

THE NUCHAL TRANSLUCENCY SCAN - ONE WOMAN'S STORY

I am a 33-year-old Aucklander, 18 weeks pregnant with my first child. I am very concerned with the present practice surrounding the 11-13 week scan in the first trimester as a result of my experiences.

As so many of my peers are currently having children, I had heard about and seen many images of the first trimester scan that other women have had. It has been so common in both New Zealand and in other countries that I saw it as a very routine test. It seemed as though the emphasis was on getting pictures of the baby, determining accurate due dates, and making sure that the pregnancy was progressing normally.

I was told by my GP that my first scan would be at 12 weeks.

In my first meeting with my midwife, she asked me if I was going to have the first trimester scan. My partner and I said yes, as it seemed the most routine and responsible thing to do. My midwife did make it clear that the test would measure the nuchal fold on the back of the baby's neck, and in conjunction with my age that I would be given a ratio as to the risk of my baby having Down syndrome.

At the time I did not think about the consequences of having a test that put me in a high-risk category. I was also not informed of what these consequences would be. As I was in the middle of what would be a two-month period of quite severe morning sickness I was not in a very strong position to think critically about what I perceived to be a routine procedure. When a friend who has had several children asked me why I was having the 12-week scan I answered "I don't really know." Looking back I guess the real answer was because I thought it was the "normal" thing to do and had not been presented with any reasons not to.

On the day of the scan my partner and I were at first both completely transfixed by the images of our 12 week old baby. However, about half way through the scan I began to feel that it had gone on long enough and that I was not very happy about invading my baby's private space and using a machine to look inside its body at its organs and even look inside its head at its brain. By the end of the scan I felt very protective, and had decided that I didn't want to have any more scans. Everything about the baby looked completely normal.

As our scan was the last of the day on a Friday, we took the images and left. The results were to be posted to my midwife and GP.

Over the weekend my feeling about the scan intensified and it became very clear to me that I did not want to have more scans. I continued to be mystified as to why I had the scan in the first place, and to why so many women did this as normal practice.

On Monday night I received a call from my midwife. I began by filling her in with the details of my visit to the A&E over the weekend. She listened, and then asked if I seen the results of the scan from Friday. I said that I hadn't. The midwife was the first person to give me the results, verbally over the phone. She calmly stated that as I was 33, my ratio begins at 1 in

415, but after the measurements had been conducted, the ratio was now 1 in 160 for this pregnancy. As the cut off for a high risk is 1 in 300, I was now considered to be in a high-risk category for Down's syndrome, and I would be offered an amniocentesis.

My mind raced, and I quickly said that I did not want an amniocentesis, and that in fact I did not want any more scans. She seemed slightly alarmed by this statement, and then very clearly asked me what my feelings were on terminating a Down's child. I did not hesitate to say that I was very clear about the fact that I would not terminate a Down's child. She then said that in that case, the risk of a miscarriage with an amniocentesis is 1%, then I am better off not to have it, as the risk of miscarriage outweighed the risk of me carrying a Down's syndrome child. (I now know that the amniocentesis risk can be as high as 3% and 5% if the operator is inexperienced.) With these ratios swimming in my head I began to question why a woman would put her child at risk to test something that was less than the risk of miscarriage. I also started to wonder why doctors would recommend such a course of action. Although I was very clear about not wanting to terminate a child with Down's syndrome, and not wanting an amniocentesis, my midwife said that I should talk to someone medical before making a decision, and recommended that I see a genetic counselor. She asked if she could make the referral, and if she could call me at work the next day. I said that was fine.

The next 24 hours were extremely upsetting and distressing for me, my partner and my parents. My overriding feelings were anxiety, fear and anger that I felt I had not been properly informed about the possible outcomes of the scan. I wished that I had not had it done in the first place and that I did not have to think about what was now a 1 in 160 chance that I was carrying a Down's baby. My feelings of anxiety continued to be high for most of the following week.

The next day I was called by a genetic counsellor. By this time I was very upset and wary of any medical intervention. I quizzed the counsellor on the phone about the need for an appointment as I was sure that I did not want an amniocentesis. She said that they did not pressure women into having one, and that I should still come in for an appointment. But I was still wary and unsure of what their agenda would be and I put off going to the appointment.

As I was feeling very angry and unsure about the whole process I started to do some research on the internet. I called MAMA and was told of concerns there are about the way in which the scan is currently being presented and followed up, and about the 2nd trimester blood test that can help to make the results more accurate. This was the first time that I had heard about the option of a blood test instead of progressing straight to an amniocentesis and the risks associated with this procedure. I told the MAMA worker that I was very unhappy about the lack of information I had prior to having my scan. Although I was very clear that I would not have an amniocentesis due to the risks, I was concerned that many women in my place would have one, and it concerned me that this was what was recommended by doctors, and could result in women putting healthy babies at risk.

As I felt so strongly about these issues, MAMA referred me to the MSCC. I was given further information about the 2nd trimester blood test, the timing of having an amniocentesis and the time it takes to get the results - information that I feel is a significant factor in the decision making process. That I was not given this information before I had a scan is very

distressing to me, and further emphasises the need to give information to women to enable them to be able to make a truly informed decision.

Underlying all this for me personally is the fact that I feel very strongly that people with Down syndrome are a part of our society, and have the possibility of a very high quality of life compared with many other birth abnormalities. I have also learnt that the percentage of miscarriage for Down syndrome babies is very high; therefore nature does have its own system in dealing with severe cases. The idea that we are spending money and time on what has become a commonplace program to screen out Downs people from existence is morally troubling to me.

It is also astounding to me that for something with such serious consequences, such as the potential to end the life of an unborn child, that the 12 week scan can be carried out in such an ad hoc fashion requiring only verbal consent, with no process to ensure that the mother has been given enough information to make an informed decision. I am greatly worried about the process of putting women in a position where having an amniocentesis can be perceived to be the next “responsible” step, when they may be putting their babies at risk unnecessarily.

My partner and I have decided against seeing a genetic counselor, and I am not going to have the 2nd trimester blood screen. I feel that more intervention could lead to more intervention and perhaps more worry, worry that will affect my baby. I trust that this is the child I am meant to have, and I am very clear that I will definitely not have an amniocentesis. I only wish that I had been better informed so that I could have chosen not to have the scan, so that I didn't have to carry these numbers around with me in the back of my mind for the next 6 months. I can only hope that better information systems are put in place so more women are able to make a truly informed choice to have a more stress free pregnancy.

“Kate”
May 2007



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Post Script

Kate's story has a happy ending

The June issue of the newsletter featured the story of one woman's experience of having an NT scan. The MSCC is delighted to report that Kate gave birth to a healthy baby girl in the birthing pool at Birthcare in October.

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