



Leicestershire Partnership
NHS Trust

MEDIA RELEASE

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Diana children's community nurse visits Westminster to lobby for improved palliative care for children



One of Leicestershire Partnership NHS Trust (LPT)'s Diana Children's Community nurses visited Westminster this week to attend the launch of a report from the All Party Parliamentary Group (APPG) for Children Who Need Palliative Care. Julie Potts, children's palliative care lead nurse (pictured far left), had already provided evidence to the APPG which informed their recommendations.

The APPG report, [End of life care: strengthening choice](#), followed a review into how the quality of palliative care that children and families are able to access varies significantly across the country, and the extent to

which, where children are concerned, the government is fulfilling its [commitment to end of life care](#) set out in 2016.

The report identifies five areas of particular concern where it feels the government needs to take urgent action to ensure equality of access. These are:

- children's palliative care out of hours and at weekends
- short breaks for respite
- age-appropriate palliative care and smooth transitions to adult services
- specialist children's palliative care teams led by level 4 (specialist) consultants
- advance care planning

As a specialist community nurse with 20 years' experience of providing palliative care for children, Julie was asked to give evidence to the APPG, alongside colleagues from the charity Together for Short Lives (the UK's leading charity for children living with life-limiting conditions and their families). She said: "It was a real honour to be involved in this important inquiry. Advances in medical technology and equipment mean that children with life-limiting conditions are living longer, but unfortunately the levels of nursing care and support available to families do not appear to be moving at the same speed. Publication of this report is a really positive step forward in addressing these challenges."

Julie is part of LPT's Diana Children's Community Service which was set up with money from the memorial fund of the late Princess Diana, and celebrates its 20th anniversary in January 2019. The service is commissioned across Leicester, Leicestershire and Rutland to provide 24/7 on call care at home for children deemed to be at the end of life. Ben Brocklebank, whose baby son Oscar was born with the genetic disorder Spinal Muscular Atrophy (SMA) type 1 in June 2017 and passed away six months later, said: "As well as kindness, understanding and emotional support, the Diana nurses offered really practical help, anticipating Oscar's needs, co-ordinating equipment and overseeing the transition to a hospice at the end of his life. Their involvement allowed my wife and I the space to just enjoy our time at home with Oscar. Every family should have access to a Diana nurse!"

Sadly, in many parts of England, families are reliant on emergency services or hospital admission if a child's condition deteriorates out of hours. MPs at Tuesday's event voted to keep the APPG going to ensure that the recommendations outlined in the report are actioned.

ENDS

NOTES TO EDITORS

- Leicestershire Partnership NHS Trust (LPT) provides community health, mental health and learning disabilities services for the one million people living in Leicester, Leicestershire and Rutland. We have a budget in excess of £275 million and employ approximately 5,500 staff. For more information visit: www.leicspart.nhs.uk. Our registered charity is called Raising Health (charity number 1057361). The charity fundraises to support excellent care initiatives, equipment and innovations which go above and beyond core NHS provision to enhance the experience of our patients, service users and staff. See www.raisinghealth.org.uk
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