

More children now living with 'life-limiting' conditions

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The number of children with conditions such as muscular dystrophy, neurodegenerative disorders or severe cerebral palsy who are surviving into adulthood has been underestimated, a new study shows.

Research led from the University of Leeds, has shown that the number of [children](#) and young adults in England with a 'life limiting condition'* is far higher than had previously been thought and is increasing year on year. As numbers continue to rise, this will place a growing burden on paediatric palliative care providers and young adult services, particularly in deprived areas.

The study, which is published in the journal *Pediatrics*, was a collaboration between the University of Leeds, Martin House Children's Hospice in Yorkshire, and the Children's Hospital, Cardiff. It was funded by the charity Together for Short Lives.

Experts agree that children who are born with or contract an illness that can shorten their life, and who may not reach [adulthood](#), should have access to specialist palliative care. This can make an enormous difference to the quality of their life and to that of their family members.

Data on the use of children's hospice services is collected by Together for Short Lives. However, the total number of children who have received any form of specialist palliative care - or who might need it in the future - is not recorded nationally and local data is patchy. This has

prompted concerns that [health authorities](#) may be underestimating the level of provision that is needed, leaving existing services under-resourced and overstretched.

To address this gap in knowledge, researchers took NHS data on children's admissions to hospitals in England from 2000 until 2010 and used an internationally recognised coding method to classify the [medical conditions](#) being treated. They found that for 2010, the prevalence of life limiting conditions in under-19s was 32 in 10,000 – exactly double the figure previously reported. From this, they estimate that there are about 40,000 children in England who are currently living with a life limiting condition.

The results showed a steady increase in the number of children living with a life limiting condition, particularly in the 16-19 age group. This suggests that the growing need for support associated with these conditions is being driven by longer survival times rather than a rise in the incidence of disease. The prevalence of life limiting conditions was also notably higher in some ethnic minority populations and areas of socio-economic deprivation.

University of Leeds researcher Dr Lorna Fraser, who led the study, said: "Children and teenagers with life limiting medical conditions will often need many years of specialist palliative care before they reach the end of their life, making it all the more important that their needs are not overlooked. Our study has confirmed doctors' suspicions and identified an escalating need for specialist paediatric care services. It is vital that health authorities now take this message on board and plan accordingly."

Dr Jan Aldridge, Consultant Clinical Psychologist at Martin House Children's Hospice, and one of the co-authors of the research, said: "Significant numbers of children with life-limiting conditions are living longer now, thanks to advances in medical care, but for many such

children life gets harder as they get older. Statutory services are either non-existent or struggle to meet the needs of these older teenagers and [young adults](#). At the moment, these children and their families place great value on the all-round support package provided by hospices such as Martin House, which help to address their medical, social and emotional needs. This model of specialist holistic care is one that health authorities and other services might draw upon."

Barbara Gelb, CEO of the UK children's [palliative care](#) charity, Together for Short Lives, added: "This study affords a real opportunity to better understand need and should help commissioners and service providers alike to better plan and deliver sustainable services when and where they are most needed. As the study shows, more young people with long term [conditions](#) are living longer; however we know that the specialist services they need are not meeting demand. Although there are some excellent services for young people; there are still major gaps in service provision and young people struggle to find appropriate care, housing, education and the work and social opportunities that they deserve."

More information: L Fraser et al. Rising National Prevalence of Life-Limiting Conditions in Children in England, *Pediatrics* 2012;129:1-7
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Provided by University of Leeds

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