

# Reflections of a Caregiver

*Former Probe staff member Rick Rood lovingly cared for his wife Polly through their twenty-year battle with the degenerative ravages of Huntington's Disease. He wrote this intensely personal and insightful essay a couple of months after Polly's death in the fall of 2003. We gratefully provide his reflections on that journey.*



*This article is also available in [Spanish](#).*

During these first few months of adjusting to being alone without my dear wife Polly, I've had occasion to reflect quite a bit not only on our nearly 32 years of marriage, but particularly on these past twenty years of walking with her through her journey with Huntington's Disease (HD). And particularly how they impacted me personally. I admit that this is going to be a very personal essay. And parts of it may be tedious at best. But I feel that at the end of this twenty year journey, this is an appropriate time for me to share some of my thoughts, and to fill in some of the gaps in Polly's story. My purpose is not only to share some of my heart, but also to provide a glimpse at some of the ways in which the Lord was at work through this experience, at least to my perception.

Polly and I met during our college years at Seattle Pacific University, and got to know each other well during the year that we both served in student government. I remember to this day being "captured" by Polly's disarming warmth and cheerfulness, as well as by her servant heart. Polly used to spend her summers working at Christian camps. And the summer before we served in student government together, she served as a summer missionary among the Indians of British Columbia. Polly was an elementary education major, and also was a very good pianist. When she was younger she had also been a cheerleader, and was a member of her school's swim team.

When we married on Sept. 11, 1971, we had no idea that thirteen years later, almost to the day, our lives would be impacted in the way they were when she was diagnosed with HD. There was no clinical test for HD back then. No way to know that you carried this illness, until the symptoms began to reveal themselves. But over the course of a year, and two visits to the University of Texas Health Science Center in Dallas, Polly's doctor concluded that he was "99% certain" that she had this illness. From that moment on, no aspect of our life would be untouched by this reality—physical, emotional, relational, social, vocational, and spiritual. We also knew that her health would gradually decline over the course of the next fifteen years or so, and that only a very small percentage of HD patients survive more than twenty years after onset.

I could detail every step of Polly's journey with HD (and later also with cancer), and fill several pages. But that's not my purpose in this essay. I will only say that her limitations affected every aspect of her person, and that they proceeded slowly and gradually over the course of the next nineteen years, until she was taken home to heaven on August 6 of this year. There were, however, certain "milestones" along the way which I will share with you. The most notable of these was when it became obvious to us that it was time for her to take up residence in a nursing home in August of 1992. Polly never held back from the challenges she was confronted with by this illness. She continued to do all she possibly could. But she gradually had to give up one activity after another: driving, cooking, dressing and feeding herself, etc., etc.

The year prior to her entering the nursing home, I was able to work almost entirely at home for the ministry I served with at the time (International Students). It was unsafe to leave Polly alone, since she easily lost her balance. And she needed someone to feed her at mealtimes, and help her with the other aspects of her life. We had discussed nursing home residency

in the past, though it was not something either of us was entirely comfortable with. But I well remember the day when she sat in our living room and said to me, "Rick, I think it's time for me to move to a nursing home." I think we both knew it was time. Polly needed someone with her at all hours of the day and night. Yet we also had two children to continue raising (Jeff and Jill were 12 and 15 at the time), and a full-time ministry to pursue.

The day I helped Polly move into her room at the nursing home, I stayed with her over the lunch hour. I had never spent much time in nursing homes before. And looking around the room, I realized that we were entering a very different world. Most of the people in this nursing home were quite disabled. It was a culture shock! But with my nightly visits, and development of relationships with the staff and the other residents, Polly's nursing home soon became my home as well. Her world became my world. The highlight of my day for the next eleven years was to drive to her nursing home to be with her in the evening, and when I could go at lunchtime to feed her her meal! At first, Polly used a walker, and we would walk down to the dining room to sit alone at a table, and talk about our day. She always wanted me to get a Dr Pepper or iced tea, and lift it to her mouth so she could drink it by straw. She loved for me to read to her from various books, and especially from the Bible. I think we read through most of the Bible together—some books several times. She loved Genesis, Isaiah, the Psalms, and the Gospels. Soon Polly was in a wheelchair, and I used to wheel her outside to a bench that was shaded by trees. We would sit and watch the birds, and pray together.

A statement Polly made to me a few days after she entered the nursing home reveals something of what kind of person Polly was. She said to me, "Rick, do you think I should start witnessing to the people here?" I've encountered people through the years whose zeal for witnessing probably had the opposite effect they desired. But Polly was not one of them.

Just her quiet perseverance and cheerful manner spoke volumes to me, as I believe it did to many others around her. The social worker at the nursing home where she spent her first four years made these comments about her: "Polly was a very cheerful person. Whenever you would see her she had a smile on her face that could cheer up the world. She was always complimenting others for things they do. She loved a challenge. She played a major part on our balloon volleyball team. Although her health condition limited her in doing some things by herself, she did as much as she could by herself, trying so hard to be independent as much as she could. I remember her face when she used to tell me that she was going out on pass to go to a ballgame, she was so excited. Polly was a very kind and sweet individual who loved her family and she will be missed."

Many fun activities were provided by the nursing home staff, including "balloon volleyball" (which Polly seemed to enjoy a lot), special holiday dinners (she would dress up in her finest dress, and accompany me down the hall to the dining room), outings to various events in the city (e.g. to concerts, the state fair). Actually, Polly's move to the nursing home enhanced our life in many ways. For the year prior to her taking up residence, almost all our time was devoted to "keeping our head above water" (which we didn't always manage to do). We were beginning to sink under the load of all the activities necessary just to maintain our life. But with all the assistance of the nursing home staff to cover many of these things, the time we spent together could now be devoted to other things that added to Polly's quality of life.

For several years I always brought Polly home on the weekends, and always scheduled a special outing or two—to a ballgame, a concert, a movie, a drive to a lake, etc., etc. I found that the anticipation of these events brought an element of hope and joy to Polly during the long weeks at the nursing home. We all need hope—the little hopes of a change of pace each

weekend. I well remember one day probably 8 or 9 years ago now when Polly looked at me and said in her then slurred speech, "Rick, you help make my life worthwhile." My reporting that to you sounds self-serving, and maybe it is. But I will tell you that that one statement stayed in my heart for many years! On another occasion I recall asking Polly how she kept going in spite of the at times overwhelming difficulties. She simply said to me, "I have the Lord. And I have my family."

About six years ago it became very difficult for Polly to continue eating, and she decided to permit her physician to insert a feeding tube in her stomach. For a while I continued bringing Polly home on the weekends. But with the tube feedings every four hours, neither of us got much sleep, and by Sunday night we were both exhausted. But even after we discontinued her coming home for these extended stays, we still went out Friday evenings (mostly to high school ballgames) and Saturday afternoons, and even to church Sunday mornings (where we sat at the back of the sanctuary). These outings brought me great joy. And it was so satisfying to see Polly smiling, even though she could barely speak anymore.

Polly's physical condition was declining pretty rapidly now. And it was getting much more difficult to transport her places. I well remember one day I think nearly four years ago, when I realized that this particular Saturday was the last time I would likely ever be able to take her out. It was. From that day on, Polly rarely was removed from her bed, except when we transported her to the shower room. Henceforth, it became a matter no longer of bringing Polly to places she could enjoy, but of bringing joy to Polly in her room. While we continued many of our daily routines, it seemed to me that worship became more and more our most meaningful activity. Polly couldn't speak at all anymore, and I am not much of a musician. But I could tell that the worship music that we frequently listened to brought a great deal of comfort to her . . . and to me too. In fact, the past few years it was

worship that brought most comfort and joy to my own heart as Polly's caregiver and husband . . . to the very last day of her life. Just before she left us, I was preparing to play some music. We never got to it. But I'm convinced that she was welcomed into heaven by far more beautiful music and meaningful worship than anything I could provide for her!

As I have reflected more and more on these past twenty years, I've asked many questions. It was only natural, especially at first, to ask "Why?" But we knew that we live in a fallen world, and none of us can claim immunity from life's struggles and even tragedies. It never really entered my mind to ask "What?" That is, "What shall I do as Polly's husband?" I knew that I was with her for the "long haul." No matter what. But I did at times ask "How?" "How are we going to do this?" How am I going to care for her, raise our two children, continue in full-time ministry, and for a few years during this journey also help care for my mother with Alzheimer's, and my dad when he was so seriously ill as a result of working so hard at caring for her. It didn't take me long to realize that apart from the Lord there was no way to do this. It was an impossible task. But I also knew that we weren't "apart from the Lord." He had shown himself faithful to us in so many ways through the years. He couldn't stop now.

Shortly after Polly was diagnosed with HD in 1984, I was reading through the Psalms, and I came to this statement: "Cast your burden upon the Lord and he will sustain you; He will never allow the righteous to be shaken (literally "totter")" (Psalm 55:22). In the margin I read that the word "burden" could be rendered "what He has given you." At that moment, the Lord impressed on me that the burden we had been handed was also in some mysterious way I could not yet understand, a "gift" from the Lord. Not something He had caused. But something that He could touch and transform. It would be many years before I would even begin to see how this could possibly be true. As I progressed through my reading of

the Psalms, I also came to this statement: "Blessed be the Lord, who *daily* bears our burden" (Ps. 68:19). I knew that if we were going to finish this race, it would be by doing what these two verses urged us to do . . . and to do it one day at a time. I had for some time kept a journal in which I recorded evidences of God's hand on our life. And over the next twenty years I returned to this discipline many times. Today, this journal is one of my most precious possessions, because it is full of the record of God's faithfulness to us, even though at times my own personal faith was very much of the "mustard seed" variety, if even that! I was also very aware that we needed the prayer support of many other people. And I cannot tell you the encouragement it was for both of us to hear from so many friends across the country that they were praying for us even daily. When I encounter people in the hospital who are under a burden too heavy for them to bear, I always encourage them to enlist the daily prayer support of as many friends as possible. And to ask them to keep praying until they go to heaven!

As I read through this journal, I find evidence of the Lord's activity in our lives in two primary ways. First, in the many things that He did *for* us. I'm sure that there were innumerable ways in which He was working in our behalf, of which we were totally unaware. But I will mention a few of the ways of which I was aware. For one, it became evident to me as the years went by that God had been *preparing* us for this long chapter of our lives—primarily by providing models for us. I think for instance of my own paternal grandparents. Among my earliest memories in life are those of watching my grandmother care for my grandfather during the years following his major stroke, in the early 1950s. Then there was the model He provided for us of Bill and Dorothea Hart, who were members of our church in the Seattle area in the late 1970s. Bill suffered from Parkinson's for many years. And he and his dear, caring wife were regular attendees at the church I pastored for five years. What a sterling example they were to us. There

was the model of Polly's mother Elsie, who tirelessly cared for Polly's brother Chris for so many years. There was my own father who was so dedicated in caring for my mom during all her years with Alzheimer's. There was the couple we met in Hayward, CA in 1987, Sherwood and Harvette Peters. Harvette had M.S., and relied on Sherwood's loving care for many years before her homegoing. There were our neighbors, Al and Jeane Olson, who lived directly across the street from us. (Little did we know what a blessing they would be to us when we bought our home, not even knowing they lived there!) Al suffered from a neurological disorder for many years, and his wife Jeane provided such a wonderful model by patiently caring for him. I could mention others, such as Greg and Lisa Hatteberg at Dallas Seminary, who are still contending with Lisa's M.S. And so many others whom God brought across our path to serve as models and examples, particularly for me.

In addition to preparing us, it was also evident that the Lord was *guiding* us and *providing* for us. God's guidance and provision was evident first of all in his enabling me to remain in full-time ministry through these past twenty years, but in ways that allowed me the flexibility to provide the increasing level of care that Polly needed. I frankly did not know how this could be. But how grateful I am for the years I was allowed to serve at Dallas Seminary, International Students, Probe Ministries, and since 1996 in hospital chaplaincy. And for the many, many faithful friends who have supported us in these efforts!

I think of the special families who lived near us, and who helped us shepherd our dear children during the years they were growing up, and we were being stretched beyond our capacities.

The Lord's guidance and provision was also evident at points along the way when we had to make important decisions. I think for instance of when it came time for Polly to enter the nursing home. It was our neighbor Melanie Miller, a nurse, who

informed us of Brentwood Place—the one facility in Dallas County that had a preponderance of younger residents (Polly was only 41); and then four years later when Polly's needs were increasing, she informed us of the opening of a new nursing home on the shores of Lake Ray Hubbard (Sr. Care) where Polly resided for over seven years. I remember also when Polly and I were discussing this decision, being captivated by a story on the evening news that very week about a couple's going through the process of making the same decision we were.

When she first entered the nursing home, we had to jump through a number of legal and financial hoops, including applying for Medicaid assistance for Polly. This was the only way we could afford this level of care. Only those whose total assets fall under a certain limit are able to qualify for this assistance, which ours did at that time. We later learned, however, that if we had waited one more month to apply, we would have been disqualified, and Polly would not have been able to enter the home for perhaps two more years. This was the Lord's doing, and his timing for her.

At other times of decision it seemed that God brought people across our path who had just the insight or encouragement we needed at that particular time. When Polly had to make a decision about a feeding tube for example (which really is a huge decision), the very day that we were contemplating it I entered a room at the hospital where I serve as chaplain, only to find a HD patient and her husband. She had made the same decision Polly was contemplating. I only encounter HD patients in the hospital about once a year! But I encountered her on the very day I needed some encouragement with regard to Polly's decision.

One of our most constant companions these past twenty years was the temptation to discouragement. I'm convinced that there is a spiritual battle that surrounds issues such as these in our lives. There is an enemy who wants to defeat and destroy us. And I found that one of the ways that the Lord encouraged

us (I'm speaking for myself here), was through the many small evidences of his presence in our lives. If you were to read several pages of my journal, you would conclude that I had recorded a number of interesting "coincidences" in our life. But when you string together so many events like these over the course of not only years but decades, it becomes not "coincidence" but "providence."

For example, I remember a day in the early 90s when a package containing a book came to my desk at Probe Ministries, where I was serving as Director of Publications. Accompanying this package was a letter from the authors of the book. They were asking if we would consider marketing and distributing this book. This was the only request like this that I remember receiving during the years I worked there. I noticed from the cover that the book was a biography or story. How they happened to send this book to us at Probe (an academic/educational ministry), I still do not know. The authors had no way of knowing me, or anything about our life. But what surprised me when I opened the book was that it was the life story of a couple, the husband being affected by HD! Polly's illness. What are the odds? We eventually met the sweet surviving wife of this man about whom the book was written!

I remember another time not long after Polly entered the nursing home that I brought her one evening to a concert at a large church in Dallas. About 4,000 were in attendance. We were a few minutes later than planned, and the lights were already dimmed. It was packed. But there was one seat at the end of one pew on the ground floor, where Polly could sit next to me in her wheelchair. We took our place. I turned to my right, and found that the person right next to me was the director of nursing from her nursing home! I didn't even know she was a believer, or that she would be there that night. What are the odds? There was also the time when I had just finished reading a portion of a book to Polly at the nursing

home, then left to attend a service at a nearby church. The pastor's message was on exactly what I had just read to Polly. What are the odds?

Given any one of these instances, I would not think a great deal about it. But these kinds of events formed a pattern over the course of many years to the very last day of Polly's life! I recounted in my memorial letter about Polly some of the evidences of God's fingerprints on our life during her final weeks and days. But for those who have not read that account, I repeat some of it here. The morning before Polly entered the hospital for the last time, I was preparing for my day and listening to a Christian radio station in the background. As is my custom, before leaving my room I walked over to my bed to sit down and read the day's selection from the devotional "Daily Bread." As I sat down, I reached over to turn off the radio. But before I did, the last words uttered by the spokesperson on the radio caught my attention. He said, "If you knew that today would be your loved one's last day, what would you say to them?" An interesting thought. Then I opened my devotional, and the reading for the day was entitled "Say It Now!" These words appeared in the article: "Recalling the good qualities of deceased friends or relatives at their funeral is appropriate, but how much better to give sincere praise to them while they are still living. It may be the encouragement they desperately need . . . Don't put it off. Say it today. Tomorrow may be too late!"

That night when I went to see Polly, I made a special point to be alone with her and to tell her how much I loved her and thanked God for her, and to thank her for all she had done for us as a family through the years. Polly had been unable to speak at all the past few years. But the look in her sweet brown eyes spoke more than words could tell. Little did I know that this indeed would be her last full day in the nursing home. The next night I would be sitting with her in the emergency room as she entered the hospital for the last time.

Two weeks later I was up early on the morning of August 6, preparing my breakfast before returning to the hospital. The same radio station was playing in the background as two weeks before. This time a commentator came on the air and said, "You know, when it comes time to die, the relationships that will support us during our time of need, are the ones we have cultivated and nurtured all our life. We die the way we lived." Less than two hours later I was standing at Polly's bed as she left this world for heaven.

I share these events with you to simply illustrate how over time I learned to take them as reminders, or "markers" along the way, of God's presence and shepherding care over our life. Even in our most difficult hours. One of the many things that the Lord did for us during Polly's long illness.

But just as important as what the Lord was doing *for* us, if not more so, was what I eventually saw as his work *in* us. At least I knew He was seeking to do this in me. Shortly after Polly died, our daughter Jill said to me (and I quickly corrected her), "Dad, I think the reason God put you with Mom was because He knew you had the qualities that would be needed to care for her." I know my heart better than she does, and I said, "Jill, I think one reason the Lord put us together was because He knew I needed to *acquire* the qualities needed to care for Mom." And it's true. I well remember a day (a moment, really), probably five years after Polly was diagnosed, that it dawned on me what God was doing in my life in this regard. And how much growing I needed to do. I can only speak for myself, but I know that when Polly became ill, God enlisted me in a life shaping process. Part of this process involved his gently and patiently chipping away at qualities that He knew needed to diminish in my life. The other part was gradually instilling in my heart the qualities He wanted me to acquire. And I saw primarily three.

The first of these was a sounder *faith* in the Lord. Not that there wasn't faith in our hearts before. But this assignment

required faith at a different level than I know I personally had. I'm not necessarily speaking of faith in God's healing power (though I know it's real). Candidly, there were occasions over the years when well-meaning individuals urged us to have faith that God would heal Polly miraculously. One fellow once told me that if we had real faith we would discontinue all of Polly's medications. I don't need to tell you that I didn't think about this suggestion very long. The kind of faith I sensed God was aiming at growing in us was a trust in His goodness, and the goodness of His purposes, even when it was unknown to us what they really were. Even though life was getting harder every year. This kind of faith comes only from God.

Over the years the Lord used such things as the reading of scripture, times of prayer, the prayers of others, and the recording of instances like those mentioned above, to nourish our faith in Him. Not that we didn't experience times of doubt or discouragement. We did. One thing I did learn, however, was that the experience of pain and sorrow is not inconsistent with faith in the Lord. Paul's letter to the Philippians is full of exhortations to joy and peace, and contains a wonderful affirmation of our hope that to be with Christ is "better by far." But in the middle of this letter Paul makes the honest confession that if his friend Epaphroditus were to die as a result of his recent illness, he would have experienced "sorrow upon sorrow" (2:27). God's word is so realistic and balanced. That fact helped me endure the stormier seasons (as it does now).

The second quality I sensed God working on, and this is really an outgrowth of the first, was *hope*. I am not by nature a very hopeful person. But I learned to grow in this area. I see hope as simply "faith oriented to the future." (I read this somewhere.) An expectation not just of "good times to come," but that as God's goodness has been revealed in the past, so it will be unveiled in the future—even if it comes through

encounter with illness and pain. That what the enemy may intend for evil (and which is evil), God can and ultimately will use for good. Even in the face of death (that alien invader into God's created order), there is the wonderful hope of eternal life in heaven, and the resurrection to come!

The third quality God was working on is the most important. That was *love*. I say "most important" because the New Testament tells us that if faith doesn't produce love, we are "nothing" (1 Corinthians 13:2). It is useless and dead. I loved Polly before. But this illness tested our love, and took aim at it. Speaking for myself, God used this illness to transform my love for Polly. I learned just how much I needed to grow in genuine self-giving and self-sacrificing love. Not that I didn't need to take time to care for myself. It is possible to neglect your own legitimate needs as a caregiver. And I see some caregivers in the hospital who do this. I remembered that even the "Good Samaritan" delegated some of his caregiving to others so that he could tend to his other obligations (Luke 10:35). But there is a difference between taking care of our needs, and catering only to our own desires. And this is what the Lord was showing to me.

He was showing me just how many ways there are to spell "love." Dressing, bathing, feeding, carrying, smiling, laughing, crying, reading, singing, just sitting quietly . . . . I learned that in a society that places its highest premium on appearance and ability, it is very easy for people whose illness robs them of these very things to feel not only diminished, but also *devalued*. At times the words and actions of others can reinforce this false belief. I learned that the most significant gift I could give to Polly was to communicate to her by my own words and by my actions that she was the most valuable human being in my life. And she was.

I must not fail to mention at this point that not only did I sense the Lord transforming my love for Polly, but also deepening my love for Him. There were times when I felt

confused and upset about what the Lord was allowing to happen in our life. I still feel the pain of some of these memories. But as the years went by, and we experienced more and more of God's shepherding care over our lives (even during the very trying times), my love for Him and sense of indebtedness to Him grew and grew. As a result, I sensed a growing passion in my heart to simply worship Him. Both private and corporate worship became the focus and highlight of my week. I remember reading as a young boy the verse that says, "We love (Him) because He first loved us" (1 John 4:19). It's true. The love I feel for Him and the worship I find flowing from my heart, is simply the natural response to His great love, expressed to us in so many ways. When my heart grows cold, and at times it does, one of the things I've learned to do is to bring to mind the many ways in which God has so graciously loved us these past twenty years. "Faith, hope and love; these three remain. But the *greatest of these is love*" (1 Corinthians 13:13).

I will tell you honestly that the greatest blessing of my life was caring for Polly. I miss it deeply. And though I would never want her to go through again what she did these twenty years, . . . if she had to, I would be first in line to go through it with her again.

Several years ago, I was reading through the Gospel of John. When I reached the end of the book my attention was drawn to a statement Jesus made to Peter in which he signified to him "by what kind of death he would *glorify God*" (21:19). I had always thought about "*living to the glory of God*." But I had never thought about our "*dying to the glory of God*." I knew at that point that Polly's remaining years were likely few. And I began praying almost daily that whenever it came time for her to leave us, that her departure would bring glory to Him in some way. That was a hard prayer for me to offer. And I don't feel like I was ready for it to be answered until her very last hospital stay. But now that that day has come and gone, I believe God has answered that prayer. In my mind, He has

answered it in part by magnifying through Polly all that He has done ***for*** us, and all He's doing ***in*** us. And will continue to do until we see Him in glory. *Soli Deo Gloria.*

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