



Children's Hospices Across Scotland

# CHAS and NHS Lothian

Enhancing neonatal care and family support in Scotland:  
a collaborative approach.



# 1. Introduction

Since 2014, Children's Hospices Across Scotland - better known as CHAS - and NHS Lothian have worked together on enhancing neonatal palliative care and the support that families receive at Simpson's Centre for Reproductive Health, Edinburgh.

A CHAS Diana Children's Nurse specialising in neonatal palliative care has been based in Simpson's neonatal unit since June 2014. A CHAS Children and Family Support Worker has also been working within the unit since June 2015. Senior medical input to their work is provided through a consultant neonatologist, part-funded by CHAS and NHS Lothian. This nursing, medical and family support input aims to work seamlessly with NHS staff working in the unit.

The service started as a pilot but is now an integral part of service delivery within the unit. The aim was to enhance the palliative care already provided within Simpson's and other CHAS services. This report aims to share the knowledge and understanding gained from this joint experience of delivering specialist perinatal and neonatal palliative care within a hospital environment.

This short summative evaluation was undertaken to understand the impact that the service is having on families who are facing the death of their baby, and whether this service is valuable to families and NHS staff. Particular emphasis was made on assessing the impact the family support element had on all families at the unit, regardless of palliative need, and whether having a regular, consistent and physical presence on the unit raised awareness of palliative care amongst families and increased contact with other CHAS services.

We are very grateful to the parents who have provided their permission to share their names and stories for this evaluation.

Maria McGill  
Chief Executive



## 2. Service structure

The CHAS Diana Children's Nurse is employed by CHAS, and is based within the neonatal unit. The postholder has a range of responsibilities including providing direct care, building knowledge and confidence across the NHS workforce, and providing policy input to neonatal palliative care delivery both locally and nationally.

The CHAS Children and Family Support Worker (CFSW) is employed by CHAS, and spends dedicated time working alongside NHS Lothian staff in the unit, including building staff confidence and sharing knowledge.

The consultant neonatologist is employed through a joint arrangement with NHS Lothian and CHAS, where CHAS funds two clinical sessions per week. The postholder provides senior clinical leadership and a senior medical link between NHS Lothian and CHAS.

## 3. Outputs

Between June 2015 and May 2016, the team supported the families of 78 babies through 172 face-to-face support sessions. Of these babies, 15 died during this period; the others had complex needs or may have been identified as having life-shortening conditions.

Support provided included memory making, bereavement support, post-discharge support, emotional support, sibling support, and benefits advice and advocacy. The initial pilot project provided the partners with confidence that it was a much-needed addition to the work of the unit and, since May 2016, this work has continued as an integral part of the service in the unit.

### **Knowledge transfer**

As well as direct support by project staff, transferring knowledge has been a key feature of the arrangement. This includes the children and family support worker sharing skills with the nursing team through a programme of learning and development that was designed to meet staff needs. Learning topics included memory making, and formal training events in communication, theories of grief, resilience, and policies and frameworks were also held. This work was undertaken during 44 planned days in the neonatal unit, 10 crisis visits, and 25 different types of learning and development opportunities.

### **Building relationships**

In some cases, families will benefit from more comprehensive and on-going support outwith the hospital unit, often through a hospice setting. Between 2014 and 2018 there was an increase in referrals from Simpson's to other CHAS services including Rachel House and CHAS at Home. The relationships established by the service have supported this to happen.

Simpson's neonatal unit (NNU) is a tertiary centre, with some babies transferred from other neonatal units across Scotland. This has led the children and family support worker to work with families from a variety of health board areas. On occasion, this involves supporting families when their baby is transferred back to their local unit for palliative care or to a paediatric intensive care unit for ongoing care. To date, the children and family support worker has supported families directly within Ninewells NNU, Dundee; Victoria Hospital NNU, Kirkcaldy; and the Paediatric Intensive Care Unit, Royal Hospital for Sick Children, Edinburgh. Work has also been undertaken in Queen Elizabeth University Hospital, Greater Glasgow and Clyde supporting the neonatal and foetal pathway development and the 'creating memories' project. This collaborative working has led to an increased awareness of CHAS services amongst NHS staff.

## 4. Outcomes and impact

Qualitative data was gathered during the pilot period from a variety of sources to demonstrate the depth and variety of work being undertaken and the range of care offered. This included family and staff questionnaires; learning and development evaluation forms; written and verbal feedback from families and staff; and case studies. Reflections on learning from challenges encountered and unintended outcomes were also collected. This range of feedback and analysis informs the current service delivery.

### Emotional and bereavement support

Emotional support has been the most widely used service provided by the children and family support worker. For many families, the associated feelings that go along with having a sick or premature baby are complex and overwhelming. The children and family support worker provided parents with opportunities to express their thoughts, fears and emotions in a safe environment with someone not clinically involved in the care of their child. Parents reported that having the opportunity to talk and build a relationship with a consistent member of the multidisciplinary team was of value to them throughout their journey in the NNU. Although very well supported by nursing and medical staff, some parents felt that they did not wish to share their more difficult thoughts and feelings with the nurse caring for their baby.

There was an increase in family self-referrals throughout the pilot period – this was attributed to having a visual presence on the unit, as well as word of mouth from parent to parent regarding the support that the children and family support worker could provide. Parents reported that they felt emotionally supported. Some comments from completed parent evaluation forms include:

“They made us laugh and smile through some very difficult and dark times. We knew we could call on her if needed.”

“They provided me with fantastic support and I was very grateful for the time she spent with me.”

“They were a very friendly face in a very daunting, scary and medical environment; she was approachable and very personable.”

## Promoting attachment and bonding

Parents have shared with the children and family support worker that they face many challenges associated with attachment when their baby is admitted to the NNU: some feel a sense of isolation from their baby; others report that they are scared to bond in case their baby does not survive. The limits to physical contact with their baby also play a part in developing a secure attachment.

The nursing team work hard to promote parent and child bonding by encouraging skin-to-skin contact and parents to undertake as much of their baby's care as possible. To promote this further, the children and family support worker provided storybooks and encouraged parents to read aloud to their baby. Being a qualified massage instructor has also allowed the children and family support worker to offer massage instruction to families after a referral from the nursing or physiotherapy team. Parents have shared that they appreciate the opportunity to undertake these natural parenting tasks.

## Sibling support

Siblings ranging from 3.5 years to 14 years of age have received face-to-face emotional and bereavement support allowing them to understand the NNU environment and the wider impact on themselves and their family.

Support and resources were provided to families in order for them to support siblings of neonatal babies, including supporting siblings of babies at end of life. Activities such as encouraging siblings to use the NNU camera to take photos of their baby brother or sister, or supporting them to participate in memory making crafts, helped children to feel involved and have a greater understanding of what was happening.

Pictures including hand or footprints of the baby and sibling together provide tangible evidence of their time together which is beneficial for very young siblings who may in the future have few memories of this time. Support and resources were also given to families to use at home in order for them to support bereaved siblings of the baby.

### Parent feedback:

“Continuity was helpful. It was lovely that she had been able to meet us at home before our son John was born. She knew something of my life, and my other children.

“One of the hardest things with being in the NNU is the separation from the other children. We were able to build a close relationship with the family support worker through the continuity of her visits, and then when we visited Rachel House we often saw her there too. One of my boys couldn't remember her name, so she was known as the “nice lady” for a while in our house.”

### Staff feedback:

“The sibling work and artwork is invaluable because otherwise our capacity for sibling support is limited.”

“Our eyes have been well and truly opened as a team to the need for sibling support.”

### Memory making

The introduction of memory making crafts by the children and family support worker has proven to be of immense value to families. Many parents wish to have their baby’s life validated, however short it may be, and memory making can be an important element of this. If a baby dies soon after birth or spends a prolonged period in hospital, many of the parents’ friends or extended family may never get to meet their baby. Parents need an opportunity to share their child with those close to them, even if this is only through stories, pictures and precious keepsakes.

CHAS provided a range of craft materials to facilitate memory making including inkpads, canvases, ceramics, pens and card. The introduction of taking hand and foot prints took some time, and challenges were encountered in ensuring they were suitable for use in hospitals. However, the activity of memory making prior to death is now firmly embedded within the unit’s practice.

Many nursing staff have been keen to develop their skills in relation to memory making crafts and the children and family support worker has observed an increased confidence and willingness of staff to undertake this task. All babies who die within the unit are now offered enhanced memory making crafts prior to, or post, death. The value of this service has been widely recognised and the Simpson’s Special Care Babies Fund is now providing ongoing funding for much of the craft materials.

Family feedback has reinforced the importance of having these invaluable opportunities for creating memories:

“Our son’s hand and footprints are amongst our most treasured possessions.”

“Our keepsakes are proudly on display. I took great comfort in this.”

## Benefits advice and advocacy

During the project, the children and family support worker assisted parents who were experiencing social and financial difficulties as a direct result of having a baby requiring long-term care in the unit. For some families the additional costs of travelling to the hospital, staying away from home, parking charges, and having to stop work put them into financial difficulties. By signposting them to areas of support and acting as an advocate to external agencies such as councils or housing associations, the Department for Work and Pensions, and banks, the children and family support worker enabled families to receive benefits such as Disability Living Allowance, community grants and council tax rebates, ultimately removing additional stressors for them.

## Collaborative working with healthcare professionals

Staff feedback demonstrated that the service provided to parents was viewed as an extremely valuable resource.

Staff comments included:

“It is good to have someone who is impartial and is not directly involved in baby’s care.”

“The CFSW can give support to parents in a way that nurses can’t.”

“This service has supported nursing staff during challenging times and gives parents, siblings and extended family extra support. I would strongly advocate this service is continued.”

“I refer mums every week if I am on shift, [I] wish it was every day.”



## 5. Case studies

### Story 1: Palliative care in two hospitals

Baby A was born in a hospital early and significantly underweight. Baby A had many complex medical needs and was transferred to Simpson's NNU for ongoing care. During this time, Baby A received surgery and returned to Simpson's NNU for post-operative care. The children and family support worker met Baby A's parents following surgery and it soon became clear that they were struggling with challenges around money, accommodation and feelings. The children and family support worker met with them regularly, providing a space to talk and share their thoughts and feelings, including sharing their fears that their baby may die. The children and family support worker supported them to raise this question with the NNU medical team, which opened conversations about palliative care.

The children and family support worker arranged a meeting between the consultant and the parents to help them understand complex medical information. Prior to the meeting, the children and family support worker helped both parents to share their questions, which she wrote down for them to take to the meeting. The CHAS Diana Children's Nurse also attended the meeting as a scribe. This enabled the parents to have the information written down in plain English so that they could refer back to it as often as they wished.

Baby A's parents suffered financial difficulties due to being away from home and not working. The children and family support worker assisted the parents with money advice, including advocacy with local authorities, financial institutions, and housing applications.

The children and family support worker helped with memory making crafts such as handprints and footprints, and family photos. Storybooks were provided to encourage parents to spend time with Baby A enabling them to carry out parenting roles, and this was positively received.

Baby A's condition deteriorated and was moved to a hospital nearer home for end of life care. Prior to Baby A's death, the children and family support worker and CHAS Diana Children's Nurse visited the family to support more memory making crafts and to bathe Baby A. A lovely afternoon was spent creating and capturing memories and helping the parents to share their wishes about Baby A's death and the time following it. Bereavement support was offered but not provided through CHAS.

## Story 2: Baby Thea

Baby Thea was born at 36.5 weeks gestation and soon became unexpectedly unwell. She was transferred from her local maternity unit to Simpson's NNU where she was ventilated. Due to the unknown nature of her illness, many tests were carried out to identify a cause. Both parents were struggling emotionally but trying to maintain a positive outlook.

A presentation of Thea's condition was poor muscle tone, therefore a referral was made to the children and family support worker to provide baby massage instruction for both parents. This proved to be a gentle, positive way to get to know the family and provide a stepping-stone to further support. Thea's parents struggled with the unknown nature of their baby's ill health and what the future may hold for them. The children and family support worker provided both parents with further emotional support at the cot-side where they could still be with their daughter.

Once a relationship with the family had been established, Thea's mum requested to meet the children and family support worker somewhere more private so that she could have the opportunity to express openly her fears and feelings. Weekly meetings became a regular opportunity for mum to share, explore and begin to make sense of her emotions. Thea had a three-year-old big brother, who visited the unit once a week. The children and family support worker was able to provide advice and reassurance about how best to support him during this time.

Thea was transferred to the Paediatric Intensive Care Unit (PICU) at Edinburgh's Royal Hospital for Sick Children for ongoing care when she was two months old. This proved to be a very challenging time for the family as they left the clinical environment of which they had become familiar. It quickly became apparent that Thea's mother would benefit from continuing emotional support from the NNU. The children and family support worker and CHAS Diana Children's Nurse visited the family in the PICU, and it was during this visit that both parents shared their very personal thoughts and feelings about what the future may look like for Thea.

Thea has since had a tracheostomy and has ongoing health needs. Both the family and medical staff are unsure of what the future holds for Thea. It is evident, however, that the family will continue to benefit from holistic family-centred care including family support.

Thea's mum, Lynsey, shared her thoughts about the support that she has received from CHAS:

*"Moving from the neonatal unit where we had got to know everyone caring for Thea was very daunting but we knew it was the right thing for her. Having the continued support from the CHAS Diana Children's Nurse and family support worker has really helped us."*

## 6. Key learning points

Developing, piloting and mainstreaming the service has provided some key learning points, and CHAS is keen to use these more broadly across Scotland in order to reach more families and children.

### **Key learning points include:**

- the need for effective communication with key stakeholders within the hospital from the outset to provide clarity about the staffing structure and activities to be undertaken, and how these could best add value to other clinical, nursing and support services in the hospital.
- the need for consultation and planning with medical professionals around the introduction of memory-making - for example, around the safety of ink pads on pre-term skin. These issues were resolved through professional dialogue and engagement.
- the need for a wide range of staff to be confident in recognising those families who might benefit from additional emotional support, advice or activities over and above that provided by the nursing team; and not to create systems that always rely on the need for referrals to be made to the children and family support worker.
- the volume of potential workload far exceeded that initially thought at the outset of the project, and that there is a need for a regular and reactive service which will allow continuity of care for referred families and increased capacity for working with a wider range of families.

## 7. Conclusions

The collaboration between the NNU and CHAS has demonstrated that families and staff truly value the very specialised support that CHAS can offer.

For some families, the option of using a children's hospice is not a viable option due to the baby being too small or sick for a transfer. Others may wish for end of life care to be delivered in the unit - the place their baby knows as home and surrounded by the nursing and medical staff they have grown to trust. These families should not be excluded from CHAS services because of this, and CHAS' ambition is to work collaboratively with the NHS to ensure that all families receive the support when and where they need it. The inclusion of CHAS services in the NNU offers choice for these families, and is an important part of CHAS into Hospitals.

The service has supported families and staff within the unit whilst also increasing referrals to CHAS for children aged under one year old. Families benefit from the specialist emotional support provided, and specifically appreciate receiving this support from a professional who is not directly involved in the care of their baby. The offer of memory making, sibling support, and bringing hospice services into the hospital has been a positive outcome within the unit, easing stressors for the families and staff who are often too busy clinically to meet this need.

Data commissioned by CHAS in 2015<sup>1</sup> and 2018<sup>2</sup> showed there is a significant need for palliative care for babies aged 0-1 years. This service has helped to meet the needs of many of these. It supports and promotes the further development of holistic palliative care for the 0-25 years age group as identified in the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care<sup>3</sup>.

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<sup>1</sup> [https://chas-assets.s3-eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5a0450190f7d3329ce4eeeb2/ChiSP\\_Report.pdf](https://chas-assets.s3-eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5a0450190f7d3329ce4eeeb2/ChiSP_Report.pdf)

<sup>2</sup> <https://chas-assets.s3-eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5c9e29910f7d334e6823390a/ChiSP2-Report.pdf>

<sup>3</sup> <https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/>

## 8. Future development

This collaboration has demonstrated a clear positive impact and positive outcomes for both families and NHS staff. The learning from the CHAS and NHS Lothian collaboration will help inform future service development discussions, including committing dedicated sessions of medical and nursing time built into any proposed service development. The combined nursing, medical and family support elements are likely to be a key feature of future work.

As part of the plan to reach every family in Scotland, CHAS will work with other health boards and neonatal units to develop new, collaborative services which support babies with palliative care needs, and their families.

The scale of need is clear from the 2015 ChiSP Study. ChiSP2 (2018) has demonstrated that neither need nor urgency has lessened.



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