Learning from Children's Deaths

A newsletter for professionals

December 2022, Issue 11

In this issue:

- Introducing Natalie Okeh
- Sepsis
- Safer Sleep
- SUDIC Webapp
- Identification of Learning Disabilities
- Cycle Safety
- Notifications
- Grief at Christmas
- GP's role in reducing inequalities
- Consumer Safety Alert

This year we are looking back with appreciation for all those who have supported our team and worked with us to support our families who have lost a child.

We wish you a happy and peaceful Christmas and every good wish for the New Year!

Suffolk Child Death Review Team

Dr Sarah Steel - Designated Doctor for Child Death Suffolk

Cindie Dunkling - Designated Nurse for Safeguarding Children and Lead for Child Death

Jacky Wood – CDR Nurse

Bernie Spiller – CDR Nurse

Natalie Okeh - CDR Nurse

Maddison Bultitude - Child Death Review Team Co-ordinator

Team Contact Details

Team phone number: 01473 770089

Team pager: 07623 951892

Email: sneeicb-ws.suffolkcdr@nhs.net

Introducing Natalie Okeh

I'm Natalie, the new CDR Nurse. I trained at the university of Hertfordshire and I have been a children's nurse for over 25 years working at Ipswich Hospital, East Anglia's Children's Hospice and my previous role as a Children's community nurse. I have been warmly welcomed into the CDR team and although still finding my feet, I am really looking forward to working with families and professionals, some who I have met before and some who are completely new to me, to ultimately review childhood deaths and make a difference to families and practice. This role is completely different to what I have done before but very interesting and I'm learning every day. I love being a children's nurse, yes, it's hard, and stressful at times, but the rewards far outweigh the negatives.

In my free time I'm a busy mum to two boys and a dog! I like to keep active and be outdoors but also love a good book!

Recognising the Signs of Sepsis

It is important to remain vigilant regarding the signs of sepsis although it is rare it can be devastating but if caught in time can be treated. Vaccination has made a huge difference to the types of infections seen however not all children have been fully vaccinated and not all bacterial infections can be prevented by the vaccinations available. It is very challenging for all those outside the acute settings and also within the acute hospitals. However, there are some tools to help:

Click here and here for the traffic light tool developed by NICE to help to identify signs of sepsis. There are also sepsis tools built into GP software (SystmOne and EMIS). These tools prompt observations and gives the likelihood for sepsis. There is an information sheet that can be given to patient/relatives. Out of hours services use algorithms. Paramedics have all had training in recognising sepsis and use tools such as the National Early Warning Score (NEWS2).

Whilst it is important to use guidelines, remember these are only guidelines so clinicians must use their clinical judgement, examine and record full observations and listen to parents who usually are the best judge of their child's health. If the parents keep returning, you are uncomfortable about the child even if someone else thinks all is ok; always look at the whole picture and do not ignore those 'gut feelings'. Remember sick children can present as irritable, some go up and down and may look 'ok' prior to collapse hence the importance of observations and repeating these.

Always safety net and tell parents what to look out for. If in doubt err on the side of caution.

Child Death Notifications — Reminder!!

All child deaths (up to 18 years) need to be notified to the Child Death Review Team within 48 hours.

Any professional who becomes aware of a death of a child which they believe has not already been appropriately notified should complete a notification using the following link: https://www.ecdop.co.uk/NorfolkSuffolk/Live/Public

Please include as much information as you have available at the time.

This notification is important for our team to:

- Notify other services involved with the child
- Coordinate appropriate meetings
- Review support for the family

If you need help or advice on completing this notification form, please contact the Suffolk CDR team on 01473 770089.

Important

Identification of Learning Disabilities and Recording on Health Records

This year admin staff within GP surgeries have had external training focusing on safeguarding processes, recording and coding within health records. It is hoped this will improve the accuracy of coding to highlight patients with a vulnerability whether this is due to safeguarding issues or the fact they have a learning disability. This is so crucial as it is only those patients that are correctly coded with an LD that are invited for annual health checks. Work has also been carried out led by the Primary Care Manager who did an LD audit looking at patients who may have historical codes on their records such as 'global developmental delay' which may have never been updated. This has led to surgeries having clearer up to date records resulting in the right patients being invited for their LD annual health checks.

Cycle Safety

All young people should undertake a cycling training course before cycling on the roads by themselves. Experts recommend a minimum age of ten years for on-road cycle training courses – below this age children are less likely to be able to successfully cope with the joint tasks of managing a bicycle and negotiating traffic situations. Cycle safety – cycling is a healthy and eco-friendly way to get around. **DO** wear helmets and high visibility clothes when possible **DO NOT** use your phone and airpods while cycling

TOP TIPS

- Ensure children wear a cycle helmet
- Young cyclists should always wear light-coloured, fluorescent and reflective clothing to help them to be seen, as well as having lights on their bike
- Investigate the density of the traffic and any problems on the route before considering letting your child out unsupervised
- Before they set off, travel the route with them a few times so that they are confident and familiar with where they'll be going. You may wish to cycle behind them for a few weeks to build their confidence
- Accidents do happen and it's important to be prepared, so ensure your child is able to respond in an emergency. Make sure they know how to make a 999 call, are aware of their home telephone number and know their own address
- There is safety in numbers, so where possible ensure your child has a cycling 'buddy' whenever they're out, such as a friend or older sibling
- As well as being road safe, it's a good idea to ensure your child knows how to respond to other risks – meeting strangers or getting lost, for example. Perhaps give them a mobile phone so they can get in touch if they run into trouble
- If your child is cycling to a friend's house, let another adult know and give them an idea of when they can expect your child to arrive

SUDIC Pathway and Professional Responsibilities flowchart.

Joint Agency Response

SUDIC PROTOCOL

https://suffolksudic.org.uk

IS NOW LIVE!

CLICK ON THE LINK ABOVE AND SAVE IT NOW TO YOUR WORK LAPTOP DESKTOP OR MOBILE

Ambulance

Coroner

The link can be saved on your phone, laptop or on any working computer desktop.

The website provides an opportunity for agencies to share a common reference to a case.

All individual team members can access the case and assign themselves to a role. You can also see the network of other professionals associated with the particular case.

Hospital Staff

Police

CDR Nurse

Consultant Paediatrician

Financial difficulties after a child dies with a life limiting condition

When a child dies of a life-limiting condition, many families suffer financial hardship on top of coping with their grief and loss. This could be due to the end of benefits such as carer's allowance, disability living allowance and child benefit. This can often compound the debt legacy which families of children with life-limiting or life-threatening conditions may have incurred as a result of the additional costs of caring for their child over a long period of time. Although some of these benefits will continue for 6-8weeks following a death, DLA stops the day the child dies, including the mobility component which often means the mobility car is collected immediately leaving vulnerable families with no transport and socially isolated.

Sadly, this is the picture for many of our Suffolk families. One parent who was their child's full time carer had their car and benefits removed immediately after death sending the family into financial crisis and isolation. This situation was made worse by Job seekers allowance rejecting their claim for JSA as they did not accept the child dying as a good enough reason for the 6 week delay in submitting the claim after death.

Together for Short Lives charity have asked ministers to consider ensuring that parents who have been full-time carers of a child who has died automatically receive Limited Capability for Work and Work Related Activities (LCWRA) for the first 12 months following the child's death, if they are in receipt of Universal Credit. This would make an incredible difference for our families in SUFFOLK but until this is considered/put in action please remember that if you are working with these families to consider the financial hardship they are under and the additional support they may need.

Previously the Butterfly Fund (Together for Short Lives) gave grants of £300 following the death of a child with a life limiting illness, sadly this is now closed to new applications due to being over prescribed. If you would like to support the fund you can donate here: Support our work - Together for Short Lives

If anyone is aware of any financial support that could help our Suffolk families following a death of a child please email us sneeicb-ws.suffolkcdr@nhs.net

National Child Mortality Database (NCMD)

The latest thematic report from the NCMD has now been published.

This report draws on the unique data that the Child Death Overview Panel's supply to them to investigate sudden, unexpected and unexplained deaths in both infants and children and young people. It also draws out the learning and recommendations for service providers and policymakers.

You can view the report here: Sudden, unexpected deaths | NCMD

Teaching

Do you want to learn more?

The CDR team are keen to educate professionals in Suffolk about the Child Death Review Process, the Child Death Overview Panel and what to do when a child dies. We are hoping to continue to be part of organised study days in trusts and organisations in 2022, so that staff will know about our role and what we do, and also to discuss the learning which is coming from children's deaths. If you would like us to be part of your teaching session or study day, please contact us at :sneeicb-ws.suffolkcdr@nhs.net

These sessions are a great opportunity for us to talk to staff about particular cases and families which they may have had involvement with.

Recognise and tackle modifiable factors

NCMD analysis of child death reviews has shown these are the most commonly recorded factors which could be modified to reduce the risk of children dying.

Smoking in parent or carer · Service delivery · Sleeping arrangements · Substance misuse in parent or carer · Maternal obesity during pregnancy

The GP's role in reducing inequalities in child mortality

NCMD
National Child Mortality Database

Encourage safe sleep practices for higher risk families

Use the 6 week baby check to talk to families who might be at higher risk of sudden infant death syndrome. This includes those who misuse alcohol or drugs or smoke. It also includes those who have had a baby born prematurely or babies of a low birth weight.

Get the Lullaby Trust safer sleep card

the lullaby trust

See them all in our report

Support bereaved parents

"They're really small things, and they could have happened in any GP practice, but I'm lucky they happened in ours" -Sarah Grogan, bereaved mum

Hear Sarah's story

Engage with child death reviews

If you are asked to contribute to the child death review process, give as much detail as possible. GPs hold key information not known by other agencies, which helps to understand how and why a child has died. Your insights support national analysis by NCMD and the publication of reports aimed at addressing inequalities in child mortality.

Learn more about child death review

Identify those at risk

The 6 week postnatal checks provide opportunities to use targeted preconception care by identifying parents and families most at risk of child mortality. Be vigilant and ensure that you follow NHS guidance to help those most in need

Read NHS guidance

Grief at Christmas

The Christmas season can be very difficult for bereaved families. Bereaved parents often feel they just want to cancel Christmas, they feel it won't be the same as it has been because the family unit is not the same. It is not complete. Often the run up to Christmas can be more difficult than the day itself, as can the looming New Year celebrations.

Cruise and The Compassionate Friends both have some great resources to give to families about grief and coping at Christmas, these resources can also help us professionals with conversations with families.

Websites: Christmas - Cruse Bereavement Support

The Compassionate Friends | Coping with Christmas (tcf.org.uk)
(leaflet that can be printed and handed out)

Helplines open over Christmas: The compassionate Friends National Helpline 0345 123 2304 (10am – 4pm, 7pm- 10pm every day).

Child Death Helpline 0800 282 986.

Child Bereavement UK Support and Information Line 0800 02 888 40.

Samaritans 116 123 (free to call).

CONSUMER SAFETY ALERT

Baby Self-Feeding Pillows

Risk of serious harm or death

Baby self-feeding pillow products are designed to be attached to a bottle so that the baby may be positioned on its back to self-feed without the assistance of a caregiver holding the bottle and controlling the feed. This is inconsistent with NHS guidance in relation to safe bottle feeding. When used as intended, even whilst under the supervision of a caregiver, it could lead to immediate, serious harm or death from choking or aspiration pneumonia.

Consumers should immediately stop using these products and dispose of them safely.

Businesses must immediately remove these products from the market as they cannot comply with the safety requirements under the General Product Safety Regulations 2005.

Office for Product Safety & Standards

Office for Product Safety and Standards
4th Floor Cannon House
18 The Priory Queensway
Birmingham B4 6BS

Safer Sleep for Babies

As we are mid-winter and the festive season is upon us, it's important the advice we give to parents on safe sleeping reflects our learning from deaths and the possibility of heightened risks over the coming months.

While carrying out our role we have seen a number of baby deaths where babies have been in circumstances outside of their normal safe sleeping routine. Babies who normally slept in a safe cot or Moses basket on their backs were placed in the bed or sofa with the parents. Parents who normally would not drink and share a bed with their baby may be tempted to over the festive period, just through shear tiredness. Professionals can help parents think ahead about when they may break from their usual routine and how to remember to check the basic SIDS safety advice.

Please remember to talk about safe sleeping if you come in to contact with parents of young babies.

The Lullaby Trust has produced advice for Safer Sleep in winter available here

Support, Advice and Signposting for families with newborn babies

across West Suffolk, Ipswich and East Suffolk, and North East Essex

Text 07708 032524

Home-Start is working in partnership with NHS Maternity & Neonatal Services to offer families a place to go for advice, support, and signposting about anything to do with

- your post-birth recovery
- looking after your baby in their first 6 months
- signposting to groups and sources of support

THIS IS NOT AN EMERGENCY NUMBER.

It will be manned Monday – Friday 10am – 2pm.

Text your question and a member of the team will contact you.

Produced by the Suffolk Child Death Review Team,
Suffolk and North East Essex NHS,
Endeavour House,
Russell Road,
Ipswich, IP1 2BX