

What can we learn from child deaths in North East Lincolnshire? 2008/9 -2015/16

Since April 2008 all child deaths of children under 18 years (excluding still births and planned terminations) are reviewed by the Child Death Overview Panel (CDOP). The panel consists of a range of people from health and social care organisations for the area. The process of undertaking CDOP reviews is a national requirement set out within *Working Together to Safeguard Children Guidance (Revised 2015)*, and undertaken locally for all children who normally live in North East Lincolnshire.

Through a set procedure all child deaths are reviewed, whether or not the death was expected. The panel does not apportion blame but looks to see whether anything can be learned, changed or done differently, either here in North East Lincolnshire or nationally, to help prevent similar child deaths. This might include changes to organisational processes but may also indicate the need to provide more support or information and guidance for families and communities.

How many children died in the local area?

There have been 98 child deaths between 2008/9 when the CDOP processes were first introduced and 2015/16. This indicates an average of 12 child deaths per year.

Expected and unexpected child deaths

Child deaths fall into the two categories of either expected or unexpected. An unexpected death is defined as 'the death of an infant or child which was not anticipated as a significant possibility for example, 24 hours before the death; or where there was an unexpected collapse or incident leading to or precipitating the events which led to the death' (HM Government, 2015).

Between 2008/09 and 2015/16, 56% (57 children) of the 98 deaths were classed as unexpected. During the first four years of the eight year period, there were more unexpected deaths than expected although in the subsequent four years, there was a greater proportion of expected deaths.

Ages of the children who died

Of the 98 child deaths over the period:

77 were under the age of 4 years old, 62 of whom were infants (aged under 1 year) including 39 infants that were under 12 days (neonatal) and 24 of the 39 were under 7 days (early neonatal). 7 children who died were aged 5-9 years, 3 aged 10-14 and 11 were in the 15-17 years age range.

What were the causes of death in the local children?

Since 2010/11 the CDOP has been required to assign each death to one of 10 nationally defined categories. For classification purposes, if there is more than one cause of death, the primary cause is used. Of the 71 child deaths since 2010/11 there are 7 that were still under investigation as at 1 July 2016 and as such, the causes of these deaths have not yet been categorised. The top 4 causes of death for the 64 that have already been categorised in North East Lincolnshire were:

1. **Perinatal / neonatal: I.e.** Death ultimately related to perinatal events, e.g. sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, and post-haemorrhagic hydrocephalus, (irrespective of age at death). This category includes cerebral palsy

without evidence of cause and congenital or early-onset bacterial infection, i.e. onset in the first postnatal week, of which there were 15 child deaths

2. Chromosomal, genetic and congenital anomalies (Includes Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis and other congenital anomalies including cardiac) – this category included 15 child deaths

3. Chronic medical condition (For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause) – There were 8 child deaths

4. Infection Any primary infection (i.e., not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc. – There were 8 child deaths

Could anything have been done differently (*known as modifiable factors*)

The CDOP also considers whether there were any 'modifiable factors' that is anything that could have been done that could have prevented the child's death and could help to prevent similar deaths. Of the 98 child deaths since 2008/09, less than 13% of classified deaths were categorised as having modifiable factors, which is lower than the national average. Locally the general trend is of decreasing the proportion of deaths with modifiable factors identified, although it has to be considered that there are seven child deaths that are yet to be classified.

Of local deaths with modifiable factors there were 8 infant deaths (1 year age). Of the local deaths with modifiable factors 12 were unexpected deaths. The cause of death for 5 deaths with modifiable factors was either sudden infant death syndrome or inappropriate sleeping. A further 3 deaths involved road traffic accidents.

Local actions to address identified modifiable factors

CDOP member agencies have continued to share the findings from child deaths within their organisations to help inform learning and practice. A joint NEL/ North Lincolnshire Child Death Review Panel was established in April 2016, this will lead broader and shared learning.

Information entitled the North East Lincolnshire and North Lincolnshire LSCB Safer Sleep Guidance has been revised and now includes a pathway of information and support from antenatal at the 34 weeks contact by midwives, through to early childhood. In addition to receiving the Safer Sleep guidance new parents also receive a safe sleeping assessment. A room thermometer is provided by midwifery during the pregnancy at around 34 week's gestation, and a follow-up assessment is undertaken by health visitors after the baby is born.

Work has also been undertaken with the Hospital and the Cremation services that has enabled clarification of local arrangements and led to further guidance being provided to bereaved families on the available options in respect of burial/ cremation

Losing a child in any circumstances is a tragedy and we need to ensure that support is in place both in the immediate and longer term as required. Although not a formal role of the CDOP, locally we have reviewed the support provided to bereaved families, including provision for surviving siblings. The review identified that there tends to be excellent support in place for those families whose deceased child had an *End of Life Plan* in place or they were already being supported by the Hospice.

What help do parents get when their child dies?

If a child or young person has a condition or illness that means their life is going to be shortened, then health and social care services provide support and care as part of something called an 'end of life plan'. The family, including the siblings if there are any, are supported through the Hospice (St Andrews) up to the time of death and beyond according to the families' needs.

The families of children who did not die in the circumstances outlined above, for example a child or young person who has died suddenly, are supported at the time of the child's death by hospital staff. Suicide Prevention Training has been developed and provided to agencies in order to help identify children most at risk and to respond to presenting crisis and where to seek support and advice. In addition a local critical incident process has been developed to support staff in helping children/adults to deal with loss or bereavement.

More information on the CDOP process and any information in this report can be obtained from the <http://nelsafeguardingchildrenboard.co.uk/child-death-process/>

For further advice and support after a child death contact your midwife, health visitor, or school nurse or the national charity Lullaby Trust on 0808 802 6868 email: support@lullabytrust.org.uk website: www.lullabytrust.org.uk