

NEWSLETTER

CHILD DEATH REVIEW TEAM



The importance of B-Forms in the Child Death Review Process.

A focus for the Child Death Review Team is to provide learning from every Child Death. It aims to give answers to some of the questions the grieving parents and wider family may have, and it provides the opportunity to take forward not just negative but also positive elements from the most tragic of events.

One of the main ways we can collate this information is the **FORM B**. Following the death of a child we send out Form B requests to the professionals involved in that child's care during their life and after death. We send them to those with the most valuable sources of information. It is part of the statutory process. It is the responsibility of those professionals to complete and return the B-forms in a timely manner. We genuinely understand the time this takes and how valuable and limited your time is, however, feel this is a chance for individuals to reflect on the case.

FORM B directory in eCDOP: Recently, we have found one of the biggest problems in reaching our GP colleagues is the reluctance from the admin teams in GP practices to pass on individual GP's NHS email addresses. Although we have the generic GP Practice email and we send a request to that inbox for the attention of a specific GP, on the eCDOP directory we can only register one GP to one email address. This allows us to only register one GP per GP practice email as we can only register one person to one email address.

We would be most grateful if you can work with us in resolving this difficulty and advise your administration teams about the requirement to complete the B-form, part of a statutory process and therefore, that you are happy for your individual NHS email address to be provided. We use it only to register individuals to the Electronic Child Death Overview Panel System to allow individual professionals to complete the B-forms. It should also be noted that as a team, we are only too happy to support you in this process and will respond promptly should you request any assistance.

Below is the link to view the advice for Statutory Guidance for the Child Death Review Process: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf

Meet the team: Ali Church- Team Administrator: alison.church1@nhs.net

I recently joined the CDR Norfolk & Waveney Team following a 3 ½ year period at NSFT. Prior to NSFT, I had spent 32 years in Dental Services.

I believe the CDR Teams provide such a valuable service and they carry out their roles with such sensitivity and kindness, always looking for positive outcomes in what is quite honestly, the worst situation imaginable. They are a brilliant team.

I have been asked to introduce myself in this newsletter, which is always a bit awkward, but very simply: I am very happily married, with three grown up children and two grandchildren. We live with our two Labradors, Paddy & Charlie in a bit of a renovation project, in Waveney, which we moved to three years ago and that we are gradually doing-up. My biggest priority is family and friends.



NEW CONTACT INFO: Team phone number: 01603 257160 (please update your records)
nwicb.childdeathreviewteam@nhs.net

Lead Nurse Sonia Furness; Deputy Nurse Julia Fothergill, Deputy Nurse Anne-Marie Freeman

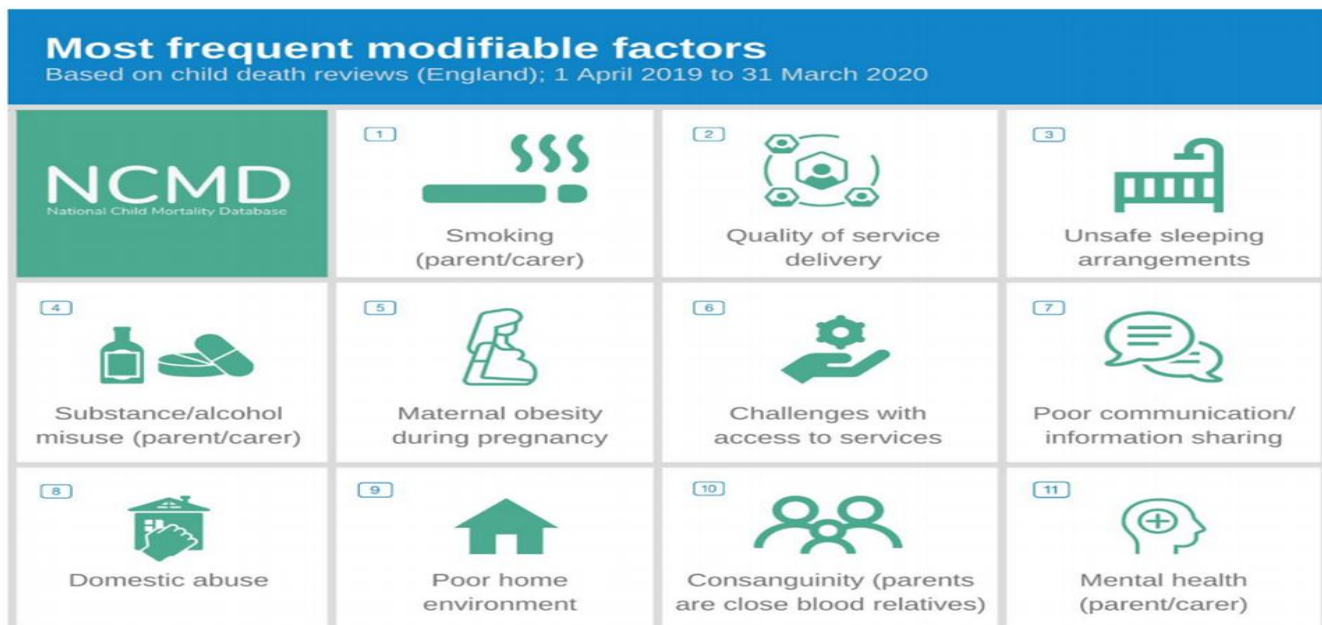
Modifiable factors

As part of the Child Death Review process we look for modifiable factors. Working Together (2018) defines modifiable factors as:

“factors which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future deaths.”

Whether a factor is thought to be modifiable is dependent on the circumstances of the death. Factors are assessed as being modifiable if there is an intervention which, once in place, could reduce the risk of future child deaths either directly, or by reducing the elements which increase children’s vulnerability or ill health. The interpretation of what factors are modifiable may vary across CDOPs nationally.

The National Child Mortality Database (NCMD) have produced the following table showing the most common modifiable factors in the child deaths between April 2019 and March 2020.



In Norfolk, Waveney and Suffolk, from April 2021 and March 2022 of all the child deaths reviewed by the panels 49% of the cases identified modifiable factors that may have contributed to the child’s death. The 2021 national average for England was 34% but there is wide variation between regions. It is not clear why there is so much variability, but it may be due to different information received by CDOP panels and how it is interpreted. It may also suggest a lack of consistency across panels in deciding whether a factor is possible to modify or not.

NCMD have introduced a training video on modifiability in CDOP reviews to improve consistency. This is available at: <https://uclpartners.com/ncmd-webinars/>. This suggests that unless there is a possible intervention, or if there had been a relevant intervention offered, for instance smoking cessation, the case should not be recorded as modifiable.

Cycle safety: Watch this space

At Suffolk CDOP we have recently reviewed the death of a teenage cyclist who collided with a moving van and died due to a serious head injury. He was not wearing a cycle helmet; his death may have been preventable if he had been wearing his helmet. The Lead Nurse for the Child Death Review Team is working with the bereaved family, local football community, Suffolk public health and education to create a campaign that is suitably targeted towards children and adolescents around cycle safety and the importance of wearing helmets.

Every year, more than 100 cyclists die on UK roads, meaning they make up around 6% of all road deaths:

BRAKE:the road safety charity

Further information on cycle safety and our local campaign to follow in the next newsletter.



Using ReSPECT documentation in children with complex health needs by Dr Sarah Steel

This is a short piece about the importance of talking to families about the long-term care their child receives. Whatever health condition a child may have, families will have different ideas and expectations about the treatment that their child should receive. As children grow parents will be included in the decisions until the child is old enough to make the choices themselves. For some children and young people their ability to understand their condition means they are not able to make decisions about their care themselves, and their family and carers will need to make those decisions for them.

Children with very complex health needs are more likely to be admitted to hospital and more likely to require interventions that require thought and planning to make sure that their health needs are met. In addition, there may be several people involved in their care. Clinicians can intervene to enable children to survive well into adulthood. However, it is both important and helpful to have an ongoing dialogue with parents and carers about what should be done to manage their health needs and for this to be updated so that if there is a hospital admission the family do not need to go through their child's history every time and there is also a plan to follow to escalate care depending on the problem arising. This can be very helpful for staff out of hours who may not be able to access a consultant who knows the child. The documentation is called '[Recommended Summary Plan for Emergency Care and Treatment: ReSPECT](#)'.

The family are key to working with clinical staff to agree what management they would like for their child and over time know what works best. It is important that discussions involve the multidisciplinary team as well as the child and their family. The common problems that arise are respiratory complications, uncontrolled seizures, problems with feeding, problems with tone management, pain, constipation, and sleep difficulties.

Where children are not able to communicate, then information about how best to communicate with them and how best to meet their physical needs, if they are not mobile, can all be added to the document to help those unfamiliar with the child. These decisions would go into an advance care plan; This is not about withdrawing care, it is about agreeing what care an individual child should receive in certain situations. Of course, it is not possible to predict all situations. A plan for respiratory symptoms might recommend what to do when the child is well and a plan for mild problems and one when they are significantly unwell. If there are problems with epilepsy, the information about medications to use to try to control the seizures is helpful. If there begin to be problems with feeding it is important to have started to discuss when to introduce alternative methods of feeding such as a nasogastric tube, intravenous fluids or gastric feeding. Managing tone can be difficult but it is helpful to have an agreed plan re escalation of treatment and different medications to try. For many children with advance care plans the decision would be to give the child full cardiopulmonary resuscitation in the event of a collapse. However, for some families and some children this might not be in the child's best interests. When a child is becomingly increasingly unwell with poor quality of life due their significant ill-health, choosing where they die may be more important than trying to extend their life and risk them dying in an intensive care unit with unfamiliar staff rather than surrounded by family and staff known to the child.

It is important to talk about the unpredictability of clinical conditions and that sometimes their child may become severely unwell. It is important for families to think about whether they would want their child to go to an intensive care unit or whether due to their underlying condition that this would not be the right decision to make. These are conversations to be had over a prolonged period, sometimes years, but sometimes it may be only weeks or days due to the nature of their child's condition. Whilst these conversations seem to be hard for staff and families, it is much harder for them if they have not been involved in planning their child's care. For many children with complex needs who survive into childhood their parents will know them inside out and thus their opinion is vital. Most importantly it is about agreeing and planning health care that enables the child to be as well and comfortable and happy as possible throughout their life.

ReSPECT Recommended Summary Plan for Emergency Care and Treatment for:		Preferred name
1. Personal details		
Full name	Date of birth	Date completed
NHS/CHI/Health and care number	Address	



SUDC★UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

<https://sudc.org.uk/> This website is co-founded by a bereaved Mum whose daughter Rosie very sadly died in 2013. "Rosie was a happy and completely healthy child until one sad night, out of the blue, aged two and quarter, she died in her sleep. We still don't know why."

The website raises awareness of Sudden Unexplained Death in Childhood, this is the sudden and unexpected death of a child aged between 1 and 18 years of age, which remains unexplained after a thorough investigation is conducted. The website provides a source of support for families and information and resources for professionals working with bereaved families. In Norfolk and Waveney there has been 1 case of SUDC in the year April 2021- March 2022.

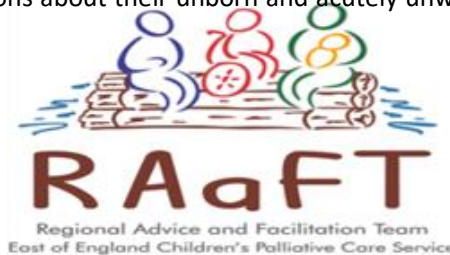
RAaFT

A new palliative care service for babies, children and young people, including support for families was launched on 26.09.22 at Cambridge University Hospitals NHS Foundation Trust. The Regional Advice and Facilitation Team (RAaFT) was set up in response to growing number of children in the East of England with life-limiting and life-threatening conditions, following funding by NHS England. This is a Multi disciplinary team consisting of two full time and one part time highly specialist doctors in children's palliative medicine, specialist pharmacist, clinical psychologist, two specialist nurses and an administrator.

RAaFT is aiming to support families and professionals around Complex Symptom Management, Advanced Care Planning and End of Life Care. The team work with families from the antenatal period, through to transition to adult services where there is a diagnosis of a life limiting or life-threatening condition. This is a 24/7 service and supports improved symptom management, advanced care planning and end of life care for families needing an extra layer of support. Also offers support for women and partners making difficult decisions about their unborn and acutely unwell babies.

Email: cuh.add-tr.paedpalliativecare@nhs.net

Telephone: 01223 217677



"Please take time to understand the fog the bereaved parents are existing in . . . losing a child is like learning to live in a foreign land, nothing makes sense and you have to take your time to understand things. What may seem straight forward to a professional is like talking a foreign language to a bereaved parent. No one should ever become complacent when dealing with bereaved families."

Quote from a bereaved family

