



## *The Smallest Things* *Campaigning for premature babies*

### **Dear Smallest Things Campaigner,**

Welcome to your *Smallest Things volunteer pack*.

This pack will help you to raise awareness of premature birth and campaign for better support for parents following their neonatal journey.

We hope you will feel inspired to get involved with our *Smallest Things campaign!*

#### **Your Smallest Things Volunteer pack includes...**

- The Smallest Things - background
- The Smallest Things in Numbers - Facts & Figures
- Preparing to meet your health visiting team
- How to arrange a meeting with your MP
- Preparing to meet your MP

Thank you for helping to  
make the Smallest Things  
matter!



[www.thesmallestthings.org](http://www.thesmallestthings.org)

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## The Smallest Things Background

The Smallest Things was founded in 2014 by mother of two small boys, Catriona Ogilvy, following their premature birth.

The Smallest Things recognises the significant impact a premature birth has upon a family, both financially and emotionally, and understands that the neonatal journey does not end when you leave hospital.

### The Smallest Things aims to:

- *Raise awareness and understanding around premature birth*
- *Campaign for better follow-up care and more support for parents following their NICU stay*
- *Campaign to extend maternity leave and statutory maternity pay for parents of premature babies*



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

**#SmallestThings**

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## The Smallest Things in Numbers

Each year in the UK **80,000** babies are born too soon.

That's **1 in every 10 babies** born before **37 weeks** gestation.

The Smallest Things recognises the significant impact both emotionally and financially a premature birth can have upon a family.

An average stay in neonatal care will cost a family **in excess of £2,000** through travel costs, meals out, parking charges, unpaid leave from work and childcare costs for siblings.

We know that the journey does not end when parents leave neonatal care.

**40%** of mothers develop **Post Natal Depression** following premature birth (compared to 5-10% of mothers delivering at full term).

More than **50%** of mothers suffer from **anxiety** and display signs of **Post Traumatic Stress Disorder** following NICU.

**60%** of mothers say that their **maternity leave** and time with their premature baby was too short.

**15,000+** people have signed our **petition** to extend parental leave for parents of babies born too soon.

**One person** can make a difference - thank you for your support!

*"Time is precious  
when you have  
such a little one."*



## Meeting with your local Health Visiting Team

When you leave neonatal care the first professional you often meet is your local health visitor.

**The Baby** - Premature babies can have very different needs to babies born at full term, developing according to their corrected age (based on their due date) rather than their birth date.

**The Mother** - Mothers may still be experiencing emotions of loss, grief and anger. They may be anxious about weight gain or infection risk and they may be struggling to process the traumatic events surrounding their baby's birth. Mothers of premature babies need specific support and a health visitor who can empathise with their journey.

**The Health Visitor** - Contact your local health visitor; let them know about your experience and help them to understand how they may better support parents of premature babies.

### *What you may like to share with your health visiting team*

- Share your story through neonatal care
  - Think about how long it was before you could first hold your baby.
  - How was your baby fed?
  - Were they on a ventilator?
  - How long did you spend in hospital?
- Explain corrected age versus developmental age.
- Let them know how time in neonatal care made you feel.
- Share our facts and figures -

*40% of mothers develop **Post Natal Depression** following premature birth (compared to 5-10% of mothers delivering at full term).*

*More than 50% of mothers suffer from **anxiety** and display signs of **Post Traumatic Stress Disorder** following NICU.*

- Ask them if their team can visit mothers in neonatal care before they bring their babies home.

*"I am so afraid of losing my children, even though they are now healthy and thriving. Flashbacks of NICU memories are crippling. To say that prematurity does not end at discharge is the bidaest understatement I've ever heard!"*



## Arrange a meeting with your MP

MPs represent local people, like you, in Parliament. They are involved in considering and proposing new laws, and can use their position to question government ministers on issues that matter.

If you are not sure who your MP is, you can look them and their contact details up online at [www.theyworkforyou.com](http://www.theyworkforyou.com)

You can write to your MP asking them to meet with you or you may book a time to visit them at one of their local surgeries. We have prepared a template letter that you can use.

Dear <MPs name>,

I'd like to arrange a time to meet with you to discuss the needs of parents following the premature birth of a child and their journey through neonatal care.

My family has first-hand experience of this following the premature birth of ....<briefly include details of your own story here>

I would be grateful if you could let me know when a next available appointment time may be free and I look forward to finding a time to meet with you soon.

Best wishes,

<your name>

<your postcode>

## It helps to be prepared when you meet with your MP

- Your meeting is likely to be between 15 and 20 minutes long.
- Structure your meeting

- *Introduce yourself and thank your MP for meeting with you.*
- *Explain why you are meeting with them and tell them your story of premature birth.*
- *Explain what you would like your MP to do; for example supporting our petition to extend maternity leave, writing to a government minister or visiting your local neonatal unit.*
- *Make notes of your MP's response and ask to be kept up to date with any developments.*
- *Before you leave, ask your MP if you can take a photo of the meeting to send to us at Smallest Things.*

- Don't forget first impressions count so make sure that you're presentable and punctual!
- You can ask a friend or relative to go with you if you'd like some moral support... and taking along your own Smallest Thing to meet your MP is always welcome, politicians can't resist a photo opportunity with a baby!
- Consider writing down a few notes before your meeting; perhaps the most important things you'd like your MP to know or questions you may have for them.
- Take photographs to show of your time in NICU.
- Don't worry if your MP asks you a question you don't know the answer to, you can always offer to find out by contacting us at The Smallest Things.
- Remember, your MP is your elected representative in Parliament. Meeting with constituents like you is part of their job!

## Questions for your MP

*Taking a list of questions for your MP can be helpful.*

1. Ask them to write to the Government minister responsible for parental leave - Business, Skills and Innovation (BIS) minister Nick Boles MP.
2. Ask them to keep you informed of any replies or developments.
3. Ask them to visit your local neonatal unit to meet with staff and parents of premature babies.
4. Ask them to tweet their support for premature babies and their families using the hashtag #SmallestThings



*Steve Reed MP speaking with parents at his local Neonatal unit*



## After your Meeting

- Don't forget to write to you MP to thank them for meeting with you. Reiterate what they have agreed to do.
- Let us at The Smallest Things know how the meeting went. We'd like to know...

*Your Name:*

*Your MPs name:*

*Date of your meeting:*

*What your MP has agreed to do:*

*Email us at - [smallestthings@yahoo.com](mailto:smallestthings@yahoo.com)*

*While NCT groups up and down the country are meeting for coffee and talking about pooing and breastfeeding, NICU mums gather in expressing rooms to discuss breathing support, surgery and methods of tube-feeding. It's like an alternative reality where life-or-death moments are discussed in the same way as nap routines."*

