



# HOW TO HEAL A BRUISE

For Families and  
Patients Living  
with Immune  
Thrombocytopenia

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Medical Disclaimer:

Nothing in this book could or should ever substitute for qualified medical advice and care.

Most things in the book are taken from my experience and the observations of those around me.

Information is anecdotal unless otherwise referenced.

This book is for everyone that has lived with ITP,  
and for Leigh, who lives with ITP through me.



## Immune Thrombocytopenia

HOW DOES IT FEEL to be told that you have an unpredictable autoimmune disorder that will affect your blood's ability to clot and heal? How does it feel to be told the treatment will impair your immune system's ability to fight off infection, weaken your bones, and interfere with your reproductive organs?

How does it feel to be told at 22-years-old that you will not be able to conceive and deliver a child without an enormous amount of medical intervention, that the medication you need to manage the disorder will most likely, over a long period of time, affect your body's ability to regulate hormones, shut down your adrenal system and increase your risk of diabetes, heart disease and obesity? Oh, and also raise your stress levels, thin your skin, weaken your nails, affect your sleep, shorten your life span and weaken your eyes?

How does it feel to be told that there is little to no information about your disorder; that every case is different and will most likely be compounded with a number of other autoimmune disorders as you age; that there is no long-term plan for the treatment of your disorder and all you can do is suppress your immune system and try to manage the side effects?

The answer to all these questions is this... Fine!

It feels fine because it will never happen to you!

That's what everyone thinks. That's what I thought; bad things happened to other people. I know it sounds like a cliché, but I really believed that I was indestructible. Chances are, though, if you're reading this book then it *has* happened to you, or someone you love.

The first time I heard that long speech, I was in shock. I thought to myself, 'Yes, yes,

that's all very well and good for someone else, but none of that will happen to me,' even though, at that exact moment it was happening to me. 'I'm just hearing the worst case scenario,' I told myself. I was in complete shock when I was diagnosed with ITP. I felt great!

My story is similar to other stories I've heard from people with ITP: having ITP sounded terrible, but I thought mine would be the kind of ITP that went away. It wasn't.

I was diagnosed with ITP while I was on my lunch break at work. I went to my GP to get blood test results in a carefully planned lunch hour that would see me hurriedly eating sushi in the waiting room. I walked up to the reception desk, unaware that my phone (on silent) had three missed calls from my doctor telling me to head straight to the ER. I sat in the waiting room blissfully unaware, looking up at the menu screen of Finding Nemo on repeat on the television above the receptionist, dripping soy sauce artfully onto chicken teriyaki rolls. I had thirty five minutes until I needed to be back at work. There were two people ahead of me, and I was worried I would be late getting back to work.

When my doctor opened his door to call in his next patient, he noticed me sitting there. He told his patient that she needed to wait and ushered me quickly into the examination room. He had bad news.

I went straight back to work, picked up my bag, and had my boss drive me to the ER; the doctors at the hospital were expecting me, and I was admitted immediately. I spent a sleepless night in a hospital ward and was still awake to watch the sunrise the next morning. I lay there looking out the window scared of what was about to happen. My friends brought flowers that I couldn't keep because the patients in the ward were immune compromised. I was immune compromised. A few days later, I was officially diagnosed with ITP.

It took a long time for me to sit down to write this book. There were a few false starts, a number of other projects popped up, and most importantly, I could not shake the feeling that I had nothing to offer. I stayed quiet.

But over the last few years, I feel like the dialogue around ITP has slowly become negative. The dialogue I see online now around ITP is sad. Patients are confused, disheartened with their treatments, feeling isolated and exhausted. The tone of the emails I receive has changed. What was once joy and excitement to find people to talk to about ITP is now frustration that there are still no answers. Haematologists have also been the target of online complaints, and it feels as though more and more patients are taking a passive approach to their health care.

Increasing awareness around ITP is coupled with the rising awareness of the seriousness and sadness of having ITP. Last year alone there were a number of sudden and startling ITP deaths.

I understand the sentiment, I feel it sometimes too. Which is why I wanted to create something positive and cohesive, something that could be a reference book for people with chronic ITP and a guide for those newly diagnosed. Something that could contribute to a positive discussion about ITP with everything collected together in one place. After more than seven years living with ITP and more than three years running one of the most visited ITP blogs, I finally decided it was time to contribute.

So what do we know? We still don't know if genetics, culture, or nationality play a part in someone's susceptibility to ITP, but that could be changing. As you read this, doctors in Australia are collecting and analysing an International ITP Register, *A Disease Registry for Adults Diagnosed with Primary Immune Thrombocytopenia (ITP) in International Countries*. The register was started in 2013 and researchers will be collecting data until December 2016. I can't wait until the research is released. News like this is very exciting and worth sharing.

As ITP is a rare disease, most patients have never heard of ITP before they are diagnosed. They have never met another person with ITP, and their general doctor has perhaps never treated anyone with ITP before. A patient's family and friends also rarely have experience

with ITP.

On top of that, everyone is different. There is no 'typical' ITP story. Even though we all have the same disorder, we are all going through something quite unique and personal. Chronic patients have different experiences to acute patients, and children are different again to adults. Meeting other people with ITP is not always that helpful - because your experience of the disorder is so different from others. Which is why this book does not focus on platelet counts, numbers, treatments, or the small details of my story. It's about everything else: it's about living with ITP, not treating ITP.

Inspired by my most popular article from ITP and Me, *The Seven Stages of ITP*, this book aims to examine and expand on those ideas while also including healing ideas and treatments, tips and advice for life (including how to ace a blood test). One of my aims here is to address our responsibility in educating those around us about ITP, and the best way to go about it. I have also included a few basic first aid tips and things I have picked up along the way.

Our perspective and attitude towards ITP is the number one thing that can instantly change our lives, and that is the point of this book. The more information there is for patients, doctors and families, the more we can remove fear for those who are new to this. The more you know, the easier it becomes.

*26 things you might not know about ITP:*

1. ITP is no longer called idiopathic thrombocytopenia purpura – the *idiopathic* and *purpura* part of the name have been dropped. It's just *immune* thrombocytopenia now, but the acronym is still ITP. Go figure. There are many doctors who don't know this, as the update happened after they left medical school. If you are looking for the most recent information online, make sure you use the new name.

2. ITP is not always simply caused by an overactive immune system as many people believe; it can also be caused by a dysfunctional immune system.

3. In some cases, ITP has been successfully cured with vitamin D treatments.
4. ITP is not always about platelet destruction. It is widely believed that ITP is caused by the destruction of platelets by the immune system, but for some of us it may also involve a lack of platelet production.
5. With ITP patients, the platelets you do have work well. The platelets in your system are often young, offering normal to advanced function.
6. You can get ITP from rubella (German measles), but it tends to correct itself soon after.
7. ITP is a potential side effect of some vaccines.
8. You can contract ITP from the MMR vaccine. The likelihood is about 1 in 40 000.
9. Acute ITP can occur after *any* viral infection.
10. Friends and family can donate platelets every two weeks (instead of whole blood every three months) via an apheresis machine.
11. ITP treatment is a growing investment industry with the apheresis equipment market expected to be worth \$2, 885, 000, 000 by 2020.
12. ITP can lower your life expectancy by up to twenty years if you are not careful. This information came out of one small study.
13. Directly exposing a bruise to the vitamin D in sunshine will speed up the healing process.
14. ITP is twice as likely to occur in women as men.
15. Taking immune suppressants will affect the validity of your travel insurance policy.
16. You can decide which specialist you see.
17. You can choose your treatment plan for ITP.
18. You can drink alcohol if you have ITP and are responsible.
19. Every year there is an International ITP Conference held in America.
20. About 5% of all pregnancies will develop gestational thrombocytopenia. This low

platelet count will normally correct itself soon after the birth.

21. Having ITP does not affect your chances of getting pregnant or having a baby.

22. ITP does impact your choices and decisions during the pregnancy and delivery of your child.

23. Having a low platelet count might limit your ability to have an epidural during a cesarian section.

24. Twenty percent of all ITP patients have *secondary ITP* as a result of another disease or autoimmune disorder.

25. Hashtags for people suffering from ITP are #itpawareness, #lowplatelets, #itpprobs, and #iknowaboutITP.

26. Alternative medicines and natural therapies do help.

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