

**BRITISH
LIVER
TRUST**

Sound the Alarm on liver disease in Wales

A call to action



The British Liver Trust is the largest UK liver charity for adults
and leads the fight against liver disease and liver cancer

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About the British Liver Trust



Dr Andrew Yeoman

**Consultant Hepatologist, Gwent Liver Unit
Clinical Lead, Wales Liver Plan**

I am delighted to support this ten-point action plan to address liver disease in Wales. Liver disease is a growing burden and is now the third biggest killer in those of working age. Since the launch of 'Together for Health – Liver Disease Delivery Plan' we have made great progress improving liver health across Wales and it is vital that we now build on this success.

I would urge all Members of the Senedd and policy makers to turn these recommendations into action so that we can reduce liver disease mortality.



The British Liver Trust, the UK's leading charity supporting adults with liver disease, and the Foundation for Liver Research, the largest UK charity funding research into liver disease, are working in partnership to highlight the unacceptable burden of liver disease in the UK and call for actions to improve liver health.

The British Liver Trust is a company limited by guarantee

Company registration number: 02227706
Charity registration number:
298858 (England and Wales),
SC042140 (Scotland)

A call to action

The British Liver Trust's Sound the Alarm on liver disease in Wales campaign is calling for urgent action to support improvements in liver disease awareness, prevention, treatment and outcomes.

It is vital we do not lose the momentum of the 'Together for Health – Liver Disease Delivery Plan; A Delivery Plan for NHS Wales and its Partners to 2020', which has been extended to finish in March 2022. This has delivered significant improvements in liver disease outcomes in Wales. Succession plans for the next steps need to be announced urgently. These ten policy proposals provide a basis to inform future planning.

Our ten-point call to action is:

1 Include liver disease as part of general health checks, when checking for other non-communicable diseases.

2 Increase access to tier 3 and 4 weight management services across Wales.

3 Actively support those suffering the effects of alcohol misuse in Wales, through the statutory backing of 24-7 Alcohol Care Teams in all Health Boards.

4 Deliver the 'Healthy Weight: Healthy Wales' programme to create an environment where healthier choices are the easiest choices for people in Wales.

5 Ensure that effective testing is offered for viral hepatitis to all 'at-risk' groups and that Wales meets the WHO 2030 target to eliminate hepatitis C.

6 Ensure the successful delivery of the 'All Wales Liver Disease Pathway'.

7 Increase the number of hepatologists; ensuring that patients have access to specialist treatment and support regardless of the geographical area in which they live.

8 Every patient with cirrhosis in Wales to have access to a specialist liver nurse, regardless of the geographical area in which they live.

9 Improve access to local services and support through better signposting and patient involvement.

10 Increase the number of referrals for liver transplants in Wales.

Sound the Alarm on liver disease in Wales

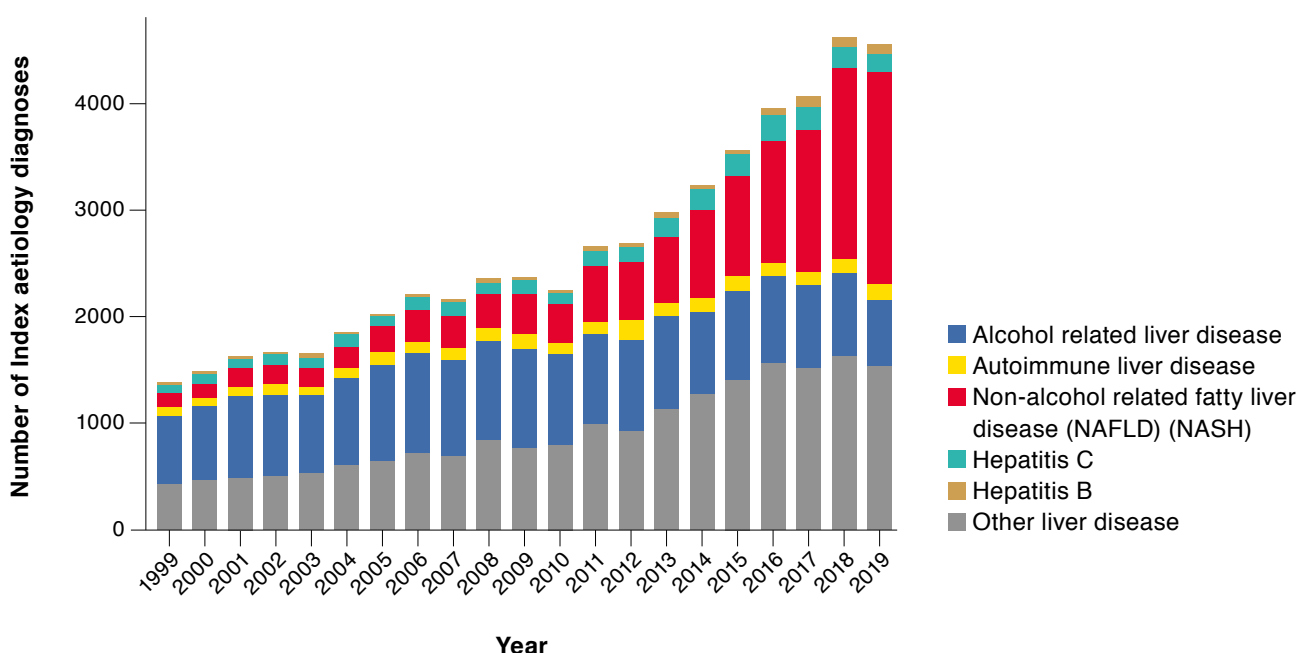
Wales is facing a liver disease crisis. Premature deaths in Wales from chronic liver disease have doubled in the past twenty years¹ and the prevalence is rising at an alarming rate. 90% of liver disease is preventable, yet it is now the biggest cause of death in those aged between 35-49 years old.

Obesity, alcohol consumption and viral hepatitis are the largest causes of liver disease. The proportion of children and adults in Wales who are of a healthy weight is dropping and around 61% of adults are overweight or obese². Approximately 330 people die from alcohol-related liver disease in Wales every year³.

The Covid pandemic has also highlighted the general risks around poor health and obesity, with 90% of those who died with Covid having significant prior poor health⁴. The key risk factors associated with liver disease and its outcomes are also directly linked to social deprivation and other inequalities.

A lack of awareness of the seriousness and prevalence of liver disease combined with no symptoms in the early stages leads to poor outcomes at the point of diagnosis.

Liver Disease Trends in Wales 2021



(The data was extracted from the Wales Liver Registry by Dr Tom Pembroke)

¹<https://gov.wales/sites/default/files/publications/2018-12/liver-disease-delivery-plan-2015-to-2020.pdf>

²<https://phw.nhs.wales/topics/overweight-and-obesity/>

³AlcoholAndHealthInWales2014_v2a.pdf

⁴Levelling+up+Health+Report+9+April+2021+FINAL.pdf (squarespace.com)

Background

As part of the Welsh Government's 'Together for Health – Liver Disease Delivery Plan', the British Liver Trust is working to raise awareness and improve liver health in Wales. We highlight the risk factors most often associated with liver disease to primary healthcare professionals and amongst the general public. Three quarters of people are currently diagnosed when it is too late for effective treatment or intervention. The aim is to detect liver disease much earlier, prevent liver disease worsening and give patients the best possible care and support.

We are calling for all stakeholders in Wales to commit to improving public awareness of liver disease, early detection in primary care and improving care and support for people who have liver disease, their families and carers.

The socio-economic impact of coronavirus and the associated delays in routine and planned healthcare make this work more important than ever before. British Liver Trust will continue to grow our reach and reduce health inequalities across all types of liver disease and liver cancer.

Alan's story

Alan from South Wales was diagnosed with Liver cancer in 2020.



When I was first told I had liver cancer it was hard to accept. Then Covid hit and my treatment was curtailed. It was a very difficult time for me and the whole family and the British Liver Trust supported me and helped me talk about my experience. Towards the end of the first Covid wave I received a call to let me know that my treatment would resume in Cardiff and it seems to be a lot better this time.

I have been one of the lucky ones, however too often I hear about others who were diagnosed too late. Liver disease really is the 'silent killer'.



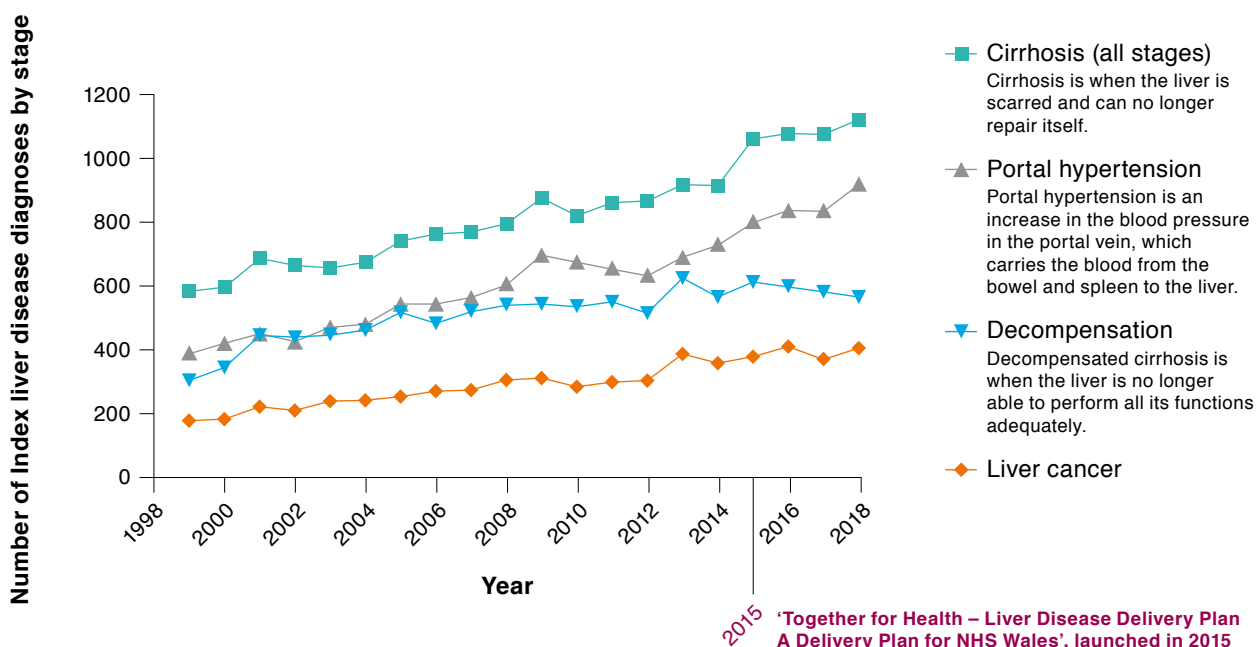
The scale of the liver disease problem in Wales

Premature deaths from chronic liver disease in Wales have more than doubled in the last 20 years.⁵

While there have been improvements in mortality from most other chronic conditions, such as strokes, heart disease and many cancers, the number of deaths from liver disease has increased by more than 400% in people aged under 65.

The graph below shows the rising trend in the serious consequences of liver disease in Wales.

Serious consequences of liver disease in Wales 1999-2019



(The data was extracted from the Wales Liver Registry by Dr Tom Pembroke)

From 1998 to 2015 the numbers diagnosed with liver disease in Wales has risen.

The graph above shows how this correlated with increases in serious liver harm. It also suggests that following the implementation of the 'Together for Health – Liver Disease Delivery Plan A Delivery Plan for NHS Wales', launched in 2015, there have been some signs of early stage improvements across some indicators. The number of cases of cirrhosis and portal hypertension continue to increase but this is to be expected as there have been improvements in diagnosing liver disease. The number of patients with decompensation seems to be decreasing, which suggests improvements in outcomes for those with cirrhosis. It is vital the Welsh Government continues to prioritise liver health so that this momentum is not lost and progress continues.

⁵'Together for Health – Liver Disease Delivery Plan A Delivery Plan for NHS Wales and its Partners to 2020', Published 2015
<https://gov.wales/sites/default/files/publications/2018-12/liver-disease-delivery-plan-2015-to-2020.pdf>

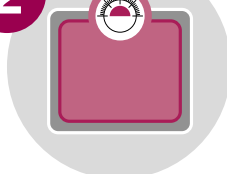
The three most common causes of chronic liver disease in Wales are:

1



Alcohol is the leading cause of liver disease deaths in Wales

2



Overweight and obesity is the major cause of non-alcohol related fatty liver disease

3



Viral hepatitis (most commonly hepatitis B or C)



One in five adults in Wales currently drinks alcohol in a way that could harm their liver

There is evidence to suggest that alcohol consumption is on the increase since the start of the COVID-19 pandemic.⁶



Effective alcohol treatment brings a substantial return on investment

For every £1 spent, £3 of social return is generated.⁷

There are now highly effective curative treatments for Hepatitis C and Wales is committed to the World Health Organisation goal to eliminate the virus by 2030. A safe and effective vaccine is available for Hepatitis B, which is now routinely given to infants.

“ *One in Five adults in Wales currently drinks alcohol in a way that could harm their liver.*

⁶‘Covid-19 and alcohol—a dangerous cocktail’, Published 20 May 2020 (<https://www.bmj.com/content/369/bmj.m1987>)

⁷Alcohol and drug prevention, treatment and recovery: why invest?, Published 12 February 2018 <https://www.gov.uk/government/publications/alcohol-and-drug-prevention-treatment-and-recovery-why-invest/alcohol-and-drug-prevention-treatment-and-recovery-why-invest>

Fighting the liver disease crisis in Wales: a framework for action

This document sets out how Wales can best achieve the aims within the ‘Liver Disease Delivery Plan 2015’, which ends in March 2022, and how to further improve liver health across the population of Wales. It is vital we do not lose the momentum of the Plan, which has delivered improvements in liver disease outcomes in Wales.

1 Include liver disease as part of general health checks, when checking for other non-communicable diseases.

The British Liver Trust scanning and screening roadshows in Wales revealed around 20% of participants from the general public required further investigation of their liver, recording a FibroScan score higher than considered healthy (above 7kpa). Many of these people would not have known they had deterioration of their liver health. When the roadshow visited Bridgend this figure reached 34% of participants.

In line with the principle of ‘Making Every Contact Count’ testing for liver disease through the programme has the potential to identify people whose liver disease could have remained undetected.

NHS Wales must achieve some major changes in the way services are delivered over the next few years. Healthcare professionals will need training to enable them to improve the early detection of liver disease and provide quick interventions such as weight management and alcohol advice to patients.

“When the Love Your Liver roadshow visited Bridgend, 34% of participants’ FibroScans showed deterioration in their liver health.

2 Increase access to tier 3 and 4 weight management services across Wales.

There is currently unequal access to tier 3 adult weight management services (non-surgical specialist management) across Health Boards in Wales. This acts as a barrier to accessing tier 4 services (bariatric surgery). Wales currently undertakes significantly fewer bariatric surgical procedures than England and Scotland per head of population.

3 Actively support those suffering the effects of alcohol misuse in Wales, through the statutory backing of 24-7 Alcohol Care Teams in all Health Boards.

Drinking too much alcohol is the leading cause of liver disease mortality in Wales.

We welcome the implementation of Minimum Unit Pricing for Alcohol in 2020 as a means of reducing consumption. In the first year of implementation (2018) Minimum Unit Pricing is estimated to have reduced net off-sales purchases in Scotland by between 4% and 5%.

To build on this, legislation on licencing should be comprehensively reviewed in Wales. Licensing authorities must be empowered to tackle alcohol-related harm by controlling the total availability of alcohol in their jurisdiction.

We call on the government to reform the sale of alcohol so that it is restricted to specific times of the day and to prevent promotional cross-merchandising in an equivalent manner to that in Scotland.

In addition, we call on the Senedd to advocate for legislation to reform alcohol packaging to include information about the health risks of alcohol on the product, including the calorie content and a clear number of units.

Finally, we call for a drug and alcohol counsellor to be available to every GP surgery in Wales (either directly or through social prescribing to a community-based service).

Calorific and alcohol unit information should be included on all alcohol products.

“ *Minimum Unit Pricing is estimated to reduced net off-sales purchases by between 4% and 5%.* ”

4 Deliver the ‘Healthy Weight: Healthy Wales’ programme to create an environment where healthier choices are the easiest choices for people in Wales.

British Liver Trust welcome the Well-being of Future Generations (Wales) Act 2015, which establishes the ambitious legal obligation to improve our social, cultural, environmental and economic well-being. We call for prevention to start early in people’s lives by safeguarding children from junk food marketing and creating healthier retail environments.

There are also clear cost benefits around incentivising a healthier environment. Illnesses associated with obesity are projected to cost the Welsh NHS more than £465 million per year by 2050⁸. Obesity rates in Wales are also very high, with around 60% of adults in Wales being either overweight or obese⁹.

We call on the Welsh Government to introduce ‘population-level measures based on the regulation of common environmental factors which help drive consumption of alcohol and unhealthy food and drink’. The Government must commit to greater investment in targeted support services and ensure they reach everyone in Wales who needs them.

⁸Welsh (English) NCD Paper.pdf

⁹Ibid

5 Ensure that effective testing is offered for viral hepatitis to all ‘at-risk’ groups and that Wales meets the WHO 2030 target to eliminate hepatitis C.

There are an estimated 8,000 people¹⁰ chronically infected with hepatitis C in Wales, with many drawn from marginalised and deprived groups in society. Many of those infected remain undiagnosed. There are now highly effective curative treatments and the Welsh Government has signed up to the WHO strategy to eliminate hepatitis C as a significant public health threat by 2030.

However, there are concerns, raised by the Senedd’s Health, Social Care and Sport Committee, around meeting this target in their 2019 Hepatitis C Report¹¹. Only around 600 people were treated for hepatitis C in Wales in 2018/19, short of the target of 900 patients accessing treatment per year. We are also concerned that hepatitis C treatment initiations were 81% lower in April 2020 than April 2019, as services were impacted by the pandemic. We would urge the Government to retain its commitment to deliver on the WHO strategy to eliminate hepatitis C by 2030 and to meet their own treatment targets.

Finally, there is uncertainty around funding for the Hepatitis C Elimination Programme as funding for dedicated posts is only confirmed until 2021. This affects many of the areas that have been put in place, including a National Project Lead role, a National Pharmacist and a Point of Care Testing Lead.

6 Ensure the successful delivery of the ‘All Wales Liver Disease Pathway’.

The ‘All Wales Liver Disease Pathway’ will ensure that every Local Health Board in Wales has commissioned a clear pathway for the early detection of liver disease that includes testing for fibrosis (i.e. FibroScan/ELF Test/FIB-4 etc.) The Pathway must include ways to support FibroScan testing, which is a quick and simple test to assess liver health, with a prompt result. They have previously only been accessible based on where the tests fall under each Health Board pathway, which has differed across Wales. It also depends on the number of FibroScan machines available in that area and those qualified to use them.

7 Increase the number of hepatologists; ensuring that patients have access to specialist treatment and support regardless of the geographical area in which they live.

The early input of liver specialists improves patient survival and is associated with $\geq 20\%$ survival¹².

At present there are 15 consultant hepatologists in Wales. However, two are academics and at least two others are part-time and four others do a significant amount of work on general gastroenterology. They are also unevenly distributed with almost two thirds practising in Cardiff and Gwent. Patients who call the British Liver Trust helpline report being unable to see a hepatologist in order to get the care and support that they need.

¹⁰<http://www.hepctrust.org.uk/campaigning/campaigning-wales>

¹¹Hepatitis C: Progress towards achieving elimination in Wales (senedd.wales)

¹²Roberts SE, John A, Brown J, Napier DJ, Lyons RA, Williams JG. Early and late mortality following unscheduled admissions for severe liver disease across England and Wales. 2019)

The British Society of Gastroenterologists recommend there should be one gastroenterologist for every 40,000 adults. There should be one hepatologist for every two to three gastroenterologists, so it's a reasonable aspiration to have one hepatologist or gastroenterologist with an interest in hepatology for every 80,000-120,000 adults. This equates to an increase in posts of 67 - 100% or an additional 10-15 full-time equivalent posts across Wales.

“ *The early input of liver specialists improves patient survival and is associated with $\geq 20\%$ survival.*

8 Every patient with cirrhosis in Wales to have access to a specialist liver nurse, regardless of the geographical area in which they live.

More areas of Wales need to have increased nursing resource to cover the work of a larger geographical area. For example, Powys has one specialist nurse to cover Ceredigion, North Powys and some patients from South Powys as well. There is also a general gastroenterologist covering this area rather than a specialist hepatologist. Conversely, Cardiff and the Vale has access to dedicated nurses for alcohol, liver disease and blood borne viruses (BBV). Whilst it is understandable to have fewer nurses per population head, the amount of travel time and geographical area needs to be considered for giving patients access to support.

There is currently no succession plan for the specialist liver nurses in Wales in terms of those approaching retirement. In addition to this, sometimes there is no cover at all for maternity or sick leave.

9 Improve access to local services and support through better signposting and patient involvement.

Improving quality of life for people with liver disease is essential. In this regard the provision of high-quality information on local services and how to navigate them is vital. Local patient support groups should be encouraged to provide feedback on services and facilitate the co-production of clinical services.

10 Increase the number of referrals for liver transplants in Wales.

Wales has historically lower rates of liver transplant referral and lower rates for successful liver transplants compared to the rest of the UK. The 2019-2020 data shows improvements but successful transplantation levels remain below the average in England, Scotland and Northern Ireland. Previous data has shown the distance from a transplant centre can negatively influence transplant rates. However, regions without a transplant centre such as the South West of England (Plymouth) and Northern Ireland, have shown what can be achieved through the development of specialist liver services and a networked approach.



About the British Liver Trust

The British Liver Trust is the largest UK liver charity for adults and leads the fight against liver disease and liver cancer.

Whilst recent years have seen great progress for patients with liver disease in Wales, there is still significant work ahead. The British Liver Trust team in Wales focuses our efforts on supporting patients using localised knowledge and relationships, including working with NHS management teams and health and wellbeing networks in every county.

Our work raises awareness of the risk factors of liver disease and provides vital advice to help people improve their liver health. We empower patients with up to date information and support including a free nurse-led helpline and online community.

We are the voice of patients, their families and carers across the nation and continually advocate for improvements in outcomes for liver health in Wales.

For further information on the British Liver Trust or this document please contact:

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