

WILTSHIRE AND SWINDON CHILD DEATH OVERVIEW PANEL (CDOP) NEWSLETTER

September Edition
2022

The Wiltshire and Swindon Child Death Overview Panel (CDOP) review every child death to identify any modifiable factors which may have contributed to the death, and what, if any, action could be taken to prevent future deaths.

This newsletter is for professionals working with parents and their children, to highlight some of the learning, guidance, and useful resources to support safe, healthy families.

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Wiltshire and Swindon Smoking Cessation Services

Smoking is the leading modifiable risk factor for poor birth outcomes to include stillbirth, miscarriage, and pre-term birth. Smoking during pregnancy and exposure to secondhand smoke is also associated with an increased risk of sudden infant death syndrome (SIDS) and serious long-term health implications for the child.



A reminder that in Wiltshire, all three maternity providers have specialist teams to support pregnant people who smoke to quit. Alongside helping people to change their behaviour, the teams can provide people with nicotine replacement therapy (NRT) or vapes to ease the nicotine cravings. All midwives can speak to pregnant people and their family members about their smoking and refer them on to support services. Help is available at any time throughout the pregnancy.

Wiltshire residents are also able to access to support to stop smoking through participating GP surgeries or the Health Improvement Coach service. Smokers can refer themselves for support or be referred in by a professional.

For more information please see [Smokefree Wiltshire – Wiltshire Council](#).

Swindon residents can access free smoking cessation support at various locations across Swindon by visiting [Stop smoking service | Swindon Borough Council](#).

For additional information about local stop smoking services, please contact: swindon.stopsmoking@nhs.net to find out more.

Training is available for staff across Wiltshire and Swindon who can support quit attempts through their roles and can be booked on at www.eventbrite.co.uk searching for Stop Smoking Training in Wiltshire or Swindon.

Antenatal Steroids in premature babies



CDOP recently reviewed a case where the provision of antenatal steroids was discussed. Professionals are reminded to support and advocate for the use of antenatal steroids in the 22+ 5 gestation group if delivery is expected, particularly making certain that:

- The use of maternal corticosteroids in the context of the individual's circumstances are discussed with the woman (and her family members or carers, as appropriate) and the multidisciplinary team ensuring they are aware of the benefits and risks
- They are given this information as early as possible both in written and oral formats
- Professionals bear in mind that the woman (and their family members or carers) may be particularly anxious.

Please visit the guidelines below for further information:

- [NICE Pre-term Labour and Birth Guidelines](#)
- [Antenatal corticosteroids to reduce neonatal morbidity and mortality](#)

Edwards Syndrome Guidance

CDOP reviewed a case of a child with Edwards Syndrome and noted the particularly good practice and personalised care provided to the child and family. Trisomy 18, also known as Edward's syndrome, is a genetic condition caused by an individual having three copies of chromosome 18. This results in a range of congenital abnormalities, which can affect every organ system, and cause intellectual disability.

Although the majority of affected children will die before birth or in the first year of life, the term "universally lethal" is misleading, as recent studies have shown that 5-8% of live-born children live to their 1st birthday without special care, and those who live to 1 year have a 60% chance of reaching 5 years. Furthermore, both 1 year and 5 year survival increases with intensive medical intervention.

The conventional view that babies with Trisomy 18 should not receive resuscitation or medical intervention is at best outdated, and at worst exposes these babies and their families to withholding of life-sustaining care. A guideline has therefore been developed, in consultation with parents and colleagues working in general and community paediatrics, palliative care, neonatology and fetal medicine, emphasising the

importance of co-operative medical and parent evaluation of the benefits and challenges of any intervention for an individual child.

Topics covered in the guideline include:

- antenatal diagnosis
- discussion of options following diagnosis
- common structural abnormalities
- care at birth
- ongoing care
- medical interventions



An initial 'diagnostic checklist' and a 'Trisomy 18 Review Document' have also been produced. Key questions to consider when counselling parents regarding an intervention have also been highlighted including:

- Will the child suffer with / without intervention?
- Is the intervention in the child's best interest?
- How many times will the child be hospitalised?
- How many procedures or operations will be necessary?
- If placed on ventilatory support, will weaning be possible?
- Should the treatments escalate at each point of organ dysfunction?
- What support is there for families at different stages?
- Where will the family stay in hospital?
- What equipment will be necessary at home?

The guideline and supporting paperwork have been presented at various paediatric conferences and are to be shared nationally via the Neonatal Network. Once signed off, the final guideline will be shared via this newsletter.

It is important to remember that every child with Trisomy 18 is unique. Not all interventions may be appropriate for every child, and decisions should be made in the best interests of the child, taking all available information into account, and in conjunction with the parents.

Every child and family must be provided with love, dignity, respect and comfort.

Voice of the Child and Family Engagement

CDOP reviewed a case of a teenager, with a terminal illness and noted the good engagement of the healthcare professionals with the young person, informing them of options and their prognosis and enabling the young person to make key decisions about their clinical care and therapeutic options. The young person made clear that no discussions were to be had with their family without them and this request was respected throughout their care.



However, the family of the young person felt that they'd had a lack of support from medical teams and following their loss emailed a detailed list of questions about their child's care. As they declined to meet with the teams, requesting a written response, the request was treated as a complaint by the hospital. The formalisation of this action led to lengthy delays in response, causing significant distress to the family. Learning was identified by the team in ensuring that a clear time for response should be provided in order to set expectations. However, CDOP concluded that rather, the service's Duty of Candour should have been more appropriately applied so as not to delay the response to the family, especially given the family themselves noted their questions were not complaints.

Remind yourself of your [Duty of Candour responsibilities on the General Medical Council website](#).

Professional Curiosity and Challenging Assumptions

CDOP reviewed a case of a child with a neurodisability, where it was not recognised soon enough how acutely unwell they had become. An assumption may have been made that the child's lack of responsiveness was due to their disability, compounded by a night-time admission leading to professionals assuming the child was asleep.



Neurodisability can result in a wide range of impacts and severity for children and this can change as they grow up. It is therefore paramount that a personal assessment of each child as an individual is made.

Professionals are reminded to liaise with family to establish what a usual response from a child would be and to ensure that [Paediatric Early Warning Systems](#) are used in conjunction with the [NICE Traffic Light System for identifying Risk of Serious Illness](#)

[in under 5s](#) and [NICE Guidance \[NG 51\] Sepsis: recognition, diagnosis and early management](#).

For more information about CDOP or if you have any suggestions for future editions of the Wiltshire and Swindon CDOP newsletter, please email: publichealth@swindon.gov.uk.

The CDOP newsletter will be produced twice a year.



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