

Foreword

When the Northern Neonatal Network was created as a new managed clinical network in March 2010, it was built on the basis of an agreed core principle and mission statement, which was

“To give the highest possible standard of safe, effective care to babies and their families.”

Over 3500 babies are cared for at one of our 11 neonatal Units across the north of England and north Cumbria. Sadly, a small number of these babies will die either in hospital or be discharged with a life-limiting illness, sometimes to another ward, care facility or home, where they can best be supported with palliative and end of life care.

Whilst the numbers of such babies are comparatively few, it is crucial that they are given the very best care possible and that their families and carers are supported through a very difficult, challenging time. It is therefore incumbent on those involved in the care to ensure that this is done in a way that recognises the unique and very individual circumstances of every baby and their families. There really is just one opportunity to “get it right” and this is what all health care professionals strive to do.

As a Network, we recognised some years ago that there were examples of excellent palliative and end of life care across our region, but that it was often difficult to “learn from each other” and try to standardise such best practice and minimise variation. In order to try and address this, a dedicated group of medics, nurses and others started a process to produce a framework to assist all those involved in providing care for babies with terminal conditions and life-limiting illnesses and prepare them and their parents and carers for death. We know on neonatal units a baby’s condition can change by the minute and this can occur without warning and very quickly, but for the cases where a death can be planned for, we have drafted this new “Care Bundle” to help that process.

This is not a “mandated” document, but rather a framework and set of tools to assist health care professionals with their care provision, trying to ensure the right conversations take place at the right time, in the right place and with the right people. This then should hopefully result in the very best care possible being provided. It is the result of a wide, multi-disciplinarily and cross-organisational collaboration and remains very much a work in progress, but hopefully will be welcomed as a helpful aid via the various constituent parts for anybody providing palliative and end of life care in a multitude of settings and places, but always with the baby and it’s family at its heart.

I would like to thank all those involved in this Bundle’s production, particularly Dr Yifan Liang & Dr Rob Tinnion from James Cook University Hospital and Stacey Williams from University Hospital, North Tees who have been pivotal in its drafting. I know they will welcome feedback and suggestions for future revision and I commend it for use across the Network as an excellent framework and hope it assists those for whom it is aimed.

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