

Appendix A:



STATE OF DELAWARE Child Death Review Commission (CDRC)

Date

Name

Address

Address

Dear ,

I am contacting you due to the recent loss of _____. I am very sorry for what you have been through.

I am a Social Worker with a State of Delaware Program that has been formed to review the deaths of women who were pregnant within the previous year. This program is called Maternal Mortality Review and its purpose is to prevent premature deaths of women in the future.

I would like to talk to you about how you are doing and invite you to participate in the program. Along with offering help and support to families who have had a loss, we also want to do everything we can to learn from these tragedies.

I have worked with grieving families for more than twenty-five years. When a person is grieving they may find it helpful to talk about their loved one, especially if they feel it may help some other family not have to experience what they are going through. The familial interviews can be the most valuable and insightful part of the review.

If you choose to take part in this program, a meeting will be scheduled with you in your home, in our office, or another place in which you would feel most comfortable. You can tell me about your loved one's experiences with the health care system and any other services that she may have used. We can also talk about your needs and the needs of your family. Referrals to programs in the community will be provided if you so desire.

Your participation in the program is completely voluntary.

Please contact me at (302) 255-1760 with any questions you may have about our program.

You and your family will remain in my thoughts.

Sincerely,

Kristin L. Joyce, B.A.
Senior Medical Social Worker

Appendix B:

**Maternal Mortality Review
Family Interview Questionnaire**

DE MMR Case # _____

Date of Interview:

1. What was your relationship to _____?
 - a. Husband--How long were you married? _____yrs
 - b. Boyfriend
 - c. Live in partner/ common law spouse
 - d. Mother
 - e. Father
 - f. Brother
 - g. Sister
 - h. Friend
 - i. Other _____
2. How long did you know _____?
_____months _____yrs

If the respondent was a boyfriend or partner of _____, ask question 3.

3. Were either of you legally married to anyone else for the last year of her life?
___Yes ___No
4. Was she ever married before? ___Yes ___No

If no, go to question 6.

5. How many times total was she married? _____
6. Did you live together during the last year of her life? ___Yes ___No

If yes, go to question 10.

7. Where did you live in relation to _____?
 - a. Next door
 - b. Same apartment building or complex
 - c. Same street
 - d. Same neighborhood
 - e. Same city
 - f. Within the state
 - g. Different state
 - h. Different country
8. During the last year of _____'s life, how often did you see her?
9. How did you keep in contact with _____? (check all that apply)
 - a. In person
 - b. By telephone
 - c. By email
 - d. Other (specify) _____
10. How would you describe your relationship with _____?
 - a. Very close
 - b. Somewhat close
 - c. Not close
11. Did you have a job in the last year of _____'s life?
12. What was your occupation then?

Now we would like to talk more specifically about _____.

13. How did she describe her racial background?
 - a. Caucasian

- b. Black
 - c. Asian, Pacific Islander
 - d. Native American
 - e. Other (specify) _____
14. What was the first language she learned to speak as a child?
- a. English (**skip to question 16**)
 - b. Spanish
 - c. Other (specify) _____
15. Would you say that she:
- a. Spoke English well
 - b. Spoke little English
 - c. Spoke no English at all
16. What country was _____ born in?
- If US, go to question 18.**
17. How long did _____ live in the United States?
18. What was _____'s religion?
- a. Catholic
 - b. Protestant
 - c. Jewish
 - d. Muslim
 - e. No religion (**skip to question 20**)
 - f. Other (specify) _____
19. Was she active in her place of worship? ___Yes ___No
20. Was _____ involved in other community organizations?
 ___Yes (specify) _____
 ___No
21. What was the highest grade or degree that _____ completed?
22. What city or town did _____ live in for the last year of her life?
23. What type of housing did _____ live in for all or part of the last year of her life? (check all that apply)
- a. Private house
 - b. Apartment building or complex
 - c. Housing project
 - d. Homeless shelter
 - e. Residential program for drug or alcohol treatment
 - f. Institution (specify) _____
 - g. Homeless
24. On a scale of 1 to 5, how would you rate the safety of the neighborhood she lived in, with 1 being very dangerous and 5 being very safe?
- Now I would like to ask you some questions about _____'s income.**
25. In the year before she died, did _____ have a job? ___Yes ___No
- If no, go to question 27.**
26. What type of work was she doing?
27. I am going to list a number of ways that people support themselves. Please tell me if you know if _____ received money from any of the following sources to support herself in the last year of her life.
- a. Wages or pay from a job
 - b. Benefits such as AFDC, Welfare, General Assistance, Food Stamps or SSI (circle all that apply)
 - c. Unemployment benefits
 - d. Child support or alimony

- e. Social security, worker's compensation, veteran's benefits or pensions (circle all that apply)
- f. Family
- g. Friends
- h. Other (specify) _____

28. Would you be willing to share with me an estimate of _____'s household (combined) annual income in the year prior to her death? ___Yes ___No

If no, go to question 31.

29. What was her total household income for the last 12 months of her life before taxes?

30. Was that similar to her income in the previous 12 months?
___Yes ___No

31. How did _____ die?

32. Do you know if _____ was pregnant at any time during the last year of her life? ___Yes ___No

33. Did _____ have any chronic health problems (such as diabetes, hypertension)?

___Yes (describe) _____
___No (**skip to question 36**)

34. Did _____ see a health care provider(s) for treatment of her condition?
___Yes (specify) _____

___No (**skip to question 36**)

35. What kind of treatment did _____ receive for her condition?

36. Did _____ ever have a serious infection (such as pneumonia, Lyme disease, TB or an STD)?

___Yes (specify) _____
___No (**skip to question 40**)

37. When did _____ have this infection?

38. Did she receive treatment?

39. Did she recover fully? ___Yes ___No (explain) _____

40. Was _____ ever diagnosed with a mental illness?

___Yes (explain) _____
___No (**skip to question 45**)

41. Did she receive treatment for the mental illness?

___Yes—Where? _____
___No (**skip to question 44**)

42. What type of treatment did she receive? (circle all that apply)

- a. Medication
- b. Counseling
- c. Electric shock therapy
- d. Short-term hospitalization (<1 month)
- e. Long-term hospitalization
- f. Other (specify) _____

43. Do you know if _____ followed her doctor's treatment for her mental illness? ___Yes ___No

44. How long before _____ died did she develop the mental illness?

45. Was there ever a time when _____ needed to go to the doctor or the hospital for any reason, but did not go?

___Yes—Why didn't she go?

___No

Now I am going to ask you some questions about some things that _____ may or may not have done that could have affected her health.

46. Did she ever smoke cigarettes? ___Yes ___No (**skip to question 49**)
47. Did she smoke cigarettes during the last year of her life? ___Yes ___No (**skip to question 49**)
48. Approximately how many cigarettes per day did _____ smoke during the last year of her life?
49. Did she drink alcohol? ___Yes ___No (**skip to question 51**)
50. Approximately how many alcoholic drinks did _____ have in an average week during her last year of life? (A drink is one glass of wine, one wine cooler, one can or bottle of beer, one shot of liquor or one mixed drink.)
51. Some women use drugs (prescribed or otherwise) for reasons other than to treat illnesses (for example, stress, weight loss, socially). Did _____ use drugs for similar reasons? ___Yes ___No (**skip to question 56**)
52. Which of the following drugs did _____ use: (circle all that apply)
 - a. Marijuana
 - b. Cocaine-inhaled
 - c. Cocaine-injected
 - d. Crack, heroin
 - e. PCP, angel dust, LSD
 - f. Barbiturates
 - g. Methadone
 - h. Prescription sedatives
 - i. Prescription diet pills
 - j. Other non prescribed drugs (specify) _____
53. How long had she been using drugs before she died?
54. Did she use drugs during the last year of her life? ___Yes ___No
55. Did she ever receive drug rehab services?
___Yes—Where and when? _____
___No

Now I would like to talk about _____'s pregnancy history.

56. How many times all together was _____ pregnant?
(**If none, go to question 116.**)
57. . Did any of her pregnancies end in: (indicate how many of each)
 - a. Miscarriage (less than 20 weeks)
 - b. Induced abortion
 - c. Still birth/ fetal death (>20 weeks)
 - d. Ectopic pregnancy
58. How many children did she have altogether?
(**If none—all pregnancies ended in spontaneous or induced abortion—go to question 69**)
59. What are the children's ages and genders?

Now I would like to talk a bit about _____'s children.

60. Were all of her children living with her at the time of her death?
___Yes (**skip to question 62**)
___No
61. What were the living arrangements of those children who lived away from _____? (circle all that apply and specify number of children)
 - a. Living with another relative
 - b. Living with a friend
 - c. Foster care

- d. Adopted
 - e. Runaway
 - f. Living independently
 - g. Other (specify) _____
62. Did the children receive any special services such as social services, behavioral therapy, physical therapy, etc?
63. Have any of _____'s children been very sick or badly injured?
 Yes
 No (**skip to question 66**)
64. Were they sick before or after _____'s death?
 before mother's death
 after mother's death (**go to question 65**)
64. Were they sick in the last year of her life? Yes No
65. What illness(es) did he/she/they have?
66. Have any of _____'s children died?
 Yes—How old were they when they died? _____
 No (**skip to question 69**)
67. When did he/she/they die?
 before mother's death
 after mother's death
68. What was/were the cause(s) of death?

**Now I have some questions about _____'s last pregnancy in mm/yy.
 If someone other than spouse or partner is being interviewed, skip to question 70.**

69. Were you the father in that pregnancy, in mm/yy? Yes No
70. Would you say that _____ planned to get pregnant?
 Yes, planned pregnancy
 No, unplanned pregnancy

If someone other than spouse or partner is being interviewed, skip to question 80.

71. Before _____ got pregnant, did the two of you use any birth control method to prevent pregnancy? Yes (**skip to question 73**) No
72. Why were you not using birth control?
Then skip to question 76.
73. What method(s) of birth control did you use?
74. Where did _____ get her birth control from?
75. How was she paying for her birth control?
76. Did you want to have a child at the time?
 Yes (**go to question 79**)
 No
77. Why didn't you want to have a child?
78. What did you want _____ to do about the pregnancy when you learned that she was pregnant?
79. Did the two of you make plans together to have a baby? Yes No
80. What was the outcome of _____'s last pregnancy of mm/yy?
- a. Live birth
 - i. Full-term baby
 - ii. Premature baby
 - b. Fetal death (>20 weeks)
 - c. Miscarriage (<20 weeks)
 - d. Induced abortion
 - e. Ectopic pregnancy

f. Other (specify) _____

If the woman had a live birth or a fetal death, continue with question 81. If she had any other outcome, go to question 83.

81. Did _____ consider having an abortion or putting the child up for adoption? ___Yes ___No
82. If she considered abortion, what kept her from doing that?
83. On a scale of 1 to 5, with 1 being strongly negative and 5 being strongly positive what was _____'s reaction when she learned that she was pregnant?
84. Did _____ receive prenatal care during her pregnancy?
___Yes ___No

If yes, go to question 86.

85. Why didn't she receive prenatal care? **Then skip to question 92.**
86. What month did she begin to receive that care? (If >4 months, why didn't she receive care sooner?)
87. Where did she go for prenatal care?
- Clinic
 - HMO
 - Private office
 - Birthing center
 - Hospital
 - Emergency room
88. Do you know how many prenatal visits she had altogether?
- 1-3
 - 4-6
 - 7+
 - Don't know
89. Did she find it difficult to keep her prenatal appointments? ___Yes ___No

If no, go to question 91.

90. What was the reason for this difficulty?
- Child care
 - Job
 - Transportation
 - Illness
 - Cost
 - Other (specify) _____
91. How did she pay for prenatal visits?
- Self pay
 - Private insurance
 - Friend/relative paid
 - Medicaid
 - Unable to pay
 - Other (specify) _____
92. Did _____ receive any additional services during her pregnancy (such as WIC, home visits, case management, community groups)?
93. Did she experience any special medical problems during her pregnancy that made it necessary for her to see a specialist?
___Yes
___No (**skip to question 97**)
94. What kind of medical problems did she have?
95. Whom did _____ see for her problems during pregnancy?
96. Did she receive any treatment, and if so what kind of treatment?

- Yes (specify) _____
 No
97. Many families and communities have traditions for pregnant women. Did _____ do any special things or see any special healers while she was pregnant?
 Yes (specify) _____
 No
98. Was _____ hospitalized at any time during her pregnancy?
 Yes
 No (**skip to question 101**)
99. What was she hospitalized for?
100. Where was she hospitalized and how many times?
101. Did _____ go to the emergency room for any problems during her pregnancy?
 Yes (explain) _____
 No
102. Did _____ attend any classes to prepare her for childbirth or the care of the baby?
 Yes (what classes?) _____
 No
103. Did _____ have any particular worries during her pregnancy (about her health, the baby, other stressors)?
 Yes (explain) _____
 No
104. What was _____'s relationship like with her health care providers?
If the woman died during pregnancy, go to question 116.
105. What was the date of the baby's birth/ termination of the pregnancy?
106. If this pregnancy ended in a birth or fetal death, indicate the delivery type:
 a. Normal vaginal delivery
 b. Complicated vaginal (forceps, vacuum)
 c. C-section
 d. Other (specify) _____
107. If this pregnancy ended in abortion, indicate the type:
 a. Spontaneous miscarriage
 b. Surgery for ectopic pregnancy
 c. Abortion, licensed provider
 d. Abortion, unlicensed provider
 e. Other (specify) _____
108. How many months pregnant was _____ at the time of delivery or termination of the pregnancy?
- If the woman died during birth or before she was discharged from the hospital, skip to question 116.**
109. After the pregnancy, did _____ keep her routine follow-up appointments?
 Yes (where) _____
 No (why not?) _____
110. Did _____ experience any medical complications after the baby was born/ the abortion?
 Yes
 No (**skip to question 114**)
111. Did _____ go to a doctor to treat the complications?

- ___Yes
 ___No (**skip to question 113**)
112. Why didn't she go to a care provider to treat the complications?
 a. lack of money
 b. transportation
 c. child care
 d. other (specify) _____
113. How did _____ do after treatment?
114. Did _____ complain of excessive pain or discomfort after the baby was born/ the abortion? ___Yes ___No
115. Did _____ receive any home visits from a nurse or community group after the birth of her baby/ the abortion?
 ___Yes (explain) _____
 ___No
116. The next set of questions is about events that may have happened to _____ in the last year of her life. I will read you a list of items and for each tell me whether or not it happened during this time in her life.
- | | | |
|--|---|---|
| a. Did she move apartments or houses? | Y | N |
| i. If yes, how many times did she move? _____ | | |
| b. Was she ever homeless? | Y | N |
| c. Did she get very sad or depressed? | Y | N |
| d. Did a close friend or family member become very sick or die? | Y | N |
| e. Did she lose her job? | Y | N |
| f. Did anyone hit, punch or kick her? | Y | N |
| i. If yes, who? _____ | | |
| g. Was she the victim of a crime? | Y | N |
| i. If yes, what type of crime? _____ | | |
| h. Was she arrested? | Y | N |
| i. If yes, for what? _____ | | |
| i. Was she involved in a gang? | Y | N |
| j. If she experienced a fetal or infant death, did she receive bereavement support services? | Y | N |
117. Did any other difficult event take place?
 ___Yes (specify) _____
 ___No
118. Is there anything else you would like to share with me about _____?
119. Did you or _____'s surviving family receive any bereavement support after her death?
 ___Yes (specify) _____
 ___No
120. Are there any services you did not receive that you wish you had available to you after _____'s death?
121. Finally do you have any advice about helping families who experience a loss similar to yours?

Completed by:
 Date:

Appendix C:



STATE OF DELAWARE Child Death Review Commission (CDRC)

Date

Name

Address

Address

Dear ,

Thank you very much for meeting with Kristin Joyce, our Senior Medical Social Worker, and for your participation in our program. It has been a few weeks since the interview and we wanted to follow up with you to see how you are doing. We realize that dealing with the loss of a (**wife, daughter, sister**) is a very long and difficult process. We would like to remind you that our office is here to offer you support.

We have enclosed an evaluation to capture your thoughts and feelings about the family interview. We are asking for your feedback to see if there are ways that we can improve our program and our interactions with families who participate. Your responses will be kept confidential.

Thank you for your courage and your commitment to helping other families in our state. If you have any questions, or if you have a need that we may be able to assist with, feel free to contact our office. Our number is (302) 255-1760 and our office hours are 8:30 a.m. to 4:30 p.m..

Sincerely,

Joan Kelley, R.N.
FIMR Program Coordinator

Evaluation of the Interview

1.) When do you feel would have been the best time for Kristin Joyce to have contacted you for the first time after the death of your loved one?

- | | |
|--|-------------------------------------|
| <input type="checkbox"/> In the hospital | <input type="checkbox"/> 1-2 weeks |
| <input type="checkbox"/> 2-4 weeks | <input type="checkbox"/> 4-6 weeks |
| <input type="checkbox"/> 6-8 weeks | <input type="checkbox"/> 8-10 weeks |
| <input type="checkbox"/> Other | <input type="checkbox"/> 10 + weeks |
- (specify) _____

2.) Which of these things contributed to your decision to participate in the program?
(Check all that apply)

- I wanted to talk about my experience.
 I wanted the opportunity to provide information that might help other families.
 I was looking for services in the community for me and my family.
 Other (specify) _____

3.) Do you feel the interview gave you an opportunity to openly share your feelings?

- Yes No Somewhat
Comments: _____

4.) Do you feel it was beneficial for you to answer questions about your loss?

- Yes No Somewhat
Comments: _____

5.) Did you feel that you would be helping other families by participating with the interview?

- Yes No Somewhat
Comments: _____

Do you have any thoughts or feelings about Kristin Joyce and your interaction with her as the maternal interviewer?

Are there other comments or suggestions you would like to make about your experience?

Thank you once again for all of your time and your support of this program. We value your opinion and the feedback that you have provided.

Together we can make a difference