

# Child Life Specialist as Part of a Multidisciplinary Perinatal Palliative Care Team

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## Purpose

To provide individualized, developmentally appropriate support to children and families experiencing perinatal loss.

## Significance

More families have the option of choosing palliative care for their unborn and newborn babies diagnosed with life-limiting conditions.

Parents of grieving children may be too overwhelmed with their own grief to adequately support siblings, and they often lack the information they need on how to support children through the grief process.

Siblings experience two types of loss in response to perinatal death: the loss of the sibling they were expecting and their parents as they knew them before the loss.

- Children experiencing perinatal loss need:
- honest, developmentally appropriate information about the baby and death
  - recognition of their grief
  - a designated support person
  - the opportunity to play as a means to cope
  - the opportunity to be involved in the experience

With specialized training in development, coping, and grief, child life specialists are a vital resource for supporting the unique needs of siblings and families experiencing perinatal loss.

## Methods

### Role of the Child Life Specialist

- Providing sibling with developmentally appropriate information about the baby and death
- Preparation to see the baby and support during the experience if needed
- Providing opportunities for play to support the child's coping
- Recognizing and supporting the sibling bond between the child and the baby
- Providing information and resources for family members and staff on how to support grieving children
- Acting as an advocate for the siblings and family
- Working with the child and family to complete memory making activities
- Creation of a "sibling birth plan"
  - preparation for the birth and/or death of the baby
  - the role of the sibling during the experience
  - plans for sibling support following the baby's death

## Case Study

A 40 year old woman whose baby was diagnosed with acrania at 20 weeks gestation. Family was referred to the Perinatal Palliative Care Team (PPCT). This mother presented with her husband and 4 year old daughter.

### Pre-Delivery Consults

- Established therapeutic relationship with sibling and parents
- Assessed family's wishes and birth plan
- Worked with the family to create a "sibling birth plan"

### Follow-Up

- Regular emails to assess how parents and sibling were coping and provided ongoing support as needed
- One in-person meeting with mother and sibling

### Day of Delivery

- Met with family at check-in then met individually with sibling to provide:
  - medical play and preparation for going into the OR
  - developmentally appropriate explanations of acrania and death
- Accompanied sibling into the OR, provided support, and answered sibling's questions
- Informed sibling when baby died
- Continued to provide emotional support to sibling and family once they arrived in PACU with baby

## Conclusion

Feedback from families who have received services from the CLS and other members of the PPCT has been very positive. Parents have expressed appreciation that the needs of their other children were recognized and supported as well as their own.

"You guys have done so much for us and we thank God for each of you."

"Thank you again for all you did and continue to do for us"

## References

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