



PRE-NATAL TESTING

Caring for your unborn child?

EVERY PARENT HOPES AND PRAYS their unborn child will be healthy. And with the aid of modern medicine, pre-natal care for pregnant women and their babies continues to advance in new and amazing ways. If a mother or her baby faces a potential health problem during pregnancy, these problems can usually be identified prior to birth and treated as effectively as possible. Ultrasounds can be particularly helpful in these circumstances and play an important role in good pre-natal care.

“before
I formed
you in
the womb
I knew you
Jeremiah 1:5”

However, with the rise of pre-natal screening of unborn children for the conditions of Down syndrome (Trisomy 21) and Edwards syndrome (Trisomy 18), pregnant women are now asked a question their mums and grandmothers never had to face: “Will you have the tests?”

Pre-natal screening and diagnostic testing have expanded exponentially over the past decade. Following recommendations of the professional obstetrician associations in the UK, US and Australia, screening is now offered routinely to pregnant women, even though 99.7 % of unborn children do not have Down syndrome and Trisomy 18 is even rarer.¹

Today, many pregnant women feel pressure to agree to have these tests. But they are also troubled by the implicit messages contained in pre-natal screening and the consequences that may follow. They wonder, “If my baby has Down’s, does that mean my baby should not live? That it would be better to have an abortion?” Tragically, evidence shows that pre-natal screening and diagnostic testing have resulted in the loss of the lives of many unborn children; a Queensland study in 2004 found that following pre-natal screening, 90% of babies with Down syndrome were aborted.²

Pre-Natal Testing: What does it involve?

The term "Pre-Natal Testing" is often used generically to refer to both pre-natal screening and diagnostic testing, but these are actually two different kinds of tests. Pre-natal screening is widely available in most regions of Australia. During the first 12 weeks of her pregnancy, an expectant mother will be offered what is known as the **Combined Test** or **Combined First Trimester Maternal Serum Screening**. This Combined Test consists of two elements:

- A blood test, conducted at 10-12 weeks. In addition to screening for health problems in the mother, a pathologist will test a mother's blood sample for two specific proteins where elevated or decreased levels may indicate a higher possibility her baby might have Down syndrome or Trisomy 18; and
- A special ultrasound called a Nuchal Translucency Scan (NT Scan) that is conducted between 11 to 13 weeks of pregnancy. This scan measures the thickness of the nuchal fluid on the baby's neck, where thicker levels may indicate an increased possibility of Down syndrome or Trisomy 18.

The combined information gained from the blood test and the NT scan is then given to the mother as a result. If women are not offered the Combined Test in their first trimester of pregnancy, they may be offered instead a blood test during their second trimester, known as the **Triple Screen** or **Quad Screen**.

These screening tests cannot tell parents if their baby has Down's or Trisomy 18; all they can do is tell them that their baby is at "low risk" or "increased risk" of one of these conditions. Following first trimester screening, one in 25 mothers will be told they are at "increased risk".³ "Increased risk" means

the possibility an unborn baby has Down syndrome or Edwards syndrome is 1 in 300 or greater.⁴



What happens when a woman is told her baby is at "increased risk"?

A pregnant woman who receives a result of "increased risk" will then be offered a **diagnostic test**, such as **Chorionic Villus Sampling (CVS)**, or, more usually, **Amniocentesis**. These tests can provide a diagnosis that is around 98% accurate, but they are considered invasive and carry a small but significant risk of the baby dying from miscarriage (around 1 in 100).⁵

Ultrasound later in pregnancy is a valuable and non-invasive diagnostic tool. From around 20 weeks onwards, many health issues in mother or baby can be identified and a treatment plan developed. Conditions such as Down syndrome, neural tube defects and heart conditions can be picked up in a second trimester ultrasound and other tests that form part of standard pre-natal care.

This can allow families time to accept the diagnosis and prepare to care for and support their child.

Why, then, is testing offered so early in pregnancy? The tragic answer is because early diagnosis prior to 20 weeks provides a ready opportunity for an abortion which is deemed to be "less traumatic" to all concerned...except the baby.

The Church's criteria for pre-natal testing

Based on natural justice, the Church teaches that pre-natal testing and diagnosis is acceptable if all the following criteria are met:

1. It respects the **life and integrity** of the unborn child;
2. It is directed towards the child's **safeguarding or healing** as an individual;
3. The child's parents are provided with sufficient information to weigh the risks and benefits of testing and make a **free and informed** decision; and
4. The **risk** to the child's life or health is proportionate to the **benefit** the child may receive from the test.⁶

Hence, providing pre-natal testing with the intention of then offering pregnant women the choice of abortion if they receive a positive test result is "gravely opposed to the moral law".⁷ Pre natal investigations must aim to provide life-affirming treatment options. A diagnosis of Down syndrome or other condition "must not be the equivalent of a death sentence."⁸

No benefit to baby

Although in-utero treatments for various conditions, including Down syndrome, are being developed,⁹ **the critical issue with early pre-natal testing is that it currently offers no therapeutic benefit for the baby. The only option offered to parents for "treating" the baby's condition is abortion.** Practices designed to eliminate children with disabilities or prevent them from being born alive are condemned by the Church as a grave evil, contrary to human dignity, the preciousness of human life and the right of a child to be loved and cared for, whatever their condition.¹⁰ **Early pre natal screening at 10-12 weeks currently offers no medical benefit to mother or baby, but often creates momentum for a subsequent decision to have an abortion.**

“The critical issue with early pre-natal testing is that it currently offers NO therapeutic benefit for the baby”



When is it okay to have pre-natal testing?

Some parents want to know if their unborn child has Down syndrome or another condition, because a diagnosis would give them time to prepare, physically and emotionally, for the birth of their child. This can be a good and valid reason for pre-natal testing – in the words of John Paul II, to help the family towards “a serene and informed acceptance of the child not yet born”.¹¹

At the present time, however, conducting a diagnostic test poses a real and significant risk to the life of an unborn child. The greater the risk to the vulnerable unborn baby, the more justification for a test is required. Amniocentesis should be justified only by “a truly urgent need for the diagnosis” and by “the importance of the results that can be achieved by it for the benefit of the unborn child himself”.¹² Sadly, because there are currently no pre-natal treatments available for Down syndrome or Trisomy 18, the unborn child can derive no benefit from this test; it will only place their life in greater danger, from either miscarriage as a result of the test or from intentional abortion.

Acceptance of children the responsibility of everyone

The rise of pre-natal testing has led, tragically, to a climate where the acceptance of unborn children is conditional, where their lives will not be valued or cared for if they are somehow “defective” or suffering a health problem. As followers of Christ, we are called to proclaim the *Gospel of Life*¹³ – to love and accept our children unconditionally and encourage others to do the same. The Church understands the tremendous challenges families face in welcoming and raising a child with disabilities. As a Christian community, we are called to provide practical support, friendship, prayer and encouragement to ensure that these families are not left to bear this burden alone. As one father regretfully explained, “We just needed someone to tell us, *You can do this. You can raise this child. You will be okay.*”

“we just needed someone to tell us, you can do this. You can raise this child.”

The true good of children

Every child is a gift from God, to be cherished and protected from their earliest moments. The Church recognises the noble calling of the medical profession to treat sickness and disability, but it must always do so in a context of profound respect for the core value of a child's life. As Pope Benedict XVI has reminded us:

*The focus of every medical intervention must always be to achieve the true good of the child, considered in his dignity as a human being with full rights. Thus it is always necessary to care for him lovingly, to help him to face suffering and sickness, even before birth, as his situation requires.*¹⁴

There are many wonderful families, organisations and caring medical and health care professionals willing to help and support parents to welcome their unborn child with special needs. The Church is pastorally concerned to do whatever it can to support these families through its parishes, schools, health care and respite services. With respect, nurture, opportunities and love, children with Down syndrome and other genetic conditions have grown to live healthy, happy and fulfilling lives. Their presence among us is the best hope for society to change and fully restore a true ethic of healing and care to pre-natal testing.

Family growth through love

One proud father of a child with Down syndrome is Richard Wilkins, the popular and award-winning entertainment journalist. Richard has spoken publicly of the tremendous value of his son's life and the impact 39-year-old Adam has had on his family's life. "I don't know what I would have done if I had known in advance that Adam was Down syndrome. Well, I probably do know what we would have done, and that would have been a dreadful mistake. Blessings come in unlikely packages and he is such a joy. My other children have also grown up realising that life can be different and wonderful. Adam has taught them a real tolerance. All of my children are my greatest achievements in life and I'm enormously proud of them all."

(Woman's Day, 2 July 2012)

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Lisa's Story

I was devastated when I got the test results. The look on my doctor's face and his tone of voice made me feel like it would be something terrible to have a baby with Down's. I didn't know there was help and support available, and my doctor didn't offer me that information. Most of all, I didn't know the love I would feel when I held my child in my arms for the first time.

Looking back, I wish I could have spared myself and my husband the anxiety of the tests. We thank God every day for our precious daughter. Her unconditional love makes us more patient and forgiving of others. When life is hard, her smile makes everything okay and her gentle spirit makes us strong. I can't wait to see the plans God has for her.

Resources

Pre-Natal Testing

A 2012 resource from the Bishops' Commission for Doctrine and Morals, Australian Catholic Bishops Conference.

Prenatal Tests by Agneta Sutton, Linacre Centre/CTS, 2007

Be Not Afraid

An outreach to parents who have received a poor or difficult prenatal diagnosis: Catholic families share their stories and support. www.benotafraid.net

International Down Syndrome Coalition for Life

www.idscforlife.org

Down Syndrome NSW

This organisation for people with Down syndrome and their families has an excellent website with extensive list of resources, videos and information about events and how to contact other families. www.downsyndromensw.org.au

Down Syndrome NSW Parent Support Team

Ph: 9841 4401

99 Balloons

(a dad's tribute to his baby boy, Eliot, who had Trisomy 18) www.youtube.com/watch?v=th6Njr-qkq0

Kelle Hampton blog

(shares the story of her Down's daughter Nella)

<http://www.kellehampton.com/p/nellas-birth-story.html>

If People with Down Syndrome Ruled the World

(by a doctor who specialises in treating adults and children with Down's) http://www.nads.org/pages_new/news/ruletheworld.html

10 Ways a Baby with Down Syndrome Will Improve Your Life

(by a mother of adult daughter with Down's) <http://doloresmonet.hubpages.com/hub/10-Ways-A-Baby-With-Down-Syndrome-Will-Improve-Your-Life>

A Gift of Time

by Amy Kuebelbeck and Deborah L. Davis
A gentle and practical guide for parents who decide to continue their pregnancy knowing that their baby's life will be brief. http://perinatalhospice.org/A_Gift_of_Time.html

Perinatal Palliative Care

Hosted by Catholic Health Australia, this website provides links to perinatal palliative care services in Australia for families whose unborn child is expected to live only a short time after birth. Perinatal palliative care recognises the unique needs of these children and their families and assists them to live to the full the time they will have together. www.pnpc.org.au

¹ J.K. Morris & Eva Alberman, Trends in Down's syndrome live births and antenatal diagnoses in England and Wales from 1989 to 2008: analysis of data from the National Down Syndrome Cytogenetic Register. *BMJ* 2009; 339:b3794.

² Michael D Coory et al, Antenatal care implications of population-based trends in Down syndrome birth rates by rurality and antenatal care provider, Queensland, 1990–2004. *MJA* 2007; 186 (5): 230-234.

³ http://www.health.wa.gov.au/docreg/Education/Prevention/Genetics/HP3131_prenatal.pdf

⁴ RANZCOG Statement on Prenatal Testing. <http://www.ranzcog.edu.au/the-ranzcog/policies-and-guidelines/college-statements/412--prenatal-screening-tests-for-trisomy-21-down-syndrome-trisomy-18-edwards-syndrome-and-neural-tube-defects-c-obs4.html>

⁵ R. Douglas Wilson et al, "Mid-Trimester Amniocentesis Fetal Loss Rate", *Canadian Society of Obstetricians and Gynaecologists*, No 194, July 2007.

<http://www.sogc.org/guidelines/documents/gui194CPG0707.pdf>

⁶ Donum Vitae, Congregation for the Doctrine of the Faith, para 1.2.

⁷ Ibid.

⁸ Ibid.

⁹ Donna K. Slonim et al, "Functional genomic analysis of amniotic fluid cell-free mRNA suggests that oxidative stress is significant in Down syndrome fetuses", *Proceedings of the National Academy of Sciences*, 27 May 2009.

¹⁰ Catechism of the Catholic Church, #2268; The Gospel of Life, para 14.

¹¹ *Evangelium Vitae*, para 63.

¹² John Paul II, Discourse to Participants in the Pro-Life Movement Congress, 3 December 1982.

¹³ *Evangelium Vitae*, para 6.

¹⁴ Address on Caring for Sick Children, Pontifical Council for Health Care Ministry 23rd International Conference, 21 November 2008.

<http://www.zenit.org/article-24322?l=english>