

The Smallest Things - Written evidence (PRT0032)

1. About The Smallest Things

The Smallest Things is a premature baby charity, established in 2014, recognising that the journey through neonatal care does not end when parents bring their baby or babies home from hospital.

Since its foundation The Smallest Things has been leading the way on better care for families after neonatal care, from award-winning campaigns to secure new Neonatal Leave and Pay Legislation, to ensuring professionals have access to training and guidance to better support families and improve outcomes for children born prematurely.

It's impossible to know what it's like behind the neonatal unit doors unless you've walked those corridors, heard the alarms and felt the fear of losing the most precious thing in the world to you. The Smallest Things is entirely led by parents who have all experienced premature birth. We get it because we've been there too. That's exactly what inspires us to support families, raise awareness and instigate change, and we are very pleased to submit this written evidence to the Preterm Birth Inquiry.

2. Preterm birth – a lasting journey

2.1 Each year in the UK approximately 50,000 babies are born prematurely (prior to 37 weeks' gestation). Following an often sudden and traumatic birth, a baby is taken straight to the neonatal intensive care unit, marking the beginning of an agonising journey of separation, anxiety and uncertainty for parents. Prematurity doesn't end, however, when parents bring their baby or babies home from hospital. While recovering from the trauma of neonatal intensive care, parents are at much greater risk of mental health difficulties, children are frequently re-admitted back to hospital, and parents tell us that their needs are often overlooked.

"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 been through only hit then too." – Mother of very preterm baby

3. Parental mental health

3.1 The long-term impact of preterm birth on parental mental health is well documented and illustrated in our most recent 2021 'After NICU Report'¹. 24% of parents who responded reported that they had been diagnosed with Post Traumatic Stress Disorder following discharge, and a high percentage of parents reported experiencing anxiety (77%), guilt (70%) and stress (64%) once they were home.

3.2 Support and psychological services for parents within neonatal units has increased over recent years, however parents tell us that it is in the months and years after leaving neonatal care when the impact of preterm birth and neonatal care is felt most acutely. There is no national standard for the support required to meet the psychological needs of parents who have experienced preterm birth once they are home, and many mothers will have their 6 week postnatal check with their GP while their baby is still in neonatal care.

The parent voice

"Guilt is one of the very first emotions you feel when you have a premature baby, and not just a small amount, an overwhelming, crushing guilt. The million and one things that you did that could have caused your premature labour run through your mind. Never in my life have I been so surrounded by caring people and yet felt

so extremely lonely.” - Parent of a baby born at 27 weeks’ gestation.

“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 found myself in tears on the motorway because an ambulance passed me. Suddenly, I felt like I was back in the ambulance praying that my contractions would stop and my baby wouldn’t die. I would hold him during the night while he cried and I would cry with him. This was partly my distress at failing to comfort him, and partly the guilt I felt because I knew some parents didn’t get to bring their babies home”. - Mother of a baby born at 24 weeks’ gestation.

4. Lack of awareness and support for families after NICU

4.1 Parents tell us that no one understands and their needs go unmet. In our After NICU report, less than a third of parents of babies born prematurely (29%) felt that their health visitor understood theirs or their baby’s needs, and only 18% percent agreed with the statement ‘My GP understood mine and my baby’s/babies’ needs.’

“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.” – Parent of an extremely preterm baby

5. Readmission to hospital and ongoing trauma

5.1 The neonatal journey does not end for families once they bring their baby or babies home from hospital, and for many families the experience of trauma is relived through repeated admissions back to hospital.

5.2 Nearly half (49%) of parents told us that their prematurely born child had ongoing medical difficulties after leaving neonatal care and more than half reported that their child was readmitted to hospital following their initial discharge. Recent research² shows the growing number of preterm born children admitted to Paediatric Intensive Care Units (PICU) after neonatal care, with the majority (82%) of PICU admissions for preterm children being unplanned, and therefore unexpected for families. It is widely known that NICU and PICU stays are linked to symptoms of post-traumatic stress disorder (PTSD) for parents. Ongoing and unexpected admissions to intensive care environments are likely to exacerbate and prolong these complex mental health difficulties for families, as well as adding to wider financial and employment challenges, caring for a child with uncertain medical needs.

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

6. The educational needs of children born preterm

6.1 While being born early does not mean a child will have special educational needs, it does increase the chances. Research tells us that children born preterm are more likely to have poor academic attainment and special educational needs compared to their classmates born at term. While we know that those born extremely preterm (before 28 weeks' gestation) are most likely to need extra support, research also highlights

that children born just a few weeks early may still face difficulties at school. With on average two to three children in every classroom having been born preterm, we believe that teachers can play a critical role in supporting prematurely born children and improving lifelong outcomes.

6.2 **The Smallest Things Prem Aware Award Scheme** was introduced to raise awareness of the impact of prematurity on development and learning, to support parents and carers, and to help schools recognise and meet the specific learning needs of children born prematurely.

6.3 The scheme promotes use of the 'Preterm Birth Information for Educational Professionals', a free online training resource developed by Professor Samantha Johnson and her colleagues in the PRISM (Premature Infants' Skills in Mathematics) Study Team, funded by the charity Action Medical Research. The online resource outlines the impact premature birth can have on a child's development and learning, and offers practical ways to support children born prematurely at school.

6.4 Importantly, The Smallest Things Prem Aware Award requires schools to update their registration forms so that parents are asked to provide information about their child's birth history. This allows teachers to identify children born prematurely in their class, enabling them to identify and provide timely support. There is no current requirement for schools to gather information about a pupil's birth history and for many reasons parents do not share this information when their child reaches school age.

Education and Health Inequalities

6.5 Lower maternal socioeconomic status and health inequality is associated with an increased risk of premature birth. Produced for the Child of the North All-Party Parliamentary Group, the 'Addressing Education and Health Inequality: Perspectives from the North of England' report highlights that action is needed to reduce the risk of children born prematurely being further educationally disadvantaged and calls for

sharing of “health” information so that schools are be better able to support these children within the classroom.

7. Making a difference

- A statutory requirement for schools to ask about a child’s birth history could be a simple yet crucial step in improving the long term outcomes for the growing cohort of children born prematurely.
- Training to understand and recognise the complex mental wellbeing needs of parents of babies born prematurely should be easily accessible for GPs and Health Visitors, with all health visiting teams and GP practices having a named and trained neonatal lead.
- Health Visitors are uniquely placed to support families and children born prematurely in a journey we know lasts long after coming home from the hospital. From supporting families through illness and repeated admissions to hospital, to supporting early years development and readiness for school. A 6-week ‘After NICU’ wellbeing check by the family GP for parents would also seek to identify mental health needs in a timely manner and signpost parents to the appropriate psychological services.

8. For further information:

1. [The Smallest Things | Life After Neonatal Care Report 2021](#)
2. [Paediatric intensive care admissions of preterm children born <32 weeks gestation: a national retrospective cohort study using data linkage](#)

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