Children's Liver Disease Foundation
fighting childhood liver disease

BRITISH LIVER TRUST

Living with Childhood Liver Disease

– Voices of Families, Children and Young People

In 2025, 325 people took part in our survey exploring the impact of childhood liver disease on daily life, education, and wellbeing. Their voices offer valuable insight into the challenges and resilience within our community.

The costs of this survey have been supported by educational grants from Ipsen and Mirum. Neither company had any influence over the content of the survey.

325 people responded to the survey, of whom:

224
were parents or carers of a child with a liver condition

43
were young people (under 25) with a liver condition

58
were adults with a childhood liver condition

> *"It is hard to find the right level of communication to explain to people what life is like with a chronic incurable condition which affects the liver."*

Mental health impact

67%
of respondents felt that childhood liver disease had a negative effect on mental health

> *"There is a lot of stigma attached to liver disease which my teenage son struggled with, and this affected his mental health."*

Education and school life

48%
feel it had a negative effect on educational attainment – a figure which rises to 59% amongst young people under 25

> *"I have been told we are at risk of prosecution if her attendance doesn't improve."*

Understanding and awareness

72%
felt there was a poor understanding outside the liver community of what it means to have a childhood liver disease

> *"No-one realises the impact that hospital stays, visits, tests etc. have on your family life and family finances."*

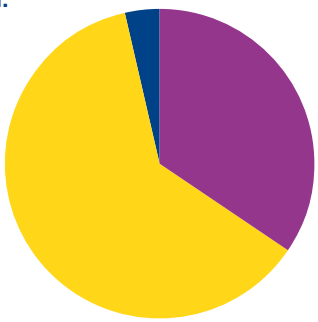
Types of Liver Condition

(by percentage of respondents)

- Biliary atresia **29.05**
- Autoimmune liver disease **16.55**
- Primary Sclerosing Cholangitis (PSC) **9.80**
- Alpha-1 antitrypsin deficiency **5.40**
- Acute liver failure **4.39**
- Alagille syndrome **3.72**
- PFIC **3.38**
- MASLD / NAFLD **2.70**
- Gilbert's syndrome **2.36**
- Undiagnosed liver condition **2.36**
- Wilson's Disease **1.69**
- Hepatitis B **1.35**
- Choledochal cyst **1.01**
- Hepatitis A **0.68**
- Not sure **0.68**
- Cystic fibrosis related liver disease **0.34**
- Hepatitis C **0.34**
- Other **14.19**

Liver transplants

Many young people with childhood liver disease grow up knowing that transplant is likely to be a reality one day. Of those we surveyed:



- **34.5%** had received a liver transplant
- **62%** had not
- **3.5%** were currently on the waiting list for a liver transplant

Additional Health Conditions

(by percentage of respondents)

- No additional health condition **25.38**
- ADHD **13.84**
- Autism **12.30**
- IBD conditions **11.54**
- Kidney disease **4.62**
- Anxiety/depression **2.69**
- Diabetes **1.15**
- Hypothyroidism **1.15**
- Learning disability **1.15**
- Coeliac disease **0.77**
- Epilepsy **0.38**
- Other **25**

The results revealed that many young people with childhood liver disease are also coping with additional health conditions. The chart opposite reflects confirmed diagnoses but many respondents told us that they or their child were currently undergoing investigations for additional health conditions, including those named.

Overall, our respondents are very happy with the care they have received from the NHS. Asked to rate their medical care since being diagnosed with a childhood liver disease, the average rating was an excellent 74%!

> *"From the point of initial bloods by GP to then secondary care becoming involved they have been fantastic."*

Families and young people living with childhood liver disease face complex challenges that affect every aspect of life – from emotional wellbeing to education, friendships and daily routines. The findings from this survey highlight the **urgent need for greater understanding of the impact of childhood liver disease**, and for better awareness across the education sector, and the wider community. They also underline the **vital role which emotional and practical support has to play**. This is something we have been providing as a charity for many years, and it is clear that this need is greater than ever.

We are grateful to everyone who took the time to take part in this survey. Your voices have been heard and will continue to shape the services and support available to you.