"An infinitely readable and well-researched book not only for patients and their families but also for health care providers at all levels."

—BENJAMIN D. ROYE, MD-MPH

Gillette Children's Healthcare Series

IDIOPATHIC SCOLIOSIS

Understanding and managing the condition: A practical guide for families

Tenner J. Guillaume, MD
Walter H. Truong, MD
Danielle Harding, PA-C
Michaela Hingtgen, MS
The VanGoethem Family

Editors
Lily Collison, MA, MSc
Elizabeth R. Boyer, PhD
Tom F. Novacheck, MD

GILLETTE CHILDREN'S

Praise for *Idiopathic Scoliosis*

"This infinitely readable and well-researched book does an amazing job of explaining everything about idiopathic scoliosis. It provides meaningful insights into scoliosis not only for patients and their families and friends but also for health care providers at all levels who have an interest in, or care for, these patients. I was particularly impressed with the patient stories interwoven with scientific information, bringing a much-appreciated, warm, human element to the book. Bravo to the team at Gillette."

BENJAMIN D. ROYE, Pediatric Orthopedic Surgeon, Morgan Stanley Children's Hospital of New York; Richard T. Arkwright–St. Giles Foundation Associate Professor, Orthopedic Surgery, Columbia University, US

"This book is great for anyone on this journey! Our daughter was diagnosed with juvenile idiopathic scoliosis right before she started kindergarten, and we were so worried and overwhelmed, and had so many questions. We wish we had this book during that time as it answers so many questions. We still have many questions and this book helps us pave a path today and for the future."

AMBER MARLATT, Parent of daughter with juvenile idiopathic scoliosis, US

"Written by experts at Gillette Children's, Idiopathic Scoliosis *is both a source of information and psychological support for families and patients with scoliosis. The information in the book is comprehensive and clear, but most important and enjoyable are the clinical stories of patients and families who have benefited from the expertise of the spine experts at Gillette Children's. Readers are provided with an objective picture of the pathology and its treatment without false illusions or easy enthusiasm. The clear drawings help readers understand even the most technical and complex aspects of idiopathic scoliosis, supported by up-to-date references. The book is a must-read!"*

FEDERICO CANAVESE, Head, Orthopedic and Traumatology Department, IRCCS Giannina Gaslini Institute, Genoa; Professor of Pediatric Orthopedics, University of Genoa, Italy

"This easy-to-read book will be an invaluable resource for parents who are new to dealing with a child or adolescent who has been diagnosed with scoliosis and who need comprehensive and validated information about the condition and treatment options. I wish this book had been available when I was faced with my teenage daughter being diagnosed with scoliosis."

EILISH MCLOUGHLIN, Parent of daughter with adolescent idiopathic scoliosis, UK

"This book, Idiopathic Scoliosis, *is a comprehensive, well-structured, easily readable resource. The information is presented in a very straightforward, logical, and understandable manner, and it is well referenced and accompanied by helpful photographs and diagrams. The input from actual patients and families provides a very personal perspective of the scoliosis journey."*

BRIAN SMITH, L.E. Simmons Chief of Orthopaedics, Texas Children's Hospital; Professor of Orthopaedics, Baylor College of Medicine, US

"The expert staff from Gillette Children's have done a remarkable job in creating a comprehensive review for families of children with idiopathic scoliosis. Family journeys are interwoven with an up-to-date review of the causes of scoliosis and modern treatment options. Discussion of nonsurgical and surgical treatments are balanced, allowing families to better prepare for discussions with their care team. Unique to this book is guidance on how best to transition to care when patients age out of pediatric health care."

SUMEET GARG, Pediatric Orthopaedic Surgeon, Children's Hospital Colorado; Professor of Orthopaedic Surgery, University of Colorado School of Medicine, US

"This book is one of the best resources available for patients and families to understand scoliosis and its treatment, both nonsurgical and surgical. The real-life stories of patients and families allow newly diagnosed scoliosis patients to understand the condition and its treatment and—more importantly—to let them know they are not alone. It covers the entire treatment landscape, with the latest techniques supported by the most recent published scientific data. I highly recommend this book to anyone who is affected by scoliosis and wants to educate themselves with the most complete resource in an easy-to-read format."

ROBERT H. CHO, Chief of Staff, Shriners Children's Southern California, Pediatric Orthopedic Surgeon, Pediatric Spine Surgeon, UCLA Clinical Assistant Professor, US

"The visuals and organization are very helpful in understanding signs, symptoms, and possible treatment plans of scoliosis. As a patient, I found the inclusion of personal narratives throughout the book comforted me about the diagnosis and the care I would be provided with."

ISABELLA VERMEDAHL, Adult with adolescent idiopathic scoliosis, US

"This comprehensive book on idiopathic scoliosis for parents of children with the condition is a gem for its clarity in explaining complex medical concepts in accessible language. It clearly lays out the chronological progression of scoliosis treatment, guiding parents through each step with precision and care. The accuracy of the information presented instills confidence in readers, making it a trusted resource for understanding and managing scoliosis effectively. This book is a must-have for parents seeking reliable information and support on navigating the challenges of scoliosis."

DAVID P. MOORE, Consultant Orthopaedic Surgeon, Children's Health Ireland

"The spine team at Gillette has done a nice job of putting together a comprehensive but accessible book on idiopathic scoliosis. The patient story is an excellent companion to the clinical information in the book. The pictures and diagrams are helpful and easy to understand. A great read!"

KEITH D. BALDWIN, Director of Orthopedic Trauma, Associate Professor, Children's Hospital of Philadelphia, US

"This unique resource provides not only information about the treatment of scoliosis but also the perspective of the patient and parent. Getting a diagnosis of scoliosis can often seem daunting. Yet as providers treating this condition, we see that even in severe cases where a spinal fusion is ultimately needed, patients typically return to full sports and activities. This book will be a welcome companion to many as they embark on their scoliosis journey."

LINDSAY M. ANDRAS, Director of Spine and Vice Chief of Orthopedics, Children's Hospital Los Angeles, US

"This book is as up-to-date and inclusive as a textbook written for medical professionals while being as easily readable as a novel for children with scoliosis and their families. Reading the story of Lila on her journey will alleviate the fears of children with scoliosis, and following her mother's testimonials step by step will soothe families' anxieties. This brief but comprehensive guide is a light to illuminate the way for both children diagnosed with scoliosis and their families, and it is an indispensable source of comfort for all scoliosis patients. Congratulations to the authors."

MUHARREM YAZICI, Professor of Orthopaedics Children's Orthopaedics and Spine Center, Ankara, Turkey; Past President European Pediatric Orthopedic Society; Past President Scoliosis Research Society

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To individuals and families whose lives are affected by these conditions, to professionals who serve our community, and to all clinicians and researchers who push the knowledge base forward, we hope the books in this Healthcare Series serve you very well.

All proceeds from the books in this series at Gillette Children's go to research.

Contents

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Series Foreword

You hold in your hands one book in the Gillette Children's Healthcare Series. This series was inspired by multiple factors.

It started with Lily Collison writing the first book in the series, *Spastic Diplegia–Bilateral Cerebral Palsy*. Lily has a background in medical science and is the parent of a now adult son who has spastic diplegia. Lily was convincing at the time about the value of such a book, and with the publication of that book in 2020, Gillette Children's became one of the first children's hospitals in the world to set up its own publishing arm—Gillette Children's Healthcare Press. *Spastic Diplegia–Bilateral Cerebral Palsy* received very positive reviews from both families and professionals and achieved strong sales. Unsolicited requests came in from diverse organizations across the globe for translation rights, and feedback from families told us there was a demand for books relevant to other conditions.

We listened.

We were convinced of the value of expanding from one book into a series to reflect Gillette Children's strong commitment to worldwide education. In 2021, Lily joined the press as Program Director, and very quickly, Gillette Children's formed teams to write the Healthcare Series. The series includes, in order of publication:

- *Craniosynostosis*
- *Idiopathic Scoliosis*
- *Spastic Hemiplegia—Unilateral Cerebral Palsy*
- *Spastic Quadriplegia—Bilateral Cerebral Palsy*
- *Spastic Diplegia—Bilateral Cerebral Palsy, second edition*
- *Epilepsy*
- *Spina Bifida*
- *Osteogenesis Imperfecta*
- *Scoliosis—Congenital, Neuromuscular, Syndromic, and Other Causes*

The books address each condition detailing both the medical and human story.

Mac Keith Press, long-time publisher of books on disability and the journal *Developmental Medicine and Child Neurology*, is co-publishing this series with Gillette Children's Healthcare Press.

Families and professionals working well together is key to best management of any condition. The parent is the expert of their child while the professional is the expert of the condition. These books underscore the importance of that family and professional partnership. For each title in the series, medical professionals at Gillette Children's have led the writing, and families contributed the lived experience.

These books have been written in the United States with an international lens and citing international research. However, there isn't always strong evidence to create consensus in medicine, so others may take a different view.

We hope you find the book you hold in your hands to be of great value. We collectively strive to optimize outcomes for children, adolescents, and adults living with these childhood-acquired and largely lifelong conditions.

Dr. Tom F. Novacheck

Series Introduction

The Healthcare Series seeks to optimize outcomes for those who live with childhood-acquired physical and/or neurological conditions. The conditions addressed in this series of books are complex and often have many associated challenges. Although the books focus on the biomedical aspects of each condition, we endeavor to address each condition as holistically as possible. Since the majority of people with these conditions have them for life, the life course is addressed including transition and aging issues.

Who are these books for?

These books are written for an international audience. They are primarily written for parents of young children, but also for adolescents and adults who have the condition. They are written for members of multidisciplinary teams and researchers. Finally, they are written for others, including extended family members, teachers, and students taking courses in the fields of medicine, allied health care, and education.

A worldview

The books in the series focus on evidence-based best practice, which we acknowledge is not available everywhere. It is mostly available in high-income countries (at least in urban areas, though even there, not always), but many families live away from centers of good care.

We also acknowledge that the majority of people with disabilities live in low- and middle-income countries. Improving the lives of all those with disabilities across the globe is an important goal. Developing scalable, affordable interventions is a crucial step toward achieving this. Nonetheless, the best interventions will fail if we do not first address the social determinants of health—the economic, social, and

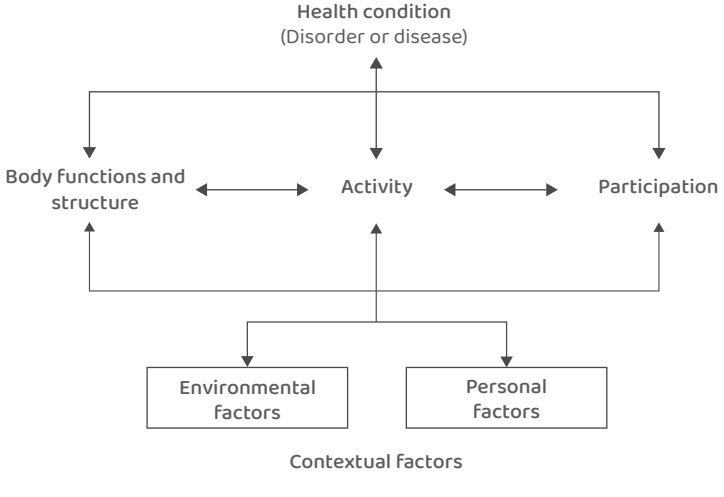
environmental conditions in which people live that shape their overall health and well-being.

No family reading these books should ever feel they have failed their child. We all struggle to do our best for our children within the limitations of our various resources and situations. Indeed, the advocacy role these books may play may help families and professionals lobby in unison for best care.

International Classification of Functioning, Disability and Health

The writing of the series of books has been informed by the International Classification of Functioning, Disability and Health (ICF).[1] The framework explains the impact of a health condition at different levels and how those levels are interconnected. It tells us to look at the full picture—to look at the person with a disability in their life situation.

The framework shows that every human being can experience a decrease in health and thereby experience some disability. It is not something that happens only to a minority of people. The ICF thus "mainstreams" disability and recognizes it as a widespread human experience.



International Classification of Functioning, Disability and Health (ICF). Reproduced with kind permission from WHO.

In health care, there has been a shift away from focusing almost exclusively on correcting issues that cause the individual's functional problems to focusing also on the individual's activity and participation. These books embrace maximizing participation for all people living with disability.

The Family

For simplicity, throughout the series we refer to "parents" and "children"; we acknowledge, however, that family structures vary. "Parent" is used as a generic term that includes grandparents, relatives, and carers (caregivers) who are raising a child. Throughout the series, we refer to male and female as the biologic sex assigned at birth. We acknowledge that this does not equate to gender identity or sexual orientation, and we respect the individuality of each person. Throughout the series we have included both "person with disability" and "disabled person," recognizing that both terms are used.

Caring for a child with a disability can be challenging and overwhelming. Having a strong social support system in place can make a difference. For the parent, balancing the needs of the child with a disability with the needs of siblings—while also meeting employment demands, nurturing a relationship with a significant other, and caring for aging parents—can sometimes feel like an enormous juggling act. Siblings may feel neglected or overlooked because of the increased attention given to the disabled child. It is crucial for parents to allocate time and resources to ensure that siblings feel valued and included in the family dynamics. Engaging siblings in the care and support of the disabled child can help foster a sense of unity and empathy within the family.

A particular challenge for a child and adolescent who has a disability, and their parent, is balancing school attendance (for both academic and social purposes) with clinical appointments and surgery. Appointments outside of school hours are encouraged. School is important because the cognitive and social abilities developed there help maximize employment opportunities when employment is a realistic goal. Indeed, technology has eliminated barriers and created opportunities that did not exist even 10 years ago.

Parents also need to find a way to prioritize self-care. Neglecting their own well-being can have detrimental effects on their mental and physical health. Think of the safety advice on an airplane: you are told that you must put on your own oxygen mask before putting on your child's. It's the same when caring for a child with a disability; parents need to take care of themselves in order to effectively care for their child *and* family. Friends, support groups, or mental health professionals can provide an outlet for parents to express their emotions, gain valuable insights, and find solace in knowing that they are not alone in their journey.

For those of you reading this book who have the condition, we hope this book gives you insights into its many nuances and complexities, acknowledges you as an expert in your own care, and provides a road-map and framework for you to advocate for your needs.

Last words

This series of books seeks to be an invaluable educational resource. All proceeds from the series at Gillette Children's go to research.

1.1

Introduction

The secret of getting ahead is getting started.
Mark Twain

If you were to look up the definition of scoliosis (pronounced SKOL-ee-oh-sis, with the capital letters showing the emphasis on that syllable), you would find many sources defining it as a sideways curvature of the spine. This is generally correct, but a more accurate definition of scoliosis is a condition in which there is an atypical three-dimensional curvature and rotation of the spine.[2]

There are many types of scoliosis with varied causes. This book focuses on a type of scoliosis called idiopathic scoliosis. The term "idiopathic" is defined as "relating to a disease of unknown cause," and it is used in the context of many medical conditions for which the cause is unclear or unknown. Idiopathic scoliosis is, therefore, scoliosis that develops from an unknown cause. There are a few theories about the mechanisms that cause the spine to grow in a curved and rotated fashion in idiopathic scoliosis; perhaps the most accepted is that the front of the spine grows faster than the back of the spine.[3] As the front grows faster, the spine begins to rotate, twist, and curve to the side. However,

ultimately, it is unclear what causes these mechanisms to develop in the first place. Individuals with idiopathic scoliosis are otherwise typically developing with no related underlying medical conditions.

Idiopathic scoliosis is the most common type of scoliosis, accounting for an estimated 80 percent of all scoliosis cases.[4] Idiopathic scoliosis affects between 0.5 and 3.0 percent of children.[3] For the large majority, no specific intervention is needed at all. For others, treatment such as bracing or surgery is needed to effectively manage the condition. While diagnosis and treatment can be challenging, individuals with idiopathic scoliosis can expect to lead typical lives.

How to read this book

To help you navigate the information in this book, it has been organized so that you can read it from beginning to end or, alternatively, dip into different sections and chapters independently. Because much of the information builds on previous sections and chapters, it is best to first read the book in its entirety to get an overall sense of the condition. After that, you can return to the parts that are relevant to you, knowing that you can ignore other sections or revisit them if and when they become relevant.

This chapter addresses the overall condition of scoliosis. Chapter 2 addresses idiopathic scoliosis, and Chapters 3 and 4 address treatment of idiopathic scoliosis. Chapter 5 looks at idiopathic scoliosis in adulthood.

Throughout the book, medical information is interspersed with personal lived experience. Orange boxes highlight the personal story of Lila VanGoethem, age 15, and her mother, Tana. Both have written about their experiences with Lila's scoliosis. Chapter 6 is devoted to vignettes from other individuals and families around the globe. Chapter 7 provides further reading and research.

At the back of the book, you'll find a glossary of key terms. A companion website for this book is available at www.GilletteChildrensHealthcarePress.org. A QR code to access **Useful web resources** is included below.

Tana

Lila was 12 years old when she was diagnosed, although her pediatrician had been monitoring her for potential scoliosis for years. Shortly after her diagnosis, Lila was fitted for a brace, and eventually she had both a daytime and a nighttime brace. While Lila wore her braces regularly for about 18 months, her curve continued to worsen. With the guidance of her doctor, we made the decision for Lila to have vertebral body tethering surgery. Today, nearly 20 months after her surgery, Lila is a happy, healthy, very active teenager. We are thankful for the care from her doctor and the care team, and grateful for Lila to have had the opportunity to have this surgery. While Lila is still a growing teen and her scoliosis journey continues, we are confident in our decisions and believe we have done everything we can to support her.

I encourage all parents and caregivers to ask questions of your care team and take in all the information (buying this book is a great step in that direction). Once you have all the information and know your options, use that knowledge to make the best decision available for your child at the time. No one knows your child as well as you do. If your child is able to weigh in on that decision, allow them to also hear the information and ask questions. Stay positive, and be brave with them through all phases of the journey. Wearing a brace in middle school is a very brave thing for a teen to do. As parents and caregivers, we can support our child by reassuring them that this time in their life does not define them, and that having to wear a brace is most often a phase. Ask your child what they need to get through this time. It may be as simple as wearing a large sweatshirt over their brace at school. And have hope. Lila's scoliosis diagnosis has been (ironically) such a positive part of her life story. It has given her fortitude, confidence, and a positive attitude.

Lila

I would tell a kid who recently got diagnosed with scoliosis to stay strong and to not focus on it too much. I thought when I got diagnosed that it was scary, and I didn't know what was going to happen to me. But it ended up not being scary at all because of all the amazing doctors (and my family) to help me through it. I always felt better knowing

that although this was really hard to deal with right now, and it's an experience that most kids don't have to go through, it will be over quicker than you realize and you will feel better about your back in the end. Every kid that I ended up eventually telling about my back braces afterwards said that they were sorry I had to go through that and they are amazed at how well I did while I was diagnosed, and now.

The VanGoethem family. Lila (left middle) and her mother, Tana (right middle).

USEFUL WEB RESOURCES

1.2

Understanding the spine

Knowing yourself is the beginning of all wisdom.
Aristotle

The spine has many names. You may hear people refer to it as the backbone, vertebral column, or spinal column. All these names refer to the same skeletal, or bony, structure that surrounds the spinal cord. In this book, "spine" is used consistently to describe this skeletal structure.

To understand scoliosis, it's important to first have a basic understanding of the spine itself: its function and anatomy, typical curvature, and development.

Spine function and anatomy

The spine serves four important functions:

- Protecting the spinal cord
- Serving as an attachment point for the ribs and supporting muscles and ligaments
- Supporting the weight of the body
- Providing points of movement for the head and torso

The spine consists of vertebrae and intervertebral discs. Key parts are described below and are illustrated in Figure 1.2.1.

- **Vertebrae** are bony structures with a hole in the middle for the spinal cord to pass through (this hole is also referred to as the spinal canal).
  - The **vertebral body** is the column-shaped part of the vertebra that bears the majority of the load or body weight.
  - The **pedicles** are bony bridges located on the left and right sides of each vertebra, connecting the front of the vertebra to the back of the vertebra.
  - The **facet joints** are the areas along the back of the spine where two vertebrae meet. Like most joints in the body, facet joints provide movement and flexibility to the spine.
  - The **intervertebral foramen** is the opening between each vertebra that allows nerves to branch off the spinal cord and travel to other parts of the body.
- **Intervertebral discs** are cartilage structures that sit between vertebral bodies. The gelatinous material in the center offers shock absorption during movement, as well as increased flexibility.

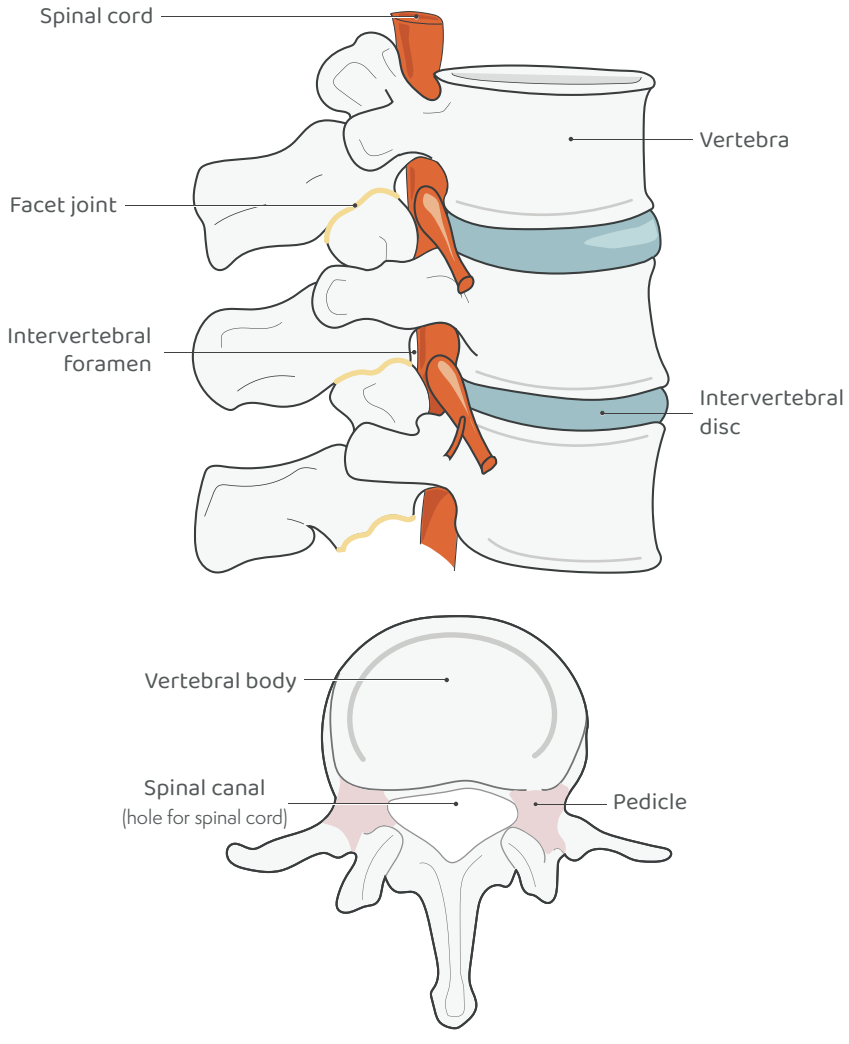


Figure 1.2.1 Anatomy of the spine and of a vertebra.

Humans typically have 33 vertebrae, which are commonly grouped into five regions of the spine: cervical, thoracic, lumbar, sacral, and coccygeal. Each region has unique characteristics and functionality. The facet joints between vertebrae are oriented differently throughout the spine, allowing for different types of motion in each region. These regions of the spine are shown in Figure 1.2.2.

- **Cervical:** There are seven cervical vertebrae, C1 to C7. These vertebrae are quite small, support the weight of the head, and enable head and neck movement.

- **Thoracic:** There are 12 thoracic vertebrae, T1 to T12. These vertebrae support the attached ribs and allow for rotation of the torso as well as side-to-side bending, with limited movement forward and backward.
- **Lumbar:** There are five lumbar vertebrae, L1 to L5. They are much larger than the thoracic and cervical vertebrae and allow for bending forward and backward, with limited side-to-side bending.
- **Sacral:** Five sacral vertebrae are fused together to form the sacrum. The sacrum connects the spine to the pelvis and provides strength and stability.
- **Coccygeal:** The four coccygeal vertebrae are partially fused and form the coccyx, commonly referred to as the tail bone. While the coccyx provides slight support for the organs in the pelvis, it has very little function in the human body.

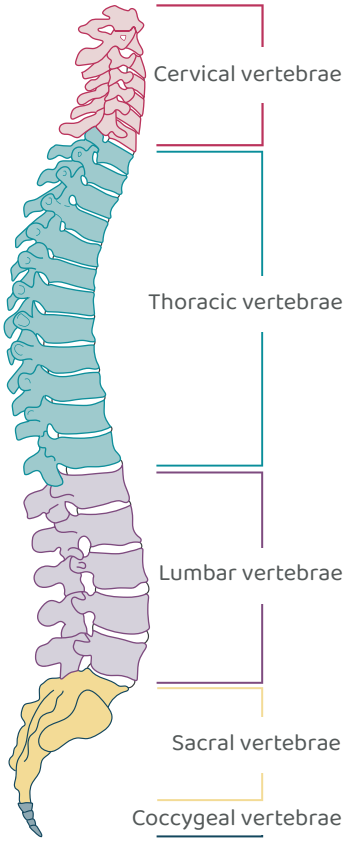


Figure 1.2.2 The five regions of the spine.

Typical spine curvature

In addition to the different structures of vertebrae and types of motion in each region of the spine, each region has a unique typical curvature. The typical curvature is also referred to as the natural curvature of the spine. When looking at a person straight on, the spine appears straight. In contrast, when looking at the side view of a person, the spine has distinct curvature. The direction of these curvatures is defined using two key terms: lordosis and kyphosis.

- **Lordosis** is an inward curvature, arching toward the center of the body.
- **Kyphosis** is an outward curvature, rounding away from the center of the body.

Figure 1.2.3 shows the typical curvature of the spine: a slight cervical lordosis, thoracic kyphosis, lumbar lordosis, and sacral kyphosis. These curvatures represent the body's preferred alignment when in an upright position and allow for an equal distribution of weight across the spine.[5]

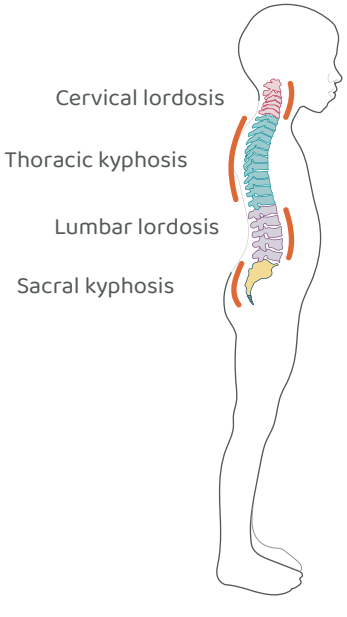


Figure 1.2.3 The typical (natural) curvature of the spine.

Spine development

Vertebrae begin to develop early in pregnancy. Around three weeks after conception, the vertebrae and ribs of the developing baby begin to form from cartilage that is later replaced by bone cells. This process of cartilage being replaced by bone cells, also called ossification, continues until about age 25.[6]

The spinal curvatures also begin developing during pregnancy and continue through childhood. Kyphosis curvatures form while the baby lies in a naturally curved (fetal) position in the uterus. In contrast, the lordotic curvatures form later in childhood: cervical lordotic curvature when babies begin to support the weight of their head, and lumbar lordotic curvature when children begin to support their body weight through standing. Because of when these curvatures develop, kyphosis is often referred to as a "primary" curvature of the spine, and lordosis as a "secondary" curvature.

Anatomical planes

Our bodies exist in three dimensions of space. Anatomical planes are imaginary divisions of the body. Anatomical planes are especially useful when discussing the spine because the typical curvature of the spine differs in each plane. Figure 1.2.4 shows the body divided into cross-sections in three anatomical planes:

- **The axial plane** separates the upper and lower halves of the body. As the observer looking at the axial plane of the body, you are above a standing person, looking down at the top of their head. This is also referred to as the transverse plane. The term "axial plane" is used throughout this book.
- **The coronal plane** separates the front and back of the body. As the observer looking at the coronal plane of the body, you are looking at a person who is facing you straight on or away from you. This is also referred to as the frontal plane. The term "coronal plane" is used throughout this book.
- **The sagittal plane** separates the left and right sides of the body. As the observer looking at the sagittal plane of the body, you are

looking at the side view of a person. This is also referred to as the lateral plane. The term "sagittal plane" is used throughout this book.

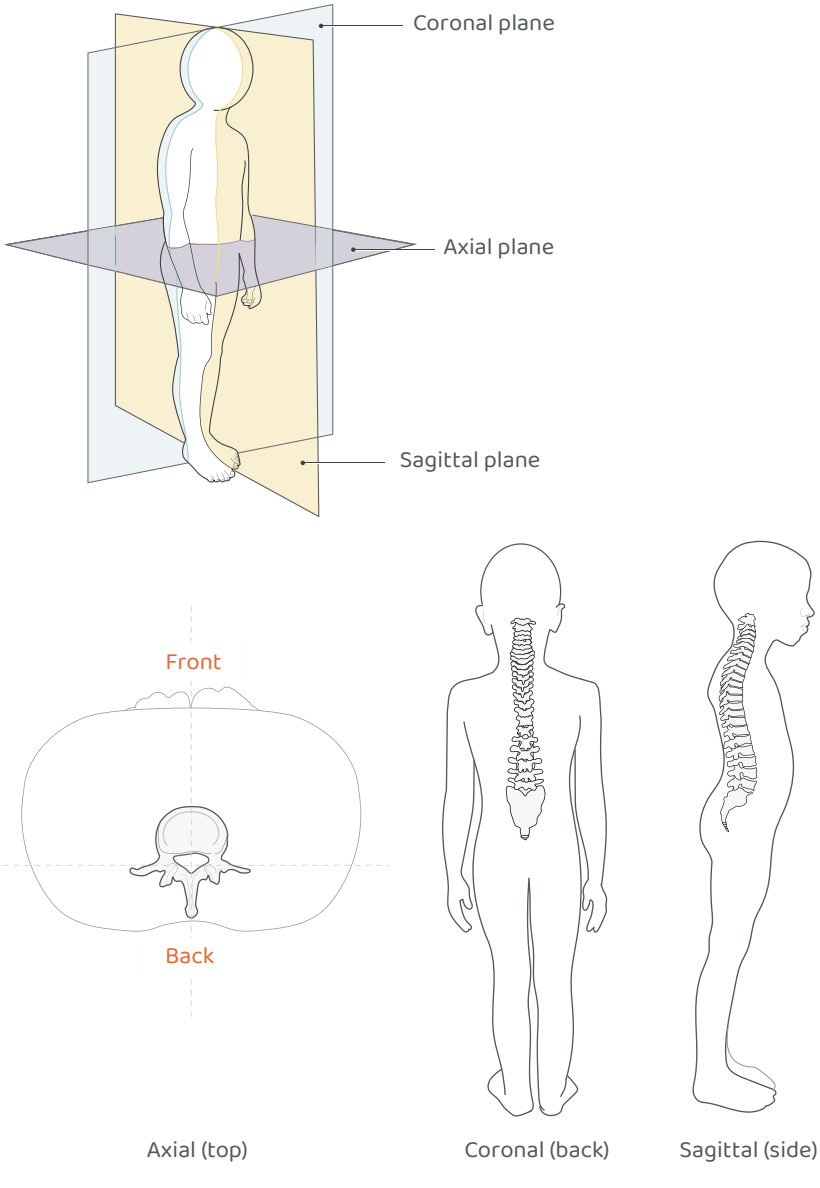


Figure 1.2.4 Anatomical planes on a human body (top) and applied to the spine (bottom).

A typical spine when viewed in the coronal plane is straight but has a notable curvature in the sagittal plane (see Figure 1.2.4). The coronal view shown in the figure is of a person facing directly away from you and shows the back of the person's body. A spine specialist will often examine the spine (in person and in X-rays) from the back. **Note:** "Spine specialist" refers to an orthopedic spine surgeon or advanced practice provider.* At some medical centers, a neurosurgeon may manage the individual's scoliosis instead of an orthopedic spine surgeon.

* In the US, an advanced practice provider (APP) is a health care provider who is not a physician but who performs medical activities typically performed by a physician. This includes a physician assistant (PA) and a nurse practitioner (NP), both medical professionals who complete graduate schooling, have greater medical privileges than nurses, and work on the care team. These roles may have different titles in other countries.

instead of a rectangular vertebra). Similarly, hypolordosis has other causes such as structural differences in the vertebrae.

See Appendix 1 (online) for a detailed list of causes of hyper- and hypokyphosis, and hyper- and hypolordosis.

Scoliosis

Scoliosis is characterized by rotation (twisting) in the axial plane, sideways curvature in the coronal plane, and flattening or exaggeration of curvature in the sagittal plane (Figure 1.3.3). While the largest change from typical spine curvature occurs in the coronal plane, scoliosis is described as three dimensional because it affects the spine in all three anatomical planes.

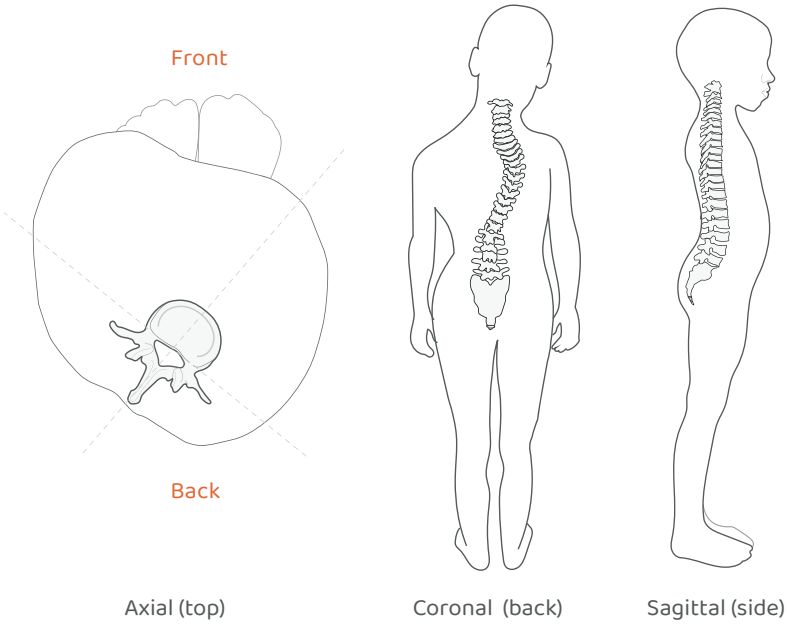


Figure 1.3.3 An example of spinal curvature associated with scoliosis in the axial, coronal, and sagittal planes.

1.4

Classification of scoliosis

Two roads diverged in a wood and I—
I took the one less traveled by,
And that has made all the difference.
Robert Frost

The two most common factors by which scoliosis is classified are cause and age at diagnosis. Classification is useful for describing someone's scoliosis and how it may progress. It also helps medical professionals make care decisions and recommend treatment options.

By cause

There are five types of scoliosis classified by cause:

- Idiopathic
- Congenital
- Neuromuscular
- Syndromic
- Other

See Table 1.4.1 for details.

Table 1.4.1 Classification of scoliosis based on cause

TYPE	CAUSE
Idiopathic	The term "idiopathic" means there is no known cause. With idiopathic scoliosis, the spine grows in a curved and rotated fashion for unknown reasons.
Congenital	The term "congenital" means present from birth. Congenital scoliosis is caused by errors in vertebral development. The child is born with an atypical spine (atypical vertebrae and/or atypical intervertebral discs) that can cause atypical growth of the spine, resulting in scoliosis.
Neuromuscular	The term "neuromuscular" means a condition involving the nervous system and/or muscles; it includes conditions such as cerebral palsy. Because nerves and/or muscles are affected, it can prevent the body from being able to physically support a growing spine, resulting in scoliosis.
Syndromic	The term "syndromic" means a group of symptoms that consistently occur together. Syndromic scoliosis is caused by a syndrome, such as Marfan syndrome or Down syndrome. These conditions can cause connective tissue (e.g., bone, blood vessels, cartilage, ligaments, tendons) to weaken, resulting in scoliosis.
Other	Other causes of scoliosis include conditions such as neural axis abnormalities, which are atypical structures within the central nervous system (brain and/or spinal cord) that can impact the growth of the spine.

By age of diagnosis

Scoliosis can also be classified by the age of diagnosis. One age-based classification is early-onset scoliosis (EOS), which is defined as scoliosis that is diagnosed prior to 10 years of age, regardless of cause or type.

There are also age-based classifications specific to idiopathic scoliosis:

- Infantile idiopathic scoliosis (IIS)—age of diagnosis 0 to 3 years
- Juvenile idiopathic scoliosis (JIS)—age of diagnosis 4 to 9 years
- Adolescent idiopathic scoliosis (AIS)—age of diagnosis 10 to 18 years

Key points Chapter 1

- The spine consists of vertebrae (bony structures with a hole for the spinal cord) and intervertebral discs (cartilage structures that sit between vertebral bodies).
- The spine protects the spinal cord, serves as an attachment point for the ribs and supporting muscles and ligaments, supports the weight of the body, and provides points of movement for the head and torso.
- Humans have 33 vertebrae, which are commonly grouped into five regions of the spine: cervical, thoracic, lumbar, sacral, and coccygeal.
- When looking at the side view of a person, the spine has distinct curvature. Lordosis is an inward curvature (arching toward the center of the body) and kyphosis is an outward curvature (rounding away from the center of the body).
- Typical spine curvature is a slight cervical lordosis, thoracic kyphosis, lumbar lordosis, and sacral kyphosis.
- Scoliosis is a condition in which there is an atypical three-dimensional curvature and rotation of the spine. The largest change from typical spine curvature occurs in the coronal plane.
- There are five types of scoliosis, classified by cause: idiopathic, congenital, neuromuscular, syndromic, and other.
- Idiopathic scoliosis is scoliosis that develops from an unknown cause. It is the most common type of scoliosis (affecting between 0.5 to 3.0 percent of the population).
- While diagnosis and treatment can be challenging, individuals with idiopathic scoliosis can expect to lead typical lives.
- Early-onset scoliosis (EOS) is scoliosis diagnosed prior to 10 years of age.
- The presence of scoliosis is verified by a spine specialist through X-ray images and a physical exam.
- The Cobb angle is the angle between the two most tilted vertebrae at the upper and lower ends of a spinal curve, as measured with X-ray images. Scoliosis is diagnosed when the Cobb angle on the coronal view is 10 degrees or greater.
- The diagnosis of idiopathic scoliosis is not assigned until all other possible causes are ruled out (diagnosis of exclusion).

There are many nuances to treatment recommendations. In addition to identifying the risk of curve progression, it is also important to consider the unique needs of the individual. The suggested treatment should be feasible for families to adhere to and match the individual's goals for function and quality of life. Decisions can be made using a shared decision-making model that includes the perspectives of the spine specialist and the individual and their family.

An overview of treatment options follows. Specific treatment indications and management strategies are addressed in Chapter 3.

Overview of treatment options and goals

Treatment options for scoliosis can range from nonsurgical methods, such as observation with repeat X-rays, to surgical methods, such as spinal fusion. Treatment options include the following (note that goals are shown in italics):

- **Observation:** Regular spine X-rays and clinical exams with a spine specialist *to monitor scoliosis curve for possible progression.*
- **Bracing:** A spinal brace that applies corrective forces to the spine *to slow or stop scoliosis curve progression.*
- **Casting:** A full-torso cast (hardened plaster or fiberglass that must be cut off to remove) that applies corrective forces to the spine *to improve the scoliosis curve (decrease the Cobb angle) or slow or stop scoliosis curve progression.*
- **Surgery:** Surgery performed *to prevent future progression and improve the scoliosis curve (decrease the Cobb angle).* There are many types of scoliosis surgery. The most common type is spinal fusion, defined as fusing (joining together) two or more vertebrae in the spine; screws and metal rods are typically used to hold the spine in the straightened position and facilitate fusion between bones.

These treatment options are shown in Figure 2.4.2.

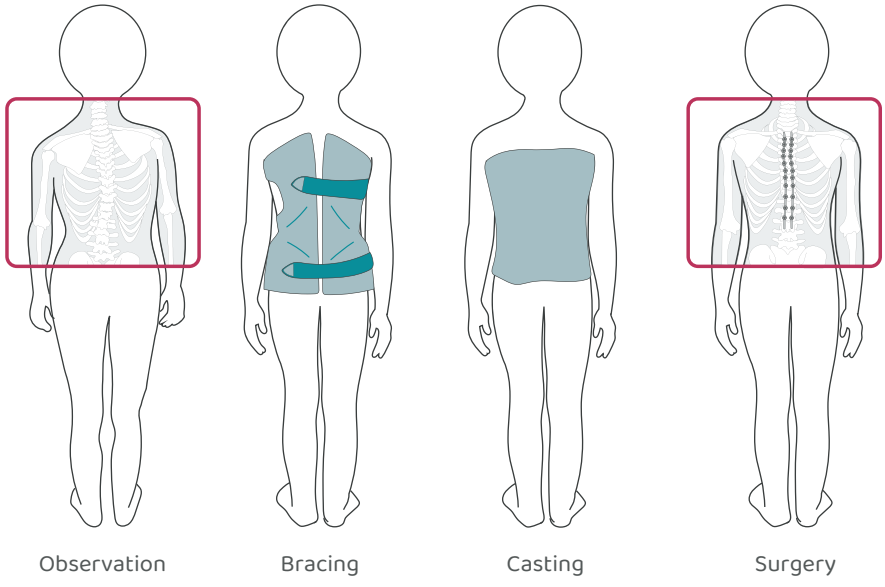


Figure 2.4.2 Four treatment options for idiopathic scoliosis.

As the child grows, the scoliosis progression may slow or increase, resulting in treatment plans changing. It is common for an individual to undergo multiple treatment types over the course of their childhood and adolescence. For example, an individual may be observed for a period of time, then prescribed bracing treatment if their curve progresses.

The appropriate treatment chosen and the related goals depend primarily on individual patient goals and specific surgical indications. Indications include, but are not limited to, size of the curve, risk of curve progression, and skeletal maturity of the child. A summary of the current indications and goals of treatment for scoliosis at Gillette Children's is given in Table 2.4.1. Treatment indications and goals may vary at other hospitals and treatment centers. Surgical guidelines are general and depend on the surgery type (see Chapter 4 for surgery types). Clinical practice continually evolves.

It is important to note that for *most* individuals, scoliosis cannot be "cured" (i.e., to achieve a Cobb angle less than 10 degrees). For some children with IIS, their curve may spontaneously resolve, or casting treatment can reduce the curve to less than 10 degrees, but that is the exception. The more common outcome and realistic goal is to have

a small enough residual curve after treatment that will not adversely affect quality of life.

Tana

Lila first met with the spine specialist shortly after she turned 12, the summer before she was starting middle school and during COVID restrictions. During that appointment, he told Lila she would need to be fitted for a brace to wear during the day. I could see Lila getting emotional behind her mask and tears welling up in her eyes. She held it together just long enough to get back to our car. Before I could say anything, she looked at me and asked, "Why is there so much wrong with me?" I instinctively responded, "There is so much that is right with you." And I meant it. I mention this because I think it set the tone for the months and years to come on Lila's scoliosis journey. Since then, while I'm certain she has had difficult feelings and thoughts, I have never heard Lila ask, "Why me?" Instead, she has faced every stage of her scoliosis with appreciation and determination.

As soon as we were home from that appointment, I immediately started researching types of scoliosis braces on the Internet. I think I was also hoping to find that the scoliosis brace that I knew kids were wearing 30 years ago had been reinvented. I saw some braces online that looked like sports bras, and secretly hoped this was all Lila would need to wear. I didn't share any of this information with Lila.

We also told Lila's brothers about her having to wear a brace, explaining what it was and why and when she would need to wear it. As a family, we agreed that we would support Lila any way we could, and that this was Lila's information to share with whomever she was comfortable sharing it with. We consistently reminded Lila that her wearing a brace did not affect who she is in any way.

Lila

At my first appointment, the doctor suggested a back brace for me that I would wear 18 hours a day. This was a shock to me as I hadn't really known what to expect at this appointment. I finally started to understand what my scoliosis treatment might look like when the doctor showed me a sample brace, explaining how I would put it on using the Velcro straps on the back and sliding my body through a small gap in the side, pointing out the padding in the sides.

The orthotist took some measurements of my back and explained the interesting shape and what the cutouts in the brace design were for. I felt very emotional about it all and I was very opposed to the idea of wearing a brace; I didn't want to talk about it anymore. My mom was with me at that appointment, and afterwards, we sat in the car and cried for a while. Everything that had been worrying me felt better as I cried, and my mom tried to help me understand a little more about the bracing.

Overall IIS management philosophy

Based on the current Cobb angle, rib phase, RVAD measurements, and observed changes with time, spine specialists determine if the curve is progressing or resolving. If it is resolving, observation is recommended with appropriate follow-up X-rays. For curves that are progressing, the best treatment plan will be recommended. This treatment recommendation may change over time depending on the amount of curve progression the child experiences, the assessed risk of further progression, and the response to treatment.

Often, with small scoliosis curves, the best treatment is observation. Children with IIS have a large amount of "growth potential," meaning they will experience a lot of skeletal growth during their first three years of life. Because skeletal growth is closely related to scoliosis curve progression, spine specialists will want to closely monitor a child as they grow to prevent rapid curve progression. If the scoliosis curve progresses during observation, further treatment options will be considered. At this stage, it is typical to recommend nonsurgical treatment

such as wearing a brace or cast to stabilize or correct the scoliosis curve. Surgical treatment is highly unlikely during the first three years of life.

Overall JIS management philosophy

Most children with JIS require treatment for their scoliosis.[17] However, observation may be appropriate in individuals who have a small scoliosis curve (less than 20 degrees) at diagnosis. If the scoliosis curve progresses, the recommendation is often to begin wearing a brace to either prevent further progression and avoid surgery, or to slow the progression enough to delay surgery. Surgical options for individuals with EOS can carry risks and high complication rates.[14] Therefore, spine specialists often hope to delay surgery in children with JIS to allow the child to reach an appropriate level of thoracic growth (chest height and width), in turn allowing their lungs to continue developing prior to surgical treatment. For individuals who experience curve progression despite brace treatment, surgery will be recommended once deemed necessary.

Overall AIS management philosophy

As opposed to identifying if the curve is progressive or resolving (as with IIS) or evaluating if the individual has reached an appropriate level of thoracic growth (as with JIS), most treatment decisions for AIS are made based on the individual's current curve size and their level of skeletal maturity. At this age, individuals have typically grown to a point that chest and lung size are no longer a concern as they are in JIS. Instead, general risk of scoliosis curve progression (based on curve size and skeletal maturity) will guide treatment recommendations.

For example, skeletally immature (still growing) individuals with a small- to moderate-size curve can wear a brace to slow or stop progression and reduce the likelihood of surgery.[32,33,34,35] In contrast, bracing is not an appropriate treatment option for individuals who are skeletally mature (almost finished or finished growing). Similarly, for surgery, a skeletally immature individual with a 45-degree curve may be considered appropriate for surgical intervention due to their likelihood of continued growth and curve progression. In contrast, surgery may not be

considered to treat a 45-degree curve in an adolescent nearing skeletal maturity because they are at lower risk of continued progression.

Table 2.4.1 Treatment options, indications, and goals for idiopathic scoliosis at Gillette Children's

TREATMENT OPTIONS	INDICATIONS	GOALS
Observation		
IIS	Cobb angle less than 20 degrees	Monitor scoliosis curve through repeat X-ray images for possible progression
JIS	Cobb angle less than 20 degrees	
AIS (skeletally immature)	Cobb angle less than 20 degrees	
AIS (skeletally mature)	Cobb angle between 30 and 50 degrees	
Bracing		
IIS	Cobb angle 20 to 45 degrees AND either: • RVAD greater than 20 degrees OR • Rib phase 2	Slow or stop scoliosis curve progression Prevent or delay surgery
JIS	Cobb angle between 20 and 45 degrees	
AIS (skeletally immature)	Cobb angle between 20 and 45 degrees	
AIS (skeletally mature)	Not an appropriate treatment once skeletally mature	
Casting		
IIS	All the following: • Age 1 to 3 years • Cobb angle greater than 20 degrees • RVAD greater than 20 degrees OR rib phase 2	Slow or stop curve progression Improve the scoliosis curve (decrease the Cobb angle) Prevent or delay surgery

Cont'd.

TREATMENT OPTIONS	INDICATIONS	GOALS
Casting		
JIS	Not typically recommended for individuals older than 3 years.	
AIS (skeletally immature)	Not typically initiated for individuals older than 3 years.	
AIS (skeletally mature)	Not typically initiated for individuals older than 3 years.	
Surgery		
IIS	Unlikely during the first three years of life; only considered if the scoliosis continues to progress and has a negative impact on the child's health and quality of life	Stop curve progression Improve the scoliosis curve (decrease the Cobb angle) Allow continued spinal growth
JIS	Cobb angle greater than or equal to 40 to 50 degrees, depending on surgery type and level of skeletal maturity OR if the scoliosis continues to progress and has a negative impact on the child's health and quality of life	
AIS (skeletally immature)	Cobb angle greater than or equal to 40 to 50 degrees, depending on surgery type and level of skeletal maturity.	Stop curve progression Improve the spinal curve (decrease the Cobb angle) Achieve a balanced spine and posture
AIS (skeletally mature)	Cobb angle greater than 50 degrees	

Evidence-based medicine and shared decision-making

Evidence-based medicine (or evidence-based practice) is "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients."[36] It combines the best available external clinical evidence from research with the clinical

Key points Chapter 2

- Individuals with a first-degree family member with idiopathic scoliosis have a higher chance of developing it.
- Idiopathic scoliosis is classified based on age at diagnosis—infantile (0 to 3 years), juvenile (4 to 9 years) and adolescent (10 to 18 years).
- It is common for infantile idiopathic scoliosis (IIS) to resolve and straighten out naturally without treatment, whereas this is rare for juvenile idiopathic scoliosis (JIS) and adolescent idiopathic scoliosis (AIS).
- Due to the presence of a scoliosis curve prior to the adolescent growth spurt, individuals with JIS are at higher risk of severe curve progression than those with AIS.
- The general treatment philosophy for idiopathic scoliosis focuses on preventing curve progression. The larger the curve, the greater the likelihood of continued progression and for it to have a negative impact on the individual's health and quality of life.
- The main concerns with untreated severe idiopathic scoliosis include cardiopulmonary function, back pain, and psychosocial (psychological and social) challenges.
- Early scoliosis treatment is important to prevent surgical intervention, optimize growth and development, and minimize surgical risks.
- Spine specialists use several factors to estimate how much growth a child has remaining: age, height tracking, signs of puberty, and skeletal maturity (using X-ray images of the hand, pelvis, or upper arm).
- Scoliosis treatment options include observation, bracing, casting, or surgery. It is common for an individual to undergo multiple treatment types.
- If children with IIS experience curve progression, it is typical to recommend nonsurgical treatment such as wearing a brace or cast.
- Most children with JIS require treatment. Spine specialists often aim to delay surgery in children with JIS to allow the child to reach an appropriate thoracic growth for optimal cardiopulmonary function prior to surgery.
- The best practice for managing idiopathic scoliosis is to have a care team skilled in providing scoliosis care engaging with a family in a shared decision-making model.

Table 3.1.1 Nonsurgical treatment of scoliosis

TREATMENT	EXPLANATION OF TREATMENT
Observation	Regular spine X-rays and clinical exams with a spine specialist to monitor scoliosis curve progression
Bracing	A spinal orthosis (removable brace) that applies corrective forces to the spine to slow or stop scoliosis curve progression
Casting	A full-torso cast (hardened plaster or fiberglass that must be removed by a clinician) that applies corrective forces to the spine to reduce the scoliosis curve size or stop/slow scoliosis curve progression; also used to improve balance and alignment of the torso
Physical therapy scoliosis-specific exercises (PSSE)	Exercise sessions with a specially trained physical therapist; involves stretching, strengthening, postural corrections, breathing techniques, and education to help the individual control their posture independently
Vitamin D_3 and calcium supplements	Daily vitamin D_3 and calcium supplements to help with low bone density in individuals with idiopathic scoliosis and that may slow scoliosis curve progression[39,40]

The overall goal of nonsurgical treatment is to slow or stop curve progression to prevent or delay surgery. Thus, early intervention with nonsurgical treatment is encouraged to optimize outcomes and maximize an individual's chance of avoiding future surgery. The decision of which and when nonsurgical treatments are appropriate is shared between the family and medical care provider.

USEFUL WEB RESOURCES

Key points Chapter 3

- Nonsurgical treatment of scoliosis is treatment that does not require surgery.
- The overall goal of nonsurgical treatment is to slow or stop curve progression to prevent or delay surgery.
- Observation for scoliosis requires regular X-rays and clinical exams with a spine specialist.
- Candidates for observation are deemed to have a low risk of scoliosis curve progression.
- The most common type of spinal brace is the thoraco-lumbo-sacral orthosis (TLSO). It is typically made from molded, rigid plastic that extends from the armpits down past the hips.
- The two types of TLSOs are full-time (prescribed for 18 to 23 hours per day) and nighttime hypercorrective (prescribed for 8 to 12 hours per day).
- In most cases of idiopathic scoliosis, wearing a brace does not improve or straighten the curve. Instead, the goal of treatment is to prevent the curve from progressing.
- Successful bracing treatment in AIS is correlated with wear time.
- Cast treatment involves the application of plaster to the torso, molded to the child's body. This plaster hardens into a cast.
- Casting is typically carried out only for individuals with IIS.
- The goal of casting in children with idiopathic scoliosis under the age of two years is to "cure" scoliosis (end treatment with a curve less than 10 degrees).
- Physical therapy scoliosis-specific exercises (PSSE) is a type of physical therapy that aims to help the individual with scoliosis control their posture.
- Physical therapy may occur before, during, or after other scoliosis treatment and is considered an add-on or complement to other scoliosis treatment.
- Alternative and complementary treatments (chiropractic therapy, yoga, Pilates, acupuncture, massage) may be helpful add-ons to the current scoliosis treatment plan but should not replace the current treatment plan.

Table 4.1.1 Description of scoliosis surgeries

TREATMENT	DESCRIPTION OF SURGERY
Spinal fusion	Fusing (joining together) two or more vertebrae in the spine to stop curve progression and improve the angle of the curve (decrease the Cobb angle), typically performed using metal rods and screws or hooks to hold the spine in a corrected position and facilitate fusion between bones.
Growth-friendly treatment	Improving the angle of the scoliosis curve (decreasing the Cobb angle) by using metal rods and screws or hooks to stabilize the spine above and below the curve. The length of the metal rods can be expanded over time. This includes traditional growing rods and magnetically controlled growing rods (MCGRs).
Vertebral body tethering (VBT)	Inserting screws and attaching a rope (tether), which is under tension, to the convex side of the scoliosis curve (the outside of the curve). As the individual grows, the growth on the convex side of the curve is slowed, allowing the concave side (the inside of the curve) to continue to grow and allowing the spine to straighten.

The specific goals of each scoliosis surgery differ, but the overall goals of scoliosis surgery are to:

- Stop curve progression
- Improve the spinal curve (decrease the Cobb angle)
- Achieve a balanced spine and posture

This chapter also discusses halo gravity traction, which is a multistage treatment for severe scoliosis to stretch and straighten the spine and soft tissues (skin, muscle, ligaments) *prior* to scoliosis surgery (see section 4.7).

Scoliosis surgeries are overwhelmingly safe, and spine specialists recommend a surgery only if they believe the benefits outweigh the potential risks for the individual. But there are risks with any surgery. Surgical risks are things that may go wrong while in or shortly after surgery while the individual is still in the hospital (in-hospital complications). Long-term complications are problems that may occur after the individual has been discharged from the hospital and may develop over the course of months or even years following surgery. Risk management is

the highest priority for hospitals and spine specialists, and many safety measures are in place to maximize safety. However, it is important for families to be aware of these risks and discuss them as part of the shared decision-making process.

Tana

The discussion of Lila potentially needing surgery occurred about 18 months after she had begun bracing. Nothing was different with Lila's spine as far as she was concerned—she didn't have pain, and the only discomfort was generally caused by the brace. Her curvature was noticeable only when she wore a swimsuit, but family members commented that they would never have known that she had scoliosis if they hadn't been told. But at this appointment, the doctor shared his concern that Lila's spinal curves had continued to worsen. She was also 13 years old and had not yet had her large growth spurt. That meant her curves were likely to continue to worsen and she would likely need surgery at some point.

Getting that news at this appointment derailed all plans we had for the day. Even though it was an early-morning appointment, Lila did not make it to school that day, and I didn't make it to work. She had an additional test or two as ordered by the doctor, more meetings with the doctor, and another with the orthotist for brace adjustments.

Lila

Talk of surgery first came up at one of my appointments when the doctor said that the brace might not be doing enough for my back and that the curve degrees were still increasing. At a later appointment, the doctor told me about the different types of surgeries I could get, one being a tether (VBT), which is basically a small rope inside of your back adjusting the curve over time. The other option is the fusion, which is having a metal rod placed in your back, which sounded very scary in my opinion (even though it is known to be effective and safe). The doctor said I was the perfect candidate for the tether surgery since I had the right amount of growth left.

On the way home from that appointment, my mom asked me how I felt about getting surgery. I was emotional because I felt bad for everyone having to do so much to help me, but I answered, "Good, because everyone is doing everything that they can to help me." My parents, still to this day, like to tell me how brave and strong I am for being so positive even though I have had to deal with a lot of things that other kids will never have to. I have always thought that I was given all the special things because I can handle it. Now looking back on it, I am so glad that I was given all these obstacles to deal with because I learned that life isn't perfect. I also learned how to deal with that, to stay positive, and to understand that all these experiences will make me a better person. I want to help others when I am older because I want to give back to all the people who have helped me.

USEFUL WEB RESOURCES

Key points Chapter 4

- The overall goals of scoliosis surgery are to stop curve progression, improve the spinal curve, and achieve a balanced spine and posture.
- All surgical procedures have potential risks and complications.
- Spinal fusion is the most common type of scoliosis surgery. It involves fusing (joining together) two or more vertebrae in the spine. Typically, metal rods and screws (termed "instrumentation" or "implants") are used to hold the spine in the straighter position and facilitate fusion between the bones.
- Spinal fusion halts the growth of the spine and is generally not appropriate for very young children.
- Growth-friendly treatment refers to treatment that places surgical instrumentation (metal rods and screws or hooks) in the spine without fusing (permanently joining together) the vertebrae or with limited fusion. The length of the metal rods can be expanded over time to limit curve progression or partially correct curves while allowing a young child to continue to grow.
- Traditional growing rods are manually lengthened during surgical procedures under general anesthesia.
- Magnetically controlled growing rods (MCGRs) are lengthened via a magnetic remote control in clinic.
- Removal of instrumentation and conversion to spinal fusion is the most common next step following the end of growth-friendly treatment.
- Vertebral body tethering (VBT) involves the surgical placement of screws in the vertebrae and is a fairly new surgery option. The screws are placed on the convex side (outside) of the curve and then connected by a rope, referred to as a tether.
- Spinal fusion is the most common and predictable treatment for AIS, however VBT has become increasingly popular for the following potential benefits: maintenance of spinal range of motion, maintenance of spine growth, less invasive surgery, and quicker recovery and return to activities.
- Reported complication rates are significantly higher for VBT than they are for spinal fusion.

Key points Chapter 5

- In most cases, an individual will have a mild curve (less than 35 degrees) at the time of skeletal maturity. For these mild curves, routine check-ins with a spine specialist are not necessary in adulthood.
- Individuals with more moderate curves (35 to 49 degrees), may be recommended to transition to adult care once they are skeletally mature.
- It is highly recommended that individuals with a Cobb angle of 50 degrees or greater undergo surgery. Skeletally mature individuals who have not received surgical treatment for their scoliosis with a Cobb angle of 50 degrees or greater are at higher risk of curve progression throughout adulthood.
- Health care transition is the planned process and skill-building to empower adolescents and their families to navigate an adult model of health care.
- Pediatric services for scoliosis care are usually much better resourced and are more proactive in following up with the individual than adult services.
- Following up with a spine specialist is recommended for all individuals with scoliosis if spine-related symptoms arise, such as signs of scoliosis progression, loss of height, or persistent back pain.
- Individuals with idiopathic scoliosis may experience higher rates of degenerative changes in the spine than individuals in the general population.
- Most individuals treated for idiopathic scoliosis (by observation, bracing, and/or surgery) typically live healthy and active adult lives relatively unaffected by their condition.
- Most women with scoliosis can conceive, carry, and deliver healthy babies without significant changes in their care or increased risk to mother or baby.

What lies behind us and what lies before us
are tiny matters compared to what lies within us.
Oliver Wendell Holmes

In this chapter, people share stories of living with idiopathic scoliosis.

Brett and Lindsey, parents of six-year-old Andrew, with infantile idiopathic scoliosis (IIS), from Minnesota, US

As a baby, Andrew was joyful, healthy, and relaxed—easy compared to his big brother—and he was meeting developmental milestones. When he was about seven months old, we noticed he favored his left side and often propped himself up on his left elbow. When rolling from tummy to back, he only ever rolled one way, and in the high chair, he predominantly used his left hand. At his nine-month appointment, the pediatrician ordered X-rays and made a referral to a pediatric orthopedic spine specialist.

On April 23, 2018, the day before Andrew turned 10 months old, we received a diagnosis of progressive infantile idiopathic scoliosis. His supine (lying down, face up) X-ray showed his spine had a curve of 65 degrees and a rib vertebral angle difference (RVAD) of 40 degrees, a significant curve that's compounded by a twisting of the spine. A curvature of 70 to 80 degrees begins to impair lung and organ development and function, so we were told that swift medical intervention was required to minimize and hopefully correct the impact.

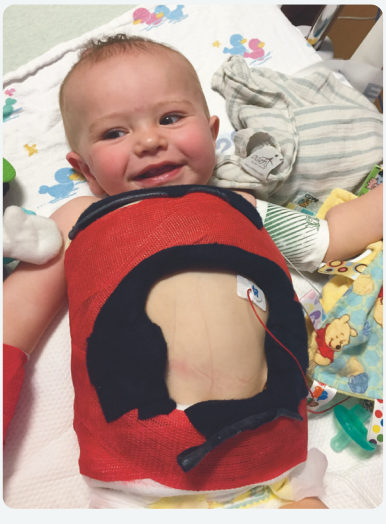
The diagnosis was frightening and completely turned our world upside down. Our healthy and happy baby suddenly needed the urgent attention of specialists. We were filled with fear and consumed by what this meant for our son's future. We scoured the Internet for resources and information about children who have had this diagnosis and were left with

few beneficial resources and many scary stories. Later, we discovered a community on social media that quickly became our trusted source for information and ideas, outlet for frustration, and giver of endless support.

Our doctors advised us that we should move to Mehta casting as soon as possible. Because Andrew was approaching his first birthday, we were acutely aware that our window for a potential cure was closing quickly. We agreed that casting would be the best nonsurgical option.

Andrew got his first cast on May 15 and was fussy and frustrated with it for about a week. He couldn't move around like he was used to, the bulk of his cast kept him from reaching and even seeing most of the food on his high chair tray, his tiny arms couldn't reach what he wanted, he couldn't find a comfortable seated position while on the floor, and it was impossible for him to get back up to a seated position from lying down. But he showed incredible resiliency and persistence, and within a week he'd figured out how to maneuver in a comfortable way.

Over the next 18 months, Andrew had five different casts, each one lasting between 6 and 12 weeks. We had several setbacks and scheduled breaks along the way, including one casting that had to be postponed because Andrew spiked a fever, but through it all, his curve continued to decrease.



Andrew in two different casts during casting treatment.

Having a casted baby brought about a whole new spectrum of challenges: The quantity of food he ate decreased dramatically, as the rigid cast restricted his stomach. Smaller frequent snacks became the norm. He lost some of his adorable baby chubbiness, and it was replaced with chiseled baby muscle from constantly hauling around a cast that weighed 20 percent of his own body weight.

Every crumb, noodle, grain, or drip had the chance of making its way down into the torso of his cast, which could lead to skin irritation, sores, and even ulcers. We quickly moved from using bibs to children's art smocks during mealtime.

Andrew playing in his cast.

Each diaper change held the possibility of a blowout. Since bathtime wasn't an option, frequent changes were necessary. We experimented with several different diaper brands and found one that worked best for Andrew's specific casts; the design was very high on the backside so we could tuck it between the cast and his lower back. And when blowouts happened (and they definitely did happen), we learned the power of using just a tiny bit of witch hazel to remove the urine-soaked moleskin smell from the cast.

Keeping Andrew's body temperature regulated was a struggle. We were told to expect him to get warm and overheat easily, but I didn't expect that would mean he would be sleeping in an air-conditioned house in just his diaper.

Messy play, finger painting, gardening, water play, sandboxes, sticky Popsicles, Play-Doh, bath time, and swimming were simply off the table. Having a child in a cast during the precious summer months of Minnesota was so frustrating.

Dressing him took some creativity. We found that the easiest way to clothe Andrew was with rompers or with full zipper sleeper pajamas. Anything with a waistband was out of the question with the fit of Andrew's cast.

Well-meaning strangers made comments about how big Andrew was, and on occasion, people we did not know would reach out and touch him. I know many people were just curious about what it was that was making him look so big and awkward, but it was an odd and irritating experience.

Following his fifth cast, Andrew's stubborn curve plateaued and was no longer responding. Under the advice of our doctors, we moved to bracing, which felt like a huge defeat. We were told that it was unlikely that bracing would provide continued improvement, and the goal now would be for Andrew's spine to hold at around 30 degrees.

Andrew in his brace.

Despite our disappointment that the casting had stopped working, the transition to bracing brought liberation, Andrew could bathe regularly again and take short breaks for swimming fun. However, this transition also landed during Andrew's fierce two-year-old struggle for independence, which meant that every day we were wrestling with an angry alligator to keep the brace on. That was the only time I ever missed casting, because once a cast is on it stays on! We're thankful this period was short for us and our easygoing Andrew soon returned.

We share our experiences and list of challenges with the hope that others will benefit from what we've learned. While frustrating at times, these specialized circumstances created opportunities for us to observe, listen, understand, and advocate for our son in a very deep way.

On July 2, 2021, 1,166 days, five casts, and two braces following Andrew's scoliosis diagnosis, we received the news we had been praying for: Andrew's curve was maintaining at under 10 degrees. He was cured! We cried, we celebrated, and we seriously considered having a cast-burning bonfire. We were so blessed through casting and bracing. And we could finally celebrate that the years spent worrying about Andrew's future while being so delicately careful with his present were all worth it.

Sarah, mother of 15-year-old Jonathan, with juvenile idiopathic scoliosis (JIS), from Minnesota, US

I never thought much about scoliosis when I was growing up. I remember getting checked for it as a kid, bending over to touch my toes while the doctor looked to make sure my spine was straight. But I never knew anyone with scoliosis until I met my husband. We had been dating only a short while when I noticed that one side of his upper back stuck out more than the other; it was obvious even through his shirt. "Oh, I have scoliosis," he told me.

Never receiving care for it as a child, it was something he had had to live with as an adult. So when our children started having scoliosis checks during their well-child visits, I paid more attention than I maybe otherwise would have.

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"Our daughter was diagnosed with juvenile idiopathic scoliosis right before she started kindergarten, and we were so worried. We wish we had this book during that time as it answers so many questions."

—AMBER MARLATT, PARENT

"As up-to-date and inclusive as a textbook written for medical professionals while being as easily readable as a novel for children with scoliosis and their families. An indispensable source of comfort for all scoliosis patients."

—MUHARREM YAZICI, MD

Idiopathic scoliosis is a condition in which, for no known reason, there is an atypical three-dimensional curvature and rotation of the spine. Idiopathic scoliosis is the most common type of scoliosis. For the large majority of people with this condition, no specific intervention is needed. For others, treatment such as bracing or surgery is needed to effectively manage the condition. While diagnosis and treatment can be challenging, individuals with idiopathic scoliosis can expect to lead typical lives. This practical guide explains idiopathic scoliosis and the evidence-based, best-practice treatments. It also includes the lived experience of families.

The writing of *Idiopathic Scoliosis* was led by Tenner J. Guillaume, MD, Walter H. Truong, MD, and Danielle Harding, PA-C, spine specialists at Gillette Children's, a world-renowned center of excellence for the treatment of brain, bone, and movement conditions. *Idiopathic Scoliosis* is part of the **Gillette Children's Healthcare Series**, a series of books for families who are looking for clear, comprehensive information. Health care professionals, researchers, educators, students, and extended family members will also benefit from reading *Idiopathic Scoliosis*.

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