

Press release – embargoed until 00.00hrs 12th October 2024

12th October 2024

World Hospice and palliative care Day

It is ten years since the World Health Organisation called for all countries to strengthen the provision for palliative care.

It is estimated that almost 100,000 children* across the UK are living with a life-limiting condition and may need palliative care¹.

Children's hospices provide a vital support to children and their families, providing respite care and short breaks, as well as critical emotional and psychological support for siblings and parents. In 2023/24, children's hospices in England received, on average, nearly 10% less funding from Integrated Care Boards (ICBs) compared to 2022/23 and over a third (31%) less funding when compared to 2021/22. Fundamentally funding from these sources has not risen to address increasing cost for energy or the increase in pay parity with NHS staff.

The Association of British Paediatric Nurses believes that the over reliance on charitable donations and fund raising is unsustainable for the future, resulting in many hospices being faced with making specialist and experienced palliative care staff redundant, along with the reduction in end-of-life care services provided.

World Hospice and Palliative Care day also gives an opportunity to celebrate the work of the staff and amazing volunteers who support children and families at the most difficult of times.

We welcome the Secretary of State for Health and Social Care's recent statement on 12 September where he said that the Government look forward to working with the palliative sector throughout the period of the spending review and the 10-year plan. However, the sector needs action now, not just words. A commitment to establishing a proper funding mechanism for children's hospices was made over a quarter of a century ago but still has not happened.

¹ Together for Short Lives, the UK charity for children's palliative care describe palliative care for children as an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.

Access to appropriate palliative care services across the UK currently depends on where you live. The ABPN says this is unacceptable, postcode lotteries have no place in the care of children and calls for:

- investment in children's community nursing to enable children to receive care at home
- sustainable and equitable funding for children's hospices across the UK
- education and training opportunities for all those working with children and their families so that they are able to provide palliative approaches at the earliest opportunity

"When hospices and other services provide an active and total approach to palliative and end of life care for children and young people and their families the benefits are immense. However, such services need significant investment. Now is the time for such investment."

Professor Bernie Carter, President

Notes for editors

The term child refers to infants, children, young people and young adults up to 25 years of age

The ABPN recognises that primary and community services, as well as child public health and mental health services, including school nurses and health visitors also have a key role in supporting children, young people and families.

Lord Darzi's report – [Independent Investigation of the National Health Service in England](#)

Association of British Paediatric Nurses position statement in relation to Lord Darzi's Independent Investigation of the National Health Service in England – see www.abpn-uk.com

Together for Short Lives – <https://www.togetherforshortlives.org.uk/>

APPG Hospice and End of Life Care report - <https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2024-02/APPG%20Report%20-%20Government%20funding%20for%20Hospices%20HUK.pdf?VersionId=0l8T4jC5V2C0zRKQLFs9CIZ5QZ5xEiOs>

The ABPN is a network of children's nurses with a wide membership of experts in clinical practice, education, leadership and research. It is the oldest children's nursing association in the world, established in 1938.

www.abpn-uk.com

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