

# **Chosen For This Gift**

**My Story of Hope, Survival and Raising a Child with  
Special Needs**

**Barb Felt**

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[www.chosenforthisgift.com](http://www.chosenforthisgift.com)

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This book is dedicated to Amy Evelyn Felt. Her life has changed mine. She has given me the opportunity to see a side of life and love I would have missed without her. She has taught me more than any university could ever teach.



# SPECIAL THANKS

It is after midnight as I write this, another late night away from my number one supporter- my husband Russ. Thank you for standing by me each time I announced, “I finished the book!” only to work on it for another year. I love you.

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Thank you to so many of you who answered my question: "What is it like to have Amy in your life?" I would have loved to include all your responses in this book. Instead, they can be read on: [www.chosenforthisgift.com](http://www.chosenforthisgift.com)

# INTRODUCTION

When a baby is born, there is a presence in the room. I can't express in words what the presence is like. You want to laugh and cry at the same time. Your mind cannot comprehend this life that has been created. It is a high like no other. New life! All the pain and agony leading up to the birth is quickly forgotten when you hold that precious new baby in your arms. All your instincts kick in, and you want to nurture, protect and love this precious gift. A baby has an indescribable smell. Their skin is so soft, their hair as smooth as silk. But what happens if the baby is not who you are expecting? Then your mind and heart are reeling and you are filled with uncertainty. You had all these hopes and dreams that your child would grow up, get married, have children- be a success! Now what? If you are anything like I was, you are scared out of your mind.

If you have just given birth to a child with Down syndrome, don't despair. As you grow to love this new life, you will realize that you too have been given a gift. A very unique gift, that you should value and treasure, because you are entering a place where most people never go. It is the world of disability. In this world, you will find some of the most amazing people. People with true character. People who love unconditionally. People who need you, need your help, your love, and your acceptance. Those of us fortunate enough to enter this world experience love in its purest form. We experience life in a deeper way than we ever imagined. Get ready for unexplainable joy, concern and pain, happiness and

tears. Get ready to fight for your child! Get ready to experience genuine and true love.

I hope as you read my story, you will become convinced that through the trials, there are always triumphs. When we are weak, He is strong. I am desperate for my Lord. He is my life, my covering, my protector, my salvation. Every breath I breathe is from Him, and I will continue to strive to give Him glory until that grand day when we meet face to face. Until that time, I will be thankful that I was chosen for this gift, the gift of Amy.

Amy continues to impact my life and the lives of so many others. I would have never dreamed she would bring so much pleasure, happiness and joy. I am a better person because of Amy. Looking back at all the struggles, all the unknowns, this much I do know: Amy is priceless, and being her mom has been one of the most rewarding experiences in my life. I truly was chosen for this gift.

# Chapter One: The Gift

We already had six children, but my husband Russ felt a longing to have another. On my birthday, my mom and I went out for lunch. I told her Russ wanted another baby. I asked her what she thought. I was sure she would say, “What? After all you have been through, you have had enough!” Instead, she said, “When you are seventy, you will never regret it!” So that June, I wrote Russ a note in church on Father’s Day saying, “My gift to you for Father’s Day is... I agree to have another baby.” The next month I was pregnant.

My seventh pregnancy was normal. I was thirty-five years old. I felt great. Tired, but great. We decided to take the kids to a neighboring city where Russ and my first pastor had come to preach. He and his wife had moved to Texas a year after we had become Christians, and we learned so much about our faith from them in that short year. It had been years since we had last seen them and wanted our children to meet them. We went out for supper before the service, and during the visit the pastor’s wife asked me about the pregnancy. Was it normal? Did I have any fears? I was caught off guard by her questions. No. I had absolutely no fear. Everything was the same as my other pregnancies. That evening during the service, there was an opportunity to go forward for prayer, so I did. When the pastor and his wife prayed for me, they gave me this scripture to hold near to my heart:

*So do not fear, for I am with you; do not be dismayed, for I am your God. I will strengthen you*

*and help you. I will uphold you with my righteous right hand. Isaiah 41:10 NIV*

I didn't understand how that scripture would apply to my life. I wasn't afraid. Everything was fine. I had no idea how much I would need that scripture, and cling to it, in the months to come.

On April 4, 1995, I was having contractions. Anna, our two year old daughter, had the worst case of chicken pox I had ever seen. She and I took a long bath together to try and relax, but my contractions were not getting better, they were getting worse. My doctor was out of town. My due date was April 15th, and my babies were never early, so this was unusual. Russ came home from work and we got to the hospital at 4:15 p.m.

My labor was intense, and when the doctor checked me he formed a strange look on his face. "What? What is wrong?" I asked frantically. He said he wasn't certain if he was feeling the baby's lips or her butt. As it turned out, she was born face first, which means her head was tilted back so instead of the top of her head coming first, it was her face. Her little cheeks looked like they were rug burned. Her face was swollen. When the doctor and nurse went out, Russ and my sister Joanie stayed in the room with me. I asked them if the baby looked Downs to them. They were both shocked I would ask. "No. She is just swollen from birth," was their response.



Barb holding Amy when she was a few hours old.

She was perfect. She nursed well, but something deep inside me was unsettled. I held her to my breast, and she nursed just like my other babies. When I nuzzled my face into her neck, she smelled just like my other babies. She made the same noises they made. She seemed so normal. The next morning the doctor came in with two nurses, looking grim. They announced they needed to do some tests on the baby. I asked if it was for Downs, and they seemed surprised I knew. A blood sample from the umbilical cord was taken for testing. They originally had left the cord longer in case she needed treatment for group B strep. They left to arrange the procedure. I could barely dial the phone as I called Russ, mom, and my sisters. My sister Donna lived about forty-five

minutes away, and when she answered the phone, I could hardly speak. I didn't want to say the words "Down syndrome." Mom, Joanie and Connie came up to the hospital as I grieved. A cloud of despair hung over the room. I felt so desperate and confused. I didn't know what to think. I was so scared of the unknown. When Russ arrived at the hospital that first day, I couldn't speak. I was selfishly thinking about what it would mean for us to raise a child with special needs and how our lives would change.

Russ held me as I sobbed uncontrollably. It was as though we'd experienced death- the death of a dream. We had all these dreams, Russ and I. We always wanted six kids. We wanted to watch them grow, guide them and teach them all that we knew. What would we teach her? What would she be like? Would she ever ride a bike? Oh, the despair and agony of the unknown. I honestly didn't know anything about Down syndrome. There was a TV show called, "*Life Goes On*" that starred a boy named Corky with Down syndrome. He could speak. He could function normally. Would she? I went in with the doctors to get the blood sample and sang during the whole procedure. "Turn Your Eyes Upon Jesus" became my theme song. The test went well and results would take eight to ten days.

We had planned on naming our baby Rachel, but after finding out she may have Downs, we thought we should give her a name that was easy to write and spell. Amy seemed perfect. Amy Evelyn Felt. Evelyn was my mom's name, and it was an honor to name our baby after her. She was so inspiring to Russ and I. If Amy grew up to be as giving and encouraging as her grandmother, we would be so thankful.

Russ had gone home from the hospital and looked up what Down syndrome meant. Our outdated encyclopedia said the most horrific things, “Mongoloid. Mental Retard. Short life span.” The hospital did not give us any information. I didn’t have Internet access and didn’t know how to use it. We were desperate to know more. A few days after birth, I went to our local library in search of knowledge. I had Amy with me. I was so nervous to ask the librarian for information on Down syndrome.

What I read in the library that day was heart-wrenching. Yes, there was some encouragement from other parents who had children with Downs, but the clinical information was grim. The list seemed to go on and on about all the problems Amy could have. She could have a heart defect, she could have a lot of respiratory problems, ear infections, weak muscle tone, intestinal problems, eye problems, even her teeth could be crooked. As if the over all picture wasn’t bad enough, I remember reading things like, “Make sure your child wears deodorant and dresses appropriately.” Or, “Your child’s teeth will most likely stick straight out, they do not fit the mouth. And, “Your child will never be able to express her feelings.” Oh my gosh! As for deodorant, I had to teach personal hygiene to all of my kids- why wouldn’t I teach Amy? I didn’t let any of my other kids dress inappropriately and I would do the same for Amy.

What I understand now about kids with Downs is that the roots of their baby teeth don’t dissolve, so the baby teeth need to be extracted to make room for the permanent teeth. Amy’s teeth do not stick out all over her mouth, they are straight. No one gave me warnings like that with my “normal” children. They had ear infections and had to wear braces. As for Amy

expressing her feelings, I would soon learn that Amy would be more vocal than all my other kids. I knew nothing yet of her precious sayings, like: “I am sooo hungry, need burger, fries NOW” or my favorite, “I love you Mom” and “You’re so cute.”

Eight days after Amy came home, the phone rang. It was my doctor. She had been out of town for the delivery and had returned now. She had some bad news. She cried as she told me. Not only did Amy have Down syndrome, her 13 and 16 chromosomes were switched, indicating a blood disorder. More tests needed to be done. My heart sank. What does this mean? The doctor said we needed to test for a heart defect as well. It is common for children with Down syndrome to have heart defects.

On April 24, I drove down to Minneapolis Children’s Hospital for a test to see if Amy’s heart was okay. It was an important appointment, but I felt comfortable going alone. I didn’t think for a minute there was something wrong with her heart. I watched the monitor and could see the blood going in and out of the heart, just perfectly. The technician smiled when I asked how the heart looked. Of course, he couldn’t tell me, one of my first lessons in the medical field. Only the doctor can give the news, good or bad.

While in the waiting room, I noticed a woman with her baby who looked like a newborn also, so we introduced ourselves. Her little Sally had been born the day before Amy, she also had Down syndrome and was getting her heart checked. Sally’s mom asked me how my parents had taken the news of Amy having Downs. I smiled and relayed my mom’s comment, how Amy would probably fool us all and be the smartest one. The woman told me that when her mother heard

the news, she had a panic attack and had to be taken to the hospital! Stories like these, outdated encyclopedias and my own naïveté made me feel like I must be missing something. Having a baby with Down syndrome must be even worse than I realized. It was confusing.

The technician's smile had rightly set my expectations. Amy's heart was okay. Once we knew Amy's heart was healthy all of our focus shifted to the blood disorder. After doing more tests we found out Amy's body was not making enough platelets. I had never even heard the word before—"Platelets." They are what cause blood to clot. We needed to be careful that Amy would not get bumped too hard, or she could bleed internally. This disease was called, Myelodysplasia. The doctor described it like burning cinders that could go out or burst into a flame. In other words, this disorder could go away or turn into full-blown leukemia. The threat of leukemia was far greater than the stress of Down syndrome. You can live with Down syndrome. You can die with leukemia. I was not prepared for leukemia.

When I rocked Amy, I longed for a normal life. I never wanted to go back in time and not have Amy. I cherished her. I loved her. She was our daughter, a part of us, and a part of our family. Still, somehow, I felt robbed. A disease was hovering over our lives. We knew she was our gift and we needed to be ready to fight, even if that meant leukemia. I don't think any parent is ready emotionally or physically for this battle.

## Chapter 2: Chosen

I am not sure that I have a clear answer as to why I was chosen for this gift. I have to believe that God was preparing our family for Amy long before she was thought of. So many experiences in our short lives, so much joy, so much pain, so much learning that has given us wisdom. Wisdom that has enabled us to fight for Amy, challenge medicine and society, and love her unconditionally. As I tell you my story, think of your own, and maybe you can see how God has prepared you too for gifts like Amy.

I am the youngest of eight children. We lived on a farm, and Mom and Dad were very much in love, raising their family in Central Minnesota. On July 19, 1968, when I was eight years old, our lives were changed forever. It was a warm summer day, and my dad had gone out to fix the hoist on a truck. He had the box up with blocks under it, and when he greased the hydraulics, the box came down, broke the blocks and killed him instantly. He was fifty-two years old.

As an eight year old, I saw things from a new perspective. Watching Mom sobbing over my dad's casket, seeing the ache in her heart and not being able to fix it. I was not able to fix the wrong things in life. Seeing my siblings barely able to function was hard. Tragedy either draws people closer together or separates them. We drew close. We realized how fragile life is. We never left each other without expressing our love.

My dad's death did not draw me close to God. I became co-dependent on my siblings. The priest said at the funeral

that God took my dad. What kind of a God takes your dad? I was afraid He would “take” my mom next! I did not know much about God at that point in my life. I blamed Him for Dad’s death. I understand now that I should have run to Him to help me.

My mom didn’t do well. For over a year she cried every day. She would be crying when we left for school and crying when we got home. She was a strong woman, but this was almost too much to bear. Dad had told Mom if anything ever happened to him, “Sell it all, and let the boys get a job in town where you know you are going to get a pay check.” Mom and my older brothers decided to have an auction, to sell the livestock and all the equipment. When it came down to actually selling the farm, they couldn’t do it, and the two oldest boys, Pete and Wayne, only twenty-one and eighteen at the time, took over farming. They struggled and had to work for the neighbors in exchange for the use of their equipment, but they were determined, and they made it.

Mom needed a fresh start and decided the rest of us should move to a neighboring town. I started attending the new school and couldn’t stand not knowing if Mom was okay or not. I started having panic attacks. I would start to think about Mom, and what if she died, and I couldn’t breathe. After a lot of testing, the doctor was alone with me and asked if I ever talked about my dad. I answered no, if I did, it would make Mom cry. He was a wise man and told Mom to take me out to lunch once a week, just her and I, and to let me talk about Dad and anything else I wanted. I was practically cured!

After four years, she met and married a wonderful man, Werner Finken, and we moved to a little town called Litchfield. Werner was nothing like my dad, and he never

tried to be him. We were great friends and never argued once! We played bingo and cards and got along great. I see now how God was preparing me for loss and recovery, for hurt and healing.

My brother Glenn was my best friend growing up. We did everything together. When he was seven and I was five, we were in charge of mowing all the lawn on the farm. We spent our days on the mower or hunting for black birds with his BB gun. I adored him. As we grew, we stayed close and I hung around him and his friends. One of Glenn's best friends was a boy named Russ. When I was fifteen, Russ started to see me as more than Glenn's little sister. We eventually started dating, and I fell in love that same month! The first time he held my hand was like magic. No one had or has ever since made me feel the way he does.

After I graduated from high school, I was confused as to what I wanted. My sisters told me to see the world, to travel, go to school and experience as much as I could before I settled down. Russ wanted to get married. I didn't know what I wanted so I signed-up to be a foreign exchange student in Germany. I was searching for something. Right before I left, a woman at church invited me to a Teens Encounter Christ (T.E.C.) meeting. I had never heard of it, but I wanted to know more about this God that I didn't understand. At the meeting, they told us about Jesus and asked if everyone was "born again". During that time in my life, not only was I searching for fulfillment, but I was struggling with anorexia, which left me feeling broken and ashamed. So, I raised my hand in curiosity and said, "What do you mean, born again?" The woman was so sweet. She smiled and asked me if I wanted to ask Jesus into my heart, to be my Lord and Savior.

I said, “Yes.” I didn’t know much, but I knew I wanted to know the Jesus she described, the Jesus that could make me whole. I asked for forgiveness of my sins and gave my life to Christ. I felt His forgiveness. I felt brand new! I came home and told Russ and all of my family what had happened to me, and they were all envious because they wanted to know God in this way too. It was the beginning of new life for me, and the seed of new life for my family.

I left for Germany right after graduation. I continued to struggle with my self-image, but with time, I learned through God’s word and life experiences to accept myself. My adventures in Germany brought me closer to God. On my way there, the flight was cancelled, changing our arrival date. All of us kids heading for Germany spent the night on the floor of the Chicago Airport, then we finally made it to Hamburg. We took a train, and after many hours, the leader told six of us the next stop was ours, and we should get off the train, and our host family would be waiting for us. When I got off, five families were there to pick up kids, but mine was not there. I couldn’t speak German. It was getting dark, and for the first time in my life I felt completely alone. I didn’t know a soul in that seemingly bleak country. I sat on my suitcase and cried out to God. I realized then that throughout my entire life, I had been loved. For the first time, I was in a situation where I was away from all the people who loved me, and it was scary. Thanks to a woman from the Red Cross I did eventually connect with my host family, but, the lesson learned then became a reoccurring theme in my life: there is security in family, but ultimate security is from God.

At first I enjoyed my freedom. Russ wrote me almost every day. The post office in Germany was eight miles away, so it