



INTERNATIONAL STILLBIRTH ALLIANCE & THE STILLBIRTH ADVOCACY WORKING GROUP

Parent Voices Initiative

RAISING PARENT VOICES ADVOCACY TOOLKIT

Health Providers' version

MARCH 2022

DEVELOPED BY:

Post Graduate Institute for Medical Education and Research
Public Health Foundation of India
The London School of Hygiene & Tropical Medicine
The International Stillbirth Alliance



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international
stillbirth alliance



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& CHILD HEALTH

The International Stillbirth Alliance (ISA) is a membership organization uniting bereaved parents and other family members, health professionals and researchers to drive global change for the prevention of stillbirth and neonatal death and bereavement support for all those affected.

This toolkit provides information on:

- Stillbirths
- The impact of stillbirth on parents
- Your role as a health care provider in supporting parents during and after stillbirth

We hope that as health care providers learn more about how stillbirth affects parents, parents will find it easier to discuss their experience of stillbirth and their needs
WITH YOU - So that ultimately, stillbirth prevention and bereavement care are improved.

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INTRODUCTION

What is the purpose of this Toolkit?

- **The Parent Voices Initiative:** The Parent Voices Initiative (PVI) was developed by the Stillbirth Advocacy Working Group (SAWG) which is co-chaired by the International Stillbirth Alliance and the London School of Hygiene & Tropical Medicine and funded by the Partnership for Maternal, Newborn and Child Health. The purpose of the PVI is to raise the voice and participation of parents bereaved by stillbirth to strengthen advocacy for stillbirth prevention and post-stillbirth bereavement support.
- The PVI includes two projects, of which one is the Advocacy Toolkit Project. Two separate toolkits have been developed. The first is a toolkit designed specifically for parents and parent organisations. This was designed and piloted with bereaved parents in Kenya. The second toolkit, specifically for health care providers, was developed and piloted in India with health care providers and parents. Each toolkit can be further adapted for use in other settings.
- **The Advocacy Toolkit Project:** Ultimately, the Advocacy Toolkit Project aims to provide a simple advocacy training toolkit for stillbirth parent support organizations in places with large numbers of stillbirths, to introduce the concept and aims of advocacy related to stillbirth, and provide guidance to support parents to learn about how to raise their voices to help ensure their views and needs are heard within their country's health goal-setting agendas.
- **The Health Providers' version of the Advocacy Toolkit Project in India:** Awareness of many healthcare providers about stillbirth and its impact on affected parents may still be limited. Communication between parents and clinicians is a necessary step in ultimately supporting parents to advocate for stillbirth prevention and bereavement support. Therefore, the focus of the Advocacy Toolkit for India is on providers working within health facilities and communities: you!
- What is in this toolkit? This toolkit will provide you with information and suggested approaches for deeper and more open communication with parents after a stillbirth, including:
 - › Delivering the news
 - › Acknowledging parents' grief
 - › Talking with parents about how and why their baby may have died
 - › Making room for them to express their need for support
 - › Discussing a safe plan for future pregnancies
 - › Providing respectful bereavement care to parents

The toolkit will also help you as a health care provider to:

- › Raise awareness and educate women and their families about stillbirth
- › Advocate within your facility for increased resources for stillbirth bereavement support
- › Amplify the voices and needs of affected parents and your fellow providers related to stillbirth bereavement support in your facility

TOOLS in this Toolkit:

- The **“Talking about stillbirth” Tool**. These are questions for discussion with your colleagues, provided in pink boxes at the end of each section. Talking about stillbirth can be difficult but it is the start of conversations that will support parents and your colleagues who are providing care to parents.
- The **“Information Brief” Tool**. This is a series of 1-page summaries of key topics related to stillbirth, some of them with infographics. The Information Briefs are designed so that they can be printed and downloaded as single pages.
- The **“Fact Sheet” Tool**. For some topics, we have provided some in-depth data for you to review, presented in a tabular or list format. These can also be printed out separately to facilitate discussion.
- The **“Dig Deeper” Tool**. This is a list of links to some key reports and studies that you can visit if you want to know more.
- The **“Parents’ Perspective” and “Providers’ Perspective” Tools**. These are brief case stories and photos that give the real voices of parents and providers who have experienced stillbirth. These can be used as discussion starters or simply shared with colleagues as a beginning of raising awareness.
- The **“Checklist” Tool**. We have provided some checklists for situations when providers may want easy-to-use reminders of supportive care. These could be posted or used as a point of discussion with senior leadership, etc.
- The **“Guidelines” Tool**. These are lists of ‘what to say’ and ‘what not to say’ that could be helpful at any point in care for parents of stillborn babies.

We hope the information and suggestions in this toolkit will enable you to further strengthen the support you already provide.

HOW WAS THIS TOOLKIT DEVELOPED?

This Advocacy Toolkit for health providers in India was developed by the Stillbirth Advocacy Working Group of the International Stillbirth Alliance, in partnership with the Post Graduate Institute for Medical Education and Research (PGMIR) and the Public Health Foundation of India (PHFI) and in consultation with the PVI Advisory Group which includes clinicians, researchers, and affected parents.

- The toolkit was developed during two workshops in India with healthcare providers and other stakeholders, and further refined based on the feedback received from interviews with bereaved parents and grandparents.
- The information in this toolkit is based on the best and most recent evidence available on stillbirth.

HOW CAN YOU USE THE TOOLKIT?

- Ideally this toolkit would be used as a training tool during your regular professional or in-service development, or as part of targeted training provided by your workplace or professional organization.
- Alternatively, you may wish to review each module on your own or as part of an informal group of colleagues, referring to the information and suggestions as you carry out your regular professional duties. Questions for discussion are provided in the pink boxes at the end of each section (“Talking about stillbirth”).
- This toolkit can be adapted in several ways. These include:
 - Translation into local language, being mindful to use culturally appropriate language, especially when translating the word “stillbirth”.
 - For example, if using the toolkit for a community health worker or community-based midwife, you may wish to simplify some of the medical language in the Fact Sheets.
 - Information from different modules can be combined to create a new module for you to use as you see best.
- If you have questions regarding adapting the toolkit for your setting, feel free to contact ISA at info@stillbirthalliance.org for more information.

MODULE 1:

What is stillbirth?

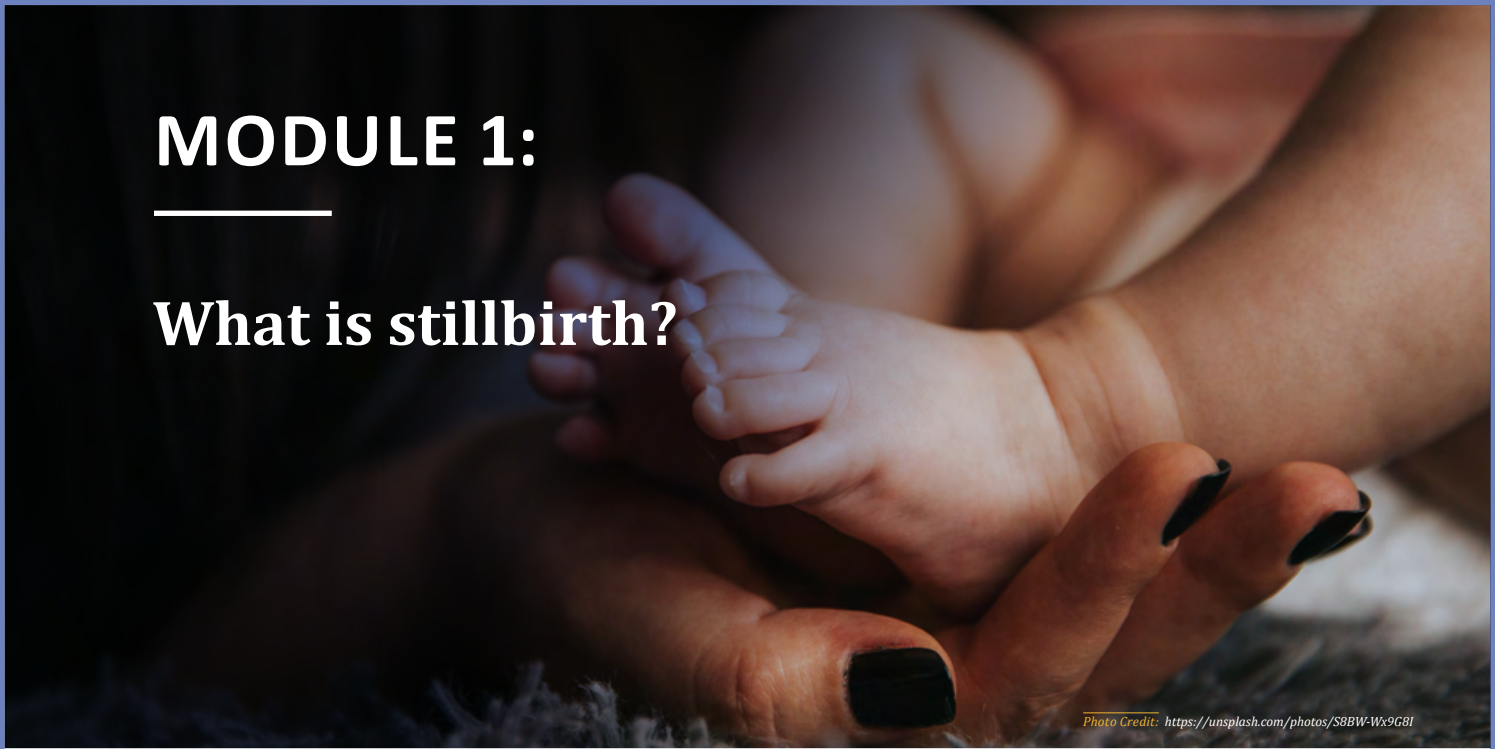


Photo Credit: <https://unsplash.com/photos/S8BW-Wx9GBI>

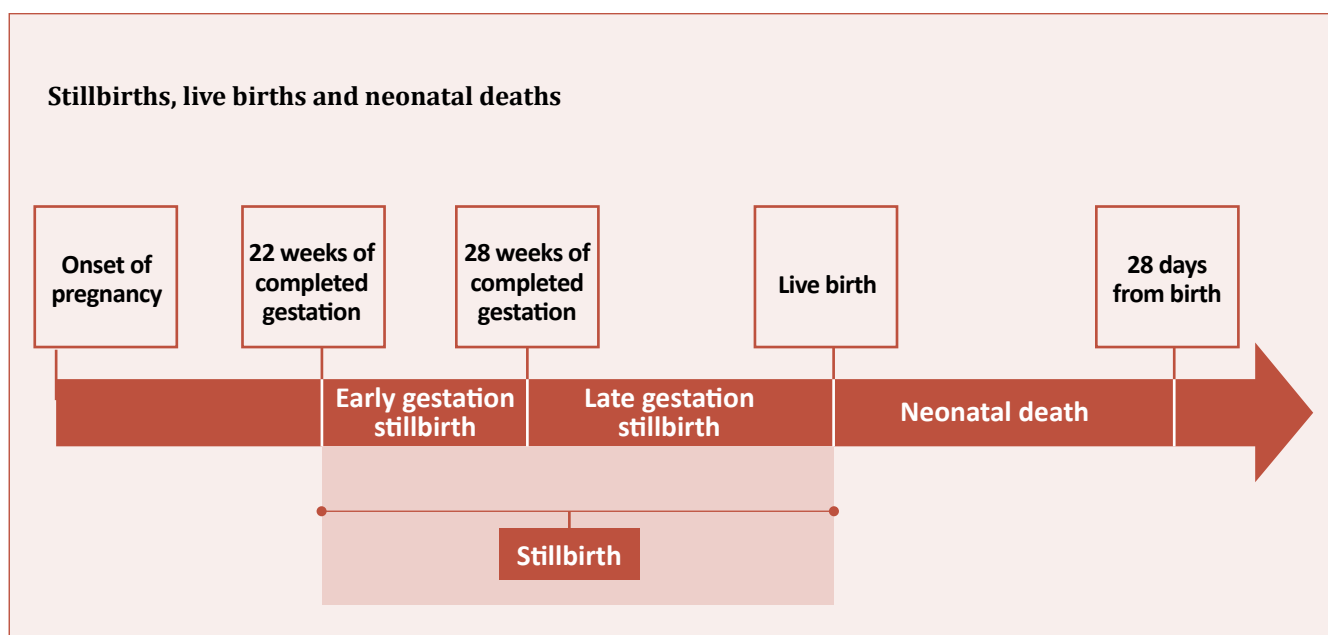
LEARNING OBJECTIVES: AFTER REVIEWING THIS MODULE, YOU SHOULD BE ABLE TO...

1. **Define stillbirth**
2. **Of stillbirths globally and in India**
3. **Identify the common causes of stillbirth**
4. **Explain potential risk factors of stillbirths**
5. **Understand how stillbirths could affect your patients**
6. **Understand why stillbirths may be ignored in the health system**



INFORMATION BRIEF: DEFINITION OF STILLBIRTH

- A stillbirth is defined by the World Health Organization (WHO) as a baby born with no signs of life at or after 28 weeks' (7 lunar months') gestation.
- Different countries have different definitions. Often, countries with greater access to advanced perinatal care count stillbirths from lower gestational ages. For example, stillbirths in Australia and the US are usually counted from 20-22 weeks' gestation.
- In India, a stillbirth is defined as "complete expulsion or extraction of baby from its mother where the fetus does not breathe or show any evidence of life, such as beating of the heart or a cry or movement of the limbs", with the following classification:
 - **Fresh stillbirth or intrapartum stillbirths are stillbirths** occurring after the onset of labour, weighing more than 1,000 grams and at more than 28 weeks of gestation;
 - **Macerated stillbirth or antepartum stillbirth** is a baby whose death occurred before the initiation of labour and there are signs of maceration, meaning skin and soft-tissue changes such as skin discoloration or darkening, redness, peeling, and breakdown.
- There is often "misclassification", meaning difficulty in deciding whether a baby was stillborn or a newborn death (a death of a liveborn baby that occurs very soon after birth). Some reasons for misclassification include differences in how stillbirth is ascertained and overlapping causes of stillbirth and newborn death. For practical purposes, stillbirth is diagnosed if the baby did not move AND did not cry AND did not breathe after resuscitation attempts.

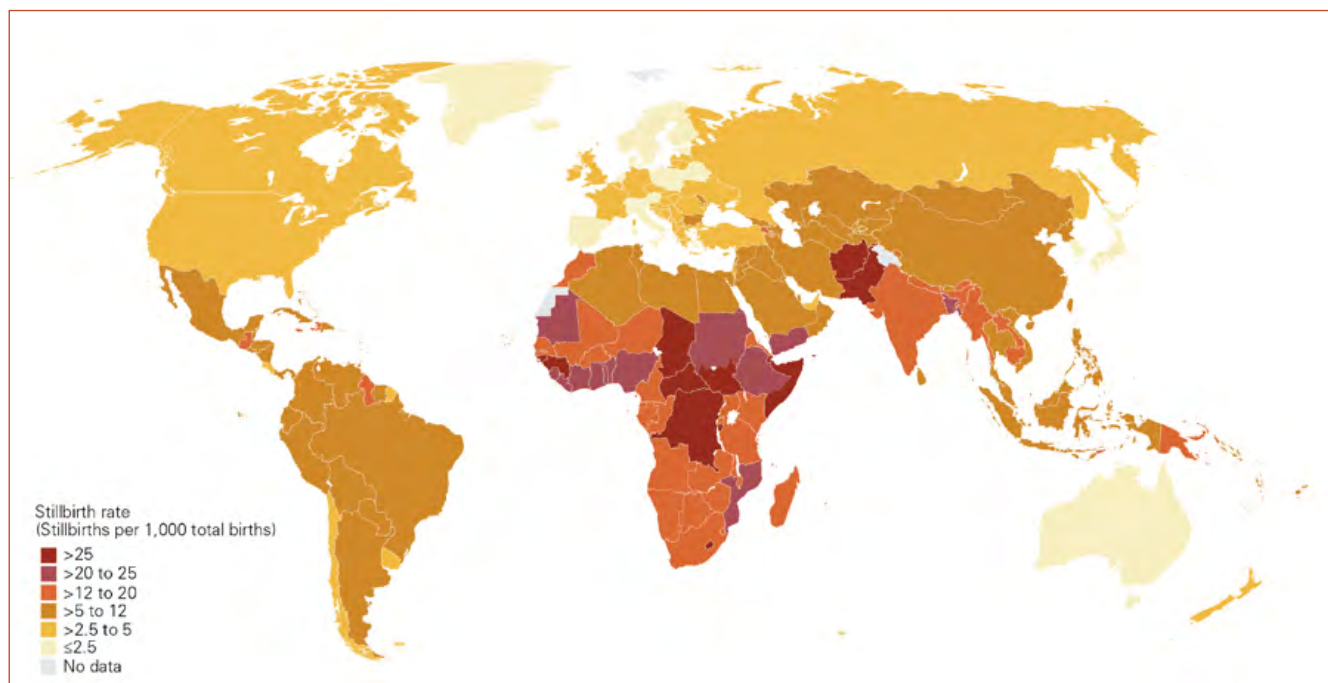


Talking about stillbirth:

- Have you delivered a stillborn baby?
- Have you experienced difficulty in ascertaining the timing of death, whether antepartum or intrapartum stillbirth?
- Have you experienced difficulty in deciding whether a baby was stillborn or liveborn?
- What might make it easier to distinguish?

INFORMATION BRIEF: WHY FOCUS ON STILLBIRTHS IN INDIA?

- Every year, about 2 million babies are stillborn around the world, using the WHO definition of stillbirth.
- Stillbirths are much more common in low- and middle-income countries, as you can see in the map below (the darker the colour, the higher the stillbirth rate).
- Half of all stillbirths occur in just 6 countries, and India is one of these countries.



Source: **A neglected Tragedy: The global burden of stillbirths**; Report of the UN Inter-agency Group for Child Mortality Estimation, 2020/UNICEF,WHO, WB,UN

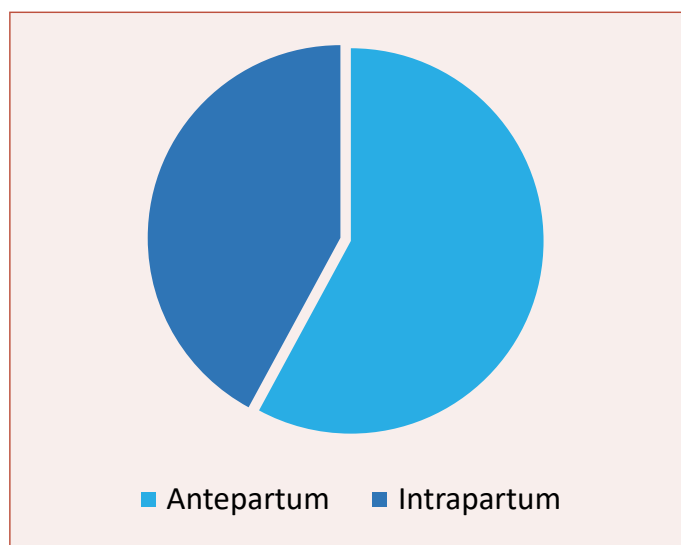
- The stillbirth rate in India was estimated to be 13.9 stillbirths per 1000 total births in 2019. This means there were an estimated 340,600 stillbirths in India in 2019.
- It is therefore apparent that stillbirths constitute a large proportion of under-5 child deaths, both in India and globally.
- Under the India Newborn Action Plan, the Government of India is committed to reducing stillbirths along with reducing neonatal deaths.
- The Indian national target is to reduce the stillbirth rate to fewer than 10 stillbirths per 1,000 total births by 2030.
- Given the high rate of stillbirths, Indian families suffer a significant burden of grief and loss. Bereavement support for parents and families whose babies are stillborn is an important service that can be provided to families while we also work to reduce the stillbirth rate in India.
- However, bereavement support is a new area that has yet to be fully developed in India.

Talking about stillbirth:

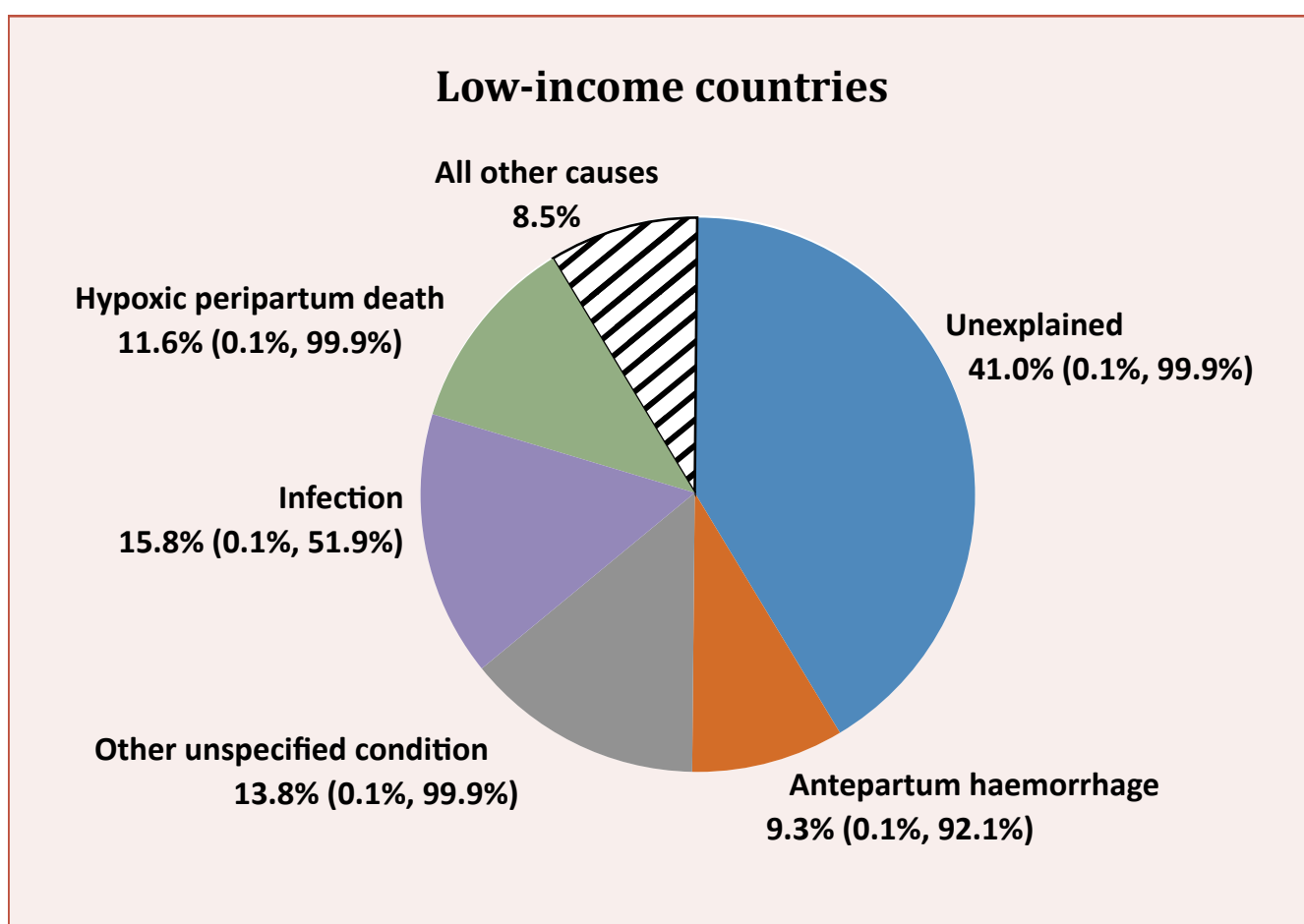
- Why does India have such a high rate of stillbirth?
- Have you heard of bereavement care for parents when their baby is stillborn?

INFORMATION BRIEF: WHAT CAUSES STILLBIRTH?

- Over 40% of stillbirths worldwide occurred during labour (see at right).
- In developing countries where women may not receive adequate antenatal care during pregnancy, it may be difficult to diagnose maternal complications and therefore it is harder to determine the cause of a stillbirth.
- In fact, for about one-third of stillbirths, the cause is unknown, even in developed countries where sufficient investigations can be performed.
- The remaining two-thirds of stillbirths are due to many known causes. Such data are not readily available from India, however, as the cause of death is not routinely identified for stillbirths, though it is available for newborn deaths. However, the causes are likely to be similar to those listed in the Fact Sheet below, which include some of the most frequently reported causes of stillbirth in settings like India.



Definitions: **Antepartum:** before labor; **Intrapartum:** during labor and delivery



Source: Reinebrant et al (2017). Making stillbirth visible: a systematic review of globally reported causes of stillbirth

FACT SHEET: COMMON CAUSES OF STILLBIRTHS GLOBALLY

(WITH ESTIMATES OF THEIR GLOBAL IMPACT)

During pregnancy (antepartum):

- **Infection:** In some cases, an infection in the fetus, placenta, or mother can cause stillbirth. Bacterial infections can move from the vagina into the womb, affecting the fetus. **(1-16% of stillbirths)**
- **Placental problems:** Poor placental development can occur due to several factors that are common in poor communities, such as poor nutrition during pregnancy and exposure to household air pollution from cooking with solid fuel. Poor placental growth can cause insufficient blood circulation to the fetus. The separation of the placenta from the womb before the baby is born (called “placental abruption”) can reduce blood flow to the fetus. In these cases, the fetus does not receive proper nutrients and oxygen. **(10-14% of stillbirths)**
- **Birth defects:** Birth defects can occur in the chest, belly, face, head, arms, and legs, increasing the risk of stillbirth. Other birth defects that can lead to stillbirth include a baby being born without parts of the skull or brain, the absence of both kidneys at birth, defects in the abdominal wall, or rupture in the inner amniotic sac. **(3-14% of stillbirths)**
- **Multiple pregnancies:** These include twins and triplets. **(3-11% of stillbirths)**
- **Medical complications in the mother:** Hypertension (mostly pregnancy-induced) is an important cause of stillbirths. Other problems with the mother’s health—such as preexisting and gestational diabetes—are also a probable or possible cause of stillbirth. **(4-6% of stillbirths)**

During labour & delivery (intrapartum):

- **Problems with the umbilical cord:** These occur when the cord is knotted or squeezed or slips down through the entrance of the womb before the baby is born (cord prolapse), cutting off oxygen to the developing fetus. **(6-8% of stillbirths)**
- **High blood pressure disorders:** High blood pressure in the mother—whether due to chronic high blood pressure or because of pregnancy (preeclampsia & eclampsia)—also contributes to stillbirths by affecting maternal blood flow to the fetus. **(3-7% of stillbirths)**
- **Preterm labour complications:** When the mother goes into labour well before her due date, the baby can suffer complications related to being underdeveloped. These include poor lung development and fetal growth. **(2-5% of stillbirths)**

FACT SHEET:

Causes of 3,678 stillbirths (2007-2016) in a tertiary care hospital in Chandigarh, India

| CAUSE OF DEATH | TOTAL CASES | % OF TOTAL |
|-----------------------------|-------------|-------------|
| Maternal conditions | 1439 | 39% |
| Preeclampsia | 720 | |
| Eclampsia | 223 | |
| Chronic hypertension | 126 | |
| Diabetes | 52 | |
| Cholestasis | 15 | |
| Other | 303 | |
| Placental causes | 719 | 20% |
| Abruption | 634 | |
| Placenta previa | 85 | |
| Congenital anomaly | 334 | 9% |
| Intrapartum causes | 159 | 4% |
| Malpresentation | 20 | |
| Prolonged/obstructed labour | 27 | |
| Ruptured uterus | 77 | |
| Fetal distress | 35 | |
| Other fetal causes | 145 | 4% |
| Allo immunization | 22 | |
| Hydrops of unknown origin | 25 | |
| Extreme prematurity | 98 | |
| Infection | 100 | 3% |
| Hepatitis | 58 | |
| Syphilis | 6 | |
| Other (Chorioamnionitis) | 36 | |
| Cord accidents | 51 | 1% |
| Loops | 4 | |
| Cord prolapse | 47 | |
| Unknown | 731 | 20% |
| Total | 3678 | 100% |

Notes: Cases were assigned a single cause of death according to the Simplified CODAC classification system. Cases included referrals from Punjab, Haryana, J&K, Himachal Pradesh, and Uttar Pradesh.

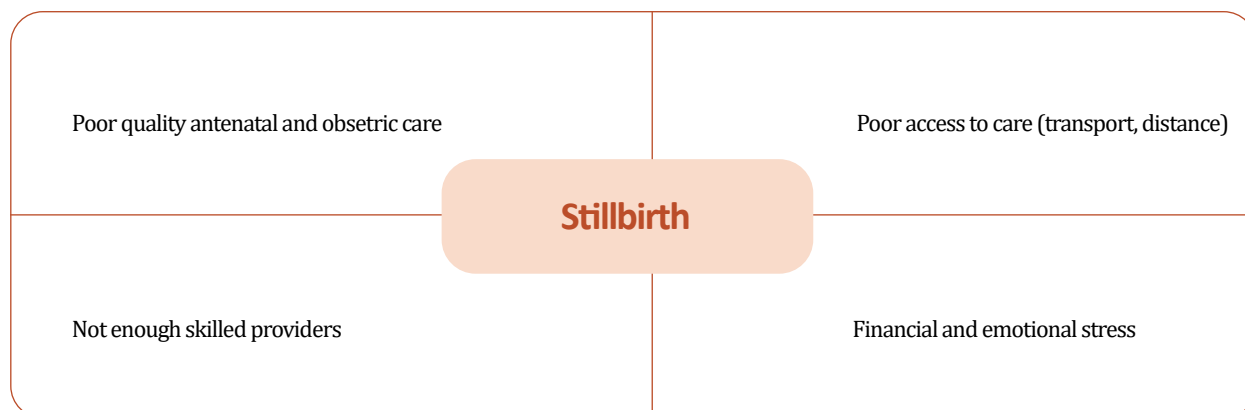
Source: Sharma B, Prasad GRV, Aggarwal N, Siwatch S, Suri V, Kakkar N. Aetiology and trends of rates of Stillbirth in a tertiary care hospital in north India over 10 years: a retrospective study. *BJOG* 2019; 126 (S4):14-20.

Talking about stillbirth:

- What are some of the causes of stillbirth in the facility where you work?
- What are some of the challenges of trying to determine the cause?
- Do you think some stillbirths could have been prevented? Why or why not?

INFORMATION BRIEF: WHAT ARE THE COMMON RISK FACTORS FOR STILLBIRTH?

- Risk factors are different from causes in that they increase the risk of stillbirth but do not directly cause death.
- Risk factors for stillbirth are common to several other adverse pregnancy outcomes including preterm birth, low birth weight, and neonatal death.
- Some common global risk factors for stillbirth are listed below; many of these are risk factors for stillbirths in India as well.



Health system factors:

- **Poor quality of antenatal care:** Pregnant women require regular access to antenatal care. Identification of pregnancies at a higher risk of adverse outcomes is important during antenatal care check-ups. Complications due to anemia, high blood pressure, gestational diabetes, multiple gestation, infection, and poor placental blood circulation can be diagnosed and managed early by a trained provider, but without this care, the risk of stillbirth is higher.
- **Skilled healthcare providers** can identify and address many complications during pregnancy before they progress to stillbirth, so lack of such care can increase the risk of stillbirth.
- **Poor quality of obstetric care:** Quality obstetric care includes the capacity to manage preterm labour, high blood pressure including preeclampsia and eclampsia, hemorrhage, breech birth, and multiple births, and to provide emergency Caesarean section.
- **Poor or delayed referral:** Sometimes delay in referring a woman for delivery by a healthcare provider in case of complications can also increase the risk of stillbirth.

Community & family factors:

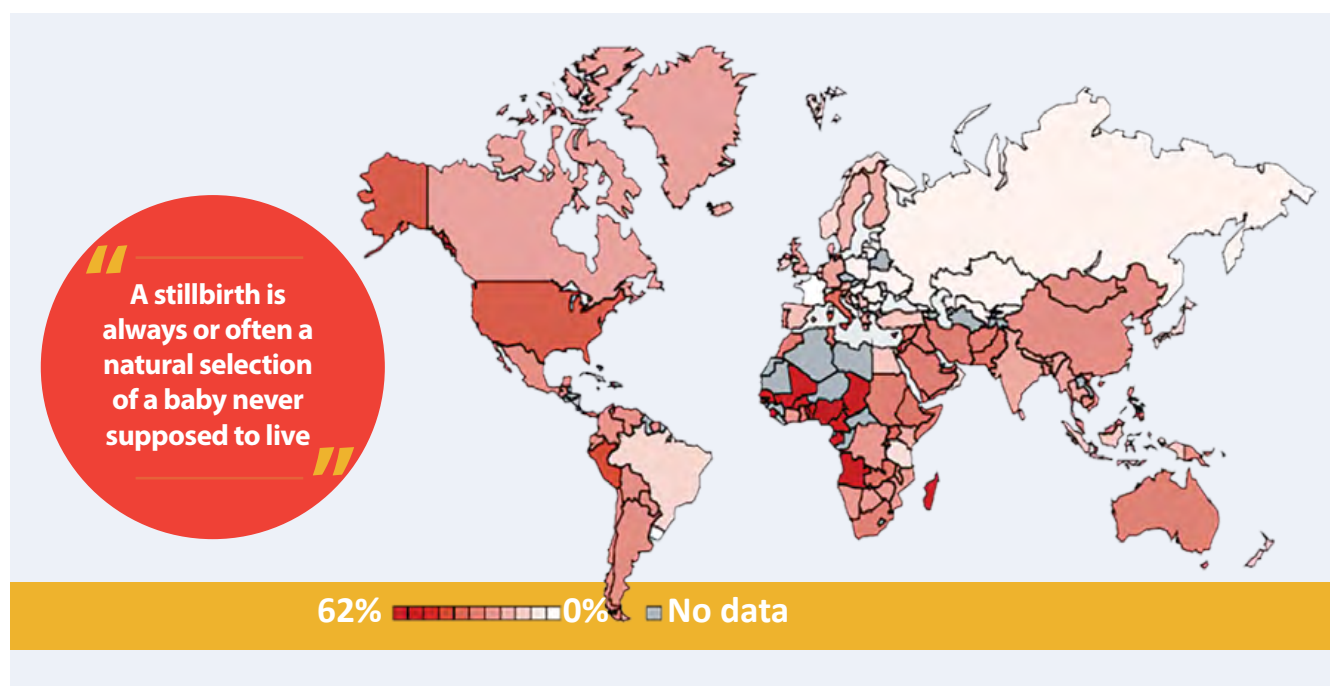
- **Long distance and poor access to health facilities:** In rural and remote areas, women may not have access to all-weather roads or transportation, reducing their ability to reach a facility in a timely manner during labour or delivery, or they may lack money to pay for transportation. Therefore, women who do experience a problem during labour and delivery may not receive the care they require to prevent a stillbirth.
- **Social determinants of health:** Financial, emotional, and other personal stressors can contribute to the risk of stillbirth. In each country, women who are more likely to have high levels of stress during pregnancy are at greater risk of experiencing a stillbirth than women who have low levels of stress during pregnancy. It is important to note that stressful events may be beyond women's control; women should not be blamed for their stress levels. Poverty and discrimination can also increase the risk of stillbirth. Indeed, numbers of stillbirths are generally higher in communities with higher proportions of families of lower socioeconomic status and education and lower quality healthcare facilities.

Talking about stillbirth:

- *What are the most important risk factors for stillbirth among the populations you serve?*
- *Are there any interventions in place which might help in addressing these risk factors?*

INFORMATION BRIEF: WHY ARE STILLBIRTHS OFTEN NOT TALKED ABOUT?

- In many settings, including in India, stillbirths are often not talked about.
- One reason many people don't talk about stillbirth is because of stigma and taboo, which keeps stillbirth "in the shadows".
- Stigma and taboo occur for many reasons. For example, mothers may be blamed for the stillbirth of their baby by their husband, their family, or their communities. This fear of being blamed can also encourage people not to talk about stillbirth.
- In many parts of the world, cultural or religious beliefs mean that a stillborn baby may be "disposed of" without any recognition. For instance, such a baby may not be named, held, dressed, or given a funeral. Stillborn babies may also be seen as taboo "objects".
- The belief that stillbirths cannot be prevented is another reason why stillbirths are often not talked about. In the map below, you can see that in some countries (darkest red), more than half of providers do not believe stillbirths can be prevented!



Source: Froen JF, Cacciatore J, McClure EM, Kuti O, Jokhio AH, Islam M, et al. *Stillbirths: why they matter*. *Lancet*. 2011;377 (9774): 1353-66.

Talking about stillbirth:

- Do you think stillbirth should be discussed in health facilities? In families' homes?
- Have you ever discussed stillbirth with each other? If not, why not?
- Can you think of more reasons why stillbirths are not talked about in India?

DIG DEEPER!

| Resources | Description and link |
|--|--|
| INDIA RESOURCES AND STUDIES | |
| 1. Ministry of Health and Family Welfare. India newborn action plan; 2014. | India's newborn action plan (INAP) lays out a vision and a plan for India to end preventable newborn deaths, accelerate progress, and scale up high-impact yet cost effective interventions. |
| 2. Ministry of Health and Family Welfare, WHO-India. Operational Guidelines for Establishing Sentinel Stillbirth Surveillance System; 2016. | India's operational guidelines used for sentinel stillbirth surveillance. These were developed by the PGIMER team in collaboration with WHO SEARO and involved multidisciplinary stakeholders. |
| 3. Sharma B, Aggarwal N, Raina A, Joshi B, Suri V, Kakkar N. Evaluating intramural still births in a tertiary care center of North India - An observational study. Indian Journal of community & Family medicine July -Dec 2017;3:02:40-5. | This study evaluates causes of stillbirths in a tertiary care referral centre. |
| 4. Newtonraj A, Kaur M, Gupta M, Kumar R. Level, causes, and risk factors of stillbirth: a population-based case control study from Chandigarh, India. BMC Pregnancy Childbirth. 2017 Nov 13; 17(1):371. | This study reports results from 181 verbal autopsies to capture the causes of stillbirth in northern India. |
| 5. Neogi SB, Negandhi P, Chopra S, Das AM, Zodpey S, Gupta RK, Gupta R. Risk Factors for Stillbirth: Findings from a Population-Based Case-Control Study, Haryana, India. Paediatr Perinat Epidemiol. 2016 Jan;30(1):56-66. | This study examines risk factors for stillbirth with a focus on sex selection drugs (SSDs). |
| 6. Dandona R, Kumar GA, Akbar M, Bhattacharya D, Nanda P, Dandona L. Deferred and referred deliveries contribute to stillbirths in the Indian state of Bihar: results from a population-based survey of all births. BMC Med. 2019 Feb 7; 17(1):28. | This is a stillbirth surveillance study documenting the burden of stillbirths in Bihar state. |
| 7. Dandona R, Kumar GA, Kumar A, Singh P, George S, Akbar M, Dandona L. Identification of factors associated with stillbirth in the Indian state of Bihar using verbal autopsy: A population-based study. PLoS Med. 2017 Aug 1;14(8):e1002363. | This study uses verbal autopsy interviews to identify the risk factors for stillbirth in Bihar state. |
| 8. Sharma B, Prasad GRV, Aggarwal N, Siwatch S, Suri V, Kakkar N. Aetiology and trends of rates of Stillbirth in a tertiary care hospital in north India over 10 years: a retrospective study. BJOG 2019; 126 (S4):14-20 | This retrospective study aimed to find the causes of stillbirth at a tertiary hospital in North India using the CODAC classification system |
| 9. Sharma B, Venkateshan S, Suri V, Choudhary N, Kakkar N, Aggarwal N. Spectrum of Birth Defects Amongst Live Birth, Stillbirths and Abortions. Indian J Pediatr. 2021 Mar 23. doi: 10.1007/s12098-021-03725-5. | This letter to the editor gives the burden of birth defects among stillbirths, observing that it is mandatory to follow the outcome of all pregnancies, and not just do screening of newborns only. |

DIG DEEPER!

| Resources | Description and link |
|---|---|
| GLOBAL RESOURCES AND STUDIES | |
| 1. United Nations Inter-agency Group for Child Mortality Estimation, You D, Hug L, et al. A Neglected Tragedy: The Global Burden of Stillbirths.; 2020. | <i>This report improves on global availability of stillbirth data and helps to drive political and public recognition of the issue. The report finds that despite progress being made since 2000, stillbirths have not declined as rapidly as maternal and newborn mortality, and if current trends continue, an additional 19 million stillbirths will take place before 2030.</i> |
| 2. Frøen JF, Tveit JVH, Saastad E, et al. Management of Decreased Fetal Movements. Semin Perinatol. 2008;32(4):307-311. | <i>Promising strategies for management of decreased fetal movement are discussed.</i> |
| 3. Heinke D, Nestoridi E, Hernandez-Diaz S, et al. Risk of Stillbirth for Fetuses With Specific Birth Defects. Obstet Gynecol. 2020; 135(1):133-140. | <i>This study compares the stillbirth risk overall in the U.S. to the stillbirth risk related to birth defects.</i> |
| 4. Ogwulu CB, Jackson LJ, Heazell AEP, Roberts TE. Exploring the intangible economic costs of stillbirth. BMC Pregnancy Childbirth. 2015; 15(1):188. | <i>This narrative review revealed a higher level of anxiety and depression in couples with stillbirth compared to those without stillbirth. The psychological effects of stillbirth adversely affect the daily functioning, relationships and employment of bereaved parents, with far-reaching economic implications.</i> |
| 5. Pinar H, Goldenberg RL, Koch MA, et al. Placental findings in singleton stillbirths. Obstet Gynecol. 2014;123(2 Pt 1):325-336. | <i>This study reports results from pathological examinations that were performed on placentas from singleton pregnancies. Placental lesions were found to be highly associated with stillbirth.</i> |
| 6. Reinebrant HE, Leisher SH, Coory M, et al. Making stillbirths visible: a systematic review of globally reported causes of stillbirth. BJOG Int J Obstet Gynaecol. 2018;125(2):212-224. | <i>Estimates of causes of stillbirths by country.</i> |
| 7. Stillbirth Collaborative Research Network Writing Group. Association between stillbirth and risk factors known at pregnancy confirmation. JAMA. 2011;306(22):2469-2479. | <i>This study reports that multiple risk factors known at pregnancy were associated with stillbirth.</i> |
| 8. Varner MW, Silver RM, Rowland Hogue CJ, et al. Association between stillbirth and illicit drug use and smoking during pregnancy. Obstet Gynecol. 2014;123(1):113-125. | <i>This study reports that cannabis, smoking, illicit drug use, and apparent exposure to second-hand smoke, separately or in combination, during pregnancy were associated with an increased risk of stillbirth.</i> |
| 9. WHO Stillbirth | <i>Here is WHO's website with general information on stillbirths.</i> |
| 10. McClure EM, Goldenberg RL. Understanding causes of stillbirth: moving in the right direction. Lancet Glob Health. 2019;7(4):e400-e401 | <i>This letter makes the case for improving investigations of stillbirth as well as a harmonised approach for evaluating the available information to ascertain the primary causes of stillbirths.</i> |

Talking about stillbirth:

- Now that you've gone through Module 1, what else would you like to know about stillbirth? Use the references and hyperlinks above to seek more information about one of these topics.
- How can you use this knowledge to improve the care provided during pregnancy & birth? How will your care practices change?

MODULE 2:

The impact of stillbirths on parents

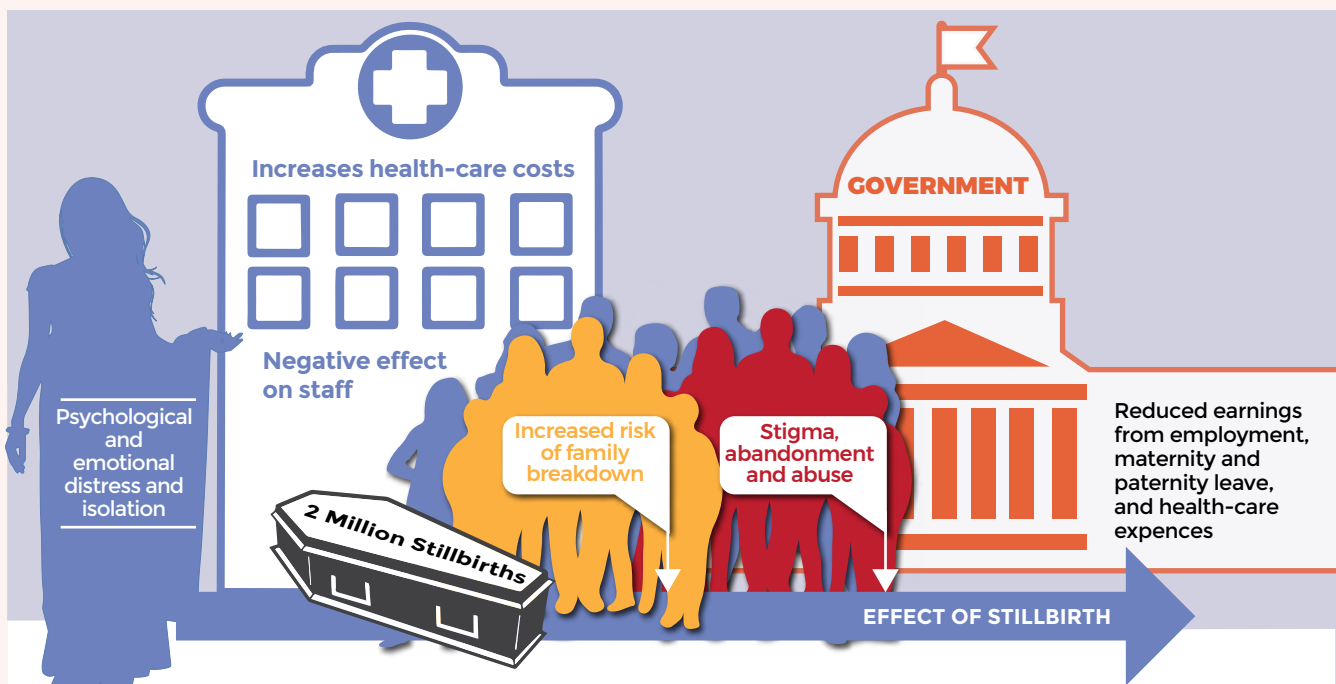
Photo Credit: https://www.freepik.com/free-photo/pregnant-woman-belly-with-henna-tattoo_7353301.htm#query=pregnant-woman-belly-with-henna-tattoo&position=3&from_view=search&track=sph

LEARNING OBJECTIVES: AFTER REVIEWING THIS MODULE, YOU SHOULD BE ABLE TO...

1. Understand how stillbirth affects parents
2. Define respectful bereavement care

INFORMATION BRIEF: WHY DO STILLBIRTHS MATTER?

- In Module 1, you saw one reason why stillbirth matters: there are so many babies who are stillborn, and there are disproportionately more of them in India.
- Stillbirth also matters because stillbirth can lead to short and long-term suffering for parents. Often, mothers are the most affected.
- Parents may experience stigma, guilt, anxiety, depression, and isolation. These feelings can harm the mother's long-term health and affect her future family planning decisions.
- Stillbirth also has financial and economic consequences for families, including lost income if parents must be out of work, and expenses related to additional health care and funeral costs.
- Health providers who care for patients with stillborn babies may also experience stress, guilt, and worry.
- Stillbirth is the loss of a life!



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Figure: The effect of stillbirth originating with the death of the baby, affecting mother, family, health services, society, and government. Widespread themes of direct, indirect and intangible costs are shown. **Source:** Heazell AE, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J. et al. Stillbirths: economic and psychosocial consequences. *The Lancet*. 2016;387(10018):604-16.

Talking about stillbirth:

- What are some of the negative effects of stillbirth on parents that you have seen?
- Do these differ according to different socioeconomic, educational, and demographic characteristics of the parents?

INFORMATION BRIEF: WHAT IS THE IMPACT ON PARENTS WHO HAVE A STILLBORN BABY?

- Both parents can be significantly affected by the stillbirth of their baby, often experiencing grief, anxiety, fear, and suffering, even if they may not express these emotions outwardly or immediately. They will often turn to family for emotional support, but this need for support is not always fulfilled.
- Stillbirth may affect parents' thinking about life and death, their self-esteem and sense of identity, and their sense of control in any future pregnancy, as well as their thinking about parenthood and child-rearing.
- After stillbirth, some parents might want to be alone, hide their grief, change their religious practice, have doubts about sexual intercourse, feel remorse or guilt about not being able to save their baby, or doubt the value of antenatal care or other health behaviors.
- Mothers and fathers may be affected differently, and their marital life may be affected in the short-term or long-term.
- Fathers may be occupied by other domestic issues such as work obligations and may not feel able to grieve as a result.
- Parents may also experience financial consequences related to lost income, additional healthcare expenses, and funeral expenses. They may find it difficult or impossible to receive any benefits to which they are entitled, such as maternity leave; or they may find that these benefits are not extended to parents of stillborn babies.

Fact:

Stillbirth can affect siblings, surviving twins, and even subsequent children. Stillbirth can also affect grandparents and other relatives.

Talking about stillbirth:

- *What has been your experience of how mothers and fathers feel about stillbirth? Are there differences?*

INFORMATION BRIEF: WHAT IS THE IMPACT ON MOTHERS WHO HAVE A STILLBORN BABY?

- There may be further impact on mothers in addition to the points listed above:
 - Women often report high rates of depressive symptoms, anxiety, post-traumatic stress, panic, fear, and even suicidal thoughts. Depressive symptoms, for example, can last several years after a stillbirth and need to be addressed in future pregnancies.
 - It is estimated that 4.2 million women have depressive symptoms as a result of stillbirth.
 - Mothers may feel blamed and pressured to get pregnant again. They may want to get pregnant again themselves. It is important to establish their need to cope with the loss in the way that would be best for them (physically & emotionally) before trying to get pregnant again.
 - Mothers of stillborn babies may also be stigmatized by neighbours, relatives, society, and community members.
 - Mothers may have no social support systems due to stigma or blame.

PARENTS' PERSPECTIVES



"At my village's Primary Health Centre, doctor could not hear sound of my baby's heart and my blood pressure was also high around 140/100 mmHg. I was having labour pains, so they referred us to District hospital, where they advised us for C-section but the operation theatre wasn't available. They, then referred us to the tertiary care hospital, but there I did not receive much attention and care. The ultrasound was delayed. They told me that my baby has died inside me since 5 days. I was devastated to find out about this but I had nothing in my hands to do except to cry. I was so depressed and I could not get up for many days."

- Rekha and Pradeep Kumar, Punjab, India

Talking about stillbirth:

- Share an example of the impact of stillbirth on mothers from your own experience.
- What did you do to try to help? What was helpful to the mother? What else could you have done to support the mother in the case you describe?

INFORMATION BRIEF: BEREAVEMENT CARE AFTER STILLBIRTH IS RESPECTFUL MATERNITY CARE

- Bereavement refers to mourning after a death, especially the death of a loved one.
- Respectful care during pregnancy, labour, and birth is a cornerstone of quality maternity care, including bereavement care when a baby is stillborn.
- Bereavement care during stillbirth is founded in basic human rights, including:
 - › The rights to respect, dignity, confidentiality, information and informed consent;
 - › The right to the highest attainable standard of health; and
 - › Freedom from discrimination and all forms of ill-treatment.
- Bereavement support is a critical component of respectful care for stillborn babies and their mothers during pregnancy and birth. Just as everyone has the right to be protected from harm and mistreatment, everyone should be able to grieve and honor a stillborn baby.
- **The time for bereavement care begins as soon as stillbirth is diagnosed and continues for as long as the parents need it.**
- Every provider who meets the parents during and after stillbirth has the opportunity to provide the bereavement care that the parents need and deserve.
- Bereavement support can be provided **formally** to parents individually, together, or with other families.
- Bereavement support can also be provided **informally**, through compassionate provision of information about stillbirth, asking the parents if they would like to see and hold their baby, supporting parents to spend time with their baby, making opportunities for parents to say goodbye to their baby, create “memories” about their baby, grieve the loss of one twin while celebrating the safe birth of the other, or simply to continue to grieve their loss.
- The box below shows 8 principles identified by an international group of providers and parents that should guide respectful bereavement care after stillbirth.

Final principles for consensus on global bereavement care after stillbirth

1. Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities
2. Provide respectful maternity care to bereaved women, their families, and their babies
3. Support women and families to make shared, informed, and supported decisions about birth options
4. Make every effort to investigate and identify contributory factors to provide an acceptable explanation to women and families for the death of their baby
5. Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment
6. Offer appropriate information and postnatal care to address physical, practical, and psychological needs, including a point of contact for ongoing support
7. Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up
8. Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team

Source: Shakespeare C, Merriel A, Bakhbakhi D, et al. The RESPECT Study for consensus on global bereavement care after stillbirth. *Int J Gynecol Obstet*.2020;149(2):137-147

Talking about stillbirth:

- Is bereavement care provided in your facility in the case of deaths of adults or children?
- What about in the case of stillbirth? Do you think the global principles listed above could be implemented in your facility?
- What policies do you think could be introduced to help provide bereavement care for mothers of stillborn babies?

DIG DEEPER!

| Resources | Description and link |
|--|--|
| 1. Gopichandran V, Subramaniam S, Kalsingh MJ. Psychosocial impact of stillbirths on women and their families in Tamil Nadu, India – a qualitative study. BMC Pregnancy Childbirth. 2018;18(1):1-13. | This study tries to understand the psychosocial impact, aggravating factors, coping styles and health system response to stillbirths in Tamil Nadu. |
| 2. Das MK, Arora NK, Gaikwad H, et al. Grief reaction and psychosocial impacts of child death and stillbirth on bereaved North Indian parents: A qualitative study. PLOS ONE. 2021;16(1):e0240270. | This study documents the grief and coping experiences of Indian parents following stillbirth and child death in Delhi. |
| 3. Roberts LR, Anderson BA, Lee JW, Montgomery SB. Grief and Women: Stillbirth in the Social Context of India. Int J Childbirth. 2012;2(3):187-198. | This study explores how poor, rural women perceive and cope with stillbirths in Central India. |
| 4. Flenady V, Boyle F, Koopmans L, Wilson T, Stones W, Cacciatore J. Meeting the needs of parents after a stillbirth or neonatal death. BJOG Int J ObstetGynaecol. 2014;121:137-140. | This brief commentary outlines some ways that parents can be supported after stillbirth or newborn death. |
| 5. United Nations Inter-agency Group for Child Mortality Estimation, You D, Hug L, et al. A Neglected Tragedy: The Global Burden of Stillbirths. 2020. | This UNICEF report from 2020 provides the latest data and recommendations on stillbirths globally. |
| 6. Frøen JF, Cacciatore J, McClure EM, et al. Stillbirths: why they matter. The Lancet. 2011;377(9774):1353-1366. | This paper explores the present status of stillbirths in the world from global health policy to a survey of community perceptions in 135 countries. |
| 7. Shakespeare C, Merriel A, Bakhbakhi D, et al. The RESPECT Study for consensus on global bereavement care after stillbirth. Int J Gynecol Obstet. 2020;149(2):137-147. | This survey of 23 global stillbirth experts concludes that the highest quality bereavement care should be enabled through training of healthcare staff to reduce stigma and establish respectful care, including acknowledgement and support for grief responses, and provision of support for physical and psychologic needs. |
| 8. The White Ribbon Alliance. Respectful Maternity Care: The Universal Rights of the Childbearing Women.; 2011. | This charter clarifies and clearly articulates the rights of women and newborns for respectful maternity care within a healthcare setting. |
| 9. Heazell, Alexander EP, et al. "Stillbirths: economic and psychosocial consequences." The Lancet 387.10018 (2016): 604-616. | This paper gives a global overview of the psychosocial effects of stillbirth. |

Talking about stillbirth:

- Now that you've gone through Module 2, what else would you like to know about stillbirth? Use the references and hyperlinks above to seek more information about one of these topics.
- How can you use this knowledge to improve bereavement care?

MODULE 3:

What can health providers do?

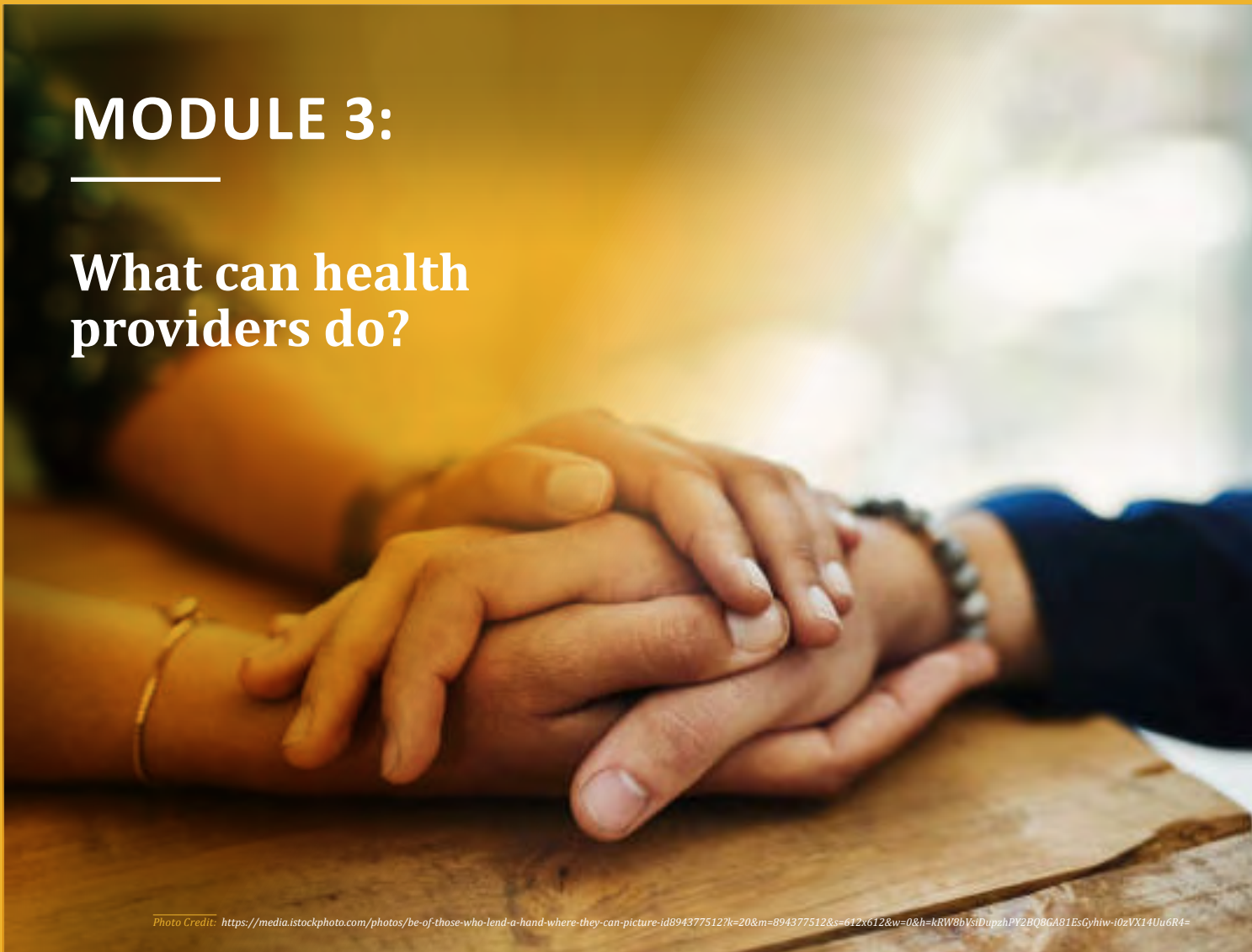


Photo Credit: <https://media.istockphoto.com/photos/be-of-those-who-lend-a-hand-where-they-can-picture-id8943775127k=20&m=894377512&s=612x612&w=0&h=krW8bVstDapzhPY2BQ8GA81EsGyhiw-i0zVX14Uu6R4=>

LEARNING OBJECTIVES: AFTER REVIEWING THIS MODULE, YOU SHOULD BE ABLE TO...

1. Understand a health provider's role in talking about stillbirth with parents. This includes doctors, nurses, and auxiliary nurse midwives (ANM)
2. Learn how to talk about stillbirth with grieving parents
3. Learn how to support parents after their baby is stillborn
4. Learn how to take care of the stillborn baby's body
5. Understand how to provide postnatal care for mothers after their baby is stillborn

INFORMATION BRIEF: WHAT IS YOUR ROLE IN PROVIDING STILLBIRTH CARE?

- A woman may come to your health facility with her baby already having died while she is still pregnant, needing to give birth to her stillborn baby, or the baby may die before birth while the mother is in labour.
- Caring for parents who experience stillbirth can be extremely emotionally challenging for providers. However, it is also your opportunity to provide compassionate care at such an important time in the parents' lives.
 - Sometimes parents feel that the health providers are less empathic and find it difficult to ask for support. It is important that your words and body language convey empathy and support.
 - Parents often look to doctors for answers and reasons why something is happening. You have an important role to play in communicating clinical information in a way that can be understood.
- Giving bad news is also an opportunity for you to provide bereavement care in a respectful manner. Your acknowledgement of the parents' grief and your support in the immediate moments following stillbirth will be an important pillar of support to their healing and recovery.
 - Many times, it is also important to include any other people they are close to or who can help them. These can be other children and family members, friends, or a religious group member.
- You can also help to create a smooth transition for mothers into postnatal care and family planning.
 - Sometimes a person's support system can fade after stillbirth as people in their life may be afraid to talk about it with them, or think that enough time has passed and they should be "over it already". You may be the only chance they have to continue to talk about their loss when they visit you for postnatal care.
- Being sad or even depressed afterward is normal. The feelings can change in the days following stillbirth. You can help the mother and parents by understanding whether there is a reason to recommend any clinical care for mental health (if symptoms are really severe).
 - It is important to distinguish between grief and trauma:
 - **Grief** refers to the process of experiencing emotional, behavioral, social and physical reactions to loss. It is a process that changes over time. It is a natural reaction. People may recognize grief from other losses they have experienced in the past.
 - **Psychological distress** may be experienced, when the person may experience extreme anxiety, anger, sadness, or guilt. Trauma can interfere with sleep and may even be felt as physical pain. People may feel low self-worth and continue to be under a lot of stress. Trauma needs psychological care. In such cases, the counselor should refer the mother/parent to a mental health care provider for clinical attention.
- Stillbirth can sometimes create some marital problems between the parents. The grief and trauma can have long-term effects if they are not talked about. One parent may feel ready to move on while the other is not, and there may be a difference of opinion about trying to get pregnant again. If both parents are present in the postnatal sessions, it is important to talk about how the experience is affecting the relationship.
- Reassure the couple that time will help, and they will not feel the same intense grief forever.
- Depending on the case and on common practice at a facility, doctors may play a part in all the steps of bereavement care, or only a few. Regardless, the quality of care that doctors provide during this time can have both immediate and long-term consequences for parents, especially in recovering and planning to try for a possible subsequent pregnancy, including any discussion of known risks, and supporting the parents to be aware of danger signs in the subsequent pregnancy and how these may change according to gestational age.
- Providers should also bear in mind that underprivileged mothers may have had limited or lower quality ANC during this pregnancy, and may face difficulties in accessing ongoing care or care during a subsequent pregnancy.
- For some parents, this may have been their last pregnancy e.g. those who may have gone through fertility treatment and cannot afford further treatment. It is important to acknowledge this and recognize any additional sorrow this may cause.
- Providing care for distressed parents is something that most health professionals do not receive any formal training in, BUT your words and actions really matter!

"I agree with you on the idea of providing support. Expressing grief is important. It is important to express our grief because what we can express by crying, we cannot do it in any other way." Father

Talking about stillbirth:

- *Have you ever counselled a parent/mother with a stillborn baby?*
- *Share a challenging time when you had to care for parents of a stillborn baby. What was the most difficult part? What could have made it easier for you? For the parents?*
- *Do many mothers/parents come back to have conversations with you?*

INFORMATION BRIEF: SUPPORTING DECISION MAKING WHEN A BABY IS KNOWN TO HAVE DIED BEFORE BIRTH

- You may need to care for a mother during her labour and birth when a baby is known to have already died.
- In cases of antepartum stillbirth (the baby has died before labour), you may include the family as you provide a clear explanation of the situation.
- Wherever possible, parents should be included in all decisions related to labour and birth (such as what may happen, how and when).
- You may also have to discuss plans for the baby's birth. It is important to discuss the planned timing of birth as well as the route of birth. This decision should be made in close consultation with the mother. Inform her of the options - expectant, induction, or Caesarean. Clearly explain the risks and benefits of each option.
- It is also important to address any misconceptions or concerns that the parents may have regarding delivering a stillborn baby (for example, the misconception that carrying a dead baby may poison the mother).

INFORMATION BRIEF: SUPPORTING THE MOTHER DURING LABOUR AND BIRTH WHEN A STILLBIRTH OCCURS EITHER BEFORE OR DURING BIRTH

- It is important that you provide information and emotional support to the mother throughout labour and birth (whether vaginal or surgical).
- Take care of the mother and her baby with same respect and dignity as you would a mother with a live baby!
- All routine medical attention that a woman gets in your facility during labour and birth of a live baby, including pain management, should also be provided to the mother who is giving birth to a stillborn baby.
- A partogram should still be completed even if the baby has died, as this gives important information about the mother and progress in labour.
- Parents need to be prepared for the birth of their baby, e.g. told about the possible or likely appearance of the baby.
- Even if you are not talking to the parents the entire time, you can communicate empathy through simple actions like holding the parent's hand, patting their shoulder, and maintaining a respectful tone of voice.
- Apart from providing information during these conversations, health providers must also focus on actively listening to the concerns of parents and address them to the best of their ability.

REMEMBER!

- It is never appropriate to decrease attention to the mother at any point after a stillbirth is diagnosed, whether before, during, or after labour and birth.
- It is never appropriate to reduce access to pain management for a mother if the stillbirth is diagnosed during labour.
- It is never appropriate to blame the mother or parents for the baby being stillborn.
- It is never appropriate to refuse to deliver a stillborn baby.

PARENTS' PERSPECTIVES



"I was in my 8th month of pregnancy. I was referred from the civil hospital to district hospital but without much information. At the district hospital, ultrasound was done which showed small baby and they referred me to another hospital without explaining anything. After reaching that hospital, I was admitted and a COVID test was done. After some time another ultrasound was done which revealed that my baby was not alive. Then they gave me injections for three days for labour to start. These 3 days were very difficult for me even though everyone at the hospital tried to comfort me but I wasn't able to adjust in the same room with other women knowing that my baby was dead."

- Khushboo, Chandigarh, India

PROVIDERS' PERSPECTIVES



"As a doctor, it is overwhelming to break the bad news to the parents. Sometimes I feel at loss as how to tell them. Losing a baby while still pregnant or birthing is devastating. I try to explain to the parents and give the support to the best of my knowledge and capacity. When the cause of fetal death is unknown, then it is even harder to explain and make them understand. I never feel satisfied and confident."

- Dr. Pratibha, Medical Officer

Talking about stillbirth:

- What action could you take during birth to support the mother of a stillborn baby?

INFORMATION BRIEF: PROVIDING OPTIONS, SUPPORTING MEMORY MAKING AND PREPARING THE STILLBORN BABY TO BE PRESENTED TO THE PARENTS

- When a baby has been stillborn there are a few options you may discuss with the parents such as whether they wish to name their baby or how they would like you to refer to their baby if they do not have a name or do not wish you to use it. If the parents have not thought of a name because it is not culturally acceptable, it is ok. Respect that decision and simply use “baby” when talking about the stillborn baby.
- Take time to explore whether the mother would like to see or hold her stillborn baby. You can explain that many parents find this helpful and that it can help ease the burden of grief in the future.
- How you handle the baby’s body immediately after birth may depend on how far along the pregnancy was. At any gestational age, however, the parents should be supported to manage their baby’s body and told that they can plan for a burial or cremation.
 - You may wrap the baby’s body in a blanket, and pass to the mother as you would a live baby (if she wants to see her baby).
 - In the case of a baby who died one day or more before birth, body integrity has already been affected. Bodily deterioration may be significant at the time of birth, as the baby may have died long before. Health providers should gently prepare parents for what they will encounter in these situations. You may use a blanket, handkerchief or shawl to wrap the baby in a way that initially covers up areas that may be concerning or upsetting for the parents.
 - Be sure to ask the family whether they have their own cloth in which they prefer to wrap the baby, or whether they want the hospital to provide it. In your hospital it may be the hospital attendant or ward boy who handles the stillborn baby, rather than a doctor or nurse. The role of the hospital attendant or ward boy is just as important as that of other care providers, to ensure that he respectfully handles the baby, for instance while wrapping the baby in a towel, or putting his hand under the baby’s neck to support its head while showing or handing the baby to mother or family.
 - Parents may also ask you to manage the baby’s body on their behalf.
- You may find the mother’s family is reluctant to share the news of the stillbirth with the mother or give her the opportunity to make choices about whether to see or hold her stillborn baby. In fact, most families may refuse your first offer of showing the baby to the mother (as is the case in many settings before it has become routine to offer and socially acceptable or even discussed).
- You may encourage and support the family to talk to the mother and present all available options to her, taking time to explain why this is important and may be of benefit to the mother as she comes to terms with the stillbirth of her baby. Explain to the family members that this helps the mother to recover and reconcile with the baby’s loss.

We recommend that this offer be made three times before the mother is discharged, to give her a chance to change her mind, if she refuses the first time.

“This was second chance for my Daughter in Law and we were cautious. Already we had experienced a stillbirth withlast pregnancy.The first time there was a boy. At that time my Daughter in law had completed 8 months and treatment was going on from our local hospital there. This time also we tried our best and they referred us to Chandigarh first but then someone told us to go to a different hospital near SD college in Ambala and we were assured that we’ll not lose this baby this time and they said this time they will do an operation. But at time I didn’t know what happened I don’t know what God’s will is. I don’t understand how did this happened suddenly twice. She started feeling pains and when we took her to USG center then they told us that the baby is not alive. I feel very sad I am not able to understand to what to do or what to say? In my last experience doctors gave the option to tell the mother about the baby’s death, and we told her which made it even worse for her. We thought that telling her after the birth would be better but this time...we didn’t! How could I have said this to her again 2nd time.”

- Mother In Law

“I would see what my wife wanted at that time. What was her thought!! Because at that time I could not say this thing directly to her, because you can only guess what is happening with her. But if I thought that she could handle herself and watch, I would have done whatever she thought was right, because it is a big deal for a mother. If my wife had spoken to see, I would have definitely given her this opportunity to see her baby, because it is the right of a mother, whether she should see it or not it’s for her to decide.”

- Father

INFORMATION BRIEF: SUPPORTING PARENTS AFTER DELIVERY

- From the moment you suspect a stillbirth may have occurred there are several actions that you can take immediately to sensitively diagnose the stillbirth, guide a mother and her family through the decision making process, provide support during labour and birth, offer opportunities to see and hold the stillborn baby and ensure a safe discharge from your facility, in order to provide respectful bereavement care for the parents.
 - › These actions are listed in the Checklist on the next page.
 - › These actions are now routinely offered to parents in many facilities and settings in countries such as the UK and Australia. We believe these actions should be taken to support parents in all settings. Your work can help to make these actions more commonly offered to parents everywhere.
 - › We recommend that you print this Checklist and display it where it is easily accessible to those who are involved in mother's care. This will facilitate provision of many actions that will benefit the mother and her family to deal with the baby's loss.
 - › Some of these actions might need to be done by more than one health provider, depending on common practice in your facility. Using this Checklist can help to ensure that *someone* has taken the necessary action, even if it is not you. You can also use the Checklist to request that others take responsibility for individual actions.
- You could cover all of these actions in just a few minutes. Use the provided scripts if it is hard to figure out what to say. Remember that even one minute of compassionate, respectful care can make a difference to mothers and fathers! Try to always start with Action 1 in the checklist ("Acknowledge the death"), and complete as many actions as possible.



| Doctor counselling parents on 1st follow-up visit after stillbirth

- It is possible that currently not all of these actions are implemented in your facility. That is ok. The Checklist shows what actions are considered important to implement as part of respectful maternity care. You can plan to work towards implementing these in your facility over time.
- It is also possible that personal feelings (biases) may affect caregiving in subtle ways. It is important to make the best effort to provide care regardless of any personal biases.

HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

DATE:

MOTHER'S NAME:

STAFF'S NAME:

| Setting | For whom? | What can you say? | How to say? | What to consider? |
|--|---------------|---|---|--|
| <input type="checkbox"/> Acknowledge the death of the baby | | | | |
| Labour and birth | Mother/father | <p>I cannot find your baby's heartbeat. Your baby is not alive. I am sad to say that your baby has died. I am sorry for your loss.</p> | <p>Address the mother with her name; be considerate, maintain eye contact, and hold hand if appropriate in your setting. Tell the mother directly that her baby has died. Use clear, simple, direct language. Do not use euphemisms. You should not ask her husband/family member to tell her about this news on your behalf.</p> <p>Avoid using language which might sound like you are blaming the parents (e.g., avoid saying things like 'You were late for your check-up' or 'You didn't bring the test reports', etc.).</p> | <p>Alert other staff to the stillbirth so they don't inadvertently ask about the baby and upset the mother. This may include an indication on the chart or by the bedside to alert staff of the death. Providing privacy is essential but don't stigmatize by being secretive.</p> <p>Acknowledge the death of the baby. This news should always be delivered as soon as known, preferably by a senior health care provider, regardless of how you perceive the mother's condition to be. She has a right to know.</p> <p>Parents may wish to have the death of their baby confirmed by ultrasound. In some cases the doctor performing the ultrasound may be the first person to diagnose stillbirth and thus the first person to acknowledge the death; as with all caregivers, this doctor should be as empathetic as possible when delivering the news.</p> <p>If you are facing difficulty in supporting the mother, you may ask for help from a senior nurse or ANM with experience in this.</p> |
| Post-partum | Mother/father | <p>I am saddened by the loss you have to bear. We will do some investigations to try to find out the reasons for your baby's death.</p> | <p>Address the mother with her name; be considerate, maintain eye contact, and hold hand if appropriate in your setting.</p> | |

HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

DATE:

MOTHER'S NAME:

STAFF'S NAME:

| Setting | For whom? | What can you say? | How to say? | What to consider? |
|---|----------------------|---|--|--|
| <input type="checkbox"/> Provide privacy | | | | |
| | Mother/father | Let us talk in detail separately where there is a little privacy, and you can get some rest. | | <p>Try to create some privacy for the mother and father. A private room is ideal. However, semi-privacy can also be created even in a shared ward, e.g. by moving mother to a bed next to a wall and then sheltering with a shawl or bed sheet. If there are multiple wards, separating the bereaved parents from actively labouring mothers can help. This is about privacy – still treat the parents with dignity and care.</p> <p>Make sure, however, that privacy does not feel to the parents as if they have been abandoned. Provide privacy without stigmatizing stillbirth; the mother should not feel she is being kept separate because she didn't have a live birth. Ensure you do not appear to be secretive while in conversation near the parents.</p> |
| <input type="checkbox"/> Inquire about baby's name | | | | |
| | Mother/father | Have you thought of a name for the baby? (if yes) Would you allow me to use that name to talk about your baby? | | <p>Ask parents if they have named their baby or how they wish you to refer to the baby, and make sure to use this name/word.</p> <p>If the parents have not named the baby, it is ok. Do not insist on naming the baby.</p> |
| <input type="checkbox"/> Ask about seeing and holding the baby | | | | |
| Post-partum ward/consultation room | Mother/father/family | Many women have found it helpful to see and hold their stillborn baby after she or he is born. Would you like to do this? | <p>Prepare the parent/family for what to expect; be respectful to the baby</p> <p>Offer support to enable this to happen and tell them what to expect regarding the baby's appearance. If there is a visible anomaly or maceration, gently tell the parents about what to expect and offer a description of their baby's appearance before they decide whether to see the baby or not. Some parents may want to see the anomaly. They may find this important for understanding why their baby died. You can explain what you propose to do with the body.</p> | <p>Privacy; address taboos and cultural norms; make it a positive experience</p> |

HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

| DATE: MOTHER'S NAME: STAFF'S NAME: | | | |
|--|-----------------------|---|---|
| Setting | For whom? | What can you say? | How to say? |
| <input type="checkbox"/> Preparing the baby | | | |
| If the mother wants to see her baby, prepare the body by bathing and wrapping it in cloth. | | | |
| <input type="checkbox"/> Seeing and holding the baby | | | |
| Postpartum ward | | I am going to bring your baby to show you. If you like you can hold your baby, but you can take your time. | Gently show the baby first. If the mother feels comfortable looking at her baby, then you may offer her to hold the baby. |
| <input type="checkbox"/> Ask about making memories | | | |
| Postpartum ward | Mother/father /family | Do you want to get footprints of your baby or would you like to click a photograph of your baby? Having baby's photograph may help you in coping in your times of grief. If you need someone to help with taking footprints or photographs, please let us know. | Explain that sometimes parents want a memory of the baby, such as a photo or footprint. Allow the parents to click as many photographs as they wish. Gently describe the appearance of the baby if baby is macerated. Advice is to get footprints done. |
| | | | Consider how you handle the baby while taking photographs or foot prints. Hold the baby as carefully as one would hold a live baby. Support the neck and limbs especially if the baby is not wrapped in cloth. (You may also use a soft cotton cloth to hold baby.) |

HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

DATE:

MOTHER'S NAME:

STAFF'S NAME:

| Setting | For whom? | What can you say? | How to say? | What to consider? |
|--|----------------------|--|--|--|
| <input type="checkbox"/> Address stigma by providing information on causes | | | | |
| Postpartum ward | Mother/father/family | <p>You may have to face people asking about the baby and they may speculate about reasons for the death according, but the reason for your baby's death are best explained by the doctors after some investigations and autopsy.</p> <p>It is important that you understand that stillbirth can happen to any mother, and it is not the mother's fault. In some cases, we are able to tell why this could have happened, but in many cases we do not know. We can do some investigations to identify possible cause of death, which I can discuss with you if you wish to.</p> <p>You may experience people holding you back and preventing you from meeting other pregnant women, thinking it will impact them also, which is completely inaccurate. If people talk to you in this way, you can try to avoid them.</p> <p>If people ask about the baby, you can explain to them about the medical information I am giving to you.</p> | <p>Conveying this message should help the parents understand and realize that there are scientific facts and reasons behind their baby's death. Try to make them understand this with the help of reports and investigations available at your disposal. Stress that the death was not mother's fault, especially in places where stillbirth carries a lot of stigma. Provide information in the form of statistics on stillbirth such as charts or graphic material to help them understand the causes and consequences of stillbirth and realize that they are not alone.</p> <p>Inform the parents with empathy and in clear language about any complications and potential causes, if known. If available, provide written information that parents can share with their families on causes of stillbirth to begin tackling stigma in their families and community.</p> <p>Find a private place to tell the fathers and the families that "It was not the mother's fault".</p> | <p>Do consider superstitious beliefs of some families which they believe to be the reason for baby's death. People tend to blame stillbirth generally on the mother. Try to help them understand this is not true, by giving scientific reasons if you have a confirmed diagnosis.</p> <p>Counseling before discharge should cover: 1) discussion with mother and father on questions they might face in society after stillbirth, and the questions and situations they may face in their immediate social circle, and 2) discussion with other family members on how to respond to the mother's needs and expectations.</p> |



HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

DATE:

MOTHER'S NAME:

STAFF'S NAME:

| Setting | For whom? | What can you say? | How to say? | What to consider? |
|--|----------------------|---|--|--|
| <input type="checkbox"/> Provide information on grief | | | | |
| At discharge | Mother/father/family | It is normal and ok to remember and talk about your baby and miss him or her. People may tell you to forget the baby and move on, but that is not necessarily the right thing to do. It is important that you talk about your baby if you want to do so. It is ok for both the mother and father to cry. | Tell the parents that grieving is a normal part of stillbirth, and that timely support, including clinical and psychosocial support, can help alleviate the effects of stillbirth. Note the emotional strain on fathers that is often hidden. | Also consider providing information to the parents how it will affect siblings and grandparents. Explain when one might need intervention in case the grief is prolonged. Introduction to peer support groups might also help. |
| <input type="checkbox"/> Discuss home self-care | | | | |
| Postpartum ward/recovery room/discharge | Mother | Because your body is prepared to nourish your baby, you will/may experience milk letdown. It will not be easy to go through this without the baby, so please ask for support as you need it. | Tell the mother what to expect in terms of physical symptoms and what she can do to care for herself at home, both physically and emotionally, including using pads for bleeding, taking pain medication, when it is safe to start having sex again, and how to ease discomfort if her milk has come in. Encourage her to seek and accept support from the father or other family members. | Consider involving other family members in this discussion so they understand the need for supporting the mother; you may need to repeat or reemphasize these points with the family at the time of discharge. Give options for lactation suppression prior to discharge. |
| <input type="checkbox"/> Discuss subsequent pregnancy | | | | |
| At discharge | Mother/father/family | Some people will ask you to get pregnant soon so that you can forget this baby. This may not be a good idea as your body is not ready for another pregnancy so soon and could impact the health of you and any new baby. Please wait for a few months and attempt pregnancy only if and when you are ready to do so both physically and emotionally. If you are thinking of getting pregnant again, it is really important for you to come back for your follow-up visit so that we can plan for this safely. | Tell the mother that people may tell her to get pregnant again soon to get over the loss of this baby. Inform her that it may not be the best idea as her body needs to recover from this pregnancy. Having another pregnancy too soon can impact on the health and wellbeing of both mother and baby. Encourage her to try to get pregnant again only if and when she thinks she is ready for it. | Consider discussing this with the family in addition to the mother/parents, as the pressure can come from them. Ensure the mother returns for a follow-up visit to maintain reproductive health and for any subsequent pregnancy to be healthy. |

HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

DATE:

MOTHER'S NAME:

STAFF'S NAME:

| Setting | For whom? | What can you say? | How to say? | What to consider? |
|--|---------------|--|---|--|
| <input type="checkbox"/> Insist on postnatal follow-up | | | | |
| At discharge | Mother/father | It's important that we schedule a follow-up appointment for you, so that we can see how you are coping with baby's loss and provide advice for any concerns that you may have, and provide advice for planning any subsequent pregnancy. | Ensure the mother returns for a follow-up visit to maintain reproductive health and for any subsequent pregnancy to be healthy by giving her a follow up visit date or appointment. | Consider suggesting nutritional supplements at discharge so that the mother returns in good health at follow-up. |
| <input type="checkbox"/> Facilitate stillbirth registration for the parents | | | | |
| At discharge | Father/family | It is important that the stillbirth of your baby is registered as per government rules. Please complete these forms and we can help you with this process. | | Ensure that the stillbirth is registered in the vital registration system using the stillbirth form. If your facility is not designated to do so, provide the relevant documents to the parents and explain to them what to do. |
| <input type="checkbox"/> Ask parents to keep all documents | | | | |
| At discharge | Father/family | Insist parents keep a record of all documents or at least the discharge summary and autopsy report with themselves as in some Indian cultural traditions, all the belongings of the child are disposed of. <i>If appropriate:</i> We may be able to determine the cause of the stillbirth of your baby. At this facility we can offer to store a dried blood sample and carry out DNA testing and will let you know what we find out. Would you like to do this? | Parents may agree to any investigations regarding cause of death. All these should be explained. Offer to store a dried blood spot sample and DNA testing if this is available at your facility | Consider parents' preference and economic viability of these procedures as these may not be feasible for people who cannot afford expensive testing techniques. For parents who can afford it, genetic testing may be suggested |

HEALTH PROVIDER CHECKLIST FOR PARENT SUPPORT AFTER STILLBIRTH

| ID#DATE: _____ MOTHER'S NAME: _____ STAFF'S NAME: _____ | | | | |
|--|----------------------|---|--|--|
| Setting | For whom? | What can you say? | How to say? | What to consider? |
| <input type="checkbox"/> Support in discharge on grief | | | | |
| At discharge | Mother/father/family | It is normal and ok to remember and talk about your baby and miss him or her. People may tell you to forget the baby and move on, but that is not necessarily the right thing to do. It is important that you talk about your baby if you want to do so. It is ok for both the mother and father to cry. | Tell the parents that grieving is a normal part of stillbirth, and that timely support, including clinical and psychosocial support, can help alleviate the effects of stillbirth. Note the emotional strain on fathers that is often hidden. | Also consider providing information to the parents how it will affect siblings and grandparents. Explain when one might need intervention in case the grief is prolonged. Introduction to peer support groups might also help. |
| <input type="checkbox"/> Discuss home self-care | | | | |
| Postpartum ward/recovery room/discharge | Mother | Because your body is prepared to nourish your baby, you will/may experience milk letdown. It will not be easy to go through this without the baby, so please ask for support as you need it. | Tell the mother what to expect in terms of physical symptoms and what she can do to care for herself at home, both physically and emotionally, including using pads for bleeding, taking pain medication, when it is safe to start having sex again, and how to ease discomfort if her milk has come in. Encourage her to seek and accept support from the father or other family members. | Consider involving other family members in this discussion so they understand the need for supporting the mother; you may need to repeat or reemphasize these points with the family at the time of discharge. Give options for lactation suppression prior to discharge. |
| <input type="checkbox"/> Discuss subsequent pregnancy you need it. Make sure to come to | | | | |
| At discharge | Mother/father/family | Some people will ask you to get pregnant soon so that you can forget this baby. This may not be a good idea as your body is not ready for another pregnancy so soon and could impact the health of you and any new baby. Please wait for a few months and attempt pregnancy only if and when you are ready to do so both physically and emotionally. If you are thinking of getting pregnant again, it is really important for you to come back for your follow-up visit so that we can plan for this safely. | Tell the mother that people may tell her to get pregnant again soon to get over the loss of this baby. Inform her that it may not be the best idea as her body needs to recover from this pregnancy. Having another pregnancy too soon can impact on the health and wellbeing of both mother and baby. Encourage her to try to get pregnant again only if and when she thinks she is ready for it. | Consider discussing this with the family in addition to the mother/parents, as the pressure can come from them. Ensure the mother returns for a follow-up visit to maintain reproductive health and for any subsequent pregnancy to be healthy. |

INFORMATION BRIEF: CONVERSATION TIPS WITH PARENTS AND FAMILY

What can you say to the parents?

- We will try to provide you with information on stillbirths and on caring for yourself that may help you to cope. It is important for you to know that it is ok to have questions.
- Coping with grief after a stillbirth is very personal. We know that for parents, the intense grief after losing a baby can cause overwhelming, possibly frightening, emotional and physical reactions. You may feel that life will never be normal again.
- Grief can sometimes be made worse when combined with the natural mood changes caused by dropping hormone levels after having a baby. This is ok and you will take some time to recover.
- Parents may grieve differently to one another; some may show more emotion than others. This is ok. You can grieve in your own way.
- It is ok to cry.
- Both parents may feel an instinct to love and hold your baby. This is perfectly natural. Mothers may still feel the baby is inside them. This is all part of the process of healing.
- Some parents may feel angry or blame themselves for loss of the baby. You may also start to worry about your other children, if you have any. These are natural reactions of grieving. Try not to blame yourself or your partner, but find ways to support each other.
- Some parents may blame the hospital or health providers for loss of the baby. It may be a natural reaction to blame someone or there can be a legitimate reason. It is best to discuss with the relevant hospital authority to understand the possible reasons for baby's loss.
- Mothers will also have some minor or major physical effects. These include heavy bleeding, pain from stitches, and breast pain from milk coming in. Any difficulty should be discussed with your health provider. It is important to keep your follow-up appointments.
- Fathers are sometimes left out of the grieving process because they may have to go to work or because the culture does not accept that men can grieve openly. Yet fathers also need to grieve and they need to be supported
- Fathers may feel the need to protect their wife and other children and to be strong for them. This is also a natural feeling. But you can protect your family while still taking time for your own sadness. It is ok to feel the loss of your baby.
- It is ok for fathers to cry, too.
- Fathers may sometimes get aggressive with mothers as a way of dealing with the baby's loss. This is not ok and is unacceptable.

What can you say to other family members?

- Allow the parents time to grieve.
- Let the parents express their grief and talk about it with people they trust.
- Provide parents, especially mothers, with help to cook, clean, watch other children, and run errands.
- Ensure mother gets proper nutrition and sleep.
- It is ok to cry together.
- It is ok for other siblings to be sad. Let them talk about it.
- Do not pressure the mother to get pregnant again too soon as she needs to recover physically and emotionally. If she waits until she is ready, she will have a healthier pregnancy.
- If the mother has some risks to getting pregnant again, try to learn about them with her.

Talking about stillbirth:

- Choose one statement from the boxes above that you think would have helped the last bereaved mother you had as a patient.
- Why do you think that would have made a difference to the mother?
- Do you think you could say this to the next mother you care for after stillbirth? Why or why not?

What you can never say to parents:

- *"It is ok, get pregnant again soon."*
- *"Do not worry, it was only a girl child."*
- *"This happened because you came late for delivery."*
- *"At least you know you can get pregnant again."*
- *"This baby was sick. It is good that the baby died."*
- *"Thank goodness you have your other children."*
- *"You can always have another child."*
- *"This baby just wasn't meant to be."*
- *"This baby's death was just meant to be."*
- *"There might have been something wrong with it."*
- *"It's for the best."*
- *"You should forget about this and move on."*
- *"At least you still have one baby" (in the case of multiples)*
- *"It was your fault: you were late for your check-up."*
- *"It was your fault: you didn't bring the test reports we needed."*

Talking about stillbirth:

- *Have you ever said one of the sentences in the red box above?*
- *What have you learned about why that wouldn't be appropriate or helpful?*
- *What could you say instead?*

INFORMATION BRIEF: SELF-CARE FOR HEALTH PROVIDERS

- Stillbirth affects more than just the parents. Stillbirth can also affect you. It is not easy to have a patient lose a baby.
- It is important that you take time to stop and reflect on what happened, and accept it.
- It is also important that you discuss the loss with your team. Not only can this help to identify factors that could be changed to reduce the risk of stillbirth for other women in the future, but it can also help to support all the providers who cared for the stillborn baby and its parents, since these providers may be emotionally affected themselves.
- Often, staff may be blamed for the stillbirth by the parent/family. This is particularly true when the stillbirth is intrapartum (occurring during labour and birth). Parents may make complaints against you or other providers, or against other hospital staff.

Talking about stillbirth:

- *How could respectful bereavement care for parents also help providers deal with stillbirth?*
- *Have you ever felt emotionally affected by stillbirth after providing care?*
- *Share your experience and what helped you to get through it.*

DIG DEEPER!

- Providers who wish to learn more about responding to women who have experienced a stillbirth can complete a 6-part online e-training on care provision around stillbirth and newborn death, called [IMPROVE](#), which is produced by the Stillbirth Centre for Research Excellence in Australia (also the International Stillbirth Alliance's Western Pacific Regional Office) and the Perinatal Society of Australia and New Zealand (PSANZ). You will need to register for this free training.

The 6 chapters (each takes 20 minutes) are:

1. Respectful and supportive perinatal bereavement care

This chapter outlines how to provide the best possible psychological and social support for women and families after a stillbirth or neonatal death.

2. Autopsy and placental examination

This chapter demonstrates the perinatal autopsy procedure and the process of placental examination.

3. Communicating with parents about perinatal autopsy

This chapter presents a framework to assist clinicians in informed consent and shared decision-making around perinatal autopsy.

4. Investigation of stillbirths

This chapter aims to explain the recommended investigations to identify the causes of fetal death.

5. Examination of babies who die in the perinatal period

This chapter demonstrates how to undertake a detailed clinical examination of stillbirths and neonatal deaths including measurements and clinical photographs.

6. Perinatal mortality audit and classification

This chapter explains the process of perinatal mortality audit and classification of causes of death and contributing factors for stillbirths and neonatal deaths.

Talking about stillbirth:

- *Now that you've gone through Module 3, what else would you like to know about how you, as a doctor, can care for mothers and families after stillbirth?*
- *Look through the resources listed in earlier modules for ideas on where you might get answers to your questions.*

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**INTERNATIONAL STILLBIRTH ALLIANCE &
THE STILLBIRTH ADVOCACY WORKING GROUP**
PARENT VOICES INITIATIVE