A Right to Care

How hospital policies delay and deny critical treatment for pregnant patients



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Written by:

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Introduction

Alison survived but she is horrified that the hospital put her life and health at risk for no medical reason. Alison learned she needed surgery to end her much-wanted pregnancy while overcome with pain in a **Bellingham** hospital bed. The news was devastating and urgent. This was Alison's fourth visit to the emergency room in less than a week with heavy bleeding. She was septic, her fever was not responding to medication and the pain in her abdomen was excruciating.

Her doctor was clear. Alison's placenta had not attached properly to her uterus and she was battling a dangerous infection. There was no hope for the fetus and without surgery Alison could die.

But the life-saving next step Alison's doctor recommended would have to wait. The hospital where Alison sought care—the one closest to her home—does not allow pregnancy terminations except in very limited circumstances.

This meant Alison's doctor could not use his medical judgment to treat his patient. Instead, as Alison's doctor explained to her, a hospital ethics committee would first need to be consulted, and the committee would decide whether Alison's surgery should be approved. If the committee did not approve Alison's procedure, she would have to travel for hours to get to another hospital. While Alison waited for the committee, she had a spontaneous miscarriage in the bathroom. She survived but she is horrified that the hospital put her life and health at risk for no medical reason. Alison never wants another person to face the same life-threatening delay in care.¹

Across Washington state many hospitals are violating medical standards by denying or delaying necessary care to pregnant patients who are miscarrying or experiencing an ectopic pregnancy. These patients' health and lives are being put at risk.

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¹ Some of the details in Alison's story were also featured in an <u>article</u> published on September 25. 2019 by Rewire.News.

We know this is true because patients and doctors have shared their stories. This report includes the voices and experiences of health care providers and pregnant patients whose medically necessary care was either delayed or denied outright when they sought treatment at hospitals where institutional policies too often take precedence over medical standards.

Pregnant patients described rushing in pain to the closest hospital, where policies and restrictions diverted decisions about their treatment from doctors and nurses to administrators or ethics committees. While patients like Alison waited, their conditions sometimes worsened, resulting in prolonged recoveries and more invasive procedures. Others faced long car rides, putting their health at further risk, to find hospitals where they could finally receive medically necessary care.

We also heard from a doctor at a hospital who was reprimanded for providing essential health care to a patient who was miscarrying. And we heard from many physicians who treat these very sick pregnant patients after they are denied care at other hospitals.

Nationally, hospitals receive billions of dollars in taxpayer money. These same hospitals should not be permitted to turn away pregnant patients seeking medically necessary care for miscarriages and ectopic pregnancies, to discriminate against women by refusing to provide critical reproductive health services, or to interfere with a doctor or nurse's ability to make medical decisions in the best interests of their patients.

Access to timely, evidence-based medical care is always important, but it is even more critical during the COVID-19 pandemic. Forcing patients to visit multiple providers and institutions without medical reason increases the risk of exposure to the virus for patients and practitioners. In addition, hospital policies that delay or deny care penalize patients who cannot afford to take time off work to attend multiple appointments or to search for treatment at another hospital.

This report highlights the harm and discrimination occurring across Washington state when hospital policies get between doctors and their patients. These policies prevent doctors from providing the evidenced-based care patients need. Our laws must change to ensure that patients like Alison receive medically necessary care regardless of where they seek treatment.² ■

Fact: Many pregnant patients in Washington, especially those living in rural areas, cannot just "go to another hospital."

² This report focuses on delays and denials of care for cisgender women experiencing miscarriages and ectopic pregnancies, but men who are transgender, and gender non-conforming patients who do not identify as women, often face additional obstacles and discrimination when seeking reproductive care. This report builds on the findings in <u>Health Care Denied</u>, an investigation into reproductive health services published in 2016 by the national office of the ACLU.

Miscarriages: Deliberations, delays and denials

When Dr. Laura Sienas received a call from a doctor about a pregnant woman at a hospital in **Bellingham** whose water broke at 16 weeks, the patient needed immediate treatment to clear her uterus of bacteria and infected tissue. An unchecked infection could threaten the patient's life and her ability to have children in the future.

As a maternal fetal medicine physician, Dr. Sienas is often asked by providers around the state to consult on high-risk pregnancies. In this case, due to hospital policy, the doctors at the Bellingham hospital were not allowed to immediately provide the evidence-based care the patient needed. The hospital's policy prohibits providers from performing procedures that end a pregnancy except in very limited circumstances. While hospital administrators deliberated over policy, the patient's infection worsened. After hours of back and forth, the hospital decided to refuse treatment for the patient and instead transferred her to a Seattle hospital. After her delivery, the patient needed a long course of antibiotics to recover from the severe infection she developed while waiting for treatment.

Unfortunately, says Dr. Sienas, the Bellingham patient's case is not uncommon. She frequently hears from doctors who work in hospitals where institutional policies require them to delay or deny care for their patients.

Fact: Pregnancy terminations are sometimes necessary for the health and lives of pregnant patients.

The American College of Obstetricians and Gynecologists (ACOG), is clear that "[t]here are situations where pregnancy termination in the form of an abortion is the only medical intervention that can preserve a patient's health or save their life."³ These types of pregnancy complications include "placental abruption, bleeding from placenta previa, preeclampsia or eclampsia, and cardiac or renal conditions."⁴

Dr. Sienas treated another patient—this time a mother of two from **Spokane**—whose water broke at 18 weeks during her third pregnancy. Her OB-GYN explained that with the protective barrier of amniotic fluid no longer intact, she was at high risk of developing a dangerous infection and her much-desired pregnancy could not continue to full-term. If she waited for her body to complete

While hospital administrators deliberated over policy, the patient's infection worsened.

^{3 &}quot;Abortion Can Be Medically Necessary," The American College of Obstetricians and Gynecologists and Physicians for Reproductive Health press release, September 25, 2019, https://www.acog.org/news/news-releases/2019/09/abortion-can-be-medically-necessary.

^{4 &}quot;Facts are Important: Abortion is Healthcare," The American College of Obstetricians and Gynecologists, last accessed January 5, 2021, <u>https://www.acog.org/advocacy/</u><u>facts-are-important/abortion-is-healthcare.</u>

FACT: PREGNANCY TERMINATIONS ARE SOMETIMES NECESSARY FOR THE HEALTH AND LIVES OF PREGNANT PATIENTS.

OTO CREDIT: S_L ON SHUTTERSTOCK

the miscarriage on its own, the patient could suffer life-threatening complications.

If she waited for her body to complete the miscarriage on its own, the patient could suffer life-threatening complications. The patient needed to receive medications to induce labor, but that evidence-based care was not available close to home. Her doctor told her that none of the hospitals in the area would treat a pregnant patient while a fetal heartbeat could be detected. Knowing that waiting could result in significant harm to her health, the patient and her husband traveled overnight with their children to a Seattle hospital for treatment.

At this point, without a hospital nearby to provide the care indicated by medical standards, the patient had no good options, Dr. Sienas says. Driving across the state significantly increased the patient's risk of complications, disrupted her family and resulted in a stressful and heartbreaking conclusion to a muchwanted pregnancy.

Fact: Many pregnant patients in Washington, especially those living in rural areas, cannot just "go to another hospital."

Many Washington residents have only one hospital near their home. Miscarrying patients in Washington have had to travel for hours to reach a hospital that would treat them. Delays in care, such as requiring a miscarrying patient to find another hospital, can pose significant risks to the health and life of the pregnant patient.

Dr. Annie Iriye's patient arrived five months pregnant in active labor at a hospital in **Olympia**. Her amniotic sac had already broken, which meant the patient's much-wanted pregnancy could not continue to full term. The patient faced one of the most difficult moments imaginable. She would have to deliver knowing the fetus had no chance of survival. When the patient's labor stalled, Dr. Iriye ordered Pitocin, a common drug used to speed up contractions.

As an experienced OB-GYN, Dr. Iriye knew the longer her patient remained in labor, the greater chance she could develop an infection. The patient agreed to the Pitocin but the nursing staff balked at the doctor's order. They told Dr. Iriye that it was against hospital policy to administer the drug while a fetal heartbeat could still be detected. By the time Dr. Iriye convinced the head nurse to proceed, the patient had developed a fever and she needed intravenous antibiotics after the delivery. Hospital administrators later reprimanded Dr. Iriye, who says she understands why the nurses reported her. She broke the rules. But she believes the rules must reflect evidence-based standards of care to ensure that patients receive the treatment they need. Hospital policies that are not guided by medical standards of care force doctors to make choices that put their patients at risk. "Health care decisions need to be made between patients and their providers," says Dr. Iriye. "Otherwise, as a clinician, you are not allowed to do the job you do best." **•**

FACT: PREGNANCY COMES WITH RISKS AND CAN RESULT IN **SERIOUS** ILLNESS OR DEATH.



"Health care decisions need to be made between patients and their providers," says Dr. Iriye. "Otherwise, as a clinician, you are not allowed to do the job you do best." In 2004, Meghan was about seven weeks pregnant when she experienced heavy vaginal bleeding. She rushed to a hospital in **Everett**, where she worked as a labor and delivery nurse and insurance covered her care. Meghan knew the hospital had strict policies that severely limited access to miscarriage care, but it was the only nearby hospital that her insurance coverage extended to, and she could not afford thousands of dollars in out-of-network costs to go elsewhere.

Once admitted, Meghan's doctor explained that she was having a miscarriage. Her pregnancy was no longer viable, and she needed a procedure to remove the remaining tissue in her uterus — the only way to stop the bleeding. But because the hospital's policy did not allow providers to terminate a pregnancy if the fetus still has cardiac activity, Meghan did not immediately receive her medically necessary care.

Instead, hospital staff delayed providing Meghan's needed care for hours, during which she endured repeated ultrasounds in search of a fetal heartbeat. The heartbreaking and futile checks ended almost seven hours later when she finally received a procedure to remove the remaining pregnancy tissue from her uterus. By then, Meghan had lost so much blood and her iron levels were so low that she needed a blood transfusion.

Only years later did she learn that the delay in care she experienced would complicate another pregnancy. During the transfusion, Meghan received blood with the antigen Kell. In response, her body developed anti-Kell antibodies which, given her husband's Kell-positive blood, put her next pregnancy at risk of sudden fetal demise. The terrifying possibility hung over her pregnancy, making it difficult to plan and hope for her baby's arrival. Thankfully, her daughter was born healthy. But Meghan could have avoided the traumatic hours in the hospital and months of agonizing over the possibility of another lost pregnancy if her miscarriage had been managed according to medical necessity rather than hospital policy.⁵

Fact: Pregnancy comes with risks & can result in serious illness or death

In 2018, there were 658 pregnancy-related deaths in the United States.⁶ The U.S. has the highest maternal mortality rate among other economically "wealthy" countries.7 Significant racial and ethnic disparities also exist, with the maternal mortality rate for non-Hispanic black persons being more than double that for non-Hispanic white persons-37.3 per 100,000 compared to 14.9 per 100,000.⁸

Ectopic pregnancies: 'Ticking time bombs'

Keri, a pseudonym, was terrified to visit an emergency room during the COVID-19 pandemic, but she had no choice. By the time she arrived at a hospital in Seattle last spring, the pain in her stomach was so severe she could not eat or walk on her own.

She noticed something was wrong three days before while visiting Vashon Island—her first tentative, socially distant trip with her fiancé during COVID. Keri was new to Seattle and did not yet have a primary care doctor. She made a telemedicine appointment to avoid an in-person exam. The provider suspected appendicitis and convinced her to go to an urgent care clinic in Ballard. At the clinic, the nurse's eyes widened after Keri's pregnancy test came back positive. Keri had an IUD, putting her at greater risk for an ectopic pregnancy. The clinic provider told her to go immediately to the emergency room.

Keri chose the closest hospital. "It was a split-second decision," she recalls. "I was in shock and I was so worried that I was dying."

A second pregnancy test at the hospital came back positive, but an ultrasound revealed no signs of a normal pregnancy. Keri's doctor told her the pain, bloating, positive pregnancy test, IUD and ultrasound results all pointed to an ectopic pregnancy.

The fetus is never viable in an ectopic pregnancy and the condition does not resolve on its own. Keri knew that ectopic pregnancies were dangerous and potentially deadly.

⁵ Some of the details in Meghan's story were also featured in an article published on September 25, 2019 by Rewire.News.

National Center for Health Statistics, "Maternal Mortality," Center for Disease Control, last 6 modified November 9, 2020, https://www.cdc.gov/nchs/maternal-mortality/index. htm.

⁷ Roosa Tikkanen et al., "Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries." The Commonwealth Fund. November 18, 2020, https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/ maternal-mortality-maternity-care-us-compared-10-countries.

Health Statistics, "Maternal Mortality." 8

Ectopic pregnancies occur when a fertilized egg implants and grows outside of the uterus, typically in a fallopian tube. The fetus is never viable in an ectopic pregnancy and the condition does not resolve on its own. Keri knew that ectopic pregnancies were dangerous and potentially deadly. If left untreated, the doctor confirmed that her fallopian tube could burst without warning, filling her abdomen with blood and requiring emergency surgery.

Despite the potentially dire consequences of waiting, Keri's doctor said she could not start treatment right away at the hospital. She pressed the doctor to explain why she could not receive the care she clearly needed and wanted. The doctor explained that the hospital had affiliated with another health system, and out of respect for this other health system's values, Keri would have to wait.

Keri asked if she could go anywhere else. The doctor said she could go to a Planned Parenthood clinic, but that she would otherwise have to return to the hospital for another blood test in 48 hours.

"I felt like my life was in danger and they wouldn't treat me," Keri says. At that point, the doctor instructed Keri's fiancé to bring her back to the emergency room immediately if her face turned pale or she passed out. She could not believe what she was hearing. "I felt like my life was in danger and they wouldn't treat me," Keri says.

Still, during the pandemic she did not want to start the whole process over again at another clinic or in a crowded emergency room at a different hospital.

Between the physical and emotional strain, Keri was not able to work for the next two days. She took the time off — a privilege she knows not everyone has — and agonized that every pain and cramp meant she had ruptured. She spent hours online and on the phone with the patient advocate available through her job searching for more information about why the hospital refused treatment and discharged her with a life-threatening condition. After 48 hours, she went back to the hospital, where her blood test again confirmed an ectopic pregnancy, and she was finally treated.

Keri feels lucky that she escaped without dangerous complications despite being forced to wait for treatment. But the trauma remains. "I felt completely helpless and so angry," Keri says. Although she wants children, pregnancy scares her now. "What if something goes wrong and I can't get the treatment I need again?" Keri wants the law to change so no other patient's care is delayed or denied because they choose the wrong hospital or have no other options. In particular, she thinks about the people who do not have flexible employers and sick time available to wait out a hospital's policy. "My experience should not just get tossed in the pile of ER records and never talked about," Keri says. "It needs to be different."

Fact: Ectopic pregnancies are a life-threatening pregnancy complication

An ectopic pregnancy is a non-viable pregnancy that occurs outside of the uterine cavity, most commonly in the fallopian tube. Tubal ruptures of ectopic pregnancies are life-threatening, with ectopic pregnancies being a significant cause of pregnancy related morbidity and mortality. While it is difficult to estimate the true numbers of ectopic pregnancies, "[t]he prevalence of ectopic pregnancy among women presenting to an emergency department with first-trimester vaginal bleeding, or abdominal pain, or both, has been reported to be as high as 18%." ^g

Dr. Sarah Prager, a professor of Obstetrics and Gynecology at the University of Washington, calls ectopic pregnancies "ticking time bombs" which do not resolve on their own and can lead to life-threatening bleeding if left untreated. That's why Dr. Prager was so disturbed when a patient came to see her after being diagnosed with an ectopic pregnancy at a hospital in **Tacoma**. The patient was discharged from the emergency room without a referral to another doctor or information about the risks associated with ectopic pregnancies. After her diagnosis, she was simply sent away from the hospital to find alternative care. When she made an appointment with Dr. Prager, the only information the patient had about the dangers of an ectopic pregnancy came from her own Google search. "If somebody doesn't know she has a life-threatening condition," says Dr. Prager, "she might be less likely to seek care urgently." That delay can be deadly.

When caught early, patients with ectopic pregnancies are often able to avoid surgery and instead receive medication. But ectopic pregnancies are unpredictable. Turning away a patient without a plan for follow-up treatment leaves them at risk for catastrophic bleeding. Providers must be allowed to offer their patients timely, evidence-based care. Even under a doctor's care, there are risks. Once you know you are treating a patient with an ectopic pregnancy, "there's no real reason to delay treatment,"Dr. Prager says.

When Dr. Erin Berry first moved to Washington two years ago, she was surprised by the number of patients with ectopic pregnancies whose care was delayed or punted to another health care setting by hospitals with policies that restrict care for ectopic pregnancies. Dr. Berry is the medical director of Planned Parenthood of the Great Northwest and the Hawaiian Islands. She says that the same scenario plays out at least twice a month at clinics around the state: a patient's ultrasound and blood tests confirm an ectopic pregnancy at Planned

After her diagnosis, she was simply sent away from the hospital to find alternative care.

"If somebody doesn't know she has a life-threatening condition," says Dr. Prager, "she might be less likely to seek care urgently." That delay can be deadly.

⁹ Committee on Practice Bulletins—Gynecology, "ACOG Practice Bulletin No. 191: Tubal Ectopic Pregnancy," Obstetrics and gynecology 131, no. 2 (2018): e65-e77, <u>http://doi.org/10.1097/</u> <u>AOG.00000000002464.</u>

FACT: ECTOPIC PREGNANCIES ARE A **LIFE-THREATENING PREGNANCY COMPLICATION.**

Erin Berry, MD, MPH Department of Gynecology & Obstetrics Parenthood, which then refers the patient to the emergency room for care to avoid dangerous complications. At the hospital, instead of treating the ectopic pregnancy, the patient is sent home to wait two more days for another blood test.

In Washington, where many hospitals have policies that prohibit pregnancy terminations, this delay of care for ectopic pregnancies is a common and potentially life-threatening pattern. "I just haven't seen this in other places," says Dr. Berry.

...the hospital sent the woman home where her fallopian tube ruptured. A ruptured fallopian tube is a life-threatening situation, and the woman had to be rushed to the emergency room for surgery. One woman's experience stands out, Dr. Berry says. The patient's pregnancy test was positive, but an ultrasound found nothing in her uterus at the Planned Parenthood clinic where she first sought care. A second round of blood tests confirmed an ectopic pregnancy was highly likely and clinic providers referred her to the emergency room at a **Seattle** area hospital. That's where the patient's care stalled. Citing the need for follow-up blood tests — a step Planned Parenthood had already completed — the hospital sent the woman home, where her fallopian tube ruptured. A ruptured fallopian tube is a life-threatening situation, and the woman had to be rushed to the emergency room for surgery.

Dr. Berry understands why providers at hospitals that restrict pregnancy terminations hesitate before treating patients with ectopic pregnancies. Hospital policies instill fear. Doctors and nurses do not want to get it wrong, Berry explains. "The reality is the ectopic pregnancy was medically confirmed and the patient suffered the consequences of waiting."

When providers delay or deny care for reasons that have nothing to do with medical judgment, patients are often left to advocate for themselves — a task not everyone is up to, especially if they are scared and in pain.

A second patient of Dr. Berry's only received the care she needed after insisting on medical treatment for her ectopic pregnancy. The patient went to the emergency room in spring 2020, during the **COVID-19 pandemic**, after tests at Dr. Berry's clinic confirmed the likelihood of an ectopic pregnancy. At the ER, an ultrasound revealed a mass in her fallopian tube — another clear sign of an ectopic pregnancy. Still, she was sent home and told she would have to return for another blood test before doctors could begin treatment.

Any delay in care for an ectopic pregnancy can have significant health implications for a patient, but in this instance requiring the patient to return was additionally burdensome. Not only was the patient scared to visit the ER for a second time during the COVID-19 pandemic, but her job required that she work nights and early morning shifts, making trips to the hospital even more difficult to schedule. "The reality is the ectopic pregnancy was medically confirmed and the patient suffered the consequences of waiting,"says Dr.Berry. After the patient returned to the hospital and received the additional blood test, hospital providers told her to follow up with Planned Parenthood. Dr. Berry does not know why the hospital further delayed the patient's care by advising her to go back to Planned Parenthood. The treatment the patient needed was available at the hospital, not at Dr. Berry's clinic. After checking with Dr. Berry, the patient returned to the hospital the next day prepared with her own research to make an argument for medical treatment. This time, the hospital agreed. But there was no medical reason to delay care in the first place, says Dr. Berry, because the patient was already at the hospital asking for treatment: "That's your opportunity to treat an ectopic before it ruptures."

CONCLUSIONS AND RECOMMENDATIONS

Across Washington state, many hospitals are violating medical standards by denying or delaying necessary care to pregnant patients who are miscarrying or experiencing an ectopic pregnancy. These patients' health and lives are being put at risk. We need stronger laws to ensure that this discriminatory and dangerous practice is not allowed to continue. A patient's treatment should be decided in consultation with their doctor, not dictated by hospital policies set without regard for medical necessity.

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