

Because We Care, we Care Always.

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INTRODUCTION:

Families who are navigating an unexpected or complex perinatal diagnosis must re-imagine their dreams for their pregnancy and baby from the time of diagnosis. ***A comprehensive care approach that is tailored to each family's unique needs provides varied layers of medical and psychosocial support from an interdisciplinary team.*** Prior literature has demonstrated that multidisciplinary counseling with synergism among disciplines decreased parental distress and allowed parents to feel empowered and supported.(Kratovil and Julion, 2017)

Care Always is the neonatal-perinatal palliative care program at Atrium Health Wake Forest Baptist Levine Children's Brenner Children's Hospital and was founded in 2015. With the stated mission to provide multidisciplinary, quality perinatal and neonatal palliative care for our patients and families, we have grown our program to include participation by Neonatology, Maternal-Fetal Medicine, family behavioral specialist, social work, child life, music therapy, nursing, ethics and legal teams. We have also partnered with **Because We Care**, our long-standing bereavement follow-up program. Through the expansion and collaboration of these two programs, we offer consistent, customized medical consultation and psychosocial support before, during and after birth, death or admission to the NICU.

** Kratovil AL, Julion WA. Health-care provider communication with expectant parents during a prenatal diagnosis: an integrative review. J Perinatol. 2017;37(1):2–12

CONTENT / ACTION:

Care Always Program's stated purpose:

- To accompany the family on their journey and be present in the moment with where they are in the journey
- To provide the family detailed medical information regarding diagnosis, prognosis, and options for management
- To support the family in decision making that is aligned with their goals of care
- To be a consistent “voice” to the medical team regarding family's desires
- To optimize quality of life

How Care Always Program achieves our stated purpose:

- Co-counseling with Maternal-Fetal Medicine and Neonatology so parents can receive detailed medical information regarding diagnosis, prognosis, and options for management for pregnancy and postnatal management.
- Patient centered counseling focused on principles of shared decision making and family's goals of care.
- Grief and emotional support for parents, siblings, caregivers and extended family.
- Memory-making and keepsakes including bereavement photography and heartbeat bears.

Family engagement in these various ways allows for our team to provide compassionate care and supports joy and dignity throughout the family's difficult journey.

LESSONS LEARNED:

1. Family feedback is critical for continuous quality improvement. We consistently hear from families that they feel supported, cared for with compassion and excellence and are deeply grateful for our services.
2. The process of obtaining and sustaining funding for dedicated providers is always a challenge. We have had better success with securing departmental funding for FTE and support from managers who see the value of and give permission for their teammates to devote time to this endeavor.
3. The benefits of having a multidisciplinary team are significant and invaluable to be able to sustain programs that provide comprehensive, consistent and high-quality support and care to families.
4. Acknowledging the emotional burden of this work, we are intentional about regular debriefing sessions and have instituted regular off-site team dinner meetings as a time to connect and recharge together.

IMPLICATIONS FOR PRACTICE:

Multidisciplinary synergistic counseling decreases parental distress and allows families to feel empowered and supported.

We plan to collect data to characterize the patient experience of the services we provide. We will use this data to demonstrate the impact and value of this program.

We hope that with this information, leaders and organizations will continue to support the personnel and resources devoted to this special population.