

# New to This?

A Guide to Being  
in the Hospital

A bright green ECG (heart rate) line is overlaid on a dark green grid background. The line starts with a small peak, followed by a sharp, tall peak, then a deep trough, then a smaller peak, then a flat line, then another small peak, then a deep trough, and finally a very tall, sharp peak on the right side of the image.

A Silver Award Project  
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## **Introduction**

This booklet is for anyone who's staying in a hospital, whether it's your first time or you've been many times before. This book is for also for those who have loved ones in a hospital, and want to understand what they are going through. Or maybe you just want to learn about what it's like in case you might go. Either way, I hope this guide helps you.

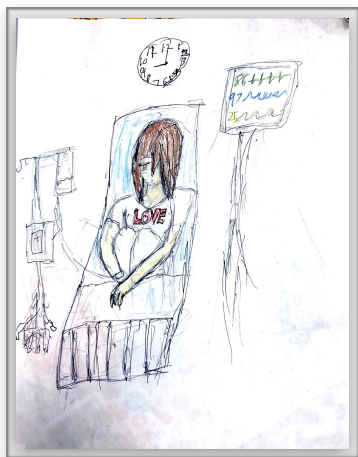
Before you start reading this, I should probably let you know that I am not a medical professional (not yet anyway). I am a former patient myself, some of these experiences are my own. However, the two main characters in this are mostly fictional. I chose not to put in their diagnoses because I wanted this to help everyone who reads this, no matter why they are in the hospital.

So, that's all you need to know. Please enjoy this guide!

## Chapter 1

### Casey's Journal

So, my mom gave me this journal for 'writing my thoughts down' while I stay in the hospital. As if I ever want to remember BEING here in the first place. I mean, this is the first time I've ever been in the hospital. Okay, that's not entirely true. I was born here. And when I was seven, I decided to be dumb and jump off a tree, thinking my mom would catch me and give me a piggyback ride. Yeah, you can guess how that went. I ended up with a cast on my arm.



So why, at thirteen years old, am I in the hospital now? I don't even want to write it down here. I should probably learn who my doctors and nurses are here, so at least I feel a little comfortable. Write soon, Casey

Being in the hospital is usually an interesting experience, whether it's your first time or you've been many times in your life. If you know you're going to stay there, you should make sure you pack. Here are some suggestions on what you should bring:

- A device to contact others and keep you from being bored (children's hospitals usually let you borrow devices, but bring your own just in case)
- Schoolwork, textbooks (contact your school to see how you can make up homework)
- Toiletries (toothbrush, toothpaste, etc.)
- Journal (optional but recommended - you can use the one in this book)
- Clothes (the hospital will probably give you a gown, but if you want to bring your own, bring button-down pajamas. If you need a cardiac monitor, it will be easier to check on the leads attached to your chest)
- Bedding, stuffed animals, etc. (They really help when you're trying to sleep).

However, sometimes you don't have time to pack and you have to go right away. When this happens, don't worry-the hospital will probably provide these things, but it always helps to prepare.

## Chapter 2

### Hope's Journal

Wow, a new roommate. Not that I'm surprised. I mean, I been here for almost a year again, thanks to my relapse. It wasn't even that long for the first time. Just, like, three months. But just when I thought that everything was better, THIS happened.

I was going in for a normal checkup, and they wanted to check to make sure I was still okay. But here I am now. In a hospital room, with a new roommate. Again.

Funny how my parents named me Hope when there is none in my life. I guess I should talk to the girl because it's the right thing to do. She looks a little younger than me—probably in middle school because she has a phone. Except even before the diagnosis, I was always a shy person. Also, she's on her phone, and it can be very risky to interrupt a preteen or teen on her phone. This should be fun.

"Hey, my name is Hope. What's yours?"

The girl looks up from her phone, probably shocked that I even talked to her. It can be lonely in the hospital, and I wouldn't be surprised if she forgot other people exist.

"Nice to, um, meet you. I'm Casey."

I should probably stop writing and actually start a conversation. So I will.

See you,  
Hope



Sometimes in the hospital, you have a roommate. If you don't know what to say to them, here are some conversation starters:

"Hello, my name is '...'. What's your name?"

"How old are you? I'm..."

"Did you see...yet? I thought it was pretty cool, what about you?/Please don't spoil it!"

"What's your favorite color/game/thing to do?"

"Do you have any siblings and/or pets?"

If you don't have a roommate, but still want to talk to another patient, you can ask to see a Child Life specialist about groups, or you could talk to a nurse or other staff member. You can also enjoy certain activities with Child Life, such as making/listening to music, creating art (like Casey and Hope) or having access to video game consoles.

## Chapter 3

### Casey's Journal

"Hey, where's the TV remote?"

"It's on the nurse call button."

"Thanks."

Well...that conversation was interesting. Nice to know that I actually have a friend now. I mean, I had friends...but only one I'm really close to. Bridget told me that she's planning on visiting this place. Now that I think of it, she's the only one who said that to me. Not that I mind. My dog probably said that in her own language too, but she's a dog, so she has to be a therapy dog before she can visit my room. (Mom and Dad, if you're reading this, please get Velvet trained! Please

train Caleb too. I really miss them!) About my brother, Caleb...he's not a bad kid. He's the best brother I could ever have. It's just...he can't resist playing with anything that he knows he should not even be near. For example, if there is a button that says "do not touch", you can guess what he will do.

So yeah. I love my brother and his curiosity. It's just well, I know hope



has a sixteen-year-old sister, so she wouldn't blame him, but I still don't want her to have serious problems because of an "innocent" four-year-old turning off her IV (intravenous line that she uses for medicine to go into her bloodstream).

Write soon,

Casey

If you have family and friends back home that want to visit, chances are there are certain rules for visiting hours, especially in winter during flu season. If younger children are visiting, make sure that they know to be careful around the machines. Also, make sure that everyone who comes and use hand sanitizer.

For example: If there's a computer in your room used for medical purposes, don't let little kids touch or play on it. Instead, let them play on your or their own device.

Don't let little kids play on the hospital floors. They can be very dirty.

Ask the staff if there is a program for siblings. There usually is, and it makes sure siblings and friends get attention as well as you. If you are the one visiting, make sure you aren't sick with anything. Diseases can be very contagious to patients, especially those with weakened immune systems.



## Chapter 4

### Hope's Journal

Wow...I didn't realize what time it was. Now I'm hungry. I should order something. Casey seems to notice that I'm reading the menu, because she asks, "Is the food here any good?"



"Oh, yeah, it's pretty good. I mean, I think it is, anyway. So do my friends. One of them asked if I could bring home some of the mac and cheese here." "Guess I should order it then. Thanks, Hope." I shrug. "You're welcome." Our food's here. It looks delicious, so I'm going to try and write while I eat.

While I'm eating, I start a conversation with Casey.

See you,  
Hope

During your hospital stay, you will probably have room service available. If you do, here is a guide to making sure you have a healthy meal:

- Make sure you know if you have any food allergies.
- If you have any dental equipment (braces, spacers, etc.) make sure to cut up hard food and be careful with foods that might break them.
- Make sure your portions are the right size. You can always order more.
- If you have a certain diet, make sure you follow it.
- If you eat in a different way, like taking formula, make sure you eat enough.
- Don't eat right before surgery or a procedure-even if you can and want to be awake for it. Even if you choose to stay awake, you might change your mind during the operation!
  - (If you are having an operation, you'll probably be told how many hours before you should stop eating).

## Chapter 5

### Hope's Journal

ugh...I can't sleep. Not at all. I know that I should probably get used to it since I've been here a long time, but beeps from the monitor don't get any quieter at night than they do during the day. What's shocking, though, is that Casey doesn't seem to have a problem with it. She's either a really heavy sleeper, or she's better at pretending than I am.

My phone is across from me on the bedside table, but I'm not planning on using it unless I'm desperate. Because once you get on your phone at night, that's what you'll be doing for the rest of the night. This is more of a problem when you're at home than at the hospital, but I really want to talk to Casey tomorrow. Then there's of course, the nurse call button. I can press the red button on it to let the nurse know I need something. Usually, I press it when I'm in pain, but I'm pretty sure the nurses can help you if you can't sleep.

I press the button. Five minutes later, my nurse, walks into the room, careful not to wake my sleeping roommate.

"Is everything ok?" she asks.

"I...I can't sleep." I respond, hoping that's a normal reason to call the person who's probably got patients with worse problems to take care of.

"That's normal" she says. Lots of patients find it hard to sleep, especially with the noise the monitors make. Is there anything I can get for you?"

"Well...I am actually a little hungry. Wait-am I allowed eating right now? At night?"

"Yes. Sometimes patients have trouble sleeping because they're hungry or thirsty, or maybe need to use the bathroom. Think about it. Have you ever woken up at home for a glass of water, or maybe for a midnight snack?"

Ah, yes. Many, many times. In fact, I would often be caught watching TV while eating and get in huge trouble. Of course, now that I'm stuck in the hospital, my parents and I agree that if I really have trouble sleeping, I'm allowed to sacrifice the chance of getting any sleep to YouTube videos, but I'm not willing to wake Casey up. I'm not sure if she likes waking up



to videos of memes at 3 am.

"Here. You can have these graham crackers. Just sit up in bed so it's less messy."

I nod, sitting up and tearing the package open. I try to eat them quickly, so I can get back to sleep.

"Thanks. I'm going to try and sleep now. Goodnight!"

"You're welcome. I'll see you in the morning unless you need me for anything else. Goodnight." She gently closes the door, leaving the room.

I'm going to turn off my flashlight and get some sleep. I'll write in the morning.

Goodnight,  
Hope

Sometimes in the hospital, it can be hard to sleep, just like at home. While you should try and get some sleep, it's okay if you can't do it. Whether you physically need something, like food, a drink, or to use the bathroom, or you feel homesick or bored, you can let the nurse know by pressing the red call button on your bed remote.

Also, don't be surprised if you find it hard to tell when it's day or night. The nurse will be there to help you out. If your parent(s) or guardian(s) are staying with you, chances are they will be able to help you if you want something. If you have a device that you want to use, make sure to ask their permission to use it.

Otherwise, you should make sure you follow your usual rules for using the device-and keep in mind that the blue light from the screen can keep you awake (Lowering the brightness of your screen reduces the impact). Also make sure to keep the volume low or use headphones/earbuds, especially if you have a roommate. Think about it-how would you feel if you were woken up by a loud noise or loud music while you were trying to sleep?

## Chapter 6

### Casey's Journal

Wow, this was the quickest visit ever. It's actually time for me to go home. I'm getting discharged today, so I'm already packing right now. I kinda wish Bridget, Dad, Caleb, and Velvet visited.

Well, if I have to go to the hospital again (I hope not), I hope they do visit. I can't wait to see them at home. But first, I'm going to have to do something.

"Hey Hope, can I please have your phone number?"

"Sure! Can I also have yours, please?"

We exchange phone numbers. (For security reasons, I'm not writing it down here).

"Do you need help packing?" Hope asks.

"Nah, I've got my toiletries, clothes, plushies, and chargers with me. I'm good."

"If you say so. Even though we just met a few days ago, I will definitely miss you."

"Same here. Thankfully, we both have phones for texting."

"Yeah, good thing."

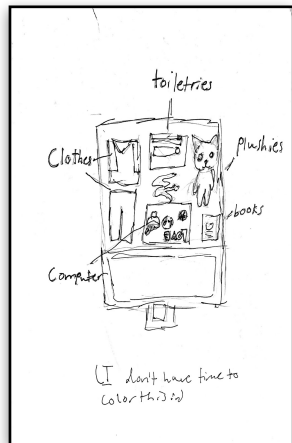
As my mom and I leave the room for hopefully the last time, Hope and I wave one final goodbye. "Text you later?" I ask. "Definitely." She smiles.

I have to go now. I'll probably write in the car or when I get home.

Write Soon, Casey

Leaving the hospital can be both exciting and sad at the same time. Exciting because you're closer to, if not already, going home. Yet it's also a little sad because you've probably made friends with the nurses, doctors and other patients. Here is a checklist to make sure you're ready to go:

- Make sure you have everything you need. If you used the checklist in Chapter 1, you can review it to make sure you packed everything.



- If you have a roommate and both of you have phones or emails, exchange contact information. Of course, you can also exchange addresses for good old letter writing.
- Thank all the staff that helped you out during your stay.



## Chapter 7

### Casey's Journal

I can't believe it. I'm FINALLY home! Okay...maybe I can believe it because the hospital visit was only three days. Still, it felt longer...but it was totally worth it because I love seeing the smile on little Caleb's face. I missed him so much, and I can tell he (hopefully) missed me too.

"you came home!" he squeals.

"Yeah," I hug him, "I'm home. I missed you so much."

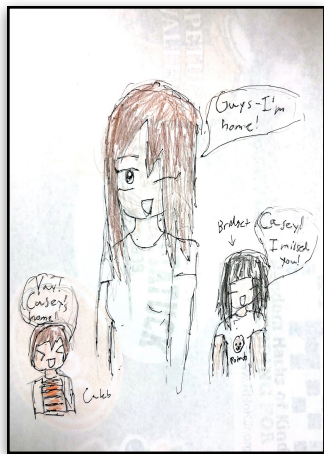
"I miss you too. Blidget and Daddy and me wanted to say hi, but it was too fast," he tells me.

"I know, little guy," I agree, "But I'm glad I can see you now."

"Casey! You're back!" I hear a familiar voice. I turn around, receiving a hug from Bridget. "I missed you SO much. How was your stay?"

"Me too. It was actually pretty nice there. I made a new friend that I think you'd really get along with."

"I hope so. I mean, I've never really been to the hospital, so you'll have to explain it to me."



My brother taps her on the shoulder. "Hi, Caleb! How are you doing-" she asks, before a black ball of fur jumps on her, "Oh my gosh! Hi Velvet!"

I'm so excited to see everyone at home. I should probably unpack right now, but first, I'm enjoying this welcome home. Then I'm going into my room to text Hope.

I'm actually going to stop writing. For now, at least.

Write Soon,  
Casey

P.S. This is Velvet's face when I came home:



Arriving home can be very exciting. It's always fun to see the family and friends you missed. Make sure you get settled back into your normal routine. If you have to stay home from school, make sure you keep in touch with classmates to let them know you are home.

Sometimes, even if you are discharged from the hospital, you might not be able to go straight home. Instead, you might stay at a recovery center or a hotel where you can get to the hospital quickly for follow-up appointments. If you are staying there, be sure to follow the rules they have. Either way, here are some things to do:

- Unpack whatever you brought with you to the hospital.
- Stay in touch with your friends if you are staying somewhere before going home.
- Finish makeup work from your school, if you haven't done so already.
- If you had a roommate in the hospital, be sure to keep in touch with them too.

## Bonus Chapter 8

### Alex's Diary

My little sister's in the hospital again.

I'm not exactly surprised, since she goes there a lot. I'm very glad they're taking care of her. It just means that since my mom's always taking care of her (she's only fourteen) I usually stay home by myself after school, living on ramen noodles until my dad gets home from work. When he does come home, he usually joins me and talks about my day at school, his day at work, all that normal stuff.

But we also talk about Hope, and we both want her to get better. I know some kids would be jealous if their sibling was getting all the attention. I mean, Mom spends pretty much almost all of her time with Hope. However, I'm not jealous. In fact, I know she needs Mom, so I'm glad she's getting the attention. Plus, I enjoy spending time alone.

I hope she does get better, and eventually comes home. That was not supposed to be a pun on her name.

Lil' sis, if you're reading this, I love you. I don't even mind that you're reading my diary (unless you're sharing it with your roommate). And I know you can get through this. But if you need me, just let me know. I promise to visit you.

Thanks for reading,

Alex



(a picture of me  
missing my sister)

I know that for most of this book, I focused on what to do as a patient, from what you should bring to helping siblings understand what you're going through.

But what if you are a patient's sibling yourself? What can you do to help?

It's normal to have different emotions about having a sibling in the hospital. On one hand, you might be jealous of all the attention they're getting. On the other hand, you probably will understand that they need this attention. Maybe you even like being independent. It's different for everyone. Chances are, your sibling needs you as much as he or she need the attention.

Here are some things that helped my siblings, and will (hopefully) help you:

- Funny videos
- Child Life
- Visits with relatives and friends
- Being near the hospital
- Holidays at the hospital
- Therapy animals
- Inclusion in hospital activities

## **Some helpful resources you can go to**

### **Child Life Services**

A group that handles the entertainment of both patients and siblings (or other visitors). For example, you can request to see an art or music therapist, a device or charger to use, crayons, movies or games, sensory materials to help patients cope, and many others things to comfort. Every hospital is different. They provide education about procedures, surgeries, and routine visits. They can work with social workers who can help your family as well as your medical team.

### **Sibshops**

If you have siblings, or you are a sibling of a hospital patient yourself, Sibshops is a program that helps kids with special needs or hospitalized siblings. You can learn more about them at <https://www.siblingsupport.org/sibshops>.

### **Therapy Pets**

Animals that help comfort people such as hospital patients. Most hospitals already have these, but if you need one, <https://petpartners.org> is a good website for finding one.

Here are some pages where you can write down any questions or concerns, take notes, or even write down what happened so far:

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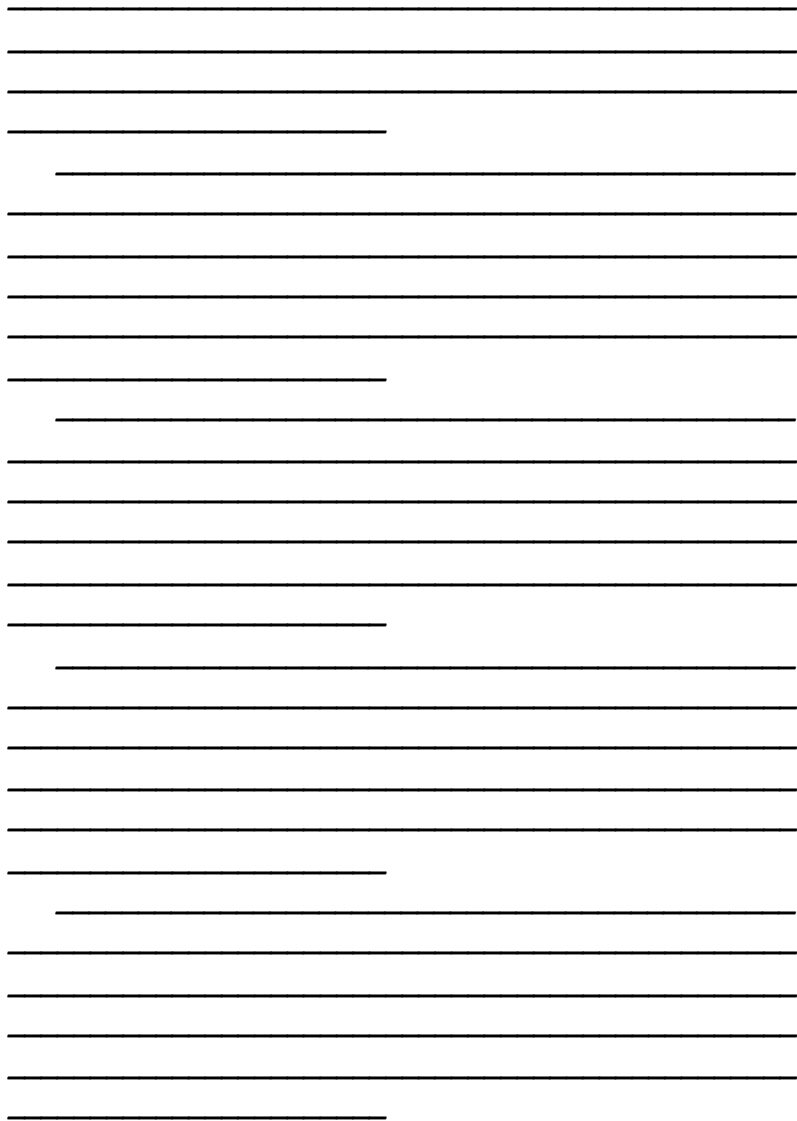
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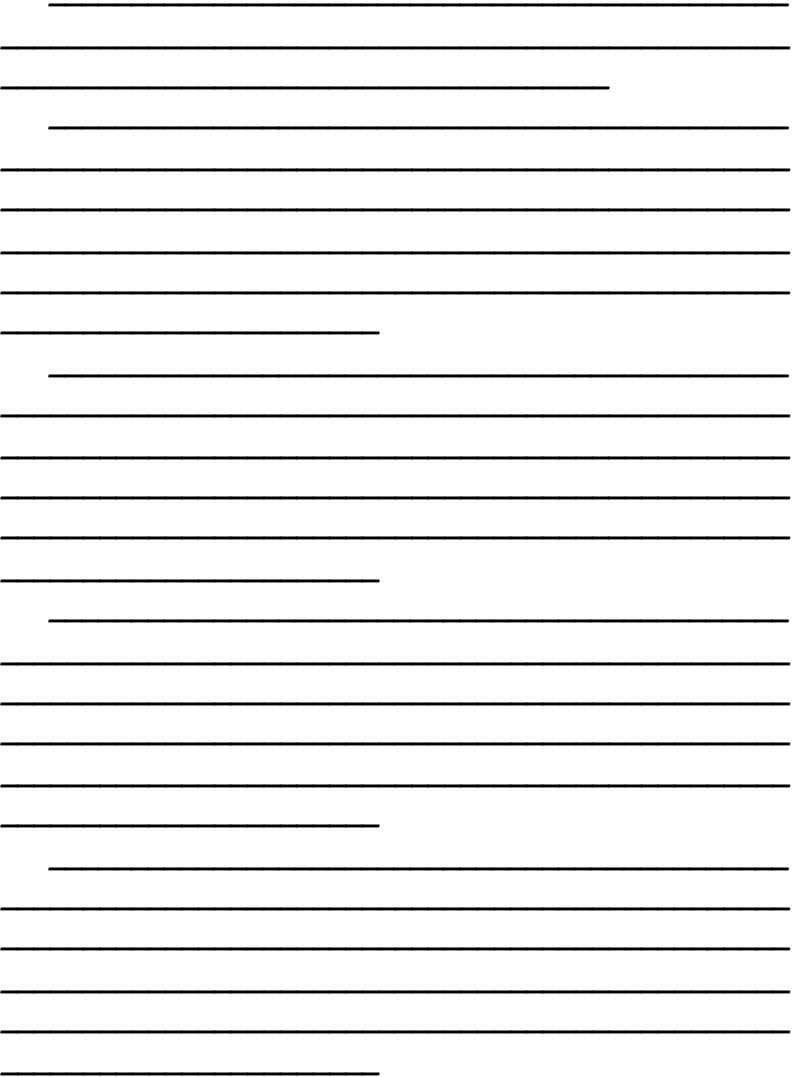
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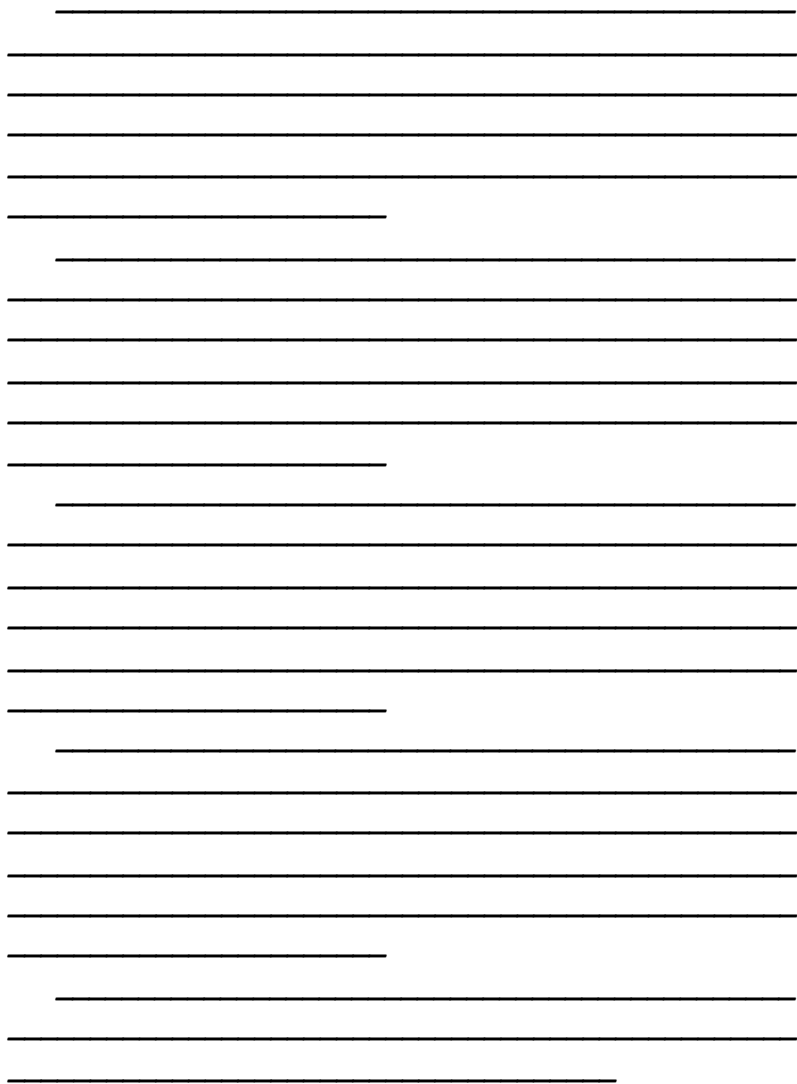
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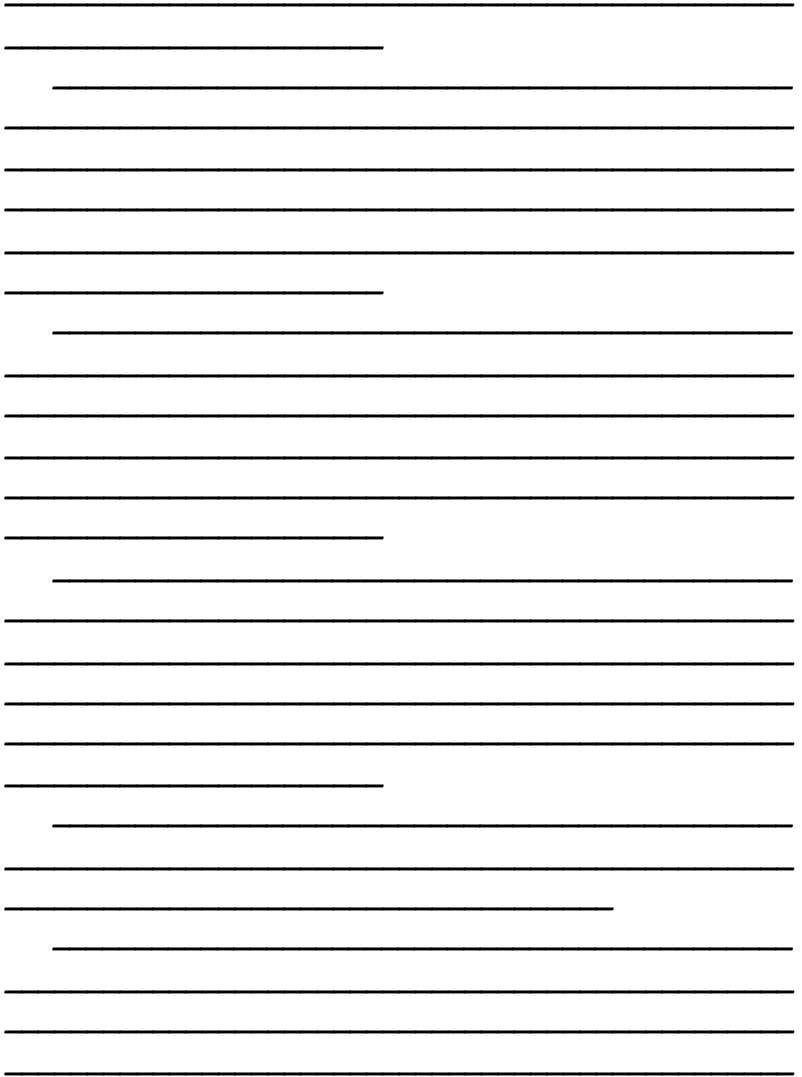




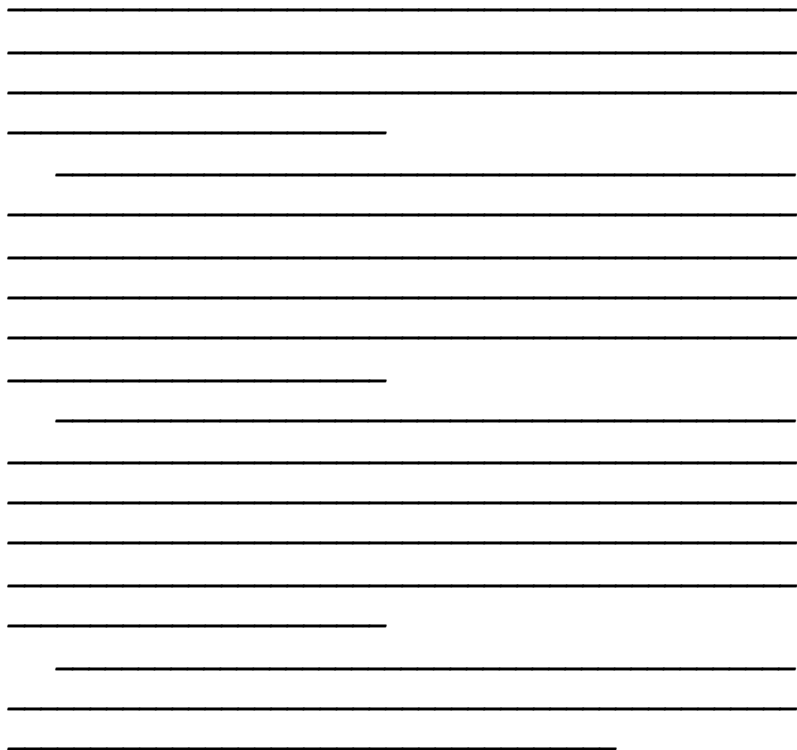




Lined writing paper with horizontal lines and periodic indentations.







## About the Author



Cora Guerin was born at the Children's Hospital of Philadelphia with a heart disease known as Hypoplastic Left Heart Syndrome, or HLHS for short. She had three open-heart surgeries—one at a day old, one at four months old, and one at three years old. When she was eleven years old, she received a heart transplant, and when

she was thirteen, she had a scoliosis surgery. She is now a freshman in high school, as well as a Senior Girl Scout. She enjoys writing and drawing manga in her spare time, which is why she illustrated this guide herself.



## **Acknowledgements**

First of all, I'd like to thank all the awesome staff at the Children's Hospital of Philadelphia for making me feel comfortable during my stay. Without you, I wouldn't have enjoyed my time there so much, let alone still be alive.

I'd also like to thank my Girl Scout and Cub Scout Families. You guys are amazing, and I don't know how to thank you. (Hopefully these acknowledgements work). A special thanks to Alex, for your editing and feedback.

Thank you to everyone who took my survey. Your results were definitely heard, and they made writing this a lot easier.

Thank you Waggles, for always being there for me when I need you. You are such a good dog, and you shall be rewarded with a million head-pats.

Thanks to all my friends, who have always supported me. I am so grateful for you all, you are one of the best parts of my life.

Thank you to my ELA teachers for teaching me how to write many different styles. This really helped me when I was creating Casey and Hope's characters and their journal entries.

Thank you, all of my school staff, for being there for me and visiting me, especially my school nurses, whom my brother calls health ninjas.

Thank you to my brother, Steve, and my sister, Amee, for always making me smile. You as well as a lot of other family members are great at encouraging me when I need it.

Thank you to my parents for driving me to appointments, taking care of me, and basically just putting up with me. I'm pretty sure that is an insanely hard task, but I hope to be worth it.

And finally, I'd like to thank my organ donor. I don't know exactly who you are, but I do know this-I literally owe you my life. I don't know how to repay you, but I hope that wherever you are, you know I will always cherish the life you gave me.