

Welsh Government issues guidance to NHS Wales on the care of babies on the threshold of survival

The guidance, which has been set out in a Welsh Health Circular (WHC), sets out what Health Boards need to do to care for babies born alive before 24 weeks of gestation, whilst also supporting their families and ensuring they are fully involved in making decisions about their care and treatment.

The WHC was developed in response to a concern from a member of the public – Emma Jones – that current professional guidance from the British Association of Perinatal Medicine (BAPM) does not state what the NHS should do to care for babies born alive before 24 weeks. This followed the death of her son, Riley, who died after he was born at the age of 22 weeks and 4 days in December 2013.

As a result, the Welsh Government has worked with Emma Jones over the last few years to develop additional guidance that promotes the highest quality, evidence-based and compassionate services for mothers and babies born alive before 24 weeks.

The guidance states that where the birth of a baby on the threshold of survival is anticipated or occurs, maternity teams should consult the on call neonatal or paediatric team (whenever possible before the baby is born), to ensure that clinical assessments are planned and undertaken.

Additionally, the family of the baby will be involved in the decision making about ongoing care. It takes into account the professional advice that is available to clinicians for the care of babies born on the threshold of survival.

Bereavement services are needed by many families, and every Health Board in Wales now has a bereavement midwife lead to promote best practice.

Concerned member of the public and mother, Emma Jones said:

“My journey for change started at the National Assembly when I presented my signed petition.

“From Riley’s death came a fight for change, which ended in success.”

The Chief Medical Officer for Wales and Medical Director of NHS Wales, Dr Frank Atherton said:

“When a baby is born very early, parents and professionals are

faced with difficult and distressing decisions. Whilst medical science has provided many advances in the care of very premature babies, especially those born under 26 weeks of gestation, there are limits to what is possible in terms of survival.

“Very tiny babies, even when they are born alive, may not be able to be resuscitated because their airways and lungs are too immature and delicate to withstand intubation and ventilation, and their blood vessels too small to administer medicines or fluids.

“We recognised there was a need for the Welsh Government to develop this additional guidance, because the current professional guidance from the British Association of Perinatal Medicine (BAPM) does not state what the NHS should do to care for babies born alive before 24 weeks.

“We are very grateful to Emma Jones for sharing her painful experiences with us, and for working with us to develop the new guidance, which will help maternity services to support sensitively mothers and families where babies are born on the threshold of survival.”