

New research reveals a significant rise in the number of children with life-limiting conditions

23 April 2020, by Julie Gatenby



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A new study shows that the number of children in England with life-limiting or life-threatening conditions has continued to rise over the last 17 years.

The Make Every Child Count study, conducted by the University of York, has revealed that the number of children in England with life-limiting or life-threatening conditions increased to 86,625 in 2017/2018 compared to 32,975 in 2001/2002.

Isolated

The research is published amid the Coronavirus crisis in the UK, which has already had a far reaching and negative impact on families caring for seriously ill children, who are feeling frightened, isolated and alone, with some families struggling to get the right care and support for their child.

Responding to predications that the number of children with life-limiting conditions will rise at least

another 11% by 2030, UK children's palliative care charity, Together for Short Lives is calling on the Government, NHS and others to make sure seriously ill children and their families can access the lifeline services they rely on.

The new research also reveals that prevalence of life-limiting conditions is by far the greatest in babies under the age of one, and that more young people with life-limiting conditions are living to the age of 19 years.

Urgent need

The reports says that more seriously ill children are living longer is cause for celebration, however there is an urgent need to make sure that children's palliative care services are properly planned, funded and delivered to ensure that these children, and their families, can live life to the full. It's hoped that the Make Every Child Count research will make it easier for government, the NHS, children's palliative care providers and others to do this.

The study used routinely collected hospital and death certificate data in England to provide an up-to-date count of children and young people with life-limiting and life-threatening conditions.

Other key findings also show:

- The prevalence of children with life-limiting conditions has increased from 7 per 10,000 in 2001 to 66.4 per 10,000 in 2017/18 and is higher in boys than girls.
- The prevalence of life-limiting conditions is highest among the most deprived groups of the population, who are least able to afford the financial burden of caring for a child with a complex condition.
- The prevalence of life-limiting conditions is

increasing across all regions of England, with the highest increase in the North West of England and Yorkshire and the Humber.

- The study's most conservative prediction suggests that the number of children with life-limiting conditions will rise to between 95,318 and 97,242 in 2030—an increase of 11%. Whilst the increase may be partly down to better recording of hospital data and improved diagnosis, the study suggests that it is also likely to be because children are living longer as a result of better care being provided and advances in medical technology.

Lead author, Professor Lorna Fraser, Director of the Martin House Research Centre at the University of York said: "Hopefully these findings will help commissioners and service providers to work together to ensure that all these children and young people have access to accessible and age appropriate health services."

Pandemic

CEO of Together for Short Lives, Andy Fletcher said: "In many ways the pandemic has exacerbated many of the challenges families were already facing in getting the support and services they need. So, we must not forget the growing number of [children](#) and [young people](#) with life-limiting and life-threatening conditions and their families who need care and support, both now and in the future."

More information: Make Every Child Count: www.togetherforshortlives.org...nce-report-Final.pdf

Provided by University of York

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