

Anonymous - Written evidence (PRT0007)

The evidence I wish to submit relates to the below element of the Call for Evidence:

- The ethnic and socioeconomic inequalities seen in relation to preterm birth, and how these could be reduced

Due to our experience with 4 different hospitals I think we are well placed to give some insight into this topic.

We believe that [Hospital A] provided many more facilities for parents including snacks, food and assistance with parking charges along with the Ronald McDonald House accommodation that gave us much more space and ability to process what was happening to our baby following the birth. [Hospital B] has far less facilities for parents in comparison. There also seemed to be an assumption in [Hospital A] that an hour to drive to the hospital (say from [REDACTED]) was too far; In [REDACTED], staff regularly suggested we drive nearly 2 hours each way between my wife's home in [REDACTED] and [Hospital B]. I think that is an unacceptable suggestion.

I understand allocation is difficult when accommodation is limited ([Hospital B's accommodation] only has 7 rooms for parents). However, both myself and my wife believe on several occasions we were excluded from the free accommodation as an assumption was made we would be able to pay for somewhere to stay. One example of this was on the evening of a meningitis scare for our baby and we were forced to pay to stay somewhere else.

Headline points

- On-site accommodation is vital for allowing parents to be present with their baby in neonatal care and providing this eliminates a

large amount of the inequality between families

- I have accumulated credit card debt of c.£20,000 since the birth of our baby last year, some of which I think could have been avoided and at least half of this is directly linked to staying and living at different hospital sites
- We paid [REDACTED] NHS Foundation Trust a total of **£3,714.08** in fees to stay in their paid for accommodation [REDACTED] on-site at [Hospital B]. We believe the Trust are profiting from parents. The Trust says it is cheaper than commercial operators, which is true – but only marginally
- NHS paid for accommodation on-site at [Hospital B] is 50% more expensive than the cost of provision of accommodation for parents and families promoted by the charity Sick Children's Trust for the same location [REDACTED]
- [Hospital A] in addition to the accommodation provided by Ronald McDonald House also offered £8 meal vouchers for their cafe each day
- Both [Hospital A] and [Hospital B] asked us to donate premature baby nappies in sizes not available on shelves in supermarkets and cotton wool, we observed that we were in a minority of parents actually providing this for their child

Kind regards,

[REDACTED]

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About our situation

My wife, [REDACTED] gave birth prematurely to our daughter, [REDACTED], at 24 weeks + 2 days on [REDACTED] **April 2023** at [Hospital C], after we had both been on a weekend away in [REDACTED]. [My wife] is British born with Mauritian heritage.

Overnight we were all transferred to [Hospital A]. We've spent the past three weeks at [Hospital A] with our critically ill daughter in the intensive care unit.

On [REDACTED] April 2023 a transfer for [REDACTED] took place to [Hospital B] (Our regional NICU, as we live in [REDACTED]) in [REDACTED]. We arrived late on Monday at the [Hospital B] site. The medical facilities at [Hospital B] are excellent and the staff provided brilliant treatment for our daughter.

On [REDACTED] July 2023 we were transferred to [Hospital D] NICU, before returning to [Hospital B] on [REDACTED] July 2023 for follow-up treatment for Retinopathy of prematurity (ROP) in the eyes. Before discharge back to [Hospital D] and finally home on [REDACTED] August.

We're still receiving a number of follow-up out-patient appointments, but generally mother and baby are doing very well.

In total we spent 130 days in Neonatal care at 4 different NHS hospitals across the country.

Main issue

Accommodation for parents on-site at hospitals a long way from home.

Our issue with the accommodation

- The expensive nature of paid for NHS accommodation on the [Hospital B] site in comparison to the Sick Children's Trust.

[REDACTED] charge £60 per night compared to £30 per night for Sick Children's Trust on the same hospital site and I believe this is unfair

- The expensive nature of commercial accommodation (particularly in [REDACTED])

This contributes to inequality because some parents are able to stay for little or no cost and others have to pay.

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Our situation on parental accommodation overview

Organisation	Total number of days stay	Total cost
[REDACTED]NHS paid for on-site at [Hospital B])	41	£2,634.96
Sick Little Children's Trust [REDACTED], on-site at [Hospital B]	20	£0.00
Ronald McDonald House, [Hospital A]	19	£0.00
[REDACTED] on-site at [Hospital B]	12	£0.00
Travelodge	7	£891.96
[REDACTED] (independent commercial	3	£187.16

hotel, similar to Travelodge)		
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*Please note: we stayed at wife's home address in [REDACTED] whilst at [REDACTED].

In total myself and my wife paid a total of **£3,714.08** on top of an approximate figure of £5,617.71 for food, clothing and parking. This is a total of £9,331.79.

To note: I had existing credit card debt that I was able to transfer to a 0% credit card to provide for the above additional extra expenditure. Including this debt I have amassed c.£20,000 of credit card debt in this period.

The free accommodation on site was vital to easing our already difficult situation and allowing us to be present at the side of our daughter's cot at all hours.

Our issues at [REDACTED]

Whilst we were extremely grateful for the accommodation provided on-site and the help afforded by staff, myself and my wife [REDACTED] did encountered a number of challenges on the fifth floor of [REDACTED], which we think made it unsuitable for a new mother to be staying in. My wife finds the flat very cold and there is a lack of bedding, no duvets.

Other issues hampering our stay...

*A number of individuals smoking cannabis at the entrance to [REDACTED] and one individual smoking it in his room (The individual in our shared flat was spoken with by [REDACTED] and the issue has been resolved satisfactorily as he has agreed not to smoke in the flat). The chemical THC can be excreted into breast milk.

*Microwave failed during the early hours of [REDACTED] April (Now repaired by [REDACTED], on-site housing service provider), preventing my wife from expressing, due to the lack of ability to sterilize equipment

*Window in Flat [REDACTED] stuck closed ([REDACTED] has now resolved this)

*Headboards on both single beds are in a state of disrepair and not attached to the back of the beds with bare screws showing

*A lack of private toilet and wash facilities unlike Ronald McDonald House at [REDACTED]

*General lack of cleanliness/hygiene around the flat and in the shared wash facilities (which we have now cleaned extensively) - we found some partially decayed leaves inside the flat bedroom

*Lack of lighting around the approaches to the building at night

We have reported a number of faults, but as you will imagine we have a sick child to attend to at [REDACTED] and do not wish to spend all of our time reporting and cleaning the flat. Of course, we are extremely grateful for the provision of accommodation for parents as this allows us to see our daughter at any time, however, we felt it important to draw these issues to your attention as we did not encounter any of them at the hospital in [REDACTED].

We reported these incidents at the time to [REDACTED], Chief Executive of [REDACTED] NHS Foundation Trust and received a reply from the Chief of Staff and the Director of Estates and Facilities.

ASDA/Pampers

I'd like to mention ASDA as they did provide credit and also support on premature baby nappies. Although the free nappies were difficult to obtain and required me contacting every ASDA in the south west and then in the East of England. On one occasion we travelled to [REDACTED] to

pick up a pack of nappies and on another we travelled to a branch of ASDA in [REDACTED] to collect a pack of nappies (both around 40 minute drives from the respective hospitals).

I believe since then ASDA and Pampers have changed the system and now allow for online ordering making this much easier for parents to obtain. I wanted to flag this as both [Hospital A] and [Hospital B] asked us to provide premature baby nappies (Sizes then not available on supermarket shelves) for our child and cotton wool. I was very happy to do this, but it seems not all parents were asked to contribute in this way. We donated a large number of nappies and on one occasion we gave 128 P2 nappies to [Hospital B] along with cotton wool.

18 March 2024