



Preterm Birth Committee

Corrected oral evidence: Preterm birth

Monday 19 February 2024

4.15 pm

[Watch the meeting](#)

Members present: Lord Patel (The Chair); Viscount Colville of Culross; Baroness Cumberlege; Lord Hampton; Baroness Hughes of Stretford; Baroness Owen of Alderley Edge; Baroness Seccombe; Baroness Thornhill; Lord Winston; Baroness Wyld.

Evidence Session No. 4

Heard in Public

Questions 50 - 61

Witnesses

I: Caroline Lee-Davey, Chief Executive, Bliss; Ciara Curran, Founder, Little Heartbeats; Catriona Ogilvy, Founder and Chair, The Smallest Things.

Examination of witnesses

Caroline Lee-Davey, Ciara Curran and Catriona Ogilvy.

Q50 The Chair: We are now being broadcast on Parliament TV so that everybody can follow this evidence session. We consider this session to be extremely important, because we would like to hear about your personal experiences as well as the knowledge you have from your members and people who engage with your organisations as to how the services, both for mothers in preterm labour and for their preterm babies, can be improved, how engaging with parents would make a difference, and where services may be lacking.

Before we start, to get it on record it would be helpful if you could introduce who you are, the organisation that you represent, and how I should address you.

Ciara Curran: I am from Little Heartbeats. I look after women who lose their waters early, or PPRM.

Baroness Cumberlege: Who have you brought with you?

Ciara Curran: This is Sinead, my teddy. We send heartbeat teddies out to women threatening preterm birth.

Catriona Ogilvy: I am the chair and founder of The Smallest Things premature baby charity, which was founded 10 years ago this year. I wear a couple of hats, though. I am also the mum of two boys, Samuel and Jack, who were born preterm. Before having my boys prematurely, I was, and still am, a children's occupational therapist. I used to work in neonatal intensive care and now work in the community with children with special educational needs.

Caroline Lee-Davey: Good afternoon. I am the chief executive of Bliss, the UK's leading charity for babies born premature or sick. We were founded in 1979 by parents who realised that not all hospitals had the equipment or specialist staff that they needed for their neonatal units. We celebrate our 45th anniversary this year.

Chair: We will go straight into questions. One of my colleagues will start the questions and we might have supplementaries. We would like to hear from you on each of the issues.

Q51 **Baroness Seccombe:** Your charities are very important, because you are the link, really, and know exactly what the mother and father are going through. Can you provide an overview of your organisations' work in relation to preterm birth? If it is appropriate, how does your personal experience inform the work that you do?

Caroline Lee-Davey: I do not have personal experience myself. I know that my colleagues do. Bliss exists to ensure that every baby born premature or sick has the best chance of survival and quality of life. That is our mission. We work with all 195 neonatal units across the UK and support the 90,000 babies each year who are admitted to neonatal care, about a third to two-fifths of whom are babies born premature.

We do that in a number of ways. Critically, we provide information and support to parents and families about their experience, concentrated mostly on the experience while their baby is on the neonatal unit and immediately after discharge. That is accredited health information and emotional support delivered through a combination of our staff team and volunteers.

We also work closely with health professionals in neonatal units to improve care, particularly through our flagship quality improvement accreditation programme called the Bliss Baby Charter, which almost all neonatal units across the country are registered with and working towards. That supports units in particular to put parents at the heart of care. You will hear me talk a lot about parental partnership in care and parental involvement in their baby's neonatal care on the neonatal unit as being essential to what we do and critical to how neonatal care can improve in the future.

We also work to raise awareness among policymakers like you and the public. We work on awareness-raising campaigns such as World Prematurity Day, which takes place in November each year. We do policy and campaigning work. I have worked with a number of colleagues here

in particular over the last couple of years on the Neonatal Care (Leave and Pay) Act, which will be game changing for families when it comes in from April next year. Baroness Wyld takes particular credit, but I know that you, Lord Patel, also spoke very movingly in the debate when it came to the Lords.

That will give both parents up to an additional 12 weeks of paid leave when their baby is admitted to neonatal care, for the duration of that neonatal stay. That will make a difference to both parents, but will in particular allow fathers and non-birthing parents to be with their baby on the neonatal unit throughout their stay and not be back at work after two weeks of paternity leave.

We also work to contribute at policy level nationally through membership of bodies such as the NHS England neonatal clinical reference group and the Neonatal Implementation Board, which is implementing the neonatal transformation programme, which my colleague, Baroness Cumberlege, knows very well from her work on the *Better Births* maternity review. I also sit on the executive committee of the British Association of Perinatal Medicine, working with health professionals on some of the professional guidance that goes out.

Through all that work, and our work to support research, we seek to bring the baby and parent perspective and voice to everything we do.

Catriona Ogilvy: The Smallest Things exists with an awareness and understanding that the journey that parents and children go through after premature birth does not end when they leave hospital and bring their baby home. That is the premise of why The Smallest Things exists and why it was founded 10 years ago.

We have a number of things that we do as a charity, all addressing the needs that last long after coming home with your baby. We have a red book sticker scheme. There are red book stickers in over three-quarters of neonatal units in the UK now, which act as a visual reminder that, when a parent takes their baby to see the health visitor, GP or any other professional in the community, they have been through a very different experience than a baby born at term.

We campaign for neonatal leave and pay, and are delighted that that is coming in, but also understand that that is not the be-all and end-all, and that families need lots more support. As a charity, we have our Employer with Heart charter, where we encourage employers to take steps now but also to go much further than the new statutory legislation that is coming in. More and more employers are now doing that voluntarily, which is great to see.

We support research looking particularly at the lasting impact of preterm birth on parents and children. We very much pride ourselves on being a voice for parents. Everybody who supports and works with The Smallest Things has had their own experience of preterm birth. We very much feel that, unless you have been in a neonatal unit and your baby whisked

away from you and taken into intensive care, it is very difficult to understand what that experience is like. As parents, we amplify the voice of other parents and make sure that it is at the heart of everything we do.

Again, we recognise that the journey does not end in the first few months or years after bringing a baby home from hospital. Children born preterm often have lasting needs. We also look at supporting the educational outcomes of children born preterm. We have a Prem Aware Award for schools, which helps teachers to identify the learning needs that children born preterm may have. We know that they are at increased risk of having special educational needs. Overall, we are looking to improve those long-term outcomes for children and for families when they come home from hospital.

We support awareness-raising campaigns. We very much shine a light on the realities of neonatal care. I often talk about neonatal care being quite a hidden world. We might all have visited a loved one in hospital, spent some time in hospitals ourselves or been to a hospital clinic, but unless you have a baby in neonatal care, you are very unlikely to step foot inside a neonatal unit and understand what that experience is like.

It is really about raising awareness of what families go through and then saying, very loud and clearly, that the journey does not finish when you bring your baby home from hospital.

Q52 The Chair: From your own experiences, what was good and what was not so good?

Catriona Ogilvy: That is a great question. You have to bear in mind that this is going back 10 or 12 years, and my sons are now in the final year of primary school and the first year at secondary school. As a parent, when you are in that neonatal unit—parents say this to us all the time—you are very much caught up in the whirlwind of neonatal care and the adrenaline: “We’re in this situation. Heads down and we’ll get through it”. I had my babies at King’s College Hospital and Croydon University Hospital and the support there was fantastic and amazing.

Some of the best experiences were when you could be a mum to your baby on the unit. That might sound a bit silly, because of course you are a parent to your baby, but in neonatal care that is a really difficult thing to do. If you think about an incubator, just being able to change a nappy, particularly for the first time, is a terrifying experience. Bear in mind that I used to work in neonatal care as a children’s occupational therapist. When my baby was in an incubator, I did not know how to move the lines or reposition the nappy. I was used to touching and supporting very small and fragile babies, and supporting other parents doing those tasks, but it is very different when it is your own child.

The simple things that you do for your child, such as dressing them, changing their nappy or doing feeds for the first time, are all so important, which is why family-integrated care is so important. That has

been a real change over the last decade. Family-integrated care was around when I was in hospital, but 10 years ago there was more talk about it rather than it being done.

You asked about the not-so-good elements. That comes back to not being able to be a parent for your baby. If I reflect back, the first time my baby wore a babygrow, somebody else had put him into it. It sounds trivial, but it was not his babygrow; it was a hospital babygrow. When you are trying to support the bonding between parents and a baby, those small things can make such a difference.

The thing that I reflect on from my experience—this is really why The Smallest Things was set up—is that when you come home from hospital, all that amazing support, whether that be peer support from other parents or support from the hospital staff, goes away. You are suddenly on your own with a baby.

Your experience of sitting in neonatal care is pretty much sitting by an incubator or a cot, with your baby attached to monitors that will constantly blink and alarm. The next morning you are at home, you are not attached to anything and nobody is with you. That can be quite a frightening thing. Parents tell The Smallest Things that it is not until months or sometimes even years later that the impact of neonatal care hits them. We know that the incidence of postnatal depression, anxiety and PTSD is much higher in these cohorts of parents. Certainly, I find that from my own experience.

Q53 The Chair: In that respect, there is this new phenomenon of having clinical psychologists helping the parents whose babies are in neonatal intensive care for a longer time. Is that helpful?

Catriona Ogilvy: It is definitely helpful. We need to see more clinical psychologists in neonatal units. At the moment, dare I say it, there is still a bit of a postcode lottery in terms of whether you have psychological support at your unit.

We need to remember, though, that having psychological support at your unit does not necessarily mean that you will have psychological support once you get home or when you really need it. Often families will talk about anniversaries: the anniversary of birth, the anniversary of due date, the anniversary of coming out of the incubator and the anniversary of coming home. All those trigger points are about a year after you have come home from hospital, when often the psychological support that is available to you in the unit is not there any more.

Ciara Curran: I have to apologise. I am really nervous, and I am dyslexic.

The Chair: You do not need to be nervous, Ciara.

Ciara Curran: I have written down stuff on my laptop, so I will follow it. Thank you very much for asking me to provide evidence to the Preterm Birth Committee and for your question.

Before I answer, I would like to make a comment about the language I will use today. In my evidence, I have used the word "woman" and "mother" in the sex meanings of female person and female parent respectively. Little Heartbeats uses sex language, because pregnancy is inherently a sex state. It is well established that language should make sex visible when sex is important in order to ensure that sex-based needs are not overlooked and to avoid sexism. It is also extremely important for women who have experienced pregnancy or infant loss to be recognised as mothers and not just as generic parents. It is a vastly different experience for a mother versus a father when an unborn or newborn infant dies and a baby is born prematurely. To refuse the status of mother in language is incredibly hurtful.

In addition, it is unfortunately the case that many women who experience PPRM feel dismissed and dehumanised in hospitals. The language being used to refer to women by the NHS is dehumanising. We are not baby carriers. We are not bodies with cervixes. When this language is used, it can be retraumatising. When I see the words "woman" and "mother" being erased, it reminds me how they saw me as only a body on the bed. I was not seen as a woman who needed healthcare.

In my advocacy work at Little Heartbeats, I keep being told that we need medical research to back any changes and policies to PPRM, yet no research is in place to support the removal of terms such as "woman" and "mother" from health communications and policy, and no one appears to have taken into account the impact of the loss of these words on women who have lost babies.

I look after women in the UK and internationally. When I set up Little Heartbeats, I did not realise that the impact of my work would go worldwide. I have women who are fighting right now to stay pregnant and to save their babies' lives without it impacting their health, yet women keep being sent home without any management plans.

We are erasing our language without any medically backed research and without understanding the impact that it is having. I have switched off from healthcare advice because it makes no sense to me when we erase language. Language does not evolve. The importance of understanding women's health will help prevent preterm birth in the future, but I feel we are damaging this.

We support women who experience PPRM, which is when your waters break before 37 weeks of pregnancy. I lost my first-born baby to this condition. My drive was about gaining answers. I requested an independent review of my care as I felt unheard. In fact, they sent me home and told me it could not be my waters.

When I did go into the main hospital, the doctor was going to send me home despite me telling him I had lost my waters. I was having blood clots. No one could explain or tell me what condition I had after a number of speculum examinations over many hours. A week later, I lost my baby. When the head of midwifery came to my home with the midwife who sent

me home, her first words were, "Sorry, I didn't know you were going to lose your baby".

I knew at that moment, only days afterwards, that an investigation should take place. It did not. I was not taken seriously because I was under 24 weeks, in that grey area. In fact, when discussing my post-mortem, the doctor told me, "You cannot sue us". The NHS ombudsman travelled from London to my little village of Chinley and spent three hours at my home. They told me: "We're sorry. We didn't think of your mental well-being. We didn't investigate". They told me that the case was on pause, because I had told them that I had taken legal action, which was settled out of court. The hospital was supposed to learn from my care. It did not. That is why I set up Little Heartbeats.

I have just had a paper published on the impact of PPRM on the mental well-being of women from before 37 weeks all the way down to before 24 weeks.¹ Many women who were told to terminate before 24 weeks, which is all dependent on the mother's health, have brought babies home. They have children here today. We need to do more.

The Chair: Thank you very much for that. We heard it clearly.

Q54 **Baroness Owen of Alderley Edge:** I would like to ask you, if you would be willing to share, about the impact of preterm birth on babies, parents and families.

Caroline Lee-Davey: I will start by talking about the immediate impact, and then Catriona can talk about the long-term impact. We know that the biggest risk from prematurity is neonatal mortality. Prematurity is the leading cause of neonatal mortality and the leading factor in all-child mortality for children up to the age of 10. I know that the evidence session that you held last week focused in particular on neonatal mortality in relation to prematurity. If it is okay with you, I will not say too much more about that, but I am happy to take further questions on it.

Thinking about the impact of preterm birth on babies who survive, the first and really important one is to think about the experience of babies immediately after birth and during their neonatal admission. Typically, a newborn baby would expect to stay with their mother, to be held an awful lot of the time and to be physically close to their mother and father during the first weeks and months of life. They would be comforted by their familiar smell, touch, voice and presence. That is how newborn babies work in the world.

A preterm baby admitted to neonatal care has not only lost some of the expected time in utero to get to term; they have also been launched into an incubator and hooked up to all sorts of machines. Those things are

¹ Note by the witness: The paper referred to here is Fiona L. Challacombe et al, 'Preterm premature rupture of the membranes (PPROM): a study of patient experiences and support needs', *Journal of Reproductive and Infant Psychology*, 2024, pp 1-18: <https://www.tandfonline.com/doi/full/10.1080/02646838.2024.2314179>

there for their medical benefit and to ensure their survival and quality of life, but for those babies it will also be a hugely scary and isolating experience not to be held by their parents, not to hear their parents' voices all the time, not to smell them or to be comforted by their presence.

It is important to remember the perspective of the baby. They cannot express it in words in the way we can, but we should remember how scary it will be for the baby and how different it is from how newborn babies would typically spend their first few days, weeks and months of life.

Equally, we need to remember how completely traumatising it is for you, as parents, not to be able to take your baby home after the first few days, to hold them whenever you want, to put them to bed, to wake up with them in the middle of the night as many times as they wake up or to have your family and friends come round and meet them for the first time. As Catriona says, those might sound like trivial things, but it is what we expect of birth and the immediate postnatal period. They sometimes call it the fourth trimester, that real nesting phase for mums, dads and babies at home.

I am sure my colleagues here will speak even more compellingly from their personal experience, but one of the things that breaks my heart the most when we hear from parents is when they talk about leaving their baby behind in hospital for the first time. Mum might be in for a couple of days, but being discharged and having to go home and leave their baby behind is one of the most difficult things for any parent to go through, and they will keep having to go through that.

At the moment, we have a system in which parents cannot typically expect to stay overnight with their baby. We do not have the facilities or the accommodation set up for parents to stay with their babies, as they might expect to stay with children who have a paediatric intensive care admission, which is a very different set of rules.

We would look for accommodation to be invested in and for those facilities to be available so that parents can be with their babies throughout their neonatal stay if they can. That allows parents to be hands-on and involved in their care, which evidence tells us is best for babies as well as for the bonding of families. Certainly, the hospital experience is enormously significant for both babies and parents.

There is one other thing I will mention before Catriona talks about the long-term impact on health and education. There is very clear evidence—a new paper has been published only in the last week—that babies who have had a neonatal admission are at a significantly higher risk of subsequent admission to paediatric intensive care. In particular, those born at the earlier end of preterm are at the highest risk of emergency admission to paediatric intensive care for respiratory infection and other illnesses.

As we have already heard, the neonatal experience does not end with neonatal discharge. Those babies are often on a trajectory of being bounced in and out of hospital, and their families are perhaps not at all equipped to plan and prepare for that and to prevent it.

The Chair: I plead for shorter answers, because I must get through the other important questions. Ciara, my apologies that I did not mention this to you. Baroness Wyld is quite right to remind me.

As a committee, we unanimously decided that we would use the terms “mother”, “parents” and “woman”. We were quite clear. I have delivered thousands of babies, all of them to mothers. To go back to Baroness Owen’s question, do you have anything to add to what Caroline said?

Catriona Ogilvy: I will try to be as succinct as possible, but bear in mind that this journey lasts a long time. I will cover each aspect, if I can.

Caroline is absolutely right about the neonatal experience. These babies should still be in the womb and often go home before their due date, before they should have been born. Parents tell us that they go home feeling shellshocked. After neonatal care, there is a hugely intensified risk of mental health difficulties for parents. We reckon that around 40% of parents will suffer from anxiety, PTSD and depression. That compares to one in 10 mums whose babies are born at term without complication.

Again, it is a journey. It is not just those first few weeks when you bring your baby home. There are high levels of readmission rates. We know that about 50% of babies will bounce back into hospital after coming back home. As Caroline says, a new piece of research has shown that about 50% of the children in paediatric intensive care were in neonatal intensive care.

When we are thinking about the care of families who are presenting with PTSD, it is quite different from one post-traumatic episode. It is an ongoing episode, which amplifies the level of difficulty that the family experiences.

It is also important to talk about that feeling of having to go home without your baby. Around 70% of parents tell us that they feel guilt after having a premature baby. A lot of that is mums thinking, “What should I have done? What could I have done differently?” A large proportion of mums will say to us, “I felt guilty for feeling bad about leaving my baby in hospital, because at least my baby is still in hospital and I know they’re okay”. The mental health needs of these families are really complex.

There is also a high level of isolation. Imagine bringing a very fragile premature baby home from hospital. As I mentioned, a lot of them have not reached their due date at that point. The normal thing to do is to invite friends and family around: “Come and meet the new baby”. You might go to mum and baby groups, or parent and baby groups, and meet other parents. If you have had a premature baby, you are really worried about the risk of infection and the risk of bouncing in and out of hospital

and keeping your baby safe. You do not meet other parents and you do not get to have those conversations.

One of the most difficult questions I used to get asked when I would meet other new mums was, "How old is your baby?" As mums, you look around and you compare. Who is sitting up? How many feeds are you having? Are you sleeping through the night? All those norms go completely out of the window when a baby is born prematurely. Your baby will do things at different times. Parents say to us that they feel like they have to explain, and then they relive the experience.

The big difficulty is that there is no support for families when they come home. In a recent Smallest Things survey, less than a third of parents told us that they felt their health visitor really understood their or their baby's needs. Because of that, parents tell us that they stop going to see their health visitor. They do not feel that the person who perhaps should be able to provide support and help really understands what they have been through. Perhaps even worse, only 18% said that their GP understood their or their baby's needs. Again, that adds to the feeling of isolation and the difficulties in accessing support.

Fast-forward to when your child starts school. All parents worry about their child setting off to school for the first time. For parents who have had that experience of early trauma and ongoing and relived trauma, school can be quite a scary time. You worry about whether they are ready for school. We know that children born prematurely are at a higher risk of special educational needs. We often thought about those born really preterm as having an increased risk of special educational needs, but in fact even those born moderately to late preterm are at higher risk of special educational needs.

The educational needs that these children are presenting with can be quite subtle. They are often to do with working memory, processing, attention or difficulties with mathematics. That is a particular challenge. Their needs are spread over a number of areas and do not have a prominent diagnosis, or there is no one prominent area of need, so they do not get picked up on and then do not get met.

We know that long-term outcomes such as earning potential and academic potential are a lot lower for children born prematurely. As I mentioned, The Smallest Things has a Prem Aware Award scheme, which seeks to train teachers to identify and meet the needs of children born preterm. On average, two to three kids in every classroom will have been born preterm. Over a whole school, that is a lot of kids who potentially have unmet needs. Unless a teacher knows which children in their classroom were born preterm, it is really difficult to identify and address these needs. We now ask schools to have something on their registration form to enable parents to talk about preterm birth history.

As a children's occupational therapist, when I brought my baby home I should have known what to do with him and what he needed, but in those first few weeks I sat and looked at him. I did not really interact

with him. When we are thinking about the long-term needs of children born preterm, parents come out of hospital absolutely shell-shocked. When we are talking about the mental health needs of parents, we need to consider the impact that has on children's development as well.

Ciara Curran: The impact of preterm birth on babies depends on a variety of factors. For PPRM, those factors include the gestation at which the mum loses her waters, her fluid levels, the complications that arise during the pregnancy and when she births the baby. It depends on the gestation of the baby.

Generally, the worst-case scenario for our women is chronic lung disease for the babies. I know children who are thriving, and you could not tell that as babies they had endured a lack of fluid when growing in their mother's womb, but the impact on the women was that they felt unheard and traumatised. Many of our women are told that their babies will not be born alive. Can you imagine? If they are, they are in the grey area of viability. Viability is between 22 weeks and 24 weeks.

Many of our women feel like their babies did not get a chance because they were not transferred to a higher level of neonatal care, and they died, sadly. Many women wanted to have information about our condition and about what to expect in neonatal and NICU. Not all our mums got that, especially between 22 and 24 weeks. In our experience, men take longer to express the impact. Many dads or partners feel helpless. Some have felt frightened due to the risks of PPRM to their wives or partners.

When women are threatening preterm birth, we forget about the children. Some women have delayed going to hospital because they could not find childcare. No one thinks about that part of preterm birth, when you are threatening preterm birth.

I have also had a number of mothers who have had an emergency c-section. When their babies were born, the babies were too poorly to go to the level 2 neonatal unit and were transferred. They could not transfer the mother and baby at the same time, and the mother was told the baby might not survive. I do not feel that that should be happening in the UK today. We can do better.

We recently conducted a study on the impact of PPRM. On Friday, we published a paper about the experiences of women and their support needs. The survey highlighted the harrowing journey for many women and their families who experience PPRM with gestations below and above 24 weeks, and how aspects of their care could be improved to ease the psychological impact on them.

The key recommendations are better information, more consistency of care and greater compassionate support with decision-making from medical providers. Research on how obstetrics professionals can support the well-being of pregnant women who choose to continue their pregnancy in the context of PPRM would be helpful. Psychological support should be considered for women, and it should be easily

accessible for both women and their families both during and after PPRM. Further work is required to assess this. Future studies should co-operate with women with lived experience to decide the most appropriate interventions for those who are going through PPRM and who have experienced PPRM.

I am talking about before preterm labour. I do not need to tell obstetricians how it is, but many of our women, and many people, think that when your waters go you automatically go into premature labour. Some of my mums can go up to five or eight weeks. It is harrowing. They are leaking most days. When they have complications, it is even scarier. You can imagine the impact on our women. Many of them go into emergency c-section. You can imagine how frightening that is for the father or the partner.

- Q55 **Baroness Cumberlege:** I am sorry. It has taken me right back to the three births I had. I will not go through them all, I assure you. I had the first two at home and the third one in hospital. My brother, who was two years older than me, came to see one baby born at home. His comment was, "My God, Julia. Are they all like that?" He was horrified by this little baby that I was so proud of. He was a bachelor and did not understand all that was going on. If home births work for the mother, the father, the family, the GP and the community nurse, they are fabulous. You are on your own territory, you can call the shots, you can say what you want, you can say what we are going to be eating for supper or whatever. It was brilliant having them at home.

For the third one in hospital, it was a process that I had to go through and it was altogether different. I am not recommending that everybody have their babies at home, because clearly that does not work for a lot of women, their partners, staff and so on. I must say, though, that if you are on your own territory, you are sending a very strong message to other people. They do treat you differently.

For those of us who have been lucky enough to give birth at home, it is a very different experience from a hospital birth. The district nurse, who was also the midwife and the health visitor, was brilliant. My father was a GP and he did home births, but he did not do mine. His partner did mine. Just knowing the people makes such a difference. When you go into a hospital—it is antiseptic; it is a very different environment—the whole thing becomes a lot scarier. I was very lucky to have had two at home.

- Q56 **Baroness Wyld:** I should say that I have met Caroline and that we worked closely together on the neonatal care Bill. I want to pay tribute to you all as such powerful campaigners.

My question is about postnatal care. We have touched on it. You have all talked about it in general terms. Specifically, could you each say what interventions or support mechanisms in the postnatal period have the most effect and could be most improved for mothers and families?

Caroline Lee-Davey: There are some immediate things. For mothers to be able to bond with their babies effectively immediately after birth,

postnatal maternity care and neonatal care need to work well together. We have heard many stories of mums on the postnatal ward going downstairs to the neonatal ward to see their baby and then missing out on a meal because they have come round to the maternity ward and not the neonatal ward. We have heard about mums having to go back upstairs to the postnatal ward to get the drugs round or the checks every four hours, whatever it may be. That is something really practical and simple that we think should be achievable.

Baroness Wyld: Is that more of a cultural issue? There is no practical reason why you should not eat if you are upstairs and your baby is downstairs, or vice versa.

Caroline Lee-Davey: In some ways, maternity and neonatal care—it varies from hospital to hospital—work well together, and in other ways they can work as completely separate services. The baby is delivered over here and we look after mum and the well babies, and then the sicker babies are over here. If a mum is still an inpatient and a baby is in neonatal ward, we need to ensure that her care is really integrated.

It is really important, as I said, to facilitate both parents to play a hands-on role in their baby's care throughout the neonatal journey, from delivery room cuddles all the way through to hands-on involvement in care and comforting babies through procedures. Practically, that requires accommodation and financial support so that parents can travel the distances involved or to pay for the food in the canteen, or potentially to get free food.

A recent Bliss survey highlighted that, on average, parents had to pay around £405 in additional costs for each week their baby was in neonatal care. For some families, that is simply not affordable. In Scotland they have an excellent scheme. It started as the neonatal expenses fund just over five years ago and is now the young patients family fund, which provides parents with financial support for subsistence, travel and accommodation throughout their baby's neonatal stay. It was so successful in the neonatal unit that they expanded it to paediatric care as well. It is a great model of financial support for families.

We have already talked about psychological support for parents to enable them to have their emotional support needs met so that they can be there for their baby. Parents need support in order that they can support their babies. That needs to be there for both parents throughout their neonatal stay and indeed beyond.

Nurses and doctors are so important, but it is very clear from recent evidence that the cohort of allied health professionals—speech and language therapists, dietitians, occupational therapists and physiotherapists—play a key role in supporting babies' development and helping parents with aspects of feeding, holding their baby and touching their baby. The role of those allied health professionals in supporting the whole family is critical. Again, it is a little patchy, although it is getting better.

Q57 **Baroness Wyld:** That is helpful. Thank you. Can we come to you, Catriona? I also want to make the point that there are two separate things going on here. First, how do you make people's lives a bit easier at a terrible time? That is the right thing to do. We did work on that through the pay Bill. Secondly, we are interested specifically in what affects outcomes for these babies and their development going forward. Anything that you can give us on that would be great.

Catriona Ogilvy: All the things that Caroline has mentioned, particularly in terms of bonding, are so important for those long-term developmental outcomes. We know that early childhood trauma and difficulties with attachment lead to lower developmental outcomes for children.

This is about getting it right from day one, talking about zero separation and ensuring that parents can be with their babies. Again, that goes back to access to the unit and financial support. It is really costly to have a baby in hospital. From the evidence that we have already heard, it is not just that time in hospital; it is because you are repeatedly readmitted to hospital.

The other thing to tease out is the importance of integrated care and joined-up services. At the moment, once your baby leaves the hospital, the neonatal journey is done, as it were. You may pop back for a check at two years or within the first few weeks. If you bounce back into hospital, you often have suddenly gone from the neonatal service to the paediatric service. We know that the paediatric service does not understand the journey that families have been on.

As Caroline says, there are now many more allied health professionals working in neonatal care. As a children's occupational therapist, I will champion that. One problem is that they are not in all units across the UK, but there is also only so much that those therapists can do within the unit. Sometimes there is short-term follow-up, but there needs to be another service for those children to be referred on to. At the moment, there is no long-term or even short-term follow-up service.

If an allied health professional has some concerns about their child's development, they have to jump over quite a high threshold to be able to access speech and language therapy, occupational therapy or physiotherapy in the community. As we all know, there is also a huge waiting list. Supporting those developmental and long-term outcomes for children born preterm means making sure that the services available in the neonatal unit, as well as increasing services such as psychological care and allied health professionals, can continue. Those services should not stop when a family comes home from hospital.

The other thing is health visitors and GPs. We hear time and time again from mums who get a phone call from their health visitor saying, "I heard you've had the baby. Can we pop round and see how you're doing?" Of course, they are still in neonatal care. Mums will say that they go to their GP for the six-week well-being check-up and are not able to take their baby with them because their baby is in neonatal care. Even though

parents tell us that they are reporting difficulties with their mental health and ability to bond with their babies, there are no services in the community to support that.

In essence, we know what needs to be done, but we have to have the support and the services to meet the needs of families and children.

Ciara Curran: Again, I look after the women who are about to give birth. They have to find information. I send them an information pack, one of these care packs. The RCOG produces brilliant guidelines and patient leaflets. We also have the NICE guidelines. We send these out, and we send them a notebook and something to help them relax.

If we could give information, information is power. We do not tell women about birth until they reach 28 weeks. We do not tell them what is going to happen in labour. We are talking about improving postnatal care. They will recall every moment of their birth. I do not think there is a woman in this room who does not remember the birth. I do not think the father does either. When you give them the information, it is important to tell them what to expect at birth. Our mums are under 24 weeks. We know that they are at a higher risk of losing their babies.

If we could get this right at the beginning, we would not have to pick up the pieces. We talk about the nought to five year-olds and about that bond to the mother. I have post-traumatic stress disorder. I can tell you that it is a horrible mental health condition. You recall every moment of that birth that you do not want to think about. Nobody told you what was going to happen in that birth. That birth and that experience will live with women postnatally.

When I send a teddy to a woman, they can record the heartbeat, the parent's voice or the baby's song. Some mums have them in neonatal so that they can record their own voices, or they give it to their children at home. We can make small gestures like this to help them. If we got these women to write down their experiences and shared that with the professionals, it would really help.

When they go through PPROM, they are not told that the first 72 hours of having a baby is the most crucial time. They do not even get told that there is a drug called nitrous oxide. I do not know whether I pronounced that right. There is research to support using this drug when women have babies in this situation.

The women who have baby loss, depending on the gestation at which they lost their baby, want a review of their care. They want to understand what has happened to them. They want to know whether it is going to happen again in a future pregnancy, whether it could have been avoided and whether they could have had better experiences.

I feel really honoured to be in this room. There are so many incredible people who I have admired from a distance. Thank you very much for bringing this inquiry. If we are going to improve postnatal care, we have

to look after mothers. It is that kind of thing. We do not screen for post-traumatic stress disorder. I have had women who have had babies taken off them because they had a breakdown and nobody understood the journey of their pregnancy. It is really traumatic. We throw them into neonatal and then send them home and say, "You can just get on with it". Then they have to organise childcare.

Baroness Wyld: Thank you. That was enormously helpful. I just wanted to say that you are reminding me of my three births. I am not going to talk about them. I would not be able to sit on the other side of the table and talk in the way that you have. You have been incredibly open and talked about very difficult and very painful things. I just want to acknowledge that and say thank you.

The Chair: Yes. On behalf of us all, thank you.

Q58 **Baroness Hughes of Stretford:** Lord Hampton and I are sharing this question, but I will start it off, if that is all right. As Baroness Wyld has said, you have given us an extremely rich and sometimes difficult-to-hear picture of all the impacts of preterm birth: on the babies, on the mothers and fathers, on the families in particular. You have done it really well.

This is a really difficult question, because you have raised so much about the whole perinatal and postnatal period and the outcomes for the children and the families themselves. If you had the chance to do something or to change something, what would your particular priorities be? I know it is a really hard question. I am sorry.

Catriona Ogilvy: I have lots of answers.

Baroness Hughes of Stretford: What would be at the top of your lists?

Caroline Lee-Davey: At the top of mine would be to implement the programmes and reports that have been set up, lots of which are excellent. In England, we have the *Saving Babies' Lives* care bundle, and the neonatal critical care review, which is being implemented. To give credit, there has been investment in neonatal care in the last few years in England. We have seen really good progress. It has not all been implemented yet.

In particular, there was a commitment in the NHS long-term plan to capital funding for accommodation for parents, which has not yet been delivered. There is lots in there. The *Getting It Right First Time* neonatology report from a couple of years ago has a series of clear and actionable recommendations, all of which are based on data. There are lots of reports and recommendations out there that need the commitment to follow through and deliver on. That would be my starting point.

One thing I really wanted to mention—it has not come up yet—is the role that health inequalities play in relation to preterm birth. We know that babies born to mothers from particular ethnic minorities and from socioeconomically deprived groups are at high risk of neonatal mortality, stillbirth and preterm birth. We do not know very much about why. We

also do not know very much about the neonatal experience of those babies after they are born.

At Bliss, our take is that there is an increasing amount of data on the maternal antenatal pregnancy experience as it relates to health inequalities and a preterm birth being an outcome for the mother, but there is almost nothing about the different neonatal experiences for babies. If you are born at 28 weeks, for example, we do not know whether your outcomes are different if you are a white British baby versus a black Afro-Caribbean baby. That data does not exist.

The National Neonatal Audit Programme, which reports annually—it is an excellent source of data for neonatal care and has been an excellent driver of quality improvement—is missing about a fifth of the data on babies' ethnicity. One can start to read some conclusions into the data. It will start to report on ethnicity for the first time next year. There are still big gaps in the data.

We have done some research on the experiences of neonatal care for parents from different minority communities. Again, those can be different. We would absolutely advocate for really consistent implementation of family-integrated care, which is an evidence-based and clinically backed model that puts parents at the heart of care.

There may be a range of barriers that parents from ethnic minority communities or socioeconomically deprived communities face to being involved in their baby's care, such as language, trust in health professionals and finances, if they live far from the unit. There is a whole range of other barriers. We need to understand much more how inequalities affect the experience of neonatal care for both babies and families, and then identify interventions that can ensure that every preterm baby has the best quality of care during their neonatal experience.

Baroness Hughes of Stretford: It seems extraordinary that no one has made that comparison between the different demographic characteristics of preterm babies, including whether they are minority ethnic.

Catriona Ogilvy: There is a two-pronged approach when it comes to outcomes for parents and outcomes for babies. Outcomes for parents will automatically improve outcomes for babies. If I had a magic wand, there would be zero separation for families and there would be support to improve that bonding.

I go back to the evidence that was given earlier about the critical developmental stage that babies are at while they are still in the incubators, the impact that having a parent present with the baby will have on the baby's outcomes and development, and the support to enable the family to support the baby once they are home.

I will borrow something from one of the leading researchers, Professor Sam Johnson, who looks at the educational outcomes for children born

preterm. She often talks about the additional support that families need when they are in the unit, but also cites how, despite more and more intervention and support being put into units, the long-term outcomes for this cohort of children have not really changed. A baby could be on a neonatal unit for 10 days, 10 weeks, 10 months or longer, but they are in education for 10-plus years.

When we are looking at improving outcomes for children born prematurely, we cannot look only at what is happening in the unit and the weeks and months after coming home from the unit. For these children, it needs to be looked at on a lifelong basis.

Ciara Curran: For our group of mums, we believe that we do not seem to be able to diagnose PPROM correctly in all hospitals. In my opinion, these decisions should include an obstetrician, with help from an ultrasound scan. In my case, I was told no; it was up to the ultrasound scan place to make the decision. I believe that an obstetrician should be helping these women.

PPROM is an emergency. If a woman gushes under 24 weeks, there is likely to be no fluid pooling as it takes time for a baby to reproduce fluids. Therefore, the sanitary towels that some women are told to put on are unlikely to work, as in my own experience. The scan was the only thing that told doctors, apart from me, that my waters had broken. This causes women to lose trust in doctors. Some women have said, "You helped save my life". It is obstetricians and neonatal doctors who saved the baby's life. They have lost trust. We need them to trust doctors. I need my women to trust doctors.

We need training on our condition and the complications that can arise. Regarding the outcomes of preterm birth, it is important to mention cord prolapse. We send out RCOG cord prolapse leaflets. This has helped to save babies' lives. Our women are not told the position. Putting a protocol in place could save us a lot of time.

Research into placenta abruption and getting the optimum timing of delivery are also on my wish list. I was part of reinstating the guidelines and patient leaflets for PPROM. When the RCOG released the press release, it said, "We can now avoid preterm birth before 37 weeks of pregnancy". I just put my head into my hands and said, "This isn't right". It is difficult, it is complicated, it depends on when the woman lost her waters and what the complications are.

From my understanding, every hospital changed its policies to say that all women can go to 37 weeks. The guidelines say that we need more research to know which women are safe to go to 37 weeks. I can tell you now that every woman who has had a preterm birth will say that they wish they had not had to go through that process. We also forget that babies born at 37 weeks can really struggle. We talk about preterm birth and trying to avoid preterm birth, but then we try to push women to 37 weeks. I have seen some seriously ill babies at 37 weeks. We need to invest in this.

It would help if every woman who was threatening preterm birth, with broken waters, had a management plan to understand this and a conversation about what to expect in birth and neonatal care. I always find it really frustrating that, as a non-profit, I cannot pick up the phone and say to the person in charge, "Can you please look after this woman?" I have had to ring up several times over the last 14 years. I rang up one hospital and said, "You have a woman who's bleeding and she needs your support". They told me that she was not a priority because she was under 24 weeks. I said, "If she ends up with a really bad infection or sepsis, or bleeds to death, she should be your priority". Within moments of coming off the phone, she looked after that woman, who brought her baby home. It is so different for different women.

I also believe that we do not look at the root causes. We know that UTIs can cause PPRM. I believe that we need more understanding of things such as urine infections. In my second pregnancy, they dipstick-ed my urine and told me that it was fine and I did not have a urine infection. I insisted that it was sent to the laboratory to check, and I had E. coli. We need to relook at dipstick tests to see whether they work for recent infections.

I work with some incredible doctors, Anna David and Tina Chowdhury, who research the resealing of the membranes when a woman's waters break. We do not spend enough money on interventions. We could avoid the risk of preterm birth and not worry about infection risk. We are not looking after women between 12 and 24 weeks. This is the crucial time of a woman's pregnancy. We need to look at that again. If we looked after these women—for many women who end up having PPRM, it was caused by a simple urine infection—they might not have preterm births.

We need to understand pain. Our women go into hospitals for pain and are not believed. They forget that they have PPRM. So many women have reported to me that they had cramping and then birthed a premature baby at home alone.

We need women to be a priority. I would love the Government to spend money on hospital beds for women and neonatal beds. One woman was transferred five times to different hospitals because they did not know when she was going to birth. She ended up seriously ill with sepsis and now lives with the long-standing effects of sepsis. Her baby was born and she is here today, but she should not have got sepsis.

There is so much more I can say on this. You can tell that I can talk. We have a new study coming out regarding the outcomes in cases of PPRM between 16 and 22.5 weeks. Doctors have been telling women that the babies have 0% chance of survival. The results were that 44% of women had a live-born baby, 26% of women brought home a baby, 18% went home without a disability. We are telling women that they should end the pregnancy when they are under 24 weeks. We really need to look at the basis on which they are told that.

The doctors we were working with wanted to have a day when we brought women together and had a focus group so that we could work out how to diagnose them. Unfortunately, they were turned down for the funding. We are going 10 steps forward to go 10 steps back.

From that research, this would be my question. Why when 44% of babies are born live are we not bringing home 44% of babies? What is going wrong with neonatal care? Is something going wrong? Do we need to do more? Do we need to give them nitrous oxide? There is so much more. What is happening? Can we change how we are seeing things?

Q59 Lord Hampton: Out of all the statistics we have been getting, the thing that really shocked me was said by Catriona and was in our documents beforehand. As you just said, fewer than a third of parents felt that health visitors understood their needs, and 18% felt that GPs understood. Why is that? What can we do about it?

Catriona Ogilvy: Why that is goes back to some of the things I talked about earlier. Neonatal care is a very hidden world unless you have been there or thought about it. There is the assumption: "Once you're home, everything's going to be okay. Why should we worry about that? That time is over".

As GPs, they will have had the discharge report or, indeed, the baby might still be in hospital. When the baby comes home from hospital, they are told that the baby is fine. There is a real lack of understanding and awareness. First, we need to be talking much more about what it is like in neonatal intensive care so that the professionals who support families when they come home from hospital can begin to understand what they have been through.

Secondly, as we all know, health services are stretched. We would love to have something in place so that every health visiting team has a neonatal link, somebody who can go into the neonatal unit and meet families before they come home. Indeed, some hospitals have that. They will have an outreach service. If you are struggling to meet the needs of families, it is very difficult for a short-staffed health visiting team to provide the support that you need to give in person.

It is worth mentioning the pandemic and the impact that has had on families. During that time, neonatal families, just like all families, were offered support via video link and those sorts of things. From my own experience, when you talk to your GP or your health visitor, it is often quite rushed. They often have somebody waiting outside the door to come in after you. Even if you divulge that you are struggling with something or are worried about something, there are no services to refer you on to.

It is almost as if they are saying, "Do you know what? I'm not going to ask. What can I do with that information?" That goes back to my earlier point: we need to have support services for families embedded in the community, ready and waiting. When a mum goes for her six-week well-

being check, her GP can ask that question and be armed with, "I can refer you on to this service. This is where you can get that support".

That support needs to be quite tailored for these families. It is very different from postnatal depression, for example, and the support and treatment that families need once they are home are very different.

The Chair: You make a good point about strengthening the community services that are linked up with neonatal services.

Q60 **Lord Winston:** Caroline, you brought this up earlier when you were talking to Baroness Wyld. Were you offered a follow-up appointment to see the consultant obstetrician three months after your birth?

Caroline Lee-Davey: I do not have personal experience of preterm birth.

Lord Winston: Did any of you have an obstetric appointment three months afterwards, not with a junior doctor but with a consultant or somebody senior in the department who could go through how you were, how you felt and what was happening?

Ciara Curran: That is the point that I brought up. Women are not referred. We tend to find that preterm mums struggle to get a review of what has happened to them in pregnancy. There should be a referral so they can speak to their own obstetrician to go through what has happened to them in their pregnancy.

Our women have reported back that they do not get a referral or a review of their care to see what has happened and to understand it. If they wish to have another baby—we forget that not all babies come home—they want to know what has happened to them. They want to understand that process: "Why did I have a preterm birth? Why did my baby end up sick for a long time?" Those questions are there. That is one thing that I would love to happen.

Q61 **Lord Winston:** I have another question that is relevant. Were each of you offered proper professional counselling after birth? If you were a patient having in vitro fertilisation, you would have that automatically by law. The regulatory authority requires that it is offered to you. I wonder whether that happened to you after your birth.

Catriona Ogilvy: That support is not in place for families.

Caroline Lee-Davey: We speak to hundreds of parents every month. It is not offered as standard.

Ciara Curran: It took me seven years to get a diagnosis of post-traumatic stress disorder and depression. I had to have a healthy baby. This is a repeat of what women are going through.

Caroline Lee-Davey: There is no automatic referral into those services.

Ciara Curran: I agree. It is needed.

The Chair: Those are two important points. The first is an explanation so that you better understand what might happen in a future pregnancy. They need a consultation with an obstetrician afterwards as to what may have gone wrong or what may have been the reasons for the preterm labour. Secondly, from the evidence we heard from you today, the neonatal care community need to consult with women on what to expect about the baby's development. You also made the important point about schools recognising special educational needs.

You have given us a lot of information today about lots of issues that may not have come out in other sessions. That is important information. It is our difficult task to weave it all into some constructive well-formulated arguments that we can make on your behalf about what services need to change.

Thank you very much indeed today. It has been a very informative session. We have learned a lot, as we thought we might, from your personal experiences. Thank you very much indeed. We will do our best to help you.