

Why Don't People Understand?

A Devotional Journal for Hope in Epilepsy

If we haven't met yet, my name is Lisa. As the mother of a teen who has battled Epilepsy his whole life, I've ridden this roller coaster for a long time. Along the way, I learned to find hope.

Our epilepsy ride includes pleasant yet expectant climbs, surprise drops of diagnoses, dark tunnels of breakthrough seizures, and spins of side-effects.

Imagine God as your seatmate, right in the car with you. When we crest the peak of a major, creaky climb, and raise our arms for a screaming descent, He hugs us around our middle and doesn't let go. Ever! Buckle in and take comfort in riding the epilepsy rollercoaster together with Jesus!

This is a five day devotional journal. Since life is crazy, give yourself grace to complete it at the pace your tribe allows. I pray at the end of this devotion you'll find more pleasure in your circumstances. Like when you visit the photo booth at the end of a ride, may your picture depict yourself, arms in the air, wrapped in God's unique comfort, with joy on your face as you grow in parenting your special child.

Love, Lisa

Contents: Why Don't People Understand?

Day 1: Staring Spectators

Day 2: Conflicted Family

Day 3: Friends or Not?

Day 4: Confused Congregation

Day 5: Supportive Spouses

The Prize!

Supplies needed:

A copy of this to write on or doodle

A pen that makes you happy

A few quiet minutes

Optional coffee or tea, as available!

1

But if you had known what this means 'I desire compassion
and not a sacrifice' you would not have condemned the
innocent. Matthew 12:7

Jesus healed a man with a shriveled, useless hand on the Sabbath, a day of worship, surrounded by staring Pharisees. People stare a lot. But, I have realized there are different types of stares and correct ways to stare.

I find myself staring at other parents of children with special needs. My stares are not judging, but a quizzical awe, a curious glance or an analyzation of techniques. In my heart, I seek a fleeting opportunity to praise the parents. Even when all seems chaotic, I like to encourage them. They often take a visible deep breath, because someone understands.

Once, I watched as a father masterfully maneuvered his physically challenged son into a restaurant booth for the family meal. I gave a well-intentioned stare differing from those which sear into your back as a melt-down occurs three feet before a cash register finish line. I watched until my husband roused me with his elbow.

When I was a first-year teacher, correcting a disruptive student, he replied, "I know you're upset and I would love to take you seriously, but you smile while you're scolding me." Once home, I tried my stern look in the mirror. My facial expression was not how I envisioned it. He was right! So, I started practicing.

Are we aware of our stares? Do we follow them up with praise or judgment? We know our situation is just as unique as everyone else's. The Pharisees were staring and judging Jesus for His compassion. The Pharisees were the rule enforcers. He clarified for them that compassion is paramount. They should have been staring in wonder, not criticism.

Look in the mirror. Make faces. See how others may perceive your stares, stern looks, or smiles of support. Remember, Jesus prefers compassion.

Prayers for
My Child:

Prayers for
Myself:

Prayers for
Others:

Don't skip this one!

And stretching out His hand toward His disciples, He said, "Behold My mother and My brothers! For whoever does the will of My Father who is in heaven, he is My brother and sister and mother,". **Matthew 12:49-50**

We are not Jesus, but we look to His teachings for guidance. If we look at this event through a wide angle lens, we see a crowd of commoners surrounds Him.

Jesus differed from the typical Jew, which caused plenty to stare in wonder. Here, his family displays how worried they are about him. They arrive to take him aside to better assess his wellbeing. They want to confirm he has not lost his marbles in front of this crowd. But, Jesus was busy teaching and did not pause for his family.

Family rarely understands raising a child with Epilepsy. We encountered two kinds of reactions from family, compassion as they drew closer, or silence as they distanced themselves. Should family be more supportive than friends?

There were many times we needed help; but few times when family was around. Maybe my requests for help weren't specific, or maybe God needed us to work through our struggles on our own.

When I clearly expressed my needs, help came as sisters and brothers in Christ, rather than biological. Maybe we're putting too much pressure on our family to understand a trial that is not theirs. Mary and Jesus' brothers seem to have stayed on the fringe of the crowd and then walked away. I suppose Mary continued to pray for him, even when He was busy about His Father's work.

Jesus didn't dismiss or discount his family; He opened up His arms to accept believers as spiritual brothers and sisters. Let's leave our assumptions about family and embrace those who embrace us. It may cause some unconventional holidays celebrations, but you'll be surrounded with joy.

Prayers for My Child:	Prayers for Myself:	Prayers for Others:
	Don't skip this one!	

Two are better than one because they have a good return for their labor. For if either of them falls, the one will lift up his companion. But woe to the one who falls when there is not another to lift him up. Ecclesiastes 4:9-10

We've had adult friends come and go over the course of our child's life. And, the memories are still fresh. When a person's character is revealed, sometimes I am in shock, but it always hurts deeply. After forgiving, I can see more clearly.

Amid a crowd where everyone was invited for a dinner party, we were then uninvited, "You know because of your son. It may be too much for him." Done. And, not expecting future invites either.

The statement seemed mean, but my son's condition scared her. She had witnessed seizures and was afraid of the unexpected, in other words, our daily reality. I didn't feel like she was my friend anymore. I expected her to understand. She wanted to be my friend, but exclude my five-year-old. Sorry, we are a team. It's all or none. Jesus's message is; Love all or none.

I mentioned a marriage retreat to a friend. She replied, "Let me keep the kids. I can dose medication and I'll call 911 if needed". Wow! My husband and I grew much closer that weekend and our son's had his first sleep-over. She let them be kids and let us be adults. It was a gift I will never forget.

A few years ago, I quit trying so hard. I decided to sift through my friends to find whom to keep close, and whom to kept at arm's length. No more pretending. Sometimes, it means coffee by myself which can feel lonely if I allow it.

Keep testing the mettle of other ladies, some will be closer than a sister! Friends may only last for a season, but God's not going anywhere! When you feel lonely, God will recharge you, he's the Best Bestie Ever, and will always lift you up. He can even listen when we can't put words to our feelings.

Prayers for
My Child:

Prayers for
Myself:

Prayers for
Others:

Don't skip this one!

Jesus answered, "It was neither that this man sinned, nor his parents; but it was so that the works of God might be displayed in him". John 9:3

When Epilepsy was discovered in our second child, I had preconceived notions about our congregation's reactions. After experiencing many prayer services over sick and dying members, I assumed they would meet our super tough health news with prayer and compassion.

Instead, we experienced judgmental heartache. Our sin-life came into question. Our son was labeled as cursed and verbally shunned. It was as if we had purposely contracted leprosy or the plague and brought it into the church.

Humans are flawed. Over time, I learned Christians can be as confused as non-believers. If we study the scriptures, my child's illness is not a curse or pay-back for something we did.

When I could no longer take the spiritual isolation, I retreated. I hid. Every Sunday, I sat on the couch and watched a preacher on TV, who could not judge me or scare me. Finding hope became impossible in the church or through my pastor. That's what the enemy wanted. He likes us to lose hope and quit pursuing Christ. The enemy wants us to retreat, feel less than worthy, and give up.

The TV preacher helped my spiritual growth while my kids played at my feet. I was comfortable, but it's not meant to be that way! God's Word says a child was sick SO THAT God displays His mighty works. I was not meant hide God's works in my living room. I did not understand what God's display would look like, but I no longer wanted to hide in fear. I had to go. Out. In. Public.

When I returned to church, my child sat on the pew with me. I moved away from the whisperers and focused on God. We positioned ourselves for the mighty work He had in store for our lives. After all, our child needed to find himself in Jesus, too.

Prayers for
My Child:

Prayers for
Myself:

Prayers for
Others:

Don't skip this one!

A man of too many friends comes to ruin, but there is
a friend who sticks closer than a brother. Proverbs 18:24

When I met my husband, we became instant friends, best friends, then engaged in such a short period that people said we were nuts. We knew it was God's design to bring us together from across the country. When my husband moved us back to his small hometown, I had nobody to turn to except him. It took years to make a friend outside the family. His family was a blessing, but so was learning to cling to my spouse.

In our marriage, I am the planner, fixer, and rule follower. He enjoys being the provider, protector and fun-guy. We work well together. But if gone unchecked, I can override him, and make him feel, diminished, untrustworthy, or left out. So, I choose him first. Always.

About twelve years into our marriage, as we discovered our son's health challenge, he dropped everything to be involved. On the way home from the initial diagnosis, we repeatedly pulled over, clung to each other, and cried. We felt hopeless and confused.

Ever since, I contact my husband first, before my mom, my friends or coworkers when there is any medical news. Why? Because, we're strongest as a team. We're in it for life! If we drift apart, because he doesn't feel trusted or worthy to care for our child, we'll be an ineffective team. We need to work together.

In this scripture, David, Jesus' ancestor, contrasts wise versus foolish choices. "Many friends" translates as associates or acquaintances whereas "friends" means devoted, unconditional love. "Sticks" means to cleave, like some of us include in our vows. We are to purposefully and unconditionally stick to each other, closer than any other relative.

Who are you clinging to? Did a rift gradually develop over time? Do you need to rearrange your acquaintance list? Explore what's going on, ask forgiveness, and make your spouse your best "friend". Your partner needs you as much as you need him.

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My Child:

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Myself:

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The Prize

After a ride on the Epilepsy roller coaster, hopefully we have a different picture of what we look like in the camera's lens. Have we grown, or are we stuck? Are we ready to disembark or ride again?

It's important to remember God only passed out a few tickets for this ride, to those He trusted most. Not everyone got a ticket, because not everyone could handle the ups, downs, curves, and steep drops. You're special and you get a ride like nobody else because you are the best qualified!

All the Bible stories used are interesting to read. They show a more complete picture of who God and Jesus really are. If you want more, I invite you to dig deeper by reading each story in its entirety, rather than these snapshots. They may reveal more about yourself, as well.

Then, if you've been couch-churching, get up. Go try a congregation full of real people. You'll know the right one when you get there. If you and your spouse are drifting, schedule a date night and talk about riding in the same rollercoaster car, rather than one of you waiting in the parking lot.

I'm praying for you to find **Hope in Epilepsy** which only God can provide. I'll be sending you some encouragement in your email and creating more devotions like this one. Hug your child a little tighter tonight, and kiss your spouse, knowing that God is hugging you, too!

Verses are from the NASB® version of the Holy Bible, but every version has these stories.

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How can I help you find Hope in Epilepsy? Drop me an email at so I can better encourage and pray for you!