



BRITISH
LIVER
TRUST

The alarming impact of
liver disease in the UK

Facts and statistics

The British Liver Trust is a company limited by guarantee
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Liver disease is a silent killer. Most people with the condition don't know they have it until the disease is at an advanced stage, yet it's the biggest cause of death in those aged between 35-49 years old.

Liver disease is also on the rise. Since 1970, deaths due to liver disease have increased by 400%. This is in stark contrast to other major killer diseases, such as heart disease and cancer, in which the number of deaths have either remained stable or decreased. A lack of awareness of the seriousness and prevalence of liver disease together with the stigma that often surrounds it means that it is consistently overlooked and underfunded.

Often – too often – the story behind liver disease is one of social deprivation. It disproportionately affects the poorest and most vulnerable in society, and provision of care continues to be worse in the regions with the greatest socioeconomic deprivation. Tragically, people who live in more deprived areas are up to six times more likely to die of liver disease than those who live in wealthier areas.

There is much to be done. Increasingly, liver disease is something that touches every one of us, as illustrated in this report. The statistics make for alarming reading. At the British Liver Trust, we continue to campaign for change, working tirelessly to raise awareness, improve early diagnosis and detection and support clinicians to give the best possible care.

Liver disease is a major public health crisis and we hope that this report will highlight the scale of the problem that we are tackling and ensure more resources are committed to liver disease in the UK.

Professor Stephen Ryder, June 2019

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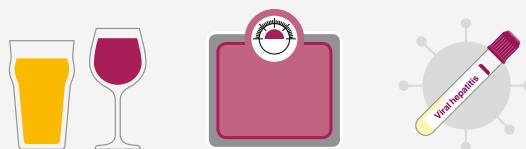
Liver disease in the UK

What is liver disease?

Liver disease refers to more than 100 conditions which affect the way the liver functions and can eventually lead to liver failure and death. It can occur because of hereditary or genetic factors, or autoimmune disorders triggered by a virus.

Liver disease is a silent killer. Most people with liver disease do not have any symptoms until the disease is at an advanced stage.

90% of all liver disease in the UK is attributable to alcohol, obesity and viral hepatitis and is therefore preventable.¹

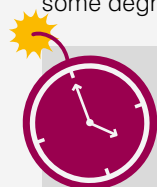


Facts and figures at a glance

More than **one in five of us** are at risk of developing liver disease²



Seven in ten people with liver disease are undiagnosed and unaware that they already have some degree of liver damage³



Liver disease is expected to overtake cardiovascular disease as the biggest cause of premature death in the next few years⁴

Over 600,000

people in the UK have some form of serious liver disease and **over 60,000** of these have cirrhosis⁵

Since 1970, deaths due to liver disease have increased by 400%

and in people below the age of 65 they have risen almost fivefold.⁶

Overall, deaths due to other major diseases have either remained stable or decreased



75% of people with liver cirrhosis are diagnosed in a hospital / emergency setting when the disease has already progressed. By this time the options for treatment are limited.⁷

It can take **up to 20 years** for liver disease to progress to a stage where symptoms begin to show⁸



Liver disease is now the leading cause of death in 35-49 year olds¹⁰

In 2016/17, there were approximately 14,696 liver disease-related deaths in the United Kingdom⁹

This means that on average, over 40 people die every day from liver disease.

Over the last 5 years, the hospital admissions rate for liver disease has significantly increased year on year. In **2016/17 more than 68,000 people were admitted** representing a **20% increase over the 5 years**

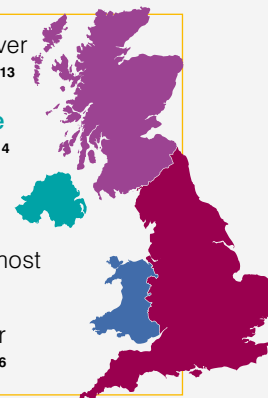
Liver disease is the only major cause of death which is **on the increase in the UK** whilst decreasing among our European neighbours¹²

Around **900 people** die from liver disease in Scotland every year¹³

In Northern Ireland **232 people** died from liver disease in 2017¹⁴

In Wales, **807 people** died of liver disease in 2015, representing an increase of almost 20% over the past five years¹⁵

Over **12,500 people** die of liver disease in England each year.¹⁶



Liver disease in the UK

The causes of liver disease in the UK



Other types of liver disease

Autoimmune hepatitis (AIH)

This condition is a rare type of hepatitis, affecting around **10,000** people in the UK, where the immune system attacks and damages the liver, which stops it from working properly.

Primary sclerosing cholangitis (PSC)

PSC is a rare autoimmune disorder whereby the bile ducts both within and outside the liver become inflamed and scarred, preventing bile from being drained away. This results in ongoing damage to the liver. It affects around one in **10,000** people in the UK.

Primary biliary cholangitis (PBC)

PBC is type of long-term liver disease that affects around **20,000** people in the UK. The immune system attacks and damages the small bile ducts within the liver, leading to a build-up of bile that damages the liver, causing scarring (cirrhosis).

Wilson's disease

Wilson's disease is a genetic condition in which the body is unable to get rid of excess copper, leading to a build-up in the liver and brain. It affects around one in **30,000** people.

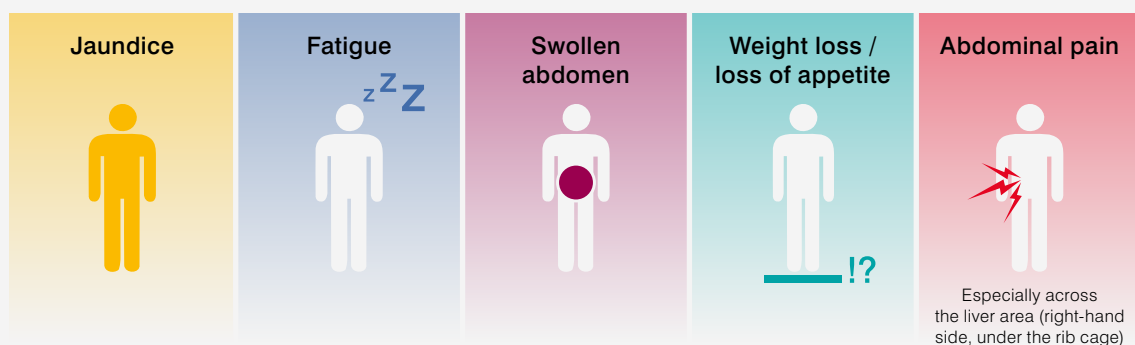
Haemochromatosis

This is a genetic condition whereby too much iron is absorbed by the body. This leads to a build-up of iron deposits, which have a toxic effect, especially on the liver. Previously thought to be a low-level health risk, new research shows that haemochromatosis quadruples the risk of liver disease and doubles the risk of arthritis. Hereditary haemochromatosis affects around one in **5000** people, although it may be far more common than previously thought.

Source: British Liver Trust

Symptoms of liver disease

Liver disease is a silent killer. It does not usually have any symptoms in the early stages. It can take **up to 20 years** for liver disease to progress to a stage where symptoms start to show. Symptoms of later stage liver disease can include:



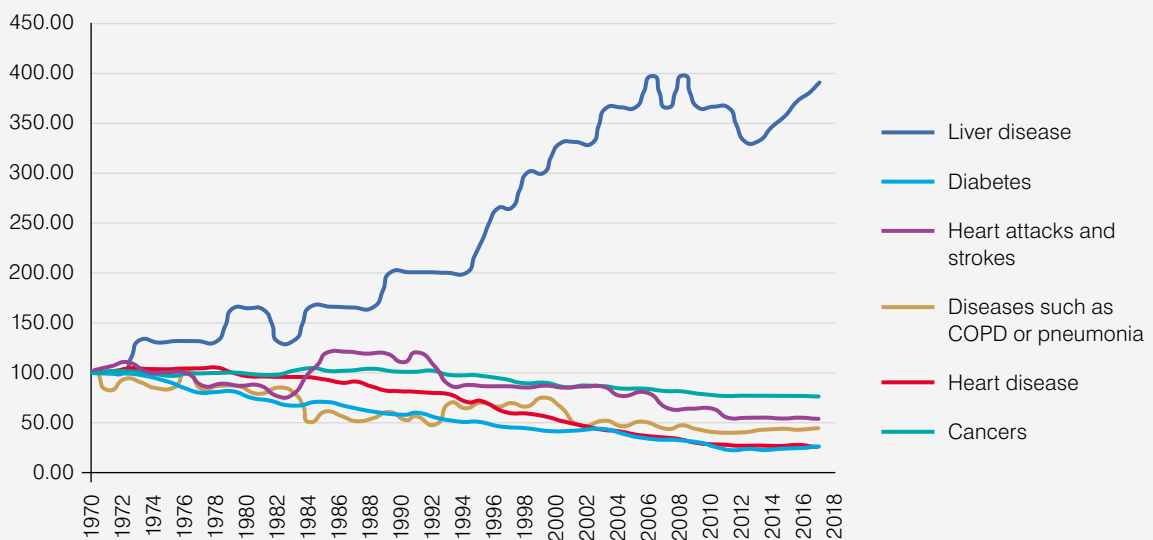
Liver disease in the UK

The prevalence of liver disease in the UK

Over the past few decades, vast improvements have been made in healthcare and the death rates have decreased for all of the major 'killer' diseases. In some areas, such as heart disease, in which large numbers of resources have been invested, the numbers of people dying from heart-related conditions have decreased substantially. Liver disease is the exception: the number of people dying from liver disease has increased by more than 400% since 1970 and in patients younger than 65, deaths have increased by almost 500%.²³

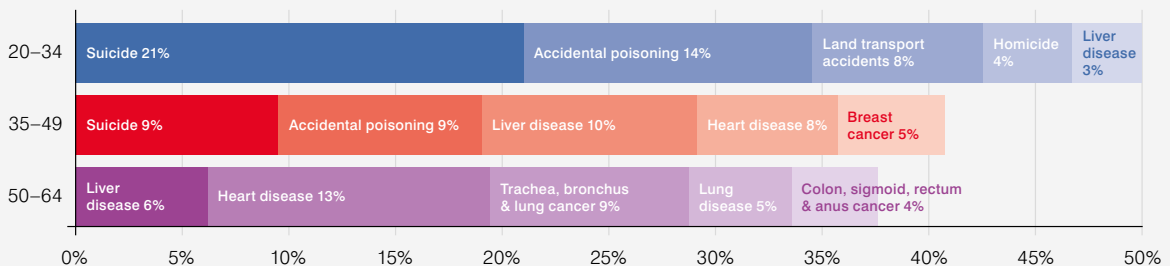
Most patients die in working age (18–65 years), making liver disease the third biggest cause of premature mortality with 62,000 years of working life lost every year.²⁴ A 2018 report published in the Lancet indicates that **liver disease is set to overtake coronary heart disease as the leading cause of premature death** in the next two years.²⁵

The rise in deaths from liver disease compared with other major diseases



Standardised UK Mortality Rate Data – All Ages

Liver disease is now the biggest cause of death in those aged between 35-49 years old



Source: Health Foundation analysis using ONS. Deaths registered in England and Wales, 2017

Top five causes of death by age, England and Wales 2017 – proportion of deaths in age group.

Liver disease in the UK

Hospital admissions due to liver disease

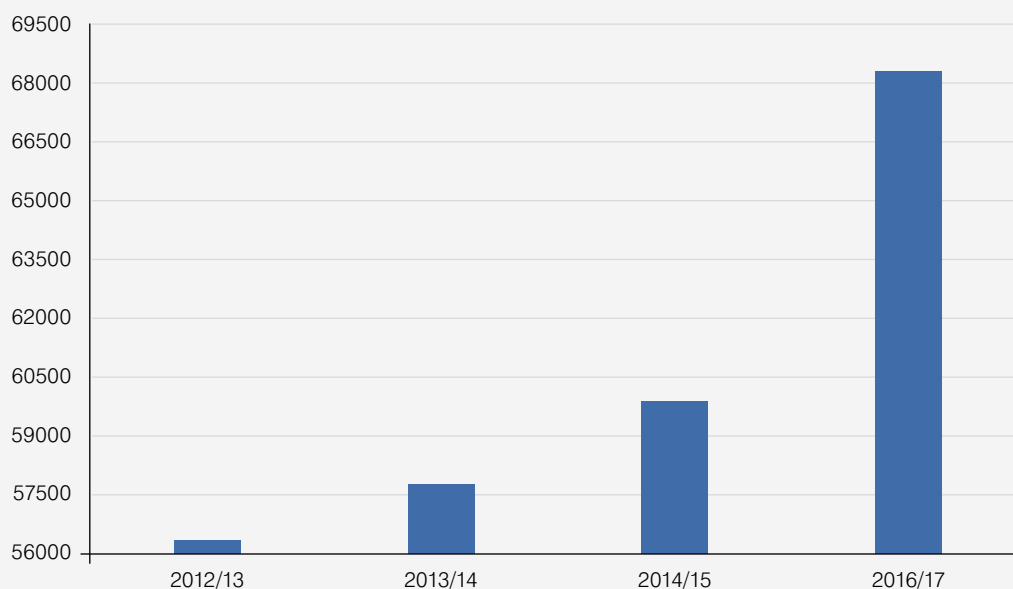
Over the last decade, the number of liver disease-related hospital admissions in England has **increased by half**, placing an even greater strain on the health service,²⁶ with **£2.1 billion per year** currently spent on treating liver disease.

- 90% of liver disease patients are admitted into hospital in their last year of life²⁷
- 1 in 5 people who die from liver disease have five or more hospital admissions in their last year of life²⁸
- Over 80% of alcohol-related liver disease deaths occur in hospital.²⁹

Hospital admissions in England

- In 2016/17, there were 68,364 admissions to hospital due to liver disease. The rate for admissions has significantly increased every year since 2012/13, when 56,545 people were admitted.³⁰

Hospital admission rate due to liver disease in England



- In 2014/15, **4,750 more people** were admitted to hospital for liver disease than in 2012/13 – an increase of **8.4%**.

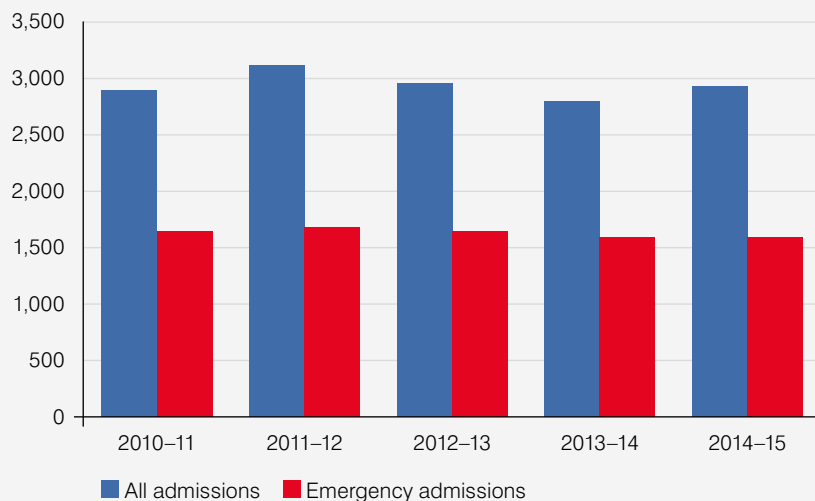
The English regions with the highest hospital admissions caused by liver disease in 2014/15 were the North East, the North West and the East Midlands.³⁰

Liver disease in the UK

Hospital admissions in Wales

- In 2016/17, the number of people admitted to hospital with liver disease was 3258.³¹

Liver disease in Wales – all hospital and emergency admissions: 2010-2015



Source: Patient Episode Database for Wales, NWIS

- In 2015/16 hospital admissions for all liver diseases in Wales reached a five-year high,³² with 3215 admissions.
- Just over half of all liver disease-related hospital admissions are emergency admissions.³³

Hospital admissions in Scotland

- In 2016/17, approximately 67% of chronic liver disease-related hospital stays included a diagnosis of alcohol-related liver disease and around 33% included a diagnosis of a non-alcohol related chronic liver disease.³⁴
- Since 1982/83, hospital stay rates for both alcohol and non-alcohol related chronic liver disease have increased. Stays with a diagnosis of alcohol-related liver disease have increased by more than fivefold, from **26 per 100,000** of the population in 1982/83 to **140 per 100,000** in 2016/17.³⁵

Liver disease in the UK

Complications of liver disease

People living with advanced liver disease (cirrhosis) may experience debilitating and uncomfortable complications because of their condition.

Hepatic encephalopathy (HE)

Hepatic encephalopathy (sometimes called HE) is characterised by confusion, altered levels of consciousness (and potential coma) due to toxic compounds usually removed from the body by the liver reaching the brain, because the cirrhotic liver is no longer able to process them.²²⁸

- One in three patients with liver disease are hospitalised with HE²²⁹
- Around 70% of people with cirrhosis experience mild symptoms of HE, with between 23-40% progressing to a more severe form²²⁹
- HE is a sign of very advanced liver disease – between half and 64% of people with HE die within a year of HE being diagnosed²³⁰
- 80% of patients with HE report irregular sleep patterns, forgetfulness and poor concentration as common symptoms.²²⁹

Ascites

Ascites is the build up of fluid in the lining of the abdominal cavity. It occurs because the scarring within the liver (cirrhosis) increases the pressure inside the liver's blood vessels, which forces fluid into the abdominal cavity.²³¹

- 60% of patients with compensated cirrhosis develop ascites within 10 years during the course of their disease²³²
- The development of ascites is associated with poor quality of life, an increased risk of infection and renal failure (hepatorenal syndrome), and poor prognosis (40% of those with ascites die one year after diagnosis, and 50% after two years).²²⁹

Variceal bleeding

Varices are dilated blood vessels or veins. They usually have no symptoms, however in people with advanced liver disease they can become enlarged and rupture. This can be life-threatening.²³²

- Varices develop and enlarge with time
- Following diagnosis of cirrhosis, the risk of development and growth of varices is 7% per year and the risk of development of first variceal bleeding is 12% per year.²³³

Liver disease in the UK

Liver disease and social deprivation



Liver disease disproportionately affects the poorest and most vulnerable in society. Provision of care continues to be worse in the regions with the greatest socioeconomic deprivation and loss of life due to liver disease is also higher in areas of socioeconomic deprivation.³⁶

In England, people in the most deprived 20% of the population who die from liver disease typically do so 10 years earlier than those in the most affluent 20% of the population who *also* die from liver disease.³⁷

In 2016, chronic liver disease mortality rates in Scotland were seven times higher in the most deprived areas (42 per 100,000 population) compared to the least deprived areas (6 per 100,000 population).³⁸

Hospital stays relating to alcohol are eight times more frequent for individuals living in the most deprived areas compared with the least deprived areas.³⁹

Although people living with deprivation are most likely to suffer liver disease, no-one is immune. As we will see, high-earners are more likely to binge drink, which puts them at risk of cirrhosis due to alcohol-related liver disease.

Alcohol-related liver disease

Facts and figures at a glance

One in five adults drink alcohol in a way that could harm their liver⁴⁰



x6

People who live in more deprived areas are up to **six times** more likely to die from alcohol-related liver disease than those who live in wealthier areas⁴¹

Alcohol is the leading cause of deaths due to liver disease⁴⁴

Around **7700**⁴³ people die from alcohol-related liver disease every year in the UK

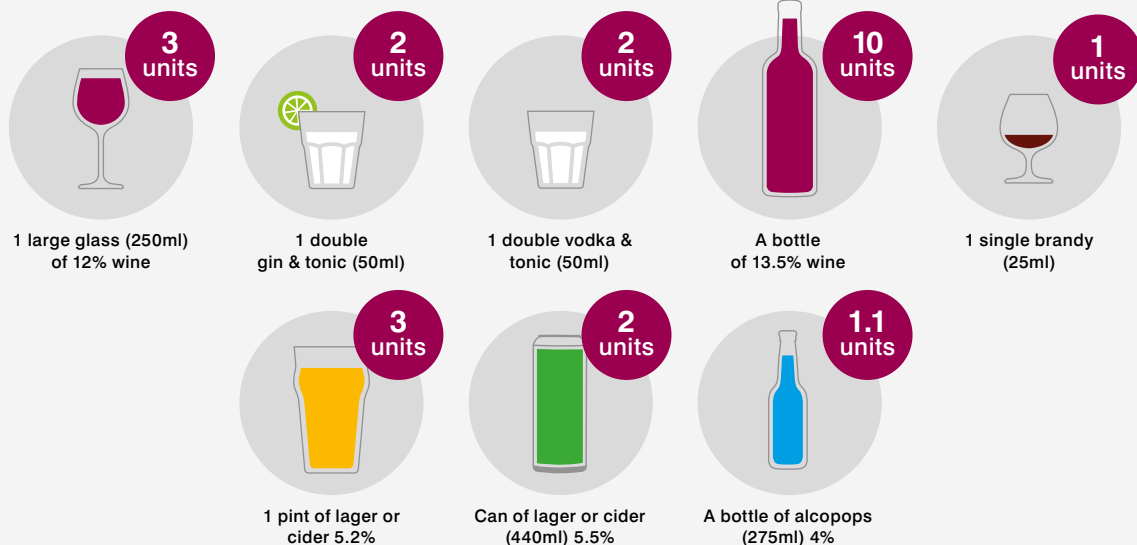
The number of hospital admissions due to alcohol-related liver disease have increased by **57%** since 2005⁴²



Effective alcohol treatment brings a substantial return on investment – for every £1 spent, £3 of social return is generated⁴⁵

Alcohol-related liver disease refers specifically to liver damage caused by excessive alcohol consumption. This is defined by the NHS as drinking more than the lower-risk limits of alcohol per week (14 units a week, spread over several days, with two or three alcohol-free days every week, ideally consecutively). Alcohol-related illnesses and deaths are a middle-aged phenomenon, with, most occurring between 40 and 65 years of age.⁴⁶

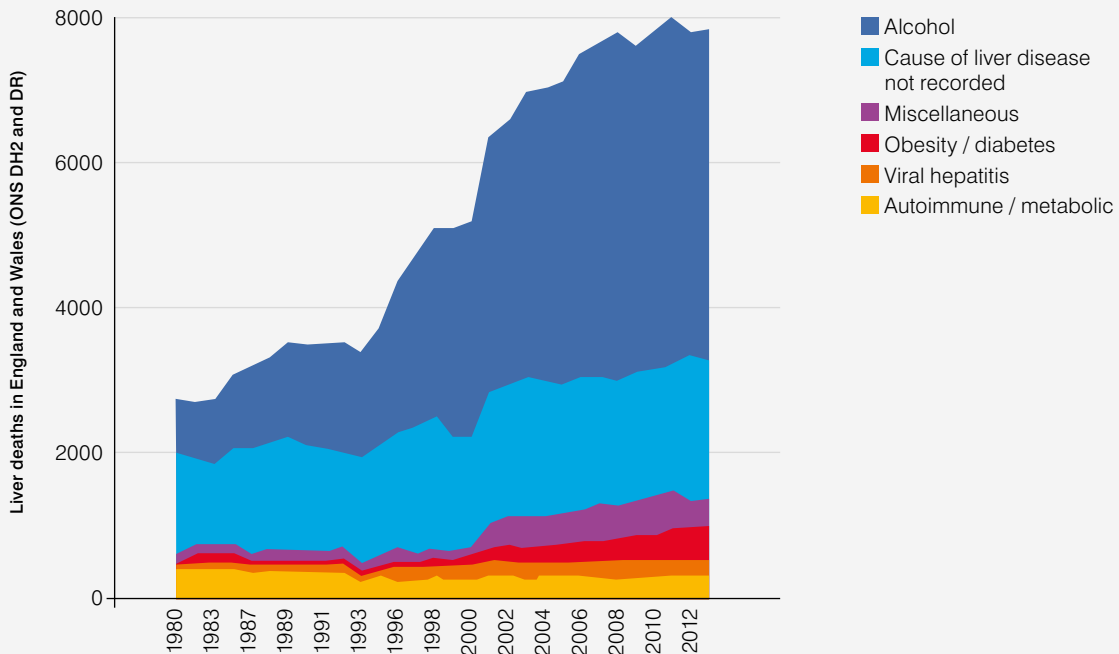
How many units in...



Alcohol-related liver disease

Cause of liver deaths in England and Wales

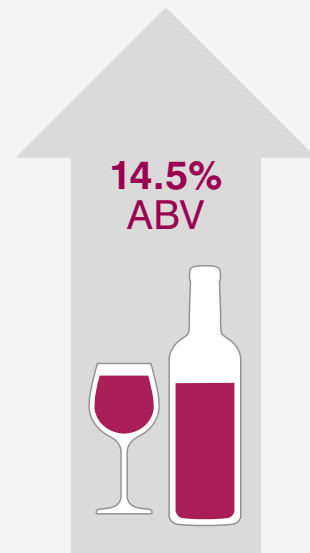
Alcohol consumption is the most common cause of liver disease in the UK, accounting for 60% of all liver disease cases.⁴⁷ Liver disease is responsible for 86% of deaths directly attributable to alcohol in the UK, and mortality rates from alcohol-related liver disease have increased 400% since 1970. In people younger than 65 this has risen by almost five times.⁴⁸



Source: Office of National Statistics data, 2018

Every year, admissions to hospital because of liver disease rise.⁴⁹ The increase in admissions and deaths is largely accounted for by higher levels of alcohol consumption over past decades,⁵⁰ which has shifted from moderate strength beer sold in pubs to strong lager, cider, wine and spirits sold in supermarkets to be drunk at home. In addition, alcohol is more affordable than ever in the UK and is now **64% more affordable than it was 30 years ago.**⁵¹

Figures from NHS Digital show a 57% increase in the number of hospital admissions for people diagnosed with alcohol-related liver disease since 2004/5, from 13,201 to 20,751 in 2016/17.⁵²



Alcohol-related liver disease

Who is at risk?



A common myth is that you have to be an 'alcoholic' to damage your liver. The term 'alcoholic' is misleading as alcohol dependency is a spectrum.

Combined data from the 2012 to 2014 Health Survey for England indicates that 20.8% of the population drink at risky levels (defined as up to 35 units per week for women, and up to 50 units per week for men). The National Institute of Health and Care Excellence (NICE) recommends that a liver scan (transient elastography) is offered to people who drink alcohol at the levels outlined here. 35 units is the equivalent of 3.5 bottles of wine, while 50 units is around 20 pints of beer.

- People in the most deprived 20% of the population who die from alcohol-related liver disease typically do so 10 years earlier than those in the most affluent 20% of the population who *also* die from liver disease⁵³
- The burden of liver disease is 17 times higher in the North West of England than in the Home Counties⁵⁴
- In England in 2015, there were an estimated 167,000 working years lost due to alcohol (16 per cent of all working years lost).⁵⁵ That means there were more working years are lost to alcohol than from the 10 most common types of cancer combined.⁵⁶



Alcohol-related liver disease

Alcohol in the UK

In the UK, every hour a person dies from alcohol-related issues and every day 35 people are diagnosed with an alcohol-related cancer.⁵⁷

Alcohol is a major public health problem across the UK, and one of the leading causes of illness and premature death.⁵⁸ Each year, it is associated with 23,500 deaths, 1.2 million hospital admissions and 12,800 cases of cancer.⁵⁹ In addition to liver disease, alcohol is causally linked to over 200 medical conditions, including heart disease and seven types of cancer.⁶⁰

- Up to 70% of A&E attendances at weekends are related to alcohol⁶¹
- Six million GP appointments each year are related to alcohol use⁶²
- In England, around 18% of men and 13% of women drink at higher risk levels⁶³
- In Scotland, there are over 7000 hospital stays each year due to alcohol-related liver disease (around 140 per 100,000 population)⁶⁴
- There were 303 alcohol-related deaths in Northern Ireland in 2017, the most deaths in any year so far this century⁶⁵
- Almost one in five high earners drink alcohol on at least five days a week⁶⁶
- There are over 595,000 alcohol-dependent adults in England⁶⁷
- More than 1 million admissions to hospital per year are the result of alcohol-related disorders⁶⁸
- Hospital stays relating to alcohol are eight times more frequent for individuals living in the most deprived areas compared with the least deprived areas⁶⁹
- Alcohol-related liver disease accounted for 80% of all alcohol-related deaths in 2017.⁷⁰



Drinking habits in the UK



In its 2017 report, *Adult Drinking Habits in Great Britain: 2017*, the Office of National Statistics found:

57% of those aged 16 years and over in 2017 drank alcohol, which equates to 29.2 million people in the population

Young people (16 to 24 years) are less likely to drink than any other age group; however, when they do drink, consumption on their heaviest drinking day tends to be higher than other ages

England had the highest proportion of adults who said they drank alcohol in the previous week (57.8%) followed by Scotland (53.5%) and then Wales (50.0%)

Binge drinking was more common in the North West and least common in the South East

20.4% of survey respondents reported that they did not drink alcohol at all.

Alcohol-related liver disease

Binge drinking

7.8 million people in the UK “binged” on their heaviest drinking day⁷¹

Those earning £40,000 and above are more likely to be frequent drinkers and “binge” on their heaviest drinking day when compared with the lowest earners.⁷²

What is binge drinking?

Binge drinking is defined by the NHS as exceeding more than six units of alcohol on a person’s heaviest drinking day (equivalent to between two and three standard 175ml glasses of wine or two and three pints of 4% strength beer). This applies to both men and women.



10.2 litres of pure alcohol were sold per adult in Scotland in 2017, equivalent to 19.6 units per adult per week.⁷³ However, self-reported data suggests that 26% of the adult population in Scotland in 2016 exceeded the low weekly drinking guideline (14 units) for men and women, a decline of 34% from 2003.⁷⁴

Rates of both alcohol-specific deaths and alcohol-related admissions are more than eight times higher in deprived areas than in the least deprived areas.⁷⁵

Where do we drink?



In 2000, nearly half (47%) of all alcohol sold was bought ‘on trade’ – in licensed premises such as pubs, bars and restaurants.⁷⁶ This number had dropped to 32% by 2016, as people moved towards buying alcohol ‘off-trade’ (in supermarkets and shops) to consume at home.⁷⁷ It’s estimated that in 2018, the average weekly spend on alcohol to be drunk at home was £8.70, compared with £8.00 on alcohol consumed elsewhere.⁷⁸

Minimum unit pricing (MUP)

In 2018, the Scottish Government set the minimum unit price (MUP) for a unit of alcohol as 50p, meaning that a 70cl bottle of 37.5% vodka could be sold for no less than £13.13, effectively raising the price of strong or ‘premium strength’ alcoholic drinks more likely to be purchased by problematic drinkers. It is estimated that MUP will save around 60 lives in the first year following implementation.⁷⁹ Wales also plans to introduce MUP.



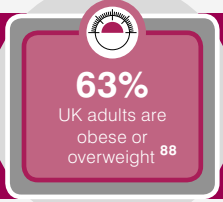
If trends are not reversed, it is estimated that the cost to the NHS of managing alcohol-related ailments over the next five years will rise to £17 billion.⁸⁰

Obesity and non-alcohol related fatty liver disease (NAFLD)

Obesity is a growing problem in the UK, with obesity rates doubling over the past two decades.⁸¹ Nearly **two thirds (63%) of UK adults are now classed as obese or overweight** and it's estimated that **one in three** people have early-stage non-alcoholic fatty liver disease (NAFLD).⁸² NAFLD is the most common cause of chronic liver disease worldwide.⁸³ About one in five people who have NAFLD develop non-alcohol related steatohepatitis, or NASH which is the more serious form of NAFLD and characterised by the liver becoming inflamed.²⁰ This means that approximately 5% of the population have NASH.⁸⁴

A healthy liver should contain little or no fat.⁸⁵ Being overweight or obese damages the liver because it causes a build-up of fat in the liver which can lead to non-alcoholic fatty liver disease (NAFLD). Over time, this can result in serious liver damage, including cirrhosis.⁸⁶

A 'fatty liver' can also be caused by drinking too much alcohol.⁸⁷



63%
UK adults are obese or overweight ⁸⁸

We use the term 'obese' to refer to someone who is very overweight, as defined by their body mass index, or BMI. The body mass index divides an adult's weight in kilograms by their height in metres in order to calculate whether they are a healthy weight. A BMI of between 25-29.9 classed as overweight and 30-39.9 as obese.⁸⁹

The main stages of NAFLD are:

1. **simple fatty liver (steatosis)** – a largely harmless build-up of fat in the liver cells that may only be diagnosed during tests carried out for another reason;
2. **non-alcohol related steatohepatitis (NASH)** – a more serious form of NAFLD, where the liver has become inflamed;
3. **fibrosis** – where persistent inflammation causes scar tissue around the liver and nearby blood vessels, but the liver is still able to function normally;
4. **cirrhosis** – the most severe stage, occurring after years of inflammation, where the liver shrinks and becomes scarred and 'nodular' (lumpy). This damage is permanent and can lead to liver failure (where your liver stops working properly) and liver cancer.

It is estimated that 3.3 million people in the UK have NASH.⁹⁰ About 20% of people with NASH will go on to develop cirrhosis.⁹¹ Many of these people will be undiagnosed and not have any symptoms. In older people the prevalence is much higher, with recent research revealing that as many as one in eight people over the age of 40 have this potentially life-threatening condition.⁹² Over the past 10 years there has been almost a tenfold increase in the numbers of people with cirrhosis caused by NAFLD who require liver transplantation (from 1.2% to 12%)⁹³



More than one in ten (12%) of liver transplants in the UK are needed because of liver disease caused by obesity.⁹⁴

In the next decade, NAFLD is predicted to become the primary cause of end-stage liver disease and liver transplantation, with the disease affecting all ages.⁹⁵

Obesity and non-alcohol related fatty liver disease

Obesity and overweight: the state of the nation



In England, the prevalence of obesity in adults rose from 14.9% to 26.9% between 1993 and 2015.⁹⁶ Over the same period, the prevalence of overweight has remained at between 36–39%

In Wales in 2015, 24% of adults were categorised as obese.⁹⁷ This is a 19% increase since 2005/6

In Scotland in 2016, 65% of adults aged 16 and over were overweight, including 29% who were obese⁹⁸

In Northern Ireland, in 2015/16, 60% of adults were overweight and obese.⁹⁹ Males (65%) were more likely than females (57%) to be overweight or obese

Approximately 27% (i.e. 12 million people) of the population in England is obese¹⁰⁰

In England, 35% of the population is projected to be obese by 2030¹⁰¹

All socio-economic groups have seen an increase in obesity in recent years but people with less education and lower socio-economic status are more likely to be obese¹⁰²

The latest data shows that social disparities persist, and have increased in some OECD countries.¹⁰³

Obesity and heavy drinking are both known risk factors for liver disease, but the risk of damage when the two are combined appears to be super-additive – that is, far greater than simply adding those two risk factors together. In obese people who also drink alcohol heavily, the risk of liver disease does not simply double but increases in a way that is far greater than the sum of their combined effects.¹⁰⁴



Obesity and non-alcohol related fatty liver disease

NAFLD and the next generation

Non-alcohol related fatty liver disease in children is relatively rare, although studies show that due to rising obesity levels in children, NAFLD is increasingly occurring in young people. Children who are obese or overweight are at increased risk of NAFLD.¹⁰⁵

One in three children is already obese or overweight by the time they leave primary school,¹⁰⁶ with some studies showing that up to 38% of obese children have evidence of non-alcoholic fatty liver disease.¹⁰⁷ The prevalence of NAFLD in adolescents in the UK has been shown to be as high as 2.5% (from the University of Bristol's Children of the 90s cohort, the largest birth cohort in the country). Alarmingly, when this same group was re-assessed as young adults (who had an average age of 24), researchers discovered that more than one in five had evidence of NAFLD. In addition, one in 40 had results suggestive of liver scarring.

Socioeconomic factors play a part: 40% of year six children from the most deprived areas of England are overweight or obese, compared with 27% in the least deprived areas.¹⁰⁸



Viral hepatitis

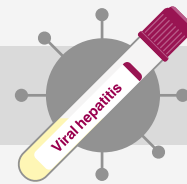
Viral hepatitis is inflammation of the liver that's due to a viral infection. It can be acute (short-term) or chronic (long-term). The five main strains of hepatitis viruses are A, B, C, D and E.¹¹³

Hepatitis A and E are typically caused by ingestion of contaminated food or water. Hepatitis B, C and D usually occur as a result of blood-to-blood contact with infected bodily fluids.¹¹⁴

In the UK:

- 180,000 people are estimated to be chronically infected with the hepatitis B virus¹¹⁵
- 21% of all chronic cases in the UK of hepatitis B cases relate to mother-to-child transmission at birth¹¹⁶
- 215,000 people are estimated to carry the hepatitis C virus.¹¹⁷

Because both hepatitis B and C can have few or no symptoms, at least 50% of hepatitis B and 40-50% of hepatitis C cases are undetected.¹¹⁸



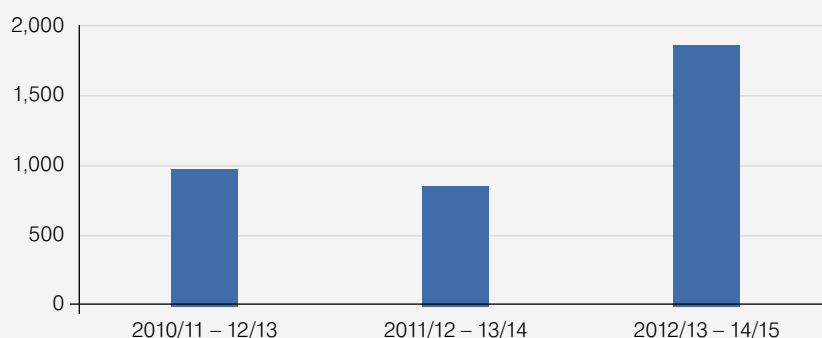
Hepatitis B

Hepatitis B is transmitted through contact with infected blood or other body fluids. It doesn't always cause symptoms and many people clear the virus within a few months. However, because there are few symptoms, chronically infected adults often remain undiagnosed and untreated until the liver is irreversibly damaged.¹¹⁹

- Around **20% of people with chronic hepatitis B will go on to develop scarring of the liver (cirrhosis)**, which can take 10 to 20 years to develop, and around one in 10 people with cirrhosis will develop liver cancer¹²⁰
- There were 453 acute or probable acute cases of hepatitis B reported in England in 2016¹²¹
- **The majority of cases (66%) were in men** and the highest incidence was in men **aged 25-34 years of age**¹²²
- Chronic hepatitis B infection is more likely to develop if the infection is acquired in childhood, although up to 10% of adults will develop chronic hepatitis B infection if the infection is acquired in adulthood.¹²³

Recent ONS data showing hospital admission rates for hepatitis B-related end-stage liver disease / liver cancer (hepatocellular carcinoma, also known as HCC) in England show that from years 2012/13 – 2014/5, 1,848 people were admitted to hospital for treatment.

Hospital admission rate for hepatitis B-related end-stage liver disease or liver cancer in England



*Data is three year pooled.

Viral hepatitis



A safe and effective vaccine for hepatitis B has been available since 1982. Since then, over one billion doses of hepatitis B vaccine have been used worldwide.¹²⁴ In countries where between 8-15% of children used to become chronically infected with the hepatitis B virus, vaccination has reduced the rate of chronic infection to less than 1% among immunised children.¹²⁵ Since 2017, babies born in the UK have been vaccinated against hepatitis B as part of their routine vaccination schedules.

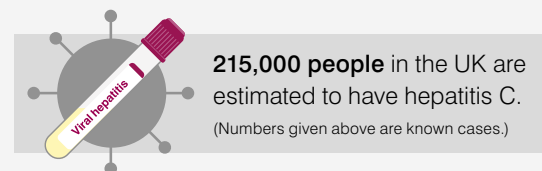
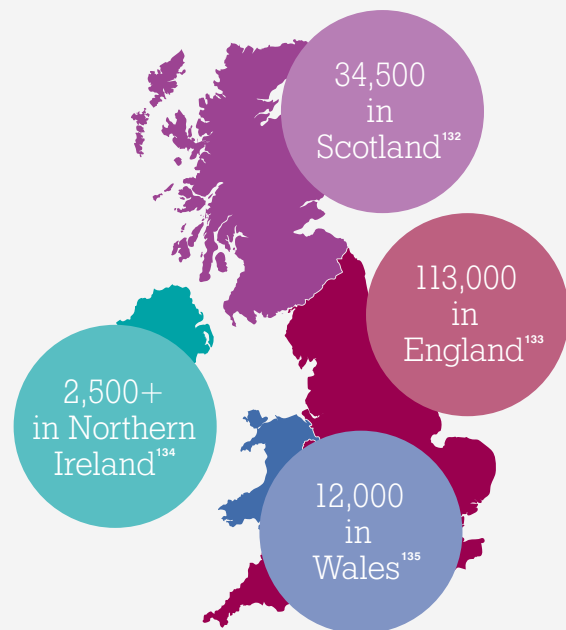
Hepatitis C

Hepatitis C is a bloodborne virus that is often asymptomatic, and symptoms may not appear until the liver is severely damaged. As a consequence, many individuals with chronic hepatitis C infection remain undiagnosed and fail to access treatment.

Hepatitis C is a curable infection, with 97% of diagnosed cases now cured with anti-viral medication. The UK aims to support the World Health Organization (WHO) in their goal to eliminate hepatitis C as a major public health threat by 2030 at the latest (see box).

- 90% of hepatitis C infections have been acquired through injecting drugs¹²⁶ which is the biggest risk factor for infection¹²⁷
- Up until 2014, deaths from hepatitis C related liver disease had been increasing in England as people who acquired their infections decades earlier progressed to advanced liver disease. However, this fell by 16.1% (from 380 deaths to 319) between 2015 and 2017, according to data from Public Health England¹²⁸
- The new highly effective curative direct-acting antiviral drugs offer the potential to significantly reduce the number of individuals progressing to serious end-stage liver disease or liver cancer
- Only around 50% of all those with hepatitis C in England are thought to be diagnosed, with around 27,000 in touch with support services¹²⁹
- In Scotland, 1685 patients were treated with direct-acting antiviral drugs between April 2016 and March 2017¹³⁰
- As well as the fall in hepatitis C deaths, greater access to new curative treatments is also linked to a reduction in the number of people with the disease requiring liver transplants. In 2017, registrations for a liver transplant due to hepatitis C fell to a 10-year low of 63, a 53% decrease compared to pre-2015 levels.¹³¹

Estimated numbers of people living with chronic hepatitis C virus

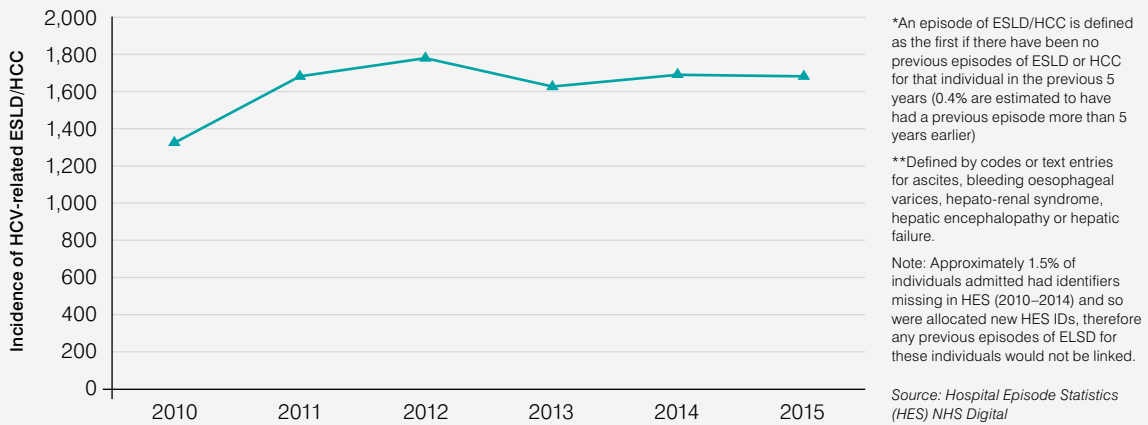


Public Health England (PHE) and NHS England have launched a national exercise to identify and treat patients who have been previously diagnosed with hepatitis C so they can access new treatments that will, in most cases, cure the condition. 11,557 people accessed treatment in 2017/18, up 22% on 2016/17 and up 127% on pre-2015 levels. An important milestone is that the World Health Organization (WHO) target to reduce hepatitis C-related mortality by 10% by 2020 has already been exceeded in England – three years ahead of time.



Viral hepatitis

Figure 2: Preliminary estimates of incidence* of hepatitis C-related end-stage liver disease/primary liver cancer in England: 2010–2015**

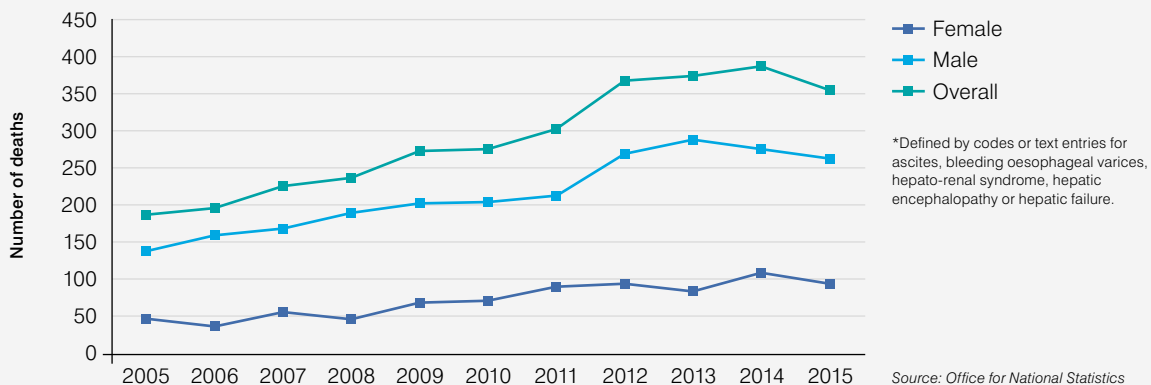


Those who are marginalised and under-served, and have poorer access to healthcare and health outcomes, are disproportionately affected by hepatitis C.¹³⁶ Many of the 40-50% of patients who remain undiagnosed are part of vulnerable populations with chaotic lives, or part of hard-to-reach groups who are out of touch with services and may not consider themselves to be 'at risk'.

- NHS England has committed to eliminating hepatitis C in England at least five years earlier than the World Health Organization (WHO) goal of 2030¹³⁷
- Estimates indicate that up to 79,000 people are currently living with undiagnosed active hepatitis C infection. This is because people with the infection often have no specific symptoms until their liver has been significantly damaged and so are unaware they are infected. When symptoms do occur, they can often be mistaken for other conditions.¹³⁸

Deaths from end-stage liver disease and liver cancer (hepatocellular carcinoma, or HCC) that were attributable to hepatitis C in England rose from 187 in 2005 to 387 in 2014 but **in 2015 there was an 8% decrease in the number of deaths occurring**. This is likely to be due to new treatments having a positive impact on mortality, as the numbers affected by alcohol-related liver disease and non-alcohol related fatty liver disease are increasing.

Figure 4: Deaths from end-stage liver disease* or liver cancer in those with hepatitis C mentioned on their death certificate in England: 2005 to 2015



Primary liver cancer

Primary liver cancer refers to cancer that starts in the liver. Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer, accounting for 90% of all liver cancers¹³⁹.

There are four main types of cancer that start in the liver:

- Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer. It is sometimes called hepatoma. It starts in the main cells of the liver, called hepatocytes.
- Fibrolamellar hepatocellular carcinoma is a rare type of primary liver cancer that usually affects younger people. The causes and risk factors are not known.
- Bile duct cancer (cholangiocarcinoma) is another type of primary liver cancer. It starts in the cells lining the bile duct.
- Angiosarcoma is a very rare type of liver cancer, which starts in the blood vessels of the liver.

Source: British Liver Trust

Facts and figures at a glance

In the UK, there are around 6000 cases of primary liver cancer diagnosed each year, which is around 16 people per day.¹⁴⁰

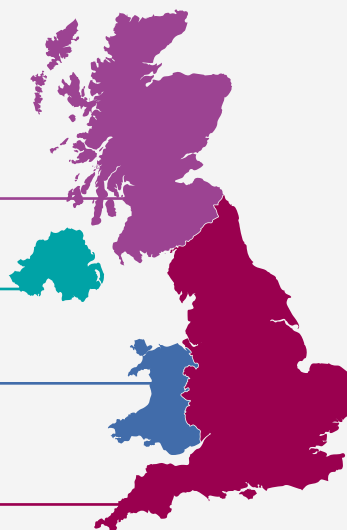
- Over the past decade, liver cancer has increased by almost two-thirds (63%) in the UK¹⁴¹
- Rates of liver cancer are projected to rise by 38% by 2035, the equivalent of 15 cases per 100,000 people¹⁴²
- Since the early 1990s, liver cancer incidence rates have more than doubled (151%) in the UK. The increase is greater in men (152%) than in women (132%).¹⁴³

In Scotland, liver cancer has increased significantly by 21% over the last decade, with 405 men and 204 women being diagnosed with the disease in 2015.¹⁴⁴ Liver cancer is the seventh most common cause of cancer mortality in Scotland, with the disease killing 572 individuals in 2015; a 52% increase since 2005.¹⁴⁵

In 2015, 80 men and 54 women in Northern Ireland received a liver cancer diagnosis (2015)¹⁴⁶

In 2015, 223 men and 97 women in Wales were diagnosed with liver cancer (2015)¹⁴⁷

In 2016, there were a total of 4,925 new cases of liver cancer diagnosed in England, with 3,235 cases diagnosed in males and 1,690 in females.¹⁴⁸



Liver cancer is the 17th most common cancer in the UK, accounting for 2% of new cases.¹⁴⁹

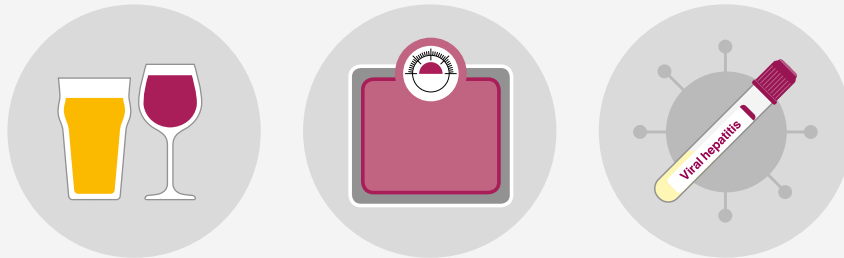
Primary liver cancer is becoming more common at all ages. It is now the 9th most common cause of cancer death and has the largest increase in mortality over the past 10 years compared to all cancers.¹⁵⁰

Primary liver cancer

Common causes of liver cancer in the UK

Most cases of liver cancer in the UK are linked to **cirrhosis** or **advanced liver disease**.¹⁵¹

Over 600,000 people in the UK have cirrhosis, but 75% are unaware as liver disease is often symptom-free until it's in the very advanced stages.¹⁵² Around four in 10 (39%) liver cancer cases in England are diagnosed as an emergency at A&E.¹⁵³



Risk factors for cirrhosis

- Heavy or harmful drinking / alcohol dependency
- Being overweight or obese – both increase the risk of developing non-alcoholic fatty liver disease (NAFLD) or non-alcoholic steatohepatitis (NASH – a more serious form of NAFLD characterised by inflammation)
- Viral hepatitis (hepatitis B or hepatitis C)
- Hereditary conditions such as haemochromatosis (where the body stores too much iron)
- Primary biliary cholangitis (a condition in which the tiny bile ducts within the liver become blocked, leading to a build-up of bile in the liver, which damages it. However, this is considered to be low-risk for liver cancer).

Source: British Liver Trust: Liver cancer publication, 2018



Around eight in every 10 cases of liver cancer are diagnosed in people aged 60 and over, although liver cancer can also develop in people younger than this.¹⁵⁴ The steady rise in liver cancer cases is a reflection of two of the most frequent risk factors (often found together): alcohol and obesity.¹⁵⁵

Liver cancer is four-to-eight times more common in men.¹⁵⁶

Liver cancer survival rates

Only around 12% of people diagnosed with liver cancer survive for five years. The prognosis is significantly worse the older someone is at diagnosis (see opposite). Around 25% of people in England aged 15-39 survive their disease for five years or more, compared with around 5% of people who are diagnosed aged 80 or over.¹⁵⁷

Net 5 year survival (%)

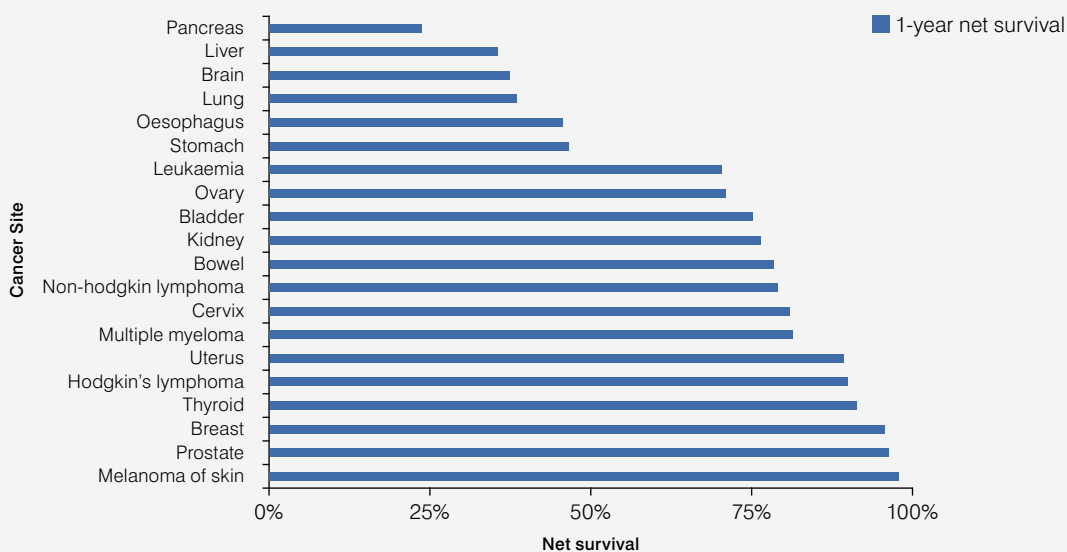
Age Range	Men	Women
15–39	22.5	29.8
40–49	23.1	22.8
50–59	21.2	15.4
60–69	13.9	12.5
70–79	8.2	6.6
80–99	5.7	1.8

Primary liver cancer

The one-year survival rate for liver cancer is one of the worst cancer survival rates – only pancreatic cancer patients fare worse.

Liver cancer suffers from a 'vicious circle' where poor survival outcomes lead to fewer researchers and funders being attracted to research. Between 2007-2016, the five least survivable cancers in the graph below received £0.3 billion in funding compared with over £1.6 billion spent on the five most survivable – a fivefold difference.

1-year net survival of different types of cancer England 2009-2013

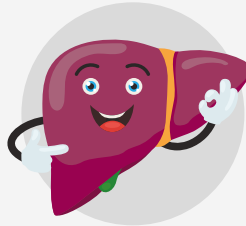


Source: Office for National Statistics and London School of Hygiene & Tropical Medicine

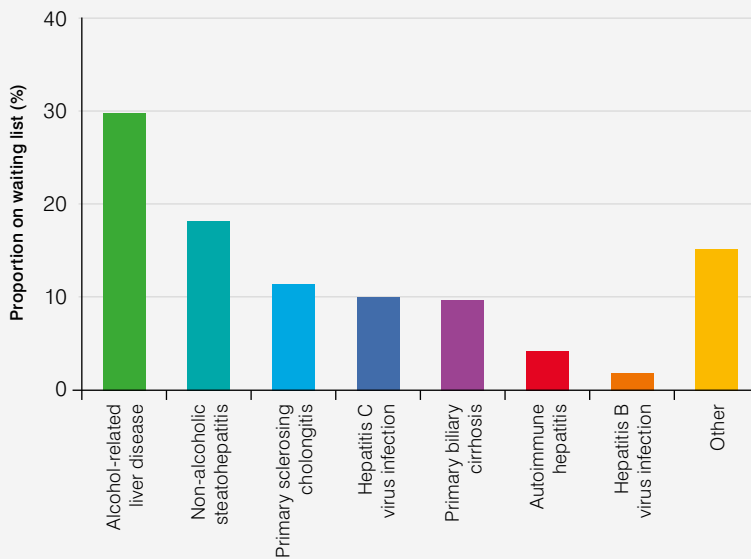
In 2016, there were 5417 deaths from liver cancer in the UK, meaning liver cancer accounted for 3% of all UK cancer deaths that year.¹⁵⁸

Liver transplantation

- Between 1 April 2008 and 31 March 2018, 8428 liver transplants were performed in the UK¹⁵⁹
- Over 1000 transplants were performed in 2018¹⁶⁰
- Around 350 people are on the waiting list at any one time¹⁶¹
- The most common reason for elective (non-emergency) transplantation is alcohol-related liver disease¹⁶²
- The outcome for elective (non-emergency) patients is good, with 95-100% of patients surviving transplantation for one year afterwards, and 80% surviving five years.¹⁶³



Causes of liver disease in patients on liver transplantation waiting list as of January 2017



In the UK, liver transplantation is usually recommended when the damage caused by liver disease / cirrhosis is extensive, resulting in liver failure or end-stage liver disease.

A liver transplant, sometimes referred to as orthotopic liver transplantation (OLT), is a procedure whereby a diseased liver is removed and replaced with a healthy donor human liver. This operation becomes necessary if the liver is damaged to the point where it is unable to work properly, can no longer repair itself and is likely to fail completely.

A liver transplant can involve a whole liver, a reduced liver or a split liver. The term 'reduced' is used when only a part of the liver is used, while a split liver is when either a right or left lobe is used. Transplants may be either 'elective' or 'super-urgent' depending on how quickly liver failure develops. 'Super-urgent' refers to emergency procedures; 'elective' to a routine procedure following selection criteria for transplant. Live liver transplants, whereby half a liver is donated from a living donor, are now regularly performed in the UK, with the mortality risk to the donor 0.8%.¹²² The procedure is now so successful that the current 1-year patient survival rates are approximately 85-90% and 10-year survival rates are around 65-75%.¹²³

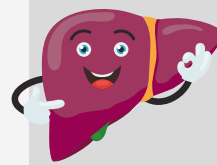
Source: British Liver Trust, Liver transplantation publication

Liver transplantation

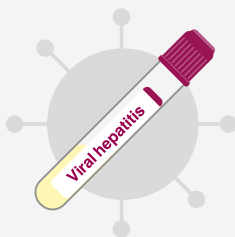
Facts and figures at a glance

- Between 2017 and 2018, a total of **1043** liver transplants were performed in the UK¹⁶⁴
- On 31st March 2018, there were **359** patients on the active transplant waiting list, a 32% decrease in the number of patients from the previous year¹⁶⁵
- **78%** of elective transplant patients receive a new liver within **two** years¹⁶⁶, although many people don't need to wait this long
- In 2016, over **two thirds** of elective transplant recipients were male and the median age was **56** years¹⁶⁷
- The most common reason for transplantation was alcohol-related liver disease (**28%**), followed by cancer (**18%**)¹⁶⁸
- 70% of people receive a transplant within one year of being listed. However, more than one in ten will either die whilst waiting for a liver to become available or have to be removed from the transplant list because their condition has deteriorated.¹⁶⁹

The highest transplant rates per million population were in **Scotland (19.1)** and **Northern Ireland (17.9)** which is twice as high as in the more affluent south of England (9.3).¹⁷⁰



It is estimated that there are currently **6,000** liver transplant survivors in the UK.¹⁷¹

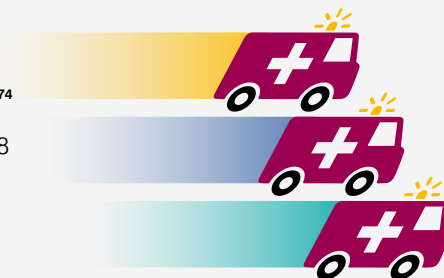


Liver transplant registrations for hepatitis C-related cirrhosis show that between 2008 and 2014, they averaged 134 per year. However, preliminary results show a decrease in 2015, by more than 40%, to an eight-year low of 83. The same trend can be seen in liver transplantations, where the numbers were stable between 2008 and 2014, at 108 transplants per year, and then decreased by 32% in 2015.¹⁷² These changes may be due to the positive impact of the management and treatment of viral hepatitis, although as yet there's no data to support this.

The most common reason donor livers aren't used for transplantation is because they are too fatty (39%). A smaller number of livers (7%) aren't used because the length of time between the liver being removed from the donor to transplantation, or 'cold ischaemia time' (ICT), is too long.¹⁷³ However, the introduction of normothermic machine perfusion means that livers which are not fully functioning for a number of reasons can be 'repaired', and their function improved using a machine where warm, nutrient-rich blood is continuously pumped into the liver for a few hours. This aims to reduce the number of livers considered unsuitable for transplant (15% of donated organs in 2016/17).

Super-urgent (emergency) liver transplantation

- The average waiting time for a super-urgent liver is 2-3 days¹⁷⁴
- The number of super-urgent transplants performed in 2017/18 was the highest in the last 10 years, at 74¹⁷⁵
- The majority of patients receiving these super-urgent liver transplants were female, with an average age of 45.¹⁷⁶



The cost of liver disease in the UK

No robust data on the cost of liver disease per se exists, so here we have given data on contributory factors. **Liver disease is the third most common cause of premature death in the UK, with an estimated 62,000 years of working life lost to the condition.**¹⁷⁷ The impact of liver disease is disproportionate, with the poorest in society worse affected than more affluent populations.¹⁷⁸

The three leading causes of liver disease are harmful or hazardous drinking, obesity and viral hepatitis.¹⁷⁹



Cost of alcohol-related liver disease

Alcohol-related liver disease accounts for 60% of all liver disease and 84% of liver-related deaths.¹⁸⁰ Around 20% of men and 15% of women drink at harmful or hazardous levels in the UK (the Department of Health recommends drinking no more than the lower-risk limits of alcohol per week, which is 14 units a week, spread over several days, with two or three alcohol-free days every week, ideally consecutively).¹⁸¹ **This is at a societal cost of around £27bn per year in England and Wales (although some research suggests this could be as high as £52bn).**¹⁸²

Costs specifically related to excessive alcohol consumption (and the associated risk factor it poses for liver disease) are:

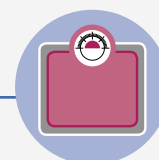


£3.5bn per year in costs to the NHS (England).¹⁸³ This includes £112m on GP consultations, £122m on specialist treatment and £696m on attendances to A&E.¹⁸⁴ Alcohol-related admissions increased approximately 17% between 2010/11 and 2015/16.¹⁸⁵



£7.3bn per year in lost productivity (UK). Liver disease poses a particular threat to economic productivity because it affects more people of working age than other life-threatening conditions,¹⁸⁶ with 90% of liver-disease related deaths occurring in people under the age of 70.¹⁸⁷

Unless this trend is reversed, it's calculated that over the next five years, the cost to the NHS alone could be as high as £17bn.¹⁸⁸

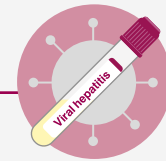


Cost of obesity and liver disease

Nearly two-thirds (63%) of UK adults are now classed as overweight and obese,¹⁸⁹ and the number of cases of non-alcoholic fatty liver disease (NAFLD), which is closely associated with the most common form of primary liver cancer, hepatocellular carcinoma, has escalated as a result.¹⁹⁰ In addition, one in three children in England are already obese or overweight by the time they leave primary school,¹⁹¹ with 38% of obese children showing evidence of NAFLD.¹⁹²

NHS spending on conditions linked to obesity, including liver disease, is £1.027bn each year, an increase of 65% in the past 10 years.¹⁹³

The cost of liver disease in the UK



Cost of viral hepatitis

Viral hepatitis is a growing problem in the UK, and is now one of the main causes of liver disease across England, Scotland, Wales and Northern Ireland.¹⁹⁴

If left untreated, viral hepatitis can lead to serious liver disease, including cirrhosis, liver cancer and liver failure. Treating these conditions puts the health system under significant financial strain.

- Between 2010 and 2015, cases of hepatitis C-related cirrhosis or hepatocellular carcinoma increased from 1336 to 1692¹⁹⁵
- Hepatitis C is estimated to affect 215,000 people¹⁹⁶ in the UK, with 180,000 being affected by hepatitis B.

Treating all those who need treatment for hepatitis C has been estimated to cost £1.5bn over the next 30 years. However, the cost of treating hepatitis C has come down significantly in recent years. Failing to treat those currently affected would cost £4.7bn due to later complications from hepatitis C-related liver disease.¹⁹⁷

Liver disease is one of the few chronic conditions for which incidence, prevalence and mortality continue to increase.

Primary care and liver disease

Early diagnosis

Primary care has an important role in the detection and management of liver disease.

- Only one in four people diagnosed with liver disease are diagnosed in general practice¹⁹⁸
- Three quarters of people with cirrhosis are not detected until they present to hospital with end-stage liver disease – when the scope for intervention is substantially reduced¹⁹⁹
- The standard 'liver function test' panel that is provided in laboratories in the UK is of little use in screening for early disease. 90% of people with early alcohol-related fibrosis and 75% of people with severe fibrosis have normal results from liver tests.²⁰⁰

To make an effective diagnosis it is necessary to test for fibrosis. This can be done through a simple non-invasive scan which is similar to ultrasound, known as transient elastography. The most common name for this kind of test is FibroScan. This is recommended as the first line test for fibrosis in those with suspected alcohol-related liver disease, although knowledge around, and access to, diagnostic testing for liver fibrosis in the UK is variable. Alternatively, doctors can use a panel of blood tests to see whether 'markers' that might indicate fibrosis are present in the blood. These can be divided into direct markers of fibrosis (such as the NICE-recommended Enhanced Liver Fibrosis (ELF) test), and indirect markers, which use combinations of commonly available blood tests. The most frequently used of these combination tests are the FIB4 score and the NAFLD fibrosis score, which are both recommended by the British Society of Gastroenterology to look for fibrosis in non-alcoholic fatty liver disease (NAFLD).

Recording of liver disease in primary care

Accurate recording of liver disease data is vital. The Royal College of General Practitioners (RCGP) Research and Surveillance Centre's data from more than 2 million primary care clinical records²⁰¹ suggests:

- Rates of recorded non-alcohol related fatty liver disease (NAFLD) are much lower than expected, suggesting under-diagnosis and under-reporting. The data show that 1% of primary care records contain a code for NAFLD in a group where we would expect around 25-30% of the adult population to have NAFLD if diagnosis and coding was comprehensive.
- Only just over a quarter of GP records (26.4%) recorded body mass index (BMI) in the previous year – the major risk factor for NAFLD
- Fewer than 18% of patients had the number of units of alcohol they consumed recorded in the previous year.

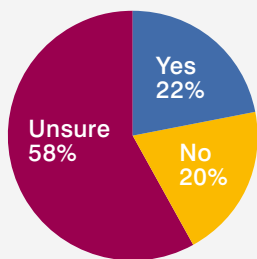
Primary care and liver disease

GPs' understanding and knowledge of liver disease

A survey conducted by the RCGP/British Liver Trust in 2017 as part of their clinical priority programme found that:

- A third of GPs who responded did not feel confident in identifying those at risk of liver disease
- 57% did not feel confident in managing patients with liver disease (either providing treatment themselves, or knowing when to refer)

GPs response when asked if they were aware of local referral pathway for patients with liver disease



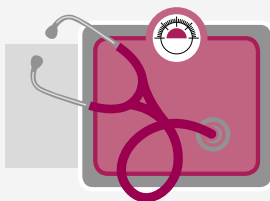
- Only 22% of GPs said their area had a pathway for liver disease; 20% said they didn't; and the majority of GPs (58%) didn't know.

Alcohol intervention in primary care

There is good evidence that alcohol interventions are effective at reducing harmful drinking in the primary care setting.²⁰² These include giving feedback on alcohol use and health-related harms, identification of high risk situations for heavy drinking, simple advice about how to cut down drinking, strategies that can increase motivation to change drinking behaviour, and the development of a personal plan to reduce drinking. A Cochrane study of 34 trials (15,197 participants) found that at one-year follow-up people who received the interventions drank less than control group participants.²⁰³



Obesity intervention in primary care



There is good evidence that losing around 10% of body weight improves liver function of people with non-alcohol related liver disease (NAFLD) and regression of fibrosis in NASH is possible, even in advanced stages.²⁰⁴

A recent review that looked at how effective exercise and dietary interventions in NAFLD could be concluded that both approaches are effective and a combination of dietary intervention as well as exercise should be recommended.²⁰⁵

However, studies have shown that GPs have mixed feelings about the effectiveness of obesity interventions and concerns about the evidence to prove them. There is evidence too that GPs feel uncomfortable discussing obesity with patients.^{206 207}

Public perceptions of liver disease

“ The idea that liver disease is all someone’s [own] fault couldn’t be more wrong. But that perception overrides the whole structure.

Professor Graeme Foster, *Liver Disease: Today’s Complacency, Tomorrow’s Catastrophe (The All-Party Parliamentary Hepatology Group Inquiry into Improving Outcomes in Liver Disease, 2014)*

“ Public attention surrounding liver disease is not always positive due to its links to health inequalities and also the stigmatisation of this disease of being ‘self-inflicted’. Liver health has been suggested as a barometer for the wider health environment and that lifestyle-induced disease is the major challenge for global health in the 21st century.

Public Health England

How do UK adults view liver disease?

In public polling undertaken in 2017 by the British Liver Trust and ComRes it was found that:

- **91%** of respondents cited alcohol as the biggest risk factor for liver disease
- **58%** recognised that obesity and overweight increased the risk of liver disease
- When prompted, **56%** recognised that viral hepatitis also increased the risk of liver disease. However, only **6%** mentioned hepatitis spontaneously.

Only **5%** of British adults say their liver would be of great concern if they had a problem with it versus **72%** for a heart problem.²⁰⁸

Older British adults are more likely to be concerned about being told they had a problem with their liver than younger counterparts (**65%** of those aged 55+ versus **54%** of 18–34 year olds).²⁰⁹

When asked whether it was true or false that there were usually no symptoms in the early stages of liver disease, **75%** of people correctly said this was true.²¹⁰ **77%** of people also correctly agreed with the statement that it was true that alcohol is more likely to damage the liver if people are overweight.²¹¹

Perceptions of alcohol and liver disease

On a scale of 0–10, with 0 being ‘not at all related’ and 10 being ‘very strongly related’, the public rates the association between alcohol and ill-health as 7.3.²¹²

80% of people correctly thought that drinking alcohol increased the risk of liver cancer.²¹³



Public perceptions of liver disease

However, 63% of people agree with the following statement: 'Alcohol, if drunk in moderation, poses no risk to your health'.²¹⁴ Indeed, only 14% of drinkers are to some extent concerned about how much they drink, and of those, most are concerned because of health reasons.²¹⁵

More generally, 67% of people think the UK has an 'unhealthy' relationship with alcohol²¹⁶ and 55% want the government to do more to address the harm caused by alcohol.²¹⁷ 52% think the government is not doing enough to help people who have problems with / alcohol dependency in the UK.²¹⁸

When asked when whether most people who develop liver disease are 'alcoholics' is a true or false statement, 47% said it was true versus 53% who said it was false.²¹⁹ 45% of people believe that liver disease is almost always caused by alcohol consumption, versus 55% who believe that statement is false.²²⁰

Perceptions of obesity and liver disease

New research suggests that more than **four in five UK adults believe people with obesity are viewed negatively because of their weight** and **62% Britons think people are likely to discriminate against someone who is overweight.**²²¹



Liver disease due to non-alcohol related fatty liver disease (NAFLD) is increasing as the numbers of people who are overweight and obese rise. However, only 34% of people link being overweight to liver disease (versus over 80% understanding the link between excess weight and heart disease, high blood pressure and diabetes).²²²

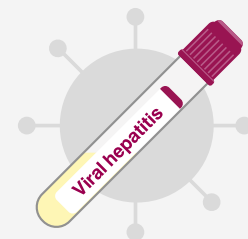
With more than 60% of the adult population now overweight or obese,²²³ and a third of children overweight by the time they leave primary school,²²⁴ predictions are that excess weight will become the primary cause of preventable liver disease, overtaking alcohol.²²⁵



Health experts suggest that around 18 million people in the UK could currently have non-alcohol related fatty liver disease (NAFLD), although only around 600,000 of these are currently on GP records.²²⁶

Viral hepatitis and liver disease

Poor awareness and the stigma surrounding hepatitis C particularly means that diagnosis and treatment rates are low (although improving – see Chapter 6). Although the condition is both preventable and treatable, it's the fastest rising cause of liver disease deaths in the UK because of its association with intravenous drug use.²²⁷



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- ² British Liver Trust Liver Disease – Are you at risk? [No Date] <https://www.britishlivertrust.org.uk/our-work/love-your-liver/love-liver-health-screener/> [Accessed: 18/03/2019]
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