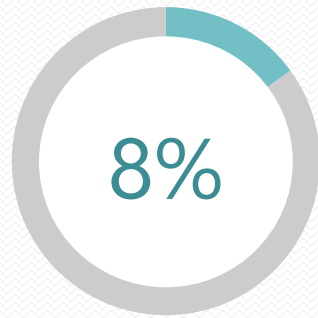


Navigating the Roller Coaster of the NICU

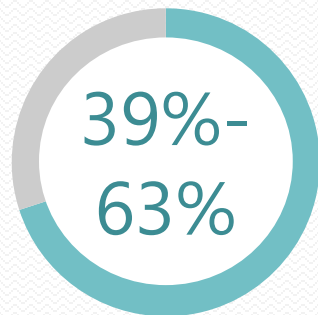




Of mothers with premature infants experience post partum PTSD.



Of fathers with premature infants experience postpartum PTSD.



Of mothers with NICU infants experience postpartum depression.

Nothing is *normal* about the NICU:

- Hopes and dreams are lost.
- Existential questions arise.
- Emotions run rampant.

You **CAN'T** fix it.
DON'T try.

Allow Grief

Allow Questions:
**Rhetorical, Theological,
Physical**

Normal

Not Normal

Staff

Parents

- Feeder Growers
- Naughty Baby
- "Events"
- Alarms
 - TPN

- I can't take my baby home.
- My baby stopped breathing/
code blue.
- Baby isn't getting better.
Grief enters with change in
discharge date.
- Shock/Baby stopped breathing/
code blue.
- I can't breastfeed.

Common *emotional* responses of parents in NICU:

- Guilt
- Shock
- Anger
- Lack of Control
- Jealousy
- Resentment

Could You Just Listen?

When I ask you to listen to me
and you start to give advice,
you have not done what I asked.

When I ask you to listen to me and you begin telling me
why I should or shouldn't feel that way,
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something to solve my problem,
you have failed me,
strange as it may seem.

Listen – all I ask is that you listen, not talk or do – just hear me.

Could You Just Listen?

Advice is cheap.

Fifty cents will get you both Dear Abby and Billy Graham in the same newspaper.

And I can do that for myself; I'm not helpless.

Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself, you contribute to my fear and weakness.

But when you accept as a simple fact that I do feel what I feel, no matter how irrational,

then I can quit trying to convince you and get about the business of understanding what's behind this irrational feeling.

And when that's clear, the answers are obvious and I don't need advice.

Could You Just Listen?

Irrational feelings make sense when we understand what's behind them.

So, please listen and just hear me.

And if you want to talk, just wait a minute for your turn,
and I'll be happy to listen to you.

Empathy

- Empathy feels with someone.
- Empathy does not judge.
- Empathy has no words.
- Something on the tip of your tongue...
- Empathy is about them.

Sympathy

- Sympathy gets sidetracked by your own similar pain or experience.
- Sympathy judges.
- Sympathy says something on the tip of your tongue.
- Sympathy says, "My or I..."
- Sympathy says, "At least..."
- Sympathy is about you.



Don't judge a book
(mom or dad)
by its cover.

Wonder – “What’s behind that?”



Possible Barriers

Language Barriers

- Always use interpreters.
- Don't assume understanding.
- Do not use family.

Go back to the basics:

"What's it like being in here and not speaking the language?"

"Do you have questions about what is going on with your baby?"

Cultural Differences

- What's important to you and your baby?
- Who is the decision maker for you and your family?
Or, who needs to be here for family meetings?
- What do we need to know that is important for you culturally or with your faith? Any specific needs or rituals?

Social/Age/Intellectual Differences:

- Do you have questions about your baby?
- What helps you the most to understand all of this?
- What is most important to you?
- Who would you like to be here for family meetings or updates from the doctor?

Tools for Listening

“It’s **MY** fault...”

“It’s **not** your fault. Nothing you did caused this. It just happened.”



"It's **MY** fault..."

"Why do you think it's your fault?"

"I just do...pause...I did everything the doctor said..."

"...so you did everything the doctor said..."

"I did, everything he said. I stopped drinking wine and coffee. I even started eating more vegetables..."



"It's **MY** fault..."

"Why do you think it's your fault?"

"I just do...pause..."

(silence)

"I was doing so good. And then I got with my old friends one night. I did drugs. It's my fault she's in here."

(tears from mom)

(Allow the tears. Honor the pain.)



“I’m **scared**...”

“**Don’t** be scared.”



"I'm **scared**..."

"What are you scared of?"

"I'm scared my baby might die."

"Did the doctor tell you your baby may die?"

"No, they're saying this is a long road. She just needs to rest; the machine is breathing for her..."



Tools for your toolkit:

- Wonder – “What’s behind that?”
- Play dominoes.
- Go back to the basics.

Ask open-ended, neutral questions:

- What is it like to see him/her with all those wires and tubes?
- Wow, that was a lot to hear...what do you do with all that information?
- What would help you most right now?
- What's the most difficult part of this?
- What's important to you now?
- How are things?

State the obvious:

- I see/saw your tears...
- You look tired today...
- Your hands are shaking today...

Empower moms and dads:

- Make decisions.
- Ask questions.
- Participate.
- Share their journey.