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PREGNANCY AND CHILDBIRTH

INTRODUCTION

This chapter contains two stories about pregnancy and childbirth. The first story is told by Cathy, a healthcare professional who became pregnant and then had a difficult time when she gave birth. In the second story we hear from James about becoming a new dad. We come across James again when he tells of his experiences of caring for his mother with dementia in Chapter 7. As we do in other chapters, at the end we pose questions arising from these stories, to simulate your thinking and reflection.

Pregnancy and childbirth are natural processes which nevertheless carry medical risk for mother and baby. Women demand choice and control in maternity services and at the same time expect safe and expert care. The recent history of maternity services in the UK can be read as the interplay between these two factors. From the 1960s there was a growth in activism in opposition to what was seen as the excessive medicalisation of pregnancy and childbirth. The National Childbirth Trust (NCT, www.nct.org.uk), founded in 1956, was central to this movement.

The landmark *Changing Childbirth* report (Department of Health, 1993) paved the way for shifts in policy and practice, including a greater emphasis on the availability of midwife-led care and more choice for women about the place of birth. General practice was also trying to listen more carefully to what women wanted (see, for example, Mellor and Chambers, 1995). In the ensuing decades, there were many improvements in the quality and outcomes of maternity care. For instance, the stillbirth and neonatal mortality rates in England fell by over 20 per cent between 2006 and 2016.

But problems remain and new challenges have emerged. More women have children at an older age. More women have complex health needs that may affect their pregnancy, their well-being and that of their baby. A recent report from researchers at Oxford University found that black women in the UK are five times more likely to die in pregnancy or childbirth, compared with white women. Asian women are twice as likely to die compared to white women (Knight et al., 2019). In the US black and indigenous Americans are two to three times more likely to die from pregnancy-related causes than white women (Petersen et al., 2019).

In addition, there have been scandals of poor and unsafe maternity care, as evidenced by the Morecambe Bay public inquiry (Morecambe Bay Investigation, 2015) and the continuing inquiry into care at Shrewsbury and Telford Hospitals NHS Trust (Ockenden Report, 2020). Hundreds of millions of pounds are spent every year compensating families for negligence during maternity care. Meanwhile, women can still find that they are denied choice and control when it comes to critical decisions about their care. These issues were considered in the *National Maternity Review* (NHS England, 2016), which set out a renewed vision for personalised, woman-centred, kinder and more professional maternity services in England.

THE STORIES

In Chapter 1 (Section 2, p. 4) we offer an understanding of patient-centred care in general as:

- Understanding and valuing what matters to patients
- Seeing the whole person
- Respecting people's rights and autonomy
- Being customer focussed

The policy rhetoric and the reality for women don't yet match up, according to the numerous care failings and the reviews mentioned above. The stories below contain further examples of shortcomings, as well as good practices. They also suggest prompts for policymakers, professionals and NHS managers to take action.

A literally life-changing event, giving birth is seemingly rarely straightforward. The two stories presented below testify to that. **Cathy**'s is a longer story because so much happened to her. **James** narrates the events of the birth of both of his children, but altogether this is a shorter

piece. In Chapter 3, the story of **Jim**, Lucinda and Justin (Story 4, pp. 61–73) includes a description of what happened when Lucinda gave birth to Jim, who had severe congenital physical and learning disabilities. All three examples demonstrate what a huge difference it makes to parents if health services are responsive when things don't go according to plan.

Story 1: Cathy

Cathy had complications in pregnancy and labour and needed an emergency caesarean section. Her postnatal care was also full of incident: her wound became infected and she had to be readmitted to hospital. By profession Cathy is a critical care nurse, and this undoubtedly shaped her expectations, her experiences and her subsequent reflections on them. Overall, she believes she received good care, with some lapses. Her story is quite a rollercoaster and the reader might be left taking a view different to Cathy's own.

Cathy: My account relates to the antenatal care and labour care of the birth of my son, who is nearly six months old now. I had a lot of complications and difficulties throughout the birth particularly, but I believe in general I received really excellent care, although I had a really tough time. I think the fact that I'm a healthcare practitioner myself allows me to realise that even though things were going horribly wrong, I was receiving really good care. So basically from the start, all my midwife appointments before I had my son were excellent because I saw the same person every single time. And having talked to a lot of other people about that, they saw a different midwife every single time. I felt like I had a real relationship, a real bond with the midwife, she was really exceptional and made me feel very comfortable. Unfortunately, during my pregnancy I was pregnant with twins and I lost one of the twins.

It's fine, it was right at the start but I was therefore very nervous and very anxious about the process and she was fantastic at reassuring me the whole way through. And I think because I'm a critical care nurse, I work in ICU [Intensive Care Unit], I always see the dangers and the difficulties around everything. I always assume the worst, not the best. So I was very much risk aware. And so, a lot of people want to go to the birth centre and have a lovely birth with the candles and all that kind of thing, but I really really didn't want to do that. And she listened to me and guided me though the steps, if you know what I mean.

So in some ways being a healthcare professional made things harder for you because you were more conscious of the risks and what could go wrong?

C: Absolutely. Because I go to all of the emergencies, I only see things while the emergency bell is pulled and everyone goes running. So I never see the lovely births, I only see the ones that go horribly wrong, and she was really good at listening to me. She was a very senior midwife, in fact she was promoted during our time together, so she should have stopped seeing patients. But I think because we'd had such a bond, she said, I'd like to see you but would you mind coming outside my working hours.

Did you ever get the sense you were getting a special service because you work in the NHS, or would that have happened anyway?

C: It's a good question. I think possibly, but she did say that she kept other patients on, other mothers on as well, that she didn't really want to give them up. So I think that she was a really exceptional midwife but also possibly had difficulties giving up her workload and doing her new role maybe.

One thing I really relished was her talking to me as a fellow health professional, and not talking down to me but also appreciating that I knew very little about midwifery. It was a relationship which I thought was very much built on mutual respect.

So I had fantastic antenatal care. And then when I went into labour things started going wrong. When I started having contractions, I couldn't feel the baby at all, couldn't feel that he was moving, and you are supposed to feel the movements. And so they told me to come into hospital to be checked and actually he was fine but they said, because you have reduced movements you can't go home. So then for several hours things passed very normally and my waters broke. And then I felt incredibly shivery, I just didn't feel right at all, and this is the one of two times I feel that I had poor care.

My midwife who had been looking after me was on her break, so I spoke to one of the other midwives and I said, look, I just don't feel right, can you please check my temperature, I think I'm having rigors [severe shivers and high fever]. And she said, oh no, it's just because your waters have broken, da da da, and refused to do it. I did feel uncomfortable saying, I'm a nurse so you should do this. And I kind of let myself be talked round because, you know, I'd never been in labour before, I'd never done any midwifery. But actually when she came back and I still felt dreadful, I spoke to my other midwife, she did my

observations straightaway and it turns out that I had sepsis. So actually there was quite a big window of time in which I could have been treated and I wasn't treated and I felt quite upset about that.

But when I actually got the care for the sepsis, it was excellent. And there is a sepsis pathway which is six steps that you should do within a certain amount of time and they did all of those. Because I know from my experience that quite often it's done quite shoddily, I felt very comfortable with that care particularly, that they were doing it correctly.

How bad a mistake was it not responding to your reports of feeling feverish?

C: Well, it could have been quite bad because the Surviving Sepsis Campaign shows that if you act within the first hour of having a temperature then you've got a much improved outcome for the patient. So she really drove down the clock on that.

So having a temperature is a serious sign in labour?

C: Yes it is, alongside several other things. So I feel that that it could have been an opportunity missed and if I wasn't a nurse myself and pushed the point and it happened to somebody else, they may not have received that care. And my labour had to be sped up because they were so scared about my son receiving the infection. Luckily he didn't, but had that been delayed then maybe he would. I certainly wasn't listened to and I don't think that was acceptable then.

But then, I know that actually people are absolutely stretched. It was a weekend, there was a ward full of people in labour, the other midwife was on her break. I can completely understand, a lady saying I don't feel quite right, and her knowing that my waters have broken, I can understand why that happened. It was just frustrating, I'd say.

I suppose a lot of the judgement of healthcare professionals is making the distinction between I don't feel that great and this is a warning sign.

C: Yes, definitely.

And it must be quite difficult to make that distinction sometimes?

C: Yes, absolutely and I'm sure that quite often women in labour aren't the most rational people who make salient points about their clinical state. So I can completely understand why that happened but I do think that, given that I'd come in with reduced movements of my baby, that

I clearly said I feel like I have a high temperature, it's a two-second job that would have said either way, whether I was right or not, and that should have happened.

Apart from that time, I did feel generally well looked after. They brought me pain relief when I asked, they said that they would come back and do monitoring of the baby: they said, I'll be back in about an hour and generally they were. So it didn't feel understaffed, it felt that they had a really good service. And another point, I think that they were generally quite good at managing expectations. It's one of the really big things in healthcare that people are, like, I'll be back but don't give you a timescale. But actually they were very good at saying, we are going to do this and then that and they stuck to it and if they didn't they came and explained why. And I thought that that was excellent.

Being reliable, doing what you said you were going to do, is probably one of the things that contributes to a sense of being properly looked after.

C: Absolutely. And if you're not going to deliver what you said you would deliver, coming in and explaining before the patient asks is such an important part of it, because otherwise they feel like they are bugging you and they are chasing you … they can't relax because they need to be on your case. If you actually can manage their expectations appropriately, then those people relax. When I felt well looked after in my labour, I relaxed a lot more and it was a lot easier. And so it actually feels like it had, not even just an effect on my emotional well-being, physically my blood pressure would have been better, et cetera.

Yes, it's really interesting this whole business about managing expectations and the link with how anxious or calm you are, and then the link to how well you can respond to care.

C: Yeah, one of my jobs is to look after deteriorating patients on the ward. So I meet a lot of disgruntled patients who say, God, well I have been telling the nurses for hours that I don't feel right. And quite often going down to the root cause, it's because the nurse has said she will do something and hasn't and hasn't managed that expectation appropriately. You can look at the board and see the under-staffing and you can understand why. But if she had just popped her head around the corner and said, I know I need to do that thing, I will be right back with you – that one sentence would have a huge impact on a patient. I don't think that that is understood really in practice.

So after that point they started monitoring me all the time. And there was a couple of times when the baby's heart rate dropped considerably, so they realised that they needed to speed up my labour. They needed to start me on a drip of oxytocin which speeds up your contractions, to try and make you have a quicker natural labour. And for that you should ideally have an epidural. So I was moved up to labour ward; that process took longer than it should have done, but they were completely full and explained to me why that happened and that was absolutely fine. I still received good enough care and they explained to me why that was. But when I eventually went up there, the midwife from the previous ward had said, oh you know you don't want an epidural, it can slow down your labour. But actually I really did want an epidural and I had written that in my birth plan. I am a nurse, I can see how good epidurals are and the labour scared me, the pain of it terrified me.

And because she was so insistent, I kind of said, yeah yeah yeah, not agreeing with her. She then went off and told the ward round that I didn't want an epidural and so when they came in, they said so we've been told by the midwife that you don't want an epidural. I said, that's absolutely not true and that led to quite a big delay in me getting an epidural. So that was the second bit of my care that I think was poor. She had a very clear opinion, which actually doesn't reflect guidelines and policy at all, and she decided that that would be my opinion and then without my consent gave something that was opposite to my wish to the ward round. And I did have a very clear birth plan that said, I would want an epidural in these circumstances.

To what extent did you get a sense that the birth plan was a meaningful document that was read and understood by the staff who were looking after you?

C: It was very staff dependent. The plan is a set of preferences but that is absolutely not necessarily how your journey will go and, actually, just because you've read in a book that this might work well, I think it doesn't at all take into account the knowledge and skills of clinicians. I do worry about them, that they set women up who are going into labour this idea of what they are going to have and it's undeliverable. Nonetheless it's a statement of preferences that ought to be taken account of, even to the extent that people say, we know that you wanted this, it's in your birth plan but …

When I got to the labour ward, I had a really good midwife there and she said, give me five minutes, I am just going to read through your birth plan. And she discussed it with me and she was like, yeah, we will try and take that into consideration as much as possible. The whole way

through my birth plan I'd said, this is my idealised plan but I completely understand that circumstances change and would relish the opportunity to talk to a clinician about x, y and z if these circumstances change. So she definitely did listen to it.

So when I got up to the labour ward, the epidural situation happened and this really good midwife said, you definitely should have an epidural, reading your birth plan, and also I know how painful it is. She called the anaesthetist straightaway. Unfortunately it didn't work, the blood came out when it shouldn't, so they had to put in a second epidural. And then because they were worried about my son developing sepsis, they had to start the drug that speeds up labour. And unfortunately the epidural wasn't in correctly so the drug that brings about labour, it brings about really really painful strong contractions and unfortunately the epidural wasn't working, so I had …

Was that just an error?

C: No, she was an incredibly senior anaesthetist and some people are just anatomically difficult, like it's really difficult to place them in some people. I was one of those people.

And you can't always tell that you have got it right until it's too late?

C: Exactly, until it's going. So she was absolutely excellent. My husband and I differ in our views on this. The reason I think that she was absolutely excellent was because she kept on coming back to check on me, calling in and saying, is the epidural right, it didn't seem like it was right. And she kept on coming to give me top-ups of medication into it to try and get it right. So she kept on coming back, she kept on asking me my opinion, and I think because I see with healthcare quite a lot of people do something and then walk away and it's impossible to get them back. I really really felt very looked after and unfortunately it didn't work.

We realised it wasn't working so she said, right, let's take it out, let's put another one in, so I had a third epidural. Unfortunately it worked apart from my left hip, here, so it was just really patchy. So when I've seen this in clinical practice, if you just top up with a bit more medication to go into the epidural then the patchiness clears up. So we tried to do that and I do worry that because I have a lot of knowledge about this then she possibly listened to me a little bit too much, because I said, oh no, I think if we top it up more I think it should go away, it's only a small area.

But because of my son's monitoring, they realised he wasn't doing so well, so they needed to top up the drug to speed up my labour. The pain just became absolutely unimaginable and I was screaming, I barely remember it. And the extreme pain on my body caused my baby's heart rate to drop and they had to put out an emergency call. So all the team ran in and I was so out of it that I didn't kind of realise what happened until everyone was there and trying to make decisions about whether I should be rushed for a caesarean to get the baby out. They decided to take the epidural out and put another one in – which also had a spinal in it as well, which is a slightly different type of pain relief – put both in together and instantly my pain just went. We didn't need to go for a caesarean straightaway so that I could try for another hour or so to see whether I would give birth naturally and if not consider having a caesarean at that point.

My husband feels that the anaesthetist botched putting the epidural in and that, had she done her job correctly, then none of that would have happened and we would have all been fine and …

Is he a healthcare professional as well?

C: No. And I think that is probably the difference between my insight into how it can be and my husband's understanding. He could just see it didn't work so therefore she is bad at her job. Whereas I could see that she was incredibly diligent, worked incredibly hard at trying to make it work. Sometimes for some people it just doesn't work and it was really unfortunate that that person was me, but that wasn't through lack of effort. And she did say to me, I'm the most senior anaesthetist on, I'm very happy to get my junior to come and have a go … if you would prefer somebody else to have a go at it. So she gave me opportunity to change the way things were going.

I've certainly seen plenty of epidurals in my practice that don't work and I've seen a lot of situations where people just go, it's fine, just top it up a little bit more, it will be fine, then walk away and leave the patient in agony. I see a lot of that in my time and that didn't happen for me.

What I think is, good care is probably more about the personal relationship that you have with that person, how diligent you are, how much effort you put in. I think of that as better care, whereas obviously I assume that if you are a senior, almost a consultant anaesthetist, then you have had your skill checked many a time. What matters to me most is how they make you feel and how well looked after you are.

So in the end I didn't progress at all, I'd been in labour for nearly forty hours. And I was only 4cm and you need to be 10. So I ended up going for a caesarean.

Can I ask a question? I mean, in retrospect, did they leave it too long before taking that decision, is it something that was foreseeable and maybe that decision should have been made at an earlier stage rather than leaving you forty hours in labour?

C: I think possibly. I think they work under the mantra that the less that they do is better, so there is a lot of post-op complications that you can get from having a caesarean, I got them all as well.

And so they tried to do as little as possible. And, actually, I was fine in the end, my son didn't develop sepsis – I mean, I had an awful time with pain relief, it wasn't anyone's real fault, so I think they probably judged it about right really. That opinion is probably formed as well having talked to some of my other friends in NCT [National Childbirth Trust], and two of them had another day on top of what I did and then had a caesarean at the end of it. So they had three-day-long labours, so actually I feel like I had a pretty easy ride, I think first-time babies do take a long time to come out. And also I had expected it would be horrendous, I think I just thought it would be awful and it was, so I think I went in with the idea that I wasn't going to be sitting listening to lovely music with candlelight and the baby just pops out …

So the caesarean was absolutely fine, it was better than I thought it would be, actually: it was quick, I felt very safe throughout the whole procedure, they talked to me, made me feel very comfortable. They did it under spinal, which is the medication that worked for me, but, yeah, they decided that they weren't sure about it because I'd had so many epidurals and spinals, it was quite unusual that he wanted to put a new spinal in, just to make sure that it definitely worked. So I think it was my fifth attempt – I know it wasn't ideal but I understood why. But I felt very reassured by all the machines and the drugs because that's what I'm used to, whereas other people would probably find it really unnerving …

After my operation, I went to the postnatal ward, which was like a living hell, to be honest. The ward was being built, there was a temporary ward and it was so hot, they had floor-to-ceiling windows but the blinds only went halfway down, so it was bright all the time. I think there were thirty-two beds and there were just curtains between all of them and so there was thirty-two screaming babies, everybody had a curtain round them, it was like a jail, it was tiny.

And suddenly you are launched into this area, I couldn't feel my legs because of my spinal, I'd just had a brand-new baby, I'd been in labour for forty hours, then had a major operation and … right, I'm going to do your observations, and then you are just left to get on with it. I thought that you would maybe get a little bit more tender loving care than, here's

the baby you've got no idea what to do with, go for it. And I don't know exactly what it is that they could have done to make that less scary, but I certainly feel that there should be a step between you having a major operation and the postnatal ward, about one or two in the morning, feeling very drugged up and groggy and out of it. And then just being given a baby to look after, and I completely understand that that is what normally happens and I had been warned about it, but I just didn't feel that safe looking after him because I was just so exhausted.

Is the expectation that family members will be around?

C: Well, my husband was there, but equally he had been awake for forty hours as well. But they have very strict visiting rules, so actually you are not allowed any family members then at all; you are only allowed one extra person apart from your partner, at really strict times. Which I understand but I just didn't feel very safe looking after my son. I don't know what could be done differently about that but I feel after a normal operation you are very much looked after and they help you recover from that. With maternity, it feels like they forget that actually a caesarean is major abdominal surgery and you just get on with it. So it feels that there is a perception that because you have got a new baby, then it doesn't really matter that you have had a caesarean because it's so common.

I know that it's important to bond with the baby and have them next to you, it's crucial, but if you are so out of it you don't know whether you can put the baby back in the cot properly or you might fall asleep with the baby on you, which would be really unsafe … Maybe more staff, just somebody to sit with you for the first hour or two, I think that would make you feel so much safer.

How long were you there for?

C: Three days because you need to have some time there after your caesarean anyway but they were worried that my son had an infection. He had some infection markers in his blood, they needed to wait for some other blood results to come back and that took three days. And it was an absolute sweatbox, it was so hot, but they were really good there. I found it really hard to breastfeed at the start, very painful, and my milk hadn't come through and my baby was just screaming. And I was so glad of the midwives that were there. Again, it was that managing expectations and I saw a difference in the midwives' ability to do this. Some midwives just said, oh, you know, babies just cry, don't worry about it. Whereas there

was this amazing midwife, she was clearly very experienced and she said, how old is he, I said day two nearly day three, and she said that is the worst possible time, the milk hasn't come through yet but it will come through by tomorrow morning. She said the next eight hours are going to be absolute hell but what we will do in the morning is, I will get you a breast pump and I will show you how to express and that will help your milk come through and then things will be better.

And she did and it was, and her giving me a plan – even though the next eight hours were horrendous, there was a light at the end of the tunnel and I could see how I was going to get out of that situation. And she was absolutely amazing, she was what made it bearable. And I don't know how people can be at home and have that experience, it must be awful. Because everyone goes through the same experience, basically the baby is just so upset because they need milk and your milk hasn't started coming out yet. Having somebody that's clearly knowledgeable, so much experience, had such a lovely manner, she was brilliant and had a plan.

It's the clinical competence along with the compassion, and one without the other doesn't work – it has to be both together. And I think that's what is wrong with a lot of healthcare: people can be very proficient at one or the other and it's those two together.

There were also healthcare assistants, they came round and did observations on myself and my son. I was able to call them and ask questions about how to look after my baby, can you help, he's crying and I don't know why. And when you ask them, they were clearly really busy but they were really good and they did help, they were fantastic. And they were very good at empowering me to look after my own child because they were very aware that you were going to be leaving sometime soon and you are going to have to do this by yourself. And no matter how many books you read about baby stuff, once baby is actually there, it's a very different situation.

And also I saw breastfeeding experts who came in; they gave absolutely conflicting advice. There were two of them, and it kind of became a bit of a running joke for my husband and I. One came in in the morning and one came in in the afternoon, I'd tell them my problem and one would say, you must feed off one breast at one time and not do the other one. And then the other one said that you had to do both each feed … So it was very little help really and it felt really frustrating, to be honest.

I saw doctors about once a day when they came on ward rounds. If there were any issues that developed, like a cold sore which I'd never had before, they said it's like the herpes virus, they were very worried

that I might give that to my son, who had obviously an immature immune system. I didn't develop that in hospital – I must have already had the virus – but because I was so run down it flared up. They were really good at getting the experts to come in and see me. I definitely did think that the teams linked up well to deliver the care, even though it was incredibly busy. So they clearly had a very efficient machine in the postnatal ward …

Then I went home and I went back in three times. Things with my son were absolutely fine, but on day five I moved him to his cot; I probably did more than I was supposed to. I was only moving my baby from there to there, my husband was having to do all of the lifting, and all of a sudden I just felt pop! and lots of warmth and looked down and the bed was covered in blood all over my shorts. I had a bleed from my caesarean wound so I had to go into hospital at five in the morning. That was quite frustrating, actually: they didn't believe me about how much blood had come out, they said, oh, no, it was just a little bit of wound juice …

I'd taken a picture of my bathroom floor, which had blood everywhere and she said, no no, that would have just been from a little bit of fluid from your wound. I said it wasn't, it was blood. So they got the doctor to have a look at my wound and they took some bloods and sent me home and said to continue my antibiotics, which I had been on because I had sepsis. And then the next day they called me up and said, actually your blood results show that your haemoglobin level, which is red blood cells, it's very low. So I found that frustrating that I wasn't … And I really don't like doing "because I'm a nurse, so I should know" kind of thing. I don't like doing that, so I pressed my point as much as I can without saying that, because I've had that done to me previously in healthcare and it's not nice, especially when it's an area for which you have no expertise. That said, I know what blood looks like and I know what a wound is. So, yeah, I felt frustrated about that.

Anyway, everything was going fine, I was doing my own wound dressings at home but I didn't get the feeling that there was a good plan, because I used to just ask for the stuff. I don't know what would have happened for somebody else who wasn't a nurse, whether they would have been given any training on how to do it or been given a district nurse referral. It was very much go on and get on with it. Which is fine because I could do it but there didn't seem to be a very linked-up service when you got out of the hospital. And also I think it was a bank holiday at the time so everything was a bit out of joint.

And then when the midwife came to see my wound on day ten, it still wasn't healing very well and looked infected, so she asked me to go back

into the hospital. So I went back in and unfortunately I think I had to wait six or seven hours to see a doctor, who just said carry on with it and we will send you into clinic to have a look at it. I think they scanned it and they said there was a bit of a collection underneath but nothing to worry about too much … but to carry on with my antibiotics. And then two days later, I was changing my dressing and there was an almighty pop and just loads of nasty stuff came out of my wound. Then about two hours later I just felt horrendous, I had a high temperature, I developed sepsis again.

So I ended up going back into hospital for another three days. Because I have got a penicillin allergy and I'd been on the frontline treatment for people with penicillin allergies since I'd left hospital, they were kind of at a loss as to what antibiotic to give to me. For a breastfeeding mum, there is loads that you can't have because it will affect the baby and I couldn't have any penicillin and I'd already had the other main one. So I ended up on really strong antibiotics, which did really affect my son. He was absolutely beside himself because his tummy, you could hear it going. So he basically didn't sleep for three days, I felt really really poorly and I think it was just exhaustion.

They were very good again at the sepsis management, they were very clinically efficient. As I was saying before, there is a one-hour timescale from when you diagnose someone with sepsis to start treatment and they did it all and they were fantastic and I was very well looked after. I went back to the horrible postnatal ward but they gave me a separate room this time because my baby was a little bit older, and so I didn't have loads of screaming new-borns, so that was really good …

I got mastitis in both sides as well, so I had a wound infection and that. I was just generally really poorly. But I again felt listened to, they were very thorough, going through everything. I saw every specialist under the sun and they came in, they reviewed me, they talked to me appropriately. And I felt, even though I had a horrible time, that everything that could go wrong, did go wrong, I still feel that I had really good care because they got the right people in at the right time. It couldn't have been known that I would get mastitis and I'd get a wound infection in general. Obviously there was the time they didn't listen to me about the bleeding and things like that, but overall I do think I had good care. Which is probably a really damning indictment of how bad I think the care can be within the NHS, that I think of that catalogue of issues, that my over-arching feeling is that I did have good care. I don't know whether I have got low expectations or not.

Well, you are relating your experience and other people might have drawn different conclusions, but that's the conclusion that you drew.

C: Yeah. I think I'm just a realist and I know what it's like, I know what care I could have had in that situation and it was much better than I have seen care be. So I feel lucky.

It does raise the question whether somebody who is not a healthcare professional who had a similar experience would have thought they might have had bad care because so many things went wrong. Did you give feedback to the hospital about your experiences?

C: Yes, I did, and I also went in, they invited me in to see the consultant after, to go through and debrief everything that happened and go through it. It wasn't just because I was a healthcare professional, I think for anybody who has had a difficult time during labour or postnatally they do invite them back, and I found that very valuable. She took a lot of time to go through everything and asked if there was anything that I felt could have been improved on. So I was able to debrief in a very informal way, that actually the next time the anaesthetist was on shift that did all the epidurals, she came in to find me on the postnatal ward and asked if we could have a chat, and asked if we could go through what went wrong. Because she was saying that she'd been feeling absolutely dreadful about it, she couldn't get over it, it was clearly a situation that was out of the normal for her. I don't know whether she would have done that with everybody. I think she would, but it was good to know that she was using my experience to reflect on current practice and learn what could have changed and what could have been done differently. So I think that was excellent.

And my midwife who I really liked from my antenatal period, she was actually on holiday when I gave birth, but as soon as she got back, she emailed me and asked how everything had gone. And she asked if I wanted a formal debrief with her as well, which I didn't need, I was absolutely fine. But I definitely do feel that the maternity service really gave an opportunity to reflect on practice and look at where things went wrong. Whether they did anything with that information and did change anything, I am not sure.

Thinking back over the whole experience, what would you say were the learning points for the NHS, particularly in relation to maternity care, but maybe more generally as well?

C: Going through it chronologically, I'd say that having a named consistent midwife is incredibly reassuring, especially if you have gone through a traumatic event in early pregnancy, like I did. I found that absolutely

invaluable and I think that even though I had an awful time at the start, I do think I had a good pregnancy apart from that. And I think that was in a big way due to the reassurance and guidance that that one midwife gave me. So I think, as much as they can, if they can have the same midwife, I think that would be fantastic.

In terms of my care in the hospital, when I said I didn't feel well and requested a set of observations, I think that's a realistic request. And if somebody says, I'm not feeling very well, do you mind doing my observations to check, I think that should be delivered. So I think that that should be reflected upon as to why that didn't happen.

I think that setting real expectations, be that of when you are going to deliver the next care, what's that going to look like, even if it's going to be bad, letting them know that. Knowing that has a huge impact upon how patients feel and there should be a huge effort to strive to do that.

I took a lot from the anaesthetist coming back and reflecting on what went wrong with me. If things had gone wrong in my practice, I will talk about it with my team but I never really go back to the patient themselves and talk to them about that, and I thought that was really valuable. And also made me feel good really, that she took the time out of her day to make sure that I was okay. So I think I would, in the future, if there was anything that went really wrong or I wasn't sure about, actually explore that not only with fellow healthcare professionals but the patient themselves. That's probably the thing I will change the most.

And they had an excellent sepsis trolley that I wanted to steal for my practice. It was this rolling six-stage what you need to do and all the equipment that you needed for sepsis management. I thought it was excellent. I have already texted my boss about that and said we should get one. So I saw things that were clinically better than in my area and have made changes.

It's essentially about having the clinical excellence and kindness to go with it. People understand that things go wrong and they get infections and that won't necessarily mean that they will think that they've had bad care, just as long as you explain why did that go wrong. It's the human factors that influence people's perception of their care, not actually the care itself sometimes.

Yes. And I think you can derive a lot of reassurance from seeing how the professionals react to something going wrong.

C: Definitely.

Judging whether something shouldn't have gone wrong is, I suppose, the more difficult one – whether it was avoidable.

C: Yeah. I think, I'm not sure if any of mine were avoidable. Everything that went wrong for me is not unexpected in labour and after in post-natal care; I just happened to have got most of them. And it's quite often the pattern that when one thing goes wrong, your body's unwell, so it's more likely for all the other things to go wrong, it's a bit of a domino effect really.

Story 2: James

James looked after his mum who had dementia for ten years (see Chapter 7, Story 23, pp. 187–192) and found himself becoming an older father, a year after his mother died. His partner was overdue with their first baby and had to be induced, which proved traumatic, and there were problems during and after the birth and in the following weeks. Two years later, James's partner gave birth to a second baby, which was also overdue. Having been called in, the parents endured a stressful wait of six days in hospital before the baby was induced.

James: I'm an older father. I spent almost ten years caring for my mother. My partner is quite a bit younger than me, she's 35 and I'm 53.

I did promise Mum that I would have grandchildren for her before she died, 'cause she really loved children. My partner was pushing me for it, but it was just impossible when I was doing that caring role. It was just absolutely impossible to think about having children while I was doing that. You think, well, what happens if I leave Mum, what's going to happen to her, she's going to go into care and she didn't want that. Thankfully, my partner was patient, and as soon as Mum passed away it was like, right, James, we're not messing about now.

And you've got two children?

J: Now I have. My little girl was born in 2018, literally a year after my mum died.

I'll be honest, caring for Mum was more difficult than caring for a baby. I think that was a good foundation course, looking after someone with dementia. A baby's a doddle because the baby just improves. With dementia and Alzheimer's, it declines.

We were hoping to have a home birth for the first and we had everything geared up for that pool at home. Then we went on these courses

where they train you on doing it naturally and … I felt like I was a bit of an old chap there because there were all these very young couples. I mean, some medium, but I was definitely the oldest dad in the playground there. But it didn't really matter. I just felt like I was more confident to ask questions about things and challenge things. I've no qualms about asking things, whereas when I was younger, I was quite shy and reserved. No one was judgemental about me at all. Which I have received, for example, from a library service … When you take your children along to a toddler and baby group at a library, people assume that you're Grandad. I went grey when I was 30, but I've just lost a bit more of it. I just didn't say anything because I thought, I don't want to embarrass you in front of everyone else and I'll just take it.

So, it didn't all happen as planned with the water birth at home?

J: Not at all. My daughter was two weeks overdue. It was quite a traumatic birth. When she was induced, waters were broken. As soon as her waters were broken, my daughter's heart rate plummeted and then it was way up, so she had a floating heart baseline. The crash team had to come in about five or six times.

In the end she had an episiotomy. She did have significant blood loss. She had to have a blood transfusion. She lost 2 litres of blood. So it wasn't the sort of lovely home birth that you'd imagine; it was like the extreme opposite.

My partner was very stressed about it. It had quite a real effect on her, to the extent that after the birth and before the next birth we just had, she asked for a debrief. The matron came along to our house and she got them to talk through what actually happened.

One of the things that really stuck in my partner's mind, there was a comment made by a doctor at the time saying that oxytocin, the drug to bring on labour … the doctor said, turn that down, it's a very dangerous drug. She was really frightened when that was said. It left quite a scar within. She was trying to work out: what really happened?

In the end the matron said that it was only a very low level of the drug that was being given anyway, quite late on in the process. So, it wasn't as big a deal as it sounded on the day and she was reassured by that.

I think they could have recognised how it affected my partner mentally better, or maybe there should have been a route for her to take to help her to put that to bed. She didn't have closure at all on it.

On to the postnatal period: my daughter was born on something like the ninetieth percentile – big baby, 9lb 8oz, two weeks overdue. Mum really wanted to breastfeed and she was really trying her best to breastfeed. It wasn't happening. Really struggled for the first two weeks. So

we went out and bought all these things so she could … She expressed and the baby started taking it off. But she lost loads of weight over two weeks, only just about within the permitted guidelines. It turns out that my daughter had a milk allergy. My partner virtually worked that out herself and stopped dairy herself and it solved it … 'cause my daughter would be sick after every feed constantly, which was worrying, and she'd feed every twenty minutes because she was being sick constantly.

I think there's something there that needs to be looked at – an early recognition about this. Because she's now on the twenty-fifth percentile from the ninetieth. That's a significant drop, isn't it?

We were referred eventually to a dietitian and they put us on the milk ladder pathway, I think it is, for my daughter to gradually build up. So, take her off everything, which we'd already done, and then gradually build her up with a tolerance. Now she's great. It was very slow, and I think that my daughter suffered for quite a good few months before anything was done. I think there could be an improvement there in the testing for it or the diagnosis of it. The warning signs were there, weren't they?

So, in terms of child health beyond the first few months and all the surveillance, how's that been?

J: Fantastic. She's been very healthy. A couple of trips to the doctor, an infection and one round of antibiotics. She's been very healthy. My partner breastfed her for fourteen months…

We now get into the second pregnancy, and I suspect we might have a bit of anxiety about the birth?

J: Absolutely. In terms of the visits, et cetera, big baby, again, in the ninety-eighth percentile. The consultant there on one of the trips to the hospital made a comment that there's no way it's going to be a home birth, it's going to be labour ward at the hospital and that's it, you've no choice, really. My partner was quite annoyed about that because it took her choices away. 'Cause she's told that every birth is different, and just because things went a bit scary the first time, you can have a normal pregnancy and have a birth at home. The midwives are saying, well even though it's a big baby, it doesn't prevent you from having the baby at home. So, you're getting mixed messages there.

We took the view: let's have a really flexible plan, let's try and go for home if we can, if not, let's have the birth centre where you've got the nice pools, and if not, let's be really open-minded about the whole lot.

But my partner was a bit disappointed that consultant said that your only option is the labour ward. That's when she discussed that with the midwives, and the midwives had a meeting with the consultant … So, all the options are still on the table when it came to it, which is great.

Again, we went over the due date. The baby was due on the 28th of December and we got to 3rd January: we were to go in and be induced and have the waters broken, et cetera. So, once the waters are broken and she's induced, the birth centre went out the window, so it was on the labour ward. Which was fine, because it had a pool there. So, we went in on the 3rd of Jan., ready to go, all bags packed, childcare sorted out with my partner's mum, staying at her house while I could stay with my partner to support her.

We went in on the 3rd all geared up. Sorry, there's no beds, so you've got to stay on this ward here. Great, we had our own side room with a fold-down bed that I could sleep in there, but we had to be on call basically to get summoned in to have the waters broken. But what happens is people come in with emergency caesareans and their waters have already broken, so even though we were number one on the list to be seen and done, we were in there six days. I couldn't believe it – we were just sat there waiting.

It's like a conveyor belt. You've got the people on the ward waiting to go into the labour ward … and then the people on the labour ward have got to be cleared out to the postnatal ward, and there's no … My partner's mum said, when can I get back to work? I don't mind doing this [babysitting] for a short while, but this is six days. We're thinking, oh my goodness, what are we going to do? So luckily her aunty stepped in over the weekend to help. But it was quite stressful.

This is such a minor thing, but it matters. We're trying to get decent sleep during the night, ready to prepare for birth. You need that rest, don't you? My partner was on paracetamol, just a mild painkiller for her. She was woken up at four in the morning, just to take a paracetamol tablet, and you think, hang on a minute …

Did she feel able to say, please don't wake me?

J: She did do. But it should be an obvious thing. You let people get their rest and then they're more prepared and fit.

So anyway, the day came … twenty past four in the morning, bang, pack your stuff, we're off, straight off up to the labour ward. We got to the labour ward and thought, hang on a minute, there's loads of empty rooms here not being used: what's this about? The reality was there just weren't enough staff … It wasn't to do with the rooms at all, no, no. We

had a student nurse who's followed my partner as part of her training development. Great, she's absolutely fantastic, and she was present at the birth. Fantastic. But the other lady, the other midwife, I think she'd been out for a couple of years working out in the field in the community, just booking in patients for visits. So she was quite rusty, shall we say, with all the equipment and everything. So it didn't instil a lot of confidence in me. But she was okay, fair play to her, but she was just a bit rusty on everything.

And you could tell: massive short-staffed. I'm thinking, right, we had all these issues with my daughter the first time, if this pans out the same way as my daughter did, I'm pretty scared about this. They broke the waters and, sure enough, my son's heart rate crashed, and we thought, oh no, here we go again. Thankfully, it came back up and levelled out so he had a stable baseline. That was it, it just happened once.

My partner was fab. They gave us an extra hour to give the natural process a chance to kick in. Sadly, it didn't kick in fast enough, so she had to have the hormone again, which accelerated it. Within two hours and five minutes of having that hormone, baby was there. Because he was so big, she started to tear slightly and she needed an extended episiotomy this time. The last ten minutes, baby's heart rate fell to Mum's heart rate, so they couldn't distinguish the difference. So they didn't know whether baby's heart rate was there or not.

So they said, right, we'll put like a little cord into his head and screw it in so we can measure baby's heart rate better. They put the cord in his head and said, right, we're going to switch the other monitor off and switch this monitor on that measures baby's heart rate. Switched it on, nothing. I just sort of looked at the student nurse and said, where's his heart rate? No one said a word. I just thought, oh my goodness, this last ten or twenty minutes you've not had a heartbeat for baby here. They went and got the sister, who came and said, oh right, yeah, I can find it. She put the other machine on and I can hear like a four or five beat difference between the two. Oh, can you hear that? That's impressive. Thankfully, it was there. But what had happened is they'd not connected the monitor properly to his head. But it was a scary moment. So of course my partner's stressing out, you know, But in the end, he came out. He was a whopper. He was 9lb 12oz, so he was another big one. He's been fab ever since.

I suppose my experience, it was a bit different than my partner's, because I saw it all while it was happening and panning out and I saw how professional … Especially the first birth with my daughter when we had the blood loss, how fantastic they worked as a team and how quickly … to get the transfusion and everything and to bring the womb down

in size. It was so professional and slick and I had total confidence in them that first time.

Whereas all my partner's memory was that doctor that said, this is a very dangerous drug, turn it down, turn it down. For me, I've been trying to give my perspective on it, but her perspective was tarnished by that thing happening.

With my son, everything's been fine since. But he's started to be sick now. It could be the same thing, milk intolerance. My partner's cut dairy out. But with my daughter she lost that huge amount of weight initially. My son has just put it on and on and on, so he's … getting what he needs.

After the birth, it took two hours to stitch my partner back together. So, when we were back home, it's quite full-on for me 'cause my partner was in bed, she had trouble getting in and out of bed, we had my daughter running around. But it's fine. We got through that first couple of weeks, which were quite tough, and then, of course, I'm back to work straightaway. So, from a dad's perspective, it was a full-on two weeks. Thank goodness you get paternity leave. It was really not a time to enjoy the baby … shopping, sort my daughter out, cooking, cleaning, make sure my partner's all right. So, it's not the dream that you have in your mind, just sat there with baby on your chest, bonding.

Being included by the NHS, well, it's helped me support my partner more, I think, and it's given me confidence. Even though everything's not perfect, is it? I've had to try and absorb my partner's stresses and concerns and manage them, I feel, but that's part of being a partner, isn't it?

PREGNANCY AND CHILDBIRTH: REFLECTIONS AND RESPONSES TO THESE STORIES

Immediate questions

1. Why was continuity of care important to Cathy during her pregnancy?
2. To what extent do you agree with Cathy's overall assessment of the quality of care she received?
3. What do both Cathy's and James's experiences tell us about the importance of managing expectations?
4. In what ways was Cathy's professional nursing experience both a help and a hindrance?

5. Should James's partner have been given more choice over the manner of her second birth? How could this issue have been differently handled?
6. What do James's and Cathy's stories suggest about good practice in how healthcare professionals communicate with partners?

Strategic questions

1. What changes in maternity services policies would improve the experience for mothers and their partners?
2. How can frontline professionals be better equipped and enabled to support women in pregnancy and childbirth?
3. What do you think are the organisational cultural barriers to person-centred maternity care? How can these be overcome?
4. What actions can you take as a policymaker, professional leader, frontline member of staff or NHS manager to improve the experience of care for mothers and their partners?

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