



Towards a world without liver disease Our strategy for 2021–2024



**Transforming liver health through increased awareness,
prevention, improved care and support**



Introduction from our Chief Executive

Liver disease is the big killer that no one is talking about. This needs to change.

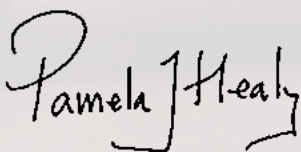
Today in the UK, liver disease is the third leading cause of premature death. Three quarters of people are diagnosed at a late stage by which time it is too late for effective intervention or treatment. There is a huge lack of awareness of how serious liver disease is and the sheer numbers of people affected. Together with stigma, this means liver disease is far too often overlooked and does not get the attention that the other big killer diseases receive. We will sound the alarm on liver disease and liver cancer and make the case for action.

I believe that over the next three years we can deliver a step change for liver disease across the UK. We will work with the national and devolved governments and health services in England, Northern Ireland, Scotland and Wales to make sure everyone in the UK gets the care they need. We are at a tipping point and by working in partnership we can greatly increase the profile of both liver disease and liver cancer, drive up standards of care and reduce the widespread variation that we see across the UK.

Every day at the British Liver Trust we hear heart-breaking stories from people who have not received the care, support and information that they need. We will be there for everyone with liver disease and liver cancer. We will support you in person, on our nurse-led helpline and through online groups. We will make sure you have the best information, when and how you need it. And we will listen to your experiences, worries and hopes, and make sure your voice is heard.

This strategy outlines how we will break the silence and raise awareness of liver disease among the general public, healthcare professionals, politicians and the media. We will tell the real story of liver disease and liver cancer. The harsh truths of poor outcomes and stigma. The promise of better care for more people. And the golden opportunities of early detection, prevention and even reversal of liver damage.

Thanks to you we have started to build the foundations for a world where liver disease and liver cancer are no longer overlooked. Help us start to make it a reality.

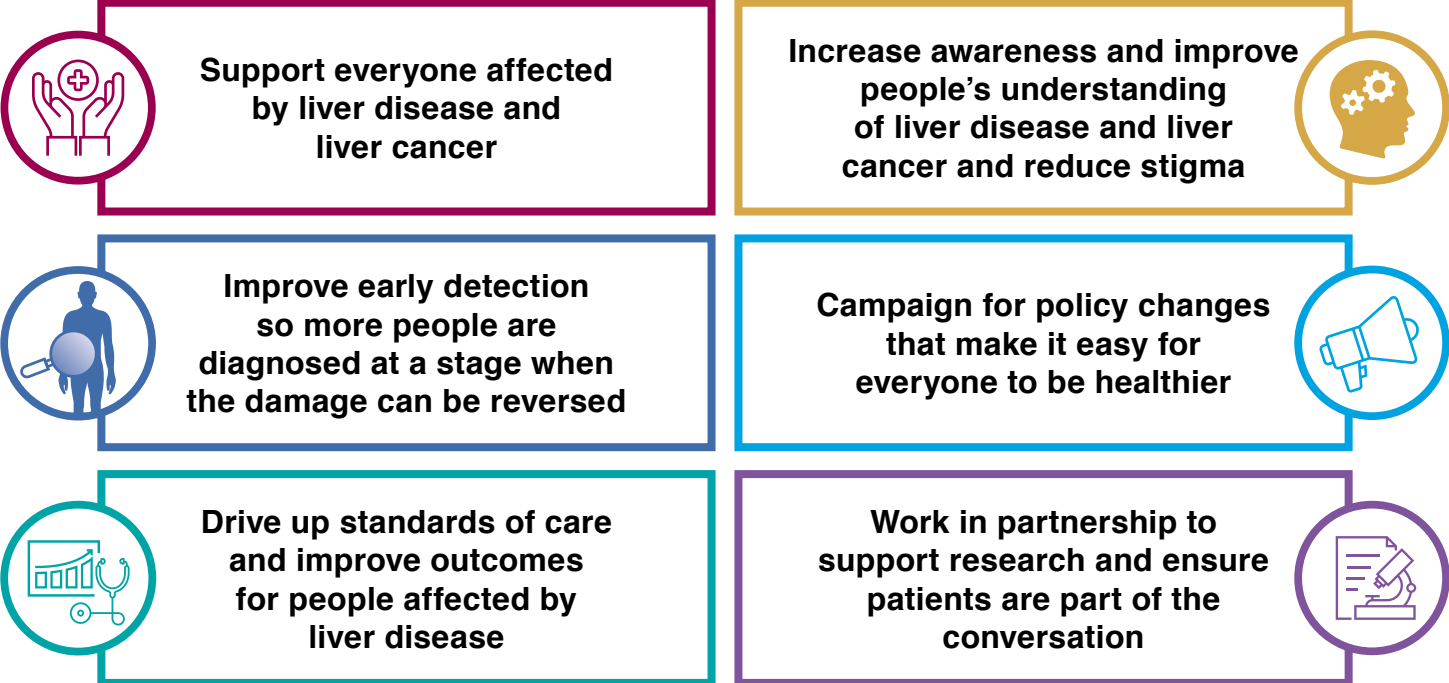


Pamela J Healy OBE
Chief Executive



Our strategic priorities 2021–2024

Our strategic priorities flow from our goals and describe the changes we will set in motion over the next three years.



Grow our capacity to deliver change and make sure we achieve our goals

- Increase our income across different streams
- Hardwire diversity and inclusion into our organisation
- Remain flexible and innovative
- Measure our progress, learn from ourselves and others, and evolve our priorities and plans accordingly



Support everyone affected by liver disease and liver cancer

In 2020, we asked over 2,000 people with liver disease or liver cancer about their care. Overwhelmingly, people told us that they aren't given enough information at diagnosis or during treatment. Nine in ten people seek out more information after appointments, usually on the internet. The British Liver Trust is a vital, credible source that people can trust – we must make sure our information is easily available to everyone who needs it.

Being diagnosed with liver disease or liver cancer often comes as a shock. Especially as many people are diagnosed with late stage disease without having felt ill or experienced symptoms. Whatever the cause, living with liver disease can be incredibly challenging. From dealing with symptoms and medical complications to making significant changes to diet and drinking habits. No one should go through this alone.

“*Being diagnosed with liver disease is like being given a diagnosis of cancer with none of the support and it is not so easy to be open about*”



“ *I know I need help but don't know how to get it*

“ *More support is needed to help with the psychological and health & wellbeing side of liver disease. Often after diagnosis it can be a scary time, there can be much unknown and approaching transplant stage I was offered no support in the form of counselling*

Double the number of people our specialist nurses support

Empower patients to demand excellent care by making sure they know what it looks like and how to discuss concerns with their medical team

Develop our engagement with healthcare professionals so patients are routinely signposted to our information and support by their healthcare teams

Increase opportunities for people to engage with us digitally, by growing our online forum and introducing online FAQs and webinars

Expand peer to peer support by growing the number of virtual and face to face groups

Put people with liver cancer and liver disease at the heart of our information by building our activities on deep insight into their needs, attitudes and motivations

Build on our existing services and use new and innovative ways to engage and empower patients so they can get the information they need however and wherever they choose to access it

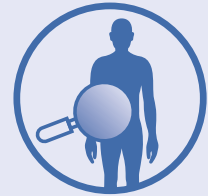


Improve early detection so more people are diagnosed at a stage when the damage can be reversed

There is a huge opportunity to change the future picture of liver disease and liver cancer. The liver is the only internal organ that can repair itself. If diagnosed early, for many people further liver damage can be prevented and existing disease reversed and effectively cured. For others, with genetic or autoimmune liver disease, earlier diagnosis means quicker access to the care they need.

Liver disease can go undetected for years because it often shows no symptoms. Many people are currently walking around completely unaware they have liver disease – it is an unrecognised major public health crisis.

Finding liver disease earlier will need GPs and primary care nurses to proactively look for it in their patients. To do this, they need clear guidelines and an easy to implement pathway to refer people for the right tests and treatment.



- ⚡** Three quarters of people with liver disease are diagnosed in hospital as an emergency by which time there is often no option for treatment or intervention
- ⚡** It can take up to 20 years for liver disease to progress to a stage where symptoms begin to show
- ⚡** Seven in ten people with liver disease are undiagnosed and unaware that they already have some degree of liver damage

Raise awareness of the risk factors through our Love Your Liver campaign and drive more people to take our online liver health screener

Increase the number of Love Your Liver Roadshow events that provide liver scanning so that we hold 75 events each year and visit every region at least every two years

Build the evidence base for early detection and share best practice

Push for national policy that puts levers in place to encourage early detection of liver disease and makes managing and referring patients part of everyday practice

Influence regional commissioning bodies to introduce a programme in their areas through a targeted campaign

Work with GPs and primary care nurses to increase their knowledge and skills to detect liver disease earlier



Drive up standards of care and improve outcomes for patients

People diagnosed with liver disease and liver cancer experience very different care depending on where they live in the UK. Many local hospitals do not have a dedicated hepatology service and many services are stretched. There needs to be a clear management pathway for everyone with liver disease and liver cancer, so their care isn't left to chance.

We work in partnership with professionals from across the health service to improve standards of care. We work with government and policy makers from all the UK nations to make sure guidelines are updated in light of new research and examples of best practice. And challenge the NHS to make sure guidelines are put into practice. By tackling all types of liver disease and working with our health systems as a whole, we can drive up standards of care for everyone.



- ⚡** Only 12% of people diagnosed with primary liver cancer survive for more than five years
- ⚡** Over 40 people die from liver disease every day
- ⚡** Four out of ten patients told us they waited more than six months for a referral

Build a UK Liver Alliance with other liver disease charities, clinicians, patient groups, and other experts to coordinate our efforts and campaign more effectively

Lobby for improvements in alcohol services, including more alcohol care teams in hospitals, so they're available for everyone who needs them

Tackle liver cancer in a co-ordinated campaign to increase the number of cancer nurse specialists and improve surveillance

Highlight preventable deaths and make sure that health services are aware of excellent practice and share new and improved ways of working

Work with the Improving Quality in Liver Services (IQILS) scheme to ensure more liver services achieve the high standards required for excellent care. Keep patients informed about the scheme, what it means for them, and how they can get involved

Bring together people affected by liver disease and liver cancer, to understand and represent their views and make sure they are part of the conversation in improving care



Improve people's understanding of liver disease and liver cancer to raise awareness and reduce stigma

Liver disease is the third biggest cause of death in working age people in the UK – and is the only big killer disease where the number of deaths continues to rise. Yet it is often overlooked and people know relatively little about it.

The first step to effectively tackle liver disease and liver cancer is for the UK public and politicians to take it seriously and understand the impact on the UK's health.

People with liver disease often face stigma and blame. High levels of prejudice are a major barrier to getting the right care and support for people with all types of liver disease. This adds to the burden of people living with a serious health condition they did not choose.

It is only by working together that we will be able to make the lives of those affected by liver disease better. We will start to break down that stigma by increasing the public's understanding of liver disease and telling the stories of people with liver disease and liver cancer.



- ⚡ Liver disease is the only major cause of death on the increase in the UK while decreasing among our European neighbours
- ⚡ Only 5% of British adults say their liver would be of great concern if they had a problem with it compared to 72% for a heart problem
- ⚡ Four in five adults believe people with obesity are viewed negatively because of their weight

Engage more people than ever before to take action on liver disease and liver cancer

Deliver our *Sound the Alarm* campaign to raise awareness of the seriousness of liver disease and call for policy change

Create a movement for change. Reach new people with our message. And activate existing and new supporters to create champions for our cause

Raise awareness of the different types of liver disease

Tell the real story of liver disease and liver cancer in the UK, drawing on people's experiences as well as the latest statistics and research

Push liver disease and liver cancer up the media and political agendas and keep it there





Campaign for policy changes that make it easy for everyone to be healthier

Our culture, what we believe and how we behave aren't fixed – they have always changed with the times. We have shown before that things that seem to be an everyday fact of life can change for the better. From seat belts becoming the norm to dramatic falls in smoking rates and plastic bag use, we can drive change in our society.

We need to address the underlying causes of preventable liver disease. Alcohol has become a central part of our culture. And we are up against a flood of unhealthy food, piled high in supermarkets and promoted wherever we turn. Two thirds of UK adults are now overweight or obese, yet this was not the case just a generation ago. This dramatic difference must be due to changes in the world around us – and we can change it for the better.

By working in partnership with bodies such as the Alcohol Health Alliance and the Obesity Health Alliance we can influence laws and policy in all the UK nations to shape a healthier future for everyone and reduce the burden of liver disease across the UK.



- ⚡** 90% of liver disease is caused by alcohol, obesity or viral hepatitis
- ⚡** 67% of people think the UK has an ‘unhealthy’ relationship with alcohol and 55% want the government to do more to address the harm caused by alcohol
- ⚡** 74% of people support a drive from the Government to address obesity in the wake of COVID-19

Raise people’s awareness of their own liver health and ways they can improve it

Work with charities and other stakeholders to campaign for joined up strategies that will improve everyone’s health

Deliver information and training to GPs and primary care nurses, giving them the tools to talk about preventing liver damage with their patients

Demand policy change to reduce the UK’s obesogenic environment and make it easier for everyone to be healthy



Campaign to change the UK’s alcohol culture including making it normal to ask for help with alcohol problems, so nobody needs to feel ashamed or to fear losing their reputation or career



Work in partnership to support research and ensure patients are part of the conversation

Research into liver disease and liver cancer is poorly funded compared with other conditions. We partner with key organisations including funders and research bodies to influence how they and others invest in research.

Patients must be part of the decisions made on research. Bringing them into the conversation from the beginning helps make sure research answers the questions that matter most to patients.

“ *The six least survivable cancers, including liver, collectively receive one quarter of the amount of government research funding given to other common cancers* ”



“ *Liver disease research needs to have the same standing and funding as for other major diseases*

Work with others to stimulate investment and ensure research meets patient needs

Provide patient and public involvement in research projects from governance and design to communication of results

Commission at least one piece of research into the impact of the British Liver Trust's work delivering early diagnosis in the community

Support researchers with grant applications and sharing results

Build the evidence base and ensure research findings are considered in the provision of care and development of new policy



Liver disease is at a tipping point.

By acting now we can slow, halt and then reverse the rising tide of deaths from liver disease and liver cancer.

But we can't do it alone.

Join our communities

Stand with us. The louder our voice, the bigger our influence. Sign up for our newsletter, follow us on social media, join our patient forum.

Raise awareness

More people need to know about liver disease and the British Liver Trust. Tell your story, share our materials, put up posters, hold an event.

Donate

Every gift helps, no matter the size. A monthly donation helps us plan for the future.





The British Liver Trust is a company limited by guarantee
Charity registration number: 298858 (England and Wales), SC042140 (Scotland)