

SUDDEN UNEXPLAINED DEATH IN CHILDHOOD

Thank you so much for attending this meeting.

Nikki Speed PhD Co-Founder CEO SUDC UK

Brian Topping, Frankie's Grandfather and SUDC Ambassador

February 2024



SUDC★UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

www.sudc.org.uk

GOALS

- SUDC incidence and epidemiology
- Challenges, SUDC research and progress
- The family experience - Frankie Grogan
- Care recommendations and data collection.
- SUDC UK resources
- Q&A

Incredible national charities already existed with a focus on baby loss. Yet, loved, happy, thriving and seemingly healthy – Rex, Yianni and Rosie – were older, and following their sudden and unexpected deaths during their sleep, their distraught families felt isolated and frustrated.



WHAT IS SUDC?

“The **sudden** death of a child older than one year of age that remains **unexplained** after a thorough investigation, including review of the clinical circumstances of death, and performance of a complete autopsy with appropriate ancillary testing.”

Sudden Unexplained Death in Childhood was never mentioned during my training; not even Paediatrics.

Tragically, the first time I heard it was when my gorgeous son Arthur died. Medical awareness has to increase; this has to change”.

Katie, a bereaved mum and GP

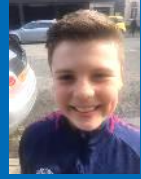


WHAT IS SUDC?

- ★ Sudden deaths with no immediately apparent cause account for nearly a fifth of all infant and child deaths in the UK.
- ★ 40 children die every year without reason; **more young children than to traffic accidents, drowning or fires.**
- ★ 1-2 seemingly healthy children are dying every fortnight, often going to sleep and never waking up
- ★ **We do not know how to predict or prevent SUDC.** Safer sleep messages for infants do not apply.
- ★ Associations: normal development, minor infection, unwitnessed, found prone, male, cardiac arrhythmias and febrile seizures. Genetic investigation is important & available.

Out now

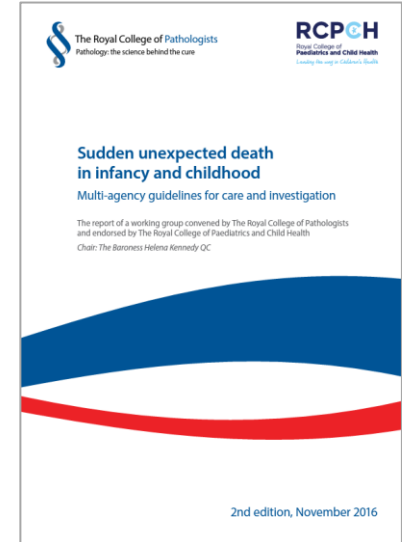
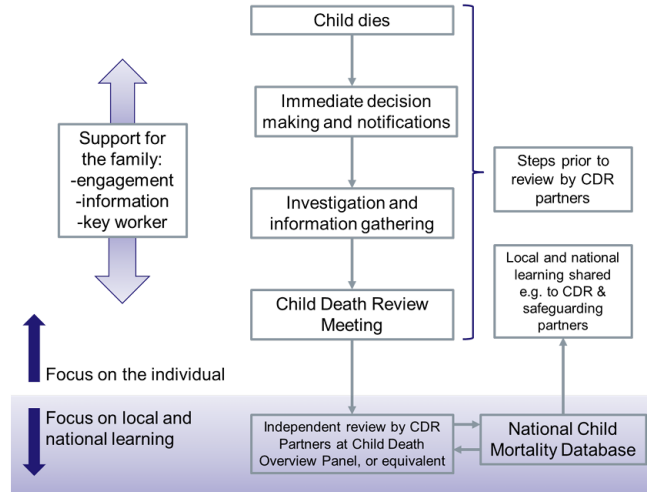
Sudden and Unexpected Deaths in Infancy and Childhood: The fourth National Child Mortality Database thematic report.



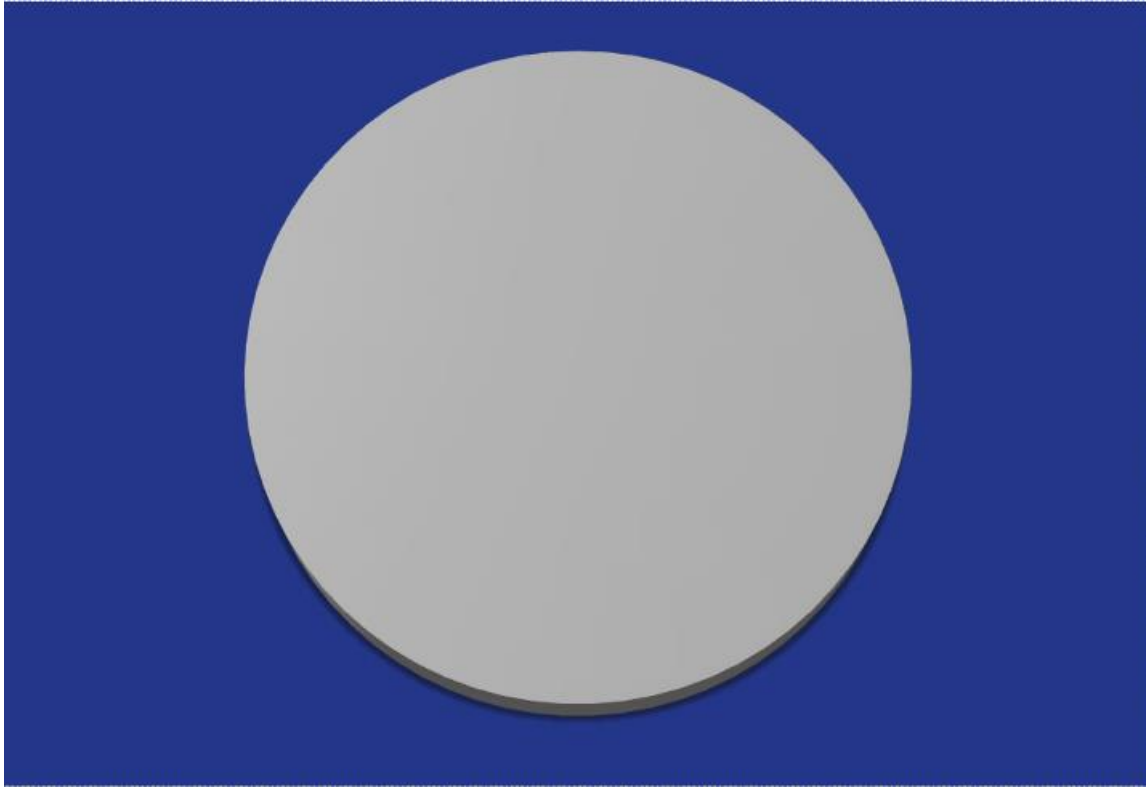
PROCESS

2018 Statutory & operational guidelines (England). Figure 1

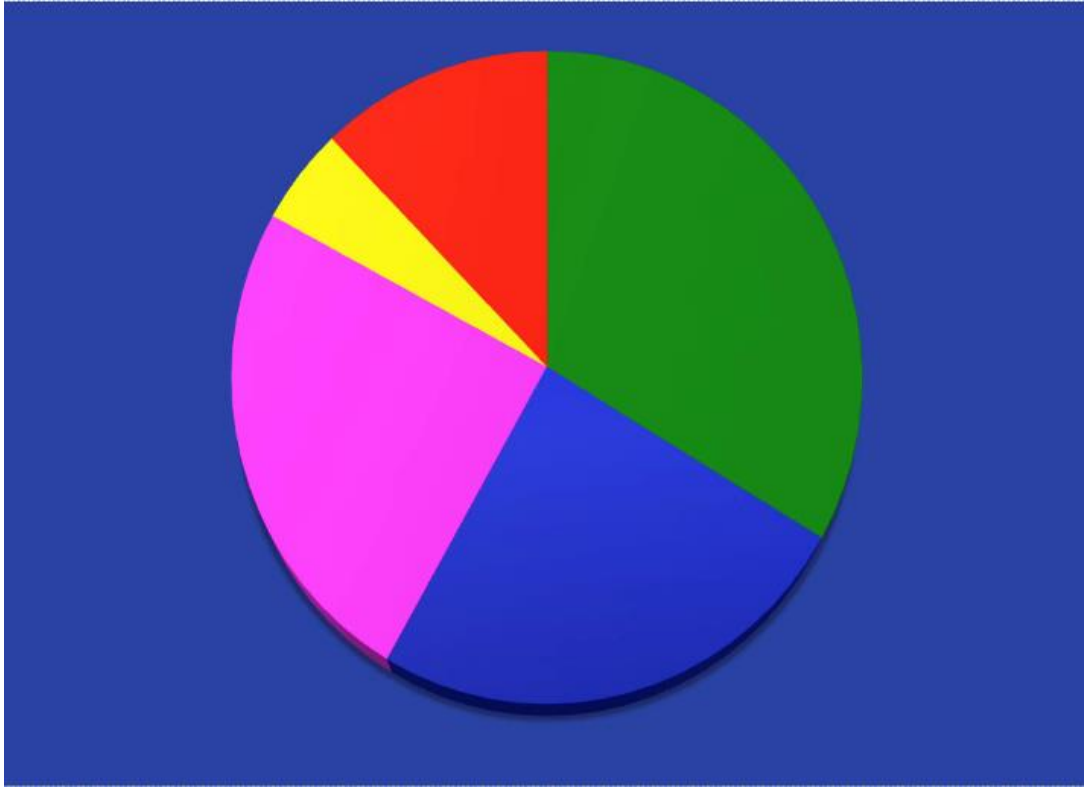
- ★ Child Death Review
- ★ Joint Agency Response
- ★ **Key worker**
- ★ Inquest... maybe
- ★ Terminology
- ★ Support limitations



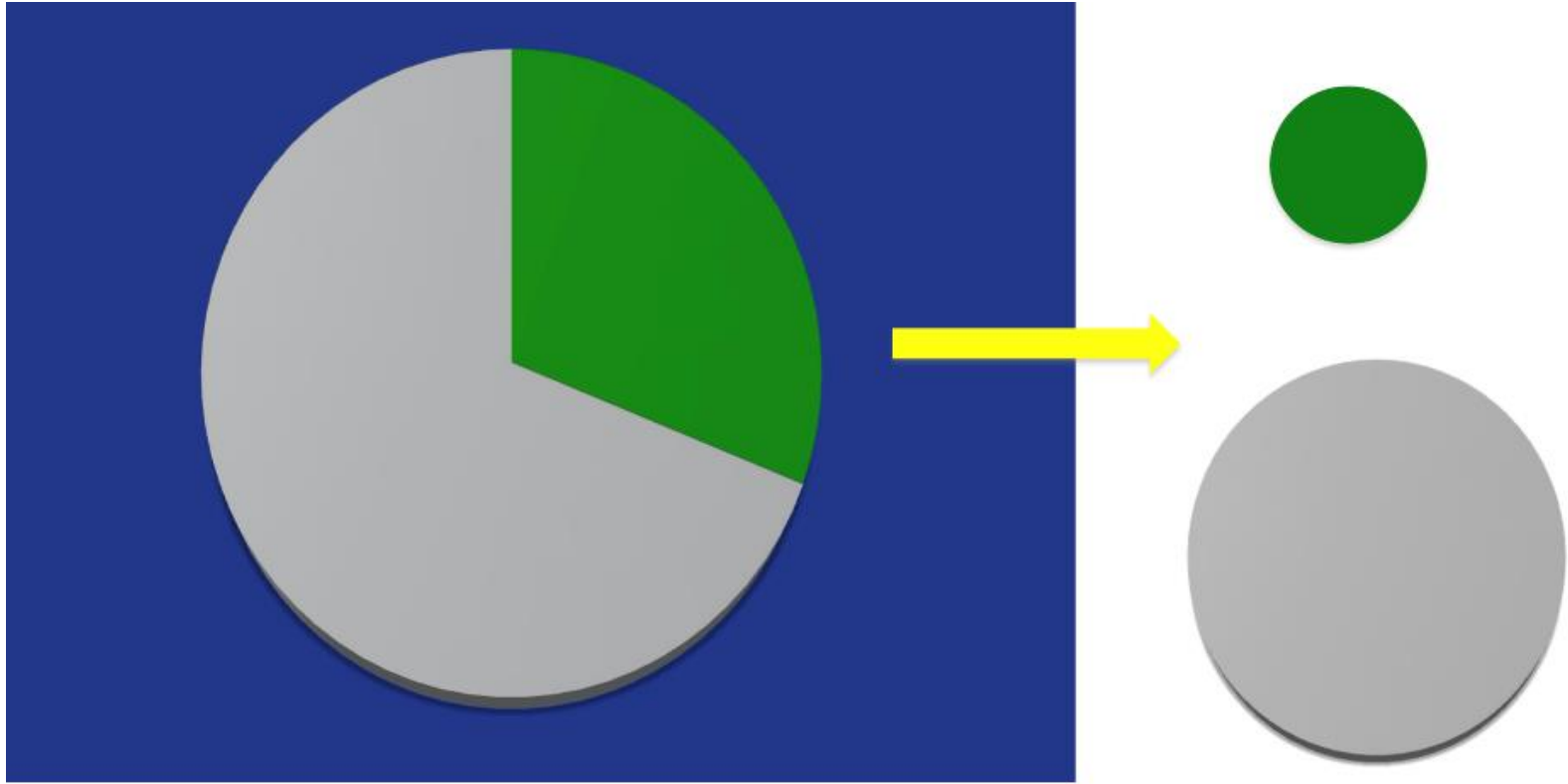
WHAT SUDC LOOKS LIKE TODAY



WHAT SUDC REALLY IS



WHAT WILL HAPPEN...



CHALLENGES

- ★ Category of death and rare so difficult to identify trends
- ★ No known modifiable risk factors or prevention strategies
- ★ Limitations in autopsy, investigation, awareness and...

RESEARCH

A simple search on PubMed
databased shows the number of
scientific publications are ...

SIDS

<1 year

13,000

SUDC

Age 1-18

70

SAD

Adult Death

29,000

PROFESSOR PETER FLEMING CBE



“Research into unexpected deaths in infancy has led to an 80% reduction in such deaths over the past 30 years in the UK. Unexpected deaths in older children are less common, much less well understood, and to date little research has been conducted in the UK to try to understand or prevent such deaths.

... I am convinced that with the right research we will soon be able to prevent many such deaths”

SUDCRRC

SUDC Registry and Research Collaborative



Largest global database of SUDC deaths. www.sudcrrc.org

The multicentre project analyses cases of sudden unexpected deaths in children between 11 months and 18 years and was created in 2014 to understand risk factors and causes and develop preventative measures.

Part-funded by SUDC UK

SUDC UK welcomes any application to help further understand SUDC, without geographical boundary but would be interested in any new UK applications and has worked to encourage UK research since founding.

SUDC UK is an introductory member of the Association of Medical Research Charities

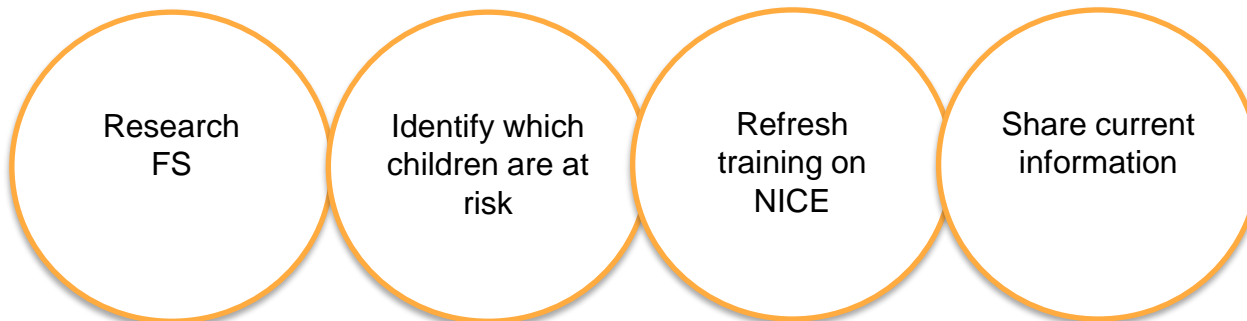


Forensic pathology meeting in Oslo - ISPID

ASSOCIATION BETWEEN HISTORY OF FEBRILE SEIZURES AND SUDC

There are multiple publications suggesting an association between febrile seizures and SUDC with a higher proportion of families reporting a history of febrile seizures than is known to occur in the general population.

Approx. one third SUDC cases have a history of febrile seizures*
January 2024 – evidence of seizures identified in children with no medical history**



Latest Articles

*28.8% history of FS (Crandall *et al*, JAMA. 2019 – 391 cases)

31.7% & the median age at death was greater in children with a FS history compared to those without (Hesdorffer DC *et al*, *Epilepsia*. 2015 – 123 cases)

27% history of convulsions (NCMD report. 2022)

PDF Report Feb 2023 – Rogers

**Gould *et al* Video Analyses of Sudden Unexplained Deaths in Toddlers. *Neurology* January 2024

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Our Vision

For SUDC to be
predictable and preventable

- ★ Raise Awareness
- ★ Fund Research
- ★ Support Families

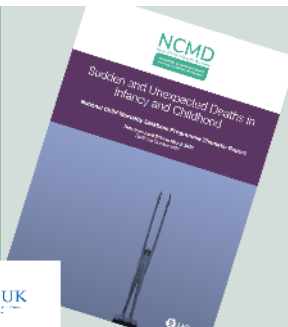


**Action to Stop
Children
Dying Without
Reason**

Advocating for SUDC families

Out now

Sudden and Unexpected Deaths in Infancy and Childhood The fourth National Child Mortality Database thematic report



"As part of the Children and Young People Transformation Programme, NHS England are reviewing information that could be provided to families and professionals around Sudden Unexplained Death in Childhood (SUDC)."

NHSE CEO Sept 2022

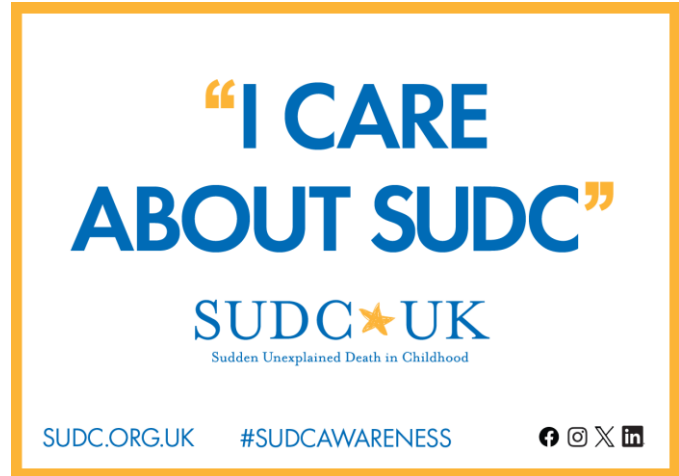
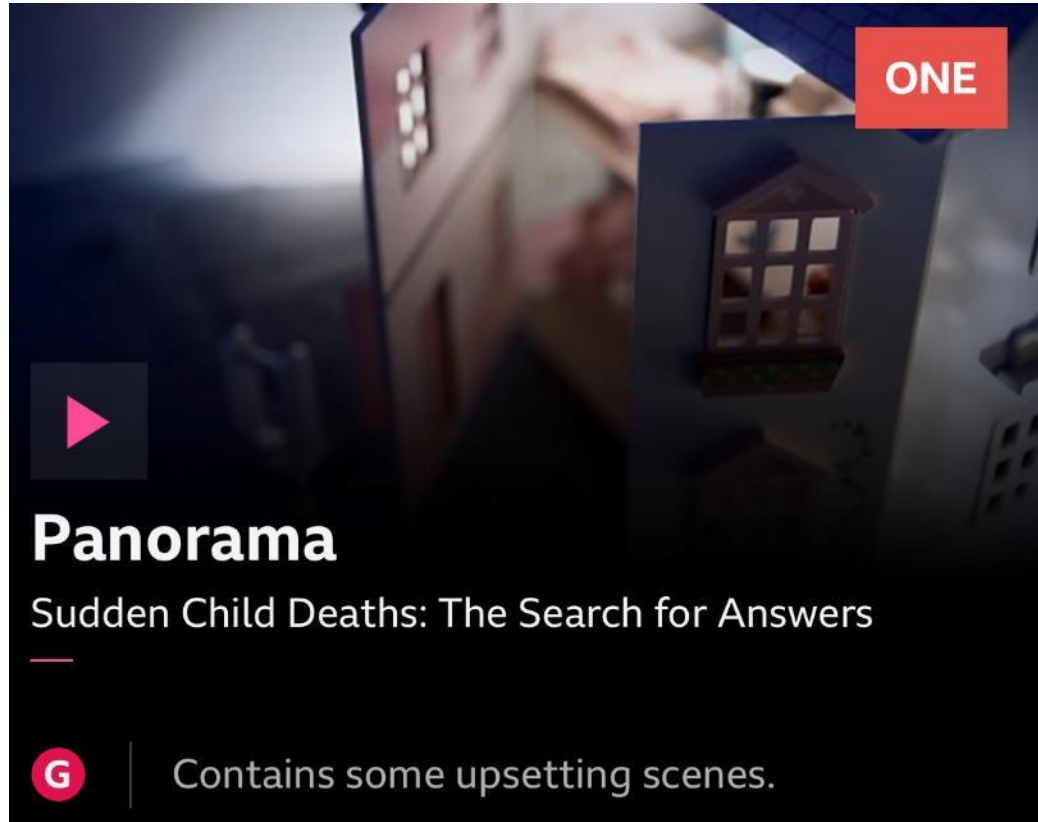


SUDC Roundtable co-hosted by DHSC and NHSE
July 2023



5th Feb Panorama and BBC News
18th March Parliamentary Reception
#SUDCAwareness day

Advocating for SUDC families



5th Feb Panorama and BBC News

**18th March Parliamentary Reception
National SUDC day**



**TOGETHER,
LET'S SHINE
A LIGHT
ON SUDC**

Share our story in the search for answers



Thank you
To All Our Incredible Volunteers!



Thank you to everyone,
everywhere for your support!



4th leading category of death for children aged 1-4 years.

“one of the most serious medical phenomena in our country—something that has not had the public attention it deserves” SUDC debate 2023

Please order a professional pack and support them in March!

This is Frankie



Story



In the moment

19 May 2019

His medical history

On the day:

- The Emergency Services
- Police involvement
- The hospital – family treatment; the paediatrician; the nursing staff; the environment
- The Chaplain
- The bereavement support boxes



The days after

- Alder Hey Bereavement Services
- The funeral
- The Coroner's Inquest
- Remembering Frankie



The impact of SUDC



- ★ Devastating for the whole family and community
- ★ Imagine not knowing why – guilt, despair
- ★ Isolation and abandonment
- ★ The day, the trauma, relationships
- ★ Particularly difficult and significant times of year
- ★ Confusion and difficulty accessing care
- ★ Invasive and long death investigations – JAR
- ★ Loss of power, confused, vulnerable
- ★ Grief complicated with PTSD and anxiety for siblings
- ★ Sibling grief at home and the effect on school
- ★ Medical screening and further investigation
- ★ Anxious pregnancies – midwives, the CONI scheme



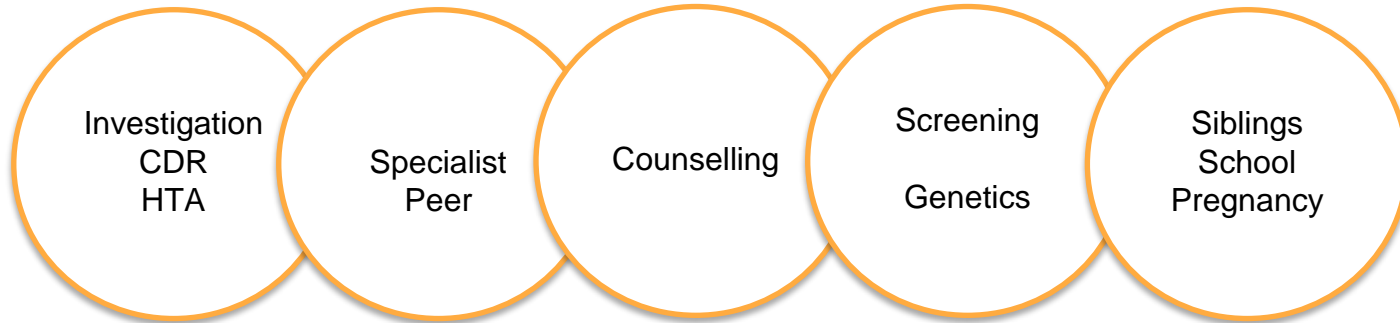
Cooper *et al.* UCLAN, unpublished (ISPID, ACDRP)

Need layered care with consistency and equality

And we will continue to raise awareness Add this to your story > wewers...

Recommendations

- Be mindful of their journey and provide proactive & compassionate communication
- Take time to involve the parents in child death review.
- Keep asking 'what layers of support do they have'? Could we do more?

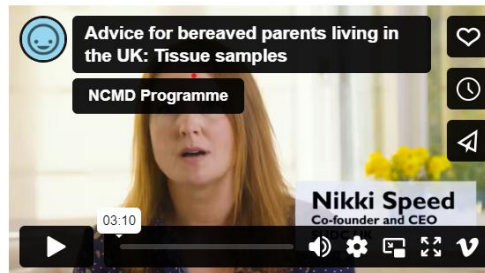


"Touch points"

1. **Immediate support** – need a key worker to be there for them from the start
2. **PM conclusions & report** – please don't send without warning. In person meeting with paediatrician should be offered to discuss.
3. **The CDR meeting** – becoming aware, feeding back, outcome – rich data collection involving parents!
4. **Inquest** – explain, case closing and further investigation – www.sudc.org.uk/process



How my GP helped



Tissue retention



Nikki Speed, Joanna Garstang, Sudden unexplained death in childhood, Paediatrics and Child Health, 2023

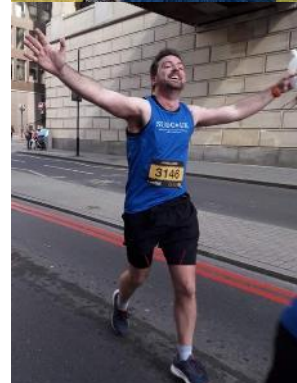


SUDC ★ UK

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- ★ Information and resources, **free leaflets on request**
- ★ Professionals and Peer support services (SUDC UK/ SUDC Foundation)
- ★ Case advocacy during the death investigation
- ★ 1-1 supportive, practical calls
- ★ Family days and supportive retreats
- ★ Medical education and professional resources
- ★ Policy & collaboration
- ★ CDOP member/Key worker role
- ★ Fund and support SUDC research, **UK applications welcome**
- ★ Supported by scientific advisors



Thank you



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www.sudc.org.uk

Email: info@sudc.org.uk

NCMD Report Dec 2022

Recommendations

Deaths of children between April 2019 and March 2021 whose death was sudden and unexpected with no immediately apparent cause.

Sudden and Unexpected Deaths in Infancy and Childhood The fourth National Child Mortality Database thematic report



2020 deaths reviewed – only if CDR complete and only England.

Prioritise research

on sudden, unexpected and unexplained deaths of children over 1 year of age to identify potential modifiable factors and support professionals working to prevent these deaths.



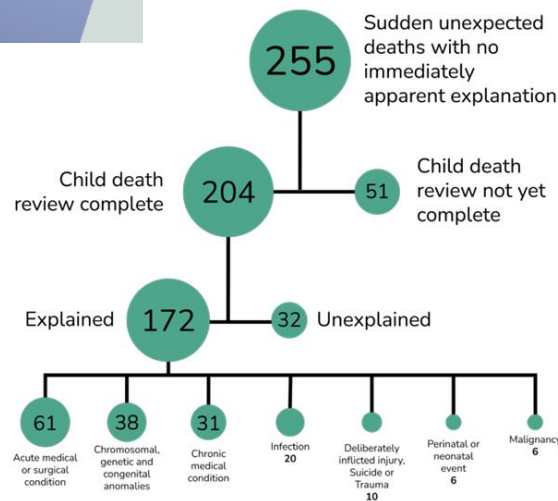
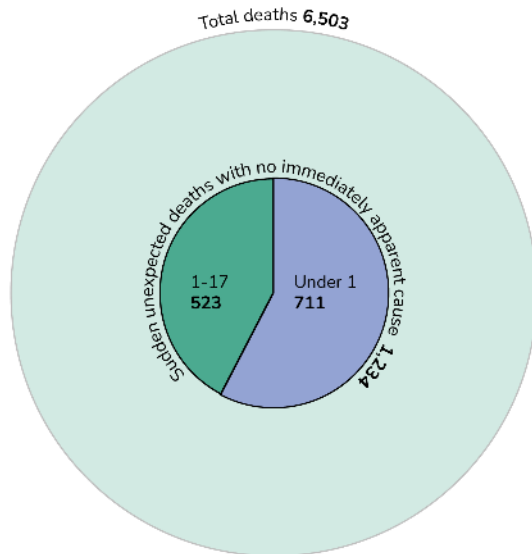
Training

This report recommends robust and consistent national training is made available on the child death review statutory process, SIDS, SUDC and available resources.



27%

of deaths among children aged 1-17 followed a history of convulsions. There are no known preventable measures for unexplained child deaths in this group.



Data source: NCMD
 • reviewed before 28 June 2022

Whilst 24% of 1-17 year olds were living in the most deprived neighbourhoods in 2020, there was a higher prevalence for both explained (36%, n=61) and unexplained deaths (32%, n=10) in the most deprived neighbourhoods.

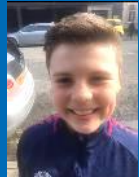
Who Does SUDC UK support?

SUDC UK supports any family whose child aged between 1 and 18 years has died suddenly with no immediately apparent cause.

Post mortem does not need to be complete.

If an explanation becomes clear at any time, SUDC UK would continue to offer support for the family and provide helpful signposting.

For information, newsletter and referrals please visit www.sudc.org.uk



The impact of SUDC



Cooper et al UCLAN, unpublished

"You're just kind of left feeling have I been forgotten...you feel like no-one cares."

"When you have a baby you go home with a newborn, and a midwife and numbers to call. We came home without him...and we were just left."



"Every time she gets ill, and she doesn't understand what something is, she gets worried it will cause her death"

"What happened after he died made the grieving process so much more complicated"

"I feel like we didn't get the option to grieve. We were thrown straight into a fight"

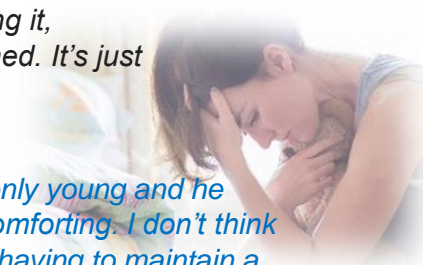
"She would come round and see us very frequently afterwards and she was really present for us and was the conduit between us and everything else that was going on"

"Would you like it back or would you like us to dispose of it ourselves? Dispose of it like he's a piece of rubbish"

"As parents we'd been out of control for everything, absolutely everything"

"There's no urgency about explaining it, they are just happy to accept it's unexplained. It's just absolutely draining"

"The police guy in the back with us, he was only young and he started to cry, but I actually found that very comforting. I don't think the police need to worry about stuff like that, having to maintain a professional edge. It was such a human reaction"



And we will continue to raise

awarenet Add this to your story > wers...