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# Not in the Medical Records

BY STEPHEN A. SCHMIDT

**My suffering fills me with anger, frustration, sadness, and sometimes despair. Yet the medical records, seriously incomplete, just say “Crohn’s disease for twenty-five years.” They don’t mention the sacramental memories that shape my faith or the grace-filled church that sustains me to face the dark questions.**

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**M**y reflections on faith and healing must begin with medical records. I have files of them. White male, seventy-one years of age, three surgeries, Crohn’s disease for twenty-five years, three bowel resections, and multiple hospitalizations for partial blockages and active Crohn’s flare ups. More recently the hospitalizations occur because of adhesions, the body’s response to multiple surgeries. Early in the experience of Crohn’s, the charts read: “Chronic intestinal inflammation, no medical cause determined.” End of entry.

There is more. I live with chronic diarrhea, chronic anemia, chronic arthritis, and fused disks at the base of the spine and in my neck. My daily diet is mush, bland and boring. When I am honest I admit to chronic anxiety. Where is the next bathroom? Dare I have breakfast with any one? Where is the nearest hospital? Emotions are not part of my hospital record. They are in my memory. I live with an unrecorded diet of despair. I experience anger, pain, frustration, sadness, depression, rage, envy, hope, and faith—not recorded. Perhaps I am blessed because my medical records are not much for meaning-making. There is no reason for my disease; I was not somehow chosen for this particular disease. Perhaps there is some hereditary connection. My grandfather died of “stomach distress.” But he died before I knew him, before Crohn’s disease had been named.

My life’s narrative is not widely known and certainly not part of my

medical record—nothing about my grandfather, or about the experiences that come with seventy years of living. There is nothing in the medical canon regarding doubt and faith, or religion and reality. Memories are not part of the medical record.

### **SACRAMENTAL MEMORIES**

The first memory is as vivid today as it was many years ago. My infant sister Henrietta was to be baptized. I surely do not remember my baptism, but the memory of hers is vivid. It was not a “high church” event. Rather, we were surrounded by our immediate family, grandparents, and the young woman who took care of us when we were very young.

Pastor Schmalz came to our home. The baptism was in our living room—our own sacred space where Christmas unfolded and family wakes were held. My mother brought a glass bowl of water and some napkins. Pastor Schmalz stood in the middle of the family. I stood on the outside, filled with wonder, certainly, but also with other unhappy thoughts. I was not important this day; everything was all about Henrietta, this new family member who took most of my mother’s time. I was not sure that I liked her at all. My parents had told me before the ceremony, “Stephen this baptism is important. You must behave. Be quiet and listen and watch.” I had my orders. Then everything changed.

Pastor Schmalz looked directly at me. “Stephen,” he said, “I think you are big enough to take a very important part of this celebration.” He asked if I was strong enough to hold the bowl of water when he baptized my sister. I must have nodded yes. Suddenly I found myself in the middle of the circle with the pastor. The bowl was not large or heavy. For just a moment, I thought about dropping it, but the thought passed quickly. The baptism began. There were Bible readings and words about the meaning of baptism. Then Pastor Schmalz told me to hold the bowl carefully while he sprinkled water three times on Henrietta’s forehead. My sister cried. I think I laughed. Every one was happy. I was suddenly important, encircled by a family as I held something I thought surely must be holy water. I was chosen by this group, I was in the middle of “church.” My first spiritual memory was mysterious and healing, a damp watery wisp of the spirit. I was changed for life.

A second memory, equally important, is of Christmas Eve when I was in the first grade. Christmas Eve was the most important day for my family. Nothing happened at home until after the church service, a vesper filled with readings, songs, and children everywhere. I was chosen to sing a wonderful German song in front of all the church. Stephen, chosen at six, to stand in the middle of the chancel and sing *auf deutsch*:

*Gott is die Liebe,  
lasst mich Er losen;  
Gott is die Liebe,*

God loves me dearly,  
grants me salvation;  
God loves me dearly,

<i>Er liebt auch mich.</i>	loves even me.
<i>Drum sag ich noch ein mal</i>	Therefore I say again
<i>Gott is die Liebe,</i>	God loves me dearly,
<i>Gott is die Liebe,</i>	God loves me dearly,
<i>Er liebt auch mich.</i>	loves even me.

I saw my parents smile, then cry. They were proud and filled with love and joy. Later when my father was one hundred years old, the last words he could form were these: “*Gott is die Liebe, Er liebt auch mich.*” My early memory of faith was also my father’s last memory—this song about being loved by God in childhood and in dying, with one hundred years separating those events. Even after my dad could not say the words, he would chant the melody. The words were a blur, but the music carried the hope.

My memories are filled not only with images of God as love, but also with images of the devil as evil. Leonard Fisher, my Lutheran school-teacher, told us the following story every year. Each morning as a child, a rooster on a fence post awakened him and he crept to the fence to frighten the rooster. He believed that if the rooster flew to the left, he would be damned, but if the rooster flew to the right, he would be saved. Each morning, damned or saved. With wide eyes, we knew the terror and the hope.

My family was religious, deeply Lutheran. We regularly attended church and Sunday school, and we children attended Christian day school. Never could we skip a service unless it was harvest time. My grandfather and father were truck gardeners, and I lived among the tomatoes, cabbages, beans, strawberries, lettuce, squash, and radishes. Each day we enjoyed a banquet of freshness. My father was a wise gardener with thirty acres of land under irrigation and a greenhouse, covering several acres, carefully managed. Yet even with all the water we could spray, we knew we were always at risk. We prayed for rain in the summer. August was the most difficult month—some years were bountiful, but in other years with no rain, the crops were only modestly productive. So our livelihood depended on God.

The highest office in God’s world belongs to the gardener, not *Herr pastor*, my dad would remind Pastor Schmalz. “Alfred you know why we were not in church the last two weeks. Tomatoes had to be picked. Remember Alfred,” father would say with a twinkle in his eye, “the first profession was farming. Clergy came much later.” Alfred Schmalz would smile, give my father a loving pat, and accept a gift of tomatoes.

During my childhood there were many funerals. Because the church was next to the school building, students heard the bells toll and knew a member had died. We counted the number of tolls and usually someone in the class knew who had died. We were filled not only with dread, but also excitement, for in the upper grades we knew the meaning of a funeral. The

day after the bells tolled there would be no school. The children sang for all funerals, so we met in the morning for choir rehearsal, and then sat in the balcony, looking down on open caskets. We saw grief and pain and love and community. We learned that suffering and death were not the end of life. We sang our hearts out, singing our young faith into the hearts of those who mourned. Funerals were difficult, but wonderful. And in the doing of the grieving we were healed. In our music we affirmed our faith and encouraged others to comfort:

Hold thou thy cross before my closing eyes;  
shine through the gloom and point me to the skies.  
Heaven's morning breaks and earth's vain shadows flee,  
in life, in death, O Lord, abide with me.

The most life-changing event of my childhood occurred while I was in the fourth grade. We lived next to our grandmother who was dying of pneumonia. She was in a coma. She experienced some suffering but little pain, and medically there was nothing left to do. Josie, who cared for my grandmother, kept her comfortable, and she would die gently.

My father announced one evening that he was going to sit with grandma. Believing she was near death, he wanted to be by her side. We children could not go with him; we were too young. Evening passed slowly, and even more slowly my father walked back to us, head bent in his own grief. He was crying. We prayed in the breakfast room with our battered *Stork's Prayer Book*. After reading three prayers, he spoke gently and softly, "I want to tell you how grandma died. She was in a deep sleep. Suddenly she awakened and saw me. She held my hand and said, 'Henry it is so good for you to be here.' She sank back into a coma. Then without warning she sat up, eyes open wide. She smiled, turned to me, and looked up toward the ceiling, toward heaven. 'Henry, I see the angels, they are coming to take me to heaven.' She laid back and was dead." My dad said he put pennies on her eyelids to hold them shut. The undertaker would not come until morning. Grandma was now in heaven; the angels were the proof. I will never forget this memory.

I live between the pennies and the angels. Pennies for holding eyes shut, pennies for home and food. Pennies for medicine and surgery. Pennies for culture and music, travel and fun, movies and books. Pennies for the future, insurance, and retirement. I know the value of pennies.

And all the while angels flutter in my memory. Martin Luther was not big on angels—he believed we should be careful about emotionalism, for some folks "swallow the dove, feathers and all." Yet we know that Luther in his adolescence had a mystical experience in the midst of a terrible storm: "St Ann," he cried, "I will become a monk." And he did.

In my life there is still the brush of angels' wings. I feel the wind and the wings, the shadow of their being. Yes, we live between the mundane

and the holy, between pennies and angels. We live with the mystery of God.

### **DARK QUESTIONS**

Can faith make sense of illness and pain? I think not, if you are asking whether religious faith can make *logical* sense of suffering. It could not make sense of the suffering and death of a six-year-old, my brother Henry Conrad—we called him “HC”—buried on my first birthday. Faith could not ease the pain my parents felt after the death of their first-born. HC had talked about being with Jesus, and my parents believed in heaven and that HC would be with Christ. But the hurt, the guilt, and a swelter of other feelings lived on in my parents after his death. Some grief is too deep to bear; it is endured, it is challenged, it becomes the stuff of reconciliation or transformation. But such grief is never erased; it enters the fabric of life and faith.

Can faith cure a chronic illness like Crohn’s? Not if you seek some quality of being. While other sinners—people just like me—parade robustly, I seek the comfort of the bathroom. I rarely go to breakfast with friends any more, for I know the aftermath. I excuse myself. I plan my social life, symphonies, operas, and plays around the solace of the bathroom. My faith helps me little as I measure the twenty-seven pills I take daily.

My youngest daughter also has Crohn’s disease. Why my daughter? Why this disease? She walks with her own faith struggle and I join her in dismay and hope.

Suffering fills me with anger, frustration, sadness, and sometimes despair. Why this body? Why me? There is no justice about health and no reason for ongoing suffer-

ing. There is no purpose, no joy, no gift, and no grace, none that I know. Yes, I smile, I try, I ignore my disease, I appear healthy, and I do not seek sympathy. Yes, I have learned dozens of lessons. But there is still, even after twenty-five years of my disease, rage and terror

and anxiety. Where is God? On some days there is stillness with a brief rumor of angels and a nudge of luminosity. But I am not sure if I fear that reality or receive comfort from it.

Through suffering, pain, the fear of death, and the slow details of dying, I am haunted with mystery, with the enigma of God’s being with us. They call into question my personal wisdom, my years of faithful habit.

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Goodness counts for naught; obedience is unrewarded. The crisis of suffering is the death of conventionality. Bad things happen to good people and good things happen to bad people.

Suffering raises dark questions: Can I love this body? Can my wife love this body? Is God my passionate companion? Here we come close to what Lutherans call a “theology of the cross,” for on the cross we meet another who is beaten, forsaken, ridiculed, naked, and despondent. And his suffering is “for us.” So, perhaps we are the most theologically accurate, have the most intimate relationship to the tradition, when we endure pain, despair, and hopelessness?

The possibilities are endless if we discover compassion in ourselves, in others, in a community, and in God. Then suffering can be re-creation. It may become the way to rebuild a world, to re-envision our place with others, and seek real intimacy. It may be a way to the center of being—our own being and the being of God.

Can I love this body—Crohn’s-filled, diarrhea-drained, aged, arthritic, and deformed—which rebels at food once loved and rejects commands of my mind? Can I celebrate this wrinkled, butchered, unattractive body? Yes, on a good day, and even on some bad days. Yes, in the middle of the night. Yes, in a regular hospital visit. Yes, when alone. Yes, sometimes.

#### **GOD’S LOVE EMBODIED**

Even in the midst of messy, stinky suffering, there is the possibility that another will love me. I have a gift—a wife who stays with me after twenty-five years of pain, messiness, and fear. She says “No” to my self-pity, self-scrutiny, and excesses of sadness. She holds, caresses, and loves me—this fragile, failing façade. She loves me passionately, and for a moment I am healed. She is my lifeline, my hope, my meaning, and my being.

And there is a compassionate community filled with the rustle of angels—the chronic illness group in Grace Lutheran Church. Here the angel wings still touch the water, stirring healing and hope. For over fifteen years, group members—a dozen or more church members and others who are equally ill—have continued to listen, pray, tease, tell, hold, and confront one another. In our monthly gatherings after we open with prayer led by a member of the group, each person reports in, telling what has happened in their life and with their illness. Each one is open to questions from the others. We challenge, encourage, tease, and hug each other into hope. We relate stories, we tell of times when each of us was hopeless. We share our frustration, doubts, anxiety, and depression. We listen carefully and respond to each person. In this kind of “sick” confession group, we disclose our faults and we absolve.

And we help each other die. Over the years as members have approached death, they have been visited in the hospital by group members and prayed for by the group. Grief is no new sentiment for the group. We

cry often, but laugh almost as much. Over time we form close friendships. We keep confidences and trust each other.

Grace Church is a parish that really prays, like the contemplative nuns of old. They pray for all of us, for me. Here is a faith tradition that claims story as central to hope, and knows that the ear is the most important organ of faith. Here is preached the theology of the cross, which is at once a story of suffering, a tradition of mystery and despair, and a promise of hope and healing. Here is a God who felt as lost and disconsolate as I have felt: "Why have you forsaken me?" (Mark 15:34; Matthew 27:46). Here is a God who has been there before, and who stays with me. Here is a God that is faithful—"For I am convinced that neither death, nor life, nor angels, nor rulers...nor powers...can separate us from the love of God in Christ Jesus our Lord" (Romans 8:38). Here is a suffering God with compassion and here a community that embodies that reality.

Can faith help make meaning in suffering? Yes, if there is a living, faithful communal embodiment of that faith. The "grace-full" church is one that is always on edge, always living in the paradox of tradition and experience, always living out God's compassion. Faithful communities embody that hope and possibility.

#### **EDITOR'S SUGGESTIONS FOR FURTHER READING**

Stauros USA is an ecumenical organization promoting reflection on human suffering from a religious point of view, particularly a Christian viewpoint. The website [www.stauros.org](http://www.stauros.org) provides many resources, including *Stauros Notebook*, edited by Dr. Schmidt, which contains articles and poetry on themes related to suffering.

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