




Josephine™
explains scoliosis



Hi, I'm Jo. Well, Josephine™, actually, but only my parents call me that.

'I have scoliosis, and I'm waiting for an operation to make it better. It's horrible finding out you have a problem with your back, but don't worry. It takes more than scoliosis to stop me from having a good time with my friends.

Introduction

If you have scoliosis, this booklet is for you. It explains what scoliosis is and how doctors treat it. It's also full of useful information for your parents.

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What is scoliosis?

It's a problem where your backbone (spine) doesn't grow straight.

It doesn't usually hurt, but it can stop you from standing up straight – and it can make it hard for you to do some things, like playing sports.

The spine isn't a single bone.

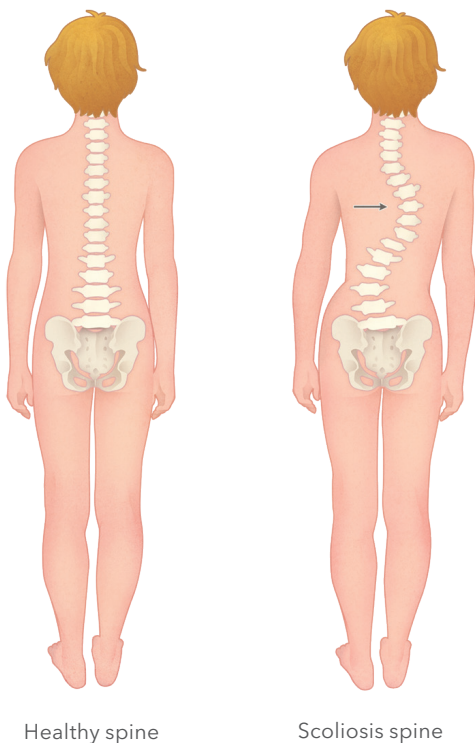
It's 33 little bones, called vertebrae, which have springy 'discs' between them. Together, they help you bend and twist.

Usually, if you look at it from the front or back, your spine should be straight.

But if you have scoliosis, your spine becomes twisted into an 's' shape.

"Scoliosis? Sounds weird, huh? It messes with your back, but once you understand it, it's not as bad as you think."





Healthy spine

Scoliosis spine

Sometimes it can affect how you look.

The twisting can mean you look unbalanced, with one shoulder or hip higher than the other. In serious cases, it can also affect your lungs. But in most cases, it's not painful or dangerous.

We don't always know what causes scoliosis.

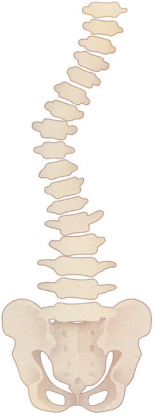
- If you have **idiopathic** scoliosis, we don't know what causes it. But it's definitely not because you didn't eat the right food or carried a heavy school bag.
- If you have **congenital** scoliosis, your spine is curved because your bones didn't grow properly when you were born.
- If you have **neuromuscular** scoliosis, the cause is a disease of your nerves or muscles. This is sometimes also called **secondary scoliosis**.

Ask your doctor which form you have if you want to know more.

We can't stop you from getting scoliosis.

But there are things that doctors can do to help straighten and stabilize your back so it doesn't get worse.

What types of treatment are there?



A spine like this might be treated with a cast or brace.



Scoliosis this serious might need surgery.



This is an extreme example of a spine with scoliosis.

How we treat you depends on a number of things.

How far your spine curves, the type of curve, and your age are all important.

If the curving isn't too serious, you'll have regular check-ups.

If your spine is only bent a little, you may just have to see your doctor every couple of months.

If the curving is more serious but doesn't need an operation, you might have to wear a brace or a scoliosis cast.

This will help stop the curve from getting worse.

If the curve is quite bad, you may need an operation.

If your spine curves quite badly, doctors may want to do an operation to stop the curve from getting worse – and to correct it.

The operation is like having braces on your teeth - but for your back.

Doctors use metal rods, screws and hooks to help straighten your back until you are fully grown.

It sounds scary, but the operation won't hurt.

Any operation is serious, and it's not nice to think about having metal rods in your back. But it's done under anaesthetic – so you'll be asleep when it happens.

“Don't be scared if you need an operation.”



Jo's story



My name is Jo and I suppose I'm different.

One: I don't like pink. Sorry if you do, but I don't and it's a free world. Two: I'm a totally fearless explorer. Really. It gets me into trouble sometimes.

My parents worry *all the time*. They always say, "Jo, be careful ..." even if it's not so dangerous. Oh, another thing: I have scoliosis.

Scoliosis. Doctors used to say it in a very serious voice that made me feel like I'd done something *really* awful. Like the time I dropped my phone while trying to take the perfect selfie, only ...

TEN TIMES WORSE!!!



But hold on, I haven't told you what else happened...

We were at the riverbank. Tom, Elise, and Me. Tom had found a vine, and we were taking turns trying to swing all the way across.

Tom made it, but I missed by a mile.

"Straighten your back!" Tom shouted from the other side. I tried again and got a massive face full of dirt.



“What is your problem, back?” I shouted.

I looked up, and there was Tom’s mom. She’s always ruining our fun. And she wears a lot of pink.

“I think it’s time for Josephine™ to go home now,”

Tom’s mom said.

“Just one more go...” I said. But secretly, I was relieved when she wouldn’t let me try.

I cried as I walked home. And I don’t **EVER** cry.

I don’t know what Tom’s mom said to them, but soon after, my parents took me to see Dr. Patterson. I was feeling very angry with my back, on account of the rope swing and Tom’s mom and everything.

Dr. Patterson listened very carefully. He said my spine is a bit crooked at the moment. It wants to grow one way, and I need it to grow a different way.

But it’s OK because we’re going to show my back who’s boss. “We have to steer it in the right direction,” he said.



I think my spine's a bit like Tom. He always wants to go his own way, even when it's *obvious* that it's a bad idea. Like when he tried to take those eggs from the bird's nest ... Mom says Tom's 'a bit crooked', but he'll be OK in the end.

Dr. Patterson says my spine is going to be OK in the end, too. Because ... I'm going to have an operation.

At first, I was a bit scared. But now I've had time to get used to the idea, I'm kind of looking forward to it. My back is not going to know what's hit it!

One day, soon, I'll be receiving my metal rods. It's sort of like when Elise got braces. Only, mine will be in my back, and it won't have those silly colored bits that she thinks are cool but are so not cool.

"I'm going to be like a robot," I told Tom.

"Half giraffe, half machine, totally unstoppable!"

I can tell he's a bit jealous because he's crazy about robots.

Of course, I won't be able to go on rope swings or play soccer after the operation. Not for a while anyway. But I know it will be worth it. Because, when I grow up, Dr. Patterson says I'll be pretty much normal.

"No, I won't," I tell him.

"Oh?" says Dr. Patterson. "Why's that?"

"I'll still be different," I explain. "Because ONE, I don't like pink."

"You don't?!" says Dr. Patterson.

"No," I say, trying to stop myself from smiling.

"And TWO, I'm a totally fearless explorer!"



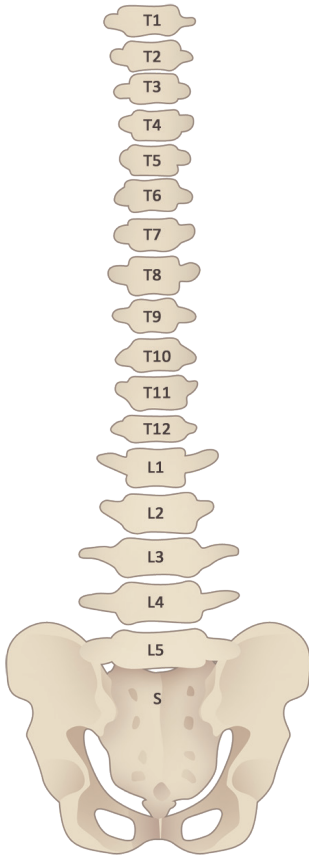
How the operation works

Will one operation sort everything out?

It might; it will depend on your exact condition, but you're likely to have at least one more once you finish growing to make sure that everything has healed properly. Discuss the possibility of additional operations with your doctor, who will be able to give you a more detailed answer.

Does having the implants put in hurt?

No, not at all. You'll be asleep when it happens. You may feel a bit sore afterward, but you'll get better.



Ask your doctor to draw the spine above to show where and how they will make the correction.

“Having metal rods in your back sounds strange, but it's really not. Implants of all kinds are pretty common these days.”



How long will I be in hospital?

You'll have to spend a couple days in the hospital and then a few weeks at home. So, you may have to miss a little bit of school.

Will I still be able to play sports?

It depends. After the operation, you'll have to take some time off sports – especially anything rough, like football or basketball. Eventually, though, you should be able to go back to playing the sports you love.

Is it safe?

No operation is risk-free, and this is a big operation. However, the doctors who do these operations are extremely skilled. Talk to your doctor about the risks associated with your specific surgery.

Having the operation and afterwards

What happens before the operation?

You might have to wait several months before the operation. Before then, you'll get to meet the doctor doing the operation to talk about it more. If you or your parents have any questions, it's a good idea to take a list with you – so you don't forget to ask anything.

What happens on the day?

Lots of things. You'll meet more doctors and nurses, including an 'anesthetist' who will put you to sleep so it doesn't hurt when the operation is being done. Your parents will have to fill out lots of forms and answer lots of questions. You won't need to do anything, though – just relax and let the doctors do the operation.

What happens after it's over?

You'll feel a bit sick and tired when you wake up, so you will need to spend a bit of time in the hospital resting. It'll be a few days before you're comfortable sitting and walking around again.

What happens when I come home?

You'll need to get some rest, start eating and drinking again, and then, over a few weeks, get your strength back.

How long will it be before I'm back to normal?

It depends. Your doctor will be able to tell you how well you're healing and let you know when you can start being more active. It could take up to a year, though.

"At first, I didn't want an operation. But I talked about it with my parents and my friends, and now I'm not so scared anymore."



Any questions?

Am I the only one with scoliosis?

Not at all. It's quite common – two or three people in every hundred have it.

Does scoliosis run in families?

We think so. At a younger age, it's most common in boys, while girls are more likely to get it when older. It also seems to run in some families. We don't know exactly why yet, though.

Are there any other treatments for scoliosis?

You may find lots of different options, especially if you look on the internet. This includes things like diets, physical therapy, or chiropractic treatment. If you have any questions about any other treatments, talk to your doctor.

Will scoliosis hold me back when I grow up?

It shouldn't. You should be able to do most jobs, travel, and play sports. It also typically doesn't stop women from having children.

Will I get back pain?

You shouldn't. People with scoliosis don't seem to have back pain more or less often than anyone else.

Will I look any different because of my surgery?

No. Once you have completed the treatment, other than a scar on your back, no one should be able to tell you've had the operation.

“When I found out I had scoliosis, I had loads of questions. Whatever you want to know, just ask your doctor.”



Help and advice

If you're worried about anything or you want to find out more about Scoliosis, just talk to your doctor or check out some of these links.

More about scoliosis

The Scoliosis Research Society
www.srs.org/patient_and_family/patient_stories

The Pediatric Orthopaedic Society of North America (POSNA)

www.posna.org

Medtronic Website

<https://www.medtronic.com/en-gb/patients/conditions-treatments/spinal-cranial-orthopedic/about-scoliosis.html>

Curvy Girls

<https://www.curvygirlsscoliosis.com/>

About this book

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Important note for the reader

This book features a short story that provides general information about scoliosis and available therapy options. It does not intend to recommend or endorse a specific therapy option for patients. Please contact your physician for information about early-onset scoliosis and therapy options. Patients should only make medical decisions in consultation with a physician. Children should read the book with the supervision of their parents.

Information contained herein is not medical advice and should not be used as an alternative to speaking with your doctor.

Discuss indications, contraindications, warnings, precautions, adverse events and any further information with your health care professional.

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