



The 11th Palliative Care Congress Glasgow 2016

Session Abstract

Transitional care – we all have to know something about this!

Dr Pat Carragher

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0830 - 0930

Children's palliative care has been recognised by the RCPCH as a sub-specialty. In 1982, Helen House was the first children's hospice to open in the UK, but there are now more than 50 children's hospice services across the British Isles. In the UK, approximately 6000 youngsters under the age of 19 die each year.

Research in 2011 (Fraser et al) identified that there were 49000 babies, children and young people (under 19) with palliative needs in the UK, and many of these have significant levels of medical and nursing complexity, with a significant proportion surviving into young adulthood. This often involves provision of a clinical team to support complex care needs, not least because this often involves a gastrostomy, polypharmacy (of medications not usually prescribed outside paediatrics), and specific anticipatory care plans, with detailed 'do not attempt cardiopulmonary resuscitation' orders. Increasingly, young people with recognised palliative needs may have a tracheostomy, intravenous access, other ostomies, and / or suprapubic catheter.

Many organisations commence a transition process from the age of 14 or 16 years, and are helping to strategically manage this challenging time for a young person, as well as their family, but many are not. Some young people liken transition to "falling off a cliff" when they get to 18 or 19 years old.

This session will use a video to allow young people to express their views to delegates, which is very informative. The session will also detail the work being undertaken by both Together for Short Lives (an umbrella organisation for children's hospices across the UK) and Children's Hospice Association Scotland (CHAS), which is the only provider of children's hospice services in Scotland. It will ask probing questions of delegates, as well as offering 'sign-posting' to other organisations which may be able to help.