

# More support needed for young adults with life-limiting conditions

August 27 2015, by Charlotte Anscombe

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A new report has called for improved training and ongoing support for young adults living with life-limiting conditions, their families and health and social care professionals.

The report was commissioned by Children's Hospice Scotland (CHAS) and put together by academics from the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care at The University of Nottingham, the Transformative Change: Educational and Life Transitions (TCELT) Research Centre at the University of Dundee, and, and senior members of CHAS.

Academics examined a range of unique cases of young adults with life-limiting conditions, interviewing them, their families, health and [social care](#) staff.

## Impact on lives

The report found that the medical conditions of the young adults impacted on other aspects of their lives, such as aspirations and plans for the future, including education, employment and relationships such as living with a partner or concerns about their sexual expression. Also, the aspirations of the young adults can sometimes be considered unsafe or unrealistic by their families and professionals.

It concluded that training and ongoing support should be available for

families and professionals to help meet the transition needs as young people move from childhood through adolescence and into adulthood. Appropriate training should also be made available for professionals to work with young adults who are living with childhood conditions.

Professor Bridget Johnston, from The University of Nottingham, said, "On the whole there was an uncertainty about the future and limited planning as parents and professionals had not expected some of the young adults to survive beyond childhood. This is entirely understandable but it does point to challenges for the future and how their needs are best met."

## **Exploring their full potential**

Libby Gold, Associate Nurse Director for Care at CHAS, said: "As a charity directly caring for young adults with life-limiting conditions, we welcome the findings of this report. Perhaps most concerning, is the uncertainty faced by young adults who have surpassed their life expectancy and want to explore their full potential, be it in a professional or personal context, like anyone else their age.

"We are a children's charity but we need to ensure that there is age appropriate care and support for young adults and their families where CHAS services are no longer suitable.

"We'd like to thank all participants that took part in the study as well as the University of Dundee and The University of Nottingham for conducting this research. We look forward to using the findings as a platform to raise awareness of the complexity of this important issue and in turn, further inform the work of our Transition Team."

## **Better support services needed**

Other findings included:

- Young adults in the 15 to 25 age range have a variety of age and stage-related needs that children's hospices may not be best suited to meet
- Families were positive about the support from CHAS and showed concern about young adults moving to adult services from CHAS
- Tensions were often apparent between young adults seeking independence and families having difficulty in 'letting go'
- Better services should be delivered to support young adults living in the community with medical, psychosocial and educational support for them and their [family](#)

"Over recent years there has been an increasing awareness and emphasis on the needs of young adults with life-limiting conditions," said Professor Divya Jindal-Snape, of the University of Dundee. "Much of this has been due to the fact that many children are surviving longer with conditions that were previously unique to childhood.

Our research highlights their multiple transitions as well as those experienced by their families and professionals. To ensure the well-being of the [young adults](#), their families and the professionals working with them, it is important to understand the needs of all concerned and to provide them with ongoing support."

**More information:** An executive summary of the report can be viewed at: [www.chas.org.uk/assets/0001/50...xecutive\\_Summary.pdf](http://www.chas.org.uk/assets/0001/50...xecutive_Summary.pdf)

Provided by University of Nottingham

Citation: More support needed for young adults with life-limiting conditions (2015, August 27)  
retrieved 19 April 2024 from

<https://medicalxpress.com/news/2015-08-young-adults-life-limiting-conditions.html>

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