

Statement from the International Palliative Care Community following the death of Charlie Gard.

This statement is issued by the International Children's Palliative Care Network (ICPCN) in conjunction with the international palliative care community represented by the Worldwide Hospice and Palliative Care Alliance (WHPCA) and the International Association of Hospice and Palliative Care (IAHPC). It is supported by UK children's palliative care charity, Together for Short Lives.

Statement

We have been deeply moved by the situation of Charlie Gard and his family and our thoughts and condolences are with them following his death, and all those involved, including all of the dedicated health professionals who have cared for him at Great Ormond Street Hospital (GOSH) and more recently at the hospice. This situation has highlighted the need not only for awareness about palliative care for children, but also the early integration of palliative care in the care for all children with life limiting and life threatening conditions. Indeed the World Health Assembly resolution on palliative care (2014) emphasises the importance of ensuring that palliative care is available to all those in need, and throughout the course of their illness and should be provided alongside treatment aimed at cure. Children's palliative care is an active and total approach to care provided from the point of diagnosis. It embraces physical, social, spiritual and psychological needs and focuses on enhancing the quality of life for the child or young person and supporting their family. Thus it is a total approach to care, from the point of diagnosis, throughout the child's illness, death and into bereavement. Palliative care is life affirming and not about giving up, but about ensuring that the child can have the best quality of life within the realities of their condition. Children's palliative care, includes pain and symptom management, comfort care and support for the child and all the family.

There are over 21 million children worldwide who need access to palliative care, with at least 8 million needing specialist care¹, yet less than 10% of children around the world can access such care. In the U.K. there are 49,000 babies, children and young people between the ages of 0 and 19 who have a life- limiting or life-threatening condition i.e. one child in every 270. Palliative care is provided in a range of settings including hospital, hospices and home, depending on what is appropriate for the child and their family. In the U.K. there are 54 children's hospice services, along with hospital and community palliative care teams, including an excellent palliative care team within GOSH itself. Palliative care services can provide support to families throughout the course of the child's care, supporting them through difficult decisions, including that of withdrawing life- sustaining treatment such as artificial ventilation. Open and honest communication between families and professionals caring for the child should be at the heart of reaching decisions around withdrawing life-sustaining treatment and thinking about end of life care choices. These are decisions that no parent wants to have to make for their child, and it is important to remember that withdrawing such treatment is not

¹ Connor SR, Downing J, Marston J. (2017) Estimating the global need for palliative care for children: A cross-sectional analysis. *Journal of Pain and Symptom Management*. 53(2):171-177. Doi: 10.1016/j.jpainsymman.2016.08.020

about abandoning care but continuing care, comfort, pain and symptom management or support for the family.

The global palliative care community is committed to the ongoing development of palliative care for children and their families, so that all children who need palliative care will have access to it, regardless of their condition or where they live in the world. The life of Charlie and his family has aroused emotions around the world and our hearts go out to his parents and family at this tragic and sad time.

About the International Children's Palliative Care Network

The International Children's Palliative Care Network (ICPCN) (www.icpcn.org) is a global network of organisations and individuals working in the field of hospice and palliative care for children. Our vision is to achieve worldwide the best quality of life and care for children and young people with life limiting illnesses, their families and carers, through communication, networking, advocacy, research, education and support and development. ICPCN represents the global voice of children's palliative care.

For more information

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Supported by

This statement has also been supported by Together for Short Lives (www.togetherforshortlives.org.uk) in the U.K. along with the following regional palliative care organisations:

- The European Association of Palliative Care (EAPC) <http://www.eapcnet.eu>
- The African Palliative Care Association (APCA) <https://www.africanpalliativecare.org>
- The Asia Pacific Hospice Palliative Care Network (APHN) <http://aphn.org>
- Asociación Latinoamericana de Cuidados Paliativos (ALCP) <http://www.cuidadospaliativos.org>

Our vision is to achieve worldwide the best quality of life and care for children and young people with life limiting illnesses, their families and carers, through networking, advocacy, information sharing, education and research.

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