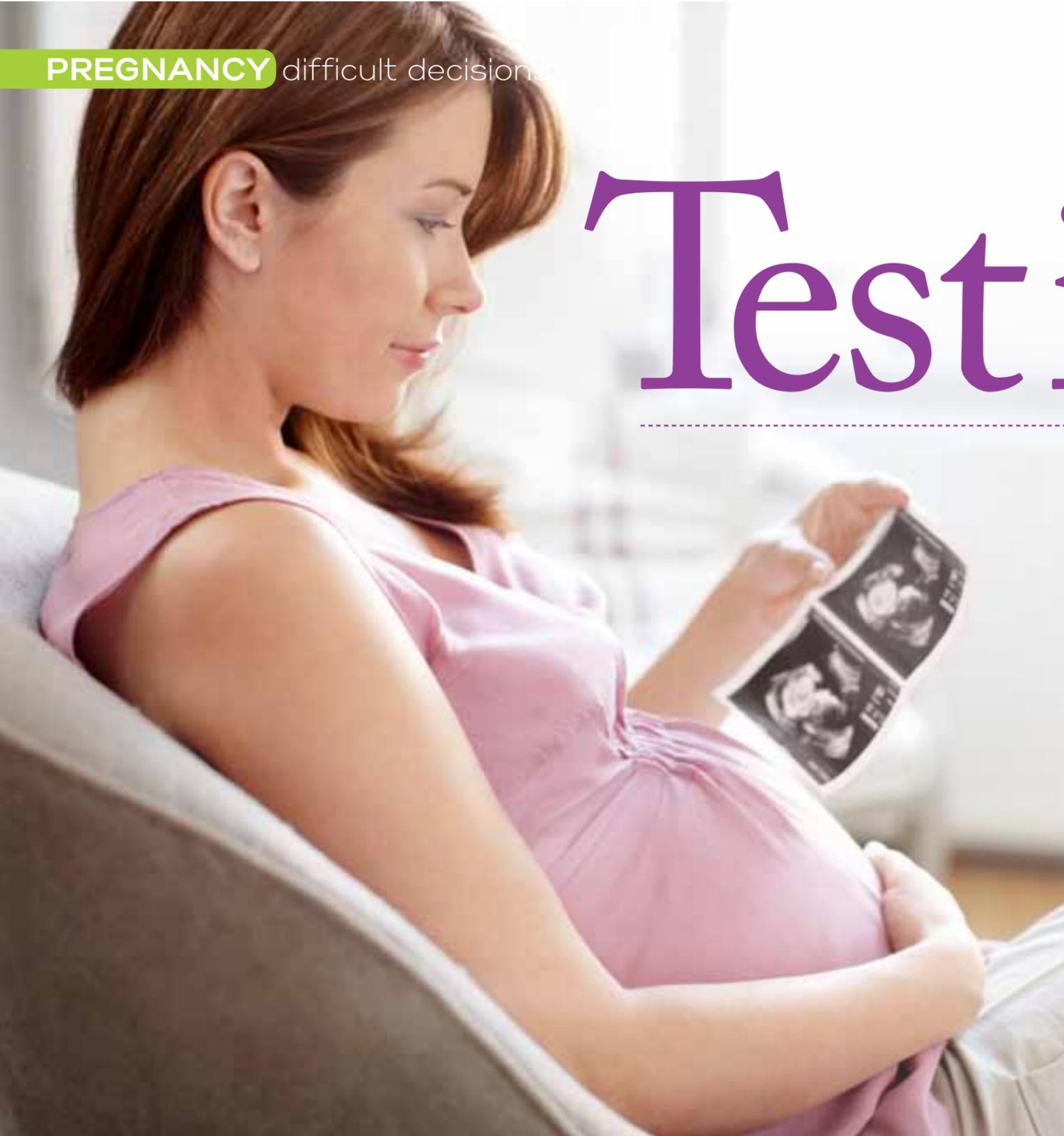


Testing *Times*



That month was one of the longest of my life. My husband and I tried in vain to put our fears to the back of our minds as we took off on our European babymoon. All I knew was that I didn't want to be faced with making any sort of 'decision' about the baby I already loved. Fortunately, the following scan showed my baby's brain to be perfect and the worry and stress, as it turns out, had been unnecessary. For some families, though, this isn't the case.

MODERN MEDICINE

"The advances with modern medicine are amazing, however they do put us into a position of being able to make many more decisions than the generations before us," says psychologist Dr Joann Lukins. "Sometimes it can be very difficult to think in hypotheticals, but in some ways this is exactly what this situation asks of parents."

There are three scans routinely carried out in modern pregnancies, though you may not experience all of them. The first is a dating scan, done as early as five weeks, to ensure the pregnancy isn't ectopic (outside the uterus) and also check for abnormalities such as blood clots which could indicate an impending miscarriage. It also allows the doctors to estimate how far along the pregnancy is.

The second, done between 11 and 13 weeks, is the nuchal translucency scan, which looks for congenital abnormalities, including Down syndrome and spina bifida. The third is the morphology scan, carried out between 18 and 20 weeks. This scan checks for structural abnormalities as well as the growth of the baby, and measures the amount of amniotic fluid around him.

More often than not, these pregnancy scans will confirm a healthy baby and give parents the precious experience of viewing their unborn child. Sometimes, though, abnormalities do show up. In these

cases, what parents receive is generally an indication of a potential problem, as opposed to a specific diagnosis.

For example, following the nuchal translucency scan, parents will find their bubs placed into either a high- or low-risk category for congenital abnormalities. "If your risk is lower than one in 300 we consider it to be 'low risk' and no further testing is usually needed at that time," says obstetrician Dr Danielle Gitsham. "If your risk is greater than this then you would be offered further investigations."

WHAT IF AN ISSUE IS DETECTED?

In the case of an abnormal result, depending on the condition, expectant parents will usually be offered either a follow-up scan or further testing to obtain a more accurate result.

"Your doctor may offer you an amniocentesis or chorionic villus sampling (CVS)," says Dr Gitsham, depending on the stage of pregnancy and potential issue. Amniocentesis involves inserting a needle through the mother's tummy under ultrasound guidance to obtain a sample of amniotic fluid to test, while CVS is where a needle is inserted either through the vagina or tummy to collect a small number of cells from the placenta. Both tests are optional and both come with their own set of risks, making the decision to proceed a difficult one.

When expectant mum Nicole Sima was told her baby was in the 'high-risk' category for Down syndrome following a routine scan, she was shell-shocked. "We sought expert advice from a radiologist and three different obstetricians, two of whom recommended we consider amniocentesis," she says Nicole.

The main risks with the testing procedure include miscarriage (less than 0.5 per cent for amniocentesis and one per cent for CVS), leakage of amniotic fluid, and limb deformities including club foot, due to the temporary interruption of blood supply to the baby during the procedure, if conducted in the very early stages of pregnancy. Another risk is that some of the baby's blood will cross into the mother's circulation, which can prompt the mum's immune system to launch a response against the baby.

"In the end, we found our risk rate of Down syndrome to be lower than the risk rates for an amnio," Nicole says. "For us, having already endured two agonising and traumatic miscarriages prior to each healthy pregnancy, a risky and invasive amnio wasn't an option. And we decided no matter what further testing revealed, we'd never abort our baby and would love it no matter what."

THE WAITING GAME

According to Dr Gitsham, many women do choose to go ahead with testing, regardless of their position on termination – while many women who receive bad news may go on to terminate, others continue with further testing with the intention of preparing themselves for the birth and what might lay ahead.

If you do decide to proceed with further testing such as amniocentesis or CVS, you can expect to wait a couple of weeks for complete results. In other cases, such as waiting for subsequent scans, you could

be looking at a month or more.

"It's a challenging time," says Dr Lukins. "The best you can do is reassure yourselves that you've done all you can do at this point. It's also useful for couples to acknowledge >

Today we have access to more information about our pregnancies than we've ever had before. But what if the results of tests and scans reveal bad news? **NICOLE MADIGAN** investigates

When the time came for my week-20 morphology scan, the only thing going through my mind was joyful anticipation. I longed to see my growing baby's arms stretch out and his tiny legs kick, and to marvel at his crinkly little face. So when I was told that my baby had a mild 'unilateral ventriculomegaly' – where one of the brain's ventricles, which contain cerebral-spinal fluid, measured larger than it should

– I felt my world begin to crumble. I was confused, bewildered and scared.

I was told the ventriculomegaly would do one of two things: either disappear or get worse. The latter would point to any one of a multitude of potential medical conditions as the cause, and most of them were extremely severe. We'd have to wait a month for a follow-up scan and if the condition remained, make a decision about how to proceed with the pregnancy.

"In the case of an abnormal result, expectant parents will usually be offered either a follow-up scan or further testing"

Pictures Getty Images, reader's own



to each other the stress of waiting and to understand it's a difficult time for both of you."

Once the results come in, if the outcome isn't what you'd hoped for you'll then be faced with the biggest decision of all. "If your baby does have an abnormality you are usually given two options, depending on the severity and the baby's prognosis. This is to terminate the pregnancy, or to continue the pregnancy," says Dr Gitsham.

THE MOST DIFFICULT DECISION

Typically there'll be a relatively short time frame in which to make this heart-rending decision, as termination can only be performed before a certain number of weeks into the pregnancy, depending on your state or territory's legislation. "Some couples can feel rushed. Seeking out accurate information and having good social support is crucial at this time," says Dr Lukins. "Working with a counsellor can greatly assist during the process."

If you do decide to terminate a pregnancy based on your test results, the first potential option is surgical termination, called a 'dilation and curettage' or 'D&C', where you're given an anaesthetic before your cervix is dilated and the contents of the uterus are suctioned out. "This procedure is only able to be performed earlier in pregnancy," Dr Gitsham explains. "Some places won't do this after 12 weeks gestation, but others will do it up until 16 weeks, so it's important to check your local hospital or abortion clinic's policy on this."

The other main option is a non-invasive medical termination of pregnancy using drugs. As of August this year, RU486 (the 'abortion pill') has been listed on Australia's

Pharmaceutical Benefits Scheme, and is used for early terminations within the first nine weeks of pregnancy.

If you're having a termination after 22 weeks gestation, some hospitals will perform a procedure where they inject the baby with medicine to stop the heart beating, after which there is the option to be induced and deliver, or to have the baby surgically removed. "All hospitals have their own process and policies for termination of pregnancy, though, so it's very important that you ask about these," Dr Gitsham reminds.

If you do need to travel any of these difficult roads, make use of the emotional support available. "It's important as a couple to talk and talk and talk," says Dr Lukins. "Counselling is also important and is there to address any guilt or trauma, to help you debrief and to work through how to come to terms with the decision you've made."

IS IGNORANCE BLISS?

With all the stresses and strains that come with the abundance of information we now receive during pregnancy, it's tempting to long for our mothers' era when scans were reserved for special circumstances – I know I've felt this way. However, too much information is better than too little, and routine scans can be potentially life-saving. Detecting a problem now means management plans can be put in place, for both you and your child. "For example, if a condition is found in the baby that will require immediate care after birth, a mum may be offered a caesarean and we know to have paediatric doctors and surgeons standing by to treat the child," says Dr Gitsham. "Had the condition not been detected during pregnancy, the baby might not have as good a prognosis." ★

"I WAS ANGRY, BITTER, SCARED"

When Tristan Fahey fell pregnant with her first baby, she and her husband were overjoyed. "We blindly went to have the 12 week scan, excited to see our little bubba," she recalls. Instead, they were told their baby had a high risk of Edwards syndrome, a life-threatening chromosomal abnormality. "The experience was one that shook me to the core."

Tristan and her husband agreed to further testing to obtain an accurate result and following an excruciatingly painful four-week wait, their worst fears were confirmed.

"I was at first numb. I remember the doctor called it a 'lethal pregnancy' and said that babies with Edwards syndrome didn't survive. Then I sobbed and sobbed, and screamed. I was angry, bitter, scared and confused," Tristan says.

"I was surprised at how resistant I was to terminating a life. I needed to hear the words 'guaranteed not to survive' in order to be comfortable about this traumatic decision."

After much soul-searching, research and seeking advice, Tristan decided to have her pregnancy terminated. "I felt physically empty, like a part of me had been ripped out," she says. "Emotionally, it was a full two years before I got through the sharpness of the grief and loss."

Tristan now has two beautiful children, aged six and four (pictured below), but says while her family brings her endless joy, they aren't a replacement for the child she lost.

"I still mourn the loss of my little boy and that I didn't get to parent him and teach him all about life. But I feel no guilt or shame about the decision because of the advice I'd been given. I live in the contentment that my Billy is dancing in heaven with his nana and we have two beautiful, loving kids."

