



The Smallest Things

LIFE AFTER NEONATAL CARE

2017 Report



The SMALLEST THINGS

“Nothing can quite prepare you for parenthood,
but for parents of premature babies the planning
and expectation of a new arrival is dramatically interrupted.”

Catriona Ogilvy – Founder



The Smallest Things
Registered charity 1171631
www.thesmallestthings.org

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CONTENTS

Executive Summary - 4,5

Acknowledgements - 6

Foreword - 7, 8

Introduction - 9

Findings

Maternal Mental Health - 10, 11, 12, 13

Ongoing Medical Needs - 14, 15

Family Life - 16

Educational Needs of Pre-Term Babies - 17

Recommendations - 18

Methodology - 19

References - 20

EXECUTIVE SUMMARY

The Smallest Things **Life after Neonatal Care Report** shares the findings of more than 1,600 mothers and is thought to be the largest survey of the needs of children and parents following premature birth in the UK. The report, which includes first-hand accounts from parents, demonstrates the complex nature and often interlinking difficulties families face following premature birth. From maternal mental health, family life, ongoing medical needs, re-admission to hospital and special educational needs, the results clearly outline a lasting journey through which parents struggle to find support.

Maternal Mental Health

63% of mothers report experiencing **anxiety** following discharge from neonatal care

One third of mothers reported feeling **isolated** following neonatal care.

44% of mothers had **flashbacks** to their time in neonatal care.

61% of mothers reported feelings of **guilt** following premature birth.

26% felt that their **health visitor** understood theirs or their baby's needs

Ongoing Medical Needs

48% of premature babies were **re-admitted** to hospital following discharge home from neonatal care.

46% of children have **ongoing medical difficulties** following premature birth.

More than **half of parents** worried about the **long-term outcomes** for their child.

Family Life

Only **35%** of mums were able to attend **mum and baby groups**.

Nearly half (49%) reported that having a premature baby **affected their financial circumstances**.

1 in 3 struggled to keep up with **social friendships** following neonatal care.

14% of mothers were **unable to return to work** as a result of their child's health needs.

Special Educational Needs

44% reported that their school age child had **additional learning needs**.

More than half of those had, or were applying for an **Education, Health, Care Plan**

Conclusions and Recommendations

The report concludes that there is an urgent need for continuity of care from hospital to home and that additional training must be made available to community practitioners in order to identify and support the specific needs of premature babies and their parents. A running theme throughout the report is the lack of awareness of the lasting journey of prematurity and the far reaching impact upon maternal mental health and family life.

Key recommendations include that all NICU parents must have access to timely and tailored psychological support, addressing the often complex mental health needs following discharge from neonatal care. In addition, parents should be encouraged to inform early years and primary school teaching staff of their child's pre-term birth, supporting early identification of additional learning needs.

THE SMALLEST THINGS

Established in 2014, The Smallest Things is a UK charity that promotes the health and wellbeing of premature babies and their families. Raising awareness of premature birth and the needs of families following neonatal care, The Smallest Things recognises that the journey through neonatal care does not end when parents bring their babies home from hospital.

“Sometimes” said Pooh, “the smallest things take up the most room in your heart”. AA Milne.

ACKNOWLEDGEMENTS

The Smallest Things received an overwhelming response to the After Neonatal Care Survey and gives special thanks to the hundreds of mothers who took time to take part, enabling the charity’s report to be based upon one of the largest surveys of UK parents of premature babies in the UK to date.

Report written by Catriona Ogilvy, edited by Sarah Miles and illustrations by Michelle Hird. Individual thanks goes to Rachel Burden, mum to Henry, born at 31 weeks. We are delighted that Rachel supports The Smallest Things, sharing her own experiences in support of the report and its recommendations.

FOREWORD



Rachel Burden

Like many parents, when my son arrived in our lives 9 weeks early and was taken into NICU, I had no idea at all what life would be like as the mother of a premature baby.

My preeclampsia had been diagnosed exactly 48 hours earlier, and most of that time had been taken up with moving to another hospital, watching and waiting to see how my condition would develop, and sorting out logistics for the rest of my family. I was still working out how we would manage with my maternity leave starting two months early to worry about how I would care for a tiny baby.

When Henry was born, I felt detached from the whole process. It was happening to me out of necessity, but the immediate care of my baby was completely out of my hands. I felt glad and grateful he was safe, but I didn't feel like he was really mine, separated by the wires and bleeps and the plastic box.

All along the way the doctors and nurses I had contact with did their best to keep me involved and informed. In the days and weeks that followed, I began to learn and accept the rhythms of life inside NICU - the regular pumping, the daily cares, the ward rounds and the sitting and watching my little boy grow gram by gram. When we moved to a unit closer to home, we got used to a new routine, adapted to a half home/half hospital life, although always feeling like each half of the family was a little compromised and left behind.

You long to get your baby home - but when I left our local neonatal unit there were a whole new set of challenges. I cried when I left the comfort of the hospital and the amazing nurses who'd looked after Henry so tenderly for so many months. I'd lost that reassuring structure of NICU life and found myself writing down every tiny detail of his sleeping, eating and bowel movements, just as we'd done in the hospital. One fairly brutal breast feeding counsellor and one fairly ineffectual health visitor did little to help my confidence. By this time, I knew more about caring for a preemie baby than she

did. And the eagerness to get him to breast feed, while he struggled to put on weight and my supply seemed to be dwindling, was a constant anxiety in those first weeks and months.

No parent should be left feeling alone at this tender time. Having a premature baby can be terrifying, bewildering and joyful and you can feel all those emotions even more acutely when you leave neonatal care. In the hospital, the baby nurses not only looked after my little boy, but they looked after me too. And now we were on our own.

But ultimately we got through the other side because - we were lucky Henry was not too tiny and in good shape. Most of the baby doctors and nurses we met along the way were brilliant and helped me through the new challenges. And I had amazing support from family and friends who all stepped up without being asked, and helped us on our way.

This report from The Smallest Things is a vital step forward in understanding the experiences and needs of mothers who may feel at their most vulnerable and fragile. I hope it will provide useful guidance to the dedicated staff working to support families of tiny babies.

Rachel Burden

Mother of Henry - born at 31 weeks, weighing 3lb.

INTRODUCTION

Premature Birth

Every year 37,000 babies in the UK are born premature (prior to 37 weeks' gestation) and make up 46 per cent of babies requiring admission to specialist Neonatal Intensive Care Units⁽¹⁾.



The World Health Organisation categorises pre-term birth as;

- Extremely preterm (less than 28 weeks' gestation)
- Very preterm (28 to 32 weeks' gestation)
- Moderate to late preterm (32 to 37 weeks' gestation).

As might be expected those born earliest require the greatest level of support, have a greater risk of co-morbidities and spend longer periods of time in hospital before coming home. All children born premature however are known to be at increased risk of respiratory and feeding difficulties and can present later with more subtle neuro-developmental difficulties as they grow. With this in mind, and as the report demonstrates, care must be taken to identify and address the needs of all pre-term children and their families.

A long journey

Every year
37,000

BABIES IN THE UK ARE
BORN PREMATURE



3/4



SAY THEIR
JOURNEY
THROUGH
NEONATAL
CARE LASTED
LONG AFTER
BRINGING
THEIR BABY
HOME FROM
HOSPITAL

80%



FEEL MORE AWARENESS OF
THE LONGER TERM NEEDS OF
PREMATURE BABIES IS NEEDED

FINDINGS

Maternal Mental Health Needs Following Premature Birth

The premature birth of a baby is a traumatic and stressful time for parents, with worry and uncertainty going hand-in-hand with life on a neonatal care unit. This time has a lasting impact upon maternal mental health, with **40 per cent of mothers experiencing post-natal depression** after premature birth⁽²⁾. The Life after Neonatal Care Report demonstrates the complex nature of mental health needs following neonatal care, including symptoms of Anxiety and Post-Traumatic Stress Disorder, and worryingly highlights the lack of support available to families at this time.

For example, just **11 per cent of mothers received formal counselling** or emotional support after leaving hospital; when in contrast **1 in 4 reported a formal mental health diagnosis** and many, many more identified features of mental health difficulties (Image 1).

Worryingly, our results show a wide variation in the level of support families received once they were discharged from neonatal care, and time and again parents reported feeling unprepared for life outside the unit. Just **22% were visited in neonatal care by their health visiting team** and only **26% felt that their health visitor understood** theirs or their baby's needs once they were home.



Image 1

Mums' mental health



OF MOTHERS EXPERIENCE ANXIETY FOLLOWING DISCHARGE FROM NICU



OF MOTHERS FEEL ISOLATED AFTER LEAVING NEONATAL CARE



40%

OF MOTHERS HAVE FLASHBACKS TO THEIR TIME IN NEONATAL CARE



Leaving Hospital

Whilst the rollercoaster ride of NICU may be behind them, families find themselves facing new challenges at home. Used to medical checks and beeping machines monitoring every aspect of care, parents are now in sole charge of their baby; and it is in this post-acute phase of care where mothers report often complex and conflicting emotions. Just **1 in 4 felt confident to be at home** with their baby following discharge, with mothers reporting a wide range of often conflicting emotions on bringing their baby home (Image 2).



Image 2

77 mothers share the three words that best describe how they felt on bringing their baby home from NICU

Isolation

Once home, mothers of premature babies can find usual avenues of support closed to them, with just **35 per cent reporting they were able to attend mother and baby groups**. Having already missed out on antenatal classes due to their pre-term labour, mothers now find themselves unable to join support networks or visit children's centers where peer support and early year services may be accessed. This is largely in part

due to the risk of infection to vulnerable babies with premature lungs, with parents often advised to avoid settings where the risk of infection may be greater. However, in addition to this, premature babies take many more months before they are ready to join baby groups, developing according to their corrected age. And for those who do attend, the comparisons with other children and questions around their birth history can be challenging; leading to unintended distress, heightened anxiety and subsequently escalating into further feelings of isolation within their ongoing journey of prematurity. Indeed, **less than a quarter felt that even friends and family understood** their journey through neonatal care.

The Ongoing Medical Needs of Children Born Premature

Pre-term babies are vulnerable when they leave hospital. They have a reduced immune system and many will not yet have reached their due date. They are more susceptible to feeding difficulties, to respiratory difficulties, as well as other ongoing medical needs, and we know that many are re-admitted to hospital in the months and years following neonatal care.

Despite this knowledge however, parents reported they didn't know that they could end up back in hospital after leaving NICU, and many describe health professionals who had a lack of understanding of their baby's needs.

I wish I was told of the dangers of preemie babies catching the RSV virus in the first year. I knew nothing about this and she did get the virus - probably through contact at my elder daughter's play groups - and as a result she was hospitalised.

The first thing my health visitor said when she came to visit upon our discharge from hospital was 'I know nothing about premature babies'. Not the greatest start for a first time Mum with a tiny baby who'd just spent 6 weeks in hospital...

There was very little support once home and I felt my Health Visitor had no insight or knowledge about pre-term infants and what their development should be.

My son is 7 year old now and is still being hospitalised. It isn't as often as it once was, but is still happening.

I would have found it helpful if more information had been given on the extra precautions needed - we may not have ended up in HDU with respiratory infection.

There are so many on-going needs that my child has, but there is no book to answer my many questions. She reaches milestones at very different times to full-term babies. I am constantly in a state of anxiety and stress and worry all the time about my child.

So much more awareness of the impact of a premature birth is needed - when I tried to talk to my GP about the guilt I felt at my daughter's ongoing health issues he likened it to a mother having a C-section when she wanted a natural birth. Not quite the same.

Going back to hospital

Nearly
1/2

OF PREMATURE BABIES
WERE RE-ADMITTED TO
HOSPITAL FOLLOWING
DISCHARGE FROM NICU

46%

OF PARENTS REPORT
THEIR CHILD TO HAVE
ONGOING MEDICAL
DIFFICULTIES FOLLOWING
PREMATURE BIRTH

51%

OF PARENTS WORRY ABOUT
THE LONG-TERM OUTCOMES
FOR THEIR CHILD



Family Life

Ongoing medical needs and repeat admissions to hospital only exacerbate feelings of anxiety, worry, and even guilt – prolonging the uncertainty of day-to-day life following premature birth. Together with the added financial costs associated with having a baby in neonatal care, estimated to be on average £2,256⁽³⁾, in addition to reduced maternity leave at home, worried about returning to work, finding an appropriate childcare setting, as well as mothers addressing their own individual health needs - the impact of pre-term birth upon family life cannot be underestimated.

- **14%** of mothers were **unable to return to work** as a result of their child's health needs.
- **23%** felt that their baby was **not ready for a childcare setting** when they returned to work.
- **7%** of mothers were unable to return to work as a result of their own health needs following premature birth.
- **60%** felt their **maternity leave was not long enough** for them or their baby.
- **Just under half** (49%) reported that having a premature baby **affected their financial circumstances**.
- **A third** (36%) said that they **struggled to keep up with social friendships** following neonatal care.

Educational Needs of Children Born Premature

In keeping with a recent Smallest Things poll, where **44% stated their child had additional learning needs, 41% of parents sighted leaning needs**, with their child requiring some level of additional learning support at school. More than half of those had, or were applying for an Education, Health, Care Plan (EHCP) and a quarter had an Individual Education Plan (IEP) in place.

The journey following neonatal care and the lasting impact of pre-term birth continues....

RECOMMENDATIONS

1.

Pathways to be established between hospital and community health visiting services ensuring smooth transition from hospital to home and supporting families in the weeks and months that follow neonatal care.

2.

Additional training to be available for health visitors in the specific needs of premature babies and their parents.

3.

All NICU parents have access to timely and tailored psychological support, addressing the often complex mental health needs following discharge from neonatal care.

4.

The Smallest Things Red Book stickers, or similar, to be available for parents in neonatal units ready for them to use as a visual reminder to community staff when they leave hospital.

5.

Parents to be encouraged to inform early years and primary school teaching staff of their child's pre-term birth, supporting early identification of additional learning needs.

METHODOLOGY

The Smallest Things 2017 “**Life after Neonatal Care**” survey was issued online and received **1,629 responses** on 14 January 2017.

Advertised via The Smallest Things Facebook Group, the survey is believed to be one of the largest of mothers of premature babies in the UK in the last 10 years. The survey asked mothers to comment on their experiences of mental health and emotional support following discharge from hospital and included questions on formal counselling and support from Health Visiting Teams. The survey also explored the ongoing medical needs of premature babies, re-admissions to hospitals as well as the learning needs of school-aged children.

All responses were given anonymously and parent quotes used throughout the report are taken directly from the “Life After Neonatal Care” Survey.

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