

Press release
For immediate release
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Pioneering palliative care guidance published by Chelsea and Westminster Neonatal Team

Chelsea and Westminster Hospital NHS Foundation Trust has published the first ever guidance of its kind to support staff caring for very young babies with life limiting conditions who need palliative or end of life care.

Despite advances in neonatal medicine, sadly many babies will suffer from conditions that mean they will not survive longer than months, days or a few minutes. The purpose of the guidance is to help clinical staff deliver care for babies that is of the highest quality, and provide families with the support they require.

Caroline Friel, mother of baby Brigid, said: “Nothing can prepare you for the death of a child. It is vital that the staff who are caring for our babies and supporting us through this difficult time are trained and equipped to do so with an understanding of the procedures and protocols that will allow our babies to die with dignity, whilst ensuring that they do not suffer unnecessarily. It is also important that this is done within a framework that allows the families to have their concerns heard and their wishes considered.

“I cannot stress enough the importance of having access to professionals who work as a team and put your baby at the forefront of their planning. Good training, guidance and support is essential to empowering them to do this and to reassure us, as parents, that we do not have to worry about the practical aspects of our babies’ condition and can concentrate on being the best parents we can be for whatever time we have left with our precious children.”

The guidance was developed by members of the neonatal team at Chelsea and Westminster Hospital that included doctors, a nurse, a psychologist and a hospital chaplain. It has been endorsed by the Royal College of Paediatrics and Child Health after several rounds of stakeholder consultation, including key charitable organisations and professionals within the field of neonatal palliative care. The development of the guidance was funded by the Department of Health and the production and publication was supported by the Chelsea and Westminster Health Charity. The guidance includes a foreword by Sir Bruce Keogh, National Medical Director for NHS England and real-life experiences of families whose babies have received such care.

Alexandra Mancini, Lead Nurse for Complex, Palliative and Bereavement Care at Chelsea and Westminster Hospital, said: “The guidance is the first of its kind in that it is based upon a systematic review of available evidence. In developing the guidance it became clear to us that there was a need for more evidence to guide best practice and we hope that this will be addressed with more funding for research in to this area of neonatal care. We would like to thank all those who have contributed and commented in the making of this document.”

Hard copies of the guidance will be sent to all neonatal units in the country during February and it will also be available to download, along with all of the supporting documents, from the Royal College of Paediatric and Child Health website. It was also be available from a number of charity and stakeholder websites including Bliss, British Association of Perinatal Medicine, Child Bereavement UK, The Multiple Births Foundation, Stillbirth and Neonatal Death Charity and Together for Short Lives.

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