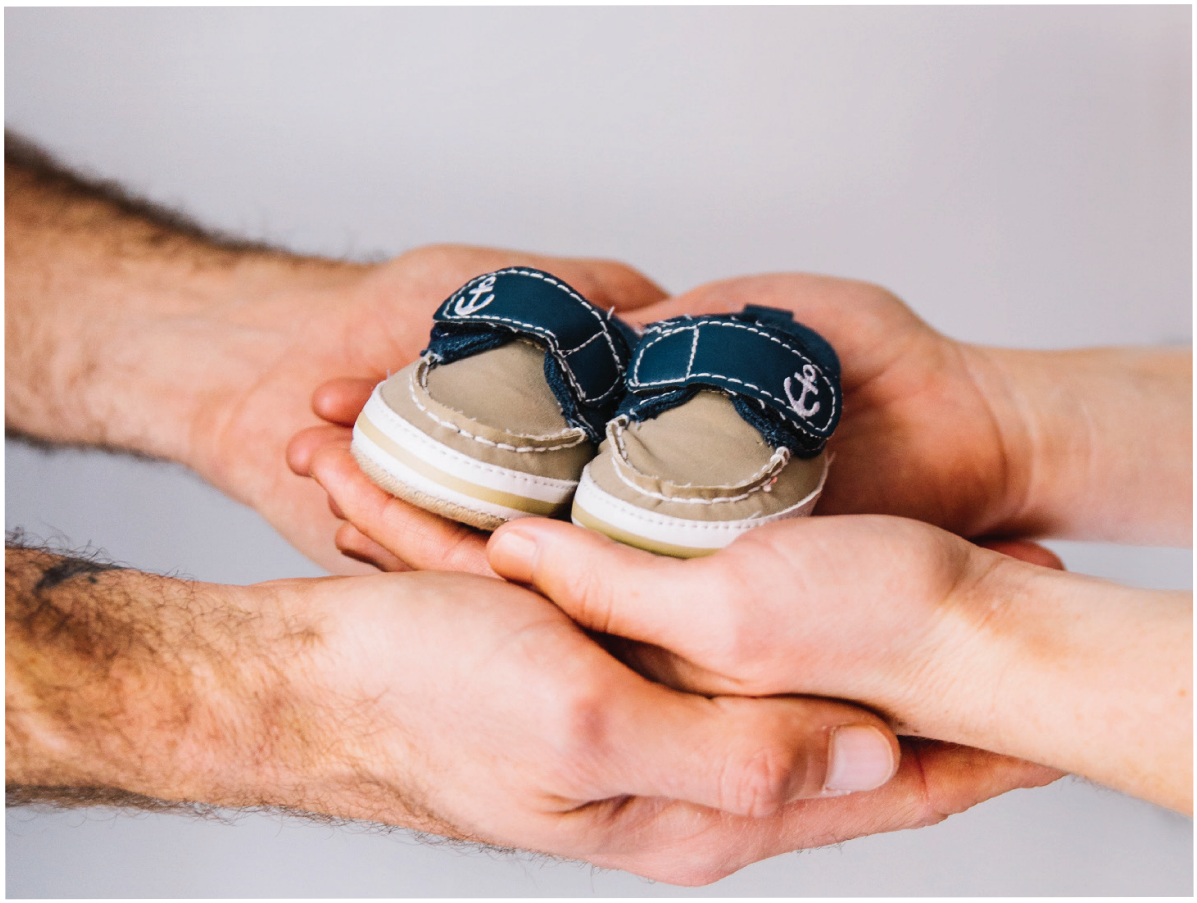
Behold YOUR Child



Pastoral Guide

ARCHDIOCESE *of* DUBUQUE

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Foreward

Introduction

You formed my inmost being;
you knit me in my mother's womb.
I praise you, because I am wonderfully made;
wonderful are your works!
My very self you know.
My bones are not hidden from you,
When I was being made in secret,
fashioned in the depths of the earth.
Your eyes saw me unformed;
in your book all are written down;
my days were shaped, before one came to be.
~ Psalm 139:13-16 ~[1]

There are unique challenges in offering ministry to those who have experienced miscarriage, stillbirth, infant death, or a life-limiting prenatal diagnosis of a child. The circumstances surrounding perinatal loss,[2] for example, are different than those surrounding the loss of an elderly family member or friend. With perinatal loss, time together is often very short, sometimes only a few weeks or less, with few memories of what was and the loss of countless dreams of what could be. What can we do as a people of faith, a community of faith, to minister to those who have suffered such loss?

The General Introduction to the Order of Christian Funerals (OCF) reminds us that "The responsibility for the ministry of consolation rests with the believing community, which heeds the words and example of the Lord Jesus: 'Blessed are they who mourn; they shall be consoled' (Matthew 5:4)."[3] Jesus speaks of being consoled, but, Consoled by whom? And when?

The Spiritual Work of Mercy, Comfort the Sorrowful, directs us to recognize that those who are sorrowful are to be comforted by us, here and now, in this life in addition to the comfort and grace offered to us through Jesus Christ.

It is our responsibility to be present to the suffering of others. The word "compassion" in Latin is compasio, meaning "one who suffers with." As the USCCB document "Called to Compassion and Responsibility" expresses, "Compassion is much more than sympathy. It involves an experience of intimacy by which one participates in another's life. The Latin word misericordia (translated as "mercy") expresses the basic idea: 'The compassionate person has a heart for those in misery'"[4]

Having "a heart for those in misery" and suffering with others is part of our call as Christians. It is our privilege and responsibility to enter into relationship with those who mourn the loss of a child. As St. Paul exhorts us in his letter to the Romans, "Rejoice with those who rejoice, weep with those who weep" (Romans 12:15).

1 Scripture texts in this work are taken from the *New American Bible, revised edition* © 2010, 1991, 1986, 1970 Confraternity of Christian Doctrine, Washington, D.C. and are used by permission of the copyright owner. All Rights Reserved. No part of the New American Bible may be reproduced in any form without permission in writing from the copyright owner.

2 "Perinatal loss" encapsulates the loss of a baby through miscarriage, stillbirth, and infant (i.e. neonatal) death. It will be used throughout this guide to refer to all three types of loss together.

3 *Order of Christian Funerals: General Introduction and Pastoral Notes,* Washington, D.C.: United States Catholic Conference (1989), 9.

4 "Called to Compassion and Responsibility," United States Conference of Catholic Bishops (1989), II, 1.

In a ministry that has as its goal to be present to those who suffer, one cannot forget that compassion and mercy must be understood to be part of a reciprocal relationship. Love, compassion, and mercy are a dialogue between two or more persons. St. John Paul II reminds us, "In reciprocal relationships between persons, merciful love is never a unilateral act or process."[5]

Ministers are not there to "save" anyone, nor are they there to solve the challenges of those who suffer, or even to provide answers to all of their questions. This ministry is a "ministry of presence," one in which listening and being available to those who suffer are the most important aspects.

This ministry is intended to provide to those who grieve, those living through loss, a place of hospitality and a place to process their grief without any expectations placed on them. Each person processes loss differently, and ministers must recognize that there is not one "right" way to grieve.

Behold Your Child was developed to help ministry leaders offer pastoral care to families who have experienced miscarriage, stillbirth, infant death, or a life-limiting prenatal diagnosis of a child. This pastoral guide is intended to offer best practices, resources, and helpful guidance for ministering to these families. This guide is not exhaustive, but will help set a strong foundation for a ministry that is centered on Christ and His mercy lived in community.

"Blessed be the God and Father of our Lord Jesus Christ, the Father of compassion and God of all encouragement, who encourages us in our every affliction, so that we may be able to encourage those who are in any affliction with the encouragement with which we ourselves are encouraged by God"
~ 2 Corinthians 1:3-4 ~

5 St. John Paul II, *Rich in Mercy* (1980), 14.

Background Information

"Each year, approximately one million pregnancies in the United States end in miscarriage, stillbirth, or the death of a newborn baby."[6] Additionally, many families are affected by a life-limiting prenatal diagnosis that may result in the death of their child in the womb or soon after birth. Since life begins at conception, perinatal loss and life-limiting prenatal diagnoses involve human beings, who have inherent dignity and eternal souls. These children of God have parents who anticipated welcoming a healthy baby, but then were confronted with the unexpected loss of their child or with news that their child would have a serious life-limiting condition. As a result, millions of parents and families are grieving, and it is almost certain that some of these hurting people are in your parish community.

MISCARRIAGE

According to the Mayo Clinic, miscarriage (also called early pregnancy loss)[7] occurs when a baby dies in the womb before 20 weeks gestation. "About 10 to 20 percent of known pregnancies end in miscarriage. But the actual number is likely higher because many miscarriages occur so early in pregnancy that a woman doesn't realize she's pregnant … Most miscarriages occur before the 12th week of pregnancy [i.e. during the first trimester]."[8]

Most women who miscarry have a healthy pregnancy later, but some experience repeat miscarriages (also called recurrent pregnancy loss). "Less than 5 percent of women have two consecutive miscarriages, and only 1 percent have three or more consecutive miscarriages."[9] Testing can be done to try to identify the cause of the recurrent miscarriages. "However, when all known and potential causes…are accounted for, almost half of patients will remain without a definitive diagnosis."[10] Thus, many families not only experience the grief of multiple losses but also the uncertainty of what (if anything) can be done to prevent future miscarriages. Still, most women who experience recurrent miscarriages (even with an unknown cause) will go on to sustain a pregnancy. In fact, "about 60 to 80 percent of women with unexplained repeated miscarriages go on to have healthy pregnancies."[11]

In the case of recurrent miscarriages, along with other gynecological or reproductive disorders, fertility awareness-based methods (i.e. Natural Family Planning), and medical technology like NaProTECHNOLOGY may be helpful in diagnosing and treating the underlying problem. Mothers experiencing these issues could be encouraged to learn about this medical science and find a doctor or Natural Family Planning (NFP) teacher who can help. Information about NFP may be found at the USCCB website www.usccb.org/nfp. Information about NaProTECHNOLOGY may be found here: www.naprotechnology.com.

6 H.Con.Res.222, "Supporting the goals and ideals of National Pregnancy and Infant Loss Remembrance Day," 109th Congress (2005-2006). https://www.congress.gov/bill/109th-congress/house-concurrent-resolution/222/text

7 Medical professionals will sometimes also refer to a miscarriage as a "spontaneous abortion." This can be off-putting and may cause the parents to feel blamed. Please note that this is simply medical terminology to distinguish between a *direct* abortion (where the intention was to end the life of the child) and a miscarriage (where the death of the child was not intended). Families who hear this terminology used to describe their loss may need clarification on the meaning in order to provide consolation that the death of their child was *not* their fault.

8 https://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/symptoms-causes/syc-20354298

9 https://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/diagnosis-treatment/drc-20354304

10 Holly B. Ford and Danny J. Schust, "Recurrent Pregnancy Loss: Etiology, Diagnosis, and Therapy," *Rev Obstet Gynecol.* (Spring 2009) 2(2): 76–83. https://www.ncbi.nlm. nih.gov/pmc/articles/PMC2709325/

11 https://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/diagnosis-treatment/drc-20354304

According to NaProTECHNOLOGY research, "a variety of factors underlie the occurrence of miscarriage. These include genetic, endocrinologic (hormonal), anatomic, immunologic and microbiologic variations."[12] Still, it is difficult to know the cause of every miscarriage. Some miscarriages, including recurrent miscarriages, can be caused by the following conditions.

Abnormal Genes or Chromosomes:
According to the Mayo Clinic, "About 50 percent of miscarriages are associated with extra or missing chromosomes. Most often, chromosome problems result from errors that occur by chance as the embryo divides and grows—not problems inherited from the parents." Chromosomal abnormalities could lead to conditions like a blighted ovum, intrauterine fetal demise, or a molar pregnancy. With a molar pregnancy, for example, both sets of chromosomes come from the father, typically resulting in abnormal growth of the placenta and no fetal development. "A partial molar pregnancy occurs when the mother's chromosomes remain, but the father provides two sets of chromosomes. A partial molar pregnancy is usually associated with abnormalities of the placenta, and an abnormal fetus. Molar and partial molar pregnancies are not viable pregnancies."[13]

Maternal Health Conditions
According to the Mayo Clinic, the mother's health condition could also lead to a miscarriage. For example, uncontrolled diabetes, an infection, or thyroid disease could factor into the cause of a miscarriage. Furthermore, miscarriages could be caused by problems with the mother's uterus, including the presence of abnormalities or scar tissue, or problems with her cervix, such as cervical insufficiency (also called incompetent cervix).[14]

Hormonal imbalances or insufficiencies in the woman's body can also lead to a miscarriage or recurrent miscarriages. For example, "polycystic ovary syndrome (PCOS) is a hormonal disorder common among women of reproductive age" that typically involves cysts on the ovaries and can result in miscarriages.[15] Additionally, "luteal phase deficiency (LPD) is a condition of insufficient progesterone exposure to maintain a normal secretory endometrium and allow for normal embryo implantation and growth."[16] Progesterone is a hormone that helps regulate periods and prepare a woman's body for becoming pregnant and sustaining a pregnancy. Thus, insufficient levels of progesterone being produced by a woman's body could lead to a miscarriage or recurrent miscarriages. Therefore, a provider may test for progesterone levels and may prescribe progesterone supplements to offset the hormonal deficiency.

Endometriosis could also be a cause of miscarriage. In fact, "in women with repetitive miscarriage, 85 percent will have endometriosis."[17] This is "an often painful disorder in which tissue that normally lines the inside of [the] uterus—the endometrium—grows outside [the] uterus … Surrounding tissue can become irritated, eventually developing scar tissue and adhesions—abnormal bands of fibrous tissue that can cause pelvic tissues and organs to stick to each other"[18]

12 https://www.naprotechnology.com/abortion.htm
13 https://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/symptoms-causes/syc-20354298
14 Ibid.
15 https://www.mayoclinic.org/diseases-conditions/pcos/symptoms-causes/syc-20353439
16 Tolga B. Mesen and Steven L. Young, *Obstet Gynecol Clin North Am.* (Mar 2015) 42(1): 135–151. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4436586/
17 https://www.naprotechnology.com/abortion.htm
18 https://www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656

Risk Factors

Factors that can increase the likelihood of a miscarriage include:[19]

- Age: The risk for miscarriage increases with age. Women over 35 are at a higher risk than younger women.
- Weight: Women who are underweight or overweight have an increased risk of miscarriage.
- Previous miscarriages: Women who have had two or more consecutive miscarriages have an increased likelihood of a future miscarriage.
- Smoking, alcohol, and illicit drugs: "Women who smoke during pregnancy have a greater risk of miscarriage than do nonsmokers. Heavy alcohol use and illicit drug use also increase the risk of miscarriage."

Ectopic (or Extrauterine) Pregnancies

According to the Mayo Clinic, "an ectopic pregnancy occurs when a fertilized egg implants and grows outside the main cavity of the uterus … An ectopic pregnancy most often occurs in a fallopian tube, which carries eggs from the ovaries to the uterus. This type of ectopic pregnancy is called a tubal pregnancy." They may also occur in other locations, such as the ovary, cervix, or abdominal cavity.[20] Between about 1 and 2 percent of all pregnancies are ectopic and about 95 percent of those occur in the fallopian tube.[21] As the pregnancy progresses, tubal ectopic pregnancies "may either diminish in size and spontaneously resolve, or increase in size and eventually lead to tubal rupture"[22]; in either case, the child will not survive. There are very rare, documented cases of abdominal ectopic pregnancies resulting in live birth where both the mother and the child survived.[23]

A tubal ectopic pregnancy is a potentially dangerous medical condition because "the resulting abnormal growth can result in rupture of the tube, severe hemorrhaging and even death for the mother."[24] In some cases, an approach of "expectant management" may be taken, that is, monitoring the situation to see if the tubal pregnancy resolves on its own through miscarriage.[25] When medical intervention in an ectopic pregnancy is needed, there are ethical considerations regarding treatment options. No treatment is considered morally permissible which is a *direct attack* on the life of the embryo and hence an instance of direct abortion.[26]

Three options are common for medical treatment of a tubal ectopic pregnancy. First, salpingectomy is a procedure which partly or completely removes the fallopian tube containing the embryo.[27] There is general agreement among Catholic theologians and ethicists that salpingectomy is a morally permissible intervention for tubal ectopic pregnancies since the death of the embryo is "indirect."[28] On the other hand, there is disagreement among Catholic theologians and ethicists about the moral permissibility of the other two common treatment options: namely, the procedure of salpingostomy and use of the drug methotrexate.[29] Salpingostomy involves slitting the affected part of the fallopian tube and the portion of the tube containing the damaged tissue and the embryo is extracted using forceps or other instruments.[30] The drug methotrexate prevents the trophoblastic cells, which are external to the embryo proper and will form the placenta, from

19 The following are adapted or quoted from: https://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/symptoms-causes/syc-20354298

20 https://www.mayoclinic.org/diseases-conditions/ectopic-pregnancy/symptoms-causes/syc-20372088

21 P. Baffoe, C. Fofie, and B.N. Gandau, "Term Abdominal Pregnancy with Healthy Newborn: A Case Report," *Ghana Medical Journal* 45/2 (June 2011): 81–83. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3158531/

22 Vinod Kumar, "Tubal Ectopic Pregnancy," *British Medical Journal Clinical Evidence* (2015). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4646159.

23 P. Baffoe, C. Fofie, and B.N. Gandau, "Term Abdominal Pregnancy with Healthy Newborn: A Case Report," *Ghana Medical Journal* 45/2 (June 2011): 81-83. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3158531/

24 Ron Hamel, "Early Pregnancy Complications and the ERDs," *Health Care Ethics USA* 22/1 (Winter 2014): 6.

25 Ron Hamel, "Catholic Hospitals and Ectopic Pregnancies," *Health Care Ethics USA* 19/1 (Winter 2011): 28; Nicanor Pier Giorgi Austriaco, OP, *Biomedicine and Beatitude: An Introduction to Catholic Bioethics* (Washington, DC: Catholic University of American Press, 2011), 64.

26 USCCB, "Ethical and Religious Directives for Catholic Health Care Services, Sixth Edition," 48.

27 Hamel, "Catholic Hospitals and Ectopic Pregnancies," 28.

28 Ibid.; Austriaco, *Biomedicine and Beatitude,* 65.

29 For an overview of the controversy, see Hamel, "Catholic Hospitals and Ectopic Pregnancies," 28; Hamel, "Early Pregnancy Complications and the ERDs," 7. For advice on making a decision about using these treatments, given the controversy, see "The Ethics of Treating Ectopic Pregnancies – Editorial Summation" in Cataldo and Moraczeweski (eds.), Catholic Health Care Ethics A Manual for Ethics Committees 10B/5. See also Hamel, "Catholic Hospitals and Ectopic Pregnancies," 28-29, http://chausa.org/publications/health-care-ethics-usa.

30 See, Albert S. Moraczeweski, O.P., "Ethical Arguments in Favor of Salpingostomy and Methotrexate" in Peter J. Cataldo and Albert S. Moraczeweski (eds.), *Catholic Health Care Ethics A Manual for Ethics Committees* (Boston: The National Catholic Bioethics Center, 2001), 10B/3; Austriaco, *Biomedicine and Beatitude,* 64.

continuing to divide and doing damage to the tube that could result in severe hemorrhaging. As a result, the embryo eventually dies.[31] For more information and consultation on ethical considerations regarding treatment for ectopic pregnancies, contact your local diocese for guidance.

Women who have tubal ectopic pregnancies may wonder if the embryo can be removed from the fallopian tube and transplanted into the uterus where it might grow normally. Unfortunately, it is not possible to do this with present medical science.[32]

STILLBIRTH

According to the Centers for Disease Control and Prevention, stillbirth is the term used when a baby dies in the womb after 20 weeks gestation, before or during delivery. "Stillbirth is further classified as either early, late, or term. An early stillbirth is a fetal death occurring between 20 and 27 completed weeks of pregnancy. A late stillbirth occurs between 28 and 36 completed pregnancy weeks. A term stillbirth occurs between 37 or more completed pregnancy weeks." In the United States, stillbirth affects about 1 in 100 pregnancies and results in the loss of about 24,000 babies yearly.[33]

While stillbirths in the United States have decreased considerably since World War II, they have reached a plateau in recent years, while they continue to decrease in some European countries. Some studies have attributed the plateau (instead of a continued decline) to many families falling through the cracks of our health care system due to race and socioeconomic status. These same studies have also attributed the plateau to a lack of sophisticated testing that might identify medical complications and hypertension disorders (in particular) earlier in a pregnancy, thereby preventing some stillbirths.[34]

Common causes of stillbirth include infections in the mother or baby, problems with the placenta or umbilical cord, birth defects or genetic conditions, and pregnancy complications, such as preeclampsia, preterm labor, trauma or injury, or an adverse health condition of the mother.[35] Yet, according to the CDC, for some stillbirths (termed "unexplained stillbirths"), the cause is unknown. Furthermore, stillbirth occurs across race and socioeconomic lines, but is more common among black women, women 35 years of age or older, those of lower socioeconomic status, smokers, and those with certain medical conditions (e.g. high blood pressure, obesity, or diabetes). Additional factors include being pregnant with multiples (e.g. triplets or quadruplets), complications in a previous pregnancy (like a preterm birth), or having had a miscarriage or stillbirth in a previous pregnancy.[36]

31 Moraczeweski, "Ethical Arguments in Favor of Salpingostomy and Methotrexate," 10B/4; Hamel, "Early Pregnancy Complications and the ERDs," 6.

32 American Society for Reproductive Medicine, "Ectopic Pregnancy: A Guide for Patients" (Revised 2014), p. 3. http://reproductivefacts.org/globalassets/rf/news-and-publications/bookletsfact-sheets/english-fact-sheets-and-info-booklets/booklet_ectopic_pregnancy.pdf

33 https://www.cdc.gov/ncbddd/stillbirth/facts.html

34 Shepherd, Emily, et.al, "Interventions for investigating and identifying the causes of stillbirth," *Journal of Obstetrics and Gynecology,* 2018.

35 Ibid.

36 https://www.cdc.gov/ncbddd/stillbirth/facts.html

INFANT LOSS

Infant loss (also called neonatal death) refers to the death of a child after live birth, whether the child passes immediately, minutes, days, weeks, or months after birth. This loss of life could follow a life-limiting prenatal diagnosis received at any point during the pregnancy, or could be the result of any number of causes that were not known during the pregnancy.

Sudden Infant Death Syndrome (SIDS), for example, is the common title used for "the unexplained death, usually during sleep, of a seemingly healthy baby less than a year old."[37] According to the Center for Disease Control and Prevention, there were 1,400 deaths due to SIDS in the United States in 2017.[38]

According to the Mayo Clinic, there are both physical and environmental factors that make a baby more susceptible to SIDS. Some infants are born with problems in the areas of the brain that control breathing and arousal, making them more likely to die of SIDS. Additionally, many infants who die of SIDS recently suffered from a cold or some other type of upper respiratory infection. Environmental factors that increase an infant's vulnerability to SIDS include sleeping on the stomach or side, sleeping on a soft bed, sharing a bed, and overheating. Additional factors that can increase the risk of SIDS include being male, being between the ages of two to four months, being a child of color, having a sibling or cousin who died of SIDS, and living in a home with second-hand smoke.[39]

LIFE-LIMITING PRENATAL DIAGNOSES

A life-limiting prenatal diagnosis involves the identification of a chromosomal abnormality, structural anomaly, or other adverse condition of a child in the womb. Prognoses for babies who receive a life-limiting prenatal diagnosis vary widely depending on the diagnosis and the severity of the condition. In the past 50 years, the field of obstetrics has come a long way in its ability not only to conduct prenatal testing, but in helping families determine how to best manage the pregnancy. Through such techniques as maternal serum screening, ultrasound, chorionic villus sampling, and amniocentesis, a family has the opportunity to learn much more about their unborn child than their parents or grandparents did.[40]

Catholic teaching does not oppose prenatal testing that respects the life of the developing child and is directed towards his or her safeguarding or healing. However, "it is gravely opposed to the moral law when this is done with the thought of possibly inducing an abortion, depending upon the results: a diagnosis must not be the equivalent of a death sentence."[41] Undertaking prenatal diagnosis is morally permissible only "when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks; when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent."[42]

37 https://www.mayoclinic.org/diseases-conditions/sudden-infant-death-syndrome/symptoms-causes/syc-20352800

38 https://www.cdc.gov/sids/data.htm

39 https://www.mayoclinic.org/diseases-conditions/sudden-infant-death-syndrome.

40 There is a difference between prenatal screenings, which can suggest a *likelihood* that a certain defect or condition may be found in a child, and diagnostic testing, such as amniocentesis, which can *confirm* a diagnosis of a certain defect or condition. If a prenatal screening indicates an increased likelihood of a particular condition, further diagnostic testing will likely be recommended to confirm a diagnosis.

41 *Catechism of the Catholic Church,* 2nd ed., Washington, DC: United States Catholic Conference (2000), 2274. See also, USCCB, *Ethical and Religious Directives for Catholic Health Care Services, 6th. ed.* (2018), no. 50. https://www.usccb.org/resources/ethical-religious-directives-catholic-health-service-sixth-edition-2016-06_3.pdf.

42 USCCB, *Ethical and Religious Directives,* no. 50.

The following are some examples of potentially life-limiting conditions detectable through prenatal diagnostic testing:

- Anencephaly – This is a birth defect in which major parts of the brain, scalp, and skull of the fetus do not form completely. While there are rare cases in which children with anencephaly have survived past a year or longer[43], about 75 percent of infants with anencephaly are stillborn and those who are born alive usually die within several hours, days, or weeks.[44]
- Patau Syndrome (Trisomy 13) – While about 10 percent of infants with this disorder survive to 1 year of life, the majority of infants with this chromosomal abnormality have a median survival time between 2.5 and 8.5 days.[45]
- Edwards Syndrome (Trisomy 18) – While approximately 5 to 10 percent of infants with this chromosomal abnormality live beyond the first year of life,[46] many babies with this diagnosis are stillborn and about half of the babies born alive with Edwards syndrome die within the first week.[47]
- Bilateral Renal Agenesis – This is a condition in which both kidneys have failed to develop. As with other conditions, some rare exceptions have occurred where children lived longer than expected. However, about 40 percent of babies with this condition are stillborn, while those born alive often live only a few hours.[48]
- Limb-body wall complex – This condition results in openings in the anterior body wall (chest and belly) and defects of limbs (arms and legs). While many affected pregnancies end in miscarriage or stillbirth, most infants born alive pass away shortly after birth.[49]
- Certain Skeletal Dysplasias – These are bone and cartilage disorders that may affect the fetal skeleton as it develops. The long-term prognosis varies greatly with the type of dysplasia and associated abnormalities. While some of these children can live long, relatively normal lives, about half of the babies with skeletal dysplasia are stillborn or die within the first six weeks of life.[50]

While these conditions (and others) will likely result in the death of the child, none of these prognoses should be cause for the denial of appropriate available care. Each child and each diagnosis is unique and each condition comes with its own complications and possible interventions. Medical research continues to seek possible treatments for various life-limiting prenatal diagnoses.[51] At the very least, palliative care should be offered to the child.

Though the journeys of families facing an adverse prenatal diagnosis vary, these families tend to share some common experiences. Many parents describe their child's diagnosis as coming out of the blue, being a shock, or going from the highest of highs (excitement for a new baby) to the lowest of lows (fear for the health and very life of their child). Parents often feel that they are traveling a path that few others understand. They experience a unique grief for the loss of the carefree pregnancy and healthy baby that was expected, and may also experience anticipatory grief given the possibility that their child may not survive.

43 Holly Dickman, Kyle Fletke, Roberta E. Redfern, *Prolonged unassisted survival in an infant with anencephaly.* BMJ Publishing Group, Vol. 2016.

44 Cleveland Clinic, *Anencephaly,* https://my.clevelandclinic.org/health/diseases/15032-anencephaly.

45 Angel Rios, Susan A. Furdon, Darius Adams, and David A. Clark, "Recognizing the Clinical Features of Trisomy 13 Syndrome," *Advances in Neonatal Care* 4/6 (Dec. 2004): 332-43. See, Robert E. Meyer, et al, "Survival of Children with Trisomy 13 and Trisomy 18: A Multi-State Population-Based Study," National Birth Defects Prevention Network, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4898882/.

46 David Perlstein, *Trisomy* 18 (Edwards Syndrome), https://www.medicinenet.com/trisomy_18_edwards_syndrome/article.htm.

47 Trisomy 18 Foundation, "What is Trisomy 18?" https://www.trisomy18.org/what-is-trisomy-18

48 Minnesota Department of Health, "Renal Agenesis/Hypoplasia," https://www.health.state.mn.us/diseases/cy/renalagenesis.html.

49 Genetic and Rare Diseases Information Center, "Limb-Body Wall Complex," https://rarediseases.info.nih.gov/diseases/3251/limb-body-wall-complex. Yet, very rare cases of survival past the first weeks of life have been reported: https://www.ncbi.nlm.nih.gov/pubmed/24975578.

50 Children's Hospital of Philadelphia, "Skeletal Dysplasias," https://www.chop.edu/conditions-diseases/skeletal-dysplasias.

51 While little to no change in treatment or life-expectancy has been documented for some life-limiting prenatal diagnoses, treatments and prognosis have changed for some with medical advancements. For example, Ventricular Septal Defect (VSD), often referred to commonly as a hole in the heart, was considered a terminal diagnosis for neonatal infants prior to the 1980s because surgery on the heart in early infancy was not available, [Aldo Castañeda, MD, PhD, "Congenital Heart Disease: A Surgical-Historical Perspective," Annals of Thoracic Surgery, *The Society of Thoracic Surgeons,* 2005], but it is now a common and relatively routine surgery with a high rate of success, so the condition is no longer likely to be terminal [M. Schipper, M.G. Slieker, P.H. Schoof, and J.M. Breur, "Surgical Repair of Ventricular Septal Defect," Contemporary Results and Risk Factors for a Complicated Course, *Pediatr Cardiol,* 2017, 38(2):264–270]. Even so, this is not the case for all conditions diagnosed prenatally.

Furthermore, families in these situations can be confronted with ambiguous and misleading terminology often used with prenatal diagnoses. Terms such as "incompatible with life" or "fatal" diagnosis may be used by medical providers to describe certain prenatal diagnoses. These terms deny the value of the life that is already clearly present in the womb, and do not properly account for the fact that the exact outcome for any particular child with any given diagnosis cannot be predicted with absolute certainty. Labeling a diagnosis as "incompatible with life" or "fatal" could be used to try to justify aborting the child, or could result in a child being denied care such as monitoring during labor, access to treatments or surgeries, and in some cases even basic care upon his/her arrival.[52] "Life-limiting diagnosis" is an appropriate term to use in place of these other, more lethal terms.

While prenatal testing can provide a helpful window into the womb for anticipating potential needs a child may have, it can also be cause for some complicated ethical questions for parents of the child with the diagnosis, as well as those involved in the care of the child. When prenatal testing reveals that the child has a condition that is, or may well be, life-limiting, this information gives parents the opportunity to choose whether or not to pursue any available treatment options and to arrange for perinatal hospice and palliative care services for the child, if needed. Unfortunately, the advances in medicine that make it possible to diagnose various conditions prenatally do not always offer the promise of treatment for these same conditions. Thus, parents carrying babies with a life-limiting prenatal diagnosis face the challenge of determining what to do with the information they are given regarding their child.

In the case of life-limiting prenatal diagnoses, some doctors will only suggest termination, and may even pressure the family to do so. Euphemistic language surrounding the treatment of the pregnancy is an issue parents should be cautiously aware of. For example, medical providers might offer an "early induction" or "medical induction" for no other reason than to end the pregnancy when the outcome is expected to be poor due to the given diagnosis. Despite the differing terminology, this is essentially a termination of the pregnancy—a direct abortion. Direct abortion is always immoral and can never be justified in the case of a life-limiting prenatal diagnosis. Unfortunately, it is estimated that more than 80 percent of parents will terminate when an adverse prenatal diagnosis is given; however, when comprehensive support for carrying to term is offered to these families, this figure can be drastically reduced.[53]

In addition to the immorality of a direct abortion, most mothers will report that terminating a pregnancy with a life-limiting prenatal diagnosis does *not* alleviate suffering. A bond has already formed between the mother and child. Terminating the pregnancy of a child with a disability can result in a more complicated grief. Research indicates that 14 months following the termination of a pregnancy of a baby with a life-limiting illness, "nearly 17 percent of women were diagnosed with a psychiatric disorder, such as post-traumatic stress, anxiety, or depression."[54]

Carrying the baby to term can allow the family to get to know their unborn child, honor each moment of his or her life, and affirm the child's inherent value and dignity, as well as give them proper time to grieve and to say goodbye to their baby when that is the outcome. Families who carried to term have reported "a beautiful, profoundly meaningful, and healing journey."[55] In addition, a recent study shows that there appears to be a psychological benefit to women to continue the pregnancy following a life-limiting diagnosis.[56] Unfortunately, parents are rarely informed or counseled regarding these potential benefits. Parents being pressured to abort should be provided with the support and encouragement needed to help them sustain the pregnancy. If a couple or individual chooses to have an abortion, ministers are not permitted to support, assist, or affirm them

52 Bridget Mora, "Prenatal Testing and the Denial of Care." *Ethics & Medics* (2018), 43(2). https://www.ncbcenter.org/em-openaccess/ethics-medics-february-2018.

53 Ibid.

54 Amy Kuebelbeck and Deborah Davis, *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief,* Baltimore: The Johns Hopkins University Press (2011), 37.

55 Ibid.

56 Perinatal Hospice and Palliative Care, "Frequently Asked Questions," https://www.perinatalhospice.org/faqs.

in having an abortion in any way. That said, those who have an abortion should not be denied pastoral care. They can still be offered the loving presence needed to help them find hope and healing, while not in any way affirming their decision to abort.[57]

Those carrying a baby to term following a life-limiting prenatal diagnosis may be faced with decisions about using or forgoing life-sustaining medical treatments when the baby is born. If the baby is delivered at a Catholic hospital, the facility's ethics committee is a resource to assist in making these difficult decisions in accord with Catholic teaching. A consult can be requested with the ethics committee. Contacting your local diocese for more assistance is also recommended.

In summary, families facing a life-limiting prenatal diagnosis need to be accompanied by those who can walk the journey with them and provide the support needed.

57 Project Rachel is a special ministry to those who have had or participated in an abortion. For more information go to the USCCB site http://hopeafterabortion.com/

Implementing the Ministry at a Parish

PARISH LEADERSHIP SUPPORT

The first step in implementing the *Behold Your Child* ministry at your parish is to request the approval of the pastor. The ministry cannot proceed if the pastor does not approve. Some pastors may choose to take an active role in the ministry, while others will be more passive, giving their approval and then letting another staff person or volunteer oversee it. Whatever the case, it is essential to have his support.

For the ministry to be successful, key ministry leaders in the parish need to be educated on what the *Behold Your Child* ministry is and how it functions in the parish. First, all parish staff (whether they are formally trained in the ministry or not) should have a basic understanding of the ministry. This would include, most especially, the priest(s), deacon(s), pastoral minister(s)/associate(s), parish nurse, faith formation leader(s), secretary, and business manager/bookkeeper. Staff members will often be the first people families will turn to if they are looking for help from the Church in a time of loss. Additionally, volunteer leaders in parish ministries may be the first point of contact for those experiencing perinatal loss, along with those who will help promote the ministry in the parish. These may include members of parish councils and committees, catechists, young adult ministry leaders, marriage enrichment leaders, small group leaders, and bereavement ministers. These parish ministry leaders should be made aware of the ministry, how it works, and where to direct people who need help.

BUILDING YOUR TEAM

Once the pastor and staff are aware and supportive of the ministry, the next step is to build your ministry team. *Behold Your Child* is a parish-based ministry and each parish will need to determine what works best for their community. Two possible models (though not the only models) of structuring would be 1) The Core Team model; or 2) The Small Leadership model. Each are outlined below:

Core Team:

- Composed of several people specifically dedicated to organizing, planning, and developing the ministry in the parish
- Includes a staff liaison on the team (or in close communication with the team)
- Team determines the scope of ministry with pastor's approval
- Members each take a particular responsibility over organizing the ministry
- Members delegate responsibilities under their purview to other ministers
- Team develops plan to recruit other ministers

Small Leadership:

- One or two people organize, plan, and develop the ministry
- Leadership may be staff or parishioners or a combination
- Leadership determines the scope of the ministry with pastor's approval
- Leaders may be responsible for all aspects of organizing the ministry on their own
- Leaders are responsible for recruiting ministers

Once the leadership model is determined, begin recruiting additional team members, as needed. Those who take on an active leadership role in the ministry and directly minister to families should go through formal training. Others, most especially parish staff, could also be encouraged to participate in training to help them receive education on perinatal loss and build their support for the ministry.

Once the structural model of leadership is determined, define the roles and responsibilities for those on the leadership team. Roles could include, for example:

- Point Person or Team Leader
- Primary Point of Contact (could be same as team leader)
- Catechist (one who will focus on providing education regarding perinatal loss in the parish)
- Communications Director (primary responsibility is to promote the ministry in the parish and community)
- Ministers of Accompaniment (those who will journey with the families experiencing perinatal loss—larger parishes may want to have multiple ministers who specialize in each type of loss)
- Event Planner (could include liturgy planning)
- Others as needed

Keep in mind roles will vary depending on the size of the team. For example, on a large ministry team, typically one person will have one primary responsibility for a single role (though will assist/collaborate on other roles), multiple people may be assigned to the same role, and more roles can be developed. Whereas, in a smaller ministry, one person may have responsibility for many different roles, collaboration is between just a few people, and it might not be possible to cover some roles.

Finally, when recruiting new ministers, please keep in mind the following principles:

- Clearly define roles in order to be able to communicate them to those being recruited.
- Develop some qualifications for being on the team. For example, team members should agree to uphold and promote Church teachings, especially on topics directly related to this ministry. Also, consider having a minimum time that must have passed since their own loss of a child, if they have experienced that. Ensure they have properly grieved and are in a good, stable place before they begin ministering to other families.
- Recruit with purpose.
- Determine what gifts are needed for each role and discern who has those gifts.
- If someone desires a particular role, consider whether they are best suited for that role before saying 'yes.'
- Cast a wide net and help people discern their role, even if it is one they did not initially desire.
- Ministry roles are not just about finding someone who can do a job, but someone who is rooted in Christ and sees the opportunity as a way to serve Christ through helping advance the mission of the Church.
- Personal invitations are always best. Don't just send out an all-call.
- Use the Discernment Application as a tool to help discern whether or not potential new team members are a good fit.

BOUNDARIES AND CONFIDENTIALITY

In this ministry, confidentiality is essential. Confidentiality means ministers may not discuss or reveal personal information about families to their friends, family members, coworkers, or employees of the parish or the diocese. One exception to this would be in the case of suicidal intent, which needs to be addressed as indicated in the section on "Assessing for Risk" under Mental Health First Aid below. Before sharing the news of the loss and any details of a family's situation, such as with a staff member or for distributing as a prayer request, you must ask the parents for permission. Only share if they give clear and explicit permission.

This ministry involves much vulnerability. While it is important to build a relationship with the family, proper boundaries must still be maintained, especially if you are a parish staff member. Always make sure the family is comfortable with the amount of help you are offering. If they refuse the help you are offering, you must honor and respect their choice.

There may also be times when you will need to tell them 'no' regarding something they are requesting. Some people in grief may become very dependent and needy, wanting you to be at their beck and call. You should set proper expectations for what you and the other *Behold Your Child* ministers can and cannot do. Keep in mind that your role is *not* to provide them with professional medical, legal, or counseling advice (unless you are certified in one of those areas), and what is included in this guide is not intended as a substitute for professional medical, legal, or counseling advice. If they need that type of assistance, please encourage them to find a professional to work with, in addition to the support provided through the *Behold Your Child* ministry.

Finally, all policies and procedures of the diocese and the parish(es) you are serving must be followed. This includes, most especially, the policies regarding the protection of children and minors. For questions regarding policies and procedures, please contact your local diocese.

RAISING AWARENESS

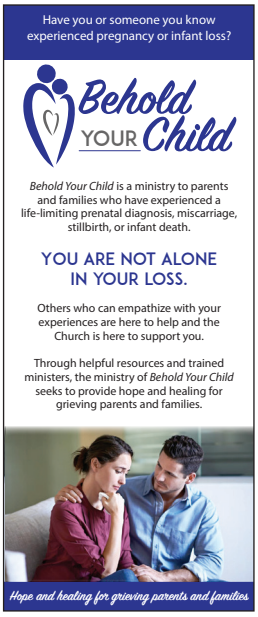
As the statistics above evidence, there is a good likelihood that many people in your parish have suffered the loss of a child through miscarriage, stillbirth, or infant death. Especially in regards to miscarriage, the loss may not be known by many others in the community. It may not have been public knowledge that the mother was pregnant. Thus, there are likely many in your parish who are grieving without you or others knowing it (including those who suffered this type of loss decades ago). Others will experience this type of loss in the future, and could benefit from knowing in advance that the parish is there to support, comfort, and guide them through the grief. Therefore, raising awareness about perinatal loss and the support available through *Behold Your Child* is essential to successfully implementing this ministry.

Parishioners can be made aware of the ministry through parish communication mediums, including:

- The parish bulletin
- Parish newsletters
- Bulletin boards and information areas
- Parish and school websites
- Social media platforms (e.g. Facebook, Twitter, etc.)

Promotional materials for *Behold Your Child* are available (in both English and Spanish), including:

- 8.5" x 3.5" Rack Cards
- 3.5" x 2" Business Cards
- 8.5" x 11" Flyers
- 11" x 17" Posters
- Social Media Tiles
- Sample bulletin and pulpit announcements



Each of these can be customized with the local site's contact information. Hard copies of the rack cards, business cards, flyers, and posters should be printed in full color.

Additionally, parish staff and volunteer leaders can be provided with guidance on how to respond when they encounter a family who has experienced a loss. The parish secretary should, in particular, know what to say and where to direct people when someone calls or stops in looking for help. Also, those who do hospital visits (whether staff or volunteers) should be aware of the ministry, and they could be provided with *Behold Your Child* business cards and/or rack cards to present as a resource when encountering someone who has experienced perinatal loss or a life-limiting prenatal diagnosis. Furthermore, if the parish has an active bereavement ministry, it is important to collaborate with those ministers, finding out what they are already doing to minister to these families and what more could be done with your team's assistance.

An important principle to keep in mind is that families who experience the loss of a child through miscarriage, stillbirth, or infant death should be offered everything any other family who experiences the loss of a loved one is offered. For example, parishes already have funeral planning processes in place, so families who have a miscarriage, for instance, could be asked if they would like to have a funeral and then could be connected with the funeral planning ministers and process if they say 'yes.' Or, as another example, if your parish already has an established bereavement card ministry, you could request for families who experience perinatal loss to be included in receiving a card on the anniversary of the death of their child, if they are not already. This ministry should integrate with what is already happening in the parish and work to expand ministries, where needed, to better serve families who experience perinatal loss or a life-limiting prenatal diagnosis. *Behold Your Child* should not act as a stand-alone ministry.

Therefore, the ministry could be highlighted in other parish programs and ministries, including:

- Adult faith formation programs
- Marriage enrichment offerings
- Marriage preparation
- Young adult ministry offerings
- Religious Education or Catholic schools parent nights
- Homilies

Furthermore, parish events and programs focused particularly on perinatal loss could be organized by the ministry team. These events can help raise awareness and provide opportunities for families who are grieving to become known to the ministry team. These could include:

- Offering a retreat for parents who have lost a child (whether recently or years ago)
- Hosting a prayer service or special Mass of healing for parents who have lost a child
- Having a communal "Naming Ceremony" (see that section below for more information)
- Organizing a craft time for parents and extended family to make something to honor and remember their child (see more about "Memory Making" in that section below)
- Facilitating a support group for parents and extended family who have experienced perinatal loss
- Having parents who have lost a child give a witness talk about their experience

It would be fitting to hold an event during October, which is Pregnancy and Infant Loss Awareness Month, as well as Respect Life Month. November is also fitting, due to the Church's focus on remembering and praying for the deceased. That said, any time of year is appropriate for holding an event for this ministry. Work with parish staff to coordinate any events and programs.

Whatever methods are used to raise awareness about the *Behold Your Child* ministry, the primary goal is to let your parishioners know that the Church is here to help and support them during and after the loss of their child, even if the loss occurred decades ago. *Behold Your Child* is not simply another parish program to promote. It is a relational ministry that will only thrive through people accompanying other people toward Jesus Christ, who is the ultimate healer.

MENTAL HEALTH FIRST AID [59]

This ministry incorporates the Mental Health First Aid model to provide information about responding to people who are in grief as a result of miscarriage, stillbirth, infant death, or a life-limiting prenatal diagnosis. Mental Health First Aid refers to the help provided to a person developing a mental health problem or experiencing a mental health crisis. Mental Health First Aid teaches you how to recognize symptoms of mental health problems, how to offer and provide initial help, and how to guide a person toward appropriate treatments and other supportive resources. The First Aid action plan includes five steps: Assess for risk, Listen non-judgmentally, Give reassurance and information, Encourage appropriate professional help, and Encourage self-help and other support strategies (ALGEE). In practice, these do not necessarily need to occur in this chronological order.

A - Assess for Risk

L - Listen Non-Judgementally

G - Give Reassurance and Information

E - Encourage Appropriate Professional Help

E - Encourage Self-help and Other Support Strategies

A - Assess for Risk

The first step in providing help is to assess for risk of suicide and non-suicidal self-injury. Studies have found that during bereavement of a first degree relative—mom, dad, brother, or sister—grief eases in intensity over the course of twelve months. The same has been found true of the grief following the loss of a child through miscarriage, stillbirth, or infant death. In fact, perinatal loss has been linked to post traumatic stress, depression, anxiety, and sleeping disorders. In addition to the parents, perinatal loss can have a significant impact on extended family members.

Normal grief, which can include the temporary impairment of day-to-day function such as retreating from social activities, intrusive thoughts, or feelings of yearning and numbness, subsides during the first year and can vary from person to person. Complicated grief lasts longer, but is also associated with pre-existing mental health conditions, such as clinical depression and bipolar disorder. This is something to be aware of as you meet and work with families.

Research has shown that more than half of the individuals studied did not show an improvement in grief two years after the perinatal loss, indicating a pervasive presence of delayed grief. According to Annette Kersting, "A consistent feeling of guilt is commonly experienced after pregnancy loss and is associated with complicated grief reactions. Self-blame may prolong the normal grieving process, especially if there was a feeling of ambivalence towards the pregnancy, or if the subject (mother) perceives having done something wrong (e.g., smoking or jogging during pregnancy). Another unique aspect of pregnancy loss is that women feel that their bodies have failed, and that their femininity has been undermined. Women who have already suffered a miscarriage show higher levels of psychological distress than women who have not experienced perinatal loss. Sometimes 'child envy'—the feeling of being envious of other people's children—can be an issue for those who have been through perinatal loss. These women often struggle to make contact with friends or family members who have children or who are at the same stage of pregnancy as that at which the loss was suffered. Difficulty

59 This section is adapted from *Mental Health First Aid USA: For Adults Assisting Young People.* Washington DC: National Council for Behavioral Health, 2016.

coping with these feelings and continuous avoidance often leads to isolation of these mothers."[60] An innocent child has died and, most often, through no fault of the parents. The parents, and especially the mother, may need reassurance that they are not to blame for their child's death.

This experience of grief is not isolated to women. Men also grieve the loss of their child but in different ways. Men tend to suppress their emotions more than women, but that does not mean they do not feel their emotions. They too, for example, may feel guilty for the loss, thinking they could have done more to protect their child and care for the mother during the pregnancy. Research and anecdotal evidence show that men who keep their feelings to themselves while their wives grieve (to be strong for their wives) experience more significant depression and a delayed grief response up to two years following the loss. Conversely, men and women who talk about their feelings and their loss together reportedly experience increased intimacy and marital satisfaction.

Often, in sensitive situations like miscarriage, stillbirth, or infant loss, it will not be obvious to other parishioners that something is wrong with a person or a family. Perinatal loss is very personal and sometimes filled with shame, because parents often feel that they did something wrong to cause the loss of the baby. Consequently, the minister may not know that a child has been lost, especially in the case of a miscarriage—in fact, you may not even know that the family was expecting a baby. So how does one assess for risk in a situation like this?

Red flags that might indicate that a woman or a family is in crisis include:

- Depression – isolation, poor sleep patterns, poor diet
- Substance abuse
- Self-harm
- Extreme distress, such as panic attacks
- The person's behavior is distressing to others (i.e. poor hygiene, missing work, not caring for living children and family)

Parents and family members may experience a roller coaster of emotions such as numbness, disbelief, anger, guilt, sadness, depression, and difficulty concentrating following the loss of a baby. Even if the pregnancy ended very early, the sense of bonding between family members and the baby can be strong. Families can also experience physical symptoms from their emotional distress. These symptoms include:[61]

- Fatigue
- Trouble sleeping
- Difficulty concentrating
- Loss of appetite
- Frequent episodes of crying
- Broken or suffering relationships with family or friends
- Self-harm/suicidal attempts or actions

These symptoms look a lot like depression and grief and can be intensified for women because of the hormonal changes that occur after pregnancy. One consequence of depression is that the depressed person often spends much time alone—ruminating, sleeping, or just being in a fog. Again, this is going to make it very difficult for you to identify who might be in need of this ministry. Keep in mind that it is not the responsibility of the minister to identify or diagnose these red flags. These are just some of the signs and symptoms to be aware of in anyone experiencing emotional distress. If you notice any of these signs or symptoms, consider asking the individual, "Are you okay?" or starting a conversation with "I've noticed that…"

60 Annette Kersting, "Complicated Grief After Perinatal Loss," *Dialogues in Clinical Neuroscience,* June 2012.

61 The following list is from https://americanpregnancy.org/pregnancy-loss/miscarriage-surviving-emotionally

Grief is a normal reaction of sadness following a loss. Depression is a mental disorder that usually requires treatment and complicates grief. Postpartum depression can look like the normal baby blues—mood swings, crying jags, sadness, insomnia, and irritability. Women who have suffered a perinatal loss can experience postpartum depression, too. The difference is that with their postpartum depression the symptoms are more severe (such as suicidal thoughts or an inability to care for themselves and others) and are longer lasting. Someone with postpartum depression might find themselves withdrawing from their partner. They might find their anxiety out of control, preventing them from sleeping or eating appropriately. They might find feelings of guilt or worthlessness overwhelming them or begin to develop thoughts preoccupied with death or wanting to be with their baby.

There may also be passive suicide intent found in statements like, "I just want to be with my child." If a person appears to be at risk of hurting themselves or others, seek professional help immediately even if the person does not want it. If you feel that there is suicidal thinking, or ideation, it is important to ask the uncomfortable question, "Are you having thoughts of suicide?" or "Are you thinking about killing yourself?" If they answer "yes" to either of these questions, ask whether or not they have a plan, such as "Have you decided when you would do it?" or "Have you decided how you are going to kill yourself?" It is also important to know your local resources, as well as the National Suicide Prevention Lifeline: 800-273-8255, or text: 741741.

National Suicide Hotline:

Call: 800-273-8255 **OR**

Text: 741741

This may mean notifying other family members who need to be present with this individual. It could mean calling 911. It could also mean accompanying the person to the emergency room or another type of appointment, or providing referrals to counseling and perhaps accompanying that person to the appointment (for support and transportation, not to sit through the session together).

Parents who experience a perinatal loss should be encouraged to reach out to those closest to them, asking for understanding, comfort, and support and to seek counseling, if needed. Family members should be encouraged to respect the parents' needs and limitations as they work through grief and begin to heal. No one should have to face this alone.

Having information about *Behold Your Child* easily accessible in parishes and openly talking about perinatal loss and life-limiting prenatal diagnoses in the parish will help remove any stigma that may be attached and will generally make it more approachable for families who could benefit from the ministry. Also, the more that information about this ministry is spread personally, by word of mouth, the more likely that families in need will learn about it.

L - Listen Non-Judgmentally

The second step in Mental Health First Aid is to listen non-judgmentally. Listening to the person in crisis is very important. Most people experiencing distressing emotions and thoughts want an empathic listener first, before being offered helpful options and resources. Success comes when ministers use verbal and non-verbal listening skills that allow them to really hear and understand what is being said, making it easier for the hurting person to feel they can talk freely without being judged. Listening non-judgmentally means not expressing any negative judgments you may have. Sometimes you may need "to spend some time reflecting on your own state of mind first to ensure you are in the right frame of mind to talk and listen without being judgmental."[62]

We need to look no further than the book of Job for both positive and not so positive active listening skills. After Job suffered the loss of his family, his belongings, and his health, he was visited by three friends. "Then

62 *Mental Health First Aid USA,* 2016.

they sat down upon the ground with him seven days and seven nights, but none of them spoke a word to him; for they saw how great was his suffering" (Job 2:13). They were present to him for seven days saying nothing. They were there to simply be present to him. And when Job finally spoke, one would think they would continue to stay silent, allowing him space to express his grief, doubts, anger and the many other emotions and thoughts going through his mind. Unfortunately, they began to chastise and argue with him. What started out as a perfect example of being present to the suffering of another, quickly turned into accusations and callousness from Job's friends. This could have occurred for many reasons, including their own discomfort with Job's suffering.

Mental Health First Aid reminds us that we need to be aware of ourselves and our own feelings: "Although the focus of your conversation is the person's feelings, thoughts, and experiences, you need to be aware of your own. Helping someone in distress may evoke an unexpected emotional response in you; you may find yourself feeling fearful, overwhelmed, sad, or even irritated and frustrated. In spite of any emotional response you have, you need to continue listening respectfully and avoid expressing any negative reaction. This is sometimes difficult and may be made more complex by your relationship with the person or your personal beliefs about the situation … Focus on the needs of the person you are helping to be heard, understood, and helped."[63] Your role is to provide a safe place for someone to express themselves.

According to Harville Hendrix, three components of effective communication are: active listening, validation, and empathy.[64] Active listening means listening without an agenda. You are literally hanging on the other person's every word with no intention of responding, other than to show you are listening by nodding your head, saying "yes" or "uh-huh" or something like that. Body language also shows you are listening—face the person who is speaking to you and make good eye contact. Listening does not mean interjecting with examples and stories of your own experience of what the person is talking about, or offering advice. It actually means being silent.

When the person has finished sharing what they want to say, it is your turn to validate them. Now you can talk. Validation means to show understanding, not necessarily agreement. You can communicate validation with comments like, "I can see where you're coming from," or "I can understand why you feel that way." You can also provide more specifics based on what the person has said to you. Again, no personal sharing or advice should be offered.

Finally, empathy means to feel for or with someone because you have "walked a mile in their shoes" or have experienced the same emotion. Now you can share a little more about yourself, but only to build a bridge between yourself and the person sharing with you, not to tell your whole story. The best way to get anyone to open up and talk is by listening in a non-judgmental way. The best way to get someone to shut down is by reacting in an overbearing way.

G - Give Reassurance and Information

Once a person feels that they have been heard, it becomes easier to give reassurance and information, the third step. Reassurance includes emotional support, through empathy and voicing hope, as well as offering practical help with tasks that may seem overwhelming at the moment.

Being able to normalize the experience and emotions of someone who is struggling can be very healing. Helping a person know that they are not alone and are not crazy for feeling the way they feel helps to build a trusting relationship. At this point, they might be more receptive to any information you have to share.

63 Ibid.

64 Harville Hendrix, PhD, *Getting the Love You Want: A Guide for Couples,* Henry Holt and Company, 1988.

Some important points to remember are:

- Catholic Social Teaching emphasizes the life and dignity of the human person. Each person's situation is unique and they may be very different than you, but it is important to respect their ability to make a decision and to know themselves. It is also very important to keep all information confidential unless there is a risk for suicide or self-harm.
- Blaming a person because they might be struggling emotionally is counterproductive to healing. Blaming stigmatizes a person and their reaction to a situation and might cause them to shut down. No one is to blame for how they feel.
- Accept the person as they are. Depression and grief can be very slow-moving processes and can be challenging to sit through, both for the depressed and for the person who accompanies them. The emotions that are being experienced are just that—emotions—and not a sign of personal failure or weakness.
- According to Mental Health First Aid, "It is more important for you to be genuinely caring than for you to say all the right things."[65] Remember the earlier listening skills of validation and empathy. Be compassionate, patient, and kind, even if it is not reciprocated.
- With time, the hurt and sadness will subside and the person you are caring for will learn how to integrate this loss into their lives.
- Sometimes it will be appropriate and necessary to help connect a family with resources that can assist with activities of daily living (see ideas under the "Meeting Practical Needs" section below).
- It's important to respect your own boundaries and know your own limitations of what you can and cannot do. It is also important not to practice outside your scope of expertise. Your role is to provide support until appropriate treatment is received and/or until the crisis has passed.

"For I know well the plans I have in mind for you … plans for your welfare and not for woe, so as to give you a future of hope."
~ Jeremiah 29:11 ~

E - Encourage Appropriate Professional Help

The next step in Mental Health First Aid is to encourage appropriate professional help. Obviously, after a miscarriage or stillbirth the mother will need possible medical care. It is important to make sure her body is able to recover after a loss and heal appropriately. Perinatal loss can also affect the emotional health of both a woman and man. Family members may experience a roller coaster of emotions such as numbness, disbelief, anger, guilt, sadness, depression, and difficulty concentrating. Some may even experience physical symptoms from their emotional distress. For women, in particular, the hormonal changes that occur after perinatal loss may intensify these symptoms.

Discuss options for seeking professional help:
You can ask the person if they have previously experienced a miscarriage and, if so, what have they done in the past that has been helpful. If the person has never experienced a loss, then it is very important to suggest appropriate professional help. If the person decides to seek professional help, make sure they are supported both emotionally and practically in accessing services. If the person does seek help, and either of you lack confidence in the medical advice received, seek a second opinion from another medical or mental health professional. Treatment and other support options available for grief are listed below.

65 *Mental Health First Aid USA*, 2016.

Professional Support Services:

- Primary Care Physician
- Doctor, Nurse, or Midwife
- Other health professionals, such as grief counselors or social workers
- Licensed mental health professionals
- Medical ethicists

For many who may be struggling after a perinatal loss, their primary care physician may be the first professional they turn to for help. A primary care physician can recognize developing symptoms and provide the following types of help:

- Determining a possible physical cause
- Providing knowledge about the type of loss and suggestions for help
- Prescribing medication, if needed
- Referring the person to a mental health professional
- Referring the person to a psychiatrist, particularly if the symptoms are severe or long lasting
- Linking the person to community support

Understanding the Healing Rights of Parents:
Parents and family members have the right to:

- Know the facts about what happened and potential implications for the future. Seek answers to their questions, look at the medical records, and take notes.
- Make decisions about what they would like to do with maternity clothes and baby items. Others might try to make quick choices for them; instead, others should help them figure out what options are best.
- Protect themselves by avoiding situations that will be difficult. Realistic goals should be set. For example, they could focus on coping one day at a time rather than an entire week.
- Take time to grieve and heal. There is no set time allotment for healing, nor is it something to rush.
- Receive support even though this may not be easy. If feeling out of control or overwhelmed, parents and family members should consider seeking help from a counselor, therapist, or support group to help guide them through the grieving process.
- Be sad and joyful. It is okay to feel sad at times but the key is to not let emotions take control. Doing enjoyable things can help parents and family members heal through laughter and joy. Celebrating bits of joy does not dishonor the loss of the child.
- Remember the baby. Healing does not mean forgetting or making the memories insignificant. Healing means refocusing. Naming the baby and doing something tangible in memory of the child help provide solace (see the "Memory Making" section below for ideas).

E - Encourage self-help and other support strategies

The last step in Mental Health First Aid is to encourage the person to use self-help and other support strategies, including the support of family, friends, parishioners, and others. Peer supporters—others who have experienced miscarriage, stillbirth, infant loss, or a life-limiting prenatal diagnosis—can provide valuable help in the person's recovery.

Encourage people who are grieving to respect their needs and limitations as they work through their grief and begin to heal. While working through the grief, encourage them to consider the following:

- Reach out to those closest to them. Ask for understanding, comfort, and support.
- Talk to a friend who has been there.
- Seek professional counseling.
- Allow plenty of time to grieve and the opportunity to remember.
- Let people know if they do not want to talk.
- Join a support group.

- Name the baby.
- Find tangible ways to remember the child.
- Keep a journal.
- Prepare for ignorant comments.
- Take time off work.
- Pursue testing with a health care provider to discover and possibly address the cause of the loss (especially if they have had more than one loss or if the loss was after 12 weeks).
- When they are ready, make a plan to try for another child.

GRIEF AND EXTENDED FAMILY

Parents are not the only ones who grieve when a child is lost to miscarriage, stillbirth, or infant death. The grief can be felt by grandparents, aunts and uncles, cousins, and godparents. In fact, sometimes extended family members may experience grief more intensely than the parents. As mentioned previously, perinatal loss can have a significant impact on extended family members, as it is linked to post-traumatic stress, depression, anxiety, and sleeping disorders. These family members need to be cared for too. At times, the parents themselves may not even be a part of your parish so your ministry may focus exclusively on the grandparents or other extended family members who are in your parish. Furthermore, it is likely that extended family members will also be the ones ministering to and caring for the parents of the child who has died and may not recognize their own need for care and support. It is important therefore to be attentive to their needs and help them recognize their need to properly grieve and care for themselves, even while trying to support and be present to the parents.

GRIEF AND SIBLINGS

Any living siblings of the deceased child will also be affected by the loss and will need care to help them cope with the grief. Children respond differently to grief and loss, depending on their age and stage of development. Regardless of their age, here are some important things to keep in mind when a child experiences a death:

- Routines should be kept as normal as possible, including school attendance. Children thrive in routine, as do adults.
- Honesty and openness with kids is important. As much information as they are developmentally able to handle should be shared.
- Non-judgmental listening applies to children too. They need to be given time to be heard and express their feelings, without interruptions.
- It is okay to use real terms like “dead” and “death.”
- Hugs, cuddling, holding, and other forms of appropriate touch provide reassurance.

With older children, who have a deeper understanding about the permanence of death, being a good listener and showing understanding of their emotions is key to helping them through a healthy grief. If a family member cannot provide this support, a trusted friend might be someone they can confide in.

Human beings make sense of loss by telling stories. This is true for children of all ages, as well as adults. Allowing children to share their experience and participate in memory making experiences, rituals, and other ceremonies is vitally important to their mental health. Children could also be included in decision-making, like choosing a name for the child, if age appropriate.

An instrumental piece in helping children following a loss is parents and adults first assessing and dealing with their own responses to the situation. Children look to adults to make them feel safe, and adults need to be models for how to manage grief and loss. Thus, parents should be encouraged to keep regular schedules as much as possible, including meals and exercise. Parents can balance out the upsetting news by reminding themselves of people and events that are meaningful, comforting, and encouraging, along with always engaging in healthy behaviors which enhance their ability to cope and heal. This includes eating well balanced meals, getting plenty of rest, building physical activity into the day, devoting time to prayer and other faith practices (e.g. Mass, Adoration, spiritual reading, etc.), avoiding drugs and alcohol, and adding relaxation techniques if necessary.

SELF-CARE FOR CAREGIVERS

As a caregiver for those grieving the loss of a child, it will be essential for you to take good care of yourself (i.e. to practice self-care). Most people underestimate and downplay the amount and effect of stress in their lives. Human beings are under a lot of stress in the course of their everyday lives—from getting to work on time and getting the kids ready and out the door to school, to helping children with homework, or accommodating the unexpected car breakdown and ensuing expense. Much of our stress is self-imposed. Americans value busyness, often equating it with being useful and productive. But we tend to put ourselves on the back burner and prioritize everything else before ourselves. In fact, if something gets eliminated from the to-do list, it is probably you!

Burning the candle at both ends can result in burnout. Burnout, both personal and professional, can look a lot like depression and anxiety. Burnout has also been defined by J. Edelwich and Archie Brodsky as "a progressive loss of idealism, energy, and purpose experienced by people in the helping professions."[66]

According to the University of Buffalo (NY) School of Social Work, "self-care refers to activities and practices that we can engage in on a regular basis to reduce stress and maintain and enhance our short- and longer-term health and well-being."[67] There are five domains of self-care: taking care of physical and psychological health; managing and reducing stress; honoring emotional and spiritual needs; fostering and sustaining relationships; and achieving an equilibrium across one's personal, school, and work lives.

For some, the idea of squeezing one more thing into an already busy day sounds like more stress. The blog *Thought Catalogue* described self-care well when Brianna Wiest stated: "True self-care is not salt baths and chocolate cake, it is making the choice to build a life you don't need to regularly escape from."[68]

When is the last time you slowed down? When is the last time you did NOTHING? Even just for 10 minutes? No phone, no television, no book, no magazine, no people, no laundry—just you and your thoughts.

Jesus is the perfect model of self-care. Jesus often removed himself from the center of action—feeding thousands with two fish and five loaves, healing the sick and wounded, casting out demons, being pulled this way and that—and he went to a lonely place to pray. He replenished Himself with time alone with His Heavenly Father, he rested, and he re-energized. (see, for example, Mark 1:35; Matthew 14:23; Luke 6:12; Mark 1:12; Luke 5:15-16; Mark 2:13; Mark 6:31-32). Our resources may look different today, but the idea is the same.

66 J. Edelwich and Archie Brodsky, *Burnout: Stages of Disillusionment in the Helping Professions* (1980), 14.

67 https://socialwork.buffalo.edu/resources/self-care-starter-kit/introduction-to-self-care.html

68 https://thoughtcatalog.com/brianna-wiest/2017/11/this-is-what-self-care-really-means-because-its-not-all-salt-baths-and-chocolate-cake/

Some general guidelines to self-care include: making sure the activity you engage in is healthy and is not damaging to yourself or others; knowing when and how you are going to use your relaxation tool (have a plan); having options in case one activity does not feel right to you in the moment; and varying the relaxation and de-stressing technique. Variety in life is a sure way to avoid burnout and stress.

If you are managing your stress in healthy and positive ways, these are some of the behaviors you are probably engaging in on a regular basis:

- Physical activity at least three times a week for at least 30 minutes each time
- Active prayer life
- Six to eight hours of sleep or more every night
- Good, healthy eating habits
- Time to relax
- Maintaining a sense of humor
- Play
- Maintaining healthy rituals and routines
- Positive thinking
- Spending time with family
- Spending time with friends
- Making plans for the future
- Figuring out ways to manage stress
- Rewarding yourself for your accomplishments

Sometimes, even armed with the best information and intentions, we do not handle stress in the best way. A repeated pattern of unhealthy behaviors and negative self-care can result in dis-ease to our body, mind, and spirit. These behaviors might look like:

- Smoking/using tobacco
- Drinking a lot of coffee or caffeinated drinks (more than 2-3 cups per day)
- Drinking alcohol (more than recommended levels of 1-2 per day)
- Overusing over-the-counter medications
- Overeating or undereating
- Spending too much money
- Watching too much television (more than 3-4 hours per day)
- Overuse of social media
- Having angry outbursts
- Taking illegal drugs
- Withdrawing from people
- Ignoring or denying stress symptoms
- Engaging in self-destructive relationships

Self-care is a good practice whether you work in the helping professions or not—it is just a way of life. Remember: live a life that you do not have to regularly escape from. You cannot give what you do not have, so it is important to care for yourself first so that you may more effectively care for others. Furthermore, what we most need to give people is Christ, who is the ultimate care-giver. Therefore, growing in your relationship with Jesus through prayer, Scripture reading/study, and the Sacraments (i.e. having a healthy spiritual life) is key to being successful in this ministry. Allow Jesus to work in and through you to touch the lives of families who have experienced perinatal loss.

Questions to Ponder in the Development of a Self-Care Plan:[69]

- When someone says "self-care," what image comes to mind? What are the positive and negative aspects of this image?
- How do you balance your time alone to renew your energy, reflect on your life, and clear your thinking with the time you spend with those who challenge, support, and make you laugh?
- What types of activities are you involved in which will help you develop a systematic and ongoing analysis of how you are progressing in life? (Ideas: journaling, therapy, reading, etc.)
- What types of exercise do you enjoy and feel would be realistic for you to commit to on a regular basis?
- How do you process "unfinished business" in your life so that you have enough energy to deal with the challenges and appreciate the joys in front of you?
- What self-care steps are more important at this stage of your life than they were at earlier stages?
- What is the next step you need to take in developing your self-care plan? How do you intend to bring this about?

69 Adapted from R. J. Wicks, *Resilient Clinician: Secondary Stress, Mindfulness, Positive Psychology, and Enhancing the Self-Care Protocol of the Psychotherapist, Counselor, and Social Worker,* Oxford University Press, 2008.

Accompanying Families

The role of a *Behold Your Child* minister can take on many different forms. First and foremost, you are a listening, caring presence to those who are suffering perinatal loss. Developing a healthy relationship of accompaniment is key to providing the support those grieving will need. An important principle of accompaniment is to meet people where they are. Walk with them in their grief and help guide them toward hope and healing. Remember the words of St. Paul, "Rejoice with those who rejoice, weep with those who weep" (Romans 12:15). Developing a relationship with the family is key to understanding their struggles and knowing how to properly respond. Prayer and discernment are necessary to help you know what to say and do in ministering to them effectively.

WHAT TO SAY, AND WHAT NOT TO SAY

Remember the wisdom of St. James: "Everyone should be quick to hear, slow to speak." (James 1:19). As has already been indicated, when ministering to a family, spend more time listening than speaking. That said, when you do speak, there are some DO's and DON'Ts.

The DO's:

- Express to them your sorrow for their loss. Simply saying, "I am so sorry for your loss," is almost always appropriate and can go a long way. In the case of a life-limiting prenatal diagnosis, saying something like, "I am so sorry for what you are going through."
- Ask them in a heartfelt, sincere manner, "How are you doing with the loss?" (Then, stop talking and listen attentively.)
- Celebrate the life of the child. Ask if the parents have named the child and what were some of their hopes and dreams for him/her. Always speak in ways that acknowledge and affirm the inherent dignity of the child. In the case of a life-limiting prenatal diagnosis, congratulate the parents on the pregnancy and help them celebrate the life of their child, regardless of what the outcome may be.
- Tell them you are there for them to help however you can. For example, say something like, "I'm here if you ever need to talk" or "I care about you and want to help however I can." Let them know that the parish community cares about them and is there to support them through this.
- Ask them, "What can I/we do to help you as you mourn the loss of your child (or, as you face a life-limiting prenatal diagnosis)?" Gently suggest concrete ways you can provide help (see the section below on "Meeting Practical Needs" for ideas).
- Validate their feelings. Show empathy for what they are going through. For example, you could say something like, "It's okay to feel … (sad, angry, upset, confused, etc.)"
- Assure them, "This is not your fault."
- Tell them you will be praying for them (as long as you actually will!).

The DON'Ts:

- Do not take too much time sharing your own story of perinatal loss or a life-limiting prenatal diagnosis. At times, it can be helpful for them to know you have "walked a mile in their shoes," but sometimes sharing your own story in their time of intense grief can just add to their grief (they will, in a sense, take on your grief too), or it can make them compare their situation to yours in an unhealthy way. Simply saying, "I too have lost a child through (miscarriage, stillbirth, or in infancy)," or "I understand what you're going through" may be enough.
- Do not say, "At least you have ___ other children" (or something similar). The child they lost is irreplaceable and cannot be made up for by other living children.

- Do not say, "At least you were only ___ weeks along." Every life is precious from the moment of conception.
- Do not say, "At least you're still young, so you can likely still have more children." This is not certain and does not help address the grief they are experiencing now.
- Do not say, "This was God's will. You need to just accept it." While God allows death and suffering as a result of collective sin, he does not directly will it for anyone.
- Do not say, "At least God gained another angel." While the child may be in heaven, human beings do not become angels when they die.
- Do not chastise anyone for something incorrect they say or do. When someone is in intense grief, it is not typically the proper time to correct their thinking on a matter (for example, the previous idea of humans becoming angels when they die), nor to chastise their actions. At times, it may be appropriate to defer a conversation about a matter to a later time or gently redirect their thinking and actions in a positive manner toward the truth.

THEOLOGICAL QUESTIONS

Most likely, families who experience the loss of a child will have many questions and concerns, some of which will pertain to aspects of faith. For example, they may ask something like, "If God is so good and powerful, why did he allow this to happen to my baby?" Or, "What have I done wrong to deserve this?" They may feel anger towards God, along with feelings of doubt or abandonment by God. While the goal is to help them move through their anger and doubt, recognizing that these feelings are a normal part of grieving is important so that they are not buried and remain unaddressed, potentially causing greater suffering in the future. It is okay for them to feel that way and to wrestle with questions and doubts.

It is not necessarily your role to provide all the answers to their questions but, rather, to help them process through their feelings. When questions pertaining to matters of faith arise, one must discern the appropriateness of providing theological answers in the moment. In some people's good intentions to help a grieving family better understand the Church's teaching, they can end up forgetting that the family may not be open or ready to have their current worldview shaken. Theological lessons in the midst of grief can be helpful, but they can also come off as calloused. It is not always important or necessary to correct someone's thinking in the moment but rather to engage in such dialogue at a later time. This is even more important if you do not already have an established relationship with the person. It is helpful for us to use Christ as a model. He often listened to the words of someone, even if they were not correct, and then took the time to affirm what he could and gently offered his teaching in a loving, compassionate, and careful way.

"Is my child in heaven?" is a particular question of faith that may be raised by parents, family, or friends of a child lost to miscarriage, stillbirth, or infant death. It is even more acute if the death happened before the child was baptized. Baptized or unbaptized, as people of faith, we entrust our loved ones to the love and mercy of God. The Catechism states, "As regards children who have died without Baptism, the Church can only entrust them to the mercy of God, as she does in her funeral rites for them. Indeed, the great mercy of God who desires that all men should be saved, and Jesus' tenderness toward children which caused him to say: 'Let the children come to me, do not hinder them,' allow us to hope that there is a way of salvation for children who have died without Baptism."[70]

This adds to the importance of our prayers and liturgies for the deceased loved one, especially children who died before baptism. It is understandable that parents worry about their child's salvation if they were not yet baptized. Once again, responding to their questions and concerns must be done with sensitivity in this

70 *CCC*, 1261.

situation. It will be important to remind them that God gave us the Sacraments, like Baptism, for our sake, and that he can and does work outside the Sacraments. God is not limited by the Sacraments. Salvation is possible for those not baptized.[71]

When questions of faith arise that you do not feel adequately prepared to address, it is recommended that you consult with your parish pastor or another theologically astute individual.

MEETING PRACTICAL NEEDS

In addition to being a listening presence and responding to particular questions and concerns, accompanying families in grief (especially when the loss is very recent) can take the form of offering assistance with daily tasks and responsibilities. This could include:

- Setting up a meal train for the family
- Offering or arranging help with household chores
- Providing or coordinating childcare for their children
- Running errands for the family
- Collecting donations of gift cards for meals, food, gas, and other services for the family
- Putting together and giving out care packages with items such as a free movie rental, snacks, and comfort items
- Assisting the parents with memory making (see next section)

Ultimately, each family's needs are different. Finding the best ways to assist and support each particular family in their grief will be a process dependent upon getting to know them so as to cater to their particular situation. There is no one-size-fits-all approach in this ministry, so please be sensitive to the unique needs of each person who has experienced the loss. Do not impose help on a family who does not want it. You can offer assistance, including the items listed above, but if they decline the help, you must respect their choice.

71 For more on this topic, see the document from the International Theological Commission entitled "The Hope of Salvation for Infants Who Die Without Being Baptized," 2007. http://www.vatican.va/roman_curia/congregations/cfaith/cti_documents/rc_con_cfaith_doc_20070419_un-baptised-infants_en.html

MEMORY MAKING

Parents can be offered tangible ideas for ways to remember their child. Start by asking them to think of their own ideas and then, as needed, provide the families with some creative ways to commemorate and memorialize their child. The following are some possible activities and actions that a family could do for memory making. These are only some examples and are not intended to be interpreted as required or necessarily encouraged by ministers. Whether they choose to use some of these examples, come up with their own, or do nothing is to be left completely to the family. Also, siblings and extended family could be encouraged to participate in memory making with the parents.

- Offer the opportunity for a naming ceremony for the child (see "Naming Ceremony" section below). At the end of the naming ceremony, a priest or deacon can fill out the "Certificate for Naming Ceremony" that can be shared with the family and framed in some fashion to offer a daily reminder of their child. This ceremony can occur with a recent loss or even one from years ago.
- Take items such as clothing, shoes, a blanket, or a toy that was purchased or gifted in preparation for the birth of the child. Set them in a shadow box together with the naming certificate or, if baptized, their baptismal certificate, and display it in the home.
- Have Masses said for the child on the anniversary of the death or the day the parents discovered they were pregnant. This is a way to remind families that, though their child is dead, we may still pray on their behalf, and they may pray on ours.
- An ultrasound picture could be scanned, printed, and framed.
- If it is known ahead of time that a child may not survive long after birth, there are organizations that will come during or after delivery and photograph the child (at no charge) in order to provide a lifelong memory of them. Photographers may be found at: www.nowilaymedowntosleep.org/find-photographers.
- A scrapbook and/or photo album could be compiled with memories. This could include pictures of the mother while she was pregnant.
- Handprints and footprints and/or hand and foot molds could be made at the hospital.
- A donation to a charity could be made in honor of the child (especially ones that support families who experience perinatal loss and whose values are aligned with the Catholic faith).
- Once enough time has passed, parents could start a memorial fund that assists other families in receiving awareness and support for miscarriage, stillbirth, and infant loss.
- A statue or grave marker could be dedicated in a Catholic cemetery to those who have experienced miscarriage, stillbirth, or infant loss. A book of names or a simple plaque could be included for families to write their child's name in, if they chose to name the child.
- Include remembrance of all the children of the parish who have died from miscarriage, stillbirth, or infant death during the All Souls commemoration on November 2nd and prayers for the deceased, especially throughout the month of November.
- A Book of Remembrance could be displayed in the Church for families to write the names of their deceased children in. A parish group could then pray for the children written in that book and for their families.
- An individual or group in the parish could knit, crochet, or sew baby mementos like small blankets, booties, or hats to give to families who have lost a child.
- Pregnancy and infant loss awareness items (including pins, bracelets, ribbons, etc.) could be ordered and given to parents or recommended to them.
- A keepsake/memory box to hold items associated with their baby could be made or purchased.
- A necklace, bracelet, ring, or Christmas ornament with their child's name on it and/or a birthstone could be made or purchased.
- A flower, bush, or tree could be planted in honor of their child.

Liturgical Rites, the Sacraments, and Prayer

The role of the *Behold Your Child* minister is to help people find hope and healing after their loss. The importance of prayer and inviting them into a closer relationship with Jesus Christ and His Church cannot be stressed enough in this ministry. Therefore, Liturgical Rites, the Sacraments, and Prayer are essential elements to this ministry.

According to the *Order of Christian Funerals,* "In the face of death, the Church confidently proclaims that God has created each person for eternal life and that Jesus, the Son of God, by his death and resurrection, has broken the chains of sin and death that bound humanity. Christ 'achieved his task of redeeming humanity and giving perfect glory to God, principally by the paschal mystery of his blessed passion, resurrection from the dead, and glorious ascension."[72]

Many parishioners are unaware of the various liturgical rites and other prayers that are available to them in the case of perinatal loss. The *Roman Missal, Order of Christian Funerals,* and *Book of Blessings* all have resources for immediately after the death of a child lost to miscarriage, stillbirth, or infant death, as well as memorials to commemorate the child.

The importance of these liturgies, especially the funeral liturgy, and prayers cannot be understated. The General Introduction of the *Order of Christian Funerals* explains: "At the funeral rites, especially at the celebration of the Eucharistic sacrifice, the Christian community affirms and expresses the union of the church on earth with the Church in heaven in the one great communion of saints. Though separated from the living, the dead are still at one with the community of believers on earth and benefit from their prayers and intercession. At the rite of final commendation and farewell, the community acknowledges the reality of separation and commends the deceased to God. In this way it recognizes the spiritual bond that still exists between the living and the dead and proclaims its belief that all the faithful will be raised up and reunited in the new heavens and the new earth, where death will be no more."[73]

Even more so, the grace that accompanies these liturgies and prayers is immeasurable. Though invisible, God's grace continues to work through them and the community to aid in healing. These graces will remain with the family even after the services have ended, providing them with spiritual strength for the days, weeks, months, and years to come.

It is the responsibility of those ministering to parents and families who experience a perinatal loss to make the various liturgical practices available to them. For example, while the "Rite of Blessing of the Child in the Womb" can be used for any pregnancy, it could especially be administered when a family knows that a miscarriage, stillbirth, or infant loss is likely, including if they have received a life-limiting prenatal diagnosis. Some of the wording of this blessing may need to be adapted to consider the sensitivity of the situation. Additionally, a priest or deacon may use the "Order for Blessing of Parents after Miscarriage" from the *Book of Blessings* after a family loses their child due to a miscarriage.

If a funeral is desired, someone should be available to help plan the service, just as is done for all members of the faith community. Some families may want a full funeral liturgy and commendation at a cemetery; others may simply want a small and intimate memorial service. Furthermore, families could have Mass intentions offered for their child (whether the loss was recent or years ago).

72 *OCF,* General Introduction, 1.

73 Ibid., 6.

The "Rite of Baptism for Children in Danger of Death When No Priest or Deacon is Available" is especially relevant for cases of a known life-limiting prenatal diagnosis, preterm labor, complications during or immediately after delivery, and/or a terminal diagnosis in infancy. Catechesis to all parishioners about when this ritual is appropriate, as well as being made aware of the ritual itself, can be a great benefit to families, especially when unexpected emergencies occur and they wish to have their child baptized immediately.

LITURGICAL RITES PERTAINING TO PERINATAL LOSS:

Following are liturgical rites that pertain to parents and families who have experienced perinatal loss.

Liturgical Rite	Minister	Notes
Rite of Baptism for Children in Danger of Death When No Priest or Deacon is Available, *Rite of Baptism for Children,* #157-164	Any suitable member of the Church	In case of extreme emergency, any person, even non-Christians, may validly baptize a child
Order for Blessing of Parents after Miscarriage, *Book of Blessings,* p. 86	Priest, Deacon, or Lay Minister	For use in hospital, home, or church
Prayers after Death, *Order of Christian Funerals, (OCF)* #101 - 108	Priest, Deacon, or Lay Minister	To be adapted for children
Gathering in the Presence of the Body *OCF,* #109 - 118	Priest, Deacon, or Lay Minister	To be adapted for children
Vigil for A Deceased Child, *OCF,* #243 - 263	Priest, Deacon, or Lay Minister	Prayers and Scripture may be selected. For use in church, hospital, home, or funeral home.
E. For the Funeral of a Baptized Child; *Roman Missal,* Masses for the Dead	Priest	
F. For the Funeral of a Child who Died Before Baptism; *Roman Missal,* Masses for the Dead	Priest	
Funeral Liturgy, *OCF,* #264-294	Priest	Prayers and Scriptures may be selected. For the unbaptized, the rites are adapted. See *OCF* rubrics.
Funeral Liturgy outside Mass *OCF,* #295 - 315	Priest or Deacon, or Lay Minister in the absence of a Priest or Deacon	Prayers and Scripture may be selected. For the unbaptized, the rites are adapted. For use in church, funeral home, or hospital chapel.
Rite of Committal, *OCF,* #316 - 326	Priest, Deacon, or Lay Minister	At cemetery after Funeral Liturgy
Rite of Committal with Final Commendation, *OCF,* #327 - 336	Priest, Deacon, or Lay Minister	At cemetery when Funeral Liturgy has not been celebrated
Rite of Final Commendation for an Infant, *OCF,* #337 - 342	Priest, Deacon, or Lay Minister	For use at cemetery, in a home or hospital
Masses for the Dead II. On the Anniversary *(Roman Missal)*	Priest	On the anniversary of the death of a child.
Masses for the Dead III. Various Commemorations *(Roman Missal)*	Priest	For use on various commemorations for the dead.
Rite of Blessing of the Child in the Womb, USCCB	Priest or Deacon	For use anywhere while child is in the womb
Sample petitions for liturgies *OCF,* General Intercessions and litanies, #6-7	Priest, Deacon, or Lay Minister	For use during liturgies or prayer services

NAMING CEREMONIES

One way to commemorate a child's life is to give them a name that they may be known by forever. Naming a child reinforces that they were a person, that they mattered, that they were loved, and that they are still loved. Being able to refer to one's child by name personalizes the relationship even more than calling the child "her," "him," or "it." Naming a child not only offers a level of dignity to the child, but offers an opportunity for the family to find some solace in being able to talk about their child by name which, in turn, may make it easier to affirm to others the life of their child. If the child's sex is not known, recommending gender-neutral names may be helpful for parents unsure of what name to give their child.

Two naming ceremonies are recommended, although others could be used or developed. These naming ceremonies were created by the Archdiocese of St. Louis and the Diocese of Fargo (accessible with the *Behold Your Child* materials).

HELPFUL SAINTS FOR PERINATAL LOSS

Mary, Mother of God - Witnessed the death of her son, Jesus. Watches over mothers and families especially when they are suffering.

St. Elizabeth Ann Seton - A servant to widows, orphans, and children. She herself lost two very young children.

Blessed Michelina of Pesaro - Lost a very young son.

St. Gianna Beretta Molla - Patroness of unborn children. The miracle for her beatification was the healing of a woman suffering consequences of a stillbirth.

St. Catherine of Siena - Patroness of miscarriages. She had many siblings who died in infancy, including her twin sister.

St. Gerard - Patron of expectant mothers and children (including the unborn).

Sts. Louis Martin and Marie-Azélie Guérin - Parents of St. Therese of Lisieux, they experienced the loss of children in infancy.

REFLECTIONS

Prayerful reflections are available in English and Spanish to provide to parents and family members who have suffered from miscarriage, stillbirth, infant loss, or a life-limiting prenatal diagnosis. These reflections allow people, at their own pace, to sit and reflect on what they are experiencing. They are also important prompts to recognize that more than just mothers mourn and grieve the loss of a child. Fathers, grandparents, siblings, and others connected to the family and to the child will experience the loss in different ways. Be aware that there may be others in your community who wish to seek support but are unaware that a ministry acknowledges their unique experiences and needs. These reflections can help the larger family and community heal from the loss of a child. Reflections for mothers, fathers, couples, siblings, grandparents, medical professionals, and ministers may be accessed from your diocesan *Behold Your Child* leadership. They may be printed and distributed or shared digitally.

Care of Fetal Remains

Since human life begins at conception, the remains of embryos and fetuses must be treated with the same respect as the remains of other human beings. Such remains should never be spoken of or considered as "mere tissue" or "medical waste," or treated in the same way as medical waste. The remains of embryos and fetuses should either be buried or cremated in a respectful manner and place. Cremated remains should either be buried or entombed. Laws and policies will vary based on jurisdictions (state, county, city) as well as from hospital to hospital. It is vital that work is done in your area to learn what the laws are and what policies hospitals have regarding the care of fetal remains.

Parents may wish to arrange for private burial and cremation with a funeral director, or may give the remains over for burial in a communal grave in a specially designated section of a cemetery. A health care facility at which the mother has been a patient during the miscarriage or stillbirth may be able to assist with these arrangements.

Families experiencing perinatal loss should be afforded all the services and support that would be offered for families who had an older child or adult die, including the proper care for and burial of their remains. Unfortunately, miscarried children are often not automatically offered the same services as children who die in infancy or stillborn. Therefore, in cases of miscarriage, more advocacy and guidance often need to be provided for families regarding obtaining and burying their child's remains, as is outlined below.[74]

OBTAINING A CHILD'S REMAINS AT HOME

When a miscarriage occurs at home, the remains of the child may be difficult to identify, depending on the age of development of the child. It is recommended that someone collects as much of the remains as possible, keeping in mind the following:

- The embryo will likely look like a large blood clot in the earlier stages of development and the child may not be easily perceived within the amniotic sac.
- It is not required to search through the amniotic sac to find the remains of the child specifically, although if the parents, a family member, or friend is comfortable doing so it can be done.
- It is important that any handling of remains should be done with proper bloodborne pathogen protections, i.e. nitrile medical gloves.
- Miscarriage collection kits are available at some doctor's offices and hospitals or could be purchased online. Parishes could have some on hand for families who know they may miscarriage.
- Place remains in a container with a saline solution and place in a refrigerator at home until burial and/or until they are transferred to the care of a funeral home. Ensure that the container will not leak, has a tight seal, and is in a place that it won't be dropped or mishandled. A possible option to make the place of reservation of the remains slightly more suitable would be to place a lit candle near the refrigerator as a sign and symbol of the importance of the child's remains.
- Remember that the child's remains are likely very small and fragile and, depending on the age of development, may be imperceptible. A miscarriage can occur and resolve in a short time, but it can also take days. When the miscarriage happens over several days, this complicates the collection of the remains, especially when the child is in early development stages, because of the other biological materials that are also expelled over this period of time.
- If someone has had a miscarriage at home, it is important for them to seek medical assistance for follow-up to ensure that nothing is still present in the uterus which could lead to infection.

74 For more on care of fetal remains, see: Ron Hamel, PhD, "Some Guidance on Disposition of Fetal Remains," *Health Care Ethics USA* (2008);

- Depending on the type of miscarriage and whether or not the fetus has been expelled from the uterus, a Dilation and Curettage (D&C) procedure may be necessary. This procedure involves the cervix being dilated by the doctor and the contents of the uterus being removed (this may include parts of the fetus, the placenta, etc.). This may be necessary whether the miscarriage happened at home or in the hospital. Some confusion surrounds the morality of this procedure as it is also used for certain types of abortion. If, however, a miscarriage has occurred and the fetus is deceased, this procedure is morally permissible and likely necessary to ensure the health and safety of the mother.
- Any remains obtained should be given a proper burial/cremation.

OBTAINING A CHILD'S REMAINS AT THE HOSPITAL

When a miscarriage takes place at a hospital, or a D&C procedure is conducted after a miscarriage, it is important for someone to obtain the remains of their child for a proper burial/cremation. Laws vary by state regarding the rights of parents to the remains of their child before the age of "viability". That said, some hospitals might have their own policies that would prohibit or dissuade parents from obtaining their child's remains for Christian burial/cremation, especially during early miscarriages. Even if a hospital does not have a policy against releasing the remains, they might not voluntarily offer the remains to the parents and might have the practice of discarding the remains as
"medical waste." Parents, therefore, ought to be advised to request the remains of their child and be provided with help, as needed, to coordinate with local funeral homes and cemeteries to properly bury or cremate the child's remains. If hospital policy prohibits parents from obtaining the child's remains for Christian burial/cremation, parents should contact the hospital legal department.

It would be beneficial for the local *Behold Your Child* ministry leaders to proactively contact hospitals to see if they have any policies regarding obtaining remains of miscarried children, especially those at very early gestation. Contacting local funeral homes and cemeteries to learn about and potentially help develop procedures for families who experience miscarriage, stillbirth, or infant loss is also highly recommended.

Important to note: Some parents may come to this ministry after having had a miscarriage in which they were unaware that they could collect their child's remains for burial/cremation and as such may have allowed the hospital (maybe unknowingly) to incinerate the remains with other "medical waste" or may have flushed the remains of their child down the toilet. This can weigh heavily on parents who may feel as though they abandoned their child, that they did not do the right thing, or regret the decision not to obtain the remains and have a burial and/or funeral for their child. It is essential to offer support for such parents in order to help them process their decision and identify what obstacles may have been present which hindered them from making a decision that they now wish they had made in hindsight.

BURIAL OF A CHILD'S REMAINS

The child's remains should be buried in a cemetery or cremated and interred in a mausoleum or columbarium. If the child is cremated, keeping ashes at home, dispersing the ashes, or making jewelry out of the ashes is not permitted according to Catholic teaching, so these should not be recommended. If appropriate, families should be counseled on what the Church teaches regarding the care for fetal remains, and why. This may be
a difficult conversation to have, so it should only be done if the family is open to the discussion. If the family intends on keeping the cremains at home, spreading them, or making jewelry, etc. it may be advisable that such a conversation happens in the future rather than during the immediate grieving period. Regardless, ministers should not facilitate anything that is not aligned with Catholic teaching, but must allow families to make decisions for themselves.

Some cemeteries have specific sections for children who died before birth. It is in the best interest of parents who will experience this type of loss for *Behold Your Child* ministry leaders to contact local funeral homes and cemeteries in order to find out what services are provided in the case of miscarriage, stillbirth, or infant death. This will allow you to have the information readily available for parents immediately during/after a miscarriage or stillbirth. Families will often ask "What do we do now?" or "Who do we call?" Having accurate information for them right away can relieve them of an enormous worry that their baby will be cared for with dignity and respect once it leaves their sight.

Some cemeteries will allow families to bury their child on another family member's plot. Inquire with the cemeteries if this is permissible at your local cemeteries. This can also alleviate the cost of purchasing a new plot or worrying that the child will not be buried with the family.

Burial at Home

In the past, families would often bury the child's remains on their own property, especially in rural areas. Important questions to consider regarding this possible option include:

- What happens if the family moves?
- Will the area be maintained in perpetuity?
- Is there a suitable place for the burial?
- Does the state, county, or municipality have any laws or regulations regarding such burials?
- Is it permitted in their area?
- Do the landowners need permission from government agencies?
- Reserving the cremains in a vessel that is placed on the mantle or on a shelf in the house is not in keeping with Catholic teaching, and so delicate pastoral care is essential in addressing this with families who choose to do so, to encourage them to consider burying or reserving the remains in a more appropriate place such as a cemetery.

Burial Vessels

Depending on the stage of development of the child, different vessels can be used for burial purposes. Some of these items can be purchased in stores, including nice jewelry boxes (wooden, brass, etc.), online, or through a local funeral home or cemetery.

The following are some recommended resources for the burial of a child's remains:[75]

- New Melleray Abbey in Peosta, IA offers small wooden caskets and urns free of charge, and they will ship them when needed to parents who have lost children. These also work for children in very early development. For more information, visit https://trappistcaskets.com/.
- CatholicMiscarriageSupport.com provides helpful guidance and recommendations on their "Caring for Your Baby's Body" and "Burials and Names" pages.
- Heaven's Gain Ministries has baby caskets (first trimester through infancy) and miscarriage kits available for purchase. To access their products and services visit: https://heavensgain.org.

75 The Archdiocese of Dubuque does not endorse all the information, resources, and services listed on these websites.

Acknowledgments

The *Behold Your Child* ministry was originally developed by the Archdiocese of Dubuque (Iowa). The ministry resources, including this Pastoral Guide, have been used with permission. To learn about the ministry in the Archdiocese of Dubuque, please visit www.DBQArch.org/BeholdYourChild. For local resources, please see the following sections of Local Resources.

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Local Resources

The Behold Your Child ministry was developed in collaboration by the Archdiocese of Dubuque offices of Marriage and Family Life, Respect Life and Social Justice, Catholic Charities, and Health Care Ethics in order to provide parishes with resources, training, and guidance for ministering to families who are hurting from a life-limiting prenatal diagnosis, miscarriage, stillbirth, or infant loss (whether recently or years ago). For helpful resources, visit www.DBQArch.org/BeholdYourChild.

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For counseling services or questions about Mental Health First Aid, contact:

https://catholiccounselors.com/tele-counseling-services/our-counselors/

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Local Resources

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