

MEDIA RELEASE

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Partnership working to maximise choices for families around palliative care

Children's Hospice Week runs from Monday 23 - Sunday 29 May 2016. This campaign raises awareness of children with life-limiting conditions and of the services, like Leicestershire Partnership NHS Trust (LPT)'s Diana Service, that support them. We celebrate our palliative care project, in partnership with the Rainbows Hospice for Children and Young People, that has been running over the last 18 months.

The project's aim is to develop care pathways that maximise the choices for families of children with life-limiting or life-threatening conditions around how and where they are cared for. The Diana service now has a palliative care lead nurse in post, with responsibility for identifying and engaging at an early stage with such families. Central to the success of the project is working closely with the local Rainbows Hospice for Children and Young People. Together we encourage hospitals to refer care out to the community and to ensure families share information with us so that we can be part of the discussions around care planning. This facilitates access for families to the full range of services provided by LPT such as the child and family support service which provides counselling, emotional support, pre/post-bereavement support and support for siblings. The partnership working has also enabled LPT to enhance staff training and development in relation to palliative care.

Julie Potts, palliative care lead nurse for the Diana Service, said: "In the UK there are 49,000 children aged 0-18 living with a life-limiting or life-threatening condition, which equates to approximately 800 living in Leicester, Leicestershire and Rutland. Our partnership with the Rainbows Hospice for Children and Young People enables us to provide a holistic approach to supporting families by offering respite within a hospice or home setting and nursing support as the child's condition changes. Both services support each other to increase the families' options at such a difficult time in their lives."

Dr. Sat Jassal, Medical Director for the Rainbows Hospice for Children and Young People said: "The joint working between Rainbows and the Diana Nursing teams has proved highly effective in terms of the support provided to dying children in the

community. The close relationship allows us to provide specialised medical advice and support whilst the Diana nurses work diligently to provide the right emotional, spiritual, psychological and nursing support that the child and family need.”

LPT has also worked on changing perceptions around hospice and home care, putting the emphasis on quality of life. Nicola Rhodes, team leader for the Diana child and family support service, explained: “We help families to build lasting, treasured memories with their children, for example by helping them to make casts of foot and handprints. Family practitioners from the team use games, books, art materials, and ‘feel good bags’ in their work to help children and their families adapt emotionally to coping with a life limiting or life threatening illness. We have set up a [wish list](#) for people wishing to make a donation to the service.”

Donna Simpson’s four year old daughter, Dallas Horne (pictured), has Cri-du-Chat syndrome, a life-limiting condition. She has accessed both the Diana Service and the Rainbows Hospice for Children and Young People for support since Dallas was six weeks old. She explains: “What’s so brilliant about both services is that they are always there for the whole family, and not just to provide care for Dallas. They help my other children to feel involved by engaging them in activities that we can do together. The knowledge that whenever Dallas is really ill or I have specific concerns I just need to pick up the phone is very comforting.”



The theme for this year’s Children’s Hospice Week campaign is ‘Time to put families first’, and will focus on improving public understanding of what life is really like for families caring for seriously ill children. Together for Short Lives - the charity leading the campaign in partnership with children’s palliative care services across the country - is keen to highlight palliative and end of life care in all settings including children and young people being cared for at home.

ENDS

NOTES TO EDITORS

- **Leicestershire Partnership NHS Trust** (LPT) provides a range of health and wellbeing services mainly for people living Leicester, Leicestershire and Rutland. The Trust serves a population of one million, has a budget in excess of £267 million and employs approximately 5,400 staff. For more information visit: www.leicspart.nhs.uk.
- **For further information contact:** Rosie Huckle, Communications Specialist, Leicestershire Partnership NHS Trust, Tel: 0116 295 0802, Email: rosie.huckle@leicspart.nhs.uk
- **Children’s Hospice Week** (23-29 May) is the UK’s only awareness and fundraising week for families caring for these seriously ill children and celebrating the organisations that support them. The week brings together the UK’s 53 children’s hospices and all the children’s palliative care charities providing vital care and support for children and families across the country.

- **Together for Short Lives:** Hearing the news that your child has a life-shortening condition and is likely to die young is completely devastating. For tens of thousands of families in the UK this is the reality. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week. Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. We are here to help children and their families to access specialist children's palliative care services when and where they need it. We provide information so families know where to go for support and have the help they need to make the right choices about their child's care. Together for Short Lives supports all the professionals, children's palliative care services and children's hospices that deliver lifeline care to children and families across the UK.

Together for Short Lives has over 900 members - individuals, teams and organisations interested in and committed to supporting children and young people (and their families) with life shortening conditions. These include children hospices, voluntary sector organisations and statutory service providers.

Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.