



Fighting liver disease
Registered charity No. 298858

Prevention and control of viral hepatitis: Role and impact of liver patient groups in Europe

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UK

History of the organisation



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- The British Liver Trust was founded in 1988 by Dame Sheila Sherlock
- It is the only national UK charity for ALL forms of liver disease
- The last decade has seen a wider recognition of liver disease in society
- Alcohol, obesity and hepatitis C has been described by the Chief Medical Officer as a 'potential triple hit'.
- Helpline was started in 2003
- Re-launched Trust website in August 2007



Objectives and role of Trust



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Mission:

The British Liver Trust aims to reduce the incidence of liver disease, and to help everyone affected by liver disease, through the provision of information, support and research.

- The British Liver Trust works to:
 - support people with all kinds of liver disease
 - improve knowledge and understanding of the liver and related health issues
 - encourage and fund research into new treatment
 - lobby for better services



Organisation of Trust



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- 18 members of paid staff
- 6 volunteers
- Three departments
 - Information and Education
 - PR, publications, marketing, helpline, website
 - Fundraising
 - Community, trust and statutory, corporate
 - Operations
 - Administration/HR/finance



Target audience



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- Wide reach in sectors of society
 - People who drink alcohol at hazardous and harmful levels
 - People who may be overweight and more susceptible to fatty liver
 - High risk groups for viral hepatitis
 - Hereditary/genetic conditions relating to the liver
- Supported by nearly 20 pharmaceuticals
- 7,000 stakeholders. They include:
 - Healthcare professionals, healthcare workers, patients, carers, families, occupational health
- In 2007:
 - Over 1 million visitors to our website
 - Publication sales increased by 128%
 - Calls to our helpline increased by 39% in 2007

Services and activities: general



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- Patient information – we produce 23 patient information publications
- Support people and their families through the whole course of liver disease: from prevention, diagnosis, treatment, and where necessary, coping with symptoms and managing complications of cirrhosis.
- Research
- Lobbying
- Public relations and press coverage



The Daily Telegraph

Services and activities: prevention

- Advice through helpline and online support
- Advice through publications
- Lobbying for better public protection through vaccination and public awareness campaigns
- Project to encourage those in custody to change behaviour to protect against blood borne viruses using graphic images & language
- Advice in other languages to respond to needs of migrants at risk of viral hepatitis and its complications
- Raise awareness of liver disease through the media



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سبھی

Hepatitis B – Multilingual patient information leaflets.

Now available in Urdu, Bengali, Hindi and Mandarin.

To download and print visit
www.britishlivertrust.org.uk/translations

BRITISH LIVER TRUST

Sponsored by an educational grant from GlaxoSmithKline

GILEAD

Support and financing



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- Trusts: 40%
- Individuals: 21%
- Statutory: 17%
- Corporate: 14%
- Community: 5%



Other patient organisations active in the UK

- Children's Liver Disease Foundation
- C-Level
- Liver transplant support
- Mainliners
- Obstetric Cholestasis Support
- PBC Foundation
- PSC Trust
- The Hepatitis C Trust
- The Hepatitis B Foundation



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Strengths



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- Umbrella organisation on all forms of liver disease
- Strong links with hepatologists
- Wide services for patients: support groups, helpline, publications and website (with online patient forum)
- Regularly quoted in national press – TV, print and online
- Use of high media & political interest in alcohol: springboard to wider work on liver.



Strengths toward improved prevention

- Submission to Department of Health review of liver services
- Campaign with stakeholders on hepatitis B awareness and lobbying for vaccination (B Aware initiative)
- Campaign with Government on hepatitis C awareness and screening (FaCe It)
- Support activities of the APPHG
- Key stakeholder in NICE
- Part of the coalition of health organisations regarding the harm that alcohol causes – Alcohol Health Alliance
- Other stakeholder work on hepatitis C for World Hepatitis Day and Parliamentary Group
- BBC Radio 4 programme on preventing liver disease
- Work to raise awareness about hazards of alcohol & ease of liver damage
- Plans for new prevention publications



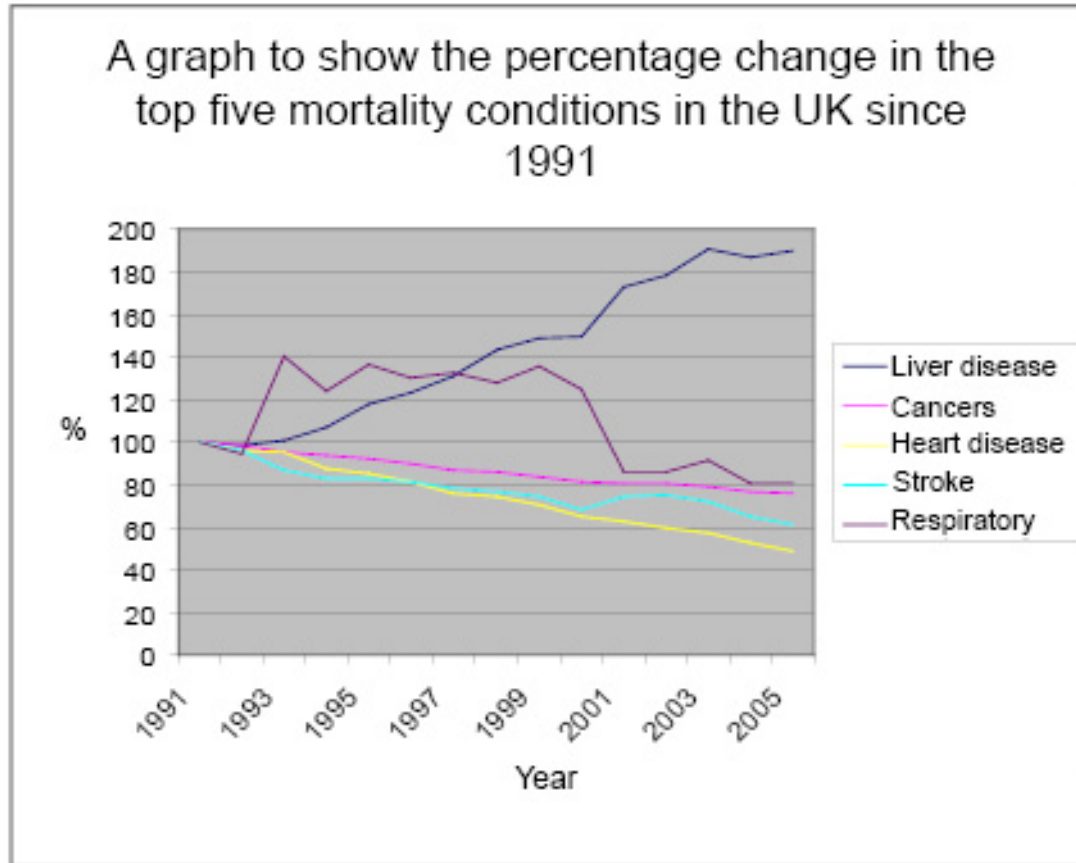
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Challenges



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Challenges



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- Stigma of liver disease: public stereotypes of liver disease as a lifestyle disease deserving little sympathy,
- Only one of 5 'big killers' with no Government action plan
- High rates of inward migration to the UK from areas of high prevalence of viral hepatitis
- Confusion between different types of viral hepatitis: high rates of hep A vaccination amongst travellers and resulting mistaken sense of protection against B and C



Challenges



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- Delays and barriers to antiviral treatment through NICE appraisal
- Fundraising: remains a challenge with corporates, government and individuals
- Low public awareness and education about the liver
- Crowded patient group sector: liver charities face competition and are relatively small
- Media hazard: alcohol provides an easy route to media coverage but can confirm stereotypes about liver disease.



Challenges in improving prevention



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- Responsibility for prevention
 - For example: policy on injecting drug users, viral hepatitis, youth policy is split between three government departments
- Lack of approved statistics on prevalence
- Primary care physicians not incentivised or covered to provide various prevention services
 - including hepatitis B vaccination they are able to charge, very rare in the NHS and a strong disincentive for UK patients
- Lack of universal hepatitis B vaccination
- Poor awareness of risk factors for hepatitis B and C
- Some disconnect between prevention work on B and C
 - FaCe It Government campaign only covers hep C).



Conclusion



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- **NHS system** offers the potential for a integrated and funded system covering prevention, diagnosis and treatment of viral hepatitis.
- Needed more than ever before with high rates of **inward migration**.
- **Policy changes** needed
 - universal hepatitis B vaccination, official prevalence studies, further public awareness campaigns to encourage prevention & screening.
- British Liver Trust is working with government, media and hepatologists as well as patients to improve protection from impact of viral hepatitis.

