

The
**Smallest
Things**
Strategy 2020-2023



#smallestthingsbigimpact

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The Smallest Things exists because we don't believe there's enough understanding of the unique needs of families of premature babies

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.



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Every year, 37,000 babies in the UK are born early.

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Creating a better world for premature babies and their families following neonatal care has always been at the heart of everything we do. We are proud of what we have achieved together already and are excited to publish our ambitious plan for the coming years.

Every year, 37,000 babies in the UK are born early. That's a lot of shocked parents thrown into the terrifying world of neonatal care – beeping machines, incubators, breathing tubes and separation as mums and dads leave their baby each day faced with uncertainty and worry. We get it because we've been there too. The Smallest Things is run entirely by volunteers who've had premature babies. And that's exactly what inspires us to support families, raise awareness and instigate change.

Making a difference

We may be a small charity, but the impact we have had over a short period of time has been huge. After years of campaigning we were delighted by the new neonatal leave and pay law announced in the 2020 budget. Parents of premature babies will receive up to 12 weeks' extra pay and leave. However, this new law won't come into effect until April 2023 so we are urging the government to move faster and make sure the entitlement applies to all families, including the self-employed and workers.

Looking ahead

Our 2020 Strategy outlines our ambitious goals for the coming years and sets out how we will achieve them while keeping the parent voice at the forefront of all we do. We understand that the neonatal journey does not end when you leave the hospital doors and believe in a world where parents have the time they need with their babies before returning to work; the care they need when they leave hospital with timely access to early intervention and mental health support and a world where all children born pre-term have the best possible long-term outcomes.

We are enormously grateful for all the support we have received, helping us to grow quickly as a charity. We will continue to grow our Smallest Things community of parents, professionals and supporters; develop a network of volunteers and seek the additional funding required to undertake the ambitious projects set out in our 2020 strategy.

Thank you for your ongoing support, working with us so that The Smallest Things continues to make a Big Impact.



Catriona Ogilvy
Founder and Chair



Smallest Things – Big Impact

The story so far →

With your support we have:



Secured new neonatal leave and pay entitlement for families whose babies are admitted to neonatal care.

- **More than 350,000** of you signed our petition calling for extended paid parental leave following the premature birth of a baby.
- **We facilitated focus groups**, enabling parents to share their experiences with government ministers as part of a parental leave review.
- **Responded to government** consultations on proposed Neonatal Leave legislation.
- **Worked with charity colleagues** at Bliss and Twins Trust to ensure that all parents in neonatal care have access to the additional time they need.

Introduced our Employer with Heart charter



- **Thanks to our charter**, over 100,000 employees in the UK now have access to extended paid leave if their baby or babies are born premature.
- **34 employers and organisations** across the UK have been awarded our Employer with Heart charter mark, with many more in the process of changing their policies to reflect the needs of families in neonatal care.
- **Signing up to our charter**, employers extend leave at full pay for parents by the number of days between a baby's birth date and their planned due date.

Let parents know that they are not alone



- **With more than 17,000 followers** on Facebook and over 5,000 on Twitter we have a wide-reaching and active online community.
- **Publishing regular stories** of premature birth and life beyond the neonatal unit on our social media channels and through our online blog series, parents tell us how these stories bring them comfort in knowing others are on the journey with them.
- **We relaunched our website** in 2019, using 'real-life' photos from parents reflecting the realities of life in NICU.
- **We've been in the news** and across mainstream media channels, raising awareness of neonatal care and the lasting impact on parents.

Supported the mental health needs of parents following neonatal care



- **Our 2017 'After Neonatal Care'** Report demonstrated the substantial impact on mental health following neonatal care and made recommendations for support.
- **In April 2019** we joined forces with Leo's Neonatal and other charities, taking part in the first ever Neonatal Mental Health Awareness Week.
- **Supported the development of NHS** 'Best practice guidance on supporting mental health within a maternity or neonatal setting'.
- **Spoken at and shared the parents'** perspective at training events and national conferences.
- **Introduced our 'Premmie Proud'** Red Book Stickers, acting as a visual reminder to health visitors and GP's that a parent following neonatal care may need additional support.

Our charity vision, mission & values





Our vision

A better world for premature babies and their families after neonatal care

Our mission

To promote the good health of premature babies and their families; raise awareness of premature birth and the needs of families following intensive care; and to promote high-quality care for parents affected by postnatal depression, anxiety and symptoms of post-traumatic stress disorder.

Our values

UNDERSTANDING

We've experienced premature birth too

COMMUNITY

We believe in the power of coming together for support and change

PASSION

We're committed to making change happen to improve lives

Our 2020 strategy objectives



1. For no parents of premature babies to feel alone



2. For all children born pre-term to have the best possible long-term outcomes



3. For professionals to have access to training, information and guidance to better support families and children after premature birth



4. For families and babies born pre-term to be supported throughout their journey beyond neonatal care

Delivering our 2020 strategy objectives

Everything we do as a charity is with the aim of delivering our vision of a better world for premature babies and their families after neonatal care.

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1

For no parents of premature babies to feel alone

We will:

- **Raise awareness** of our work and increase the profile of our charity in neonatal units across the UK.
- **Maintain an active social media presence**, supporting initiatives such as the Leo's Charity #NICUhour on Twitter and our own Friday Stories series on Facebook.
- **Increase the reach** of our Facebook Group, providing a safe and supportive online environment for parents.
- **Publish regular features** and blogs on our website, focusing on the neonatal journey and life beyond the NICU doors.
- **Continue our 'Dads Do NICU'** blog series, recognising the specific needs of fathers through the neonatal journey.



Did you know?

Just 1 in 4 mums felt confident to be at home with their baby following discharge*

*The Smallest Things After NICU Report 2017

2

For all children born pre-term to have the best possible long-term outcomes

We will:

- **Support UK-based research projects** on the lasting impact of pre-term birth and neonatal care, ensuring that the first-hand experiences of parents are included.
- **Help disseminate research** findings as well as the practical implementation of recommendations through our networks.
- **Prioritise the use of the family** and parent voice in improving services for families with premature babies through regular surveys, forums and workshops.
- **Support the development** of national guidelines that promote the good health of children born pre-term, ensuring that families are at the heart of all we do.
- **Work to improve awareness** and understanding of the lasting effect of pre-term birth during early years and education, collaborating with parents, schools, national bodies and leaders in the field to introduce a Prem Aware Scheme for education settings.



Did you know?

A third of mums feel isolated with more reporting they were unable to access usual pathways for support such as mum and baby groups*

*The Smallest Things After NICU Report 2017

3

For professionals to have access to training, information and guidance to fully support families and children after premature birth

We will:

- **Promote resources and support** existing training events for professionals working with children and families following premature birth.
- **Work together** with parents, schools, national bodies and leaders in the field to introduce a Prem Aware Award for education settings.
- **Support the development** of national guidelines that promote the good health of children born pre-term, ensuring that the voice of parents and the needs of the child are at the heart of all we do.
- **Collaborate across all sectors** to develop accessible training tools for health visitors and community services, promoting awareness and understanding of the needs of parents and children following pre-term birth.



Did you know?

Just a quarter of parents felt that their health visitor understood theirs or their babies' needs once they were home.*

*Smallest Things After NICU Report 2017

4

For families and babies born pre-term to be supported throughout their journey beyond neonatal care

We will:

- **Scrutinise the government's neonatal leave** and pay entitlement and urge it to move faster and ensure all families are included.
- **Work together with charity** colleagues and government departments to ensure that additional leave entitlements meet the needs of all families.
- **Grow our Employer with Heart accreditation** framework so that over half a million employees have access to fully paid extended parental leave following the premature birth of a baby.
- **Ensure our 'Premmie Proud' Red Book Stickers** are available in every UK neonatal unit, acting as a visual reminder to health visitors and GP's of a baby's early start and the additional support families may need.
- **Work across health and charity** sectors to ensure robust pathways are established between hospital and community services, facilitating a smooth transition from hospital to home and supporting families in the weeks and months that follow neonatal care.
- **Continue to grow our charity** by focusing on our vision, fundraising for ongoing projects, recruiting more trustees and developing a volunteer's network to help deliver our 2020 strategy.



Did you know?

More than half of parents whose babies were born prematurely worry about the long-term outcomes for their children*

*Smallest Things After NICU Report 2017

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“I’m over the moon and so grateful to all the mothers of tiny babies at the BBC who helped bring about this change. Inspired by the brilliant campaign of The Smallest Things charity – we told our stories, urged the BBC to review its own parental leave policies and they listened. It will make a huge difference to parents of premature children who face enormous stress and extra challenges in those early weeks and months. Hopefully other organisations will now be encouraged to sign up to the Employer with Heart Charter.”

BBC Presenter Rachel Burden had her son Henry at 31 weeks, weighing 3lbs

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Contacts

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