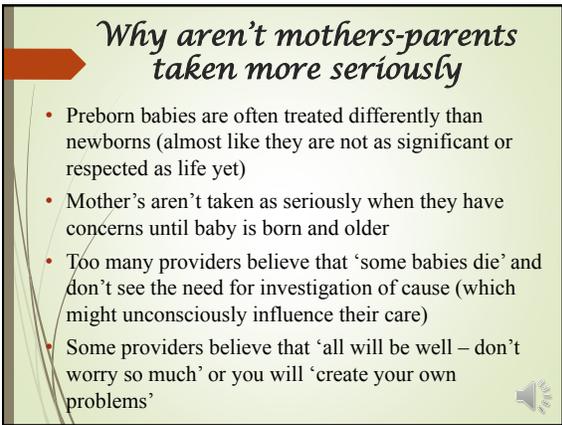


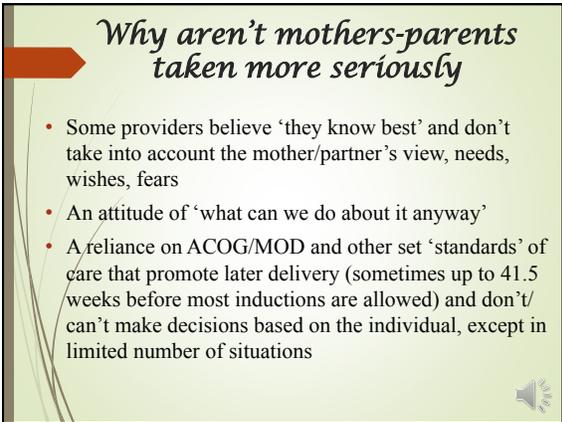
Part 2



Why aren't mothers-parents taken more seriously

- Preborn babies are often treated differently than newborns (almost like they are not as significant or respected as life yet)
- Mother's aren't taken as seriously when they have concerns until baby is born and older
- Too many providers believe that 'some babies die' and don't see the need for investigation of cause (which might unconsciously influence their care)
- Some providers believe that 'all will be well – don't worry so much' or you will 'create your own problems'





Why aren't mothers-parents taken more seriously

- Some providers believe 'they know best' and don't take into account the mother/partner's view, needs, wishes, fears
- An attitude of 'what can we do about it anyway'
- A reliance on ACOG/MOD and other set 'standards' of care that promote later delivery (sometimes up to 41.5 weeks before most inductions are allowed) and don't/can't make decisions based on the individual, except in limited number of situations



Why are mothers-parents not taking more control and responsibility

- Believe doctors/midwives know best
- Are in shock and high stress when they believe something is wrong and find it difficult to self-advocate
- Don't trust their instincts, want to be a 'good patient'
- Feel pressure they are 'imagining' or 'over-reacting'
- Common messaging from providers, childbirth world that nothing can/does go wrong, don't over react
- Don't know who to call for support or what to do if they are not listened to or taken seriously
- Can't see inside their womb or their baby, so are usually going only on personal feelings and intuition (which is not valued like a thermometer, baby's look, etc.)

Why are mothers-parents not taking more control and responsibility

- Don't know the system, the options, and how to speak to birth professionals (people in authority) in order to gain their respect and 'be heard'
- Might be new at this and don't have the experience to know when and how to 'fight for their baby' (or if that is acceptable).
- Don't know what is best, standards of care, how to work within the system, etc.
- Are afraid, which can cause feeling stuck and confused
- Are afraid their provider will drop them if they are too demanding

Why mothers-parents do not take more control and responsibility

- Women tend to shy away from conflict in general and want to be 'good' patients. Might be less likely to speak up, ask questions, ask for different path if they don't agree. True for most cultures
- Often a struggle for moms and medical staff between: "I'm worried; get my baby out," and "Be careful, you don't want to deliver too early or it will hurt the baby." Brings inherent tension and one that's hard to balance for a worried mom and even the providers.

What are mother's rights

- To change doctors and nurses, or to ask for different ones when being cared for in the clinic or hospital
- To go to the emergency room and expect to be treated – not sent away (the law). To get other opinions. To have a consultant or advocate beside you or available by cell.
- Check with insurance company about how to proceed if there are issues/problems that are serious and not being acted upon
- To speak up and ask for services. To be listened to and respected. To climb the bureaucratic ladder for other answers... talk with the patient advocate in the hospital
- To use social media and local media if needed to call attention to this care provider or hospital (last desperate resort?) While not a proponent of this, I have seen it work to get the attention of the medical community. There may be consequences that follow such actions, but you do have the right to go public if you feel it is absolutely necessary.

Love Stories

A Parent who changed the outcome
Shannon

A Provider who changed the outcome
Dr. K. G.

Mom in ER
Almost a tragedy

Five Principles Perinatal Loss Pt-centered Care (S.A.F.E.R.)™ S. Ilse

Expect the following and ask for them

- S.** Slow things down and ask them to impart information intentionally
- A.** Acknowledge (affirm) what you hear medical providers saying and ask them to hear/repeat what you are saying and needing
- F.** Ask to be 'fully informed'. Tell them you are not looking for 'protection'. You want to know the entire truth so you can make the best decisions.
- E.** Ask for help being 'empowered and supported' rather than 'protected and rescued.'
- R.** Say out loud that you wish to be respected and treated as the parents of a loved and wanted baby. This life matters and you will FIGHT FOR IT.

How to Self-Advocate

- Early on in your pregnancy (or before) find a provider who clearly listens to you and will work with you, rather than having everything his/her way. Build trust and mutual respect which helps for your ongoing care. If an unexpected outcome arises, you will probably feel more comfortable and respected in this type of relationship
- Ask lots of questions so you are fully informed before making decisions, going home, etc. Ask for clarification when not understanding (a very common thing with non-medical parents). You are not alone in this. "Let me see if I heard what you said...you suggest that we _____" is a good way to follow up and get clarification.
- Seek second or third opinions when it is serious and you need more info.



How to Self-Advocate

- Believe you do know your baby best – no one else has been with her/him 24/7 like you. Your provider may be wise and educated, but they do not love your baby like you do. You may need to fight for the care that is needed in your opinion
- Keep mutual respect and kindness (and love) in your heart when acting as a mother/father by protecting and advocating for your baby with health care providers. Providers will likely help you more than if you are angry and demanding
- Find an advocate who can work with you and your partner so you have outside help if things get too emotional. A Baby Loss Family Advisor, Bereavement Doula, Childbirth Educator, Patient Advocate...



What to do?

Infant

- Listless, rarely moving though was usually active
 - Mom feels something is not right
- Call Medical Provider or Nurseline
- They ask for description of problem, temperature, any signs that are a change or worrisome
- They say –
- Come in and we'll examine child – heart, temp, look at activity/limpness, might run tests if it looks concerning
- What if this could be LIFE or DEATH?

Preborn Baby

- Active baby and the movements have changed
 - Mom feels something is not right
- Call Medical Provider or Nurseline
- They ask for description, any signs that are a change or worrisome
- They say – Drink OJ, wait for a few hours (or come in tomorrow) then call back, or next appointment all of which delay going in but aren't medically supported in solving any problems or helping baby
- Mom can do–
- Take this seriously if it seems serious to you or even just worrisome. ACT like this is a 10 month old infant and that something CAN possibly be done to help baby. GO IN IMMEDIATELY if concerned. Don't ask for permission**
- What if this could be LIFE or DEATH?