# Stigma faced by young liver disease patients leading to isolation, charity warns

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The British Liver Trust is calling for urgent action to improve public understanding of childhood liver disease, as new survey results show that two in three young people affected experience poor mental health linked to social isolation and stigma. While medical care for childhood liver conditions has improved dramatically in the past four decades, the charity warns that social attitudes have not kept pace, leaving many families struggling for recognition and support.

The survey, which was completed by young people and parents, found that 67% felt that childhood liver disease had a negative effect on mental health, 48% believed it harmed their education (a figure which rose to 59% amongst young people under 25) , and 72% felt society has little understanding of their illness.

Michelle Wilkins, Head of Children's and Families Services at the British Liver Trust, commented: "We're fortunate in the UK that once a liver disease is diagnosed, a child will generally have excellent medical care, but the rest of society has not yet caught up. So, for example, families whose children need regular hospital treatment will receive warning letters from schools about attendance targets. Or people will automatically assume that a young person's liver disease is alcohol related when, for most childhood liver diseases, the causes are unknown. So young liver disease patients will often be dealing with stigma as well as the physical aspects of their condition.

"There are many different liver diseases which affect children and the lack of understanding means that, in addition to all the stress which having a chronically ill child brings, families can feel very isolated. Liver disease doesn't receive the same acceptance as other chronic conditions. These young people face a lifetime of medical care and in many cases a liver transplant. Greater recognition of this fact would enable them to cope better with the issues they face at school, work or in social activities."

There are around 100 different kinds of liver disease which affect babies and children, all of which are considered rare, but it is estimated that 400 new cases are diagnosed in the UK each year; thousands of young people and adults are now living with a childhood liver disease.

Dr Jane Hartley, Consultant Paediatric Hepatologist at Birmingham Women's and Children's Hospital, commented: "This is important research highlighting that paediatric liver disease can often be invisible to the outside world whilst being serious and potentially life threatening, thereby impacting on mental health. Increasing awareness of the burden of care liver disease has on a child, family or young person will help in establishing community acceptance, empower families to seek support and aid policy making. Medical care has overcome many challenges to enable children with liver disease to survive and now the emphasis should be on support to live a fulfilling life without struggling with poor mental health."

The British Liver Trust's Children and Families service can be contacted here Talk To Someone | Liver Support | Children's Liver Disease Foundation.

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