



THE STILLBIRTH ADVOCACY WORKING GROUP
Parent Voices Initiative

RAISING PARENT VOICES ADVOCACY TOOLKIT

KENYA Parents' version

9 SEPTEMBER 2021

Developed by:

Still A Mum
Post Graduate Institute for Medical Education and Research (PGMIR)
Public Health Foundation of India (PHFI)
The London School of Hygiene & Tropical Medicine (LSHTM)
The International Stillbirth Alliance (ISA)

Funded by:



international
stillbirth alliance



This Toolkit provides parents in Kenya with information on:

- Stillbirths - overview, causes and risk factors.
- The impact of stillbirth on parents.
- Advocacy as a tool for change in stillbirth prevention and bereavement care.
- Ways of advocating for change in stillbirth prevention and bereavement care.
- Coping strategies for advocacy-related stress.

We hope that as parents learn more about stillbirth, its impact, and ways to raise their voices as a way of addressing stillbirth-related challenges, they will find it easier to discuss their experience of stillbirth and speak both for themselves and on behalf of others to facilitate change in the healthcare sector, at the community and at the national level, ultimately leading to improvement in stillbirth prevention and bereavement care.

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Suggested citation: Stillbirth Advocacy Working Group Parent Voices Initiative, Still A Mum (SAM), The London School of Hygiene & Tropical Medicine (LSHTM), The International Stillbirth Alliance (ISA), "Raising Parent Voices Advocacy Toolkit: Kenya Parents' Version" (9 September 2021).

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INTRODUCTION

What is the purpose of this Toolkit?

Photo Credit: <https://i2.wp.com/www.lindaafya.co.ke/wp-content/uploads/2020/04/woman-holding-hands-1.jpg?resize=1320%2C660&ssl=1>

- **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. The pilot sites for this project are India and Kenya. You will be our pioneers in helping us learn how best to support parents bereaved by stillbirth to raise their voices!
- **The Advocacy Toolkit Project:** The Advocacy Toolkit Project aims to provide a brief, 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 Kenya Parents' version of the Advocacy Toolkit Project:** In Kenya, there are currently few stillbirth parent support organizations, and services and information for parents about stillbirth and its impact on affected families is limited. Further, we recognize that advocacy for stillbirth at a national level must start with action at the local level. Therefore, the focus of this Advocacy Toolkit is on Kenyan parents who have experienced a stillbirth and who understand the needs of others who may be going through the same, to help them to advocate for themselves and others toward providers, family and friends, and community leaders.
- **What is in this Toolkit?** This Toolkit will provide you with information relating to the experiences and rights of parents after stillbirth and suggested approaches for advocating for better post-stillbirth care, including:
 - › Common challenges experienced by parents after stillbirth
 - › Expectations and rights of bereaved parents
 - › Basic steps of advocating for better care post-stillbirth at the facility and community levels
 - › Different types of advocacy strategies (self-advocacy and group advocacy)
 - › Challenges of advocacy work and coping strategies to meet these challenges

The Toolkit will also help you to:

- › Learn more about stillbirths and why they happen
- › Raise awareness and educate other parents about stillbirth
- › Advocate in your community and with health leaders for increased resources for stillbirth bereavement support
- › Amplify the voices and needs of affected parents related to stillbirth bereavement support within families, at health facilities, and in the wider community.

TOOLS in this Toolkit:

- The **“Talking about stillbirth/Talking about advocacy” Tool**. These are questions for discussion with other bereaved parents, provided in pink boxes at the end of most sections. Talking about stillbirth can be difficult but it is the start of conversations that can open doors to change for support after stillbirth.
- The **“Information Brief” Tool**. This is a series of 1 to 2 page summaries of key topics related to stillbirth, some of them with infographics. You can skip to Briefs that are most interesting to you, or go through them in order. The Information Briefs are designed so that they can be downloaded and printed easily.
- 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 online resources that you can visit if you want to know more.
- The **“Parents’ Perspective” Tool**. These are case stories and photos that give the real voices of parents who have experienced stillbirth. These can be used as discussion starters or simply shared with other bereaved parents to help them reflect on their experiences.
- The **“Checklist” Tool**. We have provided some checklists for situations when you may want easy-to-use reminders for your advocacy work. These could be posted in a community meeting room or used as a point of discussion with advocacy targets such as clinicians, etc.
- The **“Guidelines” Tool**. These are lists of ‘what to say’ and ‘what not to say’ that could be helpful at any point in advocating for better stillbirth care.

We hope the information and suggestions in this Toolkit will enable you to further strengthen stillbirth care and support.

HOW WAS THIS TOOLKIT DEVELOPED?

- The Toolkit has been refined based on a series of workshops in Kenya with parents.
- The information in this Toolkit is based on the best and most recent evidence available on stillbirths.

HOW CAN YOU USE THE TOOLKIT?

- Ideally this Toolkit would be used as a training tool for parent advocates and parent support organizations.
- This Toolkit could also be used directly by bereaved families of stillborn babies (or those with earlier pregnancy losses) and by other relevant groups and individuals.
- You may wish to review each module on your own. Questions for discussion are provided in the green boxes throughout the Toolkit, which could be prompts for informal discussion with other bereaved parents.
- This Toolkit can be adapted in several ways. These include:
 - Translation into local languages, being mindful to use culturally appropriate language, especially when translating the word “stillbirth”.
 - Editing a module to make it more relevant for specific types of parents (e.g. parents in other parts of the country) by including examples from these groups.
 - Information from different modules can also 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://sunnewsonline.com/wp-content/uploads/2021/05/673-02138345en_Masterfile.jpg

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

1. **Define stillbirth**
2. **Understand the burden of stillbirths globally and in Kenya**
3. **Identify the common causes of stillbirths**
4. **Explain potential risk factors of stillbirths**

INFORMATION BRIEF: DEFINITION OF STILLBIRTH

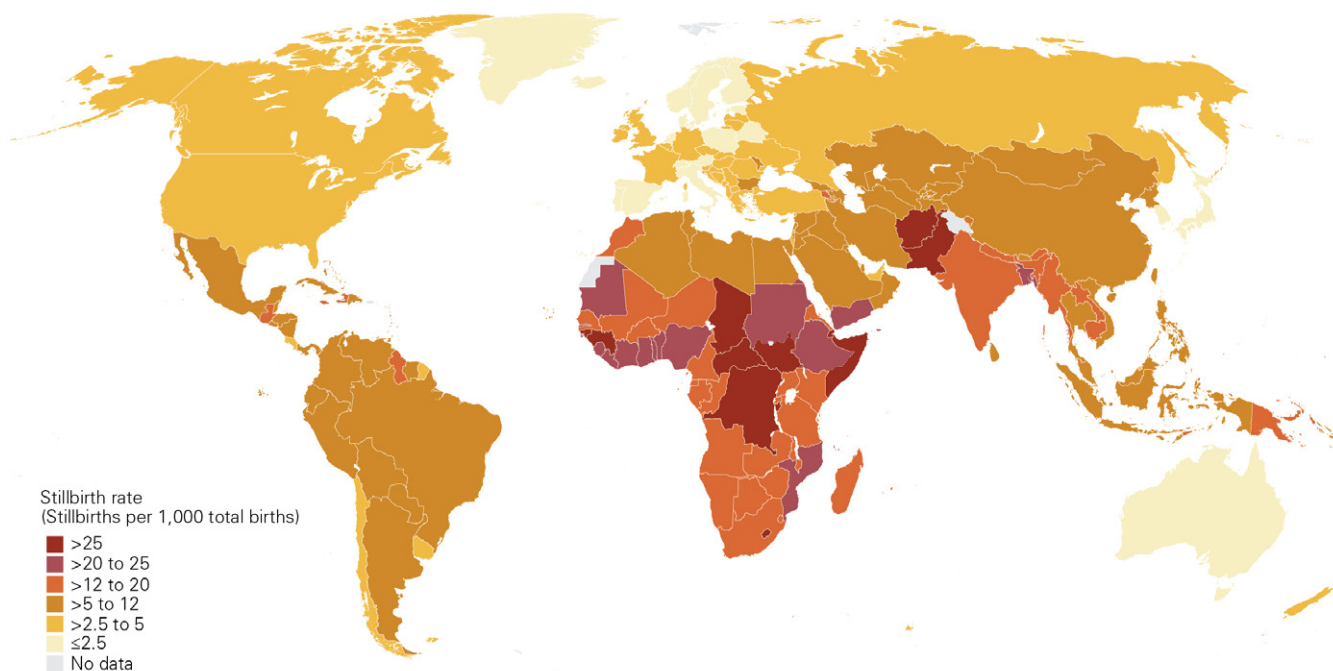
- A stillbirth is a baby born with no signs of life. Different countries use different cut-offs for the minimum number of weeks the pregnancy must have lasted to be classified as a stillbirth, with earlier pregnancy losses considered 'miscarriages'. The World Health Organization (WHO) defines a stillbirth as a baby born with no signs of life at or after 22 weeks of pregnancy, but recommends that a 28-week cut-off be used for international comparison.
- In Kenya, a stillbirth is defined as a baby who is born without any signs of life after 28 weeks of pregnancy or in the 3rd trimester.
- Any baby who is born without any signs of life before 28 weeks is considered to be a miscarriage. A late miscarriage is one that happens after the first 12 weeks of pregnancy, but before 28 weeks. The impact of these losses can be just as significant as the impact of stillbirths, and may also lead to intense psychological pain for the affected families.
- In high-income countries, pregnancy losses from 20 or 22 weeks are frequently counted as stillbirths. This lower cutoff period is related to the more advanced technology and healthcare provided to many women in these countries before and during pregnancy, which helps to ensure that babies born at lower gestational ages might survive birth in some cases even though unlikely.

The reasons for the lower gestational age cut-off for the stillbirth definition in higher-income countries suggests one possible target for stillbirth advocacy work:

To call for increased access to this advanced technology in all countries, so that all can have access to higher quality healthcare. This could then provide a rationale for the adoption of a lower gestational age threshold for stillbirths in Kenya and elsewhere, as survival for babies in these countries improves.

INFORMATION BRIEF: WHY FOCUS ON STILLBIRTHS IN KENYA?

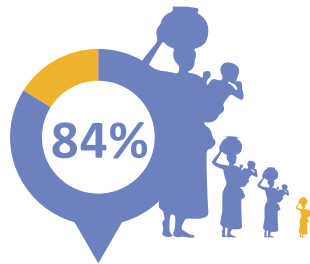
- Using the WHO international comparison definition of stillbirth, there were two million stillbirths globally in 2019 alone.
- In comparison, there are also about 2.4 million babies who died during the first month of their life in 2019, of whom 1 million died on their day of birth.



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

- In sub-Saharan Africa, the stillbirth rate is 21 per 1,000 total births. This is seven times higher than the stillbirth rate in high-income countries in Europe, Northern America, Australia and New Zealand, where it is just 3 per 1,000 total births.
- In Kenya, the stillbirth rate is 19 per 1,000 total births. This represents a huge burden for bereaved families.

A baby is stillborn every 16 SECONDS



Occur in low and lower-middle income countries



Occur in sub-Saharan Africa and Southern Asia

In every country, the risk of stillbirth is highest in the most vulnerable populations



Adapted Source: https://www.who.int/images/default-source/infographics/stillbirth/stillbirth-vulnerable-populations.jpg?sfvrsn=6b919f76_4

INFORMATION BRIEF: WHAT CAUSES STILLBIRTH?

- It is devastating to experience a stillbirth. It's okay to want to understand why the baby died. Stillbirths are caused by various factors; some are known while others are unknown. Approximately 1 in 3 stillbirths do not have known causes, even in high-income settings with advanced technology and comprehensive investigation.
- Globally, an estimated 42% of all stillbirths are intrapartum (i.e. baby born with no signs of life who was alive at the start of labor).
- An estimated 729,000 babies died during labor in 2019 in sub-Saharan Africa and Southern Asia, accounting for 88% of all intrapartum stillbirths worldwide.
- In Kenya, 53% of stillbirths occurred during labor and birth, while 47% occurred during pregnancy.
- Many stillbirths are potentially preventable. For example, stillbirths that occur during labor and birth are among the most preventable stillbirths, as long as proven interventions that improve the health of mothers and their babies are available and accessed.
- The causes of stillbirths in Kenya are similar to global causes of stillbirth.

» Stillbirth can occur during pregnancy and prior to birth, before labor begins (**antepartum stillbirth**)

» It can also occur during labor and birth (**intrapartum stillbirth**)

FACT SHEET: COMMON CAUSES OF STILLBIRTHS GLOBALLY

- **Obstetric complications** such as problems with placental development leading to vaginal bleeding or failure of transmission of nutrients to the baby.
- **Hypertensive disorders**, commonly known as pre-eclampsia and eclampsia, conditions in pregnancy characterized by high blood pressure.
- **Medical complications** such as HIV, anemia, chronic hypertension, malaria, gestational diabetes mellitus, sexually transmitted infections and bacterial infections.
- **Other causes** include but are not limited to:
 - Problems with the womb.
 - Preterm labor complications.
 - Problems with the umbilical cord.
 - Birth defects that occur as the baby develops in the womb.
 - IUGR (intrauterine growth restriction, also known as fetal growth restriction), which is when a baby does not grow as expected.

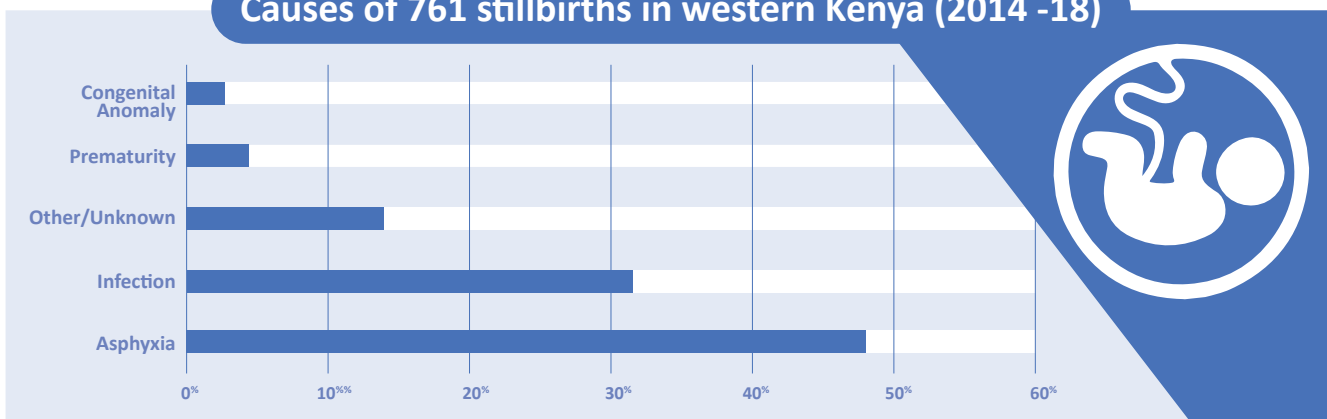
FACT SHEET:

Causes of 229 stillbirths in four tertiary hospitals in Nairobi, Kenya (2018-2019)

CAUSE OF DEATH	TOTAL CASES	PERCENT OF TOTAL
Obstetric complications		
Antepartum haemorrhage	29	12.7%
■ Placenta previa	16	7.0%
■ Abrupted placenta	13	5.7%
Hypertensive disorders	40	17.5%
■ Pre-eclampsia without severe features	13	5.7%
■ Pre-eclampsia with severe features	14	6.1%
■ Eclampsia	13	5.7%
Amniotic fluid disorders (premature rupture of membranes/ premature preterm rupture of membranes)	13	5.7%
Congenital anomalies	3	1.3%
Intrauterine growth restriction (IUGR)	4	1.7%
Post-dates	11	4.8%
Spontaneous preterm labor	9	3.9%
Multiple gestation	7	3.1%
Ruptured uterus	1	0.4%
NRFS (non-reassuring fetal status)	9	3.9%
Obstructed labor	2	0.9%
Cord prolapse	1	0.4%
Medical complications		0.0%
HIV	7	3.1%
Anemia	25	10.9%
Chronic hypertension	1	0.4%
Diabetes mellitus/gestational diabetes mellitus	11	4.8%
Trauma	6	2.6%
Unexplained	50	21.8%
Total	229	100.0%

Source: Gwako GN, Were F, Obimbo MM, Kinuthia J, Gachuno OW, Gichangi PB. Association between utilization and quality of antenatal care with stillbirths in four tertiary hospitals in a low-income urban setting. *Acta obstetrica et gynecologica Scandinavica*. 2021;100(4):676-83.

Causes of 761 stillbirths in western Kenya (2014 -18)



Source: McClure EM, Saleem S, Goudar SS, Garces A, Whitworth R, Esamai F, et al. Stillbirth 2010-2018: a prospective, population-based, multi-country study from the Global Network. *Reproductive health*. 2020;17(Suppl 2):146.

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

- Risk factors are characteristics associated with, but not direct causes of, stillbirth. Risk factors for stillbirth are described below.
- Lack of access to skilled care at birth and emergency obstetrical care such as Caesarean section if needed.
 - › In Kenya, over 1/3 of all women are not attended by a skilled birth attendant. Since complications associated with birth are one of the main causes of stillbirth, the presence of a skilled birth attendant is often important to provide effective care and prevent stillbirth.
- Socio-demographic factors, including rural residence, low socioeconomic status, lack of education, and poor nutrition.
 - › Socio-economic status can affect a mother's access to quality healthcare
 - › Level of education may affect parents' knowledge of pregnancy health and danger signs
- Inadequate support from her partner may affect the health of the mother, leading to psychological challenges which can ultimately affect her physiological health.
- Short inter-pregnancy intervals and prior stillbirths have also been associated with increased risk of stillbirth.



The most common risk factors for stillbirths in Kenya include:

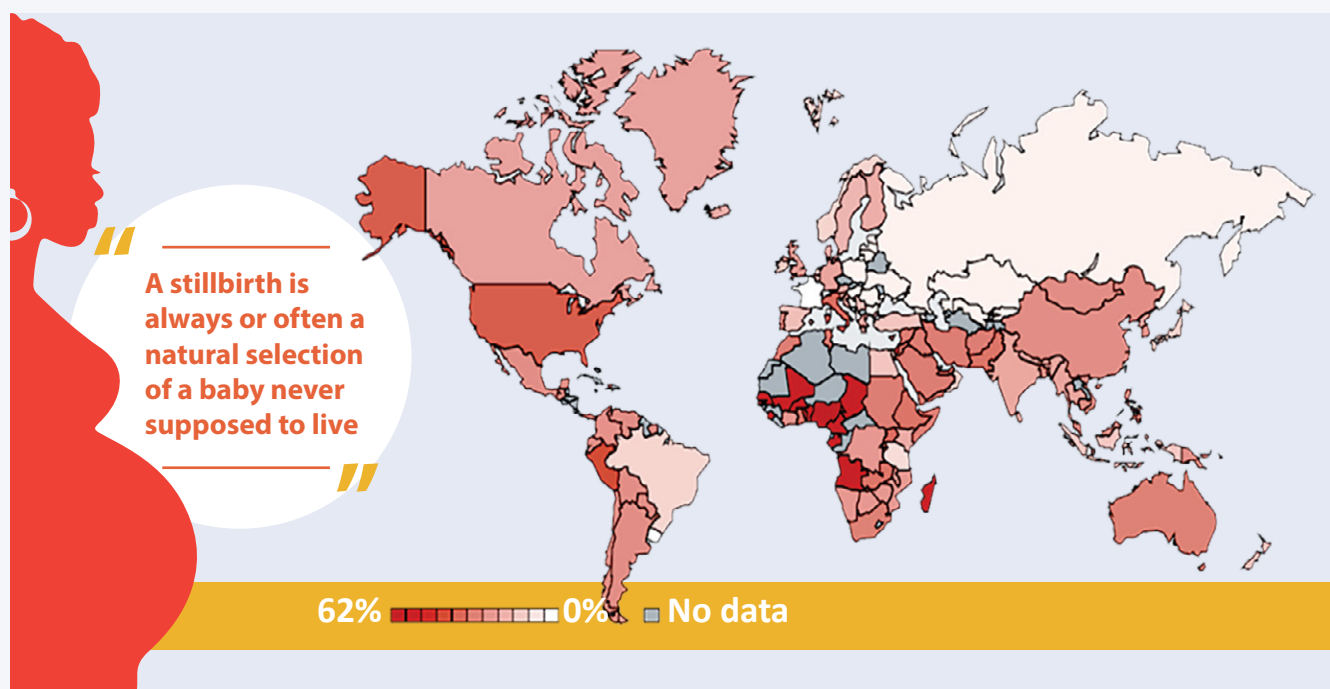
- The lack of a skilled birth attendant
- Multiple pregnancies such as twins
- Low socioeconomic status
- Poor nutrition
- Advanced maternal age (typically considered to be greater than 35 years of age)
- Poor infrastructure for maternity care

Talking about stillbirth:

- From the above description of risk factors, how do you think socioeconomic status may contribute to the risk of experiencing a stillbirth?
- What are other risk factors for stillbirth that you are aware of?
- What are some possible ways of addressing these risk factors?

INFORMATION BRIEF: FATALISM ABOUT STILLBIRTH

- The belief that stillbirths cannot be prevented is referred to as “fatalism”. 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:

- What are some of the common causes of stillbirths?
- After your stillbirth experience, were you able to understand the cause(s) or possible risk factors?
- If so, has this changed how you think about or experience any subsequent pregnancies?
- How can some stillbirths be prevented?

DIG DEEPER!

Resources	Description and link
KENYA RESOURCES AND STUDIES	
1. Gwako, George & Gichangi, Peter & Gachuno, Onesmus & Obimbo, Moses. (2020). Determinants of stillbirth in Nairobi, Kenya. 32. 21-30.	This study evaluates causes of stillbirths in four tertiary hospitals in Nairobi.
2. Tesema, G.A., Tessema, Z.T., Tamirat, K.S. et al. Prevalence of stillbirth and its associated factors in East Africa, (2021) BMC Pregnancy Childbirth 21, 414	This study explains the burden of stillbirths in East Africa and associated factors.
3. Ongeso, A., Lukorito, M., Kabo, J. (2018). Factors influencing high prevalence of Fresh Still Births in Mbagathi County Hospital, Nairobi - Kenya.	This retrospective study aimed to find the causes of fresh stillbirths in Mbagathi County Hospital in Nairobi.
4. Counting and Accounting for every stillbirth: E4A-Mamaye	This is a blog aimed to empower African mothers on reproductive health. It covers articles on stillbirth statistics in Kenya and the possible causes of stillbirth.
GLOBAL RESOURCES AND STUDIES	
1. A Neglected Tragedy: The Global Burden of Stillbirths 2020- UNICEF data	This report highlights the recent global estimates of stillbirths.
2. WHO Stillbirth	This article from the WHO website covers the definition of stillbirth and global estimates of the same.
3. Aminu, M., Bar-Zeev, S., White, S. et al. Understanding cause of stillbirth: a prospective observational multi-country study from sub-Saharan Africa, (2019) BMC Pregnancy Childbirth 19, 470	This study explores the causes of stillbirths in Sub-Saharan Africa. This was a prospective, observational study in 12 hospitals in Kenya, Malawi, Sierra Leone and Zimbabwe.
4. McClure EM, Phiri M, Goldenberg RL. Stillbirth in developing countries: a review of the literature. Int J Gynaecol Obstet. 2006;94(2):82-90.	This study reviews causes, risk factors and prevention strategies for stillbirths in developing countries.

MODULE 2:

Common challenges parents face after stillbirth



Photo Credit: <https://www.thesun.co.uk/news/5368451/guinea-faith-healer-conned-woman-pregnant/>

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

1. Explain the impact of stillbirths on parents
2. Understand the challenges related to hospital care
3. Explore the challenges related to community support
4. Understand parents' perspectives

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

- Stillbirth is one of the most devastating experiences for a parent to go through.
- Stillbirth gives rise to societal, psychological and physical challenges.
- 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 sense of worth and 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, quit their religious practice, have doubts about sexual intercourse, feel remorse or guilt about not being able to save the baby, or doubt the value of antenatal care or other health providers.
- Mothers and fathers may be affected differently, and their marital life may be affected in the short-term or long-term.
- Parents 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.
- Reports and studies of bereaved parents from different parts of the world report challenges related both to care that parents receive in healthcare facilities and how they are treated in their communities after stillbirth.

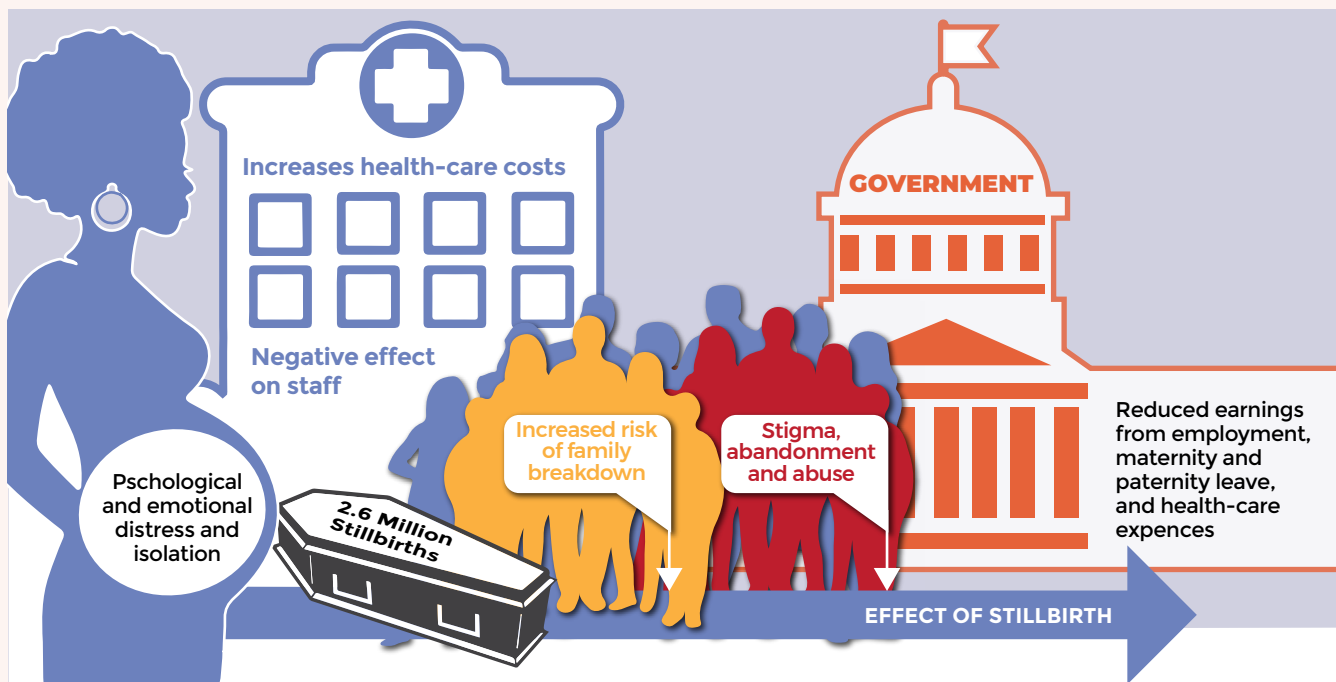
FACT SHEET:

CHALLENGES RELATED TO CARE AT THE HOSPITAL

Issue	Challenge	Parent voice	References for further reading
Key memories and experiences	Parents reported that key moments at the hospital in relation to the care that they received affected their experience. A study of bereaved parents' experiences conducted in Ireland indicated that parents who had negative experiences recalled them with anger towards the staff involved. Both positive and negative memories were shared.	<i>"I could feel the kindness off her [consultant]. I knew she really cared."</i> <i>"During the first scan she was measuring this and measuring that and she told me she was a trainee, and in my own head I was going 'go out and get someone who knows what they are doing'... she said 'maybe I'm doing something wrong, go away and come back in two weeks.'"</i>	Nuzum, Daniel, Sarah Meaney, and Keelin O'Donoghue. "The impact of stillbirth on bereaved parents: A qualitative study ."
Acknowledgement of the baby	Most parents desire to have their babies acknowledged as irreplaceable individuals. They want to have their babies treated with dignity and respect just as with any living baby.	<i>"I wish like at the beginning, especially in the hospital environment, they would have identified my daughter as a singular, as my daughter, as my first born as opposed to thinking, 'Oh, you guys get healthy and you just go out and do it again and everything will be over, be replaced ...'"</i>	Farrales, Lynn L., et al. "What bereaved parents want health care providers to know when their babies are stillborn: A community-based participatory study ."
Communication after a stillbirth	Parents have reported being unhappy with how they were told of the baby's death with delays and misinformation. Some mothers guessed that something was wrong because of staff demeanor or conversations. A common statement made by most sonographers in a study from Kenya, as shared by mothers in Swahili, was: 'mama hapa hakuna heartbeat'- 'Woman, there is no heartbeat'.	<i>One mother learned her baby had died only when the scan results were explained to medical students: "She told them, 'When this happens, I hear when the placenta detaches from the baby!!' Something like that: 'the baby suffocates, if the baby is not getting oxygen, so this has led to death, so the baby has died.' She did not tell me direct, but she told them, and I was listening, yes. So, I realized that my baby was no more." [Bukirwa, mother, Semi-rural Uganda]</i>	Mills, T. A., Ayebare, E., Mukhwana, R., Mweteise, J., Nabisere, A., Nendela, A., ... & Lavender, T. (2021). Parents' experiences of care and support after stillbirth in rural and urban maternity facilities: A qualitative study in Kenya and Uganda.
Hospital policies & practices	Some parents expressed the desire to see and hold their stillborn babies after birth. Some were able to hold their babies while others were unable to. Often, the option to hold the baby wasn't offered, due to hospital policy, and most women regretted not holding their babies. Cultural beliefs and sense of protection from fear and intense grief are some of the main constraints to introducing this option for mothers. Some of the unhelpful structures reported include sharing the same ward with nursing mothers, strict visiting hours, poor referral systems, and lack of follow-up for psychological support.	<i>You know a mother is a mother even to a dead body. I would have wished to hold the baby but I think the nurses saw my grieving and they thought that would have aggravated my pain more so they immediately took the baby away.' [Cece, mother, Peri- Urban Kenya]</i> <i>"From 5 pm that evening, through the night I slept with the baby box.... the hospital required next of kin consent to the hospital burying the body. The stillbirth really traumatized me especially having to lie down besides [a] dead baby.' [Beryl, mother, Urban Kenya]</i>	Mills, T. A., Ayebare, E., Mukhwana, R., Mweteise, J., Nabisere, A., Nendela, A., ... & Lavender, T. (2021). Parents' experiences of care and support after stillbirth in rural and urban maternity facilities: A qualitative study in Kenya and Uganda.

FACT SHEET: CHALLENGES RELATED TO COMMUNITY SUPPORT

- The effects of stillbirth reach beyond the mother (as shown in the illustration below).



Reproduced and adapted with permission of The Lancet from: <https://encrypted-tbn0.gstatic.com/images?q=tbn:AND9GcSjlu7OT69uSrP5zGSZKe9CyMZE78Wa62IEA&usqp=CAU>

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.

- Parents talk about a sense of isolation and emotional abandonment by those around them. Some received adequate care from family, friends and workmates while others felt dismissed or their experiences invalidated. This includes insensitive comments and gossip indicating the severity of stigma and shame surrounding stillbirths in some communities.
- Inadequate support at work has also been raised as a challenge during the grieving process. Inflexible policies on bereavement leave and lack of compassionate communication are very common unhelpful practices.

“Some of them are very understanding, others were suspecting that I was bewitched and others started saying I was HIV positive. All in all, I have kept my faith in the Lord.” [Kate, mother, Peri-urban I Kenya]

Quote from Mills, T. A., Ayebare, E., Mukhwana, R., Mweteise, J., Nabisere, A., Nendela, A., ... & Lavender, T. (2021). Parents' experiences of care and support after stillbirth in rural and urban maternity facilities: a qualitative study in Kenya and Uganda. *BJOG: An International Journal of Obstetrics & Gynaecology*, 128(1), 101-109.

Talking about stillbirth:

- What are some of the myths about stillbirth in your culture?
- What are the possible ways of debunking such myths?
- Why do you think hospital staff may be insensitive to a woman after stillbirth?
- What are some ways hospital staff can make a woman's experience better after stillbirth?

PARENTS' PERSPECTIVES



"I lost my baby girl in 2018 during delivery. It was a stillbirth. This was such a painful experience especially when I discovered that my baby had a higher chance of surviving if everything was done correctly. My pregnancy was categorized as high risk because of high blood pressure. It was very complicated and I would find myself on and off from the hospital.

My blood pressure was not stabilizing even after being under medication. When at week 40, I went to the hospital and I requested that the baby to be delivered. But after the ultrasound, the doctor said that the baby wasn't due. In fact, they said that the baby was just 33 weeks. That was according to the scan. This was a mistake, because my baby was ... [already affected] due to preeclampsia. And because the scan indicated that the baby was doing well, I followed what the doctor said.

One week later, I felt my water break, followed by labor pains. I was shocked because I was told the baby would come a month later even though I felt the scan wasn't right. I was rushed to the hospital. My blood pressure had spiked. My case was an emergency because I had severe preeclampsia. Unfortunately, I was at a public hospital and despite my case being an emergency there was no doctor available. The nurses did their best to have my blood pressure reduce as they wait for the doctor. Unfortunately, no doctor came for the whole night and when I delivered early in the morning my baby was no more. She didn't cry and I was so bitter because there was negligence from the hospital. Since it was a public hospital, it was hard for me to question anyone. Nobody was there to take responsibility and I was left to choose on how I would like my baby to be disposed. Even today, I still feel that my baby would have been saved but we had to move on.

- Grace Nyambura



"Around May 2019, my wife and I lost our son through miscarriage. It wasn't an easy moment for me. I remember when she missed her periods, we decided it required medical attention. We went for an ultrasound and to our surprise, there was an image of a baby. It was a surprise because you see, we were really trying to have a child. I was so happy I was going to be a dad again. I prepared my heart and my mind and created more space in there for Michael. But after around two weeks, disaster hit home. My wife started having abdominal pains. I thought it was normal and I bought some painkillers for her. Then, she started spotting and the pains ... [increased]. Now that was a red flag. We sought the services of a gynaecologist for a scan. There was no heartbeat. Baby Michael was gone. The most painful part was during the procedure to evacuate him from his mother's womb. It broke my heart to see him lying in a mass of blood in a surgical bucket.

My feelings became numb and I was traumatized. Had to be strong so I can support my wife so I postponed my mourning. My heart still got a hole to date. Each time I see a pregnant woman or a family with a new-born, the pain becomes fresh again. The cries of a new-born always break my heart. It could be Michael you see. He could be one and a half years today. It still hurts that there is still no first photo together, no first hug, no first smile, no first kiss. The only memory I have of him is of that ultrasound as he slept peacefully...and his mass in a bloody bucket...deeply sad. My soul aches for him.

I realized, when I was talking to people, whether colleagues, friends or relatives, the topic around child loss was muted. Their feelings were so suppressed it's like that child they lost never existed. Many people do not acknowledge the physical, emotional and psychological impact of child loss. You are never the same again. Most people ignore or use the wrong words to comfort you. It's a very lonely experience until you find a support group or a counsellor who will help you process the loss and the pain like Still A Mum does. The tree planting event organized by Still A Mum was very helpful; we planted trees as we supported each other as bereaved parents.

- David Wanjala

PARENTS' PERSPECTIVES



"On 19th September 2019, during my antenatal clinic at 32 weeks, the ultrasound confirmed a case of intrauterine fetal death. A case of preeclampsia. I went into denial, and pushed the baby the next day with the help of the best gynecologist. The journey of grief began until I could not bear it all alone. I joined Still A Mum in December 2019 for personalized therapy sessions and six weeks later, I joined the group sessions.

Thanks to Still A Mum for the rays of hope you give to all mums and dads who reach out. I overcame the fear of grief and now I'm a mum to a four months' Princess. To God be the Glory".

- Christine Wangeci

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Resources	Description and link
1. Ayebare, E., Lavender, T., Mweteise, J. <i>et al.</i> The impact of cultural beliefs and practices on parents' experiences of bereavement following stillbirth: a qualitative study in Uganda and Kenya. <i>BMC Pregnancy Childbirth</i> 21 , 443 (2021)	This study explored the influence of cultural beliefs and practices on the experiences of bereaved parents and health workers after stillbirth in urban and rural settings in Kenya and Uganda.
2. T.A Mills, E Ayebare, R Mukhwana, <i>et al.</i> Parents' experiences of care and support after stillbirth in rural and urban maternity facilities: a qualitative study in Kenya and Uganda. 2020.	The aim of this study was to explore the lived experiences of parents in the period immediately following the death of their babies in health facilities in Kenya and Uganda, to gain an understanding of the response of health systems and barriers and facilitators to effective support.
3. 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.

MODULE 3:

Expectations and rights of bereaved parents

Photo Credit: <https://geneticliteracyproject.org/2017/10/16/human-empathy-gene-might-determine-emotional-ability/>

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

1. Explain the differences between stillbirth rights, policies and social expectations in Kenya
2. Discuss the global rights and policies related to stillbirth
3. Explore the potential roadblocks in the way of parents' rights, preferences and expectations related to stillbirth care



FACT SHEET:

DIFFERENCES BETWEEN STILLBIRTH RIGHTS, POLICIES & SOCIAL EXPECTATIONS IN KENYA

Concept	Definition	Example	References for further reading
Rights/laws	These are legal rights identified in Kenya's Constitution and enforced by the court or through formal grievance procedures.	<p>According to the Kenyan constitution, Health Act 2017 No.21 part 5:</p> <ul style="list-style-type: none"> ■ Every person has the right to the highest and attainable standard of health which shall include progressive access for provision of promotive, preventive, curative, palliative and rehabilitative services. ■ Every person shall have the right to be treated with dignity, respect and have their privacy respected in accordance with the Constitution and this Act. 	http://kenyalaw.org/kl/fileadmin/pdfdownloads/Acts/HealthActNo.21of2017.pdf
Rules & policies	A set of guidelines that an agency or an individual aims to follow. They outline your rights and may be governed by law or not. For example, a hospital policy may be to provide care and respect to patients.	Nairobi Hospital Policy	https://thenairobihosp.org/quality-policy-statement-april-2020/
Social expectations & preferences	These are expectations or rules that every society has. As individuals we have our own ideas of how we would like to be treated. These preferences are not governed by law or policy, hence cannot be enforced as rights.	In the Kenyan culture there are social expectations related to being a woman, being a mother, being from a particular part of the country, and belonging to a specific religion, and sometimes these expectations may conflict.	Okwako, Joseph M., and Andrew G. Symon. "Women's expectations and experiences of childbirth in a Kenyan public hospital." <i>African Journal of Midwifery and Women's Health</i> 8, no. 3 (2014): 115-121.

- We may have concerns that we believe are related to our rights, but they are not considered as rights by either law or policy. However, this does not mean we cannot advocate for these to be considered as rights as we seek to facilitate change.

INFORMATION BRIEF: RESPECTFUL BEREAVEMENT CARE

- Respectful bereavement care is the support given to benefit bereaved parents to help them deal with the emotional and practical challenges experienced from the time of diagnosis and after stillbirth.

Respectful Bereavement Care by providers looks like:

- Compassion and sensitivity
- Acknowledging families' grief
- Being emotionally present by avoiding using a 'cold' professional approach
- Doing for patients what you would want done for your loved ones
- Giving privacy for grieving
- Assisting families to have positive memories such as photos and hand/footprints or other keepsakes
- Guiding and offering appropriate information
- Clarifying words that are often misunderstood such as 'spontaneous abortion'; mothers report being blamed by their partners because of such terms used by providers to mean miscarriage.
- Avoiding medical jargon
- Suggesting a family time to make memories
- Encouraging naming of baby and bonding with baby
- Ensuring the same staff work with the family to reduce stress or communication error

The above is adapted from the Respectful Bereavement Care curriculum prepared by Still A Mum.

Talking about stillbirth:

- *Did you receive respectful bereavement care after your baby was stillborn? Why or why not?*
- *What could you do to encourage staff at the facility where you gave birth to provide respectful bereavement care to other mothers?*

FACT SHEET: GLOBAL RIGHTS AND POLICIES RELATED TO STILLBIRTH

- In addition to the stillbirth-related rights that are granted to women and families by Kenyan law and policy, there are also global rights and policies that are relevant for families bereaved by stillbirth in every country. Knowing about these global rights and policies can help families to be aware of, and push for, better care during and after stillbirth.
- In every country, women have the right to available, accessible, acceptable, and good quality healthcare. Assuring this set of rights can help to prevent stillbirths and to ensure families receive respectful bereavement care when stillbirth happens.
- Two main global documents reflect these rights:
 - › In 2014, the World Health Organization issued a [statement](#) for respectful maternity care calling for the protection of a woman's "right to dignified, respectful health care" and "ending disrespect and abuse during childbirth".
 - › In 2018, the updated [Respectful Maternity Care Charter](#) was published; it states that high-quality maternity care supports and upholds the dignity of both the mother and the newborn. The Charter sets out how these human rights should be guaranteed in pregnancy and childbirth care.
- In 2016, a key [series on stillbirth](#) was published in the global medical journal, The Lancet, which emphasized that this global rights framework means that supportive, respectful care in pregnancy and childbirth, **including after a stillbirth**, is a core part of high quality healthcare for all women.
- To be high quality, such care must also be context-specific and culturally acceptable, according to the best available evidence globally about what matters for families. For example, parents in all countries should be given the option to hold a baby who has died, yet the bodies of stillborn babies in many countries are often disposed of without any recognition, name, clothes, or funeral.
- Women (and all people) have fundamental human rights, including "the highest attainable standard of physical and mental health". Respectful bereavement care is a part of this. It includes an acknowledgment of stillbirth and help for families to respond in their own ways.
- Empowerment of parents is critical to transforming these global rights into reality, through education and awareness raising, equitable decision making, woman-focused care, and greater access to resources. In fact, realizing global rights can improve health outcomes, including the prevention of stillbirths and appropriate respectful care for parents after stillbirth. Health workers' and communities' norms of complacency and fatalism related to stillbirth are common roadblocks.
- Ultimately, acknowledgment of women's rights to respectful care during and after childbirth can support the development of a common understanding of, and commitment to, respectful care during and after stillbirth as well.

The content of this Fact Sheet is paraphrased from de Bernis L, Kinney MV, Stones W, ten Hoope-Bender P, Vivio D, Leisher SH, et al. Stillbirths: ending preventable deaths by 2030. The Lancet. 2016;387(10019):703-16

Talking about stillbirth:

- *Do you think that raising awareness of women's global rights to quality dignified healthcare might make a difference to care for bereaved parents in your community? Why or why not?*

FACT SHEET:

POTENTIAL ROADBLOCKS IN THE WAY OF PARENTS' RIGHTS, PREFERENCES & EXPECTATIONS RELATED TO STILLBIRTH CARE

- You have learned a bit about some of the rights you have related to stillbirth care, and also about some of the policies and expectations that relate to this care.
- You also probably know from experience that such care is not always provided. It can be helpful to consider the possible roadblocks to different elements of respectful bereavement care. As you review the fact sheet below, think about how you might work to overcome some of these roadblocks.

You may have a right, preference, or expectation to...	But you may experience some roadblocks ...
Ask for an autopsy/post-mortem	<ul style="list-style-type: none"> ■ Might cost money that you don't have ■ Culture or preferences of other family members might mean they object to having one ■ Your facility might not offer autopsy ■ You might not know what will happen to your baby/fear the autopsy/have unanswered questions.
Experience compassionate communication	<ul style="list-style-type: none"> ■ Health providers in your facility might not be well trained in how to communicate compassionately with you after stillbirth ■ They might fear being blamed ■ Someone might decide to tell other family members 'not to upset the mother'.
Receive adequate information about the cause of stillbirth	<ul style="list-style-type: none"> ■ The doctor may not know yet until tests and exams are performed. ■ The clear cause of stillbirth might not be identified in some cases.
Hold your baby and spend some time with him/her	<ul style="list-style-type: none"> ■ It is difficult to hold your stillborn baby especially when you feel unready. Yet, it is a decision that must be made quickly because of key factors such as burial, cremation or environmental factors i.e. high temperature areas.
Create memories, including spending time with your baby, or taking hand and footprints, photos or locks of hair	<ul style="list-style-type: none"> ■ It might be challenging to create memories immediately after giving birth to your stillborn baby. The weight of grief might be too heavy and it's easy to not know what type of memento will work for you.
Care and support from family, friends, peer groups or professional counselors that can help navigate grief	<ul style="list-style-type: none"> ■ It's unfortunate that people around us might not be aware of the best ways of offering support. ■ Some hospitals might lack a psychology or counselling department for further psychological support.
Privacy as one experiences the overwhelming emotions of grief and to also minimize interaction with nursing mothers and babies	<ul style="list-style-type: none"> ■ Most facilities do not have bereavement rooms or extra rooms.
Exploring options on how to handle the baby's body, which will help to support informed decision-making based on preferences and values	<ul style="list-style-type: none"> ■ It is difficult to make this decision because of the intensity of grief ■ Some parents wouldn't want to prepare a burial ceremony but later on may regret leaving their baby at the hospital.

Talking about stillbirth:

- When your baby was stillborn, did you receive care according to your preferences? Why or why not?
- When your baby was stillborn, what care did you want?
- Do you think different parents feel differently about the care they want? Why?
- Which other preferences or rights do bereaved parents have, in addition to what is mentioned above?

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Resource	Description and link
1. Lammert, Catherine. "Right of a Parent When a Baby Dies: Choices or Mandates." <i>Pregnancy Loss and Infant Death Alliance (n.d.): n. pag. Nationalshare.org</i> . Web. 10 Dec. 2016.	This paper explains the rights a bereaved parent has at the hospital or facility.
2. 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.
3. Shakibazadeh E, Namadian M, Bohren MA, Vogel JP, Rashidian A, Noguiera Pileggi V, et al. Respectful care during childbirth in health facilities globally: a qualitative evidence synthesis. <i>BJOG</i> . 2017;125(8):932–42. doi: 10.1111/1471-0528.15015	This study synthesized data on respectful maternity care from 67 studies in 32 countries, and showed the existence of a wide range of types of care beyond simply “reduction of disrespectful care or mistreatment of women during childbirth”.
4. Respectful maternity care charter, 2018 update. Washington DC: White Ribbon Alliance; 2018	This landmark document sets out women’s and babies’ rights for quality respectful care in health facilities during pregnancy, labor and birth.
5. Heazell AEP, Siassakos D, Blencowe H, et al, for <i>The Lancet Ending Preventable Stillbirths Series Study Group</i> , with <i>The Lancet Ending Preventable Stillbirths investigator group</i> . Stillbirth: economic and psychosocial consequences. <i>Lancet</i> 2016; published online Jan 18 http://dx.doi.org/10.1016/S0140-6736(15)00836-3 .	This paper provides a global overview of the financial, emotional and psychosocial costs of stillbirth for women and families.
6. Byrom S, Downe S. The roar behind the silence: why kindness, compassion and respect matter in maternity care. London: Pinter & Martin Ltd, 2015.	This book acknowledges the challenges faced by health workers in providing quality respectful care, especially related to the culture of fear and blame, and suggests ways forward.
7. Tuncalp, Were WM, MacLennan C, et al. Quality of care for pregnant women and newborns-the WHO vision. <i>BJOG</i> 2015; 122 : 1045–49.	This commentary lays out the World Health Organization’s principles for quality care, including providing a definition of quality care as safe, effective, efficient, timely, equitable, and people-centred.
8. Langer A, Meleis A, Knaul FM, et al. Women and Health: the key for sustainable development. <i>Lancet</i> 2015; 386 : 1165–210.	This report from the Lancet’s Commission on Women and Health Commission calls for valuing, compensating and counting women in health care (both as providers and consumers) and for health systems to be accountable to women.
9. Starrs AM. Survival convergence: bringing maternal and newborn health together for 2015 and beyond. <i>Lancet</i> 2014; 384 : 211–13	This comment provides context to the Lancet’s 2014 Every Newborn series which accompanied the United Nations’ endorsement of the Every Newborn Action Plan, the world’s first (and only) framework setting global targets to end preventable newborn deaths and stillbirths.
10. Frøen JF, Cacciatore J, McClure EM, et al, and <i>The Lancet’s Stillbirths Series steering committee</i> . Stillbirths: why they matter. <i>Lancet</i> 2011; 377 : 1353–66.	This foundational paper was one of the first to lay out the global situation of stillbirths and call for increased attention. It was the first paper in the 2011 Lancet Stillbirths series.
11. WHO. The prevention and elimination of disrespect and abuse during facility-based childbirth. Geneva: World Health Organization, 2014.	This formal statement from the World Health Organization clarifies respectful care during birth as a human right and lays out actions to be taken to address violations of this right.

DIG DEEPER!

Resource	Description and link
12. Sacks E, Kinney MV. Respectful maternal and newborn care: building a common agenda. <i>Reprod Health</i> 2015; 12 : 46.	This commentary calls attention to the rights of newborns, including newborn babies who are stillborn, to receive dignified respectful care.
13. United Nations Economic and Social Council Commission on the Status of Women. Review and appraisal of the implementation of the Beijing declaration and platform for action and the outcomes of the twenty-third special session of the General Assembly: E/CN.6/2015/3, 2014.	This statement from UN Women details progress on gender equality and empowerment since the 1995 Beijing Conference on Women.
14. Lassi ZS, Bhutta ZA. Community-based intervention packages for reducing maternal and neonatal morbidity and mortality and improving neonatal outcomes. <i>Cochrane Database Syst Rev</i> 2015; 3 : CD007754.	This global review summarized the evidence on interventions for preventing maternal and newborn mortality and morbidity, including stillbirth prevention.
15. Prost A, Colbourn T, Seward N, et al. Women's groups practicing participatory learning and action to improve maternal and newborn health in low-resource settings: a systematic review and meta-analysis. <i>Lancet</i> 2013; 381 : 1736–46.	This review summarized evidence for whether women's groups are effective in reducing maternal and newborn mortality and morbidity, including stillbirth prevention

MODULE 4:

What is advocacy and why is it important for stillbirth?



Photo Credit: <https://forpurposelaw.com/wp-content/uploads/elementor/thumbs/Advancing-Advocacy-by-Philanthropies-e1562795242392-os93vh4dez99crdmm8vr1fc115p4btb3k06hgtg9bkl.png>

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

1. **Define advocacy**
2. **Explain the types of advocacy**
3. **Understand why advocacy is important for stillbirth**
4. **Explore parents' perspectives on advocacy**

INFORMATION BRIEF: ADVOCACY BASICS

- Advocacy is a process by which you attempt to gain acknowledgement, understanding and respect from others regarding your rights, preferences and entitlements, and then try to persuade them to change their minds and support your position or point of view.
- It can take place in many contexts, both formal and informal.
- It involves promoting the interests or cause of someone or a group of people, towards other groups or people whose viewpoints or decisions affect your position. In other words, **advocacy means raising voices to make a change.**
- Advocacy does not need to be confrontational. Of course, there are times when you may need to assert your rights more forcefully or even seek the help of a professional advocate.

What advocacy can achieve

Advocacy is a method to help ensure that people, particularly those who are most vulnerable in society, are able to:

1. Have their voice heard on issues that are important to them.
2. Defend and safeguard their rights and responsibilities.
3. Have their views and wishes genuinely considered when decisions are being made about their lives.
4. Lead change towards greater social justice and equality.
5. Express their views and concerns.
6. Access information and services.
7. Understand (and affect!) their choices and options.

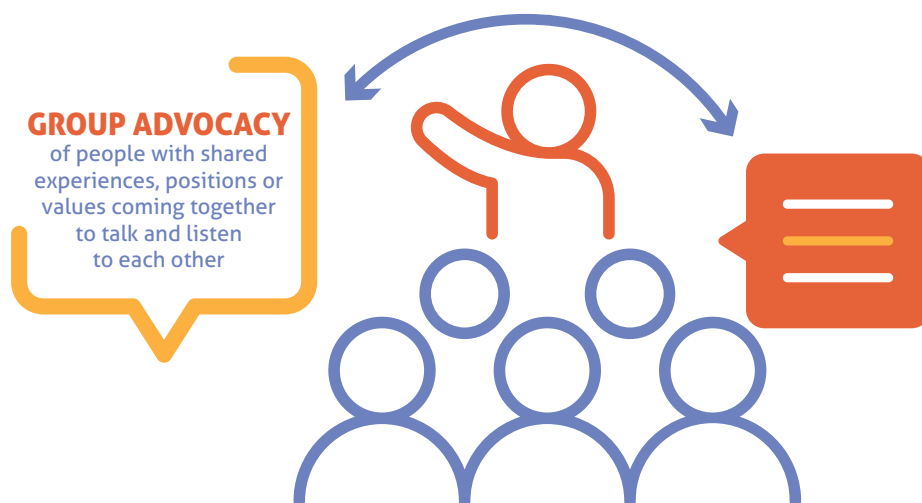
INFORMATION BRIEF: TYPES OF ADVOCACY

- There are different types of advocacy depending on the goals and needs of the group or individual, each representing a different approach to working for changes at the hospital, community, family or neighborhood level.
- There are different ways to categorize advocacy strategies. The choice of an advocacy strategy can be influenced by what and to whom you are trying to advocate, as well as by your personality and preferences.

- › **Informal advocacy** strategies involve addressing your challenges and desired changes with the person or organization with whom you have a difference of opinion.
- › **Formal advocacy** strategies generally involve bringing in an outside decision-maker such as court action or agency complaint processes.
- › **Self-advocacy** refers to an individual's ability to effectively communicate his or her own interests, desires, needs and rights in order to make change. It entails:
 - ▢ understanding your strengths and needs
 - ▢ identifying your personal goals
 - ▢ knowing your legal rights and responsibilities
 - ▢ communicating your position to others.
- › Self-advocacy is **speaking up for oneself**. It is important to bear in mind, however, that our opinions might be different from those of other individuals, so it is important to be aware that what you advocate for might not be important for a fellow bereaved parent (or might contradict their experience or preferences).
- › **Group advocacy** involves an organized group of people with shared experiences, positions or values coming together to talk and listen to each other and speak up collectively about issues that are important to them in order to make change, for instance through influencing public opinion and/or policy.



Adapted from: <https://www.nationaldeafcenter.org/sites/default/files/Self-Advocacy%20image.png>



Adapted from: https://www.google.com/url?sa=i&url=https%3A%2F%2Fwww.marketing91.com%2Fadvocacy-groups%2F&psig=AOvVaw2zXWTUPCzR1N2aHqF-PGHL&ust=1634824566350000&source=images&cd=vfe&ved=0CAwQjhqFwoTCKCp_52S2jMCFQAAAAAAdAAAAABAD

INFORMATION BRIEF: WHY IS ADVOCACY IMPORTANT FOR STILLBIRTH?

- As you have seen in earlier modules, and as you know from your personal experience, stillbirth is unfortunately a common outcome of pregnancy in Kenya, with many adverse effects on bereaved parents. At the same time, bereaved parents have certain rights, preferences and expectations related to bereavement care after stillbirth, some of which are mentioned in Module 3. Yet you also may know from your own experience that you, or other bereaved parents, may not always receive these types of respectful bereavement care.
- Sometimes we assume that society (our family, friends and community leaders) and health providers should know how best to support the bereaved parent, while in hindsight they just don't know how to. Their way of support—or whether they offer support at all—is influenced by society, culture and their personal experiences, the training they have received (or not), and policies and practices in their workplace or clinic.
- Therefore, while we may think our concerns and expectations related to the stillbirth of our baby are, or should be, obvious, frequently that is not the case.
- Further, you may have experienced clinicians or community members speaking about stillbirth as if it is inevitable. This fatalism on the part of many people about the preventability of stillbirth can also affect the care that women and families receive.
- Advocacy is an essential tool both to help ensure respectful bereavement care and to work toward stillbirth prevention.
- For example, a work colleague may offer support after stillbirth in her own way, using her own words, but this may end up being insensitive to you, e.g., “Don't worry, you can always have another baby”. In this situation, you could say to your colleague that “I think you mean to be supportive, but I miss the baby I just had, and even if I have another, she or he will not replace this one”.
- It is okay to communicate your concerns and your desired solutions. **This is a form of self-advocacy.** It can be a challenge to practice self-advocacy, though, because of fear of intimidation or due to our different personalities.
- You could advocate for better bereavement support by organizing peer support groups at your local hospital to support parents bereaved by stillbirth or to encourage the hospital to provide referrals to bereaved parents for psychological services whenever the need arises.
- You could partner with healthcare providers to organize seminars for expectant mothers to learn about pregnancy health, labor signs and danger signs to watch out for, to advocate for a healthy pregnancy and the importance of antenatal care.
- These are forms of **group advocacy** aimed at both bereavement support and stillbirth prevention.
- Advocacy that takes place at higher levels such as the national level can sometimes have a much larger impact, because these actions affect multiple areas.
- For example, on the 22nd of July 2021, Senator Sylvia Kasanga, a Kenyan senator, moved a motion on the promotion of mental health facilities for mothers. She said, ‘Women who experience stillbirth and those that lose their children during delivery go through untold pain that predisposes them to mental illness’. This statement represented a great milestone for bereaved parents and families in Kenya, because it encouraged the national government to look into setting up psychological services for bereaved parents.

PARENTS' PERSPECTIVES



"I had a smooth pregnancy. All scans were fine and no problems noted at all. His estimated due date was 05.10.20. Labor started on 06.10.20 at around 11 am though mild. It progressed and I checked in to hospital at 4pm. At admission the heartbeat couldn't be found. The doctor had initially recommended the standard 30 days [leave from work] and suggested that upon their expiry, I could seek for a two-week sick leave. I felt this wasn't adequate and contacted the Human Resource Manager. Luckily it's policy though I was not aware that full maternity leave is allowed. I had to ask and speak for myself and that's how I received more days".

- Rahab Sego



"From my experience and support that I got from Still A Mum, I decided to start a blog called mamasjoint.com. On the blog I have covered my story and other maternal related stories. My aim is to create awareness as I advocate for quality maternal services to all women. I believe this is a right for every woman despite the hospital one chooses. I have been able to encourage bereaved moms and help them find their voice."

- Grace Nyambura



"I took up this challenge to speak about the validity of the father's feelings. I gave in to interviews both in print and live media. I had TV interviews and talked about the subject. Men slowly started reaching out from the clips I posted online. We started talking, some face to face while others online and offered each other hope and comfort. I once went to meet fathers who had suffered loss in an invites-only conference room and we shared our stories. I feel more safe spaces should be created. They help us process the grief and acceptance. I also chose to talk about it to friends and explain to them what I was going through and the validity of my emotions. Some could not understand it because they have never experienced child loss. Sadly, most of the time, when you lose a child, the attention is given to the mother and the father is ignored...while he is still hurting.

- David Wanjala

Talking about advocacy:

- What type of advocacy have you tried? How did it go? What helped you to succeed or caused failure?
- What type of advocacy have you not tried? Why not?
- Based on your personal experience, what is one thing you would like to advocate for to make things better for other families?

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Resources	Description and link
West Virginia University Center for Excellence in Disabilities	This is an example of a group advocacy platform; it explains the types of advocacy and the relevance of advocating for change.
Advocacy Focus	This website contains information on the different types of advocacy and explains the importance of advocacy work in any platform.
Self-Advocacy Online	This website explains the basics of self-advocacy and highlights stories of self-advocates.

MODULE 5:

How to start advocating for change on stillbirth



Photo Credit: <https://stillamum.com/rainbow-shower-2/#>

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

1. Understand how to prepare for advocacy
2. Explain the steps for self-advocacy strategies
3. Outline the steps for group advocacy strategies
4. Understand how to deal with opposing views
5. Explore challenges of advocacy
6. Learn how to do monitoring and evaluation for advocacy work
7. Discuss examples of stillbirth advocacy activities

INFORMATION BRIEF: PREPARING TO ADVOCATE

- It is helpful to think about the advocacy process as a series of steps that you can learn. Most of those steps relate to preparation! Before you even begin to “advocate,” you will want to have determined your goal, thought about how you will proceed, and developed a plan.
- **In order to make your advocacy efforts effective, you need to:**
 - › Identify the problem or issue you are trying to address
 - › Break down the problem
 - › Educate yourself
 - › Identify your rights/preferences/entitlements or societal expectations related to the problem
 - › Develop a solution (goal) and strategy to address your challenge
- Goal setting can be different if you are doing self-advocacy. Oftentimes, this type of advocacy strategy is spontaneous, for instance if you would like to address a challenge right away. You may not formally set a goal, but still have an agenda in mind. However, regardless of the type of advocacy you are doing, it’s critical to clarify what you would like to achieve.
- We’ve explored the definition, aims, and types of advocacy, some key skills you need, and the importance of advocacy for stillbirth prevention and respectful bereavement care.
- It is important to choose an advocacy strategy that works for you, whether self-advocacy or group advocacy. Your choice will depend on the issue that needs to be changed, availability of resources to support your strategy, and your personality style. It’s key to note that both self and group advocacy strategies can be implemented either formally or informally. These two types of advocacy strategies have different ways of execution, but either is a valid approach.

INFORMATION BRIEF: PSYCHOLOGICAL PREPARATION FOR ADVOCACY WORK

- Apart from the practical steps of preparation for doing advocacy, it’s also important to check in with your emotional self. Advocacy in any form can open up unhealed emotional wounds connected to your stillbirth experience. That’s why it’s equally essential to explore whether you are psychologically ready to pursue any form of advocacy strategy.
- It’s easy to interpret challenges or roadblocks to stillbirth support through the lens of our personal experiences. However, sometimes, what went wrong for you, might have been right for someone else.
- For example, one bereaved mother might have received the best care at Facility X, while a fellow bereaved mother might have received the worst experience at that same facility.
- The differing experiences of these two bereaved mothers shows that training in respectful bereavement care should be provided for all healthcare professionals, and the mother who had received poor care could decide to advocate for this type of training.
- However, she might say to herself, *“I felt so angry because a certain mom praised her doctor for being so supportive during her stillbirth experience.”*
- A helpful question for that mother to ask herself in this context would be, *“Am I reacting angrily towards that doctor, or towards my past hospital experience where I was treated indifferently?”*
- This mother might then reflect, *“The most probable response would be that I’m reacting towards my hospital experience. This means there is unresolved anger. It would be great to work on my feelings of anger and grief **before** engaging in any advocacy work.”*



Photo Credit: <https://stillamum.com/rainbowshower-2/#>

Key emotional check-in prompts include:

- Have I adequately processed my grief, anger and trauma? Adequately processed grief means experiencing fewer grief symptoms such as irritability, low mood, crying spells, worry and extreme sadness. This could be achieved through personal self-healing strategies, or professional or peer support.
- What's my main motivation for this work?
- How would it make me feel if my strategy were met by rejection, hostility or arrogance?
- How will I appreciate myself when I'm able to achieve any goal in my advocacy strategy?
- What can I tell myself when I'm overwhelmed and feeling inadequate with my advocacy work?
- What can I do to cope in a healthy way during the bad days? This can mean talking to a support system, writing about my emotions, resting or praying. It will be helpful to use coping strategies that work for you.

CHECKLIST: STEPS FOR SELF-ADVOCACY STRATEGIES

Step	To consider	Case study for discussion
1. What is the problem or issue?	Before starting to advocate in whatever capacity, it's important to critically explore all the issues. The problems might be many, but choose to focus on one.	A bereaved mom, Lily, has been denied two extra weeks for her recovery post-stillbirth at her workplace. The Human Resources Manager mentions she doesn't want to give anyone special treatment and the leave previously given should have been enough. Lily feels frustrated because her doctor is out of town yet she would have requested a letter indicating her current state to allow her get more days for recovery. What are the key issues in this case that need to be addressed?
2. What is your goal?	After identifying the problem, set a goal for your preferred outcome.	Is your goal to create awareness of the need for better support for bereaved parents in the workplace? Or to partner with relevant agencies in order to petition for the amendment of the current Employment Act to include bereavement leave? Or simply to get the extra days of leave from your Human Resources manager?
3. What facts do you know?	Identifying the facts means recollecting what you know about the situation and outlining the events that happened with objectivity.	From the above example of Lily's experience, what are the facts of her story?
4. What additional facts or information might you need regarding this situation, such as rights, laws, rules or policies?	It's important to have your facts supported by rights, policies or laws. You can research additional facts through reaching out to key persons such as advocates, agencies in charge of patients' welfare, or advocacy groups. The internet can also provide a wealth of information to support your facts. However, you need to be careful about the sites that you use.	Is it possible for Lily to explore the organizational policies and procedures on getting extra leave days? Can Lily inquire from the worker's union to get more information on how to go about her advocacy work?
5. How can you go about gathering this information?	Gathering information means contacting the right person to help you gain more facts, for instance advocates, or advocacy/peer groups. A fellow bereaved parent can also empower you with more information to help you address the issue. This means reaching out to peer support groups which can be found online to find fellow bereaved parents.	Who are the ideal people for Lily to engage with in order to gain more information on bereavement leave?

CHECKLIST: STEPS FOR SELF-ADVOCACY STRATEGIES

Step	To consider	Case study for discussion
6. Who are the decision-makers you need to influence to solve this problem/issue?	These are individuals whom you can approach to address the issue i.e. healthcare administrators, media, religious leaders, chief or village elders, Human Resources staff, etc.	Who will be the best person for Lily to approach in solving the bereavement leave issue? Does it depend on her advocacy goal?
7. What are some possible solutions to this problem/issue?	Be specific about solutions! Knowing your rights or preferences will help you to identify possible solutions. Ask yourself, What do I really want?	In Lily's case, what would be the best solution if her goal is to get more days off from work?
8. What are some barriers to these solutions?	It will be helpful to consider what challenges are bound to develop as you pursue this advocacy strategy. For example, your concern might be dismissed or it might take resources such as money and time that are unavailable. It might be frustrating trying to educate someone on better support mechanisms for the bereaved. You might need to explore those probable barriers.	What are the possible barriers to Lily's advocacy efforts?

The above content is adapted from *Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version)*, p. 18.

CHECKLIST: STEPS FOR GROUP ADVOCACY STRATEGIES

Step	To consider	To discuss with your advocacy group
Choose a reasonable goal and specific actions for an advocacy initiative	<ul style="list-style-type: none"> ■ An advocacy initiative aims to facilitate change, including overcoming challenges that may stand in the way of that change. The advocacy goal is a broad statement of what you are trying to do. ■ The specific actions include the activities of how to accomplish this goal. 	What goal and actions could you develop to address stigma and shame around stillbirths in your community?
Carry out stakeholder and power analysis	<ul style="list-style-type: none"> ■ As you seek to address the societal challenges faced by bereaved parents, it's equally important to understand the power structure or systems so as to identify the best person/leader/department or sector to engage. This may be different depending on what you are trying to change. ■ The support of influential people such as religious leaders, healthcare leaders or the media can propel your agenda and ultimately in time help you get noticed by the key people who can make that change happen. ■ Strategic advocacy work will help to protect you from frustrations and disappointments; for instance, it can help you to understand that even though some leaders do not have the power to make the changes that you desire, they can still support your cause. ■ See the Guidelines below for more information on how to conduct this analysis. 	<p>A mom who has just experienced stillbirth asks for maternity pads at the maternal ward but unfortunately the hospital doesn't have such amenities. As a fellow bereaved parent seeking to help this mom, who would be the right person for you to reach out to in order to express your concern at the hospital?</p> <p>As a stillbirth advocacy group, you realize that most hospitals in your local area do not have a referral system where bereaved parents are linked to psychological counselors for professional support. Who are the ideal persons or organizations for you to reach out to as you seek to advocate for structured referral systems for families bereaved by stillbirths?</p>
Identify the people and organizations whose ideas and policies will need to change so that your initiative will succeed (targets)	<ul style="list-style-type: none"> ■ The objectives of your advocacy work will help you identify influential people or targets. ■ In identifying the target of your initiative, it's important to ask, who has the power to make change happen? Your stakeholder power analysis can help here. 	<p>Identifying your targets also requires understanding:</p> <ul style="list-style-type: none"> ■ Who has high influence or power? ■ Who is supportive of your objectives? ■ Who is opposed to your objectives? ■ Who has less power or influence?

CHECKLIST: STEPS FOR GROUP ADVOCACY STRATEGIES

Step	To consider	To discuss with your advocacy group
Identify people who can help you with your initiative (allies)	<ul style="list-style-type: none"> Allies are people or groups of people who have the same or overlapping interests as you, or the capacity or resources to help you. Allies are essential because you can accomplish much more if there are people who believe in your cause, who are supporting you. Allies can include groups working towards supporting and advocating for bereaved families in maternal health such as Still A Mum, Empower Mama or the Tears Foundation, or other organizations working on respectful maternity care such as Zuri Nzilani Foundation, women's rights, access to healthcare, and women's empowerment. It's great when these collaborations work, but it can be disempowering when your stillbirth experience is dismissed with the belief that you might not contribute much in maternal health settings. 	<p>Identifying your allies and ways to engage them means understanding:</p> <ul style="list-style-type: none"> Who is doing something about the issue in the community already? What are they doing? How is it going? Which strategies did they find effective? Is there some way you could work with them to achieve common goals? Who else do we know who might be interested in our issue, even though they may not be acting on it now?
Identify organizations and people who might be opposed to what you are trying to do	<ul style="list-style-type: none"> As you identify your allies (organizations/individuals who can help you in your initiative), it's equally important to identify organizations/individuals that might oppose your goals. There are opponents to just about every issue. If you stand for one thing, someone may challenge you and stand for something else. The first step in determining who your opponents might be is to again ask yourself "Who cares about your issue?" In this case, the best answer to your question is: "Anyone who might lose something from your success." It will help to create a list of opponents, including all the people, groups of people, and organizations that may have something to lose, directly or indirectly, if you succeed. They will be the ones actively trying to stop you from winning. However, in some cases they may seem to be allies and it is hard to understand how they could be in opposition. For example, sometimes people working on reproductive rights in the USA are not supportive of some stillbirth advocacy, because they think there is a conflict with abortion rights. 	<p>As you seek to advocate for bereavement leave in the workplace for moms and dads who have experienced stillbirths, who are the probable opponents to this strategy? What could you do to address this?</p>

| The above content is adapted from Nader Tadros, *Advocacy: People's Power & Participation*. People's Advocacy 2010.

GUIDELINES: STAKEHOLDER ANALYSIS

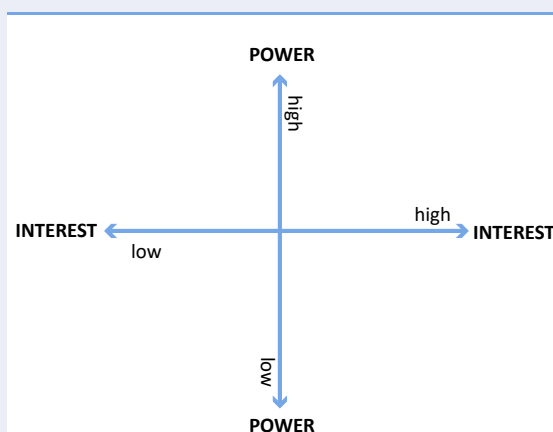
- A stakeholder analysis highlights which institutions and individuals have a stake in an issue, as well as their interests, support or opposition, influence and importance. A stakeholder analysis involves four steps:

Step	To consider
1. Identify the key stakeholders from the large array of groups and individuals that could potentially affect or be affected by your advocacy initiative.	These may include senior government officials, individuals from the Ministry of Health or Finance, non-profit organizations in maternal health and reproductive health, private sector hospital management, etc.
2. Assess stakeholder interests and the potential impact of your advocacy work on these interests.	<ul style="list-style-type: none"> ■ What are each stakeholder's expectations or beliefs in relation to your work in advocating for respectful care for bereaved parents after stillbirth and ending preventable stillbirths? ■ What benefits are likely to result for the stakeholders from this advocacy work, if any? ■ What resources might the stakeholders be able and willing to mobilize for it? ■ What stakeholder interests may conflict with your advocacy goals?
3. Assess the influence and importance of the identified stakeholders. Influence refers to the power that stakeholders might have in creating change in care after stillbirth or ending preventable stillbirths.	<p>Do the stakeholders have formal or informal control over the decision-making process? (Informal control means that their control is only related to facilitating your advocacy initiative.)</p> <p>Stakeholders who are important are often those who are likely to benefit from your advocacy work, or whose objectives converge with the objectives of the advocacy work. It is possible that some stakeholders who are very important might have very little influence, or vice versa.</p>
4. Outline a stakeholder participation strategy. This plan states ways in which the different stakeholders will ideally be involved in different stages of the advocacy planning and implementation.	<p>It will be important to plan the involvement of stakeholders according to:</p> <ul style="list-style-type: none"> ■ The interests, importance, and influence of each stakeholder. ■ The particular effort needed to involve important stakeholders who lack influence. ■ Appropriate forms of participation throughout the advocacy cycle.

| The stakeholder power analysis has been adapted from TASCO, SIPU International. (2011). *Advocacy and Policy Influencing for Social Change*.

GUIDELINES: POWER ANALYSIS

- Another key tool is power analysis, which builds on stakeholder analysis. A power analysis helps in identifying more details about the key decision makers (both institutional and individual) who hold power or influence over the issue you are advocating to change.
- The task is to identify who makes the decisions and who can directly influence these decisions. Remember: Decision-makers can be allies or opponents!
- Examples of possible decision-makers include the Cabinet secretary in charge of the Ministry of Health, a senator, a member of Parliament, staff in hospital management, or the chief of a local area.
- The diagram to the right illustrates the basic concept of power analysis; for instance, a leader may be in a position of influence but have low interest in your advocacy initiative, whilst another leader has limited power but is highly interested in your cause.



INFORMATION BRIEF: HOW TO DEAL WITH OPPOSING VIEWS

- **Prevention technique:** It's very common to experience opposition while pursuing your advocacy strategy, whether using self-advocacy or group advocacy. Planning in advance will help you figure out what to do and how to convince potential opponents to either join or not to actively oppose you.
- **Meeting people/organizations with opposing views:** It would be great to hear their opinions and you may find that the apparent opposition is caused by miscommunication or lack of understanding about the issue.
- **Developing win-win solutions:** Exploring the solutions that would possibly meet both of your shared interests can help in dealing with your opponents.
- **Turning negatives to positives:** If attacked by your opponents, whether in legal cases or confrontations, you can transform the words of the attack into educational and advocacy material to help your community better understand what you are facing, and hopefully to gather their sympathy and support.
- **Act preemptively to build stronger relationships with those who MAY be opponents, so that they end up as allies instead:** For instance, some bereaved parents face cases of stillbirth related to provider negligence, e.g. if providers ignored their concerns during pregnancy or labor such as reduced fetal movement. It is possible that building stronger communication and mutual respect in provider-patient relationships can reduce instances of mothers' concerns being dismissed, ultimately leading to better outcomes for mothers and babies. However, it is also important that parents ought not to blame themselves for the quality of their relationships with their providers.
- **Consider your opponents' position:** Your opponent may in fact also be seeking solutions to the challenges you have identified but due to lack of information, they may have given up or even be opposed to your solutions (perhaps the solutions appear too costly or ineffective to them); if so, your group may be able to join in their effort. For instance, they may be aware of the mental health challenges experienced by parents bereaved by stillbirth but they haven't figured out yet the basic strategies to address this challenge or feel they are not worth the investment. You can educate your opponents and turn them into allies.

Talking about stillbirth advocacy:

- *What are the possible solutions to addressing lack of compassionate care at hospitals?*
- *Through your advocacy activities, what type of opposition have you experienced?*
- *If so, how were you able to manage it?*
- *What are the other possible strategies of dealing with opposition?*

FACT SHEET:

SOME CHALLENGES OF ADVOCACY

Self-advocacy	Group advocacy
1. Lack of support- it can get lonely and overwhelming as you advocate for yourself.	1. Lack of dedicated resources, time, and funding.
2. Inadequate resources to finance your advocacy activities.	2. Challenges in relationship building with policy makers, influencers and key community leaders.
3. Facing resistance from the targets, possible dismissal of the issue.	3. Needing enhanced capacity to understand how the system works i.e. healthcare leadership.
4. Inadequate or lack of training/knowledge in advocacy skills and dealing with opposition.	4. Limited credibility and recognition from policy makers & community leaders, especially if your organization is not registered.
5. Lack of self-determination and leadership development. You may question your advocacy efforts or find yourself seeking the approval of others, instead of focusing on your goals and what that advocacy initiative would mean to you.	5. Need for persistence and a focus on monitoring change- it's easy to be discouraged, but advocacy calls for resilience and continuously pushing your agenda as you seek change.
6. Lack of opportunities to take risks and make decisions.	6. Need for innovation- continuous evaluation of advocacy activities is required; new approaches need to be implemented to ensure success.

- **Overcoming these challenges and moving forward with your advocacy work requires core advocacy skills, including:**
 - Strategic thinking skills, to help you to identify your goals, ideal allies and targets that you can work with as you address the challenges in your community/society.
 - Persuasion skills, to help get others to support your position. This is especially true if you will have an ongoing and hopefully collaborative and constructive relationship with allies.
 - Communication skills, including being respectful and confident in spoken and written language.
 - Patience, since advocacy work is a process that can take a long time.
 - Resilience, to help you in navigating challenges.
 - Collaborative skills, to ensure effective interpersonal and team work.

INFORMATION BRIEF: HOW TO DO MONITORING & EVALUATION FOR ADVOCACY WORK

- As you start advocating for your rights or preferences either individually or within a group, it is essential to assess the impact of your advocacy activity.
- For example, you might have proposed to engage with a local hospital through creating a peer support group for bereaved parents. Your goal is probably to offer peer support and help parents get professional support if the need arises. As you go about implementing your advocacy activities, it would be helpful to assess their impact.
- For instance, you could collect feedback from the peer support group members and explore whether they feel supported. This would help you identify areas you need to improve on or decide whether to outsource further support, if possible.
- You should bear in mind that you might not achieve all your intentions through one cycle of advocacy work; this is totally understandable. Small advocacy efforts will ultimately produce bigger results in time.
- **Assessing your progress can include:**
 - Keeping records of meetings attended or conversations with friends/family/colleagues/community leaders or healthcare professionals.
 - Following through on conversations about stillbirth in the healthcare system, or with community leaders, research organizations, policy leaders or the media.
- **It would be helpful to evaluate your impact through asking questions such as:**
 - Have I achieved my goals or intentions?
 - How many meetings have I had with targets: an employer, a friend, a doctor or community leader?
 - What were the outcomes of those meetings?
 - What actions were taken by these targets: an employer, a friend, a doctor or community leader?
 - Is the situation better than before? In what ways?
 - If there is no change, how might I change my advocacy methods?

INFORMATION BRIEF: EXAMPLES OF POSSIBLE STILLBIRTH ADVOCACY ACTIVITIES

Hospital – Hospital Administration	Place of Work	Home/ Neighborhood/ Religious Group/ Local Area
1. Advocate for training of health care professionals in respectful bereavement care and basic psychosocial support skills to address poor communication, insensitivity and stigma.	1. Advocate for inclusion of friendly human resource policies such as bereavement leave for employees experiencing perinatal loss.	1. Partner with local media stations in creating awareness on pregnancy and infant loss and sharing on ways of offering quality support. Write blogs, articles or journals addressing the shame and stigma.
2. Advocate for referral options for mental health support i.e., employment of a resident counselor or referrals to a counselor after loss.	2. Partner with parent support organizations in advocating for the amendment of Employment Rights laws and policies to include bereavement leave for parents dealing with miscarriage and stillbirth.	2. Partner with parent support organizations in creating campaigns to raise awareness on perinatal loss to address the stigma and shame.
3. Suggest to the hospital administration to fund, or raise funds for, the allocation of a private room in the maternity ward for bereaved mums.	3. Partner with mental health professionals in training the Human Resource Department in basic psychosocial support skills to empower them on how best to support a grieving employee.	3. Create peer support groups for bereaved families to empower each other on grief support and to learn how to speak for themselves and on behalf of others.
4. Prepare brochures with basic information on coping with perinatal grief and share with the hospital, to be placed at the maternity ward.	4. Advocate for mental health wellness programs at work such as resident counselors or seminars to empower the team on basic psychosocial skills.	4. Engage the local hospital in organizing public meetings to raise awareness on pregnancy and infant loss and empower the community in supporting the bereaved.
5. Partner with hospitals' health education department in preparing seminars for expectant parents to learn the basics of healthy pregnancies and danger signs.		5. Partner with local government and hospitals in advocating for quality healthcare such as periodic trainings for midwives, raising funds to build a NICU unit or a theatre in the local hospital, or including key amenities, i.e. maternity sanitary towels.
6. Advocate for the inclusion of parent support organizations in health administration meetings on matters related to maternal and child health.		6. Organize pregnancy and infant health workshops in partnership with hospitals to train the community on healthy pregnancy, both physically and psychologically.
7. Advocate to the hospital administration for the initiation of debriefing sessions at the facility level for healthcare professionals' mental wellbeing.		7. Partner with parent support organizations and hospitals in advocating to the county government for more healthcare professionals to be stationed at maternity wards/reproductive units to encourage quality healthcare.
8. Start and encourage peer bereavement support groups at the hospital or other locations.		8. Organize memorial events for bereaved parents and their families, i.e. tree planting, candle lighting.
9. Visit bereaved families at the hospital to offer support.		9. Support a bereaved parent during the funeral ceremony for their baby.

Talking about stillbirth advocacy:

- *Think about a specific advocacy strategy you might like to try. What are the obstacles you could encounter?*
- *How long might this take?*
- *Who might you need to partner with?*
- *What information would you need to know?*
- *How would you know you have 'succeeded'?*

GUIDELINES: WHAT TO SAY AND WHAT NOT TO SAY

What to say to bereaved parents:

- Use simple and straightforward language
- Be comfortable sharing emotions
- Listen to the parents
- You can say:
 - "I'm sorry"
 - "I wish things could have ended differently"
 - "I wish this pregnancy turned out as you had hoped"
 - "This must be hard for you"
 - "I am sad for you"
 - "I'm here; I want to listen"

What not to say to bereaved parents:

- "It was God's will"
- "I know just how you feel"
- "Now you have an angel in heaven"
- "At least you have other children"
- "Be strong"
- "It was not meant to be" (or any mention of fate)
- "At least you know you can get pregnant"
- "It was just a cluster of cells"
- "At least it was nice and early"
- "Everything happens for a reason"

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Resources	Description and link
1. Wisconsin Coalition for Advocacy, "Advocacy Tool Kit - Skills for Effective Self and Peer Advocacy" (2005).	This material defines self-advocacy and group (peer) advocacy and explains the steps of implementing the two strategies.
2. VeneKlasen, Lisa; and Miller, Valerie, 2002. A New Weave of People, Power and Politics: The Action Guide for Advocacy and Citizen Participation, Chapter 3. World Neighbors, Oklahoma, USA. Nader Tadros, 2010. Advocacy: People's Power & Participation. People's Advocacy, Virginia, USA.	These documents provides the steps of identifying an advocacy strategy and explains the ways of implementing group and systemic advocacy strategies.
3. Altman, D., Balcazar, F., Fawcett, S., Seekins, T., & Young, J. (1994). Public health advocacy: Creating community change to improve health. Palo Alto, CA: Stanford Center for Research in Disease Prevention.	This book is useful to both seasoned advocates and newcomers as it provides ways of formulating goals and strategies for community health advocates and professionals who are thinking of working with grassroots efforts.
4. Kretzmann, J., & McKnight, J. (1993). Building communities from the inside out: A path toward finding and mobilizing a community's assets. ACTA publications.	This paper provides links to case studies of successful community-building initiatives across the U.S. In addition to this, it outlines how a community can move toward asset-based development.
5. Sen, R. (2003). Stir it up: Lessons in community organizing and advocacy. Jossey-Bass; 1st Edition.	In this document , Sen's works have been highlighted as he goes step-by-step through the process of building and mobilizing a community and implementing key strategies to effect social change. Using case studies to illustrate advocacy practices, Sen provides tools to help groups tailor his model for their own organizational needs.
6. WHO Guide for Effective Programs: Module 6: Policy and Advocacy.	This article highlights the steps of monitoring and evaluation in advocacy work.
7. The Advocacy Initiative Legacy	This website explores the challenges faced by community and voluntary organizations in carrying out their advocacy work.

MODULE 6:

Coping with advocacy-related stress



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

1. Define self-care
2. Learn ways of practicing self-care as part of stillbirth advocacy
3. Understand ways of coping with advocacy-related stress

INFORMATION BRIEF: WHAT IS SELF-CARE?

- Self-care is a method of promoting one's ability to cope with stress and involves regular engagement in wellness-oriented activities.
- Self-care relies on resources that individuals can draw on to actively engage in coping.
- Personal self-care includes daily routines, such as exercise, meditation, engaging in leisure activities, and therapy as well as occasional activities, such as vacation.
- **Types of self-care activities include but are not limited to:**
 - **Social skills and social support:** Having the ability to communicate effectively to draw on social support resources, and having relationships with others who can serve as resources.
 - **Positive beliefs:** These refer to positivity, such as hope or an internal locus of control, as a self-care strategy. They include problem-solving skills, meaning the ability to evaluate a decision-making situation, weigh various options, and make a decision to follow through. In essence, problem-solving skills involve action-orientation as a method of self-care.
 - **Health and energy:** Being healthier and having more energy are resources for coping under stress. Examples include exercising, eating healthy foods, drinking enough water, meditation or hiking.

CHECKLIST: PRACTICING SELF-CARE AS PART OF STILLBIRTH ADVOCACY

- **Express your inner distress**
 - As you advocate on behalf of yourself and others, you may find yourself repressing your pain and frustrations. Repressing your frustrations will only worsen them.
 - When in doubt, please check in with yourself or someone else.
 - Ask yourself questions such as: 'What does this feeling indicate and where do I need support?'
 - If you feel you're on the brink of burnout, externalize that concern:
 - ❑ write it in your journal (if you keep one),
 - ❑ share it with a close confidant,
 - ❑ even say the words out loud to yourself.
 - Giving yourself the space to vent and engage in catharsis—however self-indulgent it may feel—will distance you from your challenges and grant you a stable perspective from which to analyze them.
- **Disentangle your sense of self from your advocacy work from time to time**
 - Reframe advocacy work as part of your character rather than as an all-consuming lifestyle.
 - It's easy to anchor your self-worth in how successful your advocacy work is, but try to disengage from time to time. It's not easy but totally worth it for your mental wellness. It's important to re-evaluate time spent at work, at home, for self and for advocacy.
- **Integrate self-care blocks into your schedule**
 - As a mom or dad, it is probably very challenging to make time for yourself. Often we feel guilty when we are creating time to rest. The act of blocking out an hour, half an hour, or even five minutes to practice self-care proves to yourself that you are indeed a priority.
 - Remember you can never give from an empty cup; self-care is a complete necessity, not a luxury.
- **Work incrementally, and celebrate the small victories**
 - It is easy to feel discouraged when our advocacy efforts are dismissed or when we feel we are not making much progress. Not every form of discrimination can be solved in one day; the fruits of our labor can take time to be enjoyed.
 - Establish small, achievable goals and rewards, and celebrate these victories.
 - Try listing three successes per week (however minor), and use these moments as fuel for motivation.
- **Look after your emotional health**
 - Looking after your emotional health is the practice of taking care of your mind with the same diligence with which you take care of your body.
 - As an advocate, you might believe your own emotions come second to those you're helping, and this sense of obligation can negatively affect your inner wellbeing.
- **Listen to your body**
 - Mental or emotional stress usually manifests itself physically. To resist exhaustion, you can learn to recognize the physical signs of stress and heed them.
 - ❑ Are your muscles stiff?
 - ❑ Is your skin breaking out?
 - ❑ Are you constantly exhausted?
 - Ask yourself these questions on a regular basis, and get into the habit of observing the messages your body is sending you. Your biological instincts are designed to protect you; listen to them.

CHECKLIST: PRACTICING SELF-CARE AS PART OF STILLBIRTH ADVOCACY (CONT..)

- **Reconnect with your support network and lean on your loved ones**
 - Chances are that the more isolated you feel, the more likely it is you believe there's no light at the end of the tunnel.
 - Wherever possible, plug back into your network of peers, friends, family, and loved ones for the emotional recharging you need.
 - Sometimes you might feel alone and lack a support network; you can consider seeing a therapist or spiritual leader to give you the necessary support.

Talking about stillbirth advocacy:

- *How do you deal with stress? Have you experienced stress while doing any kind of stillbirth advocacy? What was that like?*
- *What works for you in relieving the stress?*
- *What does not work for you?*

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Resource	Description and link
1. From a "culture of unwellness" to sustainable advocacy: Organizational responses to mental health risks in the human rights field.	This article presents findings from a qualitative study of how individual human rights advocates perceive well-being and mental health issues within the human rights field.
2. Sarah Knuckey, Margaret Satterthwaite, & Adam Brown, Trauma, Depression, and Burnout in the Human Rights Field: Identifying Barriers to Resilient Advocacy, 49 COLUM. HUM. RTS. L. REV. 267, 269 (2018).	This article is part of an effort to document the mental health of human rights advocates, who, in the pursuit of the rights of others, may neglect their own wellbeing.

ANNEX:

WHAT PARENTS SAID ABOUT THE PARENT VOICES INITIATIVE WORKSHOPS IN KENYA

Rahab Sego (bereaved mom)

'The two workshops that I've attended have been very educative. They have enabled me to understand the value of advocacy. Finally, you can learn to advocate for yourself through understanding advocacy skills as a way of expressing your wants and needs in a way that help others understand your position.'

Christine Wangeci (bereaved mom)

'The workshops equipped me greatly for advocacy work. I have been following up with two mums from the support group, who had cases of preeclampsia and one is now 30 weeks pregnant and healthy, and the other mum, we are continuing to trust God for the fruit of the womb. The Parents Voices Initiative workshop has enlightened and equipped me adequately on the tools of advocacy that has made my advocacy activity more targeted.'

Grace Nyambura (bereaved mom)

'The Parents Voices Initiative workshops has really changed my advocacy work. As a result of the training, I have been able to visit bereaved parents. I have listened to them, encouraged them and educated them on their rights. This has been a very fulfilling experience. The workshop has equipped me with every skill that I needed to advocate more. I have learnt a lot from it and am very ready to do even more.'

David Wanjala (bereaved dad)

'The two workshops provided more tools for me as I realized what I was doing was actually advocacy. They have helped me learn the different types of advocacy that we have, what really advocacy is and how to do it. There were two favourite parts that I enjoyed the most:

- 1. Self-care. Most of us as care givers we end up suffering compassion fatigue since we ignore our bodies as we give this care. We learnt that it was important to switch off sometimes.*
- 2. What I do from time to time was validated as advocacy. Whether major changes come or micro ones as a result of my work, I will still find satisfaction in that my purpose as a caregiver and an advocate of child loss is not in vain. Finally, it was also good to see my tribe of child loss advocates again though virtually.'*

ANNEX:

ORGANIZATIONS THAT CAN PROVIDE SUPPORT AFTER STILLBIRTH IN KENYA

- [Empower Mama](#) is an organization that raises awareness on the impact of child loss on families and society at large and advocates for the need for effective and compassionate bereavement support to grieving parents through awareness raising.
- [The Tears Foundation](#) center for child loss aims to serve bereaved families in Nairobi.
- [Zuri Nzilani Foundation](#) is a Nairobi-based non-governmental organization dedicated to creating awareness on preeclampsia, premature births and infant loss in Kenya.
- [Amani Counselling Center](#) is an independent not-for-profit voluntary organization that provides counselling services to people with emotional and psychological needs and offers training for professional counsellors as well as equipping those in helping professions with counselling skills. The organization has branches in Mombasa, Nyeri and Kisumu.
- [Niskize](#) runs support groups and individual programs to provide professional counseling services for topics that include but are not limited to loss and grief, marriage and relationships, trauma, anxiety and depression in Kenya.
- [Befrienders Kenya](#) is a charitable organization focusing on suicide prevention by offering free emotional support to those who may be in distress and therefore in danger of dying by suicide as well as creating awareness on suicide within communities in Kenya.

ACKNOWLEDGEMENTS

This Toolkit has benefited from the collective expertise and ideas of many individuals. In particular, we would like to thank the following individuals for their thoughtful contributions:

- **Diana Chepkosgei**, local consultant for the Parents Voices Initiative Kenya; program manager & psychologist, Still A Mum, Nairobi, Kenya
- **Wanjiru Kihusa**, founder & CEO, Still A Mum, Nairobi, Kenya
- **Rahab Kabiru**, co-founder, Still A Mum, Nairobi, Kenya
- **Arthur Tendwa**, creative director and illustrator for this Toolkit
- **Ben Mukoma**, IT Assistant for the Parents Voices Initiative virtual workshops
- **Bereaved parents:**
 - › **David Wanjala**, bereaved father
 - › **Rahab Sego**, bereaved mother
 - › **Christine Wangeci**, bereaved mother
 - › **Grace Nyambura**, bereaved mother
- **Claire Storey**, senior technical advisor, Parents Voices Initiative
- **Co-managers of the Parent Voices Initiative:**
 - › **Susannah Hopkins Leisher**, chair, International Stillbirth Alliance and co-chair, Stillbirth Advocacy Working Group
 - › **Hannah Blencowe**, faculty of the Centre for Maternal Adolescent and Child Health at the London School of Hygiene and Tropical Medicine (LSHTM) and co-chair, Stillbirth Advocacy Working Group
- **Members of the Parent Voices Initiative Advisory Group:**
 - › Dr Neelam Aggarwal
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 - › Dr Alexander Heazell
 - › Mary Kinney
 - › Dr Sam Murphy
 - › Sara Nam
 - › Dr Paula Quigley
 - › Sue Steen
 - › Dr Linda Vanatoo



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