Personal View

Our second child, Kate Elizabeth, was born in a West Midlands hospital in May 1987. She is a normal, healthy child and a dearly loved addition to our family. Why should I therefore take scarce space in the *BMJ* to describe a perfectly normal event? Because our personal experiences surrounding Kate's birth graphically illustrate some issues that have worried me as a health services researcher who is concerned with the management of the National Health Service.

My wife was 38 at the time of booking her first antenatal appointment at the hospital. She had had our previous child at the same hospital six years previously and we were both happy with the care provided and the way that we were treated by clinical and nursing staff. What follows is intended to be a general statement of the prevailing position in the NHS, not a criticism of the hospital concerned; indeed it is probably better than most.

As part of the antenatal care my wife was given information on the screening tests to be performed. One sheet of paper explained that she would be given a blood test to detect fetal abnormalities. If the test was negative nothing more would be done. If positive there would be a follow up including further testing. I took the blood test to mean α fetoprotein and the follow up to include amniocentesis.

The inference my wife drew from this was that all fetal abnormalities were being screened for, including Down's syndrome, although we now both agree that there was nothing in the information given that stated this explicitly. I regret that my wife and I did not explore this fully at the time and being fairly conversant with medical matters I accept my own share of the blame for not taking a closer interest in the antenatal care that was being given.

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All this came to light only subsequently when I had the occasion to discuss prenatal screening through my work. At this point the facts began to emerge: amniocentesis is currently the only reliable test for Down's syndrome and in many parts of the country it is considered advisable to offer it to women of 35 years and over. I consulted a community medicine colleague at this stage, more as a friend than as a fellow researcher. Yes, the accepted wisdom is that amniocentesis is the only reliable test for Down's syndrome, ignoring, for the moment, chorion villus sampling which is still under consideration for wider use. The policy in the West Midlands is that women should be offered amniocentesis if 37 or over, a cut off point determined partly by clinical evidence and partly by practical considerations. But not all districts adhere to this policy. My community medicine colleague told me that she was not sure whether she would have accepted amniocentesis if offered it. After all, given the fact that there were no other contraindications, the risk of spontaneous abortion from amniocentesis was around the same as that of having a child with Down's syndrome (about one in 100 or so). (One hospital I know in Canada is quoting a spontaneous abortion rate of one in 200.) The relevant question was whether my wife and I would want to terminate the pregnancy if the test for Down's syndrome was positive. I didn't know the answer to this without considering it: no one had asked us that kind of question before.

The few days immediately after these revelations were traumatic. It was too late in the pregnancy to take any further action, so we tried to put it out of our minds. I felt guilty about my own role in telling my wife about all this at the time when I did and I began to sympathise with clinical colleagues who have to explain complex issues such as relative risks to their patients. My community medicine colleague pointed out that my wife could have discovered the same facts from several sources, such as at a dinner party attended by friends who were also pregnant but from a different location where a different screening policy was applied. Certainly my own inquiries showed that there were wide variations in screening policies across the country, with some districts having no published policy.

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As time has gone by, with the happiness of Kate's birth more prominent in my mind than the previous traumas, I have begun to reflect on this experience in a more detached way and drawn the following conclusions.

- No matter how good the efforts of the clinical staff working in the NHS, it is important that patients take an interest in the care they are being given. If we had thought this through properly we would not have ended up in the position that we did.
- The critical determinant in whether amniocentesis should be given is not just the relative risks but the values that the individuals concerned place on the outcomes. That is, two women at exactly the same statistical risk may make totally different decisions for very good reasons.
- If we believe that these valuations are important we ought to be exploring them when we undertake clinical research. Also, we need to find ways of eliciting them from individual patients. The track record of research funding agencies in supporting this kind of work is poor.
- We need to develop screening policies that are flexible according to individual patient preferences and to make these policies explicit.
- We need to think carefully about how the NHS deals with resource limitations when designing policies for prenatal screening; is it right that policies should vary from district to district, depending on availability of resources, or should national guidelines be set?
- The NHS needs to pay attention to quality assurance; the way in which informed consent is obtained is probably more important than a smiling receptionist in the outpatients' department. Insufficient attention is paid to the process by which care is given. This can affect quality, even though the final outcome, as in the case described here, is good.

MICHAEL DRUMMOND
Professor of health services management
Birmingham

"Amniocentesis? Well, I can't advise you," said the obstetrician, after giving me the (incorrect) odds of a 35 year old having a baby with Down's syndrome versus the risk of the procedure resulting in miscarriage. "It's our policy to offer it at your age but it's your decision." And so it was; and rightly—or, as I believe, wrongly in my case—I took up the offer, had an amniocentesis, was reassured that all was well, and went on to produce a normal child.

So how can the decision possibly have been wrong? In an attempt to answer that question I have written this personal view in the hope that it illustrates more than the fact that pregnant women may be emotional timebombs.

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My immediate reaction to the offer of amniocentesis was "no thank you." Family history was negative, and I was convinced I would have a normal child. The thought of involuntarily precipitating the abortion of the fetus, which with my dodgy obstetric history I was lucky to have conceived, was abhorrent. I later changed my mind, however, being swayed by the advice of medical friends, who cumulatively convinced me that gut reactions were invalid and that it was my moral duty to have the test to avoid "lumbering" myself and society with a less than perfect child. Miserably apprehensive, I kept very quiet about my pregnancy. Someone had to be the "one in 100 abort after amniocentesis" statistic.

The day of the test remains vivid. On the positive side the 16 week ultrasound was incredible. No fetal movements felt, I could still get into my jeans, yet here was a perfect little individual frenetically whizzing around a few inches below my umbilicus. I almost got off the couch. "Why risk it?" said an inner voice. A minute later the procedure was over. Clear amniotic fluid, that was good news, but what had happened to the baby? Repeat screening showed the fetus to be motionless, and the doctor appeared to be having difficulty determining whether the fetal heart was still beating. I received no reassurance on this point and on my way out, feeling indescribably shaky, I ventured to ask what symptoms I might experience if something were to go wrong. The reply was terse—"Abdominal pain and leakage of amniotic fluid"—and accompanied by a look which implied that umbrage had been taken.

Needless to say, I spent a sleepless night. Every abdominal twinge heralded disaster, as did the merest hint of vaginal wetness. After all, what constituted a leak? I could not forget the motionless fetus. Could he be dead? If so it was clearly my fault. No one had twisted my arm to undergo amniocentesis.

Next morning, I read the *Lancet*, in which the results of a large randomised controlled trial from Denmark "to assess the risk attributable to amniocentesis, and to test the hypothesis that amniocentesis predisposes to postural deformities of the lower limbs and to neonatal respiratory disorders" were reported. What? I had had no idea that amniocentesis was associated with long term adverse effects on the fetus. Further reading established that although the published evidence is conflicting the results of the Danish study[1] confirmed an earlier Medical Research Council trial[2] and two additional studies,[3,4] which all pointed to a small but definite risk of mid-trimester amniocentesis causing pulmonary abnormalities in the fetus.

Why hadn't I been told? The information was surely relevant in my case, where the indications for undergoing amniocentesis were so borderline. More upset than angry, I wrote to my obstetrician asking her to let me know what the data added up to. She did not reply. Nor did she allude to the subject at a subsequent antenatal visit. Lacking informed reassurance, I let things get out of proportion. I could not get rid of the belief that I had harmed my child by undergoing an unnecessary test, and nothing my family or friends said could console me. Thirsty for information, I bombarded my medical friends with questions until I got the partially reassuring comment, "We don't think that it adds up to anything clinically."

By the last trimester of pregnancy I had calmed down, and the rest as they say is history. I have a strapping toddler who is in rude health. But I still get concerned. Several people have commented that his cries are unusually low in volume, and he seems to have a tendency to get short of breath on exertion. . . .

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More and more women are delaying having children until their 30s, and hence the demand for prenatal screening for Down's syndrome (together with other fetal abnormalities) is likely to grow. But, however routine the screening procedures become, there is a need to remember that amniocentesis and chorionic villus sampling (which, quite apart from its limited availability, carries a miscarriage rate of roughly twice that of amniocentesis) are highly invasive procedures which present a considerable hurdle to those who undergo them.

Advances in prenatal diagnosis such as the potential to detect Down's syndrome at the routine 16 week ultrasound screening may obviate the need for invasive procedures.[5] Meanwhile, obstetricians, in common with all clinicians, need to remember that most patients' decisions about whether to accept treatment or undergo investigations are based on how and what facts the doctor presents to them. Full and sensitive counselling goes a long way towards defining the "right" decision for a given patient. Especially when in reality there is no right decision, only the need to make an informed choice.

And my choice next time round? I'll stick to "no thank you" this time.

LOUISE KNIGHT

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2 Working Party on Amniocentesis. An assessment of the hazards of amniocentesis. *Br J Obstet Gynaecol* 1978;85(suppl 2):1-41.
3 Hislop A, Fairweather DVI. Amniocentesis and lung growth: an animal experiment with clinical implications. *Lancet* 1982;ii:1271-2.
4 Vyas H, Milner AD, Hopkin IE. Amniocentesis and fetal lung development. *Arch Dis Child* 1982;57:627-8.
5 Benacervaf BR, Gelman R, Frigoletto FD. Sonographic identification of second trimester fetuses with Down's syndrome. *N Engl J Med* 1987;317:1371-6.

(Louise Knight is a pseudonym.)