

**Information and advice
for the families of people
living with**

Hepatitis C

September 2018



Adfam

Families, drugs and alcohol

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Introduction

Adfam is the national organisation that works to improve life for families affected by drugs and alcohol. This resource provides helpful information for the families of people living with hepatitis C or of those who inject drugs, and are therefore at risk of contracting hepatitis C

In 2015, hepatitis C was the most common infection amongst people who inject drugs. Around two in five people who inject drugs are living with chronic hepatitis C.

Drug use can affect the whole family, as can a diagnosis of hepatitis C. Having a loved one with a drug problem or who is ill may put a lot of practical, financial and emotional pressures on family members. We hope the information in this booklet may help reduce any potential fear or emotional strain.



Adfam

Families, drugs and alcohol

What is hepatitis C?

Hepatitis C is a blood-borne virus that predominantly affects the cells in the liver. It is spread by direct exposure to infected blood, for instance through the sharing of needles.

Despite the fact that there are around 160,000 people in England infected with hepatitis C, very little is known about it by the general public.

Misunderstandings about hepatitis C can lead to the stigmatisation of those who have it. Sometimes this stigma is also felt by the families of those with the condition.

Stigma arises from ignorance; people think that hepatitis C can be caught through kissing or hugging, and they may think that it is dangerous to be around someone with the infection.

Due to the high occurrence of hepatitis C amongst people who inject drugs, the infection is associated with drug addiction, which also bears its share of stigma. Greater awareness can help to dispel the fear and prejudice that affects people living with hepatitis C. This is particularly important because the stigma attached to hepatitis C can be as damaging as the infection itself. Stigma causes depression, isolation and guilt and can prevent people from seeking treatment.



**The infection is treatable
and curable.**

**NHS England has
committed to eliminate
hepatitis C in England
by 2025.**

The symptoms

An individual can carry the virus for years without experiencing any symptoms. Often the symptoms (such as depression, fatigue, skin problems, pain and digestive problems) are attributed to other causes. For these reasons, lots of cases go undiagnosed.

Hepatitis C is often thought of as a liver disease, but it can affect other parts of the body as well, such as the lymphatic system, the immune system and the brain.

Up to 20% of people in the first stage of infection may experience one or more of the following symptoms:

- **A slight fever**
- **Fatigue**
- **Appetite loss**
- **Abdominal pain**
- **Nausea and vomiting**

Some people also experience jaundice. This is a well-known indicator of liver problems, however it is not explicitly associated with hepatitis C.

One in four people who contract the infection get rid of the virus naturally. In the three in four cases in which this doesn't occur, the infection moves into the chronic stage (meaning it is sustained: that someone is living with the infection). Symptoms may not necessarily change, however they may become more likely to occur, or more pronounced.

Many people living with chronic hepatitis C experience 'brain fog'. This refers to difficulty focusing, difficulty remembering things and difficulty completing complex tasks. This can be very confusing and frustrating. However, people who have completed hepatitis C treatment find that their ability to remember and think returns to normal.

Hepatitis C can also cause chronic fatigue. This is extreme tiredness that cannot be remedied by sleep or inactivity. In extreme cases this can prevent people from working.

Abdominal pain as well as aches and pains in joints are other possible symptoms of chronic hepatitis C.

Many people with hepatitis C complain of dry eyes, irritable bowels and irritable bladders. It is not clear if these symptoms are caused directly by the hepatitis C, or arise as a result of associated stress. The same can be said in regards to depression, which although commonly experienced by people living with hepatitis C, is likely to be caused by associated stress and stigma rather than the infection itself.

If left untreated, the effects of hepatitis C worsen. It can cause scarring of the liver, known as cirrhosis. One in every three people with chronic hepatitis C will develop liver cirrhosis within 30 years. This can lead to liver failure and liver cancer. The likelihood of developing cirrhosis is increased by drinking alcohol, having type 2 diabetes, HIV or another type of hepatitis, and increases with age.

Stopping it spreading

The most important means of stopping spread of hepatitis C infection is by those who think they might be infected being tested and if positive, going for treatment and encouraging all of their friends that might also be at risk to be tested.

Hepatitis C is transmitted through blood-to-blood contact, and so it is most commonly caused by using shared needles, which is why people who use drugs are particularly at risk.

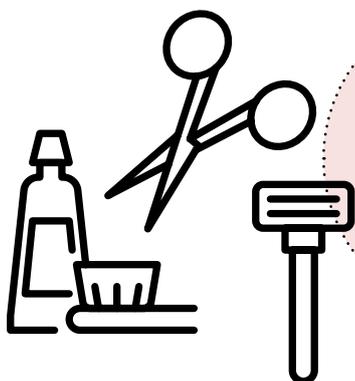
To prevent the spread of infection drug users should avoid using shared needles.

Hepatitis C can also be spread through sharing other drug paraphernalia. Due to the sensitivity of the lining of the nose, snorting utensils can cause small cuts. It is therefore possible to transmit the infection through sharing snorting utensils. Recent studies have found that people who share drug pipes are also at a greater risk of developing hepatitis C, as smoking crack cocaine causes sores and wounds in the mouth, and open wounds increase the risk of infection.

To prevent the risk of infection drug users should avoid sharing drug paraphernalia.

There is a 1 in 30 risk of getting hepatitis C as a result of being accidentally pricked by a needle stick used by someone with hepatitis C.

To prevent the spread of infection dispose of needles safely, through needle exchanges or in sharps boxes.



At home: label toothbrushes, razors and scissors of the infected family member, or perhaps keep them in a labelled container.

It can also be transmitted by sharing toothbrushes, scissors and razors as these objects can cause small cuts and harbour miniscule amounts of blood.

To prevent the spread of infection label the toothbrushes, razors and scissors of the infected family member, or perhaps keep them in a labelled container.

In room temperature, it is thought that the infection can survive in patches of dried blood for several weeks.

To prevent the spread of infection blood spillages should be cleaned with bleach, as should whatever has caused the cut. Even if this is an item of rubbish, it must be soaked in bleach before being thrown away.

Hepatitis C can also be transmitted through unprotected sexual contact (i.e. without the use of a condom) however the risk of this is very low. The risk of transmission is increased by the presence of blood. While there is no evidence to suggest that sex during a woman's period is more likely to transmit hepatitis C, the infection can be transmitted by menstrual blood.

To prevent the spread of infection use male/female condoms when having sex where there is an increased risk of blood (i.e. during menstruation or anal sex).

Very occasionally (in 5% of cases) a mother infected by hepatitis C can pass the infection onto her unborn baby. There is no evidence to suggest that it can be passed on through breast milk.

Contrary to rumour, hepatitis C cannot be transmitted through kissing, safe sex, sharing cutlery and crockery, cuddling or sharing bathrooms.

The infection is treatable and curable. NHS England has committed to eliminate hepatitis C in England by 2025.

Testing and treatment

Recent developments of new medication means that hepatitis C is no longer ‘a death sentence’. However, it must be carefully managed in order to reduce the harm it causes to an individual and those closest to them. This means that people who historically or currently inject drugs must be encouraged to get tested for hepatitis C.

Testing for hepatitis C is very simple, and can be done at GP surgeries, sexual health clinics and drug services. If you think that there is a chance that you may have contracted hepatitis C, you should get tested. **If a loved one or family member is injecting or has injected drugs in the past, encourage them to get tested.**

Often only one blood sample is required. It is tested twice. The antibody test establishes whether or not you have been exposed to the virus, and the PCR (Polymerase Chain Reaction) test establishes whether the virus is still active and in need of treatment. Some clinics may ask for two samples of blood.

There is an incubation period before the infection is registered by the body, and so it usually takes about 6–12 weeks for the antibodies to develop. This means that despite receiving a ‘negative’ test result, some people may still be encouraged to undergo further tests if they have been exposed to the virus or are experiencing symptoms.

A ‘positive’ test result doesn’t necessarily indicate the presence of infection. Up to 25% of people infected by hepatitis C clear the virus from their bodies naturally.

If an antibodies test comes back positive, the blood sample will undergo a PCR test. A PCR test detects the presence of the virus in the blood’s DNA. This test is sometimes referred to as an RNA test. A ‘positive’ result means that the virus is detectable in the blood’s DNA. Positive results are often given in terms of the amount of virus found in the blood, and this is referred to as the ‘viral load’.

Treatment

Until recently, treatment of hepatitis C involved taking a combination of medicines. Some of these were administered weekly by injection and had unpleasant side effects. However, new medicines called direct acting anti-viral drugs (DAAs) can be taken in the form of tablets once or twice a day. Treatment can take between 8 to 12 weeks depending on the nature and severity of the infection.

These new treatments are much more effective, and those in use in England are required to have a cure rate of over 95%. The new DAA treatments have far fewer side effects, with most people feeling unaffected by them.

For more information on treatment, visit:

- The NHS website
www.nhs.uk/conditions/hepatitis-c/treatment/#your-treatment-plan
- The Hepatitis C Trust website
www.hepctrust.org.uk/treatment

Or talk to your GP

- During a course of treatment a patient is likely to be looked after and supported by a number of different practitioners and bodies. GPs help patients to navigate and understand their treatment.



The family experience

Impacts on the family

The effects of hepatitis C extend beyond the person carrying the infection.

It can be very worrying for families. They may worry for the physical health of their loved one and they may also be concerned for their own health. They may be worried about the stigma associated with hepatitis C, or they may even contribute to it.

Adfam research found that a hepatitis C diagnosis can be very worrying. One family member said: *'massively scared that this [contracting hepatitis C from a loved one] is something that is possible.'*

Sometimes uncertainty is a bigger cause of stress than a diagnosis. A diagnosis can provide hope, in the form of treatment, and offers a sense of control.

The family experience varies for a number of reasons. For the families of people who currently inject drugs, it can be quite low down on a long list of worries.

One family member said: *'I am not worried about it because the aggression from my son far outweighs the hepatitis C (...) for me, it is more about managing his drug use and putting in boundaries when he is abusing steroids; that's the priority.'*

Unfortunately, some people do still face stigmatisation at the hands of the services. This is unacceptable.

An infection is not indicative of the moral character of either the drug user or their family member.

One mum recounted how she and her son were let down by the services: *'when he went into hospital, he was dealt with a lot of contempt by a lot of people.'*

In situations like this, it may be worth complaining to the NHS via the online feedback and complaints form, or talking to a Hepatitis C support group, which may be able to do so on your behalf. Visit The Hepatitis C Trust website to find support groups for hepatitis C and liver disease, or Adfam to access support for families affected by drug use (see website links on page 11).

Sadly, other people have found that they themselves have contributed to the stigmatisation of a loved one living with hepatitis C. This is usually unintentional, arising from the fear of transmission. The more a family knows about hepatitis C, the less scary it becomes.

Family members with hepatitis C often report feeling alienated or distanced from the rest of their family. Some are told to eat in a separate room, or feel that they cannot hug their children. It is unnecessary to bar physical contact with family members, or to use separate cutlery, just as it is unnecessary to cease sexual activity.

'Everyone in my family was quite distraught because we didn't know much about it and when we found out, we also found out we might be able to pick it up. My son refuses to communicate with her [my daughter] at all. He has a child and he doesn't want his child involved in her life because of the drug use and because of the contagious disease.'

Family breakdowns like this are preventable. Had the brother been more informed he would have realised that the infection is easily contained, and does not make someone dangerous to be around. The more family members know about the risks of transmission, the better able they are to prevent it.

Managed well, hepatitis C needn't interfere too much with family life.

Care and support

Supporting your loved one

The main way to support your loved one is to 'be there' in times of stress and to offer them emotional and practical support. Many readers will feel they are already doing this.

If you are able to encourage your loved one to get tested and treated for hepatitis C, then that is another crucial way of offering support. Learning about the new DAA treatment may make this easier, as in the past people have been put off treatment due to the side effects. Providing your family member with information or accompanying them to GP appointments may help to reassure them.

However, it is also very important to realise the boundaries of your own influence as a carer. One family member told Adfam: *'I often asked him to get tested and he said he was being tested. I can't do anything more if he says yes.'*

Testing and treatment may not be a priority for your loved one, as one family member told Adfam: *'When someone is in the throes of that lifestyle, they don't think rationally as you or I, they don't see it [testing] as necessary or urgent – all he needs to know is where to get his next fix.'*

When supporting a family member it is important to bear in mind what you have read here regarding the possible symptoms of hepatitis C. Brain fog, muscle aches and chronic fatigue can impede people's ability to carry out the tasks involved in day-to-day life. They may find it harder to help out around the house, work, or remember doctor's appointments. There is evidence that treating the virus successfully can improve these symptoms. Accompanying your loved one to important appointments and jotting down information may help them in their recovery.

Supporting yourself

It is equally important for carers and family members to seek support for themselves. Having a family member who uses drugs or who has hepatitis C can be really difficult and put a strain on the whole family. When a caregiver neglects their own emotional needs, the strain takes a toll on both parties. Self-care isn't selfish. It is essential. You can only support others effectively when you are happy and healthy yourself.

It is important for carers to recognise their own emotional responses to the situation. One family member told us: *'It made me incredibly sad and annoyed and angry. You become intolerant of their illness and them even though they are doing their best to present themselves well. You get the worst side of it because you are one of the only people who knows.'*

It is important to realise that your feelings are valid, and that you too deserve support.

Hepatitis C can affect sex lives, as mentioned: *'It did have quite an effect on the physical side, being aware of someone having a disease in their blood which can be quite easily transmitted. It did cause quite a bit of discomfort and a bit of distance between us for a while at the beginning.'* It is important to remember that hepatitis C is not transmitted via safe sex. It is equally valid to talk to support groups about the ways in which your relationship may change, or how to avoid changes.

All carers should aim to take some time for themselves in order to boost their own wellbeing. Simple things like going for a walk, reading or spending time with other friends and loved ones can help you cope and thrive.

Carers often find it useful to attend peer support groups where carers can talk openly about the challenges they face. Moreover, when families are well informed about hepatitis C, they are better equipped to deal with it.



The following resources provide further information and support:

- **NHS Five steps to mental wellbeing online guide:** www.nhs.uk/conditions/stress-anxiety-depression/improve-mental-wellbeing
- **The Adfam website**, allows you to find support for drug and alcohol affected families near you. It also contains lots of useful resources and information for people affected by a loved one's drug or alcohol use:
www.adfam.org.uk
- **The Hepatitis C Trust Helpline:** 020 7098 6221 (open 10.30am to 4.30pm every Monday to Friday except for bank holidays and the Christmas break). This helpline is manned entirely by people who have lived with hepatitis C themselves, and is completely confidential. Information can also be found on The Hepatitis C Trust's site: www.hepctrust.org.uk
- **Talk to Frank Helpline:** 0300 123 6600 provides friendly, confidential advice on drugs.
- **Drinkline Helpline:** 0300 123 1110 provides advice on alcohol use.
- **The London Joint Working Group on Substance Use and Hepatitis C** has led on the production of two useful resources:
'Understanding hepatitis C and staying safe'
'Living with hepatitis C and treatment options'

Available from:

www.ljwg.org.uk/what-we-do/#resources

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Adfam
2nd Floor
120 Cromer Street
London
WC1H 8BS

Telephone: 020 3817 9410
Email: admin@adfam.org.uk

www.adfam.org.uk

