



National End of Life Care Programme Improving end of life care



Deaths from liver disease Implications for end of life care in England

March 2012

Foreword

The number of people who die from liver disease in England is rising. There was a 25% increase in liver disease deaths between 2001 and 2009. This is in contrast to other major causes of death, which have been declining.

Although numbers of deaths due to cancer, vascular or respiratory disease are still much greater, liver disease kills people at a much younger age – a striking 90% of people who die from liver disease are under 70 years old. When measured as 'years of life lost', liver disease is therefore much more prominent. This report makes for stark reading on this subject.

There are a number of reasons why end of life care for people with liver disease is particularly challenging. Patients tend to be younger and often come from either isolated or ethnically diverse subcultures. They are more likely to have come to healthcare attention by circuitous routes of access. They may feel great stigma associated with their disease, the progress of which is punctuated by acute exacerbations. Most of all, perhaps, it is challenging because the cause of their death may have been preventable.

With over 70% of people with liver disease dying in hospital, this report is timely in helping us understand the challenges in managing end of life care for this patient group.

The key drivers for the growth in burden and mortality from liver disease are all preventable: alcohol, obesity, hepatitis C and hepatitis B. The outcomes frameworks which have followed on from the government White Papers *Liberating the NHS* and *Healthy Lives, Healthy People* both set an ambition for reduction of mortality in people under 75 years. Addressing the underlying causes and consequences of liver disease will therefore be important in efforts to achieve this reduction.

Even if policy and public health measures were one hundred percent effective, we know that the long 'gestation' period for progression of liver disease will result in the continued presentation of liver disease to health service providers for years to come.

Professor Martin Lombard National Clinical Director for Liver Disease

Contents

For	eword		1
Sui	mmary		3
1	Introd	uction	4
	1.1	Aims	4
2	Metho	odological notes	5
	2.1	Source of data	5
	2.2	Analysis	5
	2.3	Liver disease categories	5
	2.4	Cause of death	6
	2.5	Place of death	6
	2.6	Analysis by deprivation quintile	7
3	Resul	ts	8
	3.1	The number of deaths from liver disease	8
	3.2	Regional variation	9
	3.3	Variation with sex	12
	3.4	Variation with age at death	13
	3.5	Variations with age at death and sex	16
	3.6	Variation with deprivation	17
	3.7	Deaths with any mention of liver disease	19
	3.8	Place of death	21
4	Concl	usions and recommendations	26
5	Future	e investigations	26
Ref	ference	S	27
	•	1: Trends in deaths from alcoholic liver disease, including deaths	28
		2: Distribution of place of death by age at death for each underlying	29

Summary

This report presents key facts about deaths from liver disease in England. It highlights differences in place and cause of death by age, sex and deprivation. It is aimed at commissioners and providers of end of life care, clinicians caring for patients with liver disease, and others concerned with providing quality end of life care for this patient group, including patients themselves and their carers.

Key findings:

- Liver disease causes approximately 2% of all deaths.
- The number of people who die from liver disease in England is rising (from 9,231 in 2001 to 11,575 in 2009).
- More men than women die from liver disease (60% are men, 40% women).
- Liver disease disproportionately affects younger age groups:
 - 90% of people who die from liver disease are under 70 years old
 - more than 1 in 10 of deaths of people in their 40s are from liver disease, most of them from alcoholic liver disease.
- Alcoholic liver disease accounts for well over a third (37%) of liver disease deaths.
- There are three times as many deaths from alcoholic liver disease in the most deprived areas as in the least deprived.
- People dying from liver disease often have complex end of life care needs and over 70% die in hospital.

Death from liver disease is often associated with stigma. Many but by no means all of the people dying from liver disease come from deprived socioeconomic backgrounds. Those dying of alcoholic liver disease may have mental health problems and/or drug dependence problems which complicate their social circumstances such that they have little family or social support.

The course of advanced liver disease is also complicated, with acute and sometimes near fatal exacerbations necessitating hospital admission, but from which patients can make a good recovery.

For these reasons, end of life care discussions and planning are challenging. This report gives the first summary of high level statistics on deaths from liver disease on which future discussions can be built.

1 Introduction

In England, 2% of deaths between 2001 and 2009 were from liver disease (that is, an average of 10,544 people each year had a liver disease recorded as the underlying cause of death on their death certificate).

The proportion of deaths in England with a mention of liver disease (that is, either as the underlying cause or a contributory cause) on the death certificate, in the same time period, was 3%.

1.1 Aims

The aim of this report is to analyse and present the latest data on place of death for those with liver disease and to show how this varies with sex, age, region, socioeconomic deprivation and place.

It will help inform decisions by end of life care policy makers, commissioners and providers, and inform patients, their carers and the non-statutory bodies who support them.

The report was commissioned by the National End of Life Care Intelligence Network to support national end of life care service planning and development.

National strategy and policy supporting this work includes:

- The National End of Life Care Strategy (Department of Health, 2008)
- Improving Liver health and Outcomes in Liver disease (National Liver Plan, 2009)
- Reducing Alcoholic Harm: Health Service in England for Alcoholic misuse (National Audit Office: Department of Health, 2008)
- Public Health Outcomes Framework (Department of Health, 2012)
- The NHS Transparency in Outcomes Impact Assessment (Department of Health, 2010).

Also, a national strategy for liver disease is currently being produced by the Department of Health.

2 Methodological notes

2.1 Source of data

All data presented in this report are from the Office for National Statistics (ONS) mortality files. The mortality files contain extracts from death certificates. Key data items used for this analysis include place of death, postcode of 'normal' place of residence, date of birth, sex and cause of death.

2.2 Analysis

Data in this report are presented as absolute numbers and proportions, as well as some age-standardised rates, to support service planning.

2.3 Liver disease categories

The following liver disease categories, approved by the National Clinical Director for liver disease, were used. Definitions draw on information from The British Liver Trust (www.britishlivertrust.org.uk):

alcoholic liver disease

fatty liver disease

There should be little or no fat in a healthy liver. Fatty liver is the name given to a condition in which you have too much fat in your liver. Today it is one of the most common forms of liver disease and is known to lead to advanced conditions. The effects of having fat in the liver over a long period may lead to inflammation causing swelling and tenderness (hepatitis) and then to scarring (fibrosis). This condition can be caused by excess alcohol, and is then called alcoholic liver disease, or it can have other causes, for example diabetes, and is then called fatty liver disease.

liver cancer

In this report, liver cancer is only primary malignant tumours of the liver. Benign tumours and tumours resulting from spread of cancer from other organs of the body also occur in the liver, but deaths from these conditions have not been included.

other chronic liver disease

Deaths from conditions in this group are dominated by fibrosis and cirrhosis of the liver. Cirrhosis is the result of long-term, continuous damage to the liver and may be due to many different causes. The damage leads to scarring, known as fibrosis. Irregular bumps (nodules) replace the smooth liver tissue and the liver becomes harder. Together, the scarring and the nodules are called cirrhosis.

hepato pancreatic biliary (HPB) (Pancreatitis) patients likely to present with abnormal liver function tests (LFTs) or jaundice

This category is defined quite broadly; as alcohol is a major cause of pancreatitis, a proportion of patients with HPB will also have liver disease. Also, it can be difficult to discern whether jaundice and abnormal liver function tests have their cause in the liver, biliary tract or pancreas.

viral liver disease

Includes acute and chronic viral hepatitis.

2.4 Cause of death

The single 'underlying' cause of death is determined from the death certificate by the ONS and coded using the ICD-10 system (International Classification of Disease, tenth issue). This coding system was used to categorise cause of death in this report as follows:

Alcoholic liver disease	K70*
Fatty liver disease	K76*
Liver cancer	C22*
Other chronic liver disease	B581,D868, I820 ,J632, K770, O226, O904, Q446, T391, T864, Z944, Y830, I81, K71, K72*, K73*, K74*, K75*, K76*, I85*
Hepato pancreatic biliary (HPB) (pancreatitis) patients likely to present with abnormal liver function tests (LFTs) or jaundice	K85, K830, K831, K838, K839, K86*
Viral liver disease	B008, B251,B15*,B16*,B17*,B18*,B19*

Note: * indicates the inclusion of 4-digit ICD-10 codes

While it is acknowledged that the information on death certificates is not completely reliable, they are, however, a valuable source of information.

The 'underlying cause' of death is defined by the World Health Organisation as "the disease or injury that initiated the train of events directly linked to death; or the circumstances of the accident or violence that produced the fatal injury". It is the cause of death recorded on a death certificate.

Death certificates also record '**contributory cause**' of death where a disease or condition has contributed to the death but is not part of the causal sequence; and also up to 15 diseases or conditions which were part of the causal sequence of events leading to death.

For the purpose of this report 'mentions' refer to those deaths where liver disease is recorded as either the underlying or contributory cause of death.

2.5 Place of death

The ONS describes place of death as one of 84 communal establishment types or 'own residence' or 'elsewhere'. These are categorised further by ONS in their DH1 General Mortality Statistics publication:

- Hospital: NHS or non-NHS, acute, community or psychiatric hospitals/units.
- Own residence: the death occurred in the place of usual residence where this is not a communal establishment.
- Old people's home: Local Authority or private residential home.
- Nursing home: NHS or private nursing home.
- Hospice: many hospices are 'free standing' but some are found within NHS hospitals. At present ONS classifies the place of death as hospice only when the event occurred in a free standing hospice premises. These data will therefore under-report deaths in hospices as some will be recorded as a death in hospital.
- Elsewhere: other communal establishment or a private address other than normal place of residence or outdoor location or nil recorded.

2.6 Analysis by deprivation quintile

Lower Super Output Areas (LSOAs) are small geographical areas specifically devised to improve the reporting and comparison of local statistics. In England, there are 32,482 LSOAs (minimum population 1,000). The Index of Multiple Deprivation (IMD 2007) is a measure of how deprived each LSOA is, based on income, employment, health, deprivation, education, skills, training and geographical access to services. LSOAs are grouped into quintiles according to the rank of their deprivation score such that each quintile has an equal resident population.

The residential postcode recorded on the death certificate was used to place each deceased person in an LSOA and assign that death to the deprivation quintile of the LSOA.

Results

The number of deaths from liver disease 3.1

In England, 2% of deaths (an average of 10,544 deaths each year for the period 2001–09) were recorded as having an underlying cause of liver disease.

The number of liver disease deaths has been steadily increasing. Figure 1 shows the rise from 9,231 deaths in 2001 to 11,575 in 2009.

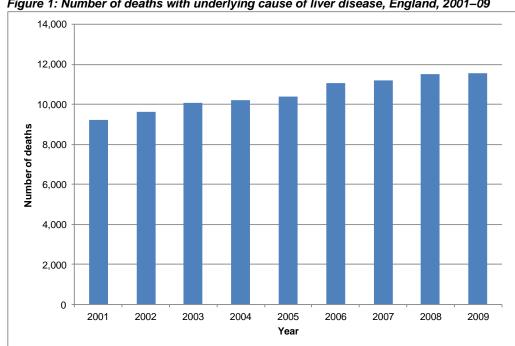


Figure 1: Number of deaths with underlying cause of liver disease, England, 2001-09

Source: ONS mortality data

Figure 2 shows the average annual number and proportion of deaths by liver disease type (underlying cause). It shows that:

- The most common cause of liver disease death is 'alcoholic liver disease' (0.8% of all deaths in England; 3,880 deaths annually).
- Liver cancer accounts for about 0.5% of all deaths in England (2,360 deaths annually).
- Other chronic liver disease accounts for about 0.4% of all deaths in England (2,000 deaths annually).
- Pancreatitis LFTs or jaundice accounts for 0.3% of all deaths in England (1,446 deaths annually).
- Fatty liver disease accounts for around 0.1% of all deaths in England (648 deaths annually).
- Viral liver disease accounts for less than 0.1% of all deaths in England (191 deaths annually).

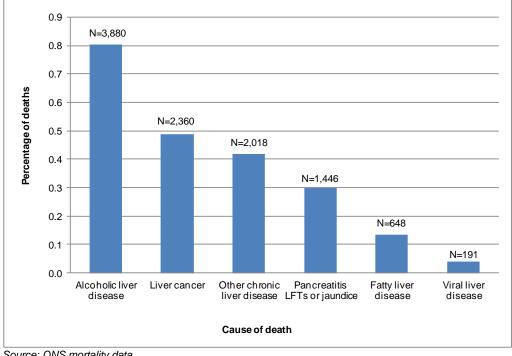


Figure 2: Cause of death (underlying cause): number and proportion of all deaths, England, 2001-09

Source: ONS mortality data

Regional variation 3.2

- Deaths from liver disease vary by former Government Office Region, ranging from 800 to 1,900 liver disease deaths each year. Figure 3 shows that the regions with the highest number of liver disease deaths are the North West (1,899), South East (1,503) and London (1,424).
- The regions with the highest average annual number of alcoholic liver disease deaths are North West (809), South East (504), and West Midlands (501).

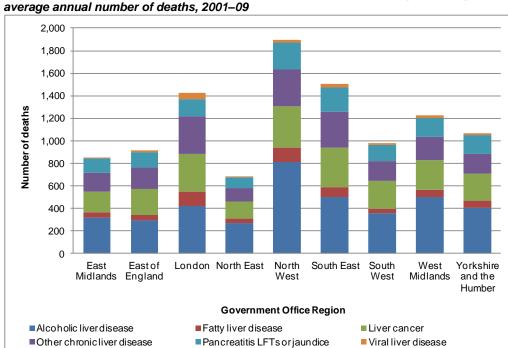


Figure 3: Cause of death (underlying cause) by Government Office Region in England: average annual number of deaths, 2001-09

- This variation is partly explained by variation in the population of each region. The South East has the largest population (8,436,000 in 2009) and the North East the smallest (2,584,262).
- To better compare 'how common' death from liver disease is in each region, Figures 4a and 4b, and Tables 1 and 2, show age-standardised mortality rates (ASMR) for males and females respectively. The ASMR is the number of deaths for each 100,000 of the population adjusted for a standard age distribution. That is, it accounts, for example, for the effect of the South West having a relatively older population and London a relatively younger population.
- The regions with the highest ASMR for liver disease are the North West and North East, for both males and females, although the rate in males is almost double that in females. The third highest ASMR for males is in London but for females it is in the West Midlands.
- The regions with the lowest ASMR for liver disease are the East of England, South West and South East, for both males and females.
- For both males and females the highest ASMR (North West) is approximately double the lowest (East of England).
- ASMRs for alcoholic liver disease follow a similar pattern to that for all liver disease, except in London where the rate is lower than that West Midlands and Yorkshire and Humber.
- The regional deaths from liver disease show some correlation with data presented in the Local Alcohol Profiles for England (North West Public Health Observatory, www.lape.org.uk) which shows that in 2010/11 the highest rates of alcohol attributable hospital admissions were in the North East, North West and Yorkshire and the Humber, while the lowest rates were in the South East, East of England and South West.

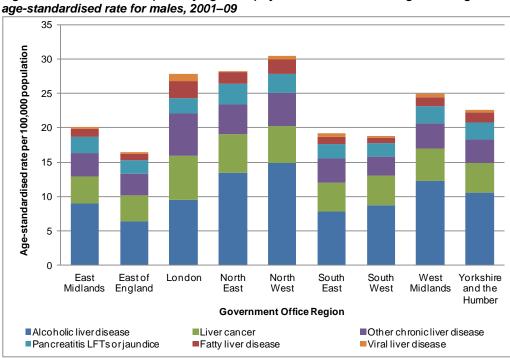


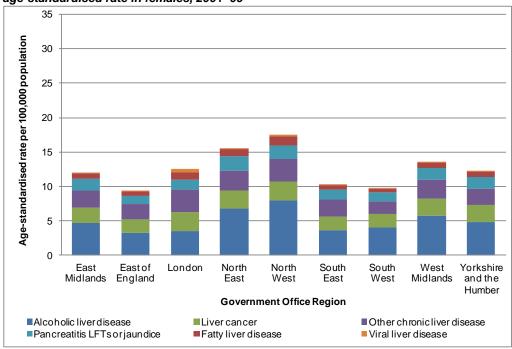
Figure 4a: Cause of death (underlying cause) by Government Office Region in England: age-standardised rate for males. 2001–09

Table 1: Age-standardised rates (per 100,000) of liver disease in males by former Government Office Region, 2001–09

Government Office Region	Alcoholic liver disease	Fatty liver	Liver	Other chronic liver disease	Pancreatitis LFTs or jaundice	Viral liver	All liver
East Midlands	9.0	1.1	3.9		•		
East of England	6.4	0.9	3.7	3.1	2.0	0.3	16.5
London	9.5	2.5	6.4	6.2	2.2	1.1	27.8
North East	13.4	1.6	5.6	4.4	3.0	0.2	28.3
North West	14.9	2.2	5.3	4.9	2.7	0.5	30.5
South East	7.9	1.1	4.1	3.6	2.0	0.5	19.2
South West	8.8	0.7	4.2	2.8	2.0	0.3	18.9
West Midlands	12.3	1.3	4.7	3.7	2.5	0.5	25.0
Yorkshire and the Humber	10.5	1.5	4.4	3.4	2.5	0.4	22.6
England	10.1	1.4	4.6	4.0	2.3	0.5	22.9

Source: ONS mortality data

Figure 4b: Cause of death (underlying cause) by Government Office Region in England: age-standardised rate in females, 2001–09



Source: ONS mortality data

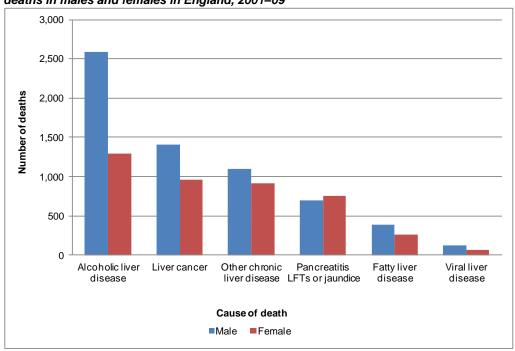
Table 2: Age-standardised rates (per 100,000) of liver disease in females by former Government Office Region in England, 2001–09

Government Office Region	Alcoholic liver disease	Fatty liver disease	Liver cancer	Other chronic liver disease	Pancreatitis LFTs or jaundice	Viral liver disease	All liver
East Midlands	4.7	0.8	2.3	2.5	1.7	0.2	12.0
East of England	3.3	0.6	2.0	2.2	1.2	0.1	9.4
London	3.5	1.1	2.7	3.3	1.4	0.5	12.6
North East	6.8	1.0	2.6	2.9	2.1	0.1	15.5
North West	8.0	1.3	2.7	3.3	2.0	0.2	17.5
South East	3.6	0.7	2.0	2.5	1.4	0.1	10.3
South West	4.0	0.5	2.0	1.9	1.3	0.1	9.8
West Midlands	5.8	0.8	2.5	2.6	1.8	0.2	13.6
Yorkshire and the Humber	4.9	0.8	2.5	2.3	1.7	0.2	12.3
England	4.8	1.6	0.8	2.3	2.6	0.2	12.4

3.3 Variation with sex

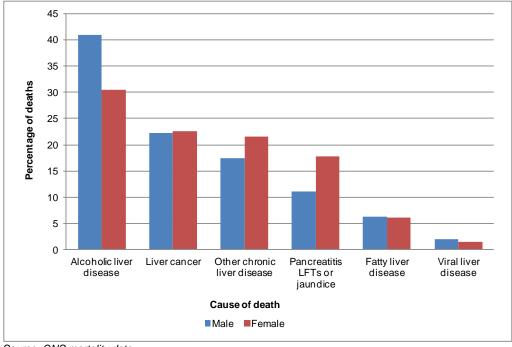
- Figures 5 and 6 indicate that more deaths from 'alcoholic liver disease' occurred amongst males (2,588 deaths, 41% of liver disease deaths annually) compared to females (1,292 deaths, 30% of liver disease deaths annually).
- For each cause of death, except pancreatitis LFTs or jaundice, deaths in males exceeded deaths in females.

Figure 5: Cause of death (underlying cause) by sex: Average annual number of liver disease deaths in males and females in England, 2001–09



Source: ONS mortality data

Figure 6: Cause of death (underlying cause) by sex: proportion of liver disease deaths in males and females in England, 2001–09



3.4 Variation with age at death

- Figure 7 shows that, the average annual number of liver disease deaths is greatest in the 50–59 age group (2,250 deaths), followed by 60–69 (2,185 deaths) and 70–79 (2,110 deaths).
- The average annual number of alcoholic liver disease deaths is greatest in the 50–59 age group (1,267 deaths), 40–49 (981 deaths), and 60–69 (865 deaths).
- Figure 8 and Table 3 show the proportion of deaths caused by liver disease. These proportions vary considerably by age group for each underlying cause of death. They are lowest for deaths at age 80+ years for each cause of death and highest for deaths at age 40–49 for each cause, except viral liver disease.
- Death from liver disease as a proportion of all deaths is greatest among 40–49 year-olds. In this age group, more than one death in ten is caused by liver disease, mostly alcoholic liver disease.
- Figures 9 and 10 show a rising trend in deaths from 'alcoholic liver disease' in the 40–49, 50–59 and 60–69 age groups respectively. See Appendix 1 for trend charts which include 2010 data.

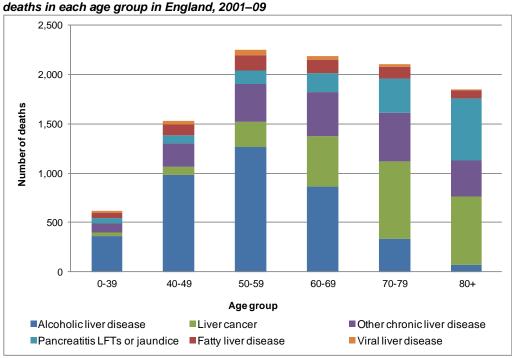


Figure 7: Cause of death (underlying cause) by age: Average annual number of liver disease deaths in each age group in England, 2001–09

12 10 Percentage of all deaths 8 6 4 2 0 70-79 0-39 60-69 80+ 40-49 50-59 Age group ■ Alcoholic liver disease Other chronic liver disease ■ Liver cancer ■ Pancreatitis LFTs or jaundice ■ Fatty liver disease ■ Viral liver disease

Figure 8: Cause of death (underlying cause) by age: proportion of all deaths in each age group in England, 2001–09

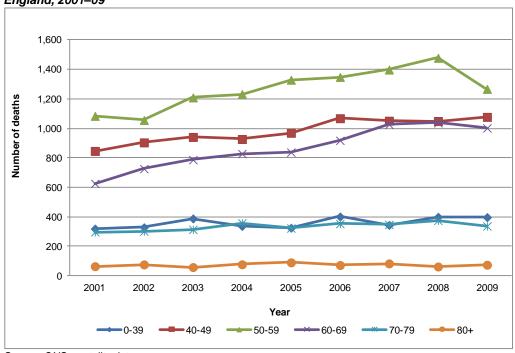
Source: ONS mortality data

Table 3: Liver disease as a percentage of all deaths by age, England 2001–09

	0-39	40-49	50-59	60-69	70-79	80 +
Underlying cause	%	%	%	%	%	%
Alcoholic liver disease	2.3	7.3	4.3	1.5	0.3	0.0
Liver cancer	0.3	0.6	0.9	0.9	0.7	0.3
Other chronic liver disease	0.6	1.7	1.3	0.8	0.4	0.1
Pancreatitis LFTs or jaundice	0.3	0.6	0.4	0.3	0.3	0.3
Fatty liver disease	0.3	0.8	0.5	0.2	0.1	0.0
Viral liver disease	0.1	0.3	0.2	0.1	0.0	0.0
All liver disease	4.0	11.4	7.7	3.8	1.8	0.7

Source: ONS mortality data

Figure 9: Trends in number of deaths from alcoholic liver disease (underlying cause), by age, England, 2001–09



Percentage of deaths from liver disease Year 0-39 40-49 50-59 60-69 0-79 +

Figure 10: Trends in deaths from alcoholic liver disease (underlying cause) as a percentage of all liver disease deaths, England, 2001–09

3.5 Variations with age at death and sex

- Deaths from liver disease in males exceed those in females for all age groups except the oldest, 80+. Figure 11 shows that male deaths are approximately double female deaths up to the age of 60, above which the gender difference reduces and eventually reverses for the oldest group.
- Figure 12 shows the same data as proportions of all recorded deaths from each cause. The proportion of deaths was higher in males than females for all age groups except the 0-39 age group, which had equal proportions of male and female deaths.
- The proportion of all deaths that are caused by alcoholic liver disease is highest in the 40-49 and 50-59 age groups (8% of 40-49 year-olds and 5% of 50-59 year-olds for males; 6% of 40-49 year-olds and 4% of 50-59 year-olds for females).

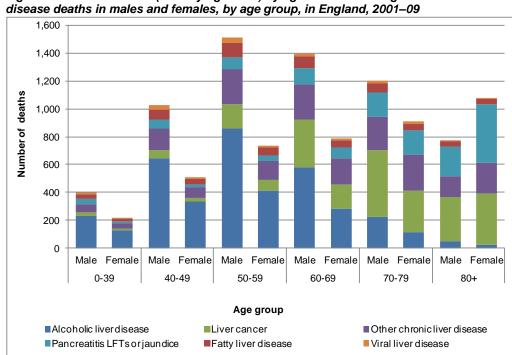


Figure 11: Cause of death (underlying cause) by age and sex: average annual number of liver disease deaths in males and females, by age group, in England, 2001-09

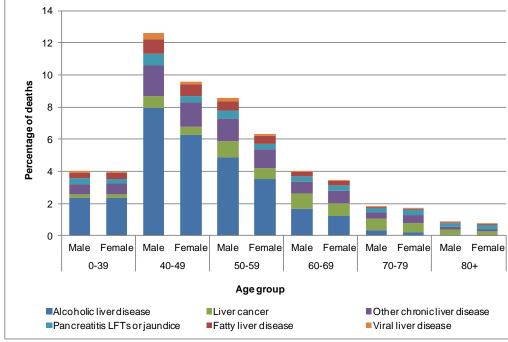


Figure 12: Cause of death (underlying cause) by age and sex: proportion of all deaths in males and females, by age, in England, 2001–09

Source: ONS mortality data

3.6 Variation with deprivation

- Figure 13 shows that the number of patients dying from liver disease was greatest in the most deprived quintiles, with a clear gradient from most to least deprived. For alcoholic liver disease, 1,345 deaths occurred annually in people who lived in the most deprived quintile in England, 3.4 times more than the 393 deaths in the least deprived quintile.
- For each liver disease type there is a deprivation gradient, with most deaths in the most deprived quintile.
- Figure 14 shows that alcoholic liver disease accounted for a much higher proportion of all liver disease deaths in the most deprived quintile (44%) compared with the least deprived (28%).

1,400 1,200 1,000 Number of deaths 800 600 400 200 0 Viral liver Alcoholic liver Liver cancer Other chronic Pancreatitis Fatty liver liver disease LFTs or jaundice disease disease Cause of death ■Most deprived Least deprived

Figure 13: Cause of death (underlying cause) by deprivation quintile: average annual number of liver disease deaths, England, 2001-09

Note: IMD=Index of Multiple Deprivation

Source: ONS mortality data

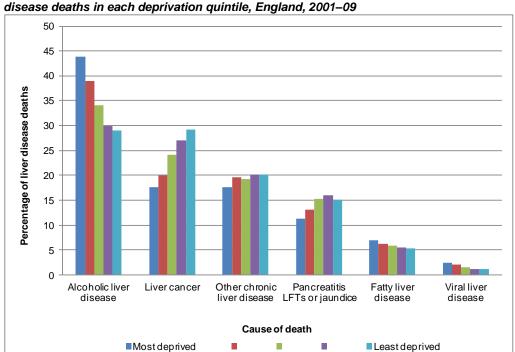


Figure 14: Cause of death (underlying cause) by deprivation quintile: proportion of all liver disease deaths in each deprivation quintile, England, 2001-09

Note: IMD=Index of Multiple Deprivation

3.7 Deaths with any mention of liver disease

Liver disease is a contributory cause of death for an average of 5,636 people each year (England 2001–09). A contributory cause is one that is recorded on the death certificate as a condition that contributed to the death. It is distinct from the underlying cause.

In this section, we present the number of deaths for which liver disease is recorded as the i) the underlying cause, ii) a contributory cause and iii) these two combined to give the number of 'mentions' for that cause (see Section 2.4).

In England, approximately 16,000 people die each year with liver disease mentioned on their death certificate (underlying or contributory cause). This represents 3.4% of all deaths (Figure 15).

Figures 16a–f show the patterns by liver disease type. There is considerable variation. Other chronic liver disease has the highest **number** of contributory cause deaths than any of the other liver disease types (4,651 deaths per year). However, fatty liver disease, with 1,801 contributory cause deaths per year, has the highest **proportion** of contributory cause deaths (277%) when calculated as a percentage of the number of underlying deaths. This compares with 230% for other chronic liver disease and 199% for viral liver disease.

Please note, some patients may have had more than one liver disease mentioned on their death certificate. For example, they may have had an underlying cause of alcoholic liver disease and a contributory cause of fatty liver disease. This means that the totals for Figure 16 may not add up to the total in Figure 15.

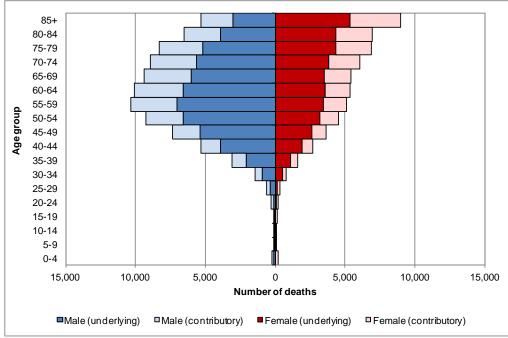
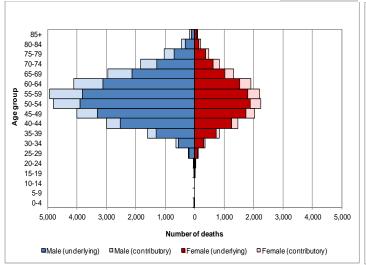


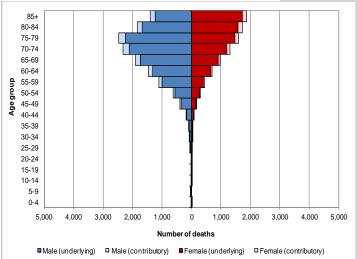
Figure 15: Cause of death as 'mentioned' in any cause field (contributory and underlying): numbers of deaths for all liver diseases, England, 2001–09

Figure 16: Cause of death as 'mentioned' in any cause field (contributory and underlying): numbers of deaths by liver disease type, England, 2001–09

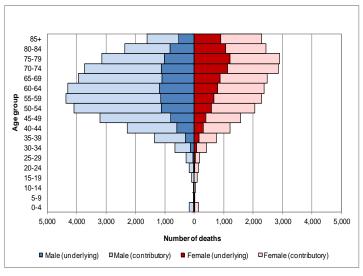
a) Alcoholic liver disease



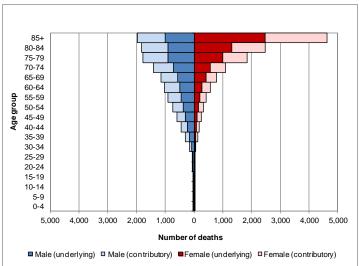
b) Liver cancer



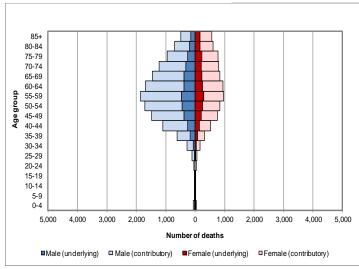
c) Other chronic liver disease



d) Pancreatitis LFTs or jaundice

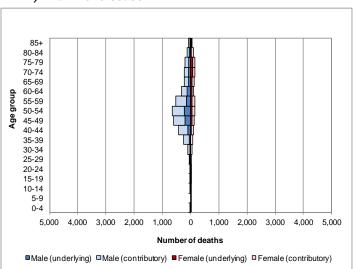


e) Fatty liver disease



Source: ONS mortality data

f) Viral liver disease



3.8 Place of death

Over two thirds of people whose death had an underlying cause of liver disease died in hospital, compared to a little over half of all recorded deaths from any cause. Figure 17 shows that 73% of liver disease deaths occurred in hospital, and 19% in 'own residence'.

80 70 60 Percentage of deaths 50 40 30 20 10 0 Hospital Own residence Hospice Nursing homes Old people's Elsewhere Place of death

Figure 17: Distribution of liver disease deaths by place of death, England, 2001-09

Source: ONS Mortality data

3.8.1 Place of death and cause of death

- Figure 18 shows that of the 7,653 liver disease deaths in hospital each year, 3,113 had an underlying cause of alcoholic liver disease.
- Of the 2,013 liver disease deaths in 'own residence', 664 had an underlying cause of alcoholic liver disease.
- Old people's homes and nursing homes are uncommon places for deaths caused by liver disease. Alcoholic liver disease, despite being the most common underlying cause of liver disease death, was a particularly rare cause of death in old people's and nursing homes. Table 4 shows that liver disease deaths in these places are primarily caused by liver cancer or 'other chronic liver disease'.
- Hospices care predominately for people with cancer. Very few liver disease deaths in hospices are from a cause other than liver cancer.

3,500 3,000 2,500 Number of deaths 2,000 1,500 1,000 500 0 Hospital Own residence Hospice Nursing homes Old people's Elsewhere homes Place of death ■Alcoholic liver disease ■Liver cancer Other chronic liver disease ■Pancreatitis LFTs or jaundice ■Viral liver disease Fatty liver disease

Figure 18: Place of death by underlying cause: average annual number of liver disease deaths in England, 2001–09

Source: ONS mortality data

Table 4: Distribution of liver disease death types (underlying cause) by place of death, England. 2001–09

Underlying cause	Hospital %	Own residence %	Hospice %	Nursing homes %	Old people's homes %	Elsewhere %
Alcoholic liver disease	40.7	33.0	3.2	13.9	13.1	35.7
Liver cancer	15.7	29.5	90.0	47.0	41.1	25.0
Other chronic liver disease	19.2	21.3	4.1	24.6	23.2	19.5
Pancreatitis LFTs or jaundice	16.3	7.0	1.3	10.1	18.1	9.0
Fatty liver disease	5.9	8.3	0.7	3.4	3.5	9.8
Viral liver disease	2.2	0.9	0.6	1.0	1.0	1.1
Total	100.0	100.0	100.0	100.0	100.0	100.0

- Figure 19 shows that, for each liver disease type, hospital is the most common place of death.
- The proportion of deaths in hospital is highest for pancreatitis LFT and jaundice (86%) and viral liver disease (87%), and lowest for liver cancer (50%).

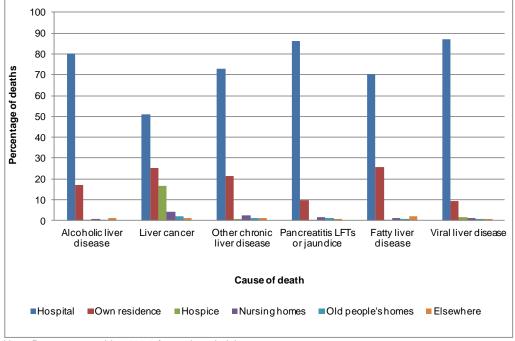


Figure 19: Distribution of place of death by liver disease type (underlying cause), England, 2001–09

Note: Percentages add to 100% for each underlying cause. Source: ONS mortality data

3.8.2 Place of death and age at death

- The proportion of liver disease deaths that occur in hospital varies little by age. Figure 20 shows that this proportion is between 71% and 74% in each age group.
- Non-hospital deaths from liver disease are most likely to be in 'own residence' for all age groups. However, death in own residence is least common for the oldest (80+).
- Nursing and old people's homes, often the usual place of residence for the most elderly, is the most common place of death for the most elderly.
- Hospices are the most common place of death in the 70–79 age group.
- The proportion of liver disease deaths occurring 'elsewhere' is highest for the youngest (0–39) age group.

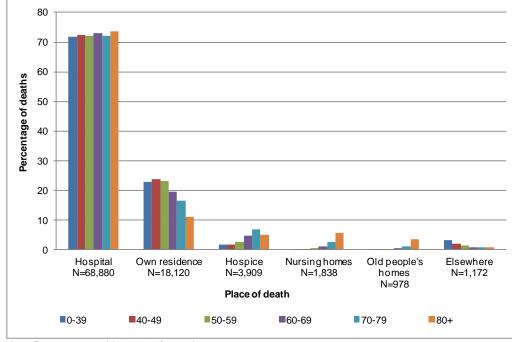


Figure 20: Distribution of liver disease deaths by place of death and age, England, 2001–09

Note: Percentages add to 100% for each age group.

Source: ONS mortality data

See Appendix 2 for charts of place of death broken down by both age and underlying cause.

For each underlying cause, the pattern of place of death by age is broadly similar to the all liver disease pattern. The strongest age effect is for deaths with an underlying cause of fatty liver disease and 'pancreatitis LFTs or jaundice'. For both of these causes, the proportion of deaths in hospital increases with age and the proportion of deaths in own residence decreases with age.

Figure 21 shows the distribution of age at death by place of death. It is clear that hospital deaths in age groups over 50 are quite evenly spread.

- Deaths in old people's homes are predominantly people aged 70 or over.
- Liver disease deaths at home peak in the 50–59 age group.
- Most hospice deaths are people aged over 60, with the highest proportion aged 70–79 years.
- More than half the liver disease deaths 'elsewhere' (that is, public places, other people's homes, or non-medical communal establishments) are aged under 60.

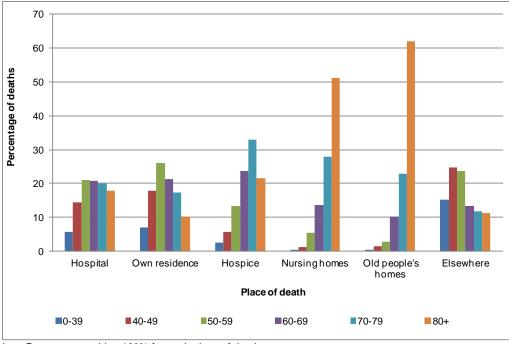


Figure 21: Distribution of liver disease deaths by age at death and place, England, 2001–09

Note: Percentages add to 100% for each place of death.

Source: ONS mortality data

3.8.3 Place of death and region

There is little variation in the distribution of place of death between former Government Office Regions. Figure 22 shows that, for each region, the proportion of liver disease deaths in hospital is between 70% and 75%.

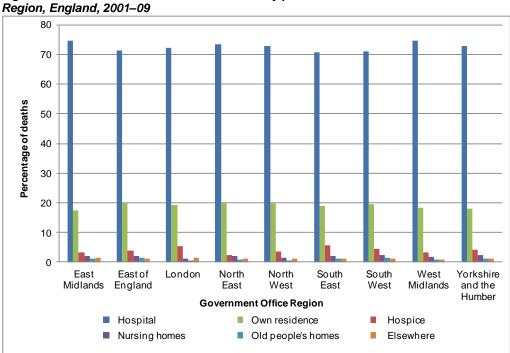


Figure 22: Distribution of liver disease deaths by place of death and Government Office Region, England, 2001–09

Note: Percentages add to 100% for each Government Office Region.

4 Conclusions and recommendations

- This report is the first to provide a high-level overview of mortality data from liver disease in England. It shows the absolute numbers of deaths by underlying cause and by underlying and contributory cause combined ('mentions').
- The data on contributory cause recording highlights how important it is to search the entire mortality record for mentions of these conditions to get a clearer picture of deaths in which liver disease is involved.
- People dying with liver disease recorded as either an underlying or contributory cause of death are likely to have specific end of life care needs related to these conditions.
- Patient choice and need for those with alcoholic liver disease should be prioritised, as alcoholic liver disease causes more deaths than the other liver diseases.
- Commissioners should review the prevalence of alcoholic liver disease and number of deaths in their population for service planning.
- End of life care needs to be considered within the broader spectrum of 'overall care' for individuals living with liver diseases. This could be achieved through raising awareness and enhancing skills for clinical staff working in liver medicine.

5 Future investigations

This report is the first in a series on end of life care for patients with liver disease. Future analyses will examine the pattern of admissions and type of care received in hospital during the last year of life for those dying both in and out of hospital.

References

Department of Health (2008). End of Life Care Strategy: promoting high quality care for all adults at the end of life. Available from:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Department of Health (2012). Healthy Lives, Healthy People: Improving outcomes and supporting transparency. Available from:

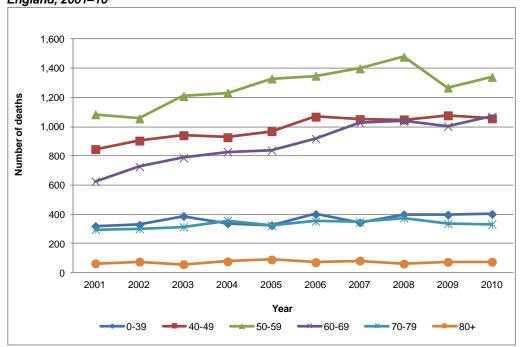
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358

Department of Health (2010). Healthy Lives, Healthy People Transparency in outcomes - a framework for the NHS: Impact Assessment. Available from: http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_117583

Eileen Kaner, et al, (2007). A rapid review of liver disease epidemiology, treatment and service provision in England. Available from: http://www.ncl.ac.uk/ihs/assets/pdfs/liverreview.pdf

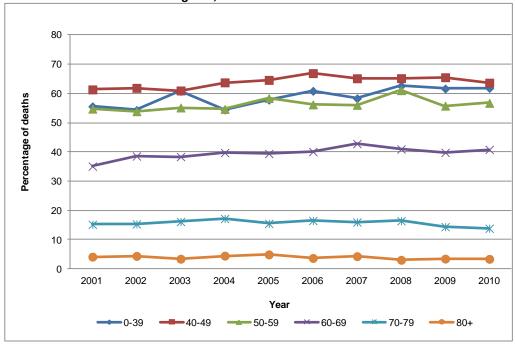
Appendix 1: Trends in deaths from alcoholic liver disease, including deaths in 2010

Figure A1: Trends in number of deaths from alcoholic liver disease (underlying cause) by age, England, 2001–10



Source: ONS mortality data

Figure A2: Trends in deaths from alcoholic liver disease (underlying cause) as a percentage of all liver disease deaths in England, 2001–10

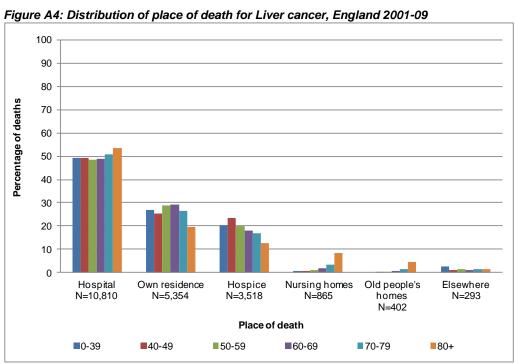


Appendix 2: Distribution of place of death by age at death for each underlying cause

Figure A3: Distribution of place of death for alcoholic liver disease, England, 2001–09 100 90 Percentage of deaths 80 60 50 40 20 10 0 Hospital Own residence Hospice Nursing homes Old people's Elsewhere N=28,018 N=5,975N=127 homes N=418 N=128 Place of death **0-39 40-49** ■50-59 **60-69** ■70-79 **80+**

Note: Percentages add to 100% for each age group.

Source: ONS mortality data



Note: Percentages add to 100% for each age group.

100 90 Percentage of deaths 80 70 60 50 40 30 20 10 0 Hospital N=13,229 Hospice N=161 Nursing homes N=452 Old people's homes N=227 Elsewhere Own residence N=3,868 N=228 Place of death ■0-39 **40-49 ■**60-69 ■50-59 ■ 70-79 **80+**

Figure A5: Distribution of place of death for 'other chronic liver disease', England, 2001-09

Note: Percentages add to 100% for each age group.

Source: ONS mortality data

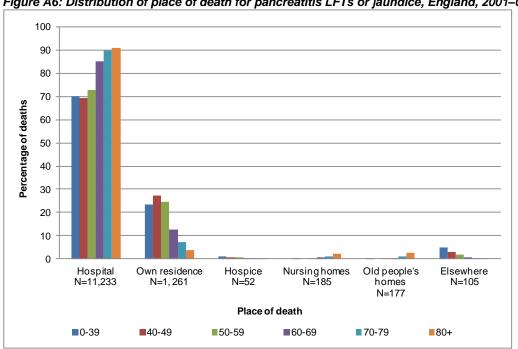


Figure A6: Distribution of place of death for pancreatitis LFTs or jaundice, England, 2001–09

Note: Percentages add to 100% for each age group.

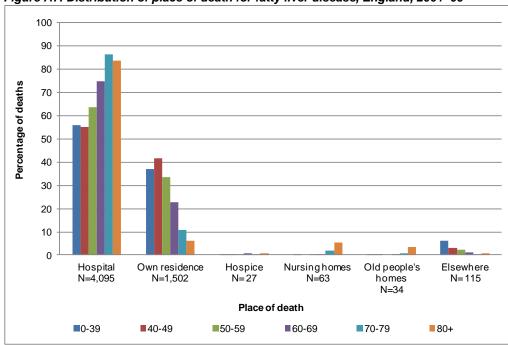


Figure A7: Distribution of place of death for fatty liver disease, England, 2001-09

Note: Percentages add to 100% for each age group. Source: ONS mortality data

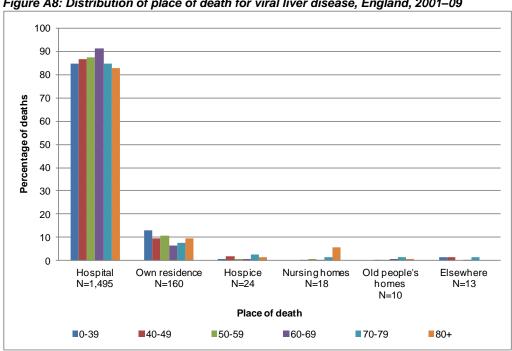


Figure A8: Distribution of place of death for viral liver disease, England, 2001-09

Note: Percentages add to 100% for each age group.



NHS

National End of Life Care Programme Improving end of life care

If you would like to know more about the National End of Life Care Intelligence Network:

- Visit the website www.endoflifecare-intelligence.org.uk
- Keep up to date with the latest news
- · Sign up to receive email alerts
- · Browse end of life care resources
- · View end of life care data
- Read our reports.



Further information

This report is available online at: www.endoflifecare-intelligence.org.uk

Author contact details

Kufre Effiong, End of Life Care Analyst, Ade Osinowo, Senior End of Life Care Analyst, Andy Pring, Senior Analyst and Julia Verne, Director

South West Public Health Observatory Grosvenor House 149 Whiteladies Road Bristol BS8 2RA

T: 0117 970 6474
F: 0117 970 6481
E: info@swpho.nhs.uk

Publication details

Published by: National End of Life Care Intelligence

Network

Publication date: March 2012 ISBN 978-0-9570224-1-6

About the National End of Life Care Intelligence Network

The Department of Health's National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN). The Network was launched in May 2010. It is tasked with collating existing data and information on end of life care for adults in England. This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care, in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families.

Key partners include the National Cancer Intelligence Network (NCIN), which will work closely with the Network to improve end of life care intelligence; and the South West Public Health Observatory, lead public health observatory for end of life care, which hosts the NEoLCIN website. The SWPHO has been commissioned to produce key outputs and analyses for the Network, including the national End of Life Care Profiles.

See www.endoflifecare-intelligence.org.uk for more information about the Network and its partners.

© Crown Copyright 2012