The
Unexpected

Also by Emily Oster

Expecting Better

Cribsheet

The Family Firm

The Unexpected

Navigating Pregnancy During and After Complications

EMILY OSTER

AND DR NATHAN FOX

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This book is dedicated to all of the people who inspired it—to those who trusted their stories with me, especially the hard ones.

—Emily Oster

To Michal, for always being my biggest fan. I love you.

—Nathan Fox

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Introduction

I remember vividly the moment I decided to write a book about pregnancy. I was 10 weeks pregnant with my first child. I was at my first real prenatal visit, and the one topic I knew we needed to discuss was prenatal testing. I had some idea of the two options available at the time—an ultrasound-based screening procedure or a more invasive, but more accurate, test—and I was ready to dive into which might be the best for my pregnancy.

Instead of the discussion I expected, I was told simply that the ultrasound procedure was the appropriate option, given my age. When I tried to push back—surely more factors were relevant than *just* age—I was told begrudgingly that if necessary I could investigate the second option. But, they emphasized, it was really nonstandard and I would have to make a decision within a few days. On my own.

I ended up, thirty minutes after the appointment, standing on a street corner in Chicago, on the phone with my husband, trying to work out what information we needed to figure this out. I spent the next several days furiously working through academic papers, datasets, and spreadsheets to try to figure out what we should do.

What I took from this, above all, was a feeling of being *unprepared*. I was ready, emotionally, to engage in this question. But I didn't have the necessary information or the right way to approach the conversation. The discussions I had with my doctor, on this and other topics, were challenging in large part because I didn't have enough information to enter them with the right questions.

I spent much of that first pregnancy trying to figure out how to ask the right questions and to find the data to inform the choices that I had to make. *Expecting Better*, the book that the pregnancy inspired, was my attempt to fix this problem for other people. Yes, much of that book is about lifestyle choices—important ones, like whether you can have sushi or coffee. But a big portion is about previewing the medical choices you'll have to make and walking through the information needed to make them, or at least to engage in productive conversations about them.

When I got to my second pregnancy, I was in a very different position. This was partly because I had written a book about pregnancy. It was also because I was very lucky. My first pregnancy was smooth. Very few new questions arose before the second. I had no significant complications previously that I felt I needed to prepare for.

This is not true for everyone. If people largely come into their first pregnancy with similar expectations, we all come into a second (or third, or fourth) pregnancy with the weight of our different experiences, good or bad. When these experiences are complicated, the landscape going forward is complicated, too.

This isn't a rare or niche problem. Complicated pregnancies affect a lot of us. If we put together all of the conditions discussed in this book—miscarriage, preterm birth, preeclampsia, hyperemesis gravidarum, and many more—we are talking about perhaps 50 percent of pregnancies. And that means that as much as half of our later pregnancies carry this extra layer of difficulty.

I wrote *Expecting Better* more than a decade ago. In that time, I have continued to work as a professor specializing in health economics and statistical methods. I have also written two other books, as well as countless issues of a newsletter, *ParentData*, about pregnancy and parenting. Through this work, through emails, DMs, research, surveys, and personal interactions, I have had the privilege to see an enormous range of pregnancy experience.

People write for help with navigating pregnancy after loss. Once, a reader wrote to share the heartbreaking news that she had lost her son at 20 weeks. She was looking for answers, which I'm sorry to say I didn't really have at the time. Then, a couple of years later, she wrote to me again, this time sharing pictures of her new baby.

People write for help with treatments—*I had preeclampsia before—should I take aspirin this time?*

They write for reassurance. *My doctor said this complication is really unlikely to happen again but . . . is that right?*

They write to share their complicated decision making around future pregnancies. *I want to give my son a sibling but I'm just not sure I can do that again.*

I feel the sadness that can come through some of these emails, but also the joy that's sometimes on the other side. I feel privileged to be with them for a portion of what can be an incredibly challenging time. I feel lucky when I can help, and frustrated when I cannot.

Ultimately, when people reached out to me with these questions about pregnancy after complications, they were almost always looking for data. They had been through an experience that was incredibly emotionally fraught, and they were trying to make the best decision possible and move forward. People craved evidence, something to help them process and contextualize what they had experienced and what it might mean for the future.

What I also heard, along with a desire for data, was a much more intense version of the same feeling I had during my first prenatal visit. Navigating or planning a pregnancy after complications can plunge you into an unfamiliar world of medical decision making. Conversations with medical providers can be hard and scary, and often people felt that they were given a choice about what to do without really having the full set of information they needed, or they weren't given any choices at all.

Data is one important input, but another key is knowing the right questions. In so many of the scenarios we'll talk about in this book, the right decision depends on the particulars of your situation. Your medical provider will be the key partner in figuring this out, which makes it all the more important that those provider conversations are as constructive as possible. That will be easier if you're coming into the office with more knowledge, with a better sense of the right set of questions.

I wrote this book to try to help people navigate these crucial moments of their lives. This goal—to empower people to make better, more confident decisions in their pregnancy and parenting—imbues everything I do in my writing. It's the reason I write every day, and the thing that I love. In that sense, this book is no different from my existing work.

What is different about this book is that I hope you do not have to read it. It is odd to write a book that you hope people will not need. I very much want people to read my other books, but this one, I wish you would be able to pass by.

However, I go back to the reality just discussed. Twenty-five percent of pregnancies end in miscarriage. Five to 10 percent of women will be diagnosed with diabetes or preeclampsia. Approximately 10 percent of births are preterm. We do not talk about this, and yet there it is. These issues affect an enormous number of pregnancies.

The lack of discussion is part of the problem. So many of the conditions experienced here are kept quiet, or secret. The secrecy of miscarriage we are perhaps aware of. But it goes beyond this. How many of us know the details of even our close friend's vaginal tearing or uterine prolapse? How frequently do you hear people discuss the experience of a child spending a month in the NICU, or the details of postpartum anxiety? Hiding these things can leave us feeling alone. That loneliness compounds an already painful situation.

It also discourages necessary research and policy discussion. There are many places in this book where we'll come to conclusions along the lines of "We don't really know what works here," even when it seems like learning what works could be within reach. But research funding often follows public discussions, and public discussions cannot happen if we are not willing to talk about these hard things.

So, this book has three goals.

First, to bring these maternal health complications into the light. As I said, I hope no one needs to read this book for themselves, but I hope everyone reads it to better understand the experiences of others.

Second, to give those of you who do need this book the data you have been asking for. For each complication, I'm going to try hard to answer two key questions: What is the risk of recurrence in a later pregnancy? And what treatments might lower that risk? This second question will usually prompt a third: How can I better prepare if it does happen again?

Third, to give people an avenue toward more productive conversations with their providers. Data will help, but to make these hard talks as useful as possible, you need a script—a way to be prepared to get the information you need, and a way to structure the conversation. You need to have some understanding of how your provider is thinking about your situation so that together you arrive at the best possible result. Having productive conversations with your provider is key to that end.

I couldn't achieve this third goal on my own. So I brought in an expert in this space: Dr. Nathan Fox, a maternal-fetal medicine specialist at Mount Sinai in New York City. Nate will wear many hats in this book—he's a key contributor to the medical details throughout. His input is integrated into many of the data sections, just as I had input from medical editors in prior books. And, once you have the data on recurrence and treatment from me, he'll end each chapter with thoughts from his side of the table based on his experience and expertise about how to move forward with your medical provider in light of these realities.

He'll give insight into how to best approach these conversations. Nate has treated thousands of patients over his career, and he's seen the many different courses these complex scenarios can take.

This book is a true collaboration (something that was hard for me, given my control tendencies—personal growth!). In nearly all cases, it was immediately clear to me why it was so important to bring the data together with a detailed medical perspective. The questions here are complicated and nuanced. They rarely have easy answers just based on the data. The challenge is about finding what is right *for you*, rather than looking for what *is right*.

With that, I will let Nate introduce himself.

I am an OB-GYN and maternal-fetal medicine (MFM) specialist practicing in New York City. I was born and raised in Chicago and then came out to New York for college, met my wife, and never left the city, at least professionally. I went to medical school at Mount Sinai in New York, stayed there for my OB-GYN residency, went twenty blocks away to NewYork-Presbyterian/Cornell for my MFM fellowship, and then returned to a private practice at Mount Sinai called Maternal Fetal Medicine Associates, where I have been ever since. My wife and I live in New Jersey now, and we have four children, one son-in-law, and two dogs.

As a doctor, I see patients every day, either in the office for prenatal care, consultations, ultrasounds, or fetal procedures, or when I'm on the labor floor delivering babies. By nature I am social, so my passion has always been spending time with patients and their families, getting to know them and trying to help them through complicated (or not complicated) pregnancies. On the side, I've always had an academic curiosity, so after my fellowship I continued to participate in medical research in areas such as twin pregnancies, preterm birth, and ultrasound.

A few years ago, I came to the realization that despite the explosion in online content, it was actually becoming harder for women to get reliable information about pregnancy and health care in general. It was difficult to navigate the sea of information and find information that was accurate but also relevant to your specific question or concern.

This led me to start my podcast, *Healthful Woman*. At the same time, in around 2017, one of my patients recommended a book on pregnancy, *Expecting Better*, written by an economist, Emily Oster. The patient told me the book read like something I could have written, and she was correct! I loved it, reached out to Emily, and we have been collaborating ever since. So it was only natural that we would write a book together, and I am very excited we are doing so.

My role in this book is complementary to Emily's. Emily is a master information gatherer, sifter, and teacher. She is able to give you tremendous insight into a wide variety of topics and how to approach them yourself and with your doctor or midwife. I hope to uncover for you how your doctor may be approaching your situation or your questions. If you are trying to plan for a pregnancy, it is best to come prepared with your own thoughts on the subject, but also with an understanding of what your doctor is thinking. This can hopefully allow you, and your doctor, to have the most productive and personalized conversation possible about what might be best for you given your specific needs, background, and health history.

In all medical decisions, there is a balance between the doctor making a decision or recommendation and your choosing the right option for yourself. I specify that it is a "balance" because how much of each is appropriate depends on the specific decision. For example, if you have pneumonia, it would be inappropriate for me as a doctor to say, "Would you like some antibiotics? Which one works best for you?" On the other hand, if we are discussing whether you should have an epidural in labor, it would also be inappropriate for me to say, "You need one" or "Do not get one" (there are exceptions to this, but those situations are rare).

One of the true arts in medicine is knowing when to be direct and make a recommendation, and when to hold back and let the patient direct the decision. As a patient, one of the ways to know you have a good doctor is when they find that right balance—you don't want a doctor who always tells you what to do and offers you no options, but you also don't want a doctor who won't ever give you their opinion.

So, my hope for this book is that it will better prepare you to have these types of conversations with your doctor, but also will give you a better insight into the medical side itself so you can have a greater sense of which decisions are best to make yourself and which decisions might make more sense to lean on the doctor for.

HOW SHOULD I USE THIS BOOK?

We designed this book to be read in two parts. The first part deals with preparation. This is intended to provide all readers a general framework for how you might approach a pregnancy with or after complications. We'll talk through what kind of information you want to collect about your own medical history, as well as some decision-making tools that may be useful in thinking about how you want to move forward.

The second part of the book is divided into condition-specific chapters. These are designed to be read as needed. In some cases, you may need multiple chapters. In others, only one. In each chapter case we talk through the data on recurrence and prevention and then offer a perspective from Nate on how to approach conversations with your providers about these issues.*

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* There will be some overlap in the book across chapters; we've intended for you to be able to read the chapters you need.

Another option, of course, is to read all the chapters. Even if a specific complication is not relevant to you, the process we go through for thinking about the issue—and developing a framework for patients to think about it with family members and doctors—might speak to you in other areas of your journey through pregnancy, or health care in general.

We have tried hard to cover a large share of the major issues that arise in pregnancy, birth, and afterward. However, there will inevitably be conditions or circumstances we have missed. In these cases, we hope that going back through the first part of the book will give you a place to begin as you proceed in conversations with your own providers.

Although this book is written primarily with an eye to second pregnancies, you may find it helpful for some complications in a first pregnancy as well. If you are struggling with a condition like hyperemesis gravidarum, gestational diabetes, or growth restriction, for instance, the chapters on these topics will hopefully give you a starting point to discuss treatment and approaches with your provider.

Finally, a note that these issues are hard. They are hard to experience, hard to read about, hard to write about. So, while I hope this book helps, I also ask you to take care of yourself when you read. Take a break and have a cup of tea, or go for a walk. Nate and I will be here when you get back.

PART 1

Preparation

Before we get into conditions, this section starts with some general principles that will apply to virtually everyone reading this book. We'll talk through these ideas in the next three chapters.

First, prepare yourself. Engage with the question of a possible future pregnancy. Is this the right choice? Is now the right time? How can you know if you're ready?

Second, prepare your material. Get your medical records. Talk to your doctor about your last pregnancy. You are the best keeper of your own information, and having it at your fingertips will be helpful. This can—and, if possible, should—be done close to the first pregnancy. This is when your case will be most fresh in your mind, and in the mind of your provider. Even if you aren't sure about a future pregnancy, you may want to collect this information just in case.

Third, prepare your script. The first visit with a provider—either before another pregnancy, or once you're pregnant—is an opportunity to set expectations and make a plan. We want you to feel prepared for this conversation. This chapter should help you think about that script.

There is one more, very crucial, note. If a pregnancy didn't go the way you planned—*regardless of the outcome*—there can be a sense of loss. Of course this is the case with miscarriage or stillbirth. But it's also true for birth trauma, for preterm birth, for having a cesarean delivery if you anticipated a vaginal birth, or for any unexpected or difficult portion of the pregnancy and birth.

We naturally come into a first pregnancy with a set of expectations for pregnancy and birth. If your experience differs from those expectations, that can bring on grief. That sense of loss is commonly dismissed—"Well, you had a healthy baby! You don't have to worry about what happened before." This is, frankly, bullshit. Yes, experiences vary, and some people are able to accept what happened more easily than others. But you deserve to process in whatever way you need to.

So before you do any of the concrete steps in this book, get the support—therapy, writing, meditation, whatever works for you—that you need now.

CHAPTER 1

Prepare Yourself

There are many technical things to do to prepare for another pregnancy after one that was complicated: collect medical records, decide about doctor changes, perhaps undergo additional testing. We'll talk about all of that in depth in the next chapter. Before any of this, though, you need to do perhaps the most important thing: prepare yourself emotionally.

So, what does that mean?

Very broadly, it means looking back on what happened before, trying to process it, and thinking deliberately about your steps going forward. It sounds straightforward in theory, yet it can be anything but.

What this means for you will depend tremendously on what happened. Complicated pregnancies take many forms, and both the medical and the emotional experience will inform what comes next.

What is obvious to most people is that your history will influence the medical choices in a later pregnancy. What may be less obvious but equally important is the recognition that the *life choices* you make may be affected by this history. More specifically: it may make sense to engage in detailed planning for a possible repeat of complications in a later pregnancy even if there is nothing to do medically.

Many of the people I spoke with for this book hadn't been encouraged to think about this step.

Consider one woman who suffered from hyperemesis gravidarum (severe nausea and vomiting):

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> *One year after our son was born, we began the discussion of a second. We talked through the cost of child care, impacts to our careers (both were taking off), desired age gap between children, and the belief in our ability to handle two children. The discussion of my experience with HG never came up . . .*

• • •

In this case, HG did return during her second pregnancy, and the experience was extremely challenging for the entire family. It is not clear that her choice to conceive again would have been impacted by this risk, but if they had grappled with it from the beginning, they would have been able to put more support in place. They could have had a more concrete plan for backup childcare. She could have had a conversation with her employer about how her team could have prepared to adapt if necessary. There are a variety of ways this might have made the experience at least somewhat easier than the previous.

One reason I think people avoid these questions is that we require acknowledgment of things we wish were not true. Acknowledging the fact that this debilitating pregnancy condition might return in a later pregnancy forces us to live with that uncomfortable reality—past, present, and future. In the moment, it's easier to live with the hope that it won't happen again. Of course, doing so may leave us unprepared. Hard as this is, I urge you not to skip this ultimately healing step.

A second problem is that it can be hard to know how to approach what comes next. Sometimes, it's hard to even know what you're trying to think about or prepare for. Is your key question whether to have another child? Is it how to prepare for that? Is it both? The issues raised by complicated pregnancies are large and varied, and it can be difficult to know where to start. Process can help.

When the questions are uncertain and hard, it is easy for your experience to drag on without resolution. It is almost impossible to know if you are making the right decision, which makes it tempting to make no decision at all. Ultimately, you'll be better prepared for whatever decision you make, though, if you commit to making it deliberately.

In my book *The Family Firm*, I talk through a structured process—the Four Fs—to approach big decisions. I think this provides a useful starting point in deciding whether to try getting pregnant again and for many of the other decisions we'll address in this book.

STEP 1: FRAME THE QUESTION

You cannot make plans or prepare without clarifying what you are trying to decide or to accomplish. The first step, then, is to frame the question.

After a complicated pregnancy, for many, the question is simply whether to try for another child. This is an example of a question where it is very important to be explicit about alternatives. It's easy to state this question as "Should we try for another pregnancy or not?" That framing isn't explicit enough about what "or not" means. There are other ways to grow a family—adoption, surrogacy—that may be a possibility for some people. "Or not" does not allow for the nuances of timing. Are you really asking whether you should have another pregnancy now or *never*? Or is it now versus waiting a year, or two, or waiting *x* amount of time and then reconsidering at that point?

For other people, the choice to have another pregnancy may be an obvious one, and the question may be about timing. After a miscarriage, for example, people often struggle with the question of whether to try again right away or to wait. The question "Should we try again now?" might be better framed as "Should we try again now or revisit the timing in three months?" Because this framing is explicit about the choice—it's not "now or never" but "now or in the relatively near future"—it may make it easier to recognize the need to wait.

Or the appropriate question may be about support. "What support systems should we have in place before trying again? Should we invite my mother to live with us in the event that the pregnancy is complicated?"

This question framing is an opportunity to clarify priorities. Are all family members committed to having more children? And if so, are you emotionally ready to consider trying again, especially after loss? It is reasonable—common—for people to differ on these questions, even people who are building a life together. They are often not questions we confront when we first start trying for a family. This moment is an opportunity to confront them, to figure out what decision we need to make about going forward.

STEP 2: FACT FIND

Get all the information you can in order to be prepared for whatever may come next.

For example, imagine your first pregnancy was complicated by preeclampsia at 25 weeks, followed by seven weeks of in-hospital bed rest and then six weeks in the NICU with your baby. When considering another pregnancy, your first question will probably be how likely this is to happen again. Should you expect a repeat experience? You'll probably also ask what might be done to reduce the risk of recurrence or to improve the outcome. It isn't possible to prevent many of the complications we discuss throughout the book, but knowing the possible risks allows you and your provider to treat the condition better and have a better outcome.

When considering another pregnancy you should also take into account how your family would approach the situation. What supports could you have in place to take care of your existing child if you had to be hospitalized again? If you are working, what preparations might you make professionally? Of course, we can vehemently hope that the condition will not recur, in which case these questions would have been unnecessary. But confronting how you would deal with these complications again should be a part of both preparing and, possibly, of making your decision about moving forward.

This step may take some time; in many cases, it will make sense to speak with your medical provider. In the particular case above, you might raise the question of alternatives to bed rest. This is an opportunity to talk about whether that's something that the provider would insist on if it happened again, or whether there would be options that might be a better fit for your family.

The goal of this step is to get the information you need—all of it—to make the decision you're facing, whatever it is.

STEPS 3 AND 4: FINAL DECISION AND FOLLOW-UP

Having asked a specific question and collected the information you need, you can come together to make a final decision.

We've intentionally left space for deliberate follow-up in some of these situations. Waiting is one possible decision. Rather than trying to conceive immediately, you may choose to wait and see how things look in three months (or six months, or a year). If you explicitly decide to wait, you can then also set a time when you'll revisit the decision.

The two approaches—committing to a decision or committing to a follow-up time, if appropriate—may help some people move forward. If you've had two miscarriages in rapid succession and the past months have been a devastating period of back-to-back losses, it may help to say, simply, "We are not going to think about this for another six months." Sometimes self-care is the only, and best, possible goal.

CHAPTER 2

Prepare Your Materials

The last chapter talked about the process of deciding whether to embark on a second pregnancy, and in what way. If you do decide on another pregnancy, you'll face more practical questions. This chapter is about the first steps in that practical stage: collecting the information you'll need to have the most productive conversations with your provider.

Remember that you are the keeper of your information, and you (and your partner) are your own best advocate. Your provider is an amazing, crucial resource, but you ultimately may need to be the one who takes ownership of your own experience and tracks your records and history.

Ground yourself in the necessity of accuracy and honesty, both for yourself and for your provider. We have a tendency to downplay our own experiences—the pain, the nausea, the discomfort "wasn't that bad." But you'll be better positioned for success if you can be open about your experiences and how they felt to you.

STEP 1: CHOOSE YOUR PROVIDER

Many people keep the same provider across pregnancies. However, there are cases in which it makes sense to switch, and this may be more true for those with complicated past pregnancies. It therefore makes sense to at least consider this possibility.

There are two possible reasons you might want to switch providers. The most obvious one is that you didn't like your doctor or midwife. It can be hard to talk about, but sometimes the doctor-patient relationship just isn't working. It should be possible to acknowledge this without layering on any value judgment. The doctor could be great, but not great *for you*. Pregnancy and childbirth are significant medical and personal experiences, and you deserve to feel comfortable, whatever that means to you. If the doctor-patient relationship didn't work for you, that is a good reason to switch. Similarly, you may prefer a larger practice with many options of providers, or you may prefer a smaller practice with only one or two providers. There are upsides and downsides to both types of practices, and your preference matters.

The second reason you might switch is if you need or want a provider with a different specialty. In the US, most babies are delivered by physicians who are specialists in obstetrics and gynecology (OB-GYNs). OB-GYNs practice at hospitals (or, in some rare cases, at birthing centers) and are trained in both vaginal and cesarean deliveries. For most women, this is the default provider specialty. Other physicians who might provide prenatal care and delivery are specialists in family practice.

Each year, about 8 percent of infants in the US are delivered by midwives. A midwife can be an excellent option if your pregnancy is low risk, but this is often not the best option if there are particular risk factors. If you used a midwife in a first pregnancy and had certain complications, it might make sense to switch to an OB-GYN.

Sometimes, based on what happened in your previous pregnancy or your current risk factors, you may want to consider consulting with, or switching to, a maternal-fetal medicine specialist (MFM). MFMs are OB-GYNs who have done three additional years of subspecialty training in high-risk pregnancies and fetal diagnosis, such as ultrasound, chorionic villus sampling (CVS), amniocentesis, and fetal blood sampling. Some MFMs continue to practice OB-GYN as well, doing prenatal care and deliveries, while others work only as consultants, seeing you in addition to your own OB-GYN either once or on an ongoing basis, based on the circumstances. Colloquially, they are sometimes called high-risk OB-GYNs or perinatologists (not to be confused with neonatologists, who take care of newborn babies).

(For example, Nate is an MFM who continues to do prenatal care and deliveries in addition to consultations and ultrasound, but he has partners who are MFMs and only do consultations and ultrasound. Nate apparently enjoys being up late at night . . .)

In the United States, the availability of MFMs differs regionally. In some areas, there are many MFMs practicing, including those who do deliveries, and in other areas there may be fewer MFMs, and none who do deliveries. If you are considering transferring care to an MFM, you need to do some research and locate MFMs near you, if any, and find out if they do prenatal care and deliveries (usually this information is listed on their website, or you can just call the office and ask). It is important to note that an MFM certification does not specifically indicate that the doctor is "better" at deliveries. The MFM distinction is mostly related to managing a high-risk *pregnancy*, not a delivery. If you have a high-risk pregnancy, there is usually nothing wrong with consulting with an MFM and being delivered by an OB-GYN. It may be more convenient to have all your care with one doctor, or one practice, but it is not necessarily better. Therefore, if all that is available to you is consultation with an MFM, and not delivery, it will still have a meaningful impact.

Having a consultation with an MFM should be an option for everyone, especially with the availability of telehealth and virtual visits. For most MFM consultations, there is no examination required; a conversation over a videoconference platform is a great way to have the initial consultation. For many pregnancies, ultrasounds are recommended for follow-up, so there will need to be some in-person visits, but the MFM should be able to provide information on which visits require ultrasounds, and where they should take place.

Typically, the increased frequency of ultrasounds would be to assess the growth, health, and development of the fetus, or to screen for the risk of preterm birth with a transvaginal measurement of the length of your cervix. The MFM should also be able to determine whether you need further MFM follow-up at routine intervals or only if certain complications arise. This will differ for each individual circumstance. It is possible you may need a referral from your OB-GYN or midwife to see an MFM for a consultation, but that differs across practices and insurances.

While we are on this topic, a short note on costs and insurance. One could easily write a whole book about the challenges of our health care system, and many have. But for our purposes here, you should be aware that some of the treatments discussed in this book, and the evaluations, can be expensive. Generally speaking, these will be covered by insurance if you have it. There may be cases in which there are a surprising number of hoops to jump through to get the treatment you need, although usually your provider can help you figure out these challenges.

Ultimately, choosing a provider—as with the first time around—should be about finding someone you are comfortable with who will serve your needs.

STEP 2: COLLECT YOUR DATA

As will be clear in much of this book, every complicated pregnancy is complicated in its own way. We can talk about some general numbers, but your experience is unique. The details of that experience are important for understanding possible steps in a later pregnancy. Especially if you switch providers, but even if not, having a complete sense of your own history is central.

As we noted at the start of this section, getting this history as close as possible to the time of your first pregnancy will be helpful. Even though you may have been through an arduous ordeal, we encourage you to ask questions. That information will empower any future attempt at pregnancy you make. It may be possible to have this conversation later, if it does not happen at the time.

Key questions to ask your providers include:

1. Are you able to explain in simple terms what happened to me and, if you know, why it happened to me?
2. What important tests did I have and what did they reveal? Were any of them abnormal?

3. What treatments did I receive? Which ones worked and which ones didn't?
4. Was I seen by other specialists? If so, what did they contribute?
5. What are the facts I need to know if I were to try to explain this accurately to another doctor?
6. Is there anything I need to do or know prior to another pregnancy?
7. Is there anything you would recommend I do differently, or a treatment I should receive, in a future pregnancy?

(You can ask the same questions about your baby, if those are relevant to your specific situation.)

In addition, getting copies of your pertinent medical records is a very good idea. Since electronic medical records are (sadly) hundreds or even thousands of pages long, here is a list of the (typically) most important records:

1. A summary of what happened, in your own words, as detailed as possible. Do not assume you will remember these details forever. Write them down!
2. A summary of what happened, written by your provider. This might be in a "pregnancy history" in your prenatal chart or a "discharge summary" if you were in a hospital. If you don't think there is a written summary available, you can ask your provider to write one for you.
3. If you had a cesarean delivery, or any other operation in pregnancy or after delivery, a copy of the "operative report" (aka the "op note"). This is a detailed description written by the surgeon of what they did during the operation, and why.

4. A copy of your "delivery summary." These take different forms, but pretty much all electronic medical records have a summary of the delivery, such as birth time, Apgar scores, blood loss, and a description by the delivering provider of what happened.
5. The results from all blood tests, imaging (ultrasound, CT scan, etc.), pathology (placenta, biopsies), and genetic testing.
6. Copies of any consultations done by other specialists. Nearly always, the specialist will write a report summarizing their findings and impressions.

This list is not comprehensive, but it's a great way to ensure that you have the most important information available to you and your future doctors. Although you may need to sign a release form and you may need to pay a nominal fee to have records printed or copied, by federal law the records are yours, not the doctor's or hospital's, and you are absolutely entitled to copies of anything and everything you request. Note: Sometimes the hospital or doctor's office will tell you that they need to send the records to another provider, but that is not correct. You are absolutely entitled to receive a copy of the records yourself.

STEP 3: POSSIBLE ADDITIONAL TESTING

Depending on the particular complication you had, there are a number of additional tests that your provider might recommend. These are discussed in more detail in the context of each condition. Regardless of your complication, however, it may make sense to consider genetic carrier screening. This screening may be possible to organize before any doctor's visit so that you have the information to begin discussions.

Genetic carrier screening is a blood test that checks if you are a carrier for any genetic conditions that can be passed on to your children. As a review from high school biology class, humans have 46 chromosomes in each cell, arranged as 23 pairs (numbered 1 through 22, with the 23rd being the X or Y chromosome). You get one set of 23 chromosomes from your father and one set of 23 chromosomes from your mother. An autosomal recessive condition is one that is caused by a genetic mutation but that manifests as a disease only if you have the mutation on *both* copies of that chromosome. If you have one mutated and one normal chromosome, you are perfectly fine, but you are a carrier.

If two carriers have a child together, there is a 25 percent chance that the child will have the full disease. Here's how that works:

A = normal gene
a = mutated gene

AA = healthy, noncarrier
Aa = healthy, carrier
aa = disease

If two carriers (Aa and Aa) conceive a child together:

	A	a
A	AA (heathy, noncarrier), 25%	Aa (healthy, carrier), 25%
a	Aa (healthy, carrier), 25%	aa (disease), 25%

Twenty-five percent will have the disease.

Seventy-five percent will be healthy (broken down as 50 percent healthy carriers and 25 percent healthy noncarriers).

A well-known example of an autosomal recessive disease is Tay-Sachs, a devastating neurological condition for which the life expectancy is only a few years. Individuals with one copy of the genetic mutation are unaffected; those with two will have the disease.

There are hundreds of autosomal genetic conditions that can be carried and passed on in this manner, and if you aren't screened for them, you would have no way of knowing you are a carrier. Given the volume of conditions, there is about a 70 percent chance you carry at least one condition, but fortunately only about a 2 to 5 percent chance you and your partner are carriers for the same condition, which is the only situation that is potentially an issue. It is important to note that many autosomal recessive conditions are not very serious, but it may still be good to be aware of them.

This testing can be done in pregnancy, but it is better done prior to pregnancy, since if you find out you are both carriers of the same condition, you have more options, including doing IVF to test the embryos for the condition (PGT, or preimplantation genetic testing) and then only use embryos without the disease.

This is also the kind of testing that needs to be updated because over the past twenty years, our knowledge of genetic disease causes has expanded exponentially as we discover more conditions or more mutations of known conditions. The panels, which initially tested for five conditions, now cover over five hundred, so if you did a screening for your first pregnancy, it would make sense to check if the screening panel has been expanded before your next pregnancy. Depending on where you live and, unfortunately, the quality of your insurance, you may have access to more or less of these tests. It is worth asking your provider what they recommend and also what they offer if you want to do more than their standard approach.

CHAPTER 3

Prepare Your Script

There is often a very large gap between the medical knowledge you can have as a patient—even as a very well-informed patient—and what your doctor knows based on their training and experience.

One of the primary goals of this book is to build a bridge over the knowledge gap, at least a bit. When we talk about individual conditions in the later sections of this book, I'll try to give a sense of the data so you have the background. Nate will talk through the perspective your doctor may be bringing to the conversation.

This information will help. But what will also help is bringing structure to the appointment. In this chapter, we'll outline a bit of a script for how to approach *any* of these conversations.

Our suggestion, based on Nate's experience, is to write a script aimed at answering four key questions:

1. What happened?
2. Why did it happen to me?