

## Written Evidence from The Smallest Things (GRC0026) June 2020

### About The Smallest Things

Established in 2014, The Smallest Things is a UK charity (registered 1171631) that promotes the health and wellbeing of premature babies and their families. Our vision is a better world for premature babies and their families following neonatal care.

Raising awareness of premature birth and the needs of families, The Smallest Things recognises that the journey through neonatal care does not end when parents bring their babies home from hospital. We promote high-quality care for parents affected by postnatal depression, anxiety and symptoms of PTSD. The Smallest Things exists because we don't believe there's enough understanding of the unique needs of families of premature babies.

### Why the Government needs to extend leave with pay for three months as a result of covid-19

#### The Prematurity Challenge

Parents of babies born prematurely face many issues even under 'normal' circumstances. The Smallest Things has campaigned for extended paid parental leave due to prematurity since 2015 (with a [petition](#) of over 350,000 signatures) and was delighted by the announcement in the Budget 2020 that new Neonatal Leave and Pay legislation will be brought in, meaning parents will receive up to 12 weeks' extra paid leave. Details of how we worked with government and BEIS to instigate this change (and introduced the [Employer with Heart charter mark](#) in the interim) can be found on [our website](#).

We passionately believe that time spent in a neonatal unit, helplessly watching your fragile baby in an incubator covered in wires and tubes and surrounded by beeping machinery, should not count as parental leave. Not only is precious time with a newborn replaced by fear and worry over health issues (or even survival), but the journey does not end when (and if) a baby leaves hospital. Our [After NICU Report](#) in 2017 found that nearly half of premature babies were re-admitted to hospital after discharge with 46% of parents reporting their child has ongoing medical difficulties following premature birth. Parents are still on this journey when it's time to return to work, making finding appropriate (and willing) childcare an issue given ongoing medical needs and the fact that milestones might not have been met based on a baby's "real" age (from actual date of birth) compare to their "corrected" age (based on when they should have been born at full term). In addition, we know from our report that 63% of mums experience anxiety following discharge from neonatal intensive care and 44% have flashbacks so mental health is another area of concern that affects a smooth return to work.

#### The Prematurity x Covid-19 Challenge

In addition to the above, as a UK-wide community of parents of premature babies, we hear about, and foresee, the following issues during this global pandemic:

- *Visiting restrictions on neonatal units* – this seems to have varied across the country but we have heard heart-breaking stories of partners and wider families being excluded from units and of parents' time with their babies being restricted or stopped altogether. Parents are not visitors: they are integral to their baby's care and wellbeing. A recent [study in The Lancet](#) revealed that family-integrated care has been shown to improve a baby's weight gain (a key factor for leaving hospital) and decrease parents' stress and anxiety. Rapid testing is needed so that parents showing symptoms of covid-19 know if they must isolate.

One mum told us, "I'm struggling to see my little 24-weeker who's 36 weeks now. We're 80 days into our journey now and he's just had his second major surgery. We only got to see him briefly. It's never enough time."

- *Coming home* - already an anxious time, this is even more fraught during the current crisis. We know parents already worry when they leave the medical support of the unit behind and have to get used to being at home without the reassurances of monitors constantly beeping and nurses taking observations. To do this during the pandemic increases anxiety around their baby (often with a fragile immune system) becoming ill again without the support systems they have come to rely on during weeks or months in hospital.

- *Time at home* - parents are already robbed of precious bonding time with their babies and now have to contend with potential shielding restrictions and lack of access to face-to-face health support, meaning further isolation and damage to mental health after a traumatic start. Many parents of premature babies tell us that all they want is to get them home and start a 'normal' experience of parenthood that involves a support network of friends, family and community. Our [After NICU Report](#) in 2017 found that 63% of mothers experienced anxiety after neonatal care and a third felt isolated. It's too early to say what those figures would look like today but we believe they would be much, much higher.

- *Returning to work* - already a hurdle for parents of premature babies, this is even more difficult in the current climate. Not only is it often impossible to visit settings to assess suitability, many childcare providers simply do not have capacity due to social distancing requirements. It can take longer to find appropriate and willing childcare for premature babies anyway (due to ongoing medical needs or health concerns) and premature babies can take longer to "settle in" so the options are narrowed down further, if available at all. Childcare is often a 'jigsaw' arrangement that involves wider family and friends too and this is currently impossible. Furthermore, parents of premature babies will usually have numerous follow-up medical appointments to attend.