



Overview

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Terminology

- Sudden Infant Death Syndrome (SIDS) is the sudden and unexplained death of an infant where no cause is found after detailed post mortem.
- Sometimes other terms such as SUDI or 'unascertained' may be used.
- Sudden Unexplained Death in Infancy (SUDI) death when there is no apparent cause
- 'Cot death' was commonly used in the past to describe the sudden and unexpected death of an infant.

A Parent's Experience





Sudden Infant Death Syndrome

Sudden infant death syndrome (SIDS) is the sudden and unexplained death of an infant where no cause is found after detailed post mortem.



National Statistics

- 198 unexplained infant deaths occurred in England and Wales in 2018, a rate of 0.30 deaths per 1,000 live births: an increase from 0.28 deaths per 1,000 live births in 2017
- Just over half (57.6%) of all unexplained infant deaths were boys in 2018 (0.34 deaths per 1,000 live births). This is an increase from 55.2% in 2017.
- The SIDS rate for babies born to mothers under 20 has declined by 16.5% since 2004. In 2018, the unexplained infant mortality rate was highest for mothers aged under 20 years, at 1.11 deaths per 1,000 live births
- 230 unexplained infant deaths occurred in the entire UK in 2018, a rate of 0.31 deaths per 1,000 live births

Regional Sudden Infant Deaths - Statistics

103 deaths

- SIDS claimed the lives of 103 babies in the North East between 2008 and 2017
- The latest results from the Office for National Statistics (ONS) showed in 2017 SIDS rates in England and Wales went down to the lowest on record.
- SIDS rates in the North East have increased from 0.31 in 2016 to 0.40 in 2017.
- The North East now has the highest rate of SIDS deaths in the country, considerably higher than the average rate in England of 0.27



Safer Sleep The Impact of Alcohol and Substance Misuse

Introduction

- Women in pregnancy are not routinely screened for drug use.
- Many women are not open and honest about drug taking due to fear of professional involvement from Agencies and having their child removed.
- The true extent of drug use in women is largely unknown as reliable figures are hard to obtain.
- Often information comes from police, social worker, professionals working with families, random urine toxicology screening.
 - Highly likely that there are many parents using substances who are caring for children.

Health Issues

- Malnutrition / anaemia
- ➢ Low BMI
- Poor Dental Hygiene
- > IV Drug use
- Blood Born Viruses eg Hep B,C,HIV
- Abscess, sinus and endocarditis
- Poor Venous access due to repeated injections/ scarring
- Respiratory problems
- > DVT / Death
- Liver Disease / deranged LFT's /issues with clotting at delivery
- Accidental Injury
- Overdose / maternal death.
- Mental Health, Depression, anxiety, psychosis, self harm.

Commonly Used Drugs

- > Cannabis
- Cocaine/crack cocaine
- Heroin
- > Benzodiazepines
- > Amphetamines
- Codeine

<u>Cannabis</u>



- Very Commonly used
- Socially acceptable
- Readily available
- More smoking "Skunk" which is stronger and more potent
- Resin used as a medicinal intoxicant
- Chemotherapy reduces nausea + vomiting
 - A.I.D.S.- appetite stimulant

Potential Medical Use

Pain, Glaucoma, Multiple Sclerosis, Epilepsy, Anxiety

Maternal Effects

Impaired judgements Inco-ordination Anxiety Dysphoria Confusion Reddening of whites of the eyes Persistent cough Tachycardia Postural hypotension

Fetal Effects

Usually mixed with Tobacco and therefore contributes to:-

Low Birth Weight Increase risk of SIDS Cot Death

Tobacco

- Miscarriage
- > IUGR
- Pre-Term Delivery
- Stillbirth Placental Abruption
- Reduction in Breast Milk production
- > SIDS
- Childhood respiratory disorders

These combined with the effects of other substances increase the morbidity of mother and foetus. Maternal effects of smoking are well publicised nationally.

Neonatal Abstinence Syndrome (NAS)

- > All drugs cross the placenta
- Group of drug withdrawal symptoms can occur in infants born to mothers dependent on certain drugs.
- NAS occurs because at birth the infant is no longer receiving a supply of the drug in which it has been exposed.
- Child Developmental delay common
- Increased risk of being orphaned due to premature parental death

SID Syndrome is 5 x greater in this group

Impact On Parenting

- Impaired judgement, memory, planning
- Risk taking behaviour
- Drowsiness, vomiting, gastritis
- > Argumentative ,aggressive behaviour
- Risk of overlay if adult falls asleep or bed sharing
- Memory blackout-due to neurological impairment
- Personality/mood changes
- > Withdrawal including depression, paranoia and anxiety
- Loss of self esteem
- Loss of emotional availability and prioritising own needs.

National Child Safeguarding Practice Review into SUDI

Out of Routine : A Review of sudden unexpected deaths in infancy in families where the children are considered at risk of significant harm.

Some of the key findings

- > Safer sleep not always simple for families to follow
- Impact of the change in routine temporary housing ; altered sleeping arrangements / disrupted routines
- Parents treated advice as a list of options from which they could choose
- > Strong belief in maternal instinct as a protective factor
- Concerns re infants safety cited as reasons for co- sleeping e.g. when baby ill
- > Deprivation and overcrowding key factors
- Parents need advice from someone they trust and believe



- > Always place your baby on their back to sleep
- Keep your baby smoke free during pregnancy and after birth
- Use a firm, flat, waterproof mattress in good condition
- Place your baby to sleep in a separate cot or Moses basket in the same room as you for the first 6 months

You should follow the advice for all naps, not just for night time sleep !!!

The Safer Sleep Message

Things to avoid



- > Never sleep on a sofa or in an armchair with your baby
- Don't sleep in the same bed as your baby if you smoke, drink or take drugs or if your baby was born prematurely or was low birth weight
- > Avoid letting your baby get too hot
- Don't cover your baby's face or head while sleeping or use loose bedding

ICON Infant Crying and How To Cope

Infant crying and how to cope



Information for parents and carers



ICON

Infant crying is normal

Comforting methods can help
It's OK to walk away
Never shake a baby

www.iconcope.org

 National Initiative
 Increased risk of shaking/impact of other injuries during Covid-19

>How can we help all parents to access this?

Infant crying and how to cope



Information for parents and carers



Aim To Reduce Infant Head Trauma

- > Also known as 'Shaken Baby Syndrome'.
- Child abuse
- Catastrophic injuries leading to:
 - Brain injury
 - Bleeding behind the eyes
 - Bony Injuries

On a national level increased presentation at A&E during the COVID pandemic

Context

- > 1 in 14 cases of abusive head trauma is fatal before hospital discharge.
- Half of severely injured survivors die before aged
 21
- > 24 of every 100,000 babies affected each year.
- > 1 in 9 mothers may have shaken their babies and up to 2 in 9 felt like doing so

Who Shakes and Why?

- 70% perpetrators are male fathers/ male surrogates (Kelser et al 2008; Altman et al 2010)
- > Can occur in every socio economic group
- Coping with crying : living on the edge
- Caregivers lose control and shake baby stops crying
- Some risk indicators include:
- Financial Hardship ; Low birth weight; prior referral to child protection services (strong risk factor) and young parents (Ottermann and Palusci 2020)
- The link with Adverse Childhood Experiences (ACEs); with each additional ACE, study participants were more likely to accept potentially harmful parenting behaviour (Clements et al 2020)

ICON Information for Parents

Touchpoints:-

- Maternity services:
 - Antenatal discussion, postnatal discharge leaflet & discussion & Initial home visit with Community Midwife

GP

 6/8 week - maternal postnatal template screening questions and reiteration of the key messages. Leaflet available to share.

Health Visitor

- Antenatal leaflet and discussion
- Reiteration of the message and discuss coping techniques at postnatal visit, 6-8 week and 9-12 month contacts.

Also opportunistic reinforcing of message and coping techniques

What We Want You To Take Away

- Children Services Teams to reiterate the 4 point message in pre-birth contacts with parents.
- Early Help/ all other teams to support the programme when working with families with unborn or young infants.
- The aim is to reduce abusive head trauma
- All to support parents reiterating the 4 point message
 - I Infant crying is normal
 - C Comforting methods can help
 - O It's OK to walk away
 - N Never, ever shake a baby

More Information

www.iconcope.org

Infant crying and how to cope



Information for parents and carers



A Parent's Message

https://youtu.be/ImUfFilc3

Local Bereavement Support

"Support at a Time of Loss"

Reflections from the Chaplaincy at South Tyneside and Sunderland Foundation Trust

What Can We Do?

- We can't turn the clock back and make things alright - but we <u>can</u> be a reassuring presence that starts pointing the way through the situation.
- We can offer a relationship based not on role, but on human compassion.

What Do Parents Want?

- Moments acknowledged in the "life" of their little one- e.g. blessing/hand-prints/photos
- Their pain taken seriously and acknowledged for many this is such new and uncharted territory.
- "Help" exploring all the options when none of the choices are what they want.
- "Understanding" that there is no best wayonly their choice to live with.

Unpacking the Situation.

- > Don't assume you know the parents' feelings
- The grief "process" may not be something that they have encountered give some reassurance:-
 - 1. The switchback of emotions
 - 2. The "gender" differences in response
 - 3. The pressure of family expectations.

Where Can You Find Support?

- If chaplaincy has been integrated into the care pathway from the start then this support will take them through funeral planning and into what lies beyond.
- This is an open door and often people returnto see the book of remembrance, and talk!
- There is a support group for just about every single situation ex. Twins; fetal abnormality; sibling issues; or just the familiar SANDS or SIDS, or more locally 4Louis.
- However, every encouragement needs to carry a warning that not all groups are the same and the support they offer may be very different. "Test it, before you purchase " is the motto!

Don't do the leg work for familiesjust give them the information.

Can We Help You?

- Making sure that you feel comfortable walking into an encounter with a grieving family is one of the keys to successful caring.
- Checking out that your feelings, thoughts and emotions are all in synch is not a luxuryit is ensuring that you will give the best possible support to this couple at what is undeniably a most horrendous time.
- Use the chaplaincy, and its experience, to check out your practice in this situation.

> 0191 5699180

Role of Designated Doctor

When a child dies, the Designated Doctor gives support to the families through;

- regular communication
- > empathy
- listening to them
- promptly communicating verbal post-mortem report
- responding to their concerns where services could have been better.

CONI Programme (Care of the Next Infant)

View training

Reachable Moments with Parents

- Every contact can count as an opportunity to engage with parents across a range of multiagency professionals
- Consider asking parents about their views on safer sleep
- Try to understand the factors that may be a barrier or influencing factor in parents decision making
- Provide the information in a format best suited to them
- Provide parents with examples risk of suffocation when co-sleeping on a sofa could improve the trust in the safer sleep message

The Lullaby Trust Safer Sleep



Who Are We?



Lullaby Trust Strategy

- Secure annual reductions in the rate of SIDS
- Ensure bereavement support is available to all families affected by sudden infant death, at any time, and with any baby born after a bereavement
- Commit to keeping SIDS on the research and policy agenda

The rate of SIDS has reduced by over 80% since the Back to Sleep message was launched in 1991

20,000 lives saved

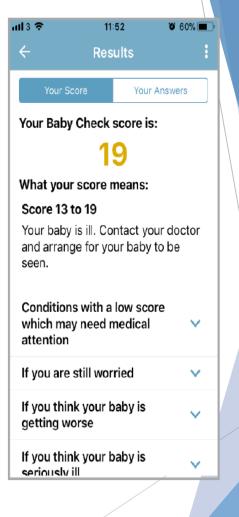
80%

SIDS claims the lives of approximately 230 babies every year in the UK: that's around 4 babies a week

Baby Check App











New jointly branded leaflets:

To purchase from our online shop in packs of 52 for £13: 25 parent guides, 25 quick reference guides, 2 professional guides Single copies free from shop for parents

Download pdf copies here:

https://www.lullabytrust.org.uk/safer-sleep-advice/cosleeping//

Our Support

FREE BEREAVEMENT SUPPORT

Personally answered 365 days a year

T: 0808 802 6868

E: support@lullabytrust.org.uk

Webchat at lullabytrust.org.uk

SAFER SLEEP SUPPORT

Single copies of our publications free to download from

site

- T: 0808 802 6869
- E: info@lullabytrust.org.uk



Publications for Bereaved Families



When a baby or young child dies suddenly and unexpectedly



https://www.lullabytrust.org.uk/professionals/sidstraining/

Little Lullaby Dedicated Project for Young Parents

- Little Lullaby wants) to stop all unexpected deaths of babies and toddlers born to young parents.
- We want young parents to feel better informed, more confident and less isolated through pregnancy, birth and beyond.
- A digital version of Little Lullaby which stretches across the UK can be found on these various platforms: <u>https://littlelullaby.org.uk/about-us/</u> Instagram: <u>https://www.instagram.com/littlelullabyuk/</u> and Twitter @littlelullabyuk

Little Lullaby Dedicated Project for Young Parents

- Our aim is to keep reaching those most vulnerable and encourage them to get in touch, join our young parent panel or write a blog for us to share their experiences.
- If you work with any young parents please tell them about Little Lullaby and joining our panel, they can get in touch with us via <u>info@littlelullaby.org.uk</u> and we are hoping to meet virtually end of March.
- With the help of our Young Parent Ambassadors, we spread safer sleep advice to young parents aged 25 or under through our safer sleep workshops, our website and our work with professional

"It is vitally important to continue to promote safer sleep messages"

Thank you

Cheryl Pearce Support and Training Officer

The Safer Sleep Message