Learning from Children's Deaths

A newsletter for professionals

August 2022, Issue 10

In this issue:

- Introducing Jackie Buck
- New app to improve inhaler techniques
- Empowering YP to access healthcare
- Non-resident parents
- Confidentiality and sensitivity
- Learning event
- Open water swimming
- Using ReSPECT documentation
- RaAFT
- Do you want to learn ?
- Further polices and procedures on SSP website

Introducing Jackie Buck

Jackie Buck has been a Consultant Paediatrician at Ipswich since 2007, and prior to this she worked in the East of England for a number of years as a trainee and in her first Consultant post at the West Suffolk Hospital. She has been involved in work with children of all ages from new-borns (including premature babies) to young children, adolescents and Young People. Unfortunately her work includes work with children who tragically pass away. She has seen how the process of investigating and supporting families who have lost a child has evolved over the years following research by a number of specialists in all areas of health, police and social care. Initially this work focussed on babies who died suddenly and was known as SUDI (Sudden Unexpected Death in Infancy), and then expanded to SUDIC (Sudden Unexpected Death in Childhood). Communication with the carers, families and the whole team has improved dramatically and developed into the Child Death Review process. She is delighted to have witnessed first hand how much benefit families gain from the one to one support of a child death review nurse in these tragic times.

Jackie took on the role of Named Doctor for Child Death at Ipswich Hospital in June 2022. Since then she has been attending meetings and offering teaching, support and advice for her Consultant colleagues and allied health care professionals. Jackie represents health as a Child Death Overview Panel member, attending panels where she is involved in identifying learning and best practice, and disseminating this to colleagues.

She commented "Of course this is an extremely challenging area of work, and each case will have unique tragic circumstances. We owe it to the young person, adolescent, child, toddler or baby to make sure we look into every aspect of their journey (whatever the duration) to their passing, and to find out all we can, and to feed this back to their loved ones in a supportive and informed manner."

New APP to improve inhaler techniques (adopted by the NHS)

In previous years we have had children sadly die from Asthma in Suffolk. A new APP has just been launched call MY SPIRA to help improve inhaler techniques. MySpira is the world's first augmented reality (AR) Asthma inhaler training app. The MySpira APP substantially improves the recall of critical asthmas information. 93% of asthma sufferers use their metered dose inhalers incorrectly. Where proper inhaler training has been put in place, emergency hospital admissions have been reduced by 50% and asthma deaths by 75%. Developed for children aged between 6 – 13, the MySpira app includes 8, fun modules, that use augmented reality and gameplay to offer the very best asthma education. Suitable for download by children, parents, schools, GP surgeries, hospitals and pharmacists.

A recent study completed by our very own University of Suffolk showed that the MySpira app substantially outperformed leaflets and video in conveying critical information on asthma and inhaler technique (Examining the Efficacy of a Novel Augmented Reality Mobile Delivery Platform for the Enhancement of Asthma Care Education for Children | International Journal of Interactive Mobile Technologies (iJIM) (online-journals.org)
MySpira | Augmented Reality Asthma Training App

Empowering young people to access healthcare

We have seen an emerging theme from CDOP where young people have not accessed healthcare for themselves when needed and their parents have not recognised the need for this health care. CDOP would like to ask all professionals to promote/empower young people in taking control of their own healthcare and encouraging them that it is ok for them to call 111/999 and to access their GP surgery themselves if needed.

Key points:

- **Encourage/empower** young people to have direct contact with their GP and to call 111/999 when needed.
- **Promote** that if deemed competent to do so by their GP surgery Young People aged from 13 years old can have an NHS account and access to GP online services which includes being able to book their own appointments and in some cases use the 'Ask my GP' system.
- **Encourage** young people (11-19) to reach out to school nursing services including the ChatHealth (texting service)

Useful links:

School nursing | Suffolk County Council

Health For Teens | Everything you wanted to know about health

Suffolk Child Death Review Team

The Suffolk Child Death Review Team went live on 1st September 2019.

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 — CDR Team Administrator

Team Contact Details

Team number: 01473 770089

Team pager: 07623 951892

Email: sneeicb-ws.suffolkcdr@nhs.net

Service available: 8am - 4pm, Monday - Friday (on call 4pm-8pm on weekdays)

Non-Resident Parents – Rights & Needs

Some of our recent cases have highlighted the need to be aware of the rights of parents that are non-resident full time with their children. These parents can have full parental responsibility but may not live with the child for various reasons. These reasons can include divorce, where the children live solely with one parent, separation, one parent experiencing mental health issues which leads to not being able to look after the children during this time and also working away overseas or in another area of the country. It is important to note that a non-resident parent will continue to hold parental responsibility regardless of whether their child lives with them or not.

Parental responsibility is defined under section 3 of the Children Act 1989 as "*all rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property*". This means their opinions and wishes should be taken into account in respect of the child's upbringing, no less than that of a resident parent. This is especially important if a child is dying or on an end-of-life pathway or when a child passes away. Both parents should receive the same support and information and professionals should be cautious about information sharing and treating both parents the same remaining as neutral as possible.

Learning from Child Death in Suffolk

The Suffolk Child Death Review Team would like to invite you to our face-to-face learning event

Date: Thursday 13th October 2022

Time: 09:00am – 16:00pm

Venue: Kesgrave War Memorial Community Centre, Twelve Acre Approach, Kesgrave, Ipswich IP5 1JF

This free learning event will cover the following topics:

- Learning identified from completed child death reviews
- Safeguarding
- Palliative care
- National Child Mortality Database (NCMD)
- Bereavement support

If you would like to book your free place at this event, please visit:

https://www.eventbrite.com/e/learning-from-child-death-in-suffolk-tickets-407859176777

Confidentiality and sensitivity following the death of a child

The death of a child is devastating for families, but it also impacts on those professionals who care for children. Often children's health and social care services are close knit communities themselves, caring for families over many years. We get to know our families well and the other childcare professionals in our networks. This is a positive and support network of professionals and families that give us strength when a child dies. However, it can also be all too easy to unintentionally break confidentially which in turn can add to the hurt of those grieving families and friends you are trying to support. Please be careful when talking about a child or family, even if it is to another professional.

The golden rules to remember are;

- Never share information or talk about a child or family unless it is within the provision care being offered or to safeguard a child or adult at risk;
- Never go into a child's health or social records unless you are doing so as part of your role for the care of the child or family. Every access to a child's records will leave a footprint and will be questioned if there is no obvious reason for a person to have opened them.
- Lastly, always be mindful of your environment when discussing any sensitive, personal information, bed curtains are not sound proof, neither is your garden and you never know in our small, close children's workforce who might know the family you are talking about on a more personal level.

If you have been affected by the loss of a child you and your team have cared for please reach out to the CDR team and we will help you access the support you need. Each child we lose, leaves their mark on us.

Here is some guidance from the ICO how to work from home securely

Open water swimming*

Swimming in lakes, rivers and the sea or '*Wild*' swimming has increased in popularity due to closure of gyms and swimming pools over lockdown. Now out of lockdown and with heat-waves surging, open water swimming continues to grow in popularity among adults and children. There are inherent risks associated with open water swimming and across England there has been several sad deaths in open water over the past few months.

The RNLI: FLOAT to live campaign is raising awareness of what to do if you get into difficulty in the water and gives safety advice when swimming in open water:

https://rnli.org/pages/water-safety/float?gclid=EAIaIQobChMIipy4poqU-QIVjZftCh0cKgs6EAAYASAAEgKkzvD_BwE&gclsrc=aw.ds

Risks

- Cold water shock: Swimming in water below 15 degrees can cause your body to go into cold water shock. Average sea temperature in the UK is 12 degrees.
- Rip currents: powerful currents that run out to sea. Choose a life guarded beach and swim between the yellow and red flags.
- Microbes: Blooms of blue green algae can spring up on warm still water over summer. Swimming in algae can cause skin rashes and allergic reactions. Weil's disease is a bacterial infection Leptospirosis carried by animals and can be caught through contact with rat or cattle urine from contaminated fresh water. There are over 400 designated bathing waters in England where you can check the water quality and water quality information is available for these places: http://environment.data.gov.uk/bwq/profiles/
- Pollution: Avoid swimming in areas of water pollution. The most common are; sewage outfalls, farmland runoff, and industrial or mine pollution. Check the pollution risk forecast and avoid swimming after high rainfall.
- Never Swim alone

*This article was created by the Norfolk CDR Team and released in their August Newsletter

Using ReSPECT documentation

This is a short piece by **Dr Sarah Steel, Designated Dr for Child Death** about the importance of talking to families about the long-term care that their child receives. Whatever health condition a child may have, families will have different ideas and expectations about the treatment that their child receives and as children grow up they will be included in the decisions until they are old enough to make the choices themselves.

For some children and young people their ability to understand their condition and makes decisions about their care is not possible 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 a number of 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 also 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.

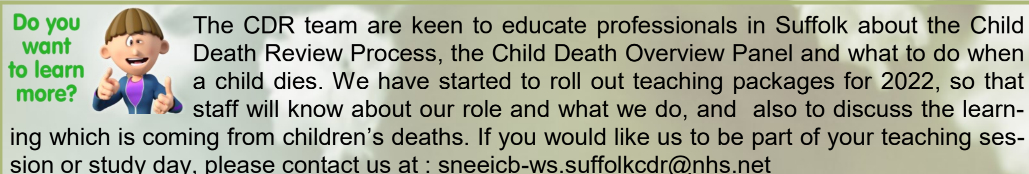
These decisions would go into an advance care plan This is not about withdrawing care it is about agreeing what care an individual child should receive in certain situations. Of course, it is not possible to predict all situations.

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, then 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. This is most commonly on the neonatal unit.

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.



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 have started to roll out teaching packages for 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.

Who are we? We are a small multi-professional team including Consultant, Nursing, Pharmacy and Psychology support.

What can we offer? RAaFT is aiming to support families and professionals around complex Symptom Management, Advanced Care planning and End of Life care. We will be working closely alongside existing palliative care services to enhance this offer. We can 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.

When are we available? Service operates 08:30-16:30 Monday to Friday. Urgent out of hours palliative care support continues to be provided by hospice services. RAaFT started supporting families in January 2022 so we are still developing our service.

Where are we based? Our base is in Addenbrookes hospital, but we will be reaching out to provide support across local hospitals, hospices and community settings.

The team has been created following a successful funding bid to NHS England to increase the existing palliative care provision across the East of England.

If you have any questions about the service, please contact us and we will be happy to provide further information. If you wish to make a referral, please contact us for a referral form.

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

Telephone: 01223 217677

If you would like to receive this newsletter, please click here to sign up.

Please see the **Suffolk Safeguarding Partnership** website for more details around CDOP, including protocols around child death.

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