

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. 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

The Lullaby Trust provides expert advice on safer sleep for babies supports bereaved families and raises awareness on sudden infant death.

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Care of Next Infant **CONI**



Welcome to CONI

(Care of Next Infant)

What is CONI?

Families who have suffered the sudden and unexpected death of a baby are often very anxious when they come to have another baby. The **Care of Next Infant (CONI)** programme was set up by the Lullaby Trust in 1988, and is run in partnership with the NHS.

The CONI scheme provides specialist advice, information and support to health professionals who, in turn, support bereaved families with their subsequent babies and help them enjoy the first year of their baby's life.

CONI Plus

CONI PLUS offers similar help to other families who may have special reason to be anxious about their baby. They may, for example:

- be close relatives of a baby that has suffered a sudden infant death
- have lost a baby to causes other than sudden infant death
- be parents whose babies have suffered an apparent life threatening event (ALTE).



Where is CONI available?

CONI is widely available and is currently used by 90% of community trusts in England, Wales and Northern Ireland. It is also available for families in the armed forces stationed in Germany. New centres continue to be set up. For current details of health trusts involved contact the national CONI organiser at:

**Room C1, Stephenson Unit,
Sheffield Children's Hospital,
University of Sheffield,
Western Bank,
Sheffield S10 2TH**

Tel: 0114 276 6452

Email: coni@sheffield.ac.uk

What is available on CONI and CONI Plus?

The help parents receive on CONI and CONI Plus can be as much or as little as they like. They can choose from:

Symptom diary

The diary allows parents to note changes in their baby's health, appearance and behaviour, which they can discuss with their health visitor.

Weighing scales

Healthy babies show regular gains in weight, ill babies may fail to gain, or may lose weight. A weight chart (the Sheffield Weight Chart) can be used to plot the baby's weight changes and those gaining weight either too slowly or too quickly can be seen by a local paediatrician.

Movement/apnoea/breathing monitor

Movement monitors detect babies' movements as they breathe. An alarm rings after 20 seconds to alert parents if breathing movements stop. A very small number of babies may have problems with their breathing, but most will be entirely normal. Although monitors do not prevent sudden infant death, anxious parents report that they are reassured by using the monitor, particularly at night.

Resuscitation training

All parents are offered training in infant resuscitation. Those who choose to take a movement monitor home must complete the infant resuscitation course.

Room thermometer

It is important that babies do not become too hot or cold. A simple room thermometer tells parents the temperature in the room.

Baby Check

Baby Check is a book designed to help parents decide whether they should take their baby to the doctor. It contains 19 simple checks which test for symptoms or signs of illness. Each check has a score and the total score indicates how unwell the baby is likely to be.

Who supports parents on CONI and CONI Plus?

Local CONI Co-ordinators run the programme in each area liaising with the family doctor, health visitor, midwife and paediatrician. The co-ordinators make sure parents know all about the programme and are trained in the use of their chosen equipment.

Health Visitors visit the family very regularly. Parents say that they particularly appreciate these contacts and value their health visitor as a 'listening ear' for their worries and as a go-between for the parents and the doctor.

Paediatricians talk with and advise parents after the death of their baby and during a subsequent pregnancy. After a new baby is born, they can offer routine checks or examine the baby if the parents are concerned. A 'baby passport' is used to fast-track babies through adult A and E departments to the paediatrician.

General Practitioners can offer advice and support, particularly during any illness in the baby.

Midwives ensure that parents are offered CONI during subsequent pregnancies and help parents as they begin to use the support programme after their new baby is born.

The national CONI office manages, monitors and evaluates CONI and provides support and training to the local CONI teams. The CONI office and much of the equipment used in each centre are funded by donations from the public.