



Meeting of the All-Party Parliamentary Group for Children Who Need Palliative Care

Tuesday 25 March 2025
4pm-5pm

Attendees

Dame Siobhain McDonagh MP (Co-Chair)
Lord Richard Balfe (Co-Chair)
Martin Vickers MP
Nigel Huddleston MP
Ben Goldsborough MP
Sir Julian Lewis MP

Summary

- The meeting involved a 2-hour reception with speeches taking place at 4pm. The event was held to raise awareness of the challenges confronting the children's palliative care, and how inequitable access is affecting seriously ill children and their families.
- The speeches began by hearing from Clare Buchanan who shared her son, Oliver's journey with high-grade glioma, from diagnosis to end of life. In doing so, Clare spoke about her experience of accessing high quality palliative care, highlighting that despite systemic barriers, the goodwill of those supporting them helped ensure the best end of life experience possible for Oliver. Clare also spoke about the importance of 24/7 end of life care at home.
- Nick Carroll (Chief Executive of Together for Short Lives) shared findings from a new report examining the extent to which children's palliative care that meets national quality standards is being formally planned, funded and provided across the UK.
- The APPG heard about how seriously ill children and their families are faced with a postcode lottery when it comes to accessing 24/7 end of life care at home, as well as the policy barriers preventing high quality children's palliative care from being sustainably planned and funded across the UK.
- Lee McGill (Head of Long-Term Conditions and Palliative & End of Life Care, Department of Health and Social Care) and Sue Bottomley (Programme Director – Palliative & End of Life Care, NHS England) then spoke about the work that is underway. Specifically, they reiterated minister's commitment to palliative care and his desire to move away from a 'sticking plaster' approach to funding. Sue noted recommendations that have been made to government concerning expanding 24/7 support to ensure real choice is available to seriously ill children and their families.
- Lord Richard Balfe thanked guests for attending and closed the speeches section of the event.