PERINATAL PALLIATIVE CARE
SUPPORTING FAMILIES AS THEY PREPARE TO WELCOME THEIR BABY AND TO SAY GOOD-BYE

Kathy Cromwell CT, MSW, LCSW
Director, Hinds Hospice
Angel Babies
HINDS HOSPICE ANGEL BABIES

Our beginning
Our Mission

The mission of Angel Babies of Hinds Hospice is to comfort, support, and uphold the dignity of families whose babies have a life limiting condition or whose babies have died.
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
WHAT IS PERINATAL PALLIATIVE CARE?

- A model of care for neonates and their families, beginning at the time of diagnosis.
- Services provide a multidisciplinary team working to meet the medical, spiritual and emotional needs of a family.
- A beautiful and practical response to rapidly advancing diagnostic technology.
- A continuum of care exists from the time of prenatal or post partum diagnosis, through the life, death and the journey of grief.
- The family is placed in the central arena of care.
Perinatal Palliative Care begins at the time of diagnosis
"WHEN I RECEIVED THE DIAGNOSIS I WAS SO SCARED AND FELT SO OUT OF CONTROL"

- Fears and concerns are identified
Families are assisted and encouraged to take time to love and enjoy their baby in the present. Anticipatory planning begins:

- The remainder of the pregnancy
- For birth
- For life
- For death
- For the journey of grief
WORLD HEALTH ORGANIZATION ~ WHAT DOES PALLIATIVE CARE DO

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications
Emotional Pain

“It is said that when an adult loved one dies, we lose what we have known. When a baby dies, we lose what is yet to be known—our future, our dreams, our hopes.”

Grief begins at the time of diagnosis:

Shock and numbing “denial”

Triggers of past losses

Guilt

Anger

Abandonment
Affirms life and regards dying as a normal process
INTEGRATES THE PSYCHOLOGICAL AND SPIRITUAL ASPECTS OF PATIENT CARE

- Provide support while families explore the existential meaning of the diagnosis/death
- Assist in integrating spiritual support as defined by family
- Psychological aspects of care: current and past influences, immediate needs in providing emotional first aid
OFFERS A SUPPORT SYSTEM TO HELP PATIENTS LIVE AS ACTIVELY AS POSSIBLE UNTIL DEATH
- will enhance quality of life, and may also positively influence the course of illness

- intends neither to hasten or postpone death
OFFERS A SUPPORT SYSTEM TO HELP THE FAMILY COPE DURING THE PATIENTS ILLNESS AND IN THEIR OWN BEREAVEMENT

USES A TEAM APPROACH TO ADDRESS THE NEEDS OF PATIENTS AND THEIR FAMILIES, INCLUDING BEREAVEMENT COUNSELING, IF INDICATED

- The Family (The Core)
- Physicians (Obstetrician, Perinatologist, Pediatrician Neonatologist)
- Nurses/HHA
- Therapists with specialized training in grief and loss
- Social Workers
- Chaplains
- Labor & Delivery staff
- Genetic Counselors
- Child birth educators
- Child life specialist
- Peer support
- Volunteers

A team approach and collaboration is essential and best practices!
THE ROLE OF THE L&D RN AND WAYS TO SUPPORT FAMILIES

Before the birth...
- If you are not in a place to support this patient and family communicate this with supervisor
- Stop, sit and listen
- Things to say and not to say
- Do they have a birth plan?
- Have the had any type of childbirth education?
- Ask if they will be having an autopsy
- If baby is still living do they want fetal monitor?
Discuss memory making opportunities

Take role of visitor “police” per their requests

Angel Babies/hospice referral

After Delivery...

Discuss seeing and having time with their baby

Describe their baby to them

Talk to their baby and call him or her by name

Sit with them initially with their baby - explain and answer questions

Take care of you
Hospice Care

- 6 Bed in-patient Facility
- Full staff
- Family Involvement

“The hospice home staff took care of our baby’s medical needs, easing our minds and allowing us to bond and cherish our time together”
HOSPICE OUT-PATIENT

“Our short stay at the hospice home allowed us the confidence we needed to take our baby home to live out the remainder of his life.”

- Families are able to have their baby in their own home
- 24 hour on-call staff is available
- Home visits are done by the hospice team
THE JOURNEY OF GRIEF...

It is said that when an adult loved one dies, we lose what we have known. When a baby dies, we lose what is yet to be known - our future, our dreams, our hopes.
GRIEF IS NOT DEPENDENT ON

- Length of pregnancy
- Whether pregnancy was planned
- Whether baby was wanted
MYTHS OF GRIEF FOR PERINATAL LOSS

- All losses are the same.
- Grief never resurfaces.
- Infant death is easier to resolve.
- Divorce rates are higher for couples whose child dies.
- Other children will diminish the sense of loss.

FEARS REGARDING GRIEF

- Loss of control
- Appearing weak to others
- Tears will never stop
- Unable to bear the loss
- Deceased will be forgotten

FACTORS INFLUENCING GRIEF FOLLOWING PERINATAL LOSS

- Often sudden and unexpected
- Social and cultural definitions of infant death
- Role Change
- Life Stressors
- Alienation from peers
- Cause: known vs. unknown
- Guilt
- Maternal age
- Health factors
- Attachment of others to baby
- Visual reminders
- Impact on partner relationship
SUBSEQUENT PREGNANCIES
BECOMING PREGNANT AGAIN

➤ Every pregnancy is a different experience

➤ New baby is not a replacement

➤ Parents struggle with feelings for previous baby(ies) while pregnant with new baby

➤ Concerns during subsequent pregnancy are different than those in previous pregnancy.

➤ Preference of sex of the baby

CONCERNS FOR PREGNANCY AFTER LOSS

- Fear of another abnormal pregnancy
- Increased anxiety
- Likely to need increased medical support
- Unfinished grief may be an issue
- Avoidance of attachment

SUPPORTING IN L&D OF SUBSEQUENT BABY

- How can you help minimize their anxiety?
- What are their concerns or fears?
- Ask about their other baby?
- Be patient with them
A MOTHER’S WISH...

Please:

- Acknowledge the sanctity of my child’s life not defined by age
- Speak my child’s name even after they have died
- Allow me to say good-bye in my own unique way
- Validate and honor me as a mother even if I have no living children
- Don’t start a sentence with "at least"
THE GIFT OF THE CARE PROVIDER

- The ability to sit and be present with families, often in silence.
- The professional expertise you bring
- Non judgmental support
- Self care
- The ability to see both the gifts that you give and that you receive