I have a dream

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Every day across the globe at least 7,300 babies are stillborn…

I have a dream…
I have a dream…

to end preventable stillbirth

What needs to happen to make my dream a reality?

A Paradigm Shift

- Think of a Paradigm Shift as a change from one way of thinking to another. It’s a revolution, a transformation, a sort of metamorphosis. It just does not happen, but rather it is driven by agents of change.
WHAT NEEDS TO CHANGE?

• PUBLIC AWARENESS THAT STILLBIRTH HAPPENS

• PREGNANT WOMAN AWARENESS OF WHAT TO LOOK OUT FOR AND WAYS TO PROTECT HERSELF AND HER BABY DURING PREGNANCY

• CARE PROVIDERS IMPROVED AWARENESS OF RISK FACTORS AND WHAT TO LOOK OUT FOR, TAKING CARE TO LISTEN TO WOMEN AND APPROPRIATELY RESPOND TO THEIR CONCERNS

AWARENESS

THERE IS LACK OF AWARENESS

- [Table or chart]

PREGNANT WOMAN AWARENESS

BUT

WHY DON'T WE TALK?

We don't talk about stillbirth because...

- Superstition
- Stigma
- Helplessness
- We will make the woman anxious
- It's only a baby
- We don't talk about stillbirth because...
THERE IS LACK OF AWARENESS


WHY DON'T WE TALK?

We don't talk about stillbirth because...

- We make the woman anxious
- The baby is only a baby
- Superstition
- Stigma
- Helplessness

There is a lack of awareness of stillbirth.
WHY DON'T WE TALK?

We don't talk about stillbirth because...

- Superstition
- Stigma
- Helplessness
- Its only a baby
- We don't talk about stillbirth because...
- We will make the woman anxious

THERE IS LACK OF AWARENESS


COMPARING SIDS TO STILLBIRTH

- NO KNOWN CAUSE
- PROBABLY MULTIFACTORIAL
- POTENTIAL TO MAKE PEOPLE ANXIOUS AND UPSET

- NO KNOWN CAUSE
- PROBABLY MULTIFACTORIAL
- POTENTIAL TO MAKE PEOPLE ANXIOUS AND UPSET
• WHAT CAN WE LEARN FROM THE SUCCESS OF THE REDUCTION IN SIDS?
• WE STILL DON'T KNOW WHAT CAUSES SIDS
• BUT
• WE HAVE WORKED OUT HOW TO PROTECT THE VULNERABLE BABY BY RECOMMENDING ALL BABIES ARE PUT TO SLEEP ON THEIR BACK

Lessons from reduction in SIDS deaths

• Public Awareness
• Simple do-able message

AWARENESS CAMPAIGN

• THE PUBLIC HEALTH PROMOTER ASKS:
  • WHY MIGHT THE AUDIENCE BE MOTIVATED TO DO WHAT YOU ARE ASKING THEM TO DO?

• IN ORDER TO PERSUADE PEOPLE TO DO SOMETHING WE MUST FIRST MAKE THEM AWARE OF THE ISSUE AND GIVE THEM FACTS (BROWN & EINSIEDEL 1990) FACTS LIKE HOW COMMON STILLBIRTH STILL IS
WHAT IS THE MESSAGE?

• STILLBIRTH HAPPENS (WHY?)
• AWARENESS (GETTING TO KNOW AND ADVOCATE FOR THE BABY)
• FETAL WELLBEING (INC. MOVEMENT)
• EMPOWERED TO ACT (THINGS TO ASK YOUR CARE PROVIDER)

TOMMY'S

• ALWAYS ASK

Practical tips from other women on how to get listened to and be taken seriously when you have a concern in pregnancy. Find out more about speaking up in pregnancy: https://www.tommys.org/alwaysask

STILLAWARE

...
The campaign highlights the importance of keeping safe during pregnancy to reduce the risk of stillbirth and aims to help expectant mothers and healthcare professionals talk about what can be done to keep safe.

http://www.1000livesplus.wales.nhs.uk/safer-pregnancy

WHAT CAN MATERNITY CARE PROVIDERS DO?

- MATERNITY CARE PROVIDER EDUCATION, SUPPORT AND AWARENESS
- AWARENESS OF RISK
- ADVOCACY
  - FETAL GROWTH
  - MATERNAL PERCEPTION OF FETAL MOVEMENTS
  - MATERNAL INTUITION
  - MATERNAL SLEEP POSITION

AWARENESS OF RISK
CURRENT IDENTIFIED RISK FACTORS INCLUDE:

- Advanced Maternal Age
- Nulliparity
- Obesity
- Ethnicity (e.g., South Asian, African American)
- Cigarette Smoking
- IVF Pregnancy
- Previous Stillbirth
- Low Socio-Economic Status
- Reduced Antenatal Care Attendance
- Reduced Fetal Movements
- Fetal Growth Restriction

PROBLEMS

- Aaest effect size
- Few amenable to modification in pregnancy

RISK FACTORS FOR STILLBIRTH

- AS A AMARASINGHE
- AGE 36 LAWYER
- PRIMIP (G1P0)
- MEDICAL HISTORY: NIL SIGNIFICANT
- FAMILY HISTORY: NIL SIGNIFICANT
- SMOKING: CURRENT (8 - 10 DAY)
- SUBSTANCE USE/ ALCOHOL: NO
- HEIGHT: 155 CM; WEIGHT 105 KG (BMI 43.7)
- IVF PREGNANCY (SINGLE FRESH EMBRYO) PCOS
- SINGLETON PREGNANCY
RISK FACTORS FOR FGR

MRS C SULLIVAN
AGE 39 LAWYER
MULTIP (G2P1) LAST BABY NOW 3 YEARS OLD WEIGHED 2480 GM AT TERM
MEDICAL HISTORY: PAPP-A <0.4 MOM
FAMILY HISTORY: (HUSBAND WAS A "SMALL BABY")
SMOKING: NIL
SUBSTANCE USE/ ALCOHOL: NO
HEIGHT: 157.5 CM; WEIGHT 50 KG (BMI 19.5)
VIGOROUS EXERCISE DAILY (GYM JUNKIE)
SINGLETON PREGNANCY

RISK FACTORS FOR FGR

MAJOR RISK FACTORS
- SMOKER ≥ 11 PER DAY
- COCAINE AND ILLICIT DRUG USE
- DAILY VIGOROUS EXERCISE
- MATERNAL AGE ≥ 40
- PREVIOUS SGA
- MEDICAL CONDITIONS INCLUDING (HYPERTENSION, DIABETES, VASCULAR DISEASE, RENAL IMPAIRMENT)
- PAPP-A <0.4 MOM
- ANTIPHOSPHOLIPID SYNDROME
- UNEXPLAINED APH
- DEAEY BLEEDING SIMILAR TO MENSES
- ECHOCARDIOGRAPHIC ABNORMALITIES
- LOW MATERNAL WEIGHT
- UNFIT FOR SPH (CERVE, FIBROIDS...)

MINOR RISK FACTORS
- BMI <20 OR BETWEEN 25-29.9
- SMOKER 1-10 PER DAY
- LOW FRUIT INTAKE PRE PREGNANCY
- MATERNAL AGE 35-39
- NULLIPARITY
- PATERNAL SGA
- PREGNANCY INTERVAL LESS THAN 6 MONTHS OR MORE THAN 30 MONTHS
- PATERNAL SGA

FGR workshop PSANZ and SANDA 2017
RISK FACTORS FOR FGR AND STILLBIRTH

- Age 39
- Lawyer
- Multip (G2P1) last baby now 3 years old weighed 2480 gm at term
- Medical history: PAPP-A <0.4 mom
- Family history: (husband was a "small baby")
- Smokers: nil
- Substance use/alcohol: no
- Height: 157.5 cm; weight 50 kg (BMI 19.5)
- Vigorous exercise daily (gym junkie)
- Singleton pregnancy

BUT
• THE PROBLEMS ARE:
  • TERM TO FIND THE SMALL
  • THEN FIND THE GROWTH
  • RESTRICTED NOT SMALL (AT RISK
  • APPARENTLY AGA)

We have to find this And perhaps that... using nothing but this

AND
WHY BOTHER?

- SGA fetuses not identified before delivery were characterized by a four-fold increased risk of adverse fetal outcome (odds ratio, 4.1, 95% CI, 2.5-6.8) (Lindqvist & Molen 2005)
WHATEVER METHOD IS USED, THE BENEFITS OF DETECTING FETAL GROWTH DISORDERS CAN ONLY BE REALIZED IF WE CAN EFFECTIVELY REDUCE RISK OF COMPLICATIONS. AT THE MOMENT, DELIVERY IS THE ONLY WAY OF DOING THIS. EVEN USING OPTIMIZED CHARTS AND_THRESHOLDS, WE ARE LIKELY TO OVERINTERVENE IN MANY NORMAL CASES TO PREVENT COMPLICATIONS IN THE FEW. ULTRASOUND ASSESSMENT OF FETAL GROWTH HAS LIMITATIONS, AND BETTER METHODS OF RISK PREDICTION ARE NEEDED TO PREVENT DEATH AND DISABILITY IN BABIES.

PARADIGM SHIFT?

A unique placental transcriptome is detectable in maternal blood at 26-30 weeks' gestation in pregnancies destined to develop late-onset FGR. Circulating placental RNA may therefore be a promising non-invasive test to identify pregnancies at risk of developing FGR at term.

FETAL MOVEMENTS
DECREASED FETAL MOVEMENTS (DFM)

- A quarter of women who present with DFM have adverse perinatal outcomes such as growth restriction and stillbirth. (Peat et al. 2012)
- 42.6% women who experienced a late-term stillbirth presented with DFMs at some time in their pregnancy compared to 9% of live born controls. (Stacey et al. 2011)

STARS STUDY

- Online survey
- Cohort study design with nested case-control arm
- Cohort: 1,714 women who had experienced a stillbirth >3 weeks prior to enrolment completed the survey
- Case-control: 153 cases who had a stillbirth ≤3 weeks prior and 480 controls who had had a recent live birth or who were still pregnant.

SUMMARY OF STARS STUDY FM FINDINGS

- Cases less likely to check fetal movements (AOR 0.54, 95% CI 0.35-0.82)
- Cases less likely to be told by a health professional (AOR 0.55, 95% CI 0.36-0.85)
- Cases more likely to report significant abnormalities in fetal movements in the preceding two weeks including:
  - Significant reduction in fetal activity (AOR 11.7, 95% CI 6.2-22.2)
  - Sudden single episode of excessive fetal activity (AOR 4.59, 95% CI 2.36-8.89)
  - Cases more likely to report frequent (daily) hiccup occurrence (AOR 2.23, 95% CI 1.04-4.78, P=0.03)

Heazell et al. under review
CAN AWARENESS OF DFM BE PROTECTIVE AGAINST STILLBIRTH?

- LARGE MULTI-CENTRED INTERNATIONAL RCT 68,000 PARTICIPANTS
- ALL RISK GROUPS I.E. ENTIRE CLINICS WERE RECRUITED
- 'COUNT TO TEN' VERSUS USUAL CARE
- NO DIFFERENCE IN STILLBIRTH RATE BETWEEN GROUPS
- BUT STILLBIRTH RATE FELL, ACROSS THE COHORT, FROM AN EXPECTED 4:1000 TO 2.8 :1000 (GRANT ET AL 1989)

SCOTLAND

- THE MATERNITY AND CHILDREN QUALITY IMPROVEMENT COLLABORATIVE (MCQC) FORMED IN 2010
- MCQC SET AN AIM THAT BY DECEMBER 2015, 95% OF ALL PREGNANT WOMEN WOULD HAVE A DOCUMENTED DISCUSSION WITH A MIDWIFE ABOUT FETAL MOVEMENT BETWEEN WEEKS 18 AND 24 OF PREGNANCY.

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- IN 2015, THE STILLBIRTH RATE WAS 3.8 PER THOUSAND VERSUS 4.9 IN 2010.
- ALTHOUGH NO ONE FACTOR CAN BE ATTRIBUTED TO THIS REDUCTION, IT IS ENCOURAGING THAT THE RATE OF STILLBIRTHS NOW AT THE LOWEST LEVEL EVER RECORDED IN SCOTLAND.

DOES TELLING WOMEN ABOUT DFM MAKE THEM ANXIOUS AND THUS MORE WORK FOR US?

- BEFORE AND AFTER INTERVENTION COHORT STUDY IN NORWAY

- INTERVENTION
- WRITTEN INFORMATION INCLUDING INVITATION TO MONITOR FMS
- STANDARDISED MANAGEMENT OF DFM FOR HEALTH CARE PROFESSIONALS

- FINDINGS
- REPORTS OF DFM DID NOT INCREASE DURING INTERVENTION
- RATES OF ULTRASOUND INCREASES BUT FOLLOW UP AND ADMISSIONS FOR INDUCTION REDUCED
- STILL BIRTH RATE FELL FROM EXPECTED 3:1000 IN THE POPULATION TO 2:1000
- NO INCREASE IN PRETERM BIRTH, FGR, NURSERY ADMISSIONS (TYET ET AL. 2009)

BUT
It is normal to feel less movement towards the end of pregnancy.

Fetal movements do not normally decrease close to term. In fact, decreased fetal movement at or near term places the pregnancy at substantial increased risk (TViet et al. 2006, O'Sullivan et al. 2009).

Women who experience DFM should be told to sit down and drink a cold or sweet drink before coming in.
• DRINKING A COLD OR SWEET DRINK OR EATING CHOCOLATE DOESN'T IMPROVE FETAL WELLBEING (DRUZIN ET AL 1993, ESIN ET AL 2013)

A well fetus moves 10 times in………

• WHAT'S WRONG WITH COUNTING AND TEN?

KICK CHARTS AND TEN
A NEW MODEL FOR THINKING ABOUT THE SIGNIFICANCE OF FETAL MOVEMENTS.

Frequency
Strength
Pattern
Fetal Wellbeing

PARADIGM SHIFT IN HOW WE ASK ABOUT FMS?

• FROM
  • IS YOUR BABY MOVING…(NORMALLY)?

• TO
  • TELL ME ABOUT YOUR BABY’S MOVEMENTS?

ASKING THE WOMAN TO TELL YOU ABOUT FMS:

EMPOWERS HER TO
• BE AWARE OF WHO HER BABY IS,
• HOW HER BABY IS AND
• IMMEDIATELY REPORT ANY CHANGE
WHAT TO DO?

- Paradigm shift from
  - "Call me back if you are still concerned"
  - To
  - "I'm concerned that you are concerned, come on in!"

- Empowers the woman!
- Means you have listened to her and appropriately responded to her concerns by properly assessing fetal wellbeing.

IT'S IMPORTANT BECAUSE.....

Throughout I was always asked "is baby moving" but never told to monitor kicks or told that babies have their own pattern of movements. I was also told baby might slow down when getting ready for labor so did not focus or put my attention on fetal movements which may have saved my baby's life.

I just wish that information about movement and the potential outcomes where talked about in more detail. I really felt no one explained this in detail, it was always very casual.

I was satisfied at the time with no thought into stillbirth because they had not once raised the issue with me. If they had, I may have been more open with my concerns.

EVERY pregnant woman should be told that fetal movements are important and getting to know your baby's pattern is number 1. Any changes to their pattern should be a cause for concern.

I say this because I had a healthy pregnancy, baby was perfect, placenta was fine, all blood work was fine yet my baby died.

They sort of just brushed off the results so as not to scare me I believe. This should not happen. Everyone needs to be very clear and to the point with possible issues to your baby. (pers com Pollock)

MATERNAL INTUITION IN PREGNANCY?
GUT INSTINCT

"DURING THIS PREGNANCY DID YOU EVER HAVE A "GUT INSTINCT" THAT SOMETHING WAS WRONG?"

No, 34.5%
Yes, 65.5%

Cohort study n=1,650 responses

No clear relationship with time since stillbirth
- 73.4% of women <6 months before survey
- 63.6% 6-11.9 months post-stillbirth (p = 0.002)
- 63.1% 12-17.9 months
- 61.7% 18-23.9 months
- 63.6% >24 months

No relationship with parity
- 521 (46.4%) were multiparous
- 601 (53.6%) were nulliparous

STARS: CASE-CONTROL STUDY

110 (75.3%) of the 146 stillborn cases (stillbirth less than 3 weeks prior) and only 28 (12.0%) of 234 live born controls (livebirth less than 3 weeks prior) answered yes to this question.

‘THEMES’

• WHEN THE GUT FEELING OCCURRED
• HOW THE GUT FEELING MADE THE WOMAN FEEL
• DREAMS AND OTHER RELATED PHENOMENA
• TELLING SOMEONE.
SO WHAT CAN WE DO ABOUT MATERNAL INTUITION IN PREGNANCY?

WHAT IS MATERNAL INTUITION?

Mother’s intuition is the natural, inborn intelligence that guides and supports her to deeply know, without external influence, what is truly right, and correct for her child’s best interest and wellbeing.” (Simona Wright)

WE ALREADY USE INTUITION IN PRACTICE

• DR. MICHAEL HOWARD, A PEDIATRICIAN WITH MORE THAN 30 YEARS IN PRACTICE. "A MOTHER BARES A CHILD FOR NINE MONTHS AND SEEMS TO POSSESS A SIXTH SENSE LIKE NO OTHER WHEN THINGS DON'T ALIGN CORRECTLY WITH THEIR CHILD," SAYS HOWARD. "ONE THING I LEARNED WAS TO ALWAYS LISTEN TO A MOTHER WHEN SHE TOLD ME SOMETHING WAS AWRY OR NOT RIGHT WITH HER CHILD DESPITE THE FACT I MAY NOT HAVE REVEALED ANYTHING ON MY PHYSICAL EXAM."

WHY?

We ask the mother because we cannot ask the child so the mother provides the voice for the child until the child can speak for themselves.
I worried throughout my entire pregnancy, but I seemed to be having an absolutely perfect, healthy pregnancy so I kept telling myself not to worry. When we hit 37 weeks I pretty much stopped worrying because I figured if anything went wrong they’d cut me open and my baby would be fine. I never even knew stillbirth was a possibility—I’d done tons of research on pregnancy, read all the books, took the classes and it never came up anywhere. I thought stillbirth had ended in the 1800s—I never knew how common it was until it happened to me. So even though I sensed something was a little off, I was very reassured by everyone’s confidence in my pregnancy. I thought it was just normal worries. If I’d really felt like anything was wrong, I would have trusted my instincts, but whatever instincts I might have had were mild enough to be easily dismissed. It’s hard to gauge in retrospect—I’d like to think I knew something was wrong, but really, nothing felt wrong enough for me to act on it. It seemed normal… yes, right from the beginning.

Not listening to my gut will always haunt me.
WE NEED TO SAY SOMETHING LIKE…

- Sometimes women have a gut feeling that something is wrong during pregnancy and if this is happening for you can you please let me know so we can work together to keep your baby safe.

MATERNAL SLEEP POSITION

CURRENT RESEARCH

<table>
<thead>
<tr>
<th>Authors</th>
<th>Country</th>
<th>Method</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
<th>PAR</th>
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<tbody>
<tr>
<td>Stacey et al 2011</td>
<td>NZ</td>
<td>Case Control</td>
<td>OR</td>
<td>2.54, 95%</td>
<td>1.04-6.18, and p = 0.003.</td>
<td>PAR for non-left-sided sleep position right before stillbirth was 37%.</td>
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<tr>
<td>Owusu et al 2013</td>
<td>Ghana</td>
<td>Cross sectional</td>
<td>OR</td>
<td>8.0, 95%</td>
<td>1.5-43.2, and p = 0.016.</td>
<td>PAR of 'typical' supine sleep position for stillbirth was 25%.</td>
</tr>
<tr>
<td>Gordon et al 2015</td>
<td>Australia</td>
<td>Case-Control</td>
<td>OR</td>
<td>6.26, with 95% CI</td>
<td>1.2-34</td>
<td>The PAR for self-reported supine sleep position in last month of pregnancy was 9.88%.</td>
</tr>
<tr>
<td>McCowan et al 2016</td>
<td>NZ</td>
<td>Case-Control</td>
<td>OR</td>
<td>3.48, 95%</td>
<td>1.67-7.27.</td>
<td>The PAR of supine sleep position for late stillbirth was 8.8%.</td>
</tr>
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WHY

• IVC compression

WHY

• Clinical experience

WHY

• Routine practice

CLINICAL EXPERIENCE

• WE TAKE CARE TO TELL WOMEN TO AVOID SUPINE POSITION DURING THE DAY
• AND
• THE SUPINE POSITION IS AVOIDED DURING LABOUR, BIRTH, OBSTETRIC ULTRASOUND, CPR, CAESAREAN SECTION ETC ETC
• YET
• WE ARE NOT CURRENTLY ADVISING WOMEN TO AVOID THE SUPINE SLEEPING POSITION!
Despite urging caution, midwives appear to have accepted the findings and are advising their patients to sleep on the left side.

This has resulted in a significant increase in left sided sleep position, from 35.9% in the Auckland stillbirth study (2006-9) to 62.5% in late 2011 (unpublished findings).

This has been associated with a reduction in late stillbirth for New Zealand.

Although we cannot exclude other reasons for the decline, it is tempting to believe that the decline is a consequence of more pregnant women sleeping on their left. (Mitchell 2014)

**HOW DO WE BRING THIS INTO PRACTICE?**

- SAY SOMETHING LIKE:
  - EMERGING RESEARCH IS SHOWING THAT SETTLING TO SLEEP ON YOUR BACK IS NOT BEST FOR BABY. I'D LIKE YOU TO TRY TO SETTLE TO SLEEP ON YOUR SIDE.
CALL TO ARMS

• RAISE PUBLIC AWARENESS OF STILLBIRTH
• LET PREGNANT MOTHERS KNOW THAT ADVOCATING FOR HER BABY BEGINS DURING PREGNANCY AND THAT SHE IS NOT BEING SILLY, "ANXIOUS" OR "THAT MOTHER" IF SHE EXPRESSES CONCERNS
• MAKE IT EVERYONE’S (CARE PROVIDERS, FAMILY AND FRIENDS) RESPONSIBILITY TO LISTEN TO AND SUPPORT THE PREGNANT WOMAN TO IMMEDIATELY ACT ON ANY CONCERNS

WHERE TO FROM HERE?

1. Access care and resources through local and national organizations.
2. Support local and national organizations working to reduce stillbirth rates.
3. Advocate for policy changes to improve maternal and infant health.
JOIN ME IN MAKING A DIFFERENCE

Every birth is a livebirth