’.

Again, approximately half of these people will not know they are infected and according to the latest United Nations Office on Drugs and Crime (UNODC) *World drug report*, more than half of the estimated 10.6m injecting drug users globally are now living with the virus.<sup>4</sup>

Hepatitis C causes inflammation and damage to the liver and, if left untreated, can lead to cirrhosis (scarring) and life-threatening complications like liver cancer.<sup>5</sup> However, as hepatitis C often doesn’t have any noticeable symptoms until the liver has been significantly damaged, in many cases people can be living with the infection without realising it.<sup>6</sup>

#### TYPES OF HEPATITIS C

Like the common cold, ‘flu and measles, hepatitis C is an RNA (ribonucleic acid) – as opposed to a DNA – virus, which means that it is much harder for the immune system to locate and destroy.

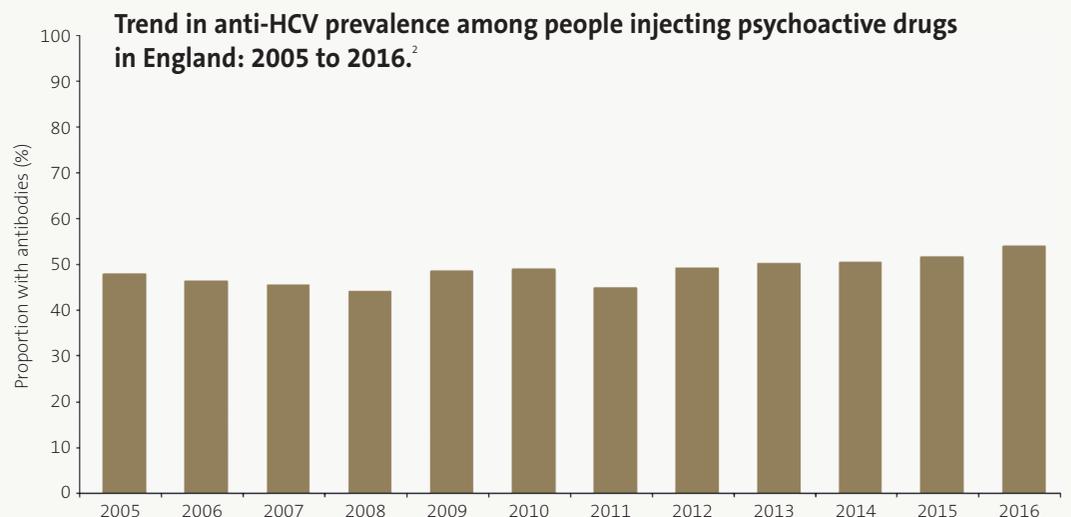
There are six major variations of HCV, known as genotypes, with different genotypes being more predominant in certain parts of the world and each having minor variations known as ‘subtypes’. Genotypes 1-3 are found worldwide, with 1a and 1b predominating in Europe and North America.<sup>7</sup>

Although it is not known if the genotype affects the progression of the disease, it can have an influence on how someone responds to treatment.

#### STAGES AND SYMPTOMS OF HEPATITIS C

Hepatitis C often displays no noticeable symptoms until the damage to the liver is significant, and the symptoms that people do experience can often be mistaken for something else. These include ‘flu-like symptoms’<sup>6</sup> such as muscle aches and high temperatures, as well as fatigue, nausea, slight fever, loss of appetite and abdominal pain.

The first stage of HCV infection is the acute stage, which refers to the first six months after initial infection. During this stage, the virus will not necessarily manifest any symptoms and in around 20 per cent of cases the body will naturally clear the virus itself without sustaining any long-term damage. The remaining 80 per cent of people, however, will go on to the second stage, which is



Source PHE – Hepatitis C in England 2018 report

chronic (*ie* long-term) infection.<sup>6</sup>

Not all chronic infections develop the same way, with some people experiencing symptoms almost immediately and others displaying none for a decade or longer. The liver damage caused by the virus begins with fibrosis – the build-up of scar tissue – which can then go on to become cirrhosis, where the scarring has built up in the organ’s tissues to the extent that it impairs its functioning.

Liver damage can lead to jaundice, the symptoms of which are a yellowing of the skin and eyes, and other people with chronic HCV will experience difficulty concentrating, poor memory and chronic fatigue, as well as joint pain – particularly in the hands and wrists – and sharp pains over the liver. People can also experience irritable bowel and bladder symptoms, although the Hepatitis C Trust points out that it is ‘still not clear whether these symptoms are related to hepatitis C infection or not’, as they could be caused – or at least worsened – by the stress associated with living with the infection.

In severe cases, hepatitis C can also lead to liver cancer. The exact links between HCV and liver cancer remain unclear, but it is thought that the virus creates the conditions for cancer to develop by causing a high turnover of liver cells, as well as possibly interfering with the mechanism that repairs damage to cell DNA.

## WHAT’S BEING DONE?

### MAJOR STRATEGY DEVELOPMENTS

Despite the huge public health threat posed by HCV, as well as the economic impact, the condition was until recently, in the words of the Hepatitis C Trust, ‘grossly under-prioritised’ by health services. That is no longer the case, however, and the most significant development in recent years is NHS England’s strategy to eliminate the virus by 2025, five years earlier than the target set by WHO.<sup>8</sup>

Announced at the start of 2018, the strategy could make England the ‘first country in the world’ to completely eliminate the virus, the NHS has said.<sup>9</sup> Working in partnership with the pharmaceutical industry, the strategy aims to identify more people living with the virus and provide best value in treatment. Deals already reached with the industry mean that England is one of the few European countries where the number of people receiving oral treatments is

## A TOXIC MIX: HOW ALCOHOL AND DRUGS INTERACT WITH HCV

**ALCOHOL** – along with recreational drugs – is processed by, and is toxic to, the liver, and in line with NHS information, The Hepatitis C Trust advises that ‘without doubt, the most effective measure anyone infected with hepatitis C can take to slow down disease progression is to avoid drinking alcohol’.

The severity of liver disease in people with HCV is much greater among those who drink – ‘this has been seen in rates of fibrosis, the development of cirrhosis, the incidence of liver cancer and finally in survival rates’, says the Trust, and most doctors caring for people with HCV will urge them to stop drinking completely. While heavy drinking can clearly do its own, independent damage to the liver – as well as exacerbating the damage caused by the virus – it is also thought that alcohol consumption can increase the viral load of someone with HCV and contribute to a poorer response to antiviral treatment.

As well as putting stress on the liver themselves, many illicit drugs will contain impurities that can also be toxic, and drugs that are injected are likely to put a greater strain on the liver as they will not have been filtered via the stomach.

Those infected are also advised to exercise and eat a healthy diet.

## WHO Regional Office for Europe interim 2020 targets<sup>10</sup>

50% of people living with chronic HCV infections diagnosed and aware of their condition

75% treatment coverage of people diagnosed with HCV infections who are eligible for treatment

75% of those at late stage of viral hepatitis-related liver disease (cirrhosis or liver cancer) diagnosed

“...the most significant development in recent years is NHS England’s strategy to eliminate the virus by 2025

increasing year-on-year<sup>9</sup> and this is already thought to have led to an 11 per cent fall in the number of deaths.<sup>1</sup>

Operational delivery networks (ODNs) have also been established across England to drive improvements in treatment and increase access, and a National Hepatitis C patient registry has been established to record and monitor diagnosis rates, treatment uptake and outcomes. PHE has also set up a National Strategic Group on Viral Hepatitis (NSGVH), and its *Hepatitis C in England: 2018 report* serves as a useful overview of the situation, setting out recommendations for improving prevention and harm reduction, boosting testing and diagnosis rates, and increasing access to treatment.<sup>1</sup>

The challenge remains substantial, however. A 2018 report from the All Party Parliamentary Group (APPG) on Liver Health concluded that ‘significantly greater’ numbers of people will need to be tested, diagnosed and treated in order to eliminate the virus.<sup>10</sup> Awareness levels among the public remain low, it found, while budget pressures are also having a negative impact on local testing and prevention initiatives.<sup>10</sup>

The APPG report is calling for treatment to be made ‘universally accessible’ and available in community settings. It also wants to see the widespread introduction of ‘opt-out’ testing in drug treatment services. Contributors to the report ‘overwhelmingly agreed’ that, as things stand, England is not on track to achieve either the NHS or WHO elimination targets, and it calls for urgent agreement on a ‘national elimination strategy’ for the virus.

# HEPATITIS C



## TESTING TIMES

### IDENTIFYING POTENTIAL PROBLEMS

*It's clearly vital that those at risk of HCV infection have access to testing and, if necessary, treatment. However stigma, chaotic lifestyles and patchy service provision can still be significant barriers*

#### LONG-TERM HEALTH ISSUES FACING PEOPLE WITH UNTREATED HCV

One in five people who become infected with hepatitis C will naturally clear the virus themselves, but for the other 80 per cent it's vital to seek treatment.

If left untreated, hepatitis C can sometimes cause scarring of the liver (cirrhosis), where the scarring has taken place to such an extent that it has altered the structure of the liver, rendering it nodular and lumpy and compromising the free flowing of blood in the organ.

Chronic infection with hepatitis C can also lead to cirrhosis, although the time this can take will vary from person to person. Between 20 and 30 per cent of people with a chronic hepatitis C infection will develop cirrhosis within 20 years, although for other people it can take much longer.<sup>2</sup>

There are two stages of cirrhosis – 'compensated', when the liver is still able to function and cope with the ongoing damage – and 'decompensated', when it ceases being able to cope or function properly.<sup>2</sup> Without treatment compensated cirrhosis will almost certainly lead to decompensated cirrhosis although, again, the rate at which this happens will vary.

Among the health issues people with compensated cirrhosis will face are tiredness, weakness, loss of appetite, nausea and vomiting. Once the cirrhosis has progressed to the decompensated stage and the liver is no longer able to function properly, people will face serious health problems that can require hospital treatment, such as jaundice, ascites (accumulation of fluid in the abdomen), internal bleeding and hepatic encephalopathy, when the liver's inability to filter

toxins leads to them building up in the brain. People can also go on to develop liver cancer, for which the five-year survival rates in England post-diagnosis are around 12 per cent.<sup>3</sup>

While it's important for people with hepatitis C to stop drinking, eat well and adopt a healthy lifestyle, those with entrenched drug problems will often be in marginalised communities and live chaotic lives. Many will have little contact with primary care or specialist drug services, which means treatment – or even testing – for HCV can be difficult to carry out.

#### PROACTIVE SUPPORT

A key element of NHS England's hepatitis C strategy is to identify more people living with the virus, and one effective means of achieving this is through proactive outreach and testing in the community. The APPG on Liver Health's report called for the introduction of 'opt-out' testing for hepatitis C in drug treatment services (which means that services users are routinely tested unless they explicitly refuse consent), while pilot projects offering testing in pharmacies have also shown impressive results.<sup>4</sup>

A 2018 report from the London Joint Working Group (LJWG) on Substance Use on the results of a four-month pilot programme at nine pharmacies with needle exchange facilities found that more than 50 per cent of those tested had HCV antibodies in their blood.<sup>4</sup> Many of those taking part in the scheme would have been unlikely to engage with a GP service to request testing, and 84 per cent of participants also reported that they would be happy to receive treatment for the virus at their local pharmacy.<sup>4</sup>

#### Key harm reduction messages that professionals can give to clients with HCV

Try to avoid illicit substances as they are toxic to the liver, but if you are going to snort drugs do not share straws or banknotes

Take regular exercise and try to maintain a positive mental attitude

Do not share crack pipes

Testing for hepatitis C involves two tests – an antibody test that establishes whether a person has ever been exposed to the hepatitis C virus, and a polymerase chain reaction (PCR) test to establish if the virus is still active and requires treatment.<sup>3</sup> Both tests are usually done from the same blood sample, however, and further testing can then be carried out to determine the extent of any liver damage, and – in the case of advanced cirrhosis – to test for liver cancer.

One significant barrier to treatment identified by the LJWG report was lack of awareness of recent advances in treatment, with almost 60 per cent of participants unaware that HCV could now be treated with oral tablets that are generally well tolerated.<sup>4</sup> In the past, long-term treatment with interferon was the norm, the side effects of which could include fatigue, fever, nausea and insomnia.<sup>6</sup>

Along with people presenting late through absence of symptoms or fear of the treatment itself, another key reason why people are reluctant to come forward for testing is the stigma that still surrounds drug use.<sup>7</sup> Some primary care professionals can still adopt a judgemental approach towards people who use drugs, and many people will be concerned about being stigmatised further in the case of an HCV diagnosis. However, GP surgeries, sexual health clinics, genitourinary medicine (GUM) clinics and drug treatment services all now offer testing for hepatitis C.

“...almost 60 per cent of participants [were] unaware that HCV could now be treated with oral tablets that are generally well tolerated”



## FOR WIDER HEALTH PROFESSIONALS DISCUSSING DRUG USE WITHOUT STIGMA

**NEGATIVE ATTITUDES** towards people who use drugs remain common in the media and in society as a whole. The sense of stigma attached to words like ‘junkie’ and ‘addict’ – and the assumptions that people can often make about people who use drugs – can have a profound impact on mental health and discourage people from seeking the help they need.

A 2017 report from the Global Commission on Drug Policy found that stigmatising language and attitudes in the media were increasing discrimination against drug users, and helping to create an image of them as ‘sub-human, non-citizens, scapegoats for wider societal problems’ and undeserving of the right to health.<sup>7</sup> The report adds that no medical condition is ‘more stigmatised’ than drug use, with former head of the Global Fund to Fight AIDS, Tuberculosis and Malaria, Michel Kazatchkine, stating that, ‘Language matters – research has shown that even trained mental health practitioners treat differently cases where patients are referred to as “substance abusers” than those alluded to as “people with a substance use problem”’.

People who have been infected with HCV via injecting drug use can often experience the ‘double stigma’ associated with their diagnosis and their drug use. Nearly two thirds of respondents in a survey of drug treatment staff by the *I’m Worth...* hepatitis C awareness campaign<sup>8</sup>, in collaboration with DDN, felt that the stigma associated with both addiction and hepatitis C meant that people were ‘often reluctant to engage with care’.

The contact with health services that comes with testing and treatment for HCV, however, can also act as a catalyst for seeking specialist support from drug treatment services – as well as help for other health issues – so all of this means that it is vital that health professionals discuss their clients’ drug use in a non-judgemental way.

Professionals should try to make sure that they interact with clients in an open and approachable manner, and work to build a professional relationship with them that is built on trust, empathy and respect. As part of this it’s essential that they avoid using terms like ‘addict’, ‘drug abuse/drug abuser’, or ‘clean’ to denote someone who is no longer using drugs.

The chaotic lifestyles experienced by many people who use drugs also means that, even if they are tested and diagnosed, they may still fail to engage with treatment, so professionals will need to adopt a positive, supportive and encouraging attitude, and provide service users with all the information they need on the next steps and available treatment options.

If you do drink alcohol, always alternate your drinks with glasses of water

Abstain from alcohol completely if possible

Eat a healthy diet with lots of fresh fruit and vegetables, and cut down on your consumption of fat and salt

Never share needles or any other injecting equipment such as syringes, spoons, swabs or filters

# HEPATITIS C

# TREATMENT OPTIONS

## NAVIGATING A WAY FORWARD

*Recent medical advances have seen significant changes to the treatment landscape, and whereas previously treatment had been lengthy, unpleasant and not always effective, oral treatments can now take as little as eight to 16 weeks, are generally well tolerated and have very high success rates<sup>1</sup>*

**T**he London Joint Working Group on Substance Use's report into pilot testing in pharmacies found that almost 60 per cent of participants were unaware of oral treatments and still believed that a positive diagnosis meant a lengthy course of treatment involving interferon.<sup>2</sup> The anecdotal reputation of interferon is so poor that it could discourage people from coming forward for testing and treatment, so clearly more needs to be done to get the message across that times – and options – have changed.

Reaching out to the undiagnosed is vital as many ODNs could otherwise risk running out of people to treat. Raising awareness of the currently available treatments could also help to tackle stigma – as Hepatitis C Trust CEO Rachel Halford told *DDN* in October 2017, 'if we can raise awareness around today's treatments then it all becomes more common. So hopefully you'll just go to your GP, get your prescription and off you go, as with something like antibiotics. That ease of access in itself would de-stigmatise it.'

“Raising awareness of the currently available treatments could also help to tackle stigma

The standard of care for hepatitis C treatment has changed within the last five years, with the availability of direct-acting antivirals. Choice and duration of treatment will depend on the genotype, the severity of any liver damage, whether someone has had HCV treatment before and what other medications they may be taking.<sup>3</sup> Availability may also vary according to where someone lives.

In the case of people with decompensated cirrhosis – when the liver has stopped functioning properly – a liver transplant may be necessary to keep them alive. Hepatitis C is the second-most common cause of liver transplants in the UK, after alcoholic liver disease, with up to 600 people on the waiting list at any one time. Although a complicated operation, most people will live for more than ten years afterwards, with many living 20 years or more.<sup>4</sup>

## TAILORING TREATMENT

### Case study 1

***Offering tailored support in a community setting is often crucial to successful HCV treatment***

Addaction is a leading UK drug, alcohol and mental health charity which works with people across Scotland and England to help them make positive behavioural changes. An important part of this work is to increase understanding of hepatitis C and its risks, as well as improving access to testing and treatment – which is vital to prevent people from unknowingly passing on their infection, and to decreasing deaths.

“Improving access to testing and treatment is vital

The organisation treated a couple in their 30s, who both had HCV genotype 1. Michael and Julie (*names have been changed*) were unable to attend hospital appointments due to their rural, isolated location in North Cornwall. They had had HCV for many years and didn't feel they were mentally stable enough to be treated with interferon. While waiting for alternative treatment options to become available, they moved house and their drinking increased.

Michael and Julie chose to be treated directly after an alcohol detox, which they felt would give them an incentive to stay abstinent. Addaction coordinated the couple's detoxes, and despite the emotional challenges of being apart, they both completed successfully.

Addaction's BBV nurse, who has an honorary prescribing contract with the local hospital, then provided the HCV treatment at home. Michael and Julie were able to support each other and have both achieved a sustained virological response.



## ‘We need to engage at all levels to reach this population’

**THERE ARE TENS OF THOUSANDS OF PEOPLE** in the UK who have already been diagnosed but have not yet been treated.

Some of these people will know that they have the virus, but are not engaging with treatment services for whatever reason. Others might have been tested at some point in their past and be unaware of their status.

To reach the first group, we need to understand that hepatitis C is a disease of vulnerable people

who might lead chaotic lifestyles, which means testing and treatment must be available where vulnerable people access care – not only GP surgeries but homeless shelters, needle exchanges, sexual health clinics, pharmacies and amongst the prison population.

To reach the second group, we need them to re-engage with services entirely. We have highly effective medicines that can cure the virus and we need to get the word out there that it can be

cured. Raising awareness and fighting stigma is critical to the success of this ambition.

If people don't know they are at risk, they won't get tested or treated, risking serious health problems in the future. We have a moral obligation to do everything we can to reach this population of hepatitis C patients.

*Prof Ashley Brown, vice chair of the Hepatitis C Coalition and hepatitis C lead for North West London*

### REMOVING BARRIERS

#### Case study 2

##### ***Awareness initiatives can counter the fear of outdated treatment methods***

Change Grow Live (CGL)'s national hepatitis C strategy aims to support all individuals who use or have used drugs intravenously to have regular access to finger-prick testing for the virus.

At the same time, preventative harm reduction advice is shared with at-risk populations by outreach teams working directly with people using drugs in high prevalence areas, on the streets or in hostel accommodation. For those who are aware that they have hepatitis C, CGL staff recognise that adverse reactions to previous treatment methods can be a barrier to re-engaging with treatment.

“ Previously disaffected cohorts are much more willing to re-engage with treatment

In the recent past, some individuals opted to stop treatment prematurely rather than endure the painful side-effects of the medication. Even for those who completed treatment, the cure rate was variable.

At the beginning of July 2018, CGL promoted hepatitis C awareness across their treatment centres, explaining the importance of testing and the range of antiviral treatments now available.

Previously disaffected cohorts are much more willing to re-engage with treatment in the knowledge that the standard of care is different now.

Alesha in Northampton had previously been treated unsuccessfully with interferon injections, and had experienced multiple, serious side effects as a result. With the support of CGL, she began treatment with direct acting anti-viral tablets, and is now clear of hepatitis C.

### HIDDEN HARM

#### Case study 3

##### ***People often have no idea that they have hepatitis C when symptoms merge with a chaotic lifestyle***

Originally from South Africa, Billy has been living in London since 1988. While she was on a flight at the age of 18 she took her first sleeping tablet, and from then until 2010 she felt a sense of belonging through using various pills. Over the years Billy developed a long history of recreational and medicinal drug and alcohol misuse, including heroin, and battled with numerous mental health problems.

Almost ten years ago, and while still using drugs, she went to the Red Cross in Oxford Street to give blood. She had no symptoms of hepatitis C and was not expecting the positive result. When she had the news, doctors referred her to take part in the first trial for interferon treatment at St Mary's Hospital in London.

Billy recalls that at that stage in her life, everything was rather chaotic and it would have been difficult for her to detect if she had been experiencing any of the symptoms such as tiredness. She was unsure of how she contracted it, whether it was due to intravenous heroin-taking or from other blood transfusions in the UK and SA.

The treatment was painful and uncomfortable but it worked and cured Billy from hepatitis C. Despite periods of sobriety, it was only in 2010 with the support of DWP – now Turning Point Drug and Alcohol Wellbeing Service (DAWS) – that her life changed permanently for the better. She joined a day programme and became involved with the service-user involvement groups, and now runs a jewellery designing and making course at drug and alcohol services at Turning Point and CGL. She has recently completed her peer-mentor training and hopes to use her recovery journey to support others.

Billy has also received training from the Hepatitis C Trust and hopes to become involved soon in testing via dry blood spots at Turning Point services.

# HEPATITIS C

“Recent advances have changed the landscape... Oral treatments can now take as little as eight to 16 weeks, are generally well tolerated, and have very high success rates’

Anyone concerned about whether or not they may have been, or are currently, at risk of contracting hepatitis C, should seek advice from a healthcare professional. GP surgeries, sexual health clinics, genitourinary medicine (GUM) clinics and drug treatment services all now offer testing for hepatitis C.

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#### Change, Grow, Live

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#### Turning Point

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#### Adfam (family support)

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#### SMMGP

(supports good treatment practice)

[www.smmgp.org.uk](http://www.smmgp.org.uk)

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