



## **Pregnancy Loss and Infant Death Alliance**

SUPPORT . ADVOCACY . AWARENESS . EDUCATION

### **Position Statement**

## **Pregnancy Termination Following Adverse Fetal or Maternal Diagnosis**



August 2016

## Position

### **Pregnancy Termination Following Adverse Fetal or Maternal Diagnosis**

Perinatal bereavement practices should be integrated into the care of families considering pregnancy termination following adverse fetal or maternal diagnosis.

## Executive Summary

Parents who receive an adverse fetal or maternal diagnosis during pregnancy face difficult decisions as they consider options: life-sustaining therapies, perinatal palliative care, adoption, and pregnancy termination. Decision-making is complicated and requires prompt and thorough education and support from an unbiased, multidisciplinary team. Grief reactions in these circumstances are similar to those throughout any other perinatal loss; thus, relationship-based care should be practiced, allowing care providers to integrate established bereavement practices into the care of families terminating a desired pregnancy.

## Background and Significance

Advances in fetal diagnosis and treatment options, as well as an emphasis on early prenatal care, have led to greater numbers of women who receive an adverse fetal or maternal diagnosis. Parents may learn that their baby's life may be very short, potentially painful, or debilitating. Couples may learn that the woman's life and/or future fertility may be threatened by the continuation of a pregnancy. The consideration of ending a desired pregnancy is extremely difficult and painful for many parents.

The integration of perinatal bereavement practices offers families the opportunity to benefit from sensitive, experienced staff and a standardized continuum of services. Many parents appreciate the opportunity to consider and discuss all of their options no matter how they ultimately decide to proceed. Many recount stories of being told they "should terminate" or, alternately, feeling that asking about termination was taboo.

Rather than assuming what the family will likely choose to do or assuming there is a correct or "best" option, care providers should engage the mother and her partner in conversations, eliciting thoughts and feelings about all options, providing education, and then providing support in doing what they believe is best. This counseling should be provided by a well-trained, multidisciplinary team which can assist the family in exploring all options including perinatal palliative care, life-sustaining fetal and pediatric treatment, adoption, as well as pregnancy termination.



## Physical Considerations

The severity of the maternal or fetal diagnosis and prognosis may have significant bearing on decision making. Parents need as much information as possible regarding the implications of the diagnosis in order to make a decision that is right for them and their family. Decisions are guided by: the certainty of the diagnosis, the certainty of the prognosis, and the meaning that prognosis to the parents. At times, it is not possible to predict an outcome with certainty; this limitation must be acknowledged by the providers.

Often, a fetal or maternal diagnosis occurs well into the 2nd trimester of pregnancy following a screening exam and then subsequent referral to specialists who can provide a more thorough diagnosis. The timing of this diagnosis in relation to availability of pregnancy termination services can significantly limit time available for thorough education, counseling, and decision making.

Some families may choose to terminate after initially deciding to continue a pregnancy. There are numerous reasons for such a decision:

- Maternal medical indications (e.g., aggressive cancer, severe cardiac disease)
- Fetal condition that may cause compromise to the mother's health (e.g., Mirror Syndrome with fetal hydrops)
- Risk of surgical complications or potential complications in a future pregnancy (e.g., worsening fetal macrosomia that would necessitate a cesarean delivery)
- Termination through selective reduction in a multiple-gestation pregnancy complicated by an adverse fetal diagnosis in order to improve the chances of survival for the remaining baby(ies)

Consideration for maternal emotional health, and/or to meet the goal of a live birth when there is a strong likelihood of stillbirth, may also lead to a decision to terminate. Palliative care measures, combined with the decision for an early delivery, can be a reasonable course of action for some parents in order to meet their goals.

## Emotional Considerations

When parents consider end-of-life decisions, they may experience both ambivalent and passionate feelings. On one hand, they are committed to their pregnancy; on the other hand, they want to protect their child, themselves, and their family from the burden of severe disability or pain. One of parents' greatest fears is that their child will experience pain at the end of life. Even after education regarding the availability of pain-relieving therapies, sometimes the choice is made to terminate a pregnancy in order to protect the baby from further perceived or anticipated pain. If the decision is to terminate, it does not equate to loving the child less or ultimately grieving less for this child.



The majority of laws related to pregnancy termination, with subsequent restrictions and requirements, are written primarily to define limits to the termination of an undesired pregnancy, often in the first trimester. These restrictions and requirements do not often take into account the situation of parents facing a second-trimester maternal or fetal diagnosis; thus, options can be limited by the parents' financial resources, access to services, geographical location, and ability to travel. Parents facing the decision to end a desired pregnancy often find a difficult situation worse and more guilt-laden due to these restrictions.

As with any perinatal loss, long-term support is often beneficial. Parents who lose their baby through pregnancy termination may feel isolated. They may be experiencing all of the same grief reactions as anyone else who has lost a baby; yet, they may not feel able to speak freely regarding the circumstances of the loss. Specialized support groups and literature, both in-person and online, are beneficial—both following the loss and during subsequent pregnancies. For most parents, the death of a baby is a traumatic event, and they commonly experience symptoms associated with acute stress. This risk can be lessened by the provision of empathic perinatal bereavement care and aftercare.

## **Opportunities for Relationship-Building**

These complex parental reactions have implications for one of the most difficult decisions they will ever make; a decision which sometimes must be made in a short period of time and while they are still processing the diagnosis. It is important to recognize that determining for themselves when and how to deliver a baby following significant maternal or fetal diagnosis acknowledges the parents' ability to make decisions about what is best for themselves and their baby and can restore some sense of control and parental authority. Therefore, individualized perinatal palliative care may include the choice to terminate a much-wanted pregnancy and much-loved baby.

The development of perinatal hospice and palliative care services have allowed families the opportunity to bond with their babies, develop birth plans, create memories, incorporate the baby into the family of siblings and extended family, and make plans for respectful disposition and legacy creation. If desired, these services and rituals can be offered and incorporated into the care of a family choosing to end a pregnancy early.

The use of relationship-based care facilitates identification of a family's interpretation/definition of the loss and subsequent individualization of care-planning to support their goals. No matter how a couple decides to proceed with their pregnancy, parents need an experienced, knowledgeable, compassionate bereavement care provider to offer a safe and sacred space where they can do what is meaningful to them. Care providers may engage in open-ended conversations with couples to listen for how they define their loss and their thoughts and feelings about their pregnancy. Just as some parents who experience a spontaneous miscarriage may consider it a pregnancy loss rather than the loss of a baby, parents ending pregnancies early will have varied responses and goals as they define the experience for themselves. As with



any pregnancy loss, some parents will want to hold and see their babies and engage in memory-making activities, while others may not feel this is right for them. The choice of a surgical or medical delivery will depend on availability of services, gestational age, and how each would meet the parents' goals. Cultivating an empathic relationship with the parents is what enables the provider to ask them about their unique emotional, physical, cultural, and spiritual needs, and to be responsive to them.

## Implications for Practice

Best practice for caring for parents experiencing a significant maternal or fetal diagnosis include

### **Access to Information**

- Facilitation of a prompt referral to maternal/fetal and pediatric specialists for further assessment and counseling so that the parents can have the ability to make well-informed decisions while they still have access to pregnancy termination services
- Access to information regarding prenatal testing options, including anticipated implications for testing and the availability of support and education regarding results
- Presentation of all options, including how each would be implemented and supported
  - Termination via surgical or medical induction
  - Fetal surgery/treatment
  - Continuation of pregnancy with a plan for expectant pregnancy management and palliative care at birth (Perinatal Palliative Care)
  - Continuation of pregnancy with a plan for adoption
  - Continuation of pregnancy with plan for life-sustaining measures at birth
  - Continuation of pregnancy with specialized healthcare following life-threatening maternal diagnosis
- Discussion of further diagnostic testing options, including prenatal and/or postnatal genetic testing and autopsy, if termination is chosen



## Sensitive, Professional Care

- Evaluation and counseling by an objective, non-directive, multidisciplinary team with experience in bereavement care to support the needs of the family following diagnosis and delivery
- Provision of care and an environment that is unbiased and supportive— neither urging parents to pursue one option nor discouraging another and never withholding access to information on all options— so that parents are freely able to make the best decision for themselves and their family
- Access to information regarding pregnancy termination or referral to another center if a caregiver's personal or institutional beliefs prohibit the provision of direct information or referral
- Individualized, relationship-based care that respects the uniqueness of each parent, family, need, and circumstance—recognizing that the family may have many of the same and many different needs than those experiencing any other types of perinatal loss
- Integration of perinatal bereavement concepts and practices when the decision is made to terminate a pregnancy
  - Options for birth planning, memory making, and disposition of the body
  - Supportive conversations and individualized guidance that include the exploration of options and possibilities, reassurances for their concerns, respect for their autonomy, and sharing what other parents have found helpful
- Specialized, ongoing support in the form of counseling, literature, and support groups following the loss and during subsequent pregnancy, if desired by the family
- Advocacy on the part of care providers and parent advocates for the integration of perinatal bereavement practices into the care of families considering pregnancy termination and regarding legislative activities that affect this population

Note: The term “parents” is used throughout this statement as many women and their partners consider themselves parents of the children who have died, regardless of the gestational age or circumstances. However, it must be acknowledged that some parents will grieve this loss as the loss of a pregnancy rather than the loss of a person and that some women will not share this loss with a partner. The use of the term “parents” is utilized for simplicity. Relationship-based care practices will allow the care provider to individualize care and terminology, as needed.



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