

Thematic Review

Neuro-disability and Infant and Child Death

2016-2020

An increasing proportion of deaths now occur in children with complex health problems who already have regular contact with health services.

What we did:

- Convened cross-sectoral panel
- Reviewed literature
- Identified and reviewed the deaths from the Child Death Overview Panel database

37 babies and children were included in this review.

54% of children were male

22% of children were Asian

24% of children lived in Woking

14% of children had a respiratory condition documented as primary cause of death

38% of children were within the lowest 30% ranking of income deprivation affecting children in Surrey

30% of children died aged 29 days to 1 year

22% of children were born before 37 weeks

41% of children had a diagnosis of epilepsy

8% of children had consanguineous parents

Opportunities not to be missed:

All parents/carers should be offered an opportunity to have a conversation with their paediatric team following the death of their child.

Surrey Safeguarding Children's Partnership (SSCP) Neglect strategy 2021-2023 should be implemented across the system.

The Child Death Review Partnership should ensure that there is effective information gathering of data.

There should be better support for parents and carers with children with a neurodisability offering better person and family centred care including respite care with a more coordinated approach and multi-disciplinary team working which is key for this group of complex patients.

The Oliver McGowan Mandatory Training in Learning Disabilities and Autism should be completed by all staff working in health and social care so they receive learning disability and autism training, at the right level for their role. They will have a better understanding of people's needs, resulting in services and improved health and wellbeing outcomes.

~ The Oliver McGowan Mandatory Training in Learning Disability and Autism. | Health Education England (hee.nhs.uk)

There should be full implementation of NICE guidance (2017) on end of life care for infants, children and young people
There should be clarity around advanced care plans for end of life care and there is a need to train professionals around implementation of advanced care plans. Professionals should also receive training on having difficult conversations with parents in relation to thresholds for intubation and decisions around giving life support or not following local and national guidance/policies.

In line with recommendations in the LeDeR annual report, services should link together within systems to improve information sharing and communication between professionals, this would allow for understanding and support around missed appointments, discharge summaries or change of circumstances, amongst other issues. General Practitioners should be aware of the potential multifaceted needs of this group of patients and access published care pathways as required.

There should be full implementation of the NICE Quality Standard Promoting health and preventing premature mortality in black, Asian and other minority ethnic groups, to address the health inequalities experienced by this population.

There should be improved access and co-ordination of services and/or appointments for children seen by the multidisciplinary team.

There should be full implementation of the NICE Quality Standard on Ante-Natal care to reduce the risks to the unborn child that may potentially lead to a neurodisability.
~ Overview | Antenatal care | Quality standards | NICE

There should be further investigation and identification of the prevalence of consanguinity amongst the population of babies and children with a neurodisability in Surrey. It may be appropriate for genetic counselling to be offered to these parents before conception.