IOWA Health and Human Services

Fetal Death Evaluation Protocol

2005/Revised 2026

IOWA Health and Human Services

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Introduction

When a stillbirth occurs, a careful evaluation of the mother, infant, umbilical cord and placenta is essential to develop an understanding of the cause. An evaluation of the stillbirth occurrence will assist in the discussions with the parents, assist in the planning of any future pregnancy and perinatal care, and contribute to the understanding of the causes of fetal disease and deaths. This may help prevent future pregnancy loss and aid other families with similar conditions.

As defined by Iowa Administrative Code 641-95, a stillbirth is "an unintended fetal death occurring after a gestation period of 20 completed weeks or more or an unintended fetal death of a fetus with a weight of 350 or more grams". A fetal death is "a death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy which is not an induced termination of pregnancy. The death is indicated by the fact that, after such expulsion or extraction, the fetus does not breathe or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles. In determining a fetal death, heartbeats shall be distinguished from transient cardiac contractions, and respirations shall be distinguished from fleeting respiratory efforts or gasps."

In Iowa, there are approximately 160 documented stillbirths each year. Many of these deaths are "unexplained." It is hoped that an organized, purposeful evaluation of a stillbirth will provide information helpful in the development of fetal death prevention programs.

Stillbirths are not included within the definition of a person as currently determined by Iowa Code. For this reason, stillbirths are not reportable to a medical examiner. Nevertheless, in the unusual event of a woman admitted to a hospital having delivered an infant alleged to have been stillborn, notification of a medical examiner is required if there is any reason to suspect that the infant had been born alive.

In cases of stillbirth, the certificate of fetal death filed with the state registrar is the official record of the fetal death.

The intent of these guidelines is to provide a resource for health-care providers, families, and support systems, and to provide a consistent format of data collection for surveillance. The Iowa Department of Health and Human Services requests that a copy of the completed Surveillance and Assessment sections be forwarded to the Center for Congenital and Inherited Disorders (address below). This information will then be available for monitoring and analysis to determine the trends and causes of stillbirths in Iowa.

Please reference the included flowchart (page 4) to help guide you through the process and fill out the evaluation form **ONLY** if this fetal death meets the definition of a stillbirth.

These guidelines were revised in 2025 with the generous support of obstetricians, perinatal pathologists, perinatal mental health therapists, nurses, and partner organizations across Iowa.

Questions about these guidelines may be directed to the Center for Congenital and Inherited Disorders Stillbirth Surveillance and Prevention Program, Iowa Department of Health and Human Services, Division of Public Health at 1-833-496-8040.

Live Birth vs. Fetal Death/Stillbirth Flowchart

If you have any questions about this process or what forms to fill out, contact:

Birth Registration
515-725-2522

Death Registration
515-281-5153

Infant/Fetus Delivered

Did infant/fetus show signs of life at time of delivery?

Yes

Complete "Official Worksheet to Establish Legal Certificate of Live Birth - Hospital Medical Worksheet" and "Official Birth Mother's Worksheet to Establish Legal Certificate of Live Birth".

Enter birth data into Iowa Vital Events System (IVES).

Did infant subsequently die?

Yes

Is funeral home involved?

Yes

Funeral home completes death certificate.

No

Contact Death Registration Bureau of Health Statistics for further guidance: 515-281-5153

No

End process

No

Did infant/fetus reach 20 completed weeks gestation?

Yes

Is funeral home involved?

Yes

Hospital starts Fetal Death Certificate.

Doctor signs Fetal Death Certificate.

Funeral home signs Fetal Death Certificate

Fetal Death Certificate filed with state.

No

Did infant/fetus reach 350 grams?

Yes

Is funeral home involved?

No

Complete "Induced Termination of Pregnancy" form OR "Spontaneous Termination of Pregnancy" form.

No

Is funeral home involved?

No

Hospital starts Fetal Death Certificate.

Doctor signs Fetal Death Certificate.

Contact Death Registration Bureau of Health Statistics to file Fetal Death Certificate: 515-281-5153

Fetal Death Certificate filed.

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Stillbirth Surveillance Evaluation Form

*If this is a multifetal pregnancy, please complete a separate form for each fetus.

(Stamper Plate/ID label)

Hospital Name: _____

Individual Completing the Form: _____

Mother's Name: _____

County of Residence: _____ Age: _____

Race: _____ Ethnicity: _____

Father's Name: _____ Age: _____

Race: _____ Ethnicity: _____

Date of Stillbirth Diagnosis: _____ Gestational Age at Diagnosis: _____

Ultrasound findings at time of stillbirth diagnosis:

_____

_____

_____

Maternal History

G _____ P _____ T _____ P _____ AB _____L _____

LMP: _____/_____/_____ EDC: _____/_____/_____

Maternal Medical History (e.g., diabetes mellitus, chronic hypertension, antiphospholipid syndrome, heart disease):

_____

_____

_____

Obstetric history (e.g., previous fetal demise, previous child with anomaly or hereditary condition, previous gestational hypertension or preeclampsia):

_____

_____

_____

Current Pregnancy (e.g., multifetal gestation, cholestasis, preterm labor or rupture of membranes, ultrasound abnormalities):

_____

_____

_____

Social Determinants of Health (SDOH) (e.g., economic stability, education access and quality, health care access and quality, neighborhood and environment, social and community support):

_____

_____

Medications (Including over-the-counter medications and herbs):

_____

_____

Tobacco or nicotine use (e.g., cigarettes, cigars, e-cigarettes/vapes, smokeless tobacco):

☐ No ☐ Yes- specify_____ Frequency: _____

☐ Former user- quit date: _____

Alcohol use: ☐ No ☐ Yes- Frequency: _____

☐ Former use- quit date: _____

Illicit Drug Use: ☐ No ☐ Yes- Frequency: _____

☐ Former use- quit date: _____

Maternal/Family Interview

Summary of discussion with the mother and other involved family members - include baby's activity patterns, when they first noticed baby wasn't moving, any discomforts during the day or night, and any other events deemed relevant by the mother or family. Consider asking- Was there any point where you felt like something wasn't right with your baby? If so, when did you start to feel that way? What did you notice? Looking back on the experience after the fact, some parents may recall things like decreased movement, or a sudden increase in movement, did you experience anything like that? Did you contact your OB provider or Triage? If so, what were you advised to do (lay down, eat something, come right to hospital, etc.)? Did you see your care provider in the days prior to the death of your baby? Was this visit routine or did you request a visit with them? What made you reach out? Were you able to see your physician or midwife for your prenatal visits? Were you instructed on what to do if you had a concern? (This provides an opportunity to express grief, ask questions, feel heard and build trust.)

_____

_____

_____

_____

_____

_____

_____

_____

Did the parents receive any education regarding tracking the movements of the baby, such as kick counting? ☐ Yes ☐ No

If yes, from whom: _____

Assessment Form

Antepartum Findings

Date of first prenatal visit: _____/_____/_____ Number of prenatal visits: _____

BMI: Pre-pregnancy: _____ Current: _____

Prenatal Labs: ABO/RH: _____ Antibody: _____ Rubella: _____ Hep B: _____

Hep C: _____ HIV: _____ Syphilis: _____ Gonorrhea: _____ Chlamydia: _____

GBS: _____ CMV: _____ Covid 19: _____

Diabetes Testing: 1 hr GTT: Pass / Fail. 3 hr GTT: Pass / Fail.

Maternal Serum Screening (e.g., first trimester screening, quad screen, integrated screen, cell-free DNA testing): Y / N Results:_____

Amniocentesis / chorionic villus sampling: Y / N Results: _____

Ultrasounds (list from most recent to initial exam):

Date: ___/___/_____ Gestational Age: _____

Findings:

_____

Date: ___/___/_____ Gestational Age: _____

Findings:

_____

Date: ___/___/_____ Gestational Age: _____

Findings:

_____

Date: ___/___/_____ Gestational Age: _____

Findings:

_____

Blood Pressure:

- ☐ Low BP (below 90/60)
- ☐ Normal BP (120/80)
- ☐ Elevated BP (above 120/80)
- ☐ Chronic Hypertension
- ☐ Gestational Hypertension (current pregnancy)
- ☐ Preeclampsia (current pregnancy)

Health At Time of Diagnosis

Fever/Rash: Y / N Explain: _____

Bleeding: Y / N Explain: _____

Pain: Y / N Explain: _____

Exposure History

Illnesses: Y / N Explain: _____

Teratogens: Y / N Explain: _____

Recent Trauma: Y / N Explain: _____

Comments: _____

Tests At Diagnosis (as ordered by attending provider)

- ☐ Kleihauer-Betke / Fetal Blood screen
- ☐ Lupus Anticoagulant
- ☐ Anticardiolipin antibodies
- ☐ Factor V Leiden
- ☐ Prothrombin gene mutation
- ☐ CBC
- ☐ TSH
- ☐ Hemoglobin A1c
- ☐ Bile acids
- ☐ Parvovirus IgG and IgM
- ☐ STORCH Titers: IgG and IgM for syphilis, toxoplasmosis, cytomegalovirus, herpes virus, and rubella
- ☐ PCR (Polymerase Chain Reaction) for STORCH
- ☐ Genetic Testing (amniocentesis): _____
- ☐ Maternal drug screen: _____

Findings At Delivery

_____

_____

_____

Gross Fetal Exam

Weight (grams): _____ Length (inches): _____ Head circumference (inches): _____

	Normal	Abnormal (describe)		
1. General Appearance	☐	☐ trauma evidence	☐ macerated +, ++, +++ ☐ edema	
2. Skin	☐	☐ meconium stained ☐ jaundice	☐ bruising ☐ petechiae	
3. Head	☐	☐ hydrocephalic ☐ collapsed ☐ neural tube defect ☐ anencephalic		
4. Scalp	☐	☐ defects ☐ masses		
5. Eyes	☐	Spacing: ☐ narrow ☐ wide Slanting: ☐ up ☐ down	☐ cataracts ☐ opaque ☐ sunken ☐ prominent ☐ eyelids fused	
6. Nose	☐	☐ flat bridge	☐ asymmetric	
7. Nostrils	☐	☐ obstructed	☐ single nostril	
8. Ears	☐	☐ abnormal position ☐ abnormal form	☐ periauricular tags/pits	
9. Mouth	☐	☐ small ☐ large	☐ cleft lip ☐ cleft palate	
10. Mandible	☐	☐ micrognathia	☐ asymmetric	
11. Neck	☐	☐ short	☐ excess skin	☐ cystic mass
12. Chest	☐	☐ asymmetric ☐ small	☐ nipples wide spaced ☐ constricted	☐ sternal defects ☐ barreled
13. Abdomen	☐	☐ flattened	☐ distended	☐ wall defect
14. Back	☐	☐ sacral dimple ☐ scoliosis	☐ Neural tube defect ☐ kyphosis	
15. Arms	☐	☐ short ☐ abnormal muscle development	☐ long ☐ absent	☐ abnormal positioning
16. Hands	☐	☐ creases abnormal ☐ extra digits	☐ webbing fingers ☐ absent digits	☐ abnormal positioning ☐ abnormal nails
17. Legs	☐	☐ short ☐ abnormal muscle development	☐ long ☐ absent	☐ abnormal positioning
18. Feet (length: _____ in)	☐	☐ club foot ☐ extra toes	☐ webbing toes ☐ absent toes	☐ abnormal positioning ☐ abnormal nails
19. Genital-Rectal	Sex ☐M☐F	☐ hypospadias ☐ ambiguous	☐ undescended testes ☐ imperforate anus	

Other Tests/Exams After Delivery (as ordered by attending provider)

- ☐ Iowa newborn blood spot screen obtained and sent to lab
- ☐ Whole body x-ray (limbs extended)
- ☐ Autopsy (consent obtained)
- ☐ Photographs (body, face, extremities, palms)
- ☐ Chromosomal analysis: Cell source (circle one)- amniotic fluid (obtained via amniocentesis at time of prenatal diagnosis of demise is preferred), placental block (1x1 cm, taken from below cord insertion site of unfixed placenta), umbilical cord segment (1.5 cm), internal fetal tissue specimen (such as costochondral junction or patella- skin is not recommended). DO NOT PLACE SAMPLE IN FORMALIN.
- ☐ Placenta to pathology

Gross Placental Exam

Weight: _____

1. Complete	☐ yes	☐ no If incomplete, amount apparently missing- ____%
2. Maternal surface	☐ normal	☐ abnormal: ☐ ragged, ☐ adherent tissue
3. Diameter	Approximately ___cm	
4.Thickness	Approximately ___cm	
5. Shape	☐ discoid ☐ oval	☐ bi-lobed ☐ succenturiate lobe present ☐ other anomaly present _____
6. Consistency	☐ normal	☐ soft ☐firm ☐gritty
7. Hemorrhage	☐ no	☐yes Approximate size of hemorrhage: ____ cm. Consistency of hemorrhage: _____ Adherence of clot ☐yes ☐no
8. Other abnormalities	☐ Amniotic nodules ☐ Malodor	☐ Staining of amniotic surface ☐ Amniotic bands ☐ Other: _____

Gross Umbilical Cord Exam

1. Insertion	☐ Central	☐ Eccentric ☐Velamentous	☐ Marginal
2. Length	Approximately _____cm		
3. Diameter	Approximately _____cm		
4. Knots	☐ No	☐ Yes Describe: _____	
5. Cord around body	☐ No	☐ Nuchal x ___ ☐tight ☐loose	☐ Around torso or shoulder x ___
6. Number of vessels	_____	☐ Single artery	
7. Thromboses	☐ No	☐ Yes Describe_____	
8. Wharton's Jelly	☐ Present	☐ Absent	
9. Torsion	☐ No	☐ Yes	

Return form to:
Director, Center for Congenital and Inherited Disorders
Iowa Department of Health and Human Services
321 E. 12th Street
Des Moines, IA 50319-0075
OR fax to 515-242-6013
Call 1-833-496-8040 for questions.

Grief and Family Support

See Appendix C

Notification of death (as appropriate per hospital policy and procedure): ☐ Yes ☐ No

Mother offered private room off maternity ward if desired: ☐ Yes ☐ No

Mother offered private time with baby: ☐ Yes ☐ No

Father, children, grandparents, and others offered time with baby: ☐ Yes ☐ No

Photographs / Handprints / Footprints / Crib card / Name band / Lock of hair / Baby blankets / Video (circle). Other mementos: _____

Family support available (chaplain, social worker, family, friends, others): _____

_____

Grief packet provided: ☐ Yes ☐ No

Funeral / Body disposition arrangements (e.g. funeral home, cremation services, hospital affiliated programs): _____

Funeral home notified (if applicable): By whom: _____ Date and time of notification: _____

Referrals for grief counseling, support group, and mental health provider information shared: ☐ Yes ☐ No

Referral to genetic counselor: ☐ Yes ☐ No

Education for the mother regarding physiological changes postpartum (e.g., breast milk coming in, lochia, pain, infection, DVT's, etc.): ☐ Yes ☐ No

Follow-up appointments (may vary depending on provider):

- 1–2-week mood check (phone/in-person): _____
- 6–12-week postpartum visit: _____

Follow-Up Visit / Phone Call

Date: _____

Support system for family: _____

_____

Parents received grief counseling or attending a support group: _____

_____

Follow-up appointment with health care provider made/ attended: Date: _____

Assessment for depression or other medical issues done: ☐ Yes ☐ No

Explain: _____

Other concerns or additional follow-up needed: _____

_____

_____

Directions For Completing Evaluation Form

Maternal Investigation

1. If a stillbirth is suspected, an antenatal ultrasound should be performed to confirm the absence of fetal heart rate prior to induction of labor or delivery. Amniotic fluid volume, heart (full or empty), fetal position, and possible anomaly detection are all potentially diagnostic, and problems may not be evident after delivery. If amniotic fluid is abundant, genetic amniocentesis before delivery may produce better results than post-delivery samples, particularly if delivery is not imminent.

2. Review relevant maternal and medical history to help identify specific risk factors:

- Maternal history:

  -previous venous thromboembolism

  -diabetes mellitus

  -chronic hypertension

  -thrombophilia

  -systemic lupus erythematosus

  -autoimmune disease

  -epilepsy

  -severe anemia

  -heart disease

  -tobacco, alcohol, drug, or medication use

- Obstetric history:

  -recurrent miscarriages

  -previous child with anomaly or hereditary condition or growth restriction

  -previous gestational hypertension or preeclampsia

  -previous gestational diabetes mellitus

  -previous placental abruption

  -previous fetal demise

- Current pregnancy:

  -maternal age

  -gestational age at stillbirth

  -gestational age at onset of prenatal care

  -medical conditions complicating pregnancy (cholestasis)

  -pregnancy weight gain and body mass index

  -complications of multifetal gestation (twin to twin transfusion syndrome, twin reversed arterial perfusion syndrome, and discordant growth)

-placental abruption

-abdominal trauma

-preterm labor or rupture of membranes

-abnormalities seen on ultrasound image

-infections (e.g., STI/treatment, CMV) or chorioamnionitis

3. Maternal bloodwork: refer to page 10 for recommended bloodwork

Stillborn Infant

1. Perform an initial examination of the stillborn infant, umbilical cord, and placenta. This examination should be done by someone experienced in the examination of the newborn and placenta and should be similar to, and as thorough, as that performed for a live-born infant. The findings are documented in the medical chart. The purpose of this initial examination is twofold:

- It may constitute the only examination of the infant if autopsy permission is not obtainable.
- The examination will detect growth abnormalities and fetal anomalies thus aiding in directing further investigations of the attending physician.

2. Obtain parental permission to take clinical photographs and x-rays. These photographs are in addition to bereavement photos. Verbal consent is sufficient but should be documented in the medical chart. The purposes of doing these are threefold:

- These may be the only x-rays and photographs obtained of the stillborn infant.
- They will supplement the initial examination already performed for consultation and future review.
- In the case of x-rays, they may uncover anomalies not suspected on the initial examination.

Photographs and x-ray report are stored in the medical chart.

3. Request and obtain written consent for an autopsy. An autopsy is recommended even if the cause of death seems evident to document and confirm the antenatal or intrapartum diagnosis. The stillborn infant, placenta, and the clinical history should be sent to a pathologist familiar with the examination of placentas and stillborn infants. The stillborn infant and placenta should be sent "unfixed" (i.e., not in formalin). Clinical information should include maternal age, obstetric history, expected date of delivery, results of any antenatal investigations, labor and delivery information, and any other pertinent information. Physicians requesting an autopsy should discuss the procedure of an autopsy and the appearance of the body after an autopsy with the parents.

If consent is not given for a full autopsy, ask the parent to consider a limited autopsy, which can include any or all of the following:

- External examination by pathologist.
- Internal examination limited to brain and/or spinal cord; chest organs or abdominal organs as appropriate.

- Clinical photographs/x-rays.
- Removal of small skin or organ samples by needle biopsy (for DNA analysis or cytogenetics studies as appropriate).

It is important to clearly indicate to the pathologist performing the autopsy any limitations in the information accompanying the infant and placenta.

Placenta and Cord

1. In the delivery room:

- Obtain cytogenic specimen (after getting consent). Accepted specimens are: 1. amniotic fluid obtained by amniocentesis at time of prenatal diagnosis of demise, 2. placental block (1x1) taken from below the cord insertion site on the unfixed placenta, 3. umbilical cord segment (1.5 cm), 4. internal fetal tissue specimen such as costochondral junction or patella (skin is not recommended).
- Obtain a 1 cm piece of placenta with sterile instruments for culture including anaerobes, GBS and Listeria. Inform the lab that Listeria is in the differential. Sensitivities are not usually required.
- If TB is suspected, a separate piece of placenta is obtained and sent for mycobacteria.

2. When consent for autopsy is obtained, the above samples of placenta are still taken. The remaining placenta, including the cord and membranes, should accompany the stillborn infant to pathology in accordance with hospital policy.

3. If consent for autopsy is not obtained, the placenta, accompanied by clinical history, should be sent to pathology for examination by a pathologist. Send the placenta to pathology in accordance with hospital policy.

Counseling of the family

In addition to investigating the medical aspects of a stillbirth, it is important to consider the psychological effects on the family. The following steps are recommended:

- Grief support should be initiated as soon as the diagnosis is made.
- A packet of material should be given with immediate needs/decisions highlighted (for instance give a book or pamphlet open to the page that addresses issues the parents are facing at the time).
- All family members, especially the father and other children, should be included in discussions about what is happening, common responses, suggestions for decision-making, etc.
- Encourage picture taking if the parents feel comfortable doing this. Offer a hospital camera if they don’t have their own.
- Explain that the results of all investigations may take two or three months for completion.

- All results of investigations should be forwarded to the physician who will be attending to the mother following her return home after delivery. An appointment for follow-up should be made with this physician prior to discharge.

At the follow-up appointment:

- Discuss and explain the results of all the investigations and their significance.
- Discuss need for genetic counseling and/or obstetric consultation if indicated.
- Discuss issues they are presently dealing with.
- Assess if they need help understanding and working with other children.
- Assess if they need more resources and guidance for facing upcoming days, events, etc.
- Obtain specimen for fasting blood sugar if relevant.
- Assess need for further grief counseling/support groups etc.
- Assess for signs of depression or dysfunctional coping.
- Ask for feedback on how the staff handled them and their crisis – any ideas for improvement (this gives them a chance to not just receive but share something that may be of value).

Appendices

Appendix A: Placental and Umbilical Cord Exam

A pathologist with experience in the examination of placentas should always examine the placenta(s) and umbilical cord from a delivery resulting in a stillbirth or early neonatal death. However, occasionally decisions must be made before a pathological examination of the placenta and umbilical cord is complete. Therefore, it is important that the attending physician conduct a gross exam of the placenta and umbilical cord as soon postpartum as possible.

The attending clinician should also work with the pathologist to provide maternal and fetal history, and other information that may aid in the examination.

To Fix or Not to Fix?

Place the placenta in the refrigerator as soon as possible after the gross exam. Do not let it sit on the counter. Changes go on in the placenta after it is born that could compromise the ability to identify certain pathology.

Each institution should establish its own guidelines. In the fresh state, it is easier to appreciate placental surface changes, to make membrane rolls, to palpate for solid lesions, and to perform injection studies on twin placentas. Placentas show minimal gross and microscopic changes when held at 4 degrees C for up to seven days.

Appendix B: Autopsy Consent Information Form

It is important to know there are certain circumstances in which a stillbirth needs to be reported to the medical examiner: Iowa Administrative Code 641.127.

Benefits of Autopsies

Fetal autopsy is one of the most useful diagnostic tests in determining the cause of death. It is important to understand that an autopsy may or may not give clear answers and sometimes the results are inconclusive.

- Benefits for families: For families, the autopsy has both tangible and psychological benefits. Uncertainty regarding the cause of an individual's death can delay payment of insurance benefits. The autopsy can also uncover genetic or environmental (for example, bacterium or fungus) causes of disease that could affect other family members. Psychologically, the autopsy provides closure by identifying or confirming the cause of death. The autopsy may demonstrate to the family that the care provided was appropriate, thereby alleviating guilt among family members and offering reassurance regarding the quality of medical care. Lastly, the autopsy is a mechanism that enables the family to participate in medical education and research.

- Benefits for the clinician and the hospital: The procedure can confirm the accuracy of the clinical diagnoses and the appropriateness of medical care. The autopsy findings can be utilized to educate physicians, nurses, residents, and students, thereby contributing to an improved quality of care.

- Benefits to society: Many of the benefits of the autopsy are experienced by society as a whole. The autopsy aids in the evaluation of new diagnostic tests, the assessment of new therapeutic interventions (drugs, devices, surgical techniques), and the investigation of environmental and occupational diseases. Autopsy data are useful in establishing valid mortality statistics. Data derived from death certificates in the absence of autopsy data have repeatedly been shown to be notoriously inaccurate. New medical knowledge on existing diseases that are derived from autopsy-based research is important for everyone.

Responsibility for Autopsy Costs

The family is responsible for autopsy cost unless the autopsy is requested by the Office of the State Medical Examiner.

Guidelines for Informing and Involving Families

Traditionally, professionals have sought to protect families from information that they may find distressing. However, experience has shown that timely information provided in a sensitive manner can empower families and is far less distressing than later disclosure.

Bereaved families have the right to clear, factual and sensitive communication from a skilled professional. Institutions have a responsibility to ensure that in each case there is a specifically trained staff member whose role is to engage with the bereaved family and provide clear, factual information in a sensitive manner following the death of a patient. The approach to the family regarding autopsy is most appropriately made by the attending clinician treating the patient requesting an autopsy and discussing organ retention and use, and other sensitive information, should be conducted face to face.

The appropriately trained person whose priority is the needs of the bereaved family should support the clinician in this role. The capabilities of such persons in providing assistance to the bereaved family should include:

- An understanding of the dynamics of the grief process.
- Counseling and communication skills to convey information at a pace and by using language that the family can understand.
- The capacity to recognize the needs of families where English is not the first language, and the potential for diminishing fluency and comprehension or reversion to the native language.
- Communication and advocacy skills to ensure the wishes of the family are conveyed and respected.
- A good understanding of the autopsy process including the need for tissue/organ retention and options available for future use, release or disposal.
- Knowledge of all aspects of funeral arrangements.

Institutions involved with the bereaved family must recognize and provide for the following needs:

- A quiet, private area to undertake these discussions.
- Time to assimilate the impact of the death before being approached to discuss autopsy. While it is acknowledged in certain situations the treating clinician may have had extensive discussions about the prognosis of the patient and the benefits of an autopsy may have already been raised with the family, in most situations it is inappropriate to raise the issue until the family has had time to take in the death of the baby.
- Information about events leading to the death, treatment attempts etc. before feeling ready to discuss other issues.
- Support to facilitate their “goodbye” to their baby.
- Any special religious or cultural rituals that must be acknowledged and met where possible.
- Clear, honest information.
- Specifically, families must be clearly informed of their rights:
  -to decline the performance of a hospital autopsy
  -to limit the extent of the examination and retention of tissue and organs, understanding that such limitations may compromise the information obtained from the autopsy
  -in regard to disposal options for retained tissues and organs
  -to be advised about uses other than diagnosis to which retained tissues/organs can be put
- Access to interpreters and appropriate health workers where necessary.
- Information and assistance to make funeral arrangements.

- Assessment and referral for ongoing counseling if required.
- Provision of autopsy results in an understandable form. In some situations, discussion with the pathologist may be appropriate.

Consent Procedures

Parental consent must always be obtained for an autopsy of a stillborn baby.

Appendix C: Grief and Family Support

When an older child dies, or an adult loved one dies, the mourning process includes relating closely to the deceased by remembering times and relationships shared. When a child dies during pregnancy or as a newborn, there has been little time to share a relationship with the child as a separate person. As a result, the family is left to mourn the loss of a part of themselves without the aid of memories and mementos.

It is recommended that the care givers talk of the tasks of grief and the feelings of grief (tasks being to share stories and memories, create and nourish any and all memories, say hello before goodbye, make the best decisions they can, keep their love alive, plan for and celebrate holidays and anniversaries including their baby whenever possible, taking care of themselves, feeling their feelings – not denying them, etc.). Feelings of grief may include shock or denial, anger, bargaining (usually with God), guilt, depression, and sadness; plus, anguish, emptiness, shame/blame, hopelessness and hopefulness, love, etc. All these feelings may come and go in an uncontrollable manner. Not to be predicted or even understood but hopefully accepted as the process of mourning.

These emotions are real and a normal part of grieving. Grieving is a process of making meaning out of the loss of hopes, dreams and wishes that were real long before the loss of a baby. Grieving is an unpredictable process, and parents may move back and forth between these stages. Grieving is necessary to work through the pain toward healing.

While the initial response to keeping footprints, pictures, crib card, or lock of hair may be negative; these items take on special significance as proof that the child existed. It is important to encourage families to spend time saying hello, getting to know their child. This is critical before they say goodbye. They are “squeezing” a lifetime of memories and mothering/fathering into those few hours and days. Naming the child, which can be done at any time, can help to confirm the reality. A funeral or memorial service is appropriate according to the parent’s wishes. It is the one thing they can do for their child and is an important ritual for saying goodbye, also providing for memories that can help heal over time.

Mothers and fathers can be expected to mourn and grieve in different ways. One spouse may believe their role is to protect the other, and without meaning to, shut them out of the important decisions in which they may need to have a part. An example may be funeral arrangements. One spouse may feel that if only he or she can contain their expression of grief, they will not burden the other. Family members may blame each other for things they should have or should not have done or said. At this point, misunderstandings abound. Communication is key for grieving parents. Couples may need to set aside time to talk about their loss and their feelings about it. This can provide some sense of control in a situation where the feeling of having lost control can be overwhelming.

Another way for parents to have some control over the situation is to develop a birth plan. In circumstances where a stillbirth is anticipated, or where it is known that the infant will not survive beyond the initial newborn period, a birth plan can help the family make it through the pregnancy, delivery, and what follows. A birth plan can be developed from the questions asked in the Grief and Family Support Section of the manual.

What You Can Do to Support the Family

The most important thing you can do is just be there as the family asks. They need your understanding right now. You might not know what to say or do, but don’t let your discomfort keep you away from supporting the family. When in doubt, error on the side of silence. Offer eye contact or the squeeze of

your hand. You don't have to have all the answers. Provide an environment in which the family can talk about the baby who has died. Talk candidly about the baby by name. Ask sensitive questions without being intrusive (e.g., "Does her red hair come from your side of the family?" or "Is (blank) a family name?").

Be sure to offer help with decisions; helping them to see that it might be easy to take what they think is the easier road of avoiding pain right now, but in the long run the good decisions they make now will sustain them over time. While seeing, bathing, holding, taking movies and pictures, including other children and family members, etc. may seem hard, it will likely be better in the long run as they have this to hold on to. One nurse described it in this way, "When a child scrapes her knee, she may say don't touch it; leave it alone; it hurts. However, if we don't clean out that wound it may get infected over time. If, however, we do the hard and painful job of cleaning it, in time it will heal. Embracing the baby and doing the hard, painful work of spending time with the baby who has died or is dying, will bring comfort over time and keep one from being haunted by regrets and even more pain."

The following contains some dos and don'ts for friends and family supporting grieving parents.

What to say and do to and for grieving parents:

- First, be yourself and act normally.
- You can send flowers, cards, or take food, but do not wear out your welcome.
- Do say:
    - "I love you."
    - "Can I do anything for you?"
    - "I am here to listen when you want to talk about (baby's name)."
    - "Can I watch the other children so you can rest?"
    - "Can I clean the house for you (or run errands, etc.) so you can rest?"
- The greatest gift you can give them is your love and support in any way they need.

What not to say or do:

- Do not avoid the couple because you are uncomfortable.
- Do not try to distract the parents from grieving and cheer them up.
- Do not ask, "How are you doing?"
- Do not say:
    - "Don't think about it."
    - "I know how you feel."
    - "I understand."
    - "You shouldn't feel bad (or sad)."
    - "Don't question God's will, or say it was God's will."
    - "It was for the best."
    - "You'll get over it" or "you're so strong."
    - "You should be over it by now."
    - "You need to get on with your life."

As a trusted friend or family member, you have the opportunity to monitor the bereaved person. This can be tricky, because you do not want to be perceived as insensitive or offering unwanted advice. Instead of telling the person what to do, try stating your own feelings or observations. For example, “I noticed you haven’t been sleeping – perhaps you should talk with your doctor”.

The following warning signs need to be taken seriously:

- Extremely poor personal hygiene.
- Drastic weight gain or loss.
- Alcohol or drug abuse.
- Pain or constriction in the chest.
- Disturbed sleep patterns.
- No interest in previously enjoyable activities.
- Persistent suicidal thoughts.

Encourage or seek professional help for the person if they demonstrate any of these warning signs. Especially pay attention to the person who seems to be stuck, needs plenty of advice, wants to ward off problems and seems to need more help than they are getting (this is prevention and a good idea); as well as if they have any of the more serious issues that go on and on.

Cultural Sensitivity

Sensitivity to cultural beliefs is of utmost importance during the event of a stillbirth. Care should be taken to understand and respect the family’s cultural beliefs and practices. The practice of trauma-informed care can inform the provider on the life-long impact of family/patient trauma to positively impact patient relationships and promote health.

Appendix D: Iowa Code and Administrative Rules

Iowa Code

- Vital Statistics (includes definition and information on fetal death). 144.pdf
- Congenital and inherited disorders (describes activities related to surveillance of fetal deaths). 136A.pdf

Iowa Administrative Code

- Vital records: general administration (includes definitions of fetal death). 641.95.pdf
- Death registration and disposition of dead human bodies (includes registration of fetal death). 641.97.pdf
- Center for congenital and inherited disorders (describes fetal death surveillance activities). 641.4.pdf

Appendix E: Resources

Support Groups and Educational Material:

- **The Compassionate Friends**- Online support and local chapters supporting family after a child dies.

Website: compassionatefriends.org

- **No Foot Too Small**- In person and virtual support groups for parents who experienced pregnancy or infant loss.

Website: nofoottoosmall.org

- **Share Pregnancy and Infant Loss Support (has a free app)**- A community for anyone who has experienced the death of their baby including parents, grandparents, siblings, and friends. In person and virtual support groups are offered, as well as comfort kits and sibling bags.

Website: nationalshare.org

- **Star Legacy Foundation** (support line- call or text 952-715-7731)- A non- profit organization dedicated to reducing pregnancy loss and neonatal death and improving care for families who experience such tragedies.

Website: starlegacyfoundation.org

- **Chasing the Rainbows** (24/7 support- call or text 1-833-852-6262)- Offers a variety of support programs and services such as daily virtual support groups, peer mentor, individual trauma therapy, community events and advocacy, and a weekly podcast.

Website: chasingtherainbows.org

- **Postpartum Support International** (Helpline- call or text 1-800-944-4773)- Offers several different support groups, peer mentor programs, and specialized support coordinators.

Website: postpartum.net

- **The Tears Foundation**- Offers comprehensive bereavement care in the form of grief support groups and peer companions. Also provides financial help with funeral costs after completing an application (based on guidelines).

Website: thetearsfoundation.org

Grief/Loss Books

- **From Hurt to Healing**- The March of Dimes Booklet. Website to fill out form to request the free booklet: www.marchofdimes.org/bereavement-booklet
- **Still: A Collection of Honest Artwork and Writings from the Heart of a Grieving Mother**- by Stephanie Paige Cole
- **Before I let Go**- by Kennedy Ryan
- **An Exact Replica of a Figment of My Imagination**- by Elizabeth McCracken
- **Empty Cradle, Broken Heart: Surviving the Death of Your Baby**- by Deborah L. Davis
- **They Were Still Born: Personal Stories about Stillbirth**- by Janel C. Atlas
- **Ghostbelly**- by Elizabeth Heineman
- **When Hello Means Goodbye**- by Paul Kirk
- **Grieving Dads: To the Brink and Back**- by Kelly Farley and David DiCola
- **Unexpecting: Real Talk on Pregnancy Loss**- by Rachel Lewis