Confidence and confidentiality

By Colleen Walker

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What does confidentiality mean? Colleen Walker explores the issue from her own experience of the maternity services

Confidentiality - exactly what does it mean?

To me, it means being able to say something without fear of it going further; you are speaking 'in confidence'. Ah, confidence, confidentiality - of course, the words are related.

Look them up in a thesaurus. 'Confidence' leads you to 'belief', 'faith', 'trust', 'support' and 'loyalty'. Other synonyms are 'certainty' and 'conviction'. A third is 'secret' and this is tied to 'intimacy'. 'Confidentiality' leads to 'privacy' and 'discretion.'

Well, what perfect words to use with regard to birth. You should feel confident in your own body. Your caregivers should support you in this notion; you should feel that they are confident in their own skills, not afraid of the process of birth. There should be trust between you, and a conviction that they will not betray that trust. And, given how intimate the role of caregiver is, isn't privacy essential?

If an issue needs to be addressed, a woman should feel that she can raise it without it going further than she intended, at least not without her permission. Wouldn't it deter her from expressing her concerns if she felt that this was not the case?

Surely, anyone involved in maternity care should see that all of the above concepts are an essential part of their role?

When I first knew I was going to become a mother, I wanted to get all the information I could about it. What amazed and pleased me the most was the instinctive confidence I felt I had in my own body. With a sudden rush of gladness, I thought, "Hey, I think I could enjoy this!"

But hypertension during my pregnancy led to induction in a filthy hospital environment staffed by midwives who, for the most part, seemed utterly disinterested in me and irritated by my presence. I was vulnerable and afraid; it was my first experience of childbirth and I wanted support, reassurance. Three days of no sleep in a stinking antenatal ward was followed by a four-hour labour and a healthy baby.

Now at first, I was euphoric; after all, we had our little girl. So I tried to brush away the memories of the way they had treated me; I even talked of sending them a thank-you card. But, as time went on, my real
feelings surfaced. I began to have flashbacks. I was shaky and tearful, and I couldn't go near the hospital for months - because what I carried away from that place was the feeling that I had failed.

I had failed to keep my blood pressure stable. I had failed to control my emotions. I had admitted being scared, admitted needing support. I had failed to act as a model patient; I wanted to know what was being done to me, why, and how necessary it was. I had failed to keep the printout going on the monitor because I moved around. I had failed to keep quiet during labour. I had failed to get my baby out quickly enough as I had not put enough effort into it. Mostly, I failed to understand why it had to be such a bad experience, why it had not been possible to monitor my blood pressure without putting me through so much stress.

Two-and-a-half years later, I was pregnant again. I registered with a new group of community midwives near my home. This time, I thought, it would be different. I would get to know these women - they would be my allies. It was still difficult for me to think about the first birth; I 'confided' in them how awful it had been and they seemed to be very sympathetic.

For a while, the baby was breech. They told me I couldn't possibly stay at home to give birth; they had never attended a breech birth before, and it was clear they didn't want to. "Oh, no," said one, shuddering, "I'd be terrified. That's for an obstetrician to deal with."

Luckily the baby turned round... but he didn't come on the due date, or the day after... It was clear they had no confidence in my body to keep my baby safe. They said I would have to go into hospital to be induced. I begged them to at least come with me, reminding them what a bad time I'd had before. "Oh yes, don't worry," they said. "We promise."

But when I awoke with contractions the next day, I couldn't get hold of my midwife on the phone. She had called in sick, but no one thought to tell me. Despite being in spontaneous labour, I ended up in the same hospital as before, with a part-time midwife who showed no interest in me. And as I lay on my back, wired up to a machine and being instructed to push, I could not help but feel terribly let down. I had confided in those women; they had given me a promise but, in the end, I couldn't rely on them.

And so we come to this pregnancy. I wanted assurance that there would be cover for the birth at home, as I wasn't going into hospital without good cause. But I learned then that 'staff shortages' meant that no one knew whether there would be cover or not, and there was no way of telling until I went into labour.

When I asked what would happen if I just sat tight, the community midwife told me that I would be breaking the law. This was one of the women I felt I needed, and she was threatening me with prosecution.
So I wrote to the Trust, requesting confirmation that a midwife would be sent. In the letter, I recounted how traumatised I had been in their hospital in the past, and also pointed out my history of extremely short labours. I stated that I had no intention of going to the hospital. I didn’t put phone number on the letter because I wanted the Trust’s decision in writing.

Yet, when I returned home after being away for Christmas, the answer machine was jammed with telephone messages. The head of community midwifery was anxious to "talk" with me. Perhaps I could go to see her? But nothing came in writing.

Eventually, a letter arrived from the Trust (see box), confirming that, in case of staff shortage, I would be requested to come into hospital. If this was not satisfactory, then I could go to another hospital and see if they did home births, or I could pay for an independent midwife. For good measure, they had copied the letter to my community midwives.

So my telephone number was given out to the Trust by my midwives, without my permission, and then details of my correspondence with the Trust were sent to the community midwives, again without my permission. Where was the confidentiality? At a vulnerable time when I was being misinformed and bullied, who was protecting my interests?

Perhaps it was not done maliciously, but it was done - at best - with complete disregard for my privacy. Now my words, just like my body in hospital, were being treated as public property.

So, at an extremely vulnerable time in their lives, when women need to turn inward, they are being intimidated, sidelined, ignored and betrayed by those on whom they must rely for care. And if they complain, if they stand up for themselves, they will find themselves undermined with no one in the system they can turn to.

It seems a shocking abuse of power for a Trust to subject a woman to stress and uncertainty at this crucial time. Presumably the hope is that she will back down, unable to face a fight; after the birth, she will be too exhausted or too busy to pursue a lost cause.

The infuriating thing is that there is no need. Staffing is a problem in the NHS and will not be resolved overnight, although I would like to know what steps are being taken to sort it out. But that is no excuse for the Trust’s attitude. A bank or independent midwife can be employed to ensure that the Trust upholds its duty of care, and why should a woman with a traumatic hospital experience and a history of fast labour put herself at risk because of a staffing problem.
I admit I couldn’t take it any more. I was lucky enough to find independent midwives, who have taken me on despite my financial circumstances. But it should not have come to this. Ostensibly, women have the right to choose where they give birth, but what does that mean in practice when they find themselves let down, bullied and threatened by their caregivers? What happens when our legal right to confidentiality is so thoughtlessly breached? Where does that leave us?

Trust, belief, support, intimacy, privacy and discretion. Confidence and confidentiality. To pregnant women, these words mean so much. To the NHS Trust concerned, it is evident they mean nothing at all.

WHAT THE HOSPITAL SAID

The letter from the midwifery manager at St Thomas’ Hospital says it all. Polite and ‘informative’, it nevertheless confirmed to Colleen that her details had been passed on to several individuals without either her permission or her knowledge.

Dear Ms Walker,

Thank you for your letter dated 16th December. I am responding on [your midwife’s] behalf as community midwifery manager.

I have rung you on several occasions including today, 2nd January and prior to Christmas. I have left on your answer machine my contact details in the hope that we could meet to discuss the issues raised in your letter.

We currently do have a homebirth service operating in all areas of the community. Due to staffing shortages we cannot, however, guarantee that you would have a midwife that you know attending you and on some nights when we are unable to provide complete cover. On those occasions, we would request that women would come into the home from home unit. The midwives working in this area support women who have uncomplicated pregnancies and labours similar to those having a home birth.

I am sorry that we are unable to provide you with an independent midwife. This, however, would be something that you could organise privately. Alternatively, Lewisham Hospital may be able to accommodate you with a more suitable service at this time.

I really hope that we can meet in order to discuss the issues further. I would like to support you in providing the best service that we can at this time. If you would like to make an appointment, please ring my secretary on [phone number omitted].

Yours sincerely,

Sandra Houston

Editor’s comment: Colleen Walker’s story is a fascinating take on the issue of confidentiality. Many midwives would no doubt consider that the ‘sharing’ of information was an integral part of both professional duty and courtesy. Nevertheless, from the woman’s perspective, trust and confidentiality
has been breached. We welcome any comments from other mothers and midwives.