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Mary and I had waited five years to have children. We hadn't prayed about it, but we based our decision on other factors such as having good jobs and our own home.

Jenny, our first child, was born in December 1972. She was blind and profoundly retarded.

My wife was much more prepared than I was. She had been involved in an intensive Bible study program; but I was a more nominal Christian, rarely studying the Bible to gain wisdom and strength.

Mary came home on Christmas day, but Jenny remained in the hospital while doctors waited to see if the convulsions would subside. We opened our presents as usual, but our tensions only increased



Jenny

Is Hers a Life Worth Living?

by James McAlister



as we waited. We felt emotionally drained.

The real difficulties began after Jenny came home. We were scared of her. The convulsions were frightening. Their frequency varied—sometimes an hour apart, at other times only a few minutes.

Doctors offered little hope as they experimented with medicine to control the seizures. Not knowing what to expect, we lived one day at a time, always hopeful for some good news.

I had never enjoyed children, especially those that cried. Now I had a baby whose crying never stopped, even when she was eating. She slept for only short periods of time, and sleepless nights were common.

At first, I began to withdraw, letting Mary bear the whole burden of caring for Jenny. She wanted me to love and accept our baby, but she didn't press the issue. Whenever I came home from work, Mary would take Jenny to another room to keep from disturbing me.

It wasn't until Jenny was again hospitalized, two months later, that Mary succeeded in showing me how I was isolating myself. From then on, we began spending more time together as a family.

Eventually the seizures were controlled; and, although she still cried a lot, Jenny's sweet personality emerged. She enjoyed music and simply being touched. Bouncing on our knees gave her a special thrill.

At four months, she smiled for the first time. Overcome with surprise and joy, Mary cried. It was the first deliberately

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controlled action Jenny had ever made.

Her responsiveness encouraged us to discover other things that gave her pleasure; we were soon rewarded with "ahhh's" and "ungahhh's," her special sounds that gave us pleasure.

Tests of Jenny's brain revealed extensive damage, and the complete picture of her condition evolved over some time. Doctors' predictions were guarded: "She may get better, but she may also stay the same."

Jenny never learned to roll over, grasp anything, or hold up her head. Her lack of motor ability increased the daily stress of caring for her. She required total attention.

A turning point came, however, when we began taking her to church. Nursery workers reserved a permanent place for her in the "bed baby" class. One summer, she even "graduated" from vacation Bible school and brought home a diploma!

Because Jenny never had a fixed schedule, we often had to take turns going to church. It was difficult, but we knew that God had not abandoned us to an impossible situation (Heb. 13:5). We were encouraged, knowing that He had a special purpose for us in our trials.

We tried to establish a regular routine of family life; but, with Jenny, "normal" was never simple. Her special needs required some unusual adaptations.

Her hypersensitivity to sounds (even a small, sharp sound like ice cubes being dropped into a glass) would wake her immediately. We

adjusted by putting foam rubber "bumpers" on all of our door facings. Releasing door knobs slowly enough to avoid clicks and thumps became a habit.

When Jenny was a year old, we enrolled her in a program for retarded infants and discovered she enjoyed being exercised. After that, my first job upon coming home from work was to exercise her, stretching all her muscles slowly and deliberately. She thanked me with her sighs and giggles.

My involvement after work and on the weekends gave Mary enough relief to make it through the days. With Jenny in my lap, I spent countless hours gliding in our porch swing, tooting out "Buffalo Gal" on the harmonica. She squealed with delight at the top of her lungs.

Mealtimes were special, too. We bounced her on our knees until our legs gave out, and she would coo with pleasure.

Even with her impairments, she adapted well to these patterns, but a departure from them had its consequences—usually bad.

She would become restless and fussy, for instance, if I didn't make it home on time. Somehow she seemed to know we were supposed to be exercising and "watching" our favorite TV program together.

One especially endearing incident took place after I had been out of town for a few days, and Jenny had cried a lot. When Mary picked me up at the airport, Jenny was crying so loudly she didn't even realize I was in the car.

Tolerating the fuss, Mary and I drove home in silence. But after the

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car stopped, I leaned over Jenny's face and said, "What's the matter with Daddy's girl?"

Immediately, the crying stopped. Her eyes opened wide, and she smiled a long "ahhh." She had been missing her daddy.

During those years, Jenny was just like our baby doll. We dressed her in pretty pink and white dresses to show her off. We were so proud of her.

Although she would never be able to use the books, toys, and music boxes that made her room so special, the atmosphere reflected our feelings for her. As she grew larger, however, the demands of her total care continued to increase.

Vacations were few, but we were blessed with friends who willingly gave us relief from time to time. One dear lady from our church kept her every Wednesday so Mary could continue attending Bible study.

As the months passed, we often prayed about our future with Jenny. One day, we set aside a special time of fasting and prayer for her needs. A few days later, an answer came.

Without our asking, Jenny was chosen (from a long waiting list) to participate in a program at a nearby total care facility for retarded children. The most difficult decision we have ever had to make was whether or not to let her go.

As Jenny's parents, we knew what she needed most of all was constant love and attention. And we didn't see how anyone else could give that to her better than we could.

Before making up our minds, however, we decided to see firsthand what could be done for her. As we toured the center, we saw physical therapists, audiologists, nutritionists—people who offered

more than we had ever considered.

We knew then she would be helped in a way we couldn't help her, and we were glad she would have that opportunity; but it broke our hearts to let her go.

The day we enrolled her, we were surprised to learn they were not going to continue her daily exercise program from the start. A complete medical evaluation would be required first. Although we realized it was intended for her good, we were also distressed over it. Exercise had become such an important part of her day.

Mary said to me, "I can't remember why we put her in there. She must be picked up. I feel we've forsaken her."

The next morning, my wife went to her Bible study convinced the Lord would speak to her and give her peace. And He did.

The lecturer described how David had every opportunity to be discouraged and to feel inferior when Samuel tried to anoint his seven brothers before him.

But his heart was inclined toward God, and he wrote these words: "When my mother and father forsake me, then the Lord will take me up" (Ps. 27:10).

For Mary and me, the Lord faithfully confirmed that even though we had "forsaken" Jenny, He would "take (lift) her up." That promise has helped sustain us over the years.

Outwardly, we joke and talk about her being away at "college," but inwardly we miss her desperately. Part of us is gone, and our nest is empty much sooner than we had ever expected.

For the past five and one-half years, our top weekend priority has been Jenny. We either visit her or bring her home.

Our time with her includes exercising her, massaging her (with cream to keep her skin soft), praying with her, and reading Scripture to her. Sometimes, though, when the weather is good, we just take her out for a walk.

Our travel time to visit her has become a special family time. We discuss family problems, encourage one another, memorize Scripture, and pray.

When we can't be there during the week, Jenny often goes to sleep listening to a tape of our voices that

includes singing and Bible verses. It soothes her when she's restless.

The only thing more difficult than adjusting to life with Jenny has been adjusting to life without her. We still close the doors carefully and probably always will.

Jenny is always on our hearts. As often as we think of her, our prayers go up to God, pleading for His protection and compassion for her.

As Jenny's father, I continually

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struggle to know God's will for her and how we should respond to it. She now grows older without apparent improvement.

But her life takes on special significance when I consider David's words:

"For Thou didst form my inward parts; Thou didst weave me in my mother's womb. I will give thanks to Thee, for I am fearfully and wonderfully made; wonderful are Thy works, and my soul knows it very well.

"My frame was not hidden from Thee, when I was made in secret, and skillfully wrought in the depths of the earth. Thine eyes have seen my unformed substance; and in Thy book they were all written, the days that were ordained for me, when as yet there was not one of them" (Ps. 139:13-16 NASB).

She is a gift from Him (Ps. 127:3, 4), and in relation to eternity, her afflictions (as well as ours) are only momentary (2 Cor. 4:17, 18).

Looking back over the past few years, I'm amazed at how the Lord has been able to change my own attitudes because of Jenny. Could He have done it any other way? "How unsearchable are His judgments, and His ways past finding out" (Rom. 11:33).

But Jenny isn't merely a tool used to shape character into my life. She is one of God's special creations—so unique that her an-

gel constantly beholds His face (Matt. 18:10). And in His wisdom, He has simply allowed me to be a steward over her.

Therefore, it is my responsibility to see that she develops to her full potential and usefulness to Him. Even now I pray that He will exercise His prerogative to heal her by His power, but He hasn't yet chosen to do so.

Every time I look at her, I get tears in my eyes because of the progressive deterioration of her body. Her teeth now point in several directions because her medicine causes swelling of the gums. Her hands are permanently deformed through lack of use. She has chronic infections and still has some seizures.

Nevertheless, she is God's child, and He knows her needs. He also knows the plans He has for her life—plans for success and not calamity.

As parents, it means a great deal to us to have so many of her workers show continuing love toward her. Just knowing she is being cared for with love and tenderness helps to make the situation bearable.

I'm not sure that anyone but a parent who has faced similar circumstances can fully understand our feelings at this point, that we could possibly let someone else care for our child.

It's so easy to say, "I would never give up my child to anyone." But the choice is not as simple as it may seem. The child's physical needs must be satisfied, and we are forced to ask: "Who can *best* meet them?"

Jenny functions at the lowest level. She can't chew, so all her food must be blended. She can't drink, so liquids must be poured down her (and even that with great difficulty).

She has no head or muscle control at all, and her limbs and body move only with reflexes, never deliberately or under control. She literally requires around-the-clock care. We were able to give that attention to some degree when she was a baby, but the problems (and her needs for special training) have become greatly compounded by her growth.

Some parents abdicate their God-given responsibility for the sake of convenience.

We see children every week

whose parents have literally deserted them—no visits, no presents, no contact at all. They are "out of sight, out of mind," never again to be mentioned or fondly remembered. But we feel our responsibility has to embrace the good of the child.

We're not the first to transfer our parental responsibilities to another. Hannah entrusted young Samuel into Eli's hands to fulfill a vow to the Lord. Nevertheless, she would make him a robe and take it to him from year to year (1 Sam. 2:19). Although someone else provided his daily care and instruction, she stayed involved with her son.

To preserve his life, Moses' mother placed her three-month-old son in a wicker basket in the reeds beside the Nile. The baby's sister stood at a distance to find out what would happen to him. Under God's sovereign hand, Pharaoh's daughter found the child and reared him. Moses became the son of Pharaoh's daughter (Exod. 2:10), but his mother stayed involved as his nurse.

Keeping involved spiritually, emotionally, and physically makes the difference.

We have felt both grief and guilt over our decision, yet we have done what we felt was best for Jenny. Our being able to be continually involved with her is the compensating factor.

Prayerfully weighing things out, I changed jobs and put up our house for sale so we could move closer to Jenny and see her every day. After almost a two-year wait, the house has sold and we moved this past July.

Since Jenny's birth, we've had to make a lot of important decisions. It took us seven years to decide to have another child. When both Mary and I had peace for an extended period of time, we decided that another child was God's will. Jenny's baby brother Barrett is now two. We anticipate his developing strength of character and compassion because of Jenny.

But what about Jenny herself—is her life worth living?

We often judge a person's worth in light of our own expectations. Obviously, Jenny doesn't have the same mental and physical capacities other children do, but does that make her life of any less value in

God's eyes?

Luke 1:44 records Elizabeth's telling Mary: "For behold, when the sound of your greeting reached my ears, the baby leaped in my womb for joy" (NASB).

Joy is a manifestation of God's Spirit. Before he was ever born, John the Baptist responded to the Holy Spirit. Likewise, Jenny's spirit is not limited by the confines of her body. That raises the standard of her worth to a higher level.

The Hebrew exiles in Babylon

It's so easy to say 'I would never give up my child to anyone.' But the choice is not as simple as it may seem.

considered their lives not worth living when they said, "By the rivers of Babylon, there we sat down and wept, when we remembered Zion" (Ps. 137:1).

God, however, knew of their plight beforehand and had already prepared words of encouragement and purpose. They were to be His witnesses, and surely He would destroy Babylon. They were not to dwell on their past but look to Him to do something new—to create a roadway in the wilderness and rivers in the desert (Isa. 43:10, 14, 18, 19).

Worth, then, is not a function dependent upon mental competency. Purpose, value, meaning, and quality of life come from realizing we are God's children and that He sees our lives within the context of His plan and purpose formed long ago (2 Tim. 1:9). God saw worth in the exiles' lives, although they saw none.

I'm sure the Lord sees Jenny in much the same way. She was created by Him and for Him. And because of her, He has opened up countless opportunities for us to tell others of His goodness. Doesn't that count to her credit?

But what about her viewpoint? If she could communicate explicitly, would she say her life is worth living?

I know she would. It's very evident she has definite preferences and dislikes. She enjoys soft music. She delights in being touched. She understands and responds to her

environment.

Any child's self-esteem is bolstered when he realizes he is precious to those who are close to him. It's the same with Jenny; she just has a different way of expressing that realization.

Her inability to speak to us in words isn't really all that important. Though God uses Scripture to tell me I'm His child and that I have value to Him (John 15:16), His most intimate communication of that fact is expressed without any words—His Spirit bears witness with my spirit (Rom. 8:16).

When I, in turn, want to communicate to Him with thoughts and feelings that I can't express or even understand, it's the Holy Spirit who intercedes for me with groanings too deep for words (Rom. 8:26).

I've no reason to believe that Jenny's spirit is not likewise sensitive and responsive. If that's true, it would appear she is aware of things that can only be revealed by God's Spirit, without the need for intellectual understanding (1 Cor. 2:10-13).

I realize some people see children like Jenny as being less than human. That attitude leads them to permit infanticide or abandonment, denying that "all things were created by Him and for Him" (Col. 1:16 KJV).

Our little girl is now almost ten years old, but we still think of her as we did nine years ago when Mary wrote in her baby book:

Jenny is very precious now. So sweet and very, very beautiful. Every person who sees her is awed because she looks like "a great big baby doll."

I've taken her shopping with me several times, and everyone makes over her, for she is such a special baby. Her eyes are like sparkling stars. Whenever she opens them wide, they are a light blue.

Her lips are very red and perfectly shaped. They can be small and prim, or they can be large and full.

She has an infinite number of expressions—all so precious.

Her cheeks are always pink and soft. Her nose is beautiful and perfect. Her lashes are long, but not extremely thick. They make her eyes look like stars—I can't explain how.

Her hair is light, but not actually blond-yellow. It's more silvery. It will probably be brown. Her hands and feet are perfect. They're beautiful. . . .

We love her. □