

INFORMED CONSENT & ANTENATAL SCREENING

Kate's story is just the tip of the iceberg when it comes to the lack of informed consent around antenatal screening in New Zealand. As the number of tests and screening procedures being performed during pregnancy increases, due in part to developing technology and a variety of social changes, so too, does the complexity of trying to navigate one's way through the nine months of pregnancy.

Thirty years ago the piece of technology that inspired the most anxiety in pregnant women was the scales. Blood tests and urine tests about which women were told very little were nothing compared to that moment during an antenatal visit to the GP when a pregnant woman was asked to hop on the scales. Putting on too much or too little weight was all that most women had to worry about.

Things have changed dramatically in the past three decades. Pregnancy has now become a minefield in which women negotiate their way around an ever-increasing number of obstacles in order to prove to the satisfaction of health professionals that they and their baby are okay. Women today no longer embark upon the nine-month journey to motherhood with a sense of confidence, a feeling of well-being and a healthy optimism for the future. Increasingly they too look to the marvels of modern medicine to give them the reassurance they now seem to need that both they and their baby are fine. The normal excitement tinged with anxiety once experienced by most newly pregnant women has been replaced with something deeper and more sinister.

The current environment for pregnant women is now a fairly hostile one. In today's world pregnant women and their unborn children are not healthy unless an increasing number of screening tests have returned "negative" results saying they and/or their baby are probably fine. Pregnancy has become more like a potential illness that must be managed and sometimes treated. Even when test results are negative (meaning no problems have been detected) women often remain anxious or extremely worried. It is not until they hold a live, healthy baby in their arms that the anxiety about the baby begins to subside. There can be long lasting, even semi-permanent, side effects such as the reduction or loss of self-confidence, and the belief that her body cannot be trusted to grow this baby safely or give birth to it or feed it without further medical interventions. Reduced self reliance and increased levels of anxiety do not make for a healthy and positive start to motherhood.

One thing that has not changed much over the past few decades is the informed consent component to blood (serum) tests, ultrasound scans, and the various physical examinations that women are asked to undergo during their pregnancy. For example, the vast majority of women obligingly go for their first antenatal blood tests without knowing exactly what their blood is going to be tested for. Few women are aware that they are being tested for syphilis, for example. And these days a blood test is increasingly likely to include a test for HIV.

Antenatal blood tests

Five different tests are usually done on what are called the first antenatal bloods:

- Finding out the woman's blood group and Rhesus factor (positive or negative)
- Full blood count to check iron levels
- Checking to see if the Hepatitis B virus is present
- Checking to see if the woman has immunity to rubella
- Checking for syphilis

As already noted, the vast majority of women do not know they are being tested for syphilis, and there have been calls for other STIs (sexually transmitted infections) to be added to the above list, eg chlamydia.

Currently a sixth test – testing for HIV – is in the process of being included in the first set of blood tests. However, it is important that women are told that like all the other tests, it is optional. Unfortunately, many women are being tested for HIV without their knowledge or consent as many doctors have started ticking the box on the laboratory form without checking first with the woman as to whether she agrees to have an HIV test.

Ultrasound scans

As Kate's story so poignantly illustrates, many women having an ultrasound scan do not fully understand what the scan is really for, and are completely unprepared when they are told that they have been assessed as being high risk for carrying a baby with Down syndrome or with some other condition, or that an abnormality has been detected and diagnosed during the scanning process. Ultrasound scans have unfortunately become the norm during pregnancy and are now being heavily marketed as 'in utero' baby photos or first videos.

Polydose and Oral Glucose Tolerance Tests (OGTT)

Over the past 10 – 15 years screening for gestational diabetes has become a routine part of antenatal care for the majority of pregnant women. The first test is performed when the woman is 28 weeks pregnant and involves drinking 50g of glucose and having a blood test taken one hour later. If the blood glucose test is over a certain level the woman then takes an Oral Glucose Tolerance Test – a diagnostic test – which involves a woman fasting overnight and her blood glucose levels are tested with her not having eaten for 12 hours. She is then given 75g of glucose to drink and her blood glucose level is tested again two hours later. These tests carry their own physical “challenges” or stressors to both the mother and her unborn baby.

Screening for Domestic Violence & Sexual Abuse

There are also other kinds of “screening” being undertaken during pregnancy which include being asked about domestic violence, and sexual abuse. While this sort of questioning does not involve the type of physical invasion that blood tests, ultrasound scans and OGTT tests do, they are all part of an increasing number of risk assessments and diagnostic tests now being routinely carried out on pregnant women.

Unfortunately, because pregnancy is a time when women usually become frequent and regular “users” of primary health care, pregnant women are now being treated as targets for a rapidly increasing number of physical, emotional and social risk assessments. How much information is given and consent sought for all these tests has become a moot point as the lack of informed consent has not acted as a deterrent to more and more screening and diagnostic testing of women during pregnancy. How much any of this results in significant and measurable benefits to the mother and her baby is often debatable.



Pregnancy as a 9-month screening event

It seems that all it takes is one overly enthusiastic health professional with a bee in their bonnet about a particular issue, whether it be gestational diabetes, HIV, amniocentesis for Down syndrome, chlamydia,

or sexually transmitted diseases, and at some point the health system/Ministry of Health responds to the increasing pressure it is being subjected to and begins organising meetings, forming advisory groups, producing documents and eventually implementing yet another antenatal screening programme. In fact pregnancy now seems to have become the domain of the National Screening Unit. When the MSCC wrote a letter recently to Pat Tuohy at the Ministry of Health asking what systems had been put in place prior to the changes being introduced to the maternity schedule on 1 July, we got a response from the NSU!

At a recent advisory group meeting earlier this year a great deal of time was spent discussing how to get an accurate figure for the number of pregnant women in New Zealand each year, how the health system could capture the total number of pregnancies, including miscarriages and abortions, given that many women do not go to the doctor or go into hospital when experiencing a miscarriage. At some point towards the end of this discussion it seemed as if pregnancy had simply become a data-gathering event, and an opportunity for the health system to gather statistics and percentages.

The MSCC's main concerns around the increasing amount of antenatal screening, in addition to the long tradition of a lack of informed consent, are about the impact that such screening has on the woman and her experience of her pregnancy, the growing dependence on outside technology to confirm her health and that of her baby, and the ability of her body to care for her baby before birth, to give birth, and to breastfeed her baby after the birth. Pregnancy has now become a 9-month long medical event in which women are encouraged to subject themselves to frequent testing, data collection, and an increasing amount of technology in order to help guarantee a perfect baby, and a painless and stress-free birth.

The physical, emotional and psychological demands of pregnancy and birth are important and essential aspects of preparing women for the demands of motherhood. As Penny Armstrong and Sheryl Feldman wrote in their book "A Wise Birth" published in 1990:

*"We must question accepted truths and consider the possibility that the safest, healthiest births are not those that are medically managed. We must relinquish unnecessary dependence on technology and re-evaluate female reproductive capacity. **We might even have to reassert the importance of parenting work.** We must, in other words, take on the prevailing culture. It isn't easy, not only because it feels like it requires courage, but because it does in fact, require looking at our own culture as a stranger might see it."*

The current culture that surrounds pregnancy and birth is one that increasingly results in mothers who, having disengaged from these processes, then struggle with demands of nurturing and raising the child they have produced (as opposed to giving birth to). The plethora of books on taming babies ("baby whispering"), getting them into artificial and unnatural routines, "managing" and "controlling" them, as well as the growing number of TV programmes featuring childless women teaching mothers and fathers how to manage their out-of-control children are all powerful symbols of how disempowered women/parents have become when taking on one of the most important roles they will ever have. That women will be guided by such self-professed experts, some of whom have never given birth or raised their own children, is almost beyond belief.

As we begin to grapple with global warming, greenhouse gasses and carbon footprints, we would do well to consider the words of Michel Odent. At the end of his book "The Farmer and the Obstetrician" he commented that the current industrialisation of childbirth should become the main preoccupation of those interested in the future of humanity and the planet.

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