



# **The Smallest Things**

*Campaigning for premature babies and beyond*

**Dear Smallest Things  
Campaigner,**

Welcome to your **Smallest Things Volunteer Pack.**

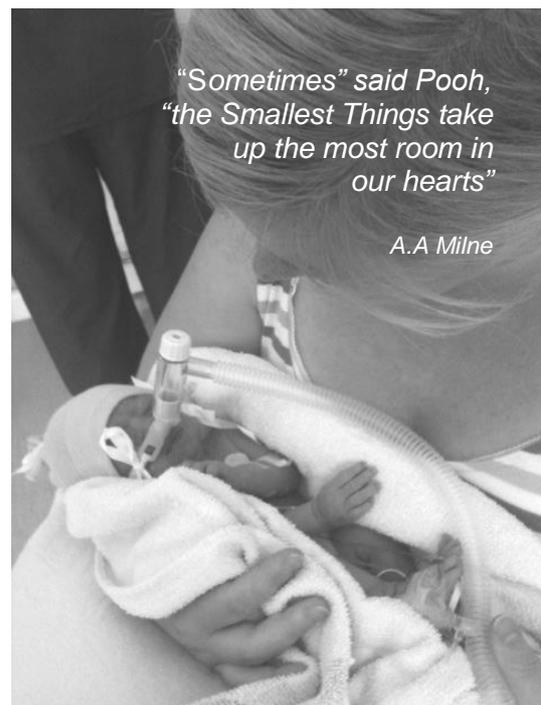
This pack will help you to raise awareness of premature birth and campaign for better support for parents following their neonatal journey.

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

- The Smallest Things: Background
- The Smallest Things in Numbers - Facts & Figures
- Preparing to meet your Health Visiting Team
- Meeting with your Member of Parliament
  - Arranging a meeting with your MP
  - Preparing to meet your MP
  - Questions to ask your MP
  - After your meeting

*Thank you for helping  
to make the Smallest  
Things matter!*

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



# The Smallest Things Background

The Smallest Things was founded by Catriona Ogilvy in 2014, following the premature birth of both her sons.

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.

Supported entirely by volunteers, The Smallest Things has run award winning campaigns and has received national media attention.

## The Smallest Things:

- *Raises awareness and understanding around premature birth*
- *Campaigns for better follow-up care and more support for parents following their neonatal intensive care admission*
- *Campaigns to extend parental 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 approximately **35,000** babies are born too soon, requiring specialist medical input from NHS neonatal units.
- 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 experience **anxiety** and report symptoms of **Post-Traumatic Stress Disorder** following neonatal intensive care.
- **60%** of mothers say that their **maternity leave** and time with their premature baby was too short.
- **126,000+** 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 their baby's weight gain or risk of infection, as well as 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.

"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 biggest understatement I've ever heard!"

## *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?
  - Did you express, were you able to produce milk, when were you able to put your baby to the breast?
  - Was your baby on a ventilator?
  - How long did they spend in hospital?
  - How did leaving your baby in hospital make you feel?
  - How do you feel now?
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- Explain to your health visitor corrected age versus chronological age. Your baby will develop according to their corrected age and Red Book health records may need to be adapted to reflect their premature start.
- Mothers of babies born too soon are likely to need more emotional support
- 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 experience symptoms of **Post-Traumatic Stress Disorder** following neonatal intensive care.



- Ask your health visiting team if they visit mothers in neonatal care before families bring their babies home. Is this a service they could offer to families in the future?
- For more information, Health Visitors can contact The Smallest Things or their local neonatal unit directly.



*Smallest Things "Premie Proud" Red Book Stickers can alert Health Professionals to a baby's premature birth and neonatal intensive care history*

## Meeting with your Member of Parliament

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 can book a time to visit them at one of their local surgeries.

**We have prepared a template letter that you may like to 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>



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

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

- Your meeting is likely to be between 15 and 20 minutes long.
- 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 pictures along to the meeting, show your MP what time in neonatal intensive care was like.
- 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!

### NOTES:

- Steve Reed MP introduced the Maternity and Paternity (Premature Birth) Bill on 16 October 2016
  - The bill has received cross-party support and the second reading will be held on 24 March 2017
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## 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 campaign for extended parental 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.*

## Questions for your MP

*Taking a list of questions or things you'd like your MP to do can be helpful. For example;*

- Ask them to write to Steve Reed MP, expressing their support for his parliamentary bill to extend parental leave for families affected by premature birth.
- Ask them to write to the Government minister responsible for parental leave – Margot James MP, Parliamentary Under Secretary of State at the Department for Business, Energy and Industrial Strategy.
- Ask them to keep you informed of any replies or developments.
- Ask them to visit your local neonatal unit to meet with staff and parents of premature babies.



*Margot James MP (Minister);  
Steve Reed MP; Sarah Miles (Smallest Things)*

- Ask them to tweet their support for premature babies and their families using the hashtag **#SmallestThings**

## After your Meeting

- Write to thank your MP 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)*

- Don't forget to Tweet or share photos of your meeting on our Smallest Things Facebook page!

**#NotMatLeave | #SmallestThings**

“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.”



**“Sometimes” said Pooh, “The Smallest Things take up the most room in our hearts”**

