

A National Conversation: Children's Palliative Care in Scotland

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**Children's
Hospice
Association
Scotland**

Children, young
people and
their families
at the heart of
all we do.

Background

In 2011, two national organisations in the United Kingdom dedicated to children's palliative care agreed to host three collective conversations about children's palliative care in Scotland. These conversations were called 'Square Table' events.

“Children and young people want to have a life, not to be labelled by their limitations and medical issues.”



“In Scotland we need a single voice for paediatric palliative care. We have got to try and forget our professional boundaries – we should focus our minds on excellence of palliative care for all.”

The Participants

Children's Hospice Association Scotland (CHAS) is a national charity in Scotland and the sole provider of vital hospice services for children and young people with life-shortening conditions. It works at a national, local and regional level.

Together for Short Lives is the UK voice for children and young people who are not expected to live to reach adulthood, and their families. Its aim is to ensure that families have the best quality care and support – wherever they live and for as long as they need it.

The UK Square Table programme, developed by Together for Short Lives, involved 1,500 people through 42 events.

The Method

The events were called Square Table to symbolise the equal weight and importance of all participants' views. The conversations provided a structured environment, chaired by a leading Advocate. Aspirations and challenges of children and young people with life-limiting and life-threatening conditions, together with the views and concerns of their parents and key carers, were heard and understood in a common forum. Key representatives from the entire children's palliative care provider community attended, including health, social care and education professionals.

CHAS and Together for Short Lives used this approach to host each Square Table in Scotland and discussed the same three key themes:

- The setting for the provision of services in Scotland
- Transitions
- An exploration of collaborations

Outcomes

The intention of this national listening exercise was to identify ways in which young people, their families, society and state – locally and nationally – could work together to improve services for them. There was unanimous agreement that all those involved in the care of children, young people and their families across Scotland are focused on achieving a responsive and reliable service that offers families flexibility and choice. The Learning and Evaluation Report of these Scottish events has influenced the ongoing development of children's palliative care in Scotland.

- Many of the principles of the conversations are clearly embedded within the new, soon-to-be-published National Framework for Paediatric Palliative Care.
- CHAS, in collaboration with Marie Curie Cancer Care, developed a transition pathway which gives genuine choice to a young person, over 16 years, who wishes to die at home.
- Together for Short Lives has established a Transition Task Force to move the policy agenda forward, and to lobby governments to co-ordinate cross-departmental working on transition issues.
- CHAS is currently in early discussions with two NHS Boards in Scotland on the joint appointment of clinicians, which will further enhance collaborative working across the voluntary and statutory sectors.

Next Steps

In November 2012, CHAS will host a Scottish Square Table at the Assembly Rooms in Edinburgh. The event will bring together parents, young people and senior national leaders from health, social care, education and different faiths across Scotland. All have a shared interest in improving children's palliative care to make a difference to the lives of thousands of children, young people and their families. Participants will be asked to outline their pledge to take action to improve children's palliative care.

“In Scotland we need to get much better at anticipating transitions and not just wait for them to happen and then wonder what we should do.”

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