

The
Smallest
Things



Life After
Neonatal Care

A POST PANDEMIC SURVEY

2021 Report

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The Smallest Things

The Smallest Things Registered charity 1171631 / thesmallestthings.org

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Executive Summary

84% of parents feel more awareness of longer term needs of children born prematurely is needed

The Smallest Things Life After Neonatal Care Report 2021 shares the findings of a survey of more than 500 parents whose babies have been born since 2017 (the year of our last After NICU Report), both before and during the Covid-19 pandemic. It includes parents' personal experiences and addresses the complex and problematic issues families can face following premature birth. Exploring parental mental health, family life, ongoing medical needs, special educational needs and the impact of the Covid-19 pandemic, the results show that parents struggle to access support and understanding during their ongoing and often difficult journey after having a premature baby.



Executive Summary

Parental mental health

- **77% of parents** reported that they have experienced anxiety following discharge from neonatal care
- **24% of parents** who responded have been diagnosed with Post Traumatic Stress Disorder following discharge from neonatal care
- **70% of parents** reported feelings of guilt following premature birth
- **49% of parents** reported feeling isolated following neonatal care
- **29%** felt that their health visitor understood theirs or their baby's needs

Ongoing medical needs

- **49% of children** have ongoing medical difficulties after leaving neonatal care
- **Over half of parents** reported that their children were readmitted to hospital following discharge from neonatal care
- **18% agreed** with the statement 'My GP understood mine and my baby/babies' needs'

Family life

- **Over half of parents** struggled to keep up with social friendships following neonatal care
- **21% of parents** felt that family and friends understood their journey through neonatal care
- **48% of parents** reported that having a baby born prematurely affected their financial circumstances



Executive Summary

Special educational needs

- **32% of parents** did not feel they had a good understanding of the developmental and/or learning needs a child born prematurely may have
- **43% of parents** with children who attend a childcare or nursery setting felt that staff don't understand the learning or development needs of children born prematurely

Before and during the Covid-19 pandemic

- **24% of parents** of babies born prematurely between March 2017 and May 2021 reported a diagnosis of Post Traumatic Stress Disorder compared to 10% in The Smallest Things survey 2017
- **77% of parents** of babies born prematurely between March 2017 and May 2021 reported experiencing anxiety following discharge from neonatal care compared to 63% in The Smallest Things survey 2017



Executive Summary

Conclusions and recommendations

This report concludes that there is a pressing need for increased continuity of care from neonatal unit 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. Throughout the report it is clear that there is a consistent lack of understanding of the impact of premature birth in many aspects of life; from medical staff to family and friends to educational practitioners. Parents should not only be encouraged to inform early years and primary school teaching staff of their child's preterm birth to support early identification of additional learning needs but also teachers must equip themselves with the knowledge and understanding of how to best support a child born prematurely.

This report indicates an increase in emotional difficulties and diagnosed mental health needs in parents of babies born prematurely since The Smallest Things After NICU Report 2017. It also shows an increase from the pre-pandemic period (between March 2017 and February 2020) compared to those of babies born during the Covid-19 pandemic (March 2020 to May 2021). This suggests that longer term experience of having a premature baby and of Covid-19 and consequent influencing factors have had a significant impact on the mental wellbeing of parents of babies born prematurely, making the need for access to timely psychological support addressing the often complex mental health needs following discharge from neonatal care increasingly significant.



About The Smallest Things and Acknowledgements

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.

Acknowledgements

The Smallest Things received an incredible response to the After Neonatal Care: Post Pandemic Survey and gives special thanks to the hundreds of parents who took time to take part, enabling the charity to report on the real life experiences of families of babies born prematurely. Thanks also go to Kirsten Genard and Remy for permitting inclusion of their photographs.

Report written by Catriona Ogilvy and Fiona Hatcher, edited by Sarah Miles, designed by Martin Cotterell with illustrations by Michelle Hird.

“

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

AA Milne

”



Foreword



Every year, tens of thousands of babies are born prematurely in the UK and families face the agonising journey of uncertainty and trauma through neonatal intensive care. But parents tell us all the time that their journey does not end when they leave the neonatal unit and we know that the needs of parents and children born prematurely last long after leaving hospital.

Our latest report demonstrates again the complex and wide-ranging needs of families and children after premature birth and most importantly gives a voice to parents. That is why you'll hear no more from me in this foreword as we put parents at the very heart of this report. **This is their story:**

Catriona Ogilvy
Founder, Chair and
Mother of a 29-weeker
and a 34-weeker

“Reflecting on our neonatal journey, I still get emotional thinking about it and worry about my baby’s development, both physically and emotionally, and how being premature may affect her; when she starts school/later in life. Have I done enough to ensure she has had the best start in life?”

“My 27-weeker is three now and I really feel that nobody gets the ongoing health issue that ex premature babies have. Her age was adjusted to corrected age when she turned two, but she is still not on a par physically or mentally to a child that was born at term. I am so, so nervous about sending her to playschool in September.”

“There is a lot of trauma associated with going through a neonatal care journey that few understand unless they’ve been through it. The impact lasts long beyond them coming home, even if physically they are ok. The worries are also different and I don’t feel the support is always there to reassure you, perhaps due to Covid-19.”

“No-one tells you that leaving NICU isn’t the end of the journey. I knew we would have a follow-up appointment with our daughter’s consultant but I thought that would be a one-off. Three and a half years later we are still under his care. This had a huge impact on me as I was made to feel like I’d failed my little girl, even after we’d been allowed to go home.”

The findings of this report, recognising the significant impact of the Covid-19 pandemic, will shape our ongoing charitable work and we urge health care professionals, educators, commissioners, and NHS trusts to take action now to support the needs of parents and their children born prematurely.

Introduction

Premature birth

Every year 60,000 babies in the UK are born premature (prior to 37 weeks' gestation) and the majority will require admission to specialist Neonatal Intensive Care Units.

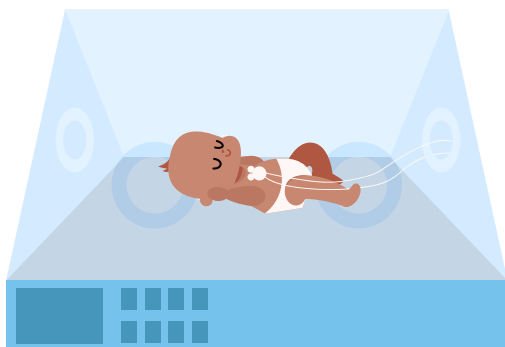
The World Health Organization categorises pre-term birth as:

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 are known to be at increased risk of respiratory and feeding difficulties and can present later with more subtle neurodevelopmental 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.



Every year
60,000
babies in the UK are
born premature

Findings

Parental mental health needs following premature birth

The premature birth of a baby is a stressful, worrying time for families, often involving trauma and uncertainty. Life on a neonatal care unit can have a long term impact upon parental mental health, as is illustrated by the 24% of parents who responded that they have been diagnosed with Post Traumatic Stress Disorder following discharge from neonatal care. A high percentage of parents report experiencing anxiety (77%), guilt (70%), stress (64%) and isolation (47%) which shows the widespread and often complicated effects of having a baby born prematurely.

The Life after Neonatal Care Report 2021 highlights the complex mental health needs of parents following neonatal care, including anxiety and Post-Traumatic Stress Disorder yet there seems to be a lack of available support with just 19% receiving counselling or formal emotional support following discharge from neonatal care. Over a third of respondents reported a formal mental health diagnosis which is a concerning disparity, particularly considering that only 29% felt that their Health Visitor understood their and their baby's/babies' needs and just 18% felt that of their GP.

Only 55% of parents felt they were able

to bond with their babies in neonatal care and just 41% of parents felt comfortable to be at home with their babies following neonatal care which indicates a clear need for greater support and understanding once care moves from the neonatal unit to the community.

There was also a clear increase in reported mental health and emotional issues from The Smallest Things After NICU Report 2017. The percentage of parents of babies born prematurely who reported a diagnosis of Post Traumatic Stress Disorder rose from 10% to 24%. This increase could be influenced by a number of factors including increased general awareness and destigmatisation of postnatal mental health issues and more timely diagnosis.

Survey results show a peak in anxiety for parents of babies born prematurely between pre-pandemic March 2017 and February 2020 (24% compared to 14% of parents of babies born prematurely during the pandemic between March 2020 and May 2021). This suggests that the long term effects of having a baby prematurely combined with the long term impact of COVID-19 have had a tangible effect on the mental health of parents.





‘Mental health support is key. I was diagnosed with PTSD three and a half years after the birth of my children. No support was offered whilst they were inpatients and it would have been so helpful to both me and my husband.’

Mother of extremely preterm baby

‘I felt we were near on totally abandoned after we were discharged from hospital, partly due to the pandemic. I felt the health professionals did not support us well with weaning my baby off his NG tube. I have received no emotional support at all after leaving neonatal care. My GP didn’t even provide the well woman check after my delivery as I didn’t have my baby with me.’

Mother of extremely preterm baby

‘The health visitor did not seem to have any knowledge of the specialist care of premature babies and only visited once.’

Mother of extremely preterm baby

‘I have felt very isolated and alone. I do not enjoy taking my baby out because of his reflux and being tube fed.’

Mother of extremely preterm baby



Leaving hospital

Leaving the NICU is a huge milestone for families, however being at home brings with it new challenges. Without the reassurance of medical staff constantly being on hand and machines monitoring your baby's progress, caring for your baby can feel overwhelming and frightening. This is a complex and confusing feeling for parents to deal with.

Just 27% of respondents were able to attend parent and baby groups (**compared to 35% in the 2017 report**) and **52%** struggled to keep up with social friendships following neonatal care. This can lead to parents finding it difficult to build a support network, particularly as they have often missed out on antenatal groups and activities due to giving birth prematurely.

Attending parenting and baby groups can be challenging with a baby who was born prematurely, as inevitable comparisons of milestones and birth experiences are made. This can lead to increased anxiety and isolation for the parents alongside their concerns about their baby potentially being more vulnerable to common infections. **With 84% of parents** reporting that the journey through neonatal care lasts long after bringing your baby/babies home from hospital, it is clearly a huge hurdle to overcome





‘My twin girls were really outgoing and sociable pre-pandemic. However when lockdowns occurred and we couldn’t attend toddler groups, go out as normal etc. they became quite anxious and clingy once we were able to start doing things again. This really impacted on them starting nursery, it took them a long time to settle and not sob when we dropped them off. Thankfully they are a lot more settled now and they are enjoying nursery but it has taken over 3 months to get to that position.’

Mother of very preterm twins

‘General societal changes have affected my daughter, she doesn’t think it’s unusual for someone to stand in the garden and speak to you inside the house instead of coming inside.’

Mother of very preterm baby

‘Having been in NICU for 139 days, our baby didn’t meet any other babies (bar 2 occasions when he was next to a neonate) until he went to nursery at 15 months old, as a result of lockdown.’

Mother of extremely preterm baby



The ongoing medical needs of children born prematurely

Nearly three quarters (71%) of respondents reported that they worried about the long term outcomes for their pre-term babies, which is completely understandable as babies born prematurely are vulnerable when they leave hospital due to their reduced immune system and potentially not having reached their due date.

Babies born prematurely are more susceptible to feeding and respiratory difficulties and we know that many are readmitted to hospital in the months and years following neonatal care. Over half of parents reported that their baby was readmitted to hospital following neonatal care and many anecdotally describe health professionals who had a lack of understanding of their and their baby's needs.





‘My 24 weeker didn’t begin to display any difficulties until March 2020 (just as the pandemic hit) and suddenly his regular appointments either stopped or were moved online so the support fell away. I am now fighting to access the appointments he needs and there are long delays.’

Mother of baby born at 24 weeks

‘Baby came home 2 months before the first lockdown and we have had very limited face to face appointments with healthcare professionals to monitor progress.’

Parent of very preterm baby

‘My child was just starting Speech and Language Therapy (SALT) services when the pandemic started and all her activities stopped. As a micro prem, she’s delayed and even more so due to being locked away for over a year.’

Mother of extremely preterm baby

‘Definitely more info needed for people on long term needs - many people think once baby comes home everything is fine especially if they have no medical concerns. But developmentally and behaviourally issues can arise long after neonatal care ends and not enough is known by general healthcare or care providers about this so getting the right help can be difficult.’

Mother of extremely preterm baby



Family life

The impact of premature birth on family life is not something that can be underestimated. It touches all aspects, from financial and professional to personal. The added financial costs associated with having a baby in neonatal care were estimated in 2014 (and so have likely increased significantly) to be on average £2,256 ⁽¹⁾ in addition to reduced maternity leave at home. Returning to work was not possible for **11% of parents due to their own medical needs** and **16% because of their baby's needs. Only 21% of parents felt that family and friends** understood their journey through neonatal care.

Life following premature birth can be uncertain due to ongoing medical issues and heightened concerns about returning to work (**60% of parents felt that their maternity leave was not long enough** for them and their baby/babies and **23% felt their child was not ready to enter a childcare** setting when their maternity leave ended). Over half of parents also reported that they struggled to keep up with social friendships following neonatal care – all of these factors combined can make life after the neonatal unit difficult and stressful to navigate.





‘I feel many people feel once your child leaves hospital, that is it, they are fine. For some children that is the case. But not for all. For us the journey still hasn’t ended as we have appointments, physio etc.’

Parent of very preterm baby

‘I feel that I ran on adrenaline during the eight weeks that my boy was in the NICU and it hit me like a bus once we returned home – anxiety, postnatal depression, PTSD. I think the lack of understanding from some relations was a big factor in this. Also, the reality of all myself and my baby had only been through only hit then too.’

Mother of very preterm baby

‘My maternity ended when baby was only 5 months corrected and had yet to meet family due to Covid-19. I didn’t feel liked could put her in childcare when still zero interactions, therefore had to take unpaid/holiday leave.’

**Mother of extremely preterm baby
born during the COVID-19 pandemic**



Educational needs of children born prematurely

While being born early does not mean a child will have special educational needs, it does increase the chances. Educational needs of children born prematurely, however, are not widely understood, with 93% of parents of a baby born prematurely feeling that there needs to be more awareness/understanding of the educational needs of children born preterm⁽²⁾.

43% of parents reported that they did not feel the childcare setting they used had a good understanding of the impact of premature birth on a child's learning and development and 32% of parents felt that they do not have a full understanding of the developmental/learning needs a child born prematurely may have.

These two factors combined put children born prematurely at a

significant disadvantage in maximising their educational potential.

The Smallest Things has created the Prem Aware scheme to support teachers and schools to better understand how prematurity can affect development, recognise additional learning needs and support children through their educational journey to achieve their potential. More information can be found at thesmallestthings.org/prem-aware-award.

Long-term impact on education from the Covid-19 pandemic has yet to be measured, however nearly a quarter (23%) of parents of children born prematurely between March 2017 and February 2020 reported that the pandemic delayed their child starting nursery.

'My child started nursery this year, but having face to face meetings with those caring for her has been impossible. She has some neurological differences from other children and it's very difficult to think of her in a situation where she may be struggling without the proper support.'

Mother of extremely preterm baby

'There needs to be more training/understanding in all schools (state & private) so that children born prem don't have their development/behaviour/progress misunderstood.'

Parent of extremely preterm baby

'I think premature children's development needs should be part of mandatory training for all childcare settings, but my personal experience was good and the nursery I chose understood and supported me.'

Parent of very preterm baby

Recommendations

- 1 Neonatal Leave and Neonatal Pay** to be brought forward by the Government from the proposed implementation date of 2023
- 2 Pathways to be established between all hospital and community health visiting services** as standard best practice, ensuring smooth transition from hospital to home and supporting families in the weeks and months that follow neonatal care
- 3 Training in the specific needs of premature babies and their parents** to be easily accessible for GPs and health visitors and for all health visiting teams and GP practices to have a named and trained neonatal lead
- 4 All NICU parents have access to timely and tailored psychological support**, addressing the often complex mental health needs following discharge from neonatal care
- 5 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
- 6 All schools and teachers to become Prem Aware, supporting the learning needs of pupils born prematurely** Parents are encouraged to inform early years and school staff of their child's premature birth. In addition, parents themselves should have increased access to information on understanding the potential impact of premature birth on learning and development. The Smallest Things aims for all schools in the UK to achieve Prem Aware status by 2030

Methodology

The Smallest Things 2021 “Life after Neonatal Care - a Post Pandemic Survey” was issued online and received 529 responses by 22 September 2021. Advertised via The Smallest Things Facebook Group and widely shared by partners on social media, the survey asked parents 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, readmissions 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 **“Life after Neonatal Care - a Post Pandemic Survey”**.

References

1. **Bliss. (2014).** It’s not a game: the very real costs of having a premature or sick baby
2. **The Smallest Things (2020)** Parents experience of SEN support for children born preterm survey