



5

THINGS I WISH I'D  
KNOWN WHEN OUR  
DAUGHTER WAS  
DIAGNOSED WITH  
**DOWN SYNDROME**

AMY JULIA  
BECKER



On December 30, 2005, our firstborn daughter came into the world. It was an easy delivery—a little early, but not premature, no signs of distress or trouble, just a shock of black hair and a puffy face, and eyes the color of the sea on a cloudy day. But two hours after Penny was born, we learned that she had Down syndrome, the presence of a third copy of chromosome 21 in every cell of her body. We thought we had been given terrible news.

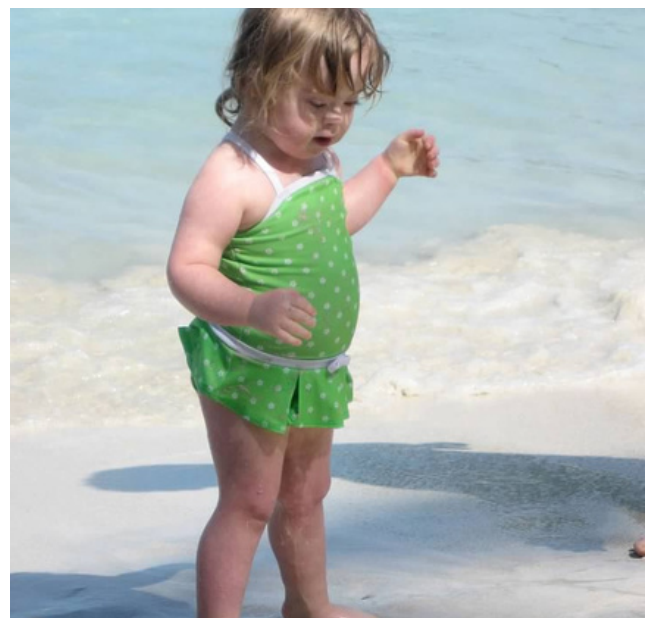
Now, I look back on that young mother, and I want to be able to hold her hand and look into her frightened, angry, sorrowful eyes and tell her not just that it will all be okay. I want to tell her why it will be more than okay. I want to tell her how her daughter will change her life in ways she never could have expected. I want to take her worry and grief and confusion. If I could, these next few pages are what I would say to her.

*Amy Julia Becker*

# 1

## YOU THINK DOWN SYNDROME MEANS TRAGEDY.

And people will compare your experience to that of losing a child in a car accident or to cancer or some other horrible fate. And though you will experience a sense of loss, you will realize eventually that you have lost a hypothetical child, and that the child right in front of you, this child, with her sparkling eyes and crooked teeth and warm soft hand, this child is a blessing. In time, because of the privilege of knowing and loving her, you will realize that your grief has turned to gratitude and that your worry has turned to wonder.



# 2

## YOU THINK DOWN SYNDROME MEANS ISOLATION.



PHOTOS BY ASHLEY MONOGUE | HOPE HEALS CAMP

But you will discover that instead it brings a world of connections. It's not only that you will now feel a bond with other parents of children with Down syndrome throughout the country and around the globe. It's that having a child who looks and acts somewhat different from what you expected, a child whom you see as beautiful and funny and kind and smart and brave, will help you to recognize that same beauty in everyone else.

You will think your world has become smaller, when it has only begun to grow.

# 3

## YOU THINK THAT DOWN SYNDROME MEANS HARDSHIP FOR YOU AND YOUR DAUGHTER.

You're right. As with any child, there will be sleepless nights. There will be doctors' visits. There will be a time when you find her sitting up in bed with eyes sunken into her head from dehydration after a stomach flu, and you will rush her to the hospital and she will stay for two days. There will be meetings with her teachers who talk about behavior plans. You will worry about her health, her ability to make friends, her future. And yet you will also realize that every life arrives with hardship. And every life arrives with the potential for inexpressible joy.



# 4

## YOU THINK DOWN SYNDROME MEANS SPECIAL TREATMENT.



And other people will, with very good intentions, treat her as if she can't learn and can't sit still and can't communicate. But you will believe in her abilities, and you will discover those abilities together. That she can communicate through sign language before she is able to talk with words. That she will work harder than any kid you've ever known as long as she is motivated, and that even though it takes longer for her, she will learn—to read, to swim, to tie her shoes, to use gentle hands with her baby sister. You will learn not to treat her as special, but as her own person, with particular struggles and particular gifts.

# 5

## YOU THINK DOWN SYNDROME MEANS GIVING MORE THAN YOU HAVE TO GIVE.

And some days it will feel that way, as it will with each of your children. But then she will come over to you, with your head in your hands after a fight with your son, and she will say, “Mom, should we pray?” She will come home from school and embrace you and say, “I had a happy day, Mom!” She will give back far more than she has ever taken. She will break your heart. Wide open. And you will be forever forever grateful.



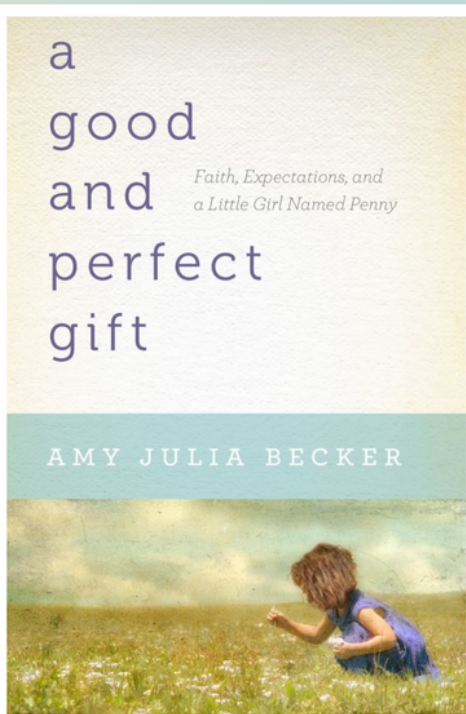


## I hope you'll also read *A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny*

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Recognized as one of the top 10 Best Books of 2011 by Publishers Weekly religion category, this book is a spiritual memoir about coming to understand that every human life is a gift.

A Princeton grad and seminary student pregnant with her first child, Amy Julia confronts her own prejudices and privilege when her daughter Penny is diagnosed with Down syndrome at birth. Covering the first few years of Penny's life, this story explores questions of faith, social structures, and what it means to live a full life.



## A Good and Perfect Gift

Faith, Expectations, and a Little Girl Named Penny

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Amy Julia Becker makes herself vulnerable to enlighten us, not just about Down syndrome, but about the intrinsic gifts of life. This book is a must-read, and not just for families and friends of children with Down syndrome.

**Sara Groves**

Singer and songwriter, International Justice Mission advocate

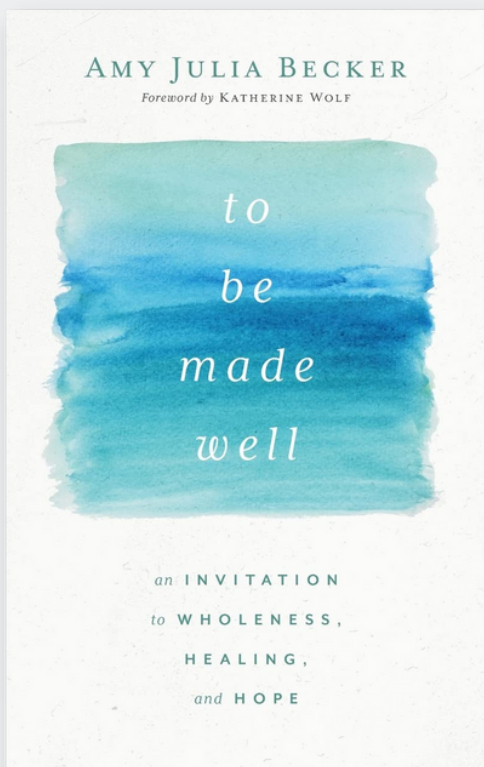




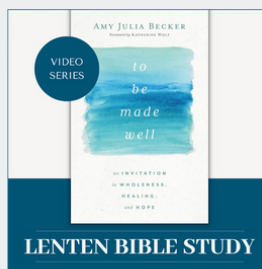
## Have you read *To Be Made Well*?

From hurting bodies and souls to hurting relationships and communities, it's clear that things are not as they should be. The gospels brim with stories of Jesus healing people, but what does that mean for us today? In *To Be Made Well*, I weave together my own story with reflections on biblical accounts of Jesus' healing work, providing fresh insight into both the nature of healing and the pathway to healing, then and now. This book is an invitation to personal, spiritual, and social healing as we reconnect to our bodies and souls, to God, and to our communities.

For anyone struggling with pain or loss, for anyone concerned about the things that divide us, this book goes beyond wellness and beyond miraculous physical transformations to explore how we can—personally and collectively—be made well.



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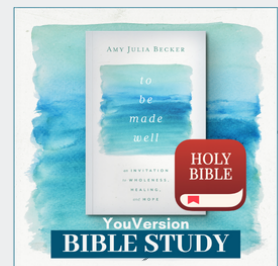
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# ABOUT AMY JULIA

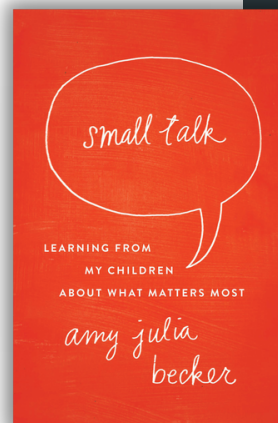
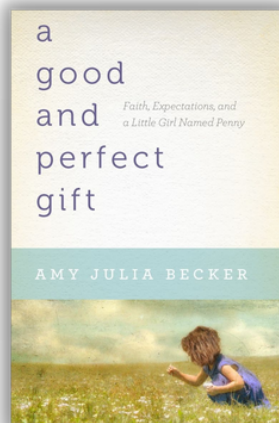
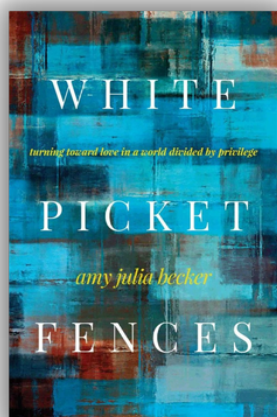
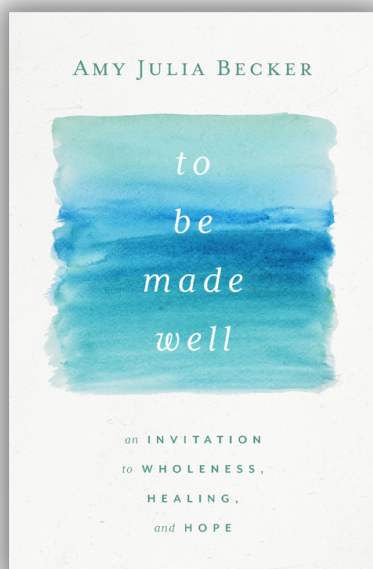
[amyjuliabecker.com](http://amyjuliabecker.com)

Amy Julia Becker is an award-winning writer and speaker on disability, family, faith, and culture. She is the author of four books, including *To Be Made Well: An Invitation to Wholeness, Healing, and Hope*, a guest opinion writer for national publications, and the host of the *Love Is Stronger Than Fear* podcast.

Becker is a graduate of Princeton University and Princeton Theological Seminary (MDiv). She lives with her husband and their three children in western Connecticut.

# BOOKS

FIND AMY JULIA'S BOOKS AT  
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