CHILDREN BY CHOICE
ASSOCIATION INCORPORATED

Protecting the health care of pregnant women in the second trimester

Response to Proposal to remove Medicare Item No. 16525

KEY POINTS

- In Australia, it is estimated that 94% of terminations occur in the first trimester, and that only 0.7% occur at 20 weeks or later.

USE OF ITEM No. 16525

- Medicare Item 16525 recognises the medical care provided to pregnant women in their second trimester (14 -26 weeks) who experience diagnosis of intrauterine fetal death, gross fetal abnormality and life threatening maternal health condition.

- The Medicare Item no. 16525 can only be utilised by private medical practitioners providing care to patients in a private hospitals or private patients in public hospital. Removal of the Medicare item number will not affect these services when provided in public hospitals. It is a cynical attempt that will punish pregnant women accessing care outside of the public hospital system.

- Much misinformation surrounds the use of Item No. 16525. It is not used by medical practitioners in private clinics in Brisbane and Melbourne providing surgical termination of pregnancy in the second trimester as was claimed in Senator Barnett's briefing paper.

- If the aim of removal of Item no. 16525 is to restrict termination of pregnancy over 20 weeks it is unnecessary and unwarranted. Second trimester medical termination for fetal abnormality over 20 weeks gestation is generally heavily regulated via legal restrictions, hospital review panels and committees, along with doctors working in team consultation with their colleagues.

- Management of second trimester labour with induction is an accepted international and Australian medical practice for termination with serious medical conditions.

FETAL VIABILITY

- Despite medical advances, fetal viability in the late second trimester remains very low and outcomes of survival are extremely poor. Since 1990 there has been no improvement the survival rate of infants born before 24 weeks.

- Despite medical advances, fetal viability in the late second trimester remains very low and outcomes of survival are extremely poor. The British Association of Perinatal Medicine regards the minimum threshold for viability to be at 22- 26 weeks - this is known as a "grey zone". There is very little chance of survival at 22 weeks, survival at 23 weeks is very rare and still low at 24 weeks. Infants delivered prior to 26 weeks of gestation face a high risk of death and lifelong severe disability. In NSW and ACT it is acceptable medical practice not to initiate intensive care during the "grey zone" at the parent's request and after appropriate counselling.

ABORTION AND MENTAL HEALTH

- The Fergusson study finding in relation to young women's mental health following abortion has been criticised internationally for flawed methodology. The American Psychological Association has reviewed 20 years of evidence in relation to abortion and mental health (including the Fergusson study) and concluded that the risk of mental health problems is no different for women terminating a pregnancy or carrying it to term. It also found that women who experience miscarriage, still birth, death of a new born or termination of a wanted pregnancy due to fetal abnormality have equivalent negative psychological reactions but these are less than women who deliver a child with life-threatening abnormalities. Organisations such as SANDS provide emotional and practical support to women who have experienced this form of reproductive loss.

FETAL ABNORMALITY

- Best practice medical care of pregnant women in Australia and internationally now incorporates the offer of routine antenatal screening for fetal health and abnormality. RANZCOG offers guidelines to practitioners on counselling and information giving around antenatal screening, including the option of termination of pregnancy following the diagnosis of a severe abnormality and/or life threatening medical condition of the fetus. Item no. 16525 recognises this important component of providing medical care to pregnant women in their second trimester**.**

- Antenatal screening commences in late first trimester. If women are diagnosed at being higher risk for these certain fetal abnormality conditions, further testing such as Amniocentesis and Chorionic Villus Sampling can be undertaken in early second trimester. All pregnant women undergo a routine ultrasound scan at 19-20 weeks pregnancy for structural fetal abnormalities, in particular neural tube defects, and pregnancy wellbeing. Many lethal and severe fetal abnormalities cannot be detected until this time.

- Following a positive diagnosis of serious abnormality many women will have further tests to confirm diagnosis and outlook, consider options of medical treatment with their doctors, find out what support is available if pregnancy continues and take some time to absorb the information and make a decision. Some hospital and other services offer counselling and support at this time for women.

- The diagnosis of severe abnormality can be very difficult and distressing experience for women and their partners. According to a British Medical Association report: *'Once a diagnosis has been made, parents experience deep shock at the loss of what they had believed previously was a normal pregnancy, whatever the abnormality and whatever the decision they subsequently make. In shock, and experiencing symptoms of acute grief including anger, despair, guilt, inadequacy, sleeping and eating difficulties they have no choice but to make decisions about the management and outcome of the pregnancy*.'

- Decisions about the fate of pregnancies in which the fetus has been diagnosed with a lethal abnormality or serious disability are difficult and very personal ones. They are decisions that can only be made by the woman and her family based on their own situation and values.

- The Victorian Women with Disabilities Network is pro choice, and recognises the right of all women, including women with a disability, to choose whether or not to have an abortion. It also advocates for better access, education and counselling to be provided regarding the effect of having child with a disability and improved access to adequate support services for the parents of children with a disability.

INTRAUTERINE FETAL DEATH

- In 2005 there were 1411 fetal deaths in Australia. Fetal deaths are recorded at 20 weeks or greater gestation or if over 400 grams weight. Fetal demise earlier in the second trimester is not recorded. Fetal death can be caused by a maternal health condition (such as very serious complications from diabetes), lethal fetal congenital abnormality, or for medically unexplained reasons.

MATERNAL DISEASE

- Some women experience life threatening disease during pregnancy, such as heart disease or a cancer diagnosis. In some cases, women and their doctors may consider that it is in the best interests of their continuing life and health to terminate the pregnancy. This is an extremely difficult decision for women, their families and their doctors.

WOMEN'S STORIES

Fiona's story…

My name is Fiona. I am 34 years old and married to Max. I have a 2 year old son and am currently 7 months pregnant with our second child.

In 2003 I found out I was pregnant. The pregnancy was an unplanned gift for both of us and we were overjoyed. We had tests early on in the pregnancy and everything seemed normal. We discovered we were having a little girl and we decided to call her Rachael.

But our joy was short-lived. A routine ultrasound at 18 weeks revealed the first hint of problems. A visit to a specialist soon revealed our baby's heart was covered in inoperable tumours.

The specialist told me our baby would die inside me or as she was being born. I was 20 weeks pregnant and needing time to think but there wasn't any time. I felt depressed and nearing a nervous breakdown.

We made the difficult decision to terminate.

Whether it's a 16-year-old girl who decides to terminate her pregnancy for whatever reason, or a 30-year-old whose baby is dying, that is a very personal thing. No-one should butt in, especially not a politician. You've got to decide what you think is right for yourself.

No-one else could have decided that for me. I was the one carrying that baby. I was the one suffering. It was my loss, it was my grief, I had to deal with it the only way I knew how to.

Ella's Story….

My name is Ella. I live with my husband and 3 children, aged 8, 5 and 3. We fell pregnant with our second child, James, in 2001 – a very much-wanted baby. I had no problems with my first pregnancy so I had no inkling that anything would be wrong with my second until we got to the 12 week scan.

At the 12-week scan they first identified an exomphalos abnormality. This meant that all of his internal organs were developing outside of his body.

Also at the 12-week scan they detected a very thick nuchal fold and potential heart defects. A CVS revealed severe chromosomal problems. We had several meetings with the geneticists about the chromosomal problems but, as they had never seen such a case before, they just couldn't tell us in any detail what to expect, and this was incredibly frustrating.

The team doing the ultrasounds recommended that we came back in 2 weeks time when our baby's heart would be bigger. I wasn't prepared to make the decision not to keep the pregnancy at that time so I was prepared to wait. I waited until 16 weeks. It was absolute torture because I was looking more pregnant and I could feel him moving.

I kept asking myself 'if he survived the operation to put his organs back in, what kind of a life would he have?'. I've never regretted it. For me the most important thing now is to continue acknowledging him.

Some women lose children they have had for some time and that is tragic beyond belief. I lost the dream of a child and I think that is equally devastating. Unfortunately there was no positive or concrete answer. At 16.5 weeks we decided not to continue with the pregnancy. It was the worst thing I could ever imagine doing.

Further Information:

RANZCOG, College Statement March 2007– *Prenatal Screening tests for Trisomy 21 (Downs Syndrome), Trisomy 18 (Edwards Syndrome) and neural tube defects*. www.ranzcog.edu.au

AIHW, *Australia's Mothers and Babies 2005* http://www.npsu.unsw.edu.au/

BMA, *Briefing Paper - Abortion Time Limits – Diagnosing Fetal Abnormality* May 2005. http://www.bma.org.uk/ap.nsf/Content/AbortionTimeLimits~Factors~Diagnosing

Victorian Law Reform Commission, *Law of Abortion – Final Report*, March 2008.

Prochoice Forum *Late Abortion: A review of the Evidence.* www.prochoiceforum.org.uk

Royal College Obstetricians and Gynaecologists, *The Care of Women Requesting Induced Abortion,* 2004. www.rcog.org.uk

Royal College Obstetricians and Gynaecologists, *Briefings and Q&A - Human Fertilisation and Embryology Bill* 2008 www.rcog.org.uk

Lui, K e tal, *Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop* MJA 2006; 185 (9): 495-500