



Care of Next Infant

**CONI**

25th Anniversary 2013



# The Lullaby Trust is committed to saving lives by supporting the CONI programme.



## About The Lullaby Trust

The Lullaby Trust provides specialist support for bereaved families and promotes expert advice on safer baby sleep.

Working with the NHS we run a national health visitor led service for bereaved parents, the Care of Next Infant (CONI) programme, which supports families before and after the birth of their new baby.

We are committed to supporting research to understand why babies die suddenly and unexpectedly and to find out more about how to prevent these tragic deaths.

The Lullaby Trust also runs an information line for parents and professionals (**0808 802 6869**) and a dedicated line for bereaved families (**0808 802 6868**). Both are free to call from landlines and mobiles.

Advice including factsheets and the latest research can be found at [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

We campaign tirelessly, lobbying government to keep sudden infant death on the public health agenda.

# 25 years of The Lullaby Trust's CONI

When I was seven, I won a prize for a poem I wrote at school. I don't remember the exact words, but it was about a star and the last word was "Please?", written in big pencil letters. I wished on that star to meet Thomas – the big brother I had never known, but who, in my mind, was the coolest big brother anyone could wish for.

Like many parents, Mum and Dad never found out why Thomas died in 1987 when he was six weeks old. His post mortem was completely normal - they just found him cold one morning.

We talked a lot about Tom when my brother Sam and I were growing up and Dad used to joke that I looked like an alien when he and mum stuck breathing monitors to me.

But it wasn't until The Lullaby Trust asked me to write this booklet that I really asked Mum how she felt "caring for the next infant" – me.

When I was two months old, Mum said, my monitor suddenly went off. There I was, lying in my Moses basket, very pale. She grabbed me. Her sense of panic, feeling it was all happening again at the same age Tom died, was terrifying. Yet knowing she had heard the monitor, that she was in control, and that in the end I was fine meant everything.

My mum was given a monitor as part of the Foundation for the Study of Infant Deaths' (FSID) infant home surveillance project in 1988, from which CONI developed.

Today CONI is available through the NHS, with additional support from The Lullaby Trust (formerly FSID), in 90 per cent of England, Wales and Northern Ireland.

**The service is offered to parents who have suffered a sudden infant death - never mind how long ago. Parents can choose to have a monitor, a symptom diary, Baby Check booklet, weight charts, a room thermometer, resuscitation training and a "baby passport" – to fast-track to a specialist baby doctor (paediatrician).**

Most importantly, they also get one-to-one contact with a CONI co-ordinator, the local expert on CONI and with their health visitor who visits them regularly. They can text or call both with any worries.

All the parents I talked to said this was the best part of the programme – not just another piece of equipment, but skilled professionals who took a personal interest in them and their baby.

Many said knowing CONI was available gave them the strength to have another baby and enjoy being parents again.

Sudden infant deaths have reduced by around 70 per cent since 1991, but are still the number one cause of postnatal mortality in the UK. I was amazed at how many of these mums whose babies died as recently as 2009 or 2010 said they hadn't known basic advice such as "don't put your baby to sleep on its front", emphasising how crucial the work of CONI and The Lullaby Trust is.

One mother said: "Thank your mum for being brave enough to have you". This meant a lot coming from someone with the courage to share her heart-breaking and personal experience with me. And although these stories often made me cry, I found them inspiring and uplifting. Thanks to the support they received, these parents had babies they now adore and are immensely proud of.



A handwritten signature in black ink that reads "Ellie Buchdahl".

Ellie Buchdahl, Journalist

## Alison Waite

Alison Waite is the National CONI Co-ordinator. In 1985, Alison was involved in a research study in Sheffield into whether breathing monitors prevented repeat deaths in families who had already suffered a sudden infant death. The trial involved 625 families who were randomly allocated either a breathing monitor or weighing scales and were visited regularly by their health visitor. The study highlighted one thing: the need for a system of care for bereaved families. In 1988, FSID agreed to fund a draft protocol for care of the next infant. "That," says Alison, "was the birth of CONI..."

Every now and then I pause and think how many families CONI has touched since 1988 – over 8,600 families and 12,000 babies. Sudden infant death has fallen so much in 25 years, but it's still the leading cause of postnatal mortality.

The emotional cost to every family affected is immeasurable. Preliminary data suggests that since it began, CONI has saved over 50 lives.

CONI offers sensible reduce the risk advice, but it also offers emotional support. A strong theme of complaint with parents is that GPs, family members and friends all tell them "don't worry", and try to persuade them to see the new baby as the opening of a different chapter in their lives. But bereaved parents are often still thinking of the baby who died. They can be frightened to love the new baby and scared to talk to anyone about their feelings.

When parents talk about their health visitor, the first thing they say is always: she or he listens. That listening and professional support are crucial.

The apnoea monitors and charts are great for peace of mind, but it's down to the health visitor to give parents a structure and a timeline – otherwise those kids would be going off to work or university still attached to the monitor! Because they are professionals, they know when the goalposts need to be moved to give parents more time.

There's still a lot of work to be done, especially in reaching lower socioeconomic groups where sudden infant death levels are especially high. In terms of spreading the message of reduce the risk, CONI is a very effective option. There's no programme for bereaved parents that provides such intense support. What's more, without that controlled support from our health visitors, a lot of parents would be turning up to A&E every time they were worried, at enormous cost to the NHS.





Photograph by George Brooks

## The Toms story

**Michelle Toms' son Connor died in 1999 when he was 16 months old. Michelle found out she was pregnant again six weeks later. Both her daughters – Amber, now 14, and Georgia, who is one year old – were on the CONI programme. Michelle, 42, describes how CONI is still supporting her after more than a decade – and how much the programme has come on in that time.**

Amber kicked in the same way as Connor had done.

I had the same cravings for chocolate, bacon and cheese at the same times.

That frightened me. I didn't want to be around new mums on the ward – I thought I'd scare them by talking about the death of a child.

The CONI co-ordinator got me straight into a private room – she understood I needed that space. At the doctor's, you can see Mr X one week and Mr Y the next. The CONI health visitor was somebody I could speak to about my girls and Connor every week.

She was there when everyone else – my family, my friends – just got upset.

If I have any worries now with Georgia, I just phone her and we run through the symptom diary and she tells me it's all OK.

Amber was old enough to turn off the monitor by herself by the time I stopped using it! I'm much more relaxed with Georgia – thank goodness! When I compare her CONI plan, how detailed the checks are, I see how much it's developed over the years. It's brilliant.



Photograph by Harriet Armstrong

## The Bissmire story

**Sophie & John Bissmire's daughter Neave died aged 13 weeks and 2 days old. Sophie had only just attended a support day for parents where she was told about CONI, when she fell pregnant with Johnny who was born on December 18, 2000. Sophie's daughter Jorgina was 7 years old.**

I couldn't get the memory of Neave lying on a bean bag where she had fallen asleep, now grey and not breathing and John trying to resuscitate her, out of my head.

I wanted to enjoy my pregnancy but was terrified that it was all going to happen again – I just couldn't imagine that this baby would survive.

CONI gave me the support I needed. They arranged for St John's Ambulance to come and give us resuscitation training, which was such a relief and gave me confidence.

Johnny was under the care of the CONI paediatrician at our local hospital too for the first year which was very reassuring.

Me and best friend Tonia, whose baby had also died suddenly, were pregnant at the same time and Luke and Johnny were born 4 weeks apart. CONI wasn't available in Tonia's area.

I remember telling my CONI health visitor how sorry I felt for her – I wished she could have had the same support I did.

## The Gillham story

**Connor Gillham was just 12 hours old when he died in hospital in 2004. Four months later, Rachel Gillham was pregnant again with Alex, now seven. He and his brother Ewan, five, were both on the CONI programme.**

I took everything CONI could offer me – the apnoea monitor, the growth charts, the weekly visits – I was all ready for Alex when he arrived. I was petrified while I was pregnant and even more after he was born.

The first night in hospital I managed to drop the monitor and break it, and what with that and all the memories of Connor dying there, I discharged myself as soon as I could.

CONI was brilliant. I got a new monitor to use at home and filling in the records gave me a focus and made me feel I was doing something positive, especially when the health visitor came round and told me I was doing a really good job.

When I'd been having all these doubts about myself and why Connor died, it was great to have someone telling me I was a good mum. When Ewan was born, he went on the CONI scheme and we got the same health visitor.

This time she encouraged me to join a local postnatal group, to go out and be proud of my baby. I only needed the home visits for two months with Ewan, instead of six months with Alex. I was so much more confident – but I could never have done it on my own.



Photograph by Harriet Armstrong



Photograph by Harriet Armstrong

## The Thompson story

**Cate Thompson's son Jac died in July 2000 and her husband left her shortly afterwards because, she says, "we grieved completely differently". Cate found a way of coping by getting involved in the Baby Bereavement Support Group in Hartlepool, founded by her bereavement counsellor Val Lake in 1994. Cate helped transform the BBSG into a registered charity with PCT funding and a web base.**

Today it supports parents who have suffered miscarriages, stillbirths or sudden infant death.

In the first few weeks after Jac died, I didn't want to do anything. I didn't want to get dressed, I didn't eat – I alternated between being completely numb and just sobbing.

I swore I would never have another baby. But Imogen was determined. I'm so glad it worked out this way. But the day the doctor told me I was pregnant; all I could do was scream: "No, no, no..."

The CONI programme got in touch early on when my midwife referred me. I was lucky that I already had the BBSG to turn to for support.

But it was CONI that gave me the feeling of being in control when I was on my own with Imogen. The diaries and weight chart helped, but the monitor was my absolute lifeline. I don't think I'd have slept without it.

A couple of times it did go off and Imogen had actually stopped breathing – all I had to do was nudge her and she started again, but I knew I had the baby passport so she would have been seen immediately in A&E if we'd needed it. Without CONI I wouldn't have been strong enough. I definitely wouldn't have been.

## The Webster story

Louise Webster's three-month-old daughter Abbie died suddenly in the back of the car in January 2009. Her children Tom and Hannah, who were seven and eight at the time, were in the car with her. Louise, 41, from Thornby, wasn't sure she ever wanted another baby. But she knew Tom and Hannah missed having a little sister.

That was what made me decide to have another baby – finding out about CONI and knowing the support was there.

Tom and Hannah idolised Abbie and I wanted to do it for them. But I was terrified. My health visitor Sheena was wonderful. When she came round to do the resuscitation training, seeing that doll to practise on brought it all back to me. I couldn't bear to do it but she taught my husband Ian and I tried to take it all in.

The first time I drove with Sam on my own was a big step because Abbie died in the car. Sheena talked me through the drive. She understood everything.

She was there when Sam had his second lot of injections, because Abbie died the day before she had hers. She came on the anniversary of Abbie's birthday, because she knew it was a bad time. Even now she'll call to chat about how everything's going.

Sam has brought happiness back into our lives. Every night we light a candle for Abbie. Sam points to her picture and says "Abba". He knows he's got a little sister in heaven.





Photograph by Harriet Armstrong

## The Eagleton story

**When Stevie Jay-Jay died in summer 2006, Shelley Eagleton's doctor said to her: "I wouldn't advise having another baby. You're in shutdown mode because of grief and your body won't allow it." Shelley, 32, now lives in Hayes, Middlesex, with her husband, Stevie's big sister Ella – and twins Jamie and Lacie, who were born in 2007.**

When they told me I was pregnant with twins I almost collapsed. I always knew I couldn't not have another baby – where would all that caring go?

I thought, Stevie's blessed me with two so I won't have time to think about all the bad stuff. Diane, my CONI lady, was fantastic.

I met her when I was seven months pregnant to go through the programme and after the babies were born she rang me every other week to see how things were.

I was so nervous, especially with two, so it was always nice to hear her on the end of the phone.

It meant I wasn't forever going to the hospital to make sure everything was all right. It was less frightening knowing that if the twins were really ill, we had the letter from CONI to make sure the doctors did all the right checks.

We celebrated what would have been Stevie's first birthday with a charity night, a disco and a raffle. We raised £2,000 and which we gave to FSID - with half to be used for CONI - because without CONI I'd have been a nervous wreck.

## The Stephens story

**Shanine Stephens lost Braighdon when he was exactly 100 days old. Her second son Carey, born in June 2009, had to be rushed into intensive care as well. Shanine, 25, from Nottingham, always wanted a family. Carey is now three and has a little brother, Derron, who is two.**

When Carey was born, he had an infection and they had to resuscitate him. They never found out what it was – just like they never found out with Braighdon.

Carey's immune system still isn't very good. Every time he gets a little cold I feel so scared. That's why the baby passport is amazing – both my kids will be seen straight away by a paediatric consultant.

The best thing is Sue, my CONI co-ordinator. She's watched my kids grow up and she'll tell me how lovely it is to see me getting back to normal after I used to look so lost.

She's not just a staff member – she's human. I often say to her there should be more information out there about cot death.

After Braighdon died, I felt like I wasn't meant to be a mum. Now I think I will have more kids, but I never do it without CONI and without Sue. I think it's a fantastic service. They deserve a medal, all of them.



Photograph by Harriet Armstrong

# How CONI works.

## **The Lullaby Trust works with NHS service providers to ensure families get the support they need.**

Each area offering CONI has a local CONI co-ordinator who is usually a health visitor and a local CONI paediatrician.

## **Families are referred to their local co-ordinator when a new baby is expected and the co-ordinator will meet with the parents to explain the support and help them plan what they need for when their baby is born.**

While their baby is young their health visitor will support them with very regular contacts in the home, at clinic, by phone and text. If there is any concern about their baby, they can be fast-tracked to see a paediatrician for expert advice.

Some babies are seen regularly by a paediatrician for reassuring check-ups. The extra support mostly lasts for 6 months but may be longer. We cannot overstate how valuable the support of these interested professionals is to the families.

## **The Lullaby Trust funds the CONI office situated in the University of Sheffield's Academic Unit of Child Health based in Sheffield Children's Hospital. From there the National CONI Co-ordinator provides training and on-going advice and support for the local co-ordinators.**

With consent, data from the families is collated to help us learn more about reducing the risk of sudden infant death in this vulnerable group.

Questionnaires completed by parents give CONI feedback on what has helped and what could be improved and this can be shared anonymously with the local teams.

## **Over 50% of the equipment used on CONI is paid for by The Lullaby Trust or as a result of the charity's work in actively seeking other donors.**



Photograph by George Brooks

This Diagram shows how The Lullaby Trust works together with the NHS service providers to ensure families get the support they need. For more information, please contact: [coni@sheffield.ac.uk](mailto:coni@sheffield.ac.uk)



# Securing CONI's future.

CONI combines two of The Lullaby Trust's key priorities:

Without this vital service it would be impossible to achieve the charity's goal to halve the rate of sudden infant death by 2020.

## #1

Supporting bereaved families

Healthcare commissioning has undergone enormous change, with decisions on service provision being made at a local level.

The Lullaby Trust is campaigning to secure CONI's future by raising

## #2

Preventing more babies from dying

awareness of the programme with local commissioners; emphasising the crucial and cost effective support it offers to some of their most vulnerable families and the impact the service can make on reducing infant mortality across England, Wales and Northern Ireland.



Emilia Fox, actor

## A note from our Ambassador.

*"I am proud to be an ambassador for **The Lullaby Trust** because of their commitment to provide every family with the very best advice on baby sleep and for the life-line they offer to bereaved parents.*

*"Grieving families supported by their **Care of Next Infant (CONI)** programme experience enormous comfort and reassurance before, during and after the birth of their subsequent baby. Without this help, their early months together would be full of fear and anxiety instead of joy."*





## The Lullaby Trust

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<b>President</b>	Mr C de Selincourt OBE
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