Church Crookham baby death sparks national review into care for newborns

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15 years since the tragic death of their newborn daughter, Anne and Graeme Dixon have welcomed an investigation into the care of babies who need extra support

- Chris Whiteoak

Graeme and Anne Dixon

A health watchdog has released the results of a national review into the care of newborns who need extra support, sparked by a Church Crookham couple who tragically lost their baby.

Anne and Graeme Dixon's daughter Elizabeth was born at Frimley Park Hospital in 2000 and was brain damaged after her high blood pressure was not treated for 15 days.

She was left disabled and needed a tracheostomy, or tube, to breathe, but suffocated and died at home days before her first birthday when it was not maintained during a home visit by an agency nurse who transpired to be newly-qualified.

The Care Quality Commission (CQC) investigation found there is a significant risk to hundreds of babies and children because of inconsistent practice and a lack of clear guidance on treatment.

The watchdog said it has uncovered concerns about the way the NHS identifies and manages clinical risk in unborn and newborn babies.

In the first report of its kind, it also raises fears that key information might not be shared between clinical teams and says there needs to be more consistent support for families with children requiring long term ventilation at home.

Among its recommendations for improvement, the CQC says every unborn fetus should be assigned a unique identification number to ensure important information from a mother's clinical notes is properly transferred to the baby's records after birth.

'Great deal of variation'

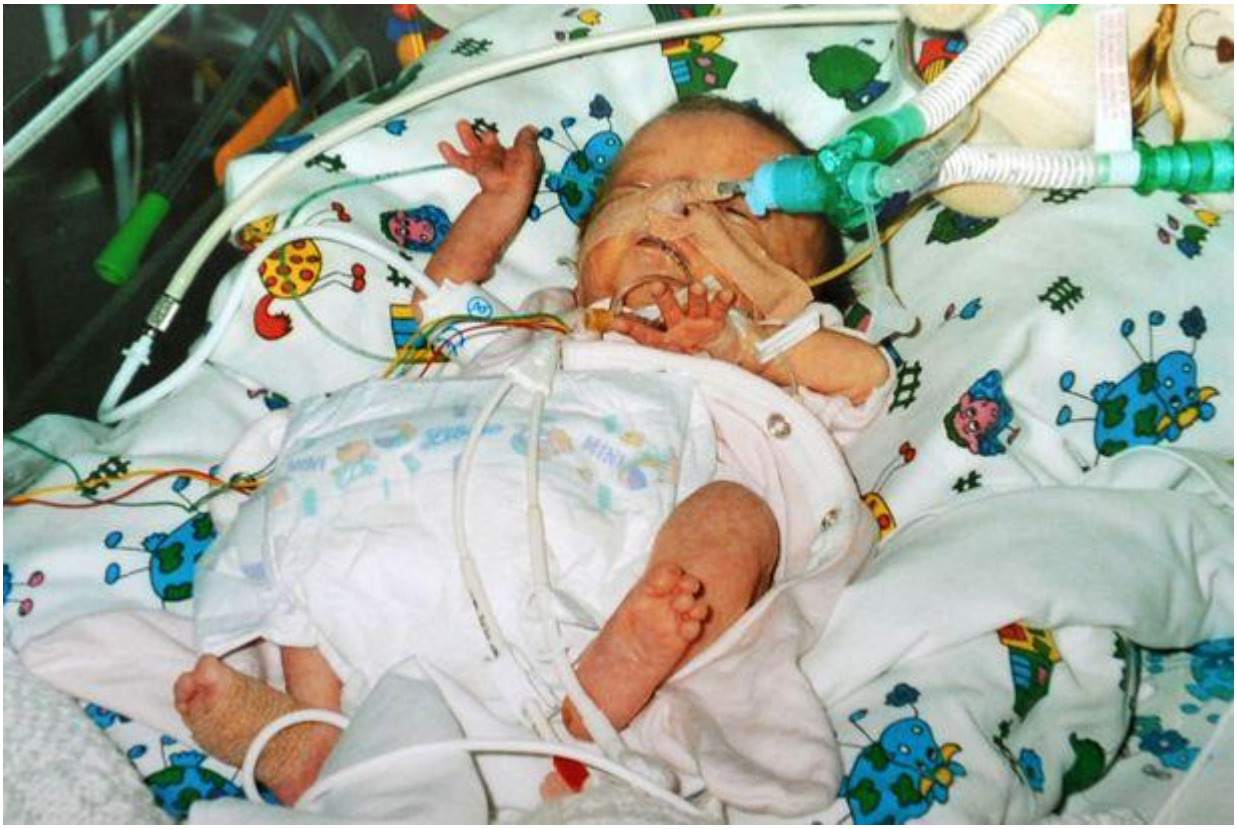
The CQC and NHS England were due to carry out an independent investigation into baby Elizabeth's care in 2014, but NHS England pulled out at the last minute.
As a result, the CQC agreed to examine the wider themes raised by her case to identify any gaps in current practice.

It examined practise at 19 acute hospital trusts and took evidence from commissioners, and from families whose children require ventilation support at home.

Commenting on the review, Professor Edward Baker, deputy chief inspector of hospitals at the CQC said: "We found some excellent examples of good and outstanding practice and there is no doubt about the dedication and skills of staff that provide this very specialist care.

"However, we found a great deal of variation in the way that services manage clinical risks in babies before and immediately after birth, and in the management of infants that need support once discharged home.

"For all anomalies detected during pregnancy communication between specialist teams is essential. However, when major problems are identified, multidisciplinary meetings need to take place including obstetrics, fetal medicine and neonatal specialists. In some hospitals, this is routine, but in others it isn't always happening."



Baby Elizabeth Dixon died in 2001

Elizabeth’s parents said they were pleased the CQC had listened to their concerns.

“We are alarmed that the potential for harm and death is still there in 2016 and that no organisation or person has until now, done anything positive to learn from the failures in Lizzie’s care or to tell us the truth, something we had to find for ourselves,” added Mrs Dixon.

“We are grateful that the CQC took heed of our plea that they extend the terms of their review to look at monitoring and management of all children’s blood pressure, not just neonates.

“It was a relief to have the CQC take some of our concerns on board and we are moved by their efforts to ensure that some learning comes from Lizzie’s suffering and we are particularly appreciative that they haven’t just published a report on their review, they have taken steps to ensure that organisations who can take forward suggestions and transform these into guidelines for healthcare professionals, are willing to and have already started to do this.

“Our hope now is that the further work suggested in the report is done without delay and that there is a more detailed review of how the NHS and private care companies manage vulnerable children (and adults) needing long term breathing support in the community and that assessment of experience and skills of all nurses and carers

placed in community care packages becomes mandatory and steps are taken to ensure they are fit to undertake the work.”

Following the failure of national organisations to investigate Elizabeth’s death, health secretary Jeremy Hunt intervened and ordered an independent inquiry last year.
The South West Surrey MP said it was "an incredibly distressing" and "frankly heart-breaking" case.
“It does need an investigation and I think for various unintended reasons, the case was passed around the system and it’s happened for far too long,” he added.