

Planning for the move from children's to adult palliative care

October 21 2014

The differences between children's and adult palliative care services are too wide for young people with life-limiting conditions to negotiate, according to research by Bangor University. Commenting on the findings, the researchers call for adult palliative care services to extend their scope to better meet the needs of young people with life-limiting conditions and their families.

The research team brought [young people](#) with life-limiting [conditions](#), parents and professionals from children's and adult [palliative care](#) services together to share their experiences of transition.

Planning for the move from children's to adult palliative care was often not focussed on the [young person](#) and what they wanted or needed. Many young people did not have a 'key worker' or someone to support them in organising their transition so it was easy for young people to get lost and fall through the gaps. Important things such as the young person's views on their fluctuating pain and symptom management and changes in the way that the young person liked or needed to eat and drink were often not covered by current transition plans.

Young people and parents also highlighted the differences between children's and adult palliative care services and how this affected them. Young people with life-limiting conditions were used to 'parallel planning' whereby children's palliative care services provided holistic support from diagnosis onwards for young people and their families to enjoy life as well as planning ahead for end of life care when needed.

Young people said that holistic palliative care services for the entire family that had been of great benefit during childhood frequently ceased on transfer to adult services. Adult palliative care services, on the other hand, were more geared to meet the needs of primarily older people with conditions such as cancer or heart failure towards or at the end of life. Adult palliative care professionals were experienced at managing conditions such as Muscular Dystrophy and common symptoms such as pain and being sick, but were less familiar with managing the vast range of relatively uncommon life-threatening conditions that originated in childhood.

Professor Jane Noyes from Bangor University's School of Social Sciences said that 'Bringing together children's and adult palliative care professionals with young people with life-limiting conditions and parents was invaluable. Children's and adult palliative care services have grown up separately with different groups of people in mind. It is not surprising that adult services find it challenging to accommodate young people with life-limiting conditions that originated in childhood.'

'Young people with life-limiting conditions and palliative care needs simply fall through the gaps during transition from [children's](#) to adult palliative care services. Adult [palliative care services](#) need to extend their scope to better meet the needs of young people with life-limiting conditions and their families.'

More information: 'Bridging the Gap' guide and toolkit for professionals. The guide covers the commonly forgotten elements of palliative care during and after transition, and the important principles of person-centred planning and communication:

www.bangor.ac.uk/so/bridging-the-gap/Transition

[%20key%20worker%20planning%20guide%20V1%20%2010-2014.pdf](http://www.bangor.ac.uk/so/bridging-the-gap/Transition%20key%20worker%20planning%20guide%20V1%20%2010-2014.pdf)

A short film to show how important good palliative care transition planning is from the perspective of young people and their parents:
'Bridging the Gap' project report describing the project and key findings:

www.bangor.ac.uk/so/bridging-the-gap/Final

%20Report%20Bridging%20the%20Gap%20between%20children%27s
%20and%20adult%20palliative%20care%2010-14.pdf

[www.bangor.ac.uk/so/bridging-t ... the-gap-video.php.en](http://www.bangor.ac.uk/so/bridging-t...the-gap-video.php.en)

Provided by Bangor University

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