# Hearing the Call to HIV/AIDS Ministry

# A Convocation Presentation by Pat Hoffman December 13, 2012

"Listen to your life. Listen to what happens to you because it is through what happens to you that God speaks...It's in language that's not always easy to decipher, but it's there powerfully, memorably, unforgettably."

Frederick Buechner

I'm grateful for this opportunity to tell the story of my Call to AIDS Ministry: the people through whom that call came and the people who helped me.

Many of you here knew me in the '70s and '80s when my husband Cecil and I were living in the Los Angeles area and I was working with the National Farm Worker Ministry, doing organizing and writing in support of the United Farm Workers.

But by 1989, after more than 20 years with the farmworker movement, I was needing a change and was thinking of some kind of one on one work, but I didn't know what it might be. Cecil suggested I do some volunteer work to try out a different role. Chris Glaser, who was the Director of the Lazarus Project at West Hollywood Presbyterian Church, was a good friend. He had been talking about the growing AIDS pandemic and how painful it was to have friends dying. I decided to apply to be a volunteer with AIDS Project Los Angeles. What APLA needed at the time was hospital visitors. That choice didn't appeal to me. I didn't like hospitals and over the preceding three years I had had ear surgery, bilateral knee surgeries, and a hysterectomy. But, if that's what they needed, I'd give it a try and signed up for their training.

In May, 1989 I started as the APLA hospital volunteer at the small Daniel Freeman Marina Hospital, not far from our North Inglewood home. I went regularly two afternoons a week to visit patients on a new dedicated AIDS unit with about a dozen patient rooms available.

On that first day, Bryle, the Unit Supervisor, introduced me around as the APLA visitor. He and the Charge Nurse, Martha, took me to meet the four patients on the unit that day: David, Tom, Mark and Neal.

From that first day, I kept a journal, as both a witness to the experiences of the men I was meeting and a setting for allowing my full range of thoughts and emotions to surface. Here are several brief entries I made about Neal over a five day period.

#### May 18th

Martha took me down the hall to meet Neal and his mother, who was from Bellevue, Washington. Neal looked awfully sick and didn't feel like talking. He had a nose tube to help his breathing. He resembled his mother. They both had brown hair with a lot of body. Her's was flecked with gray. Neal's was cut in a butch and it had grown out quite a bit.

His mother said she and her husband were going home that evening. I had an urge to tell Neal I could be around like a substitute mother, but I knew that really wasn't true. I was a comma inserted into this man's life. I knew nothing of what had gone before or how it affected the present. And no one knew what would follow my comma of a moment.

[A little later] I was walking down the hall, ready to leave the hospital. Neal's mother came walking toward me. I stopped and said, "It must be hard to leave." She acknowledged that it was, but they had to get back home. She mentioned wishing Neal's Presbyterian church was more active in visiting him. She seemed so happy to discover that my husband is a Presbyterian clergyman and had some things in common with her and her husband that she rushed me down the hall to Neal's room to meet Neal's father, who seemed relieved to carry on even a brief conversation about more comfortable topics related to the church.

Then he said to Neal concerning his congregation, "They ought to bring you communion." ... Turning to me he said, "Neal was ordained an elder." Neal, who was sitting up on the bed, trying to get air and get comfortable, managed to interject, "That was a long time ago." p.4,5

Sunday, May 21st

I wanted to go by to see Neal for a few minutes. I had been thinking about how sick he was and that he might be missing his parents. So, this afternoon I went by to see him, carrying with me a red rose from our garden.

He was very ill and whispered to me that he had a fever. I touched his forehead. My hand felt cool against his hot forehead. He reached up, took my hand and held it tight against his chest. We stayed that way in silence. After a few minutes he began to cough. I got him some water. He sat up to drink it. Then I told him I was going and would see him in a couple of days. He looked at the rose and with great effort he said, "The flower is beautiful. God be with you."

Who is being ministered to here?" p.5

#### Tuesday, May 23rd

I went first to see Neal. His fever was down to about 100 degrees. He still spoke in a whisper and with effort. We talked a little about his parents. He let me know he had a good relationship with them and they were coming back to Los Angeles to be with him on the weekend.

Before I left, I let him know that a pastor, [Rev. David Meekhof], was nearby and [I was pretty sure] he [would know] Neal's parents. Would Neal like the pastor to contact his parents while they were in Los Angeles for the weekend? He looked surprised that this man, whom he had known as a child, was nearby. He said, "Just five minutes away?" I said yes, just five minutes away. "I'll call him if you want me to." He nodded yes. Then he said he was ready to rest.

Throughout this conversation he was holding my hand. Or was I holding his? He was lying on top of the covers in his hospital gown. His legs were young and strong. I noticed his feet and ankles seemed swollen... p.6,7

## Thursday morning, May 25th

I got a phone call at home from the social worker at the hospital. "Pat, I wanted to let you know before you came in this afternoon that Neal has died." I hung up and ..began to cry. I was surprised at my tears. I

felt I needed to do something, needed to get closure. Maybe I just wanted activity to blunt the sorrow. I phoned Rev. David Meekhof, the minister who was planning to visit Neal and his parents the next day, and told him the news...

I had known Neal for five days, had spent maybe altogether 45 minutes with him. How could his death so affect me? But there was, with only a few words, an intensity. He allowed me into the circle of his life in simple, direct ways during the last two days of his life. He held on to me, did not, could not, hide his suffering. I had come to share it and he allowed it.

"I have thrush," he said, and displayed the fungus on his tongue.
"Does that create some swelling," I asked? "Yes," he had said. "I have a fever," and I touched his head. p.9

I had met four patients on my first day. Forty-three days later and after their several hospitalizations, three of the four men had died, men who should have been in the prime of life.

Tom, one of those first patients, died at 7:08p.m. on June 30th in the hospital. His companion, Robert, was with him as he always was.

A week or so later, Robert returned to the hospital and invited me to a home memorial service. This was the first of many memorial services I would attend. And this one became part of God's call to me.

### Monday, July 17th

Yesterday I attended a memorial celebration for Tom...[It] was not in a church. It was held at the apartment Robert had shared with Tom...

In the AIDS-affected community, memorial services in homes and apartments are going on frequently, but this was the first one I had attended.

It was a small, attractive apartment with a little patio by the front door, large windows opening between the living room and patio. People were arriving for about an hour until finally there were around forty crowded into the living room or outside the open windows on the patio. I was one of the earlier arrivals, warmly greeted and introduced around by

Robert as the volunteer who had visited Tom frequently. I was served a glass of champagne and sat in a canvas sling chair watching.

A young gay couple, maybe in their twenties, arrived. One held a bunch of sunny-hued flowers. The young men looked uncomfortable, like boys at a funeral. What are we supposed to do? How should we seem?

A woman arrived with her infant. Robert greeted them and took the baby, cradling it, carrying it around the room, sharing this miracle of new life with guests, then holding it up in the air with love, as though to let everyone see this sign of hope among the milling of the bereaved.

Later, Robert stood in the middle of the room and gathered our attention for a brief time of remembrance. Everyone was offered a glass of champagne for the toast to Tommy, as they all called him, that would come.

Robert stood in the midst of friends with the glass of champagne in one hand and a greeting card in the other. He told us the message seemed to fit how Tommy would want to be remembered. And then he read it, his hands shaking hard. But he got through it and raised his glass in a toast to Tommy. p.46

It wrung my heart to see this gentle, loving man, a few days after a major loss, trying to lead this memorial gathering. I asked myself, "Where is the church that people are having to do their own services? And God's Spirit began to say, "You can help."

By 1990 I was wanting to find employment in the AIDS field. I didn't know what I wanted to do or would be suited for. I saw an ad in the Los Angeles Times for a position at Cal. State Long Beach in the AIDS Research and Education Project as a Program Assistant. I applied for the job and was contacted for an interview and I was hired. The young psychologist I was to assist was overwhelmed and had no clear idea of what he wanted me to do. But we quickly sorted out what I could do to help.

I became part of a planning team for trainings under a National Institute of Mental Health grant. We were training social workers and healthcare workers who were coming in contact with people with AIDS and needed to learn how to keep safe and be compassionate. After a short time I learned that the Project's most pressing need was to get physicians on-board to look for symptoms in their patients and to offer appropriate care. The Project was in the second year of a three year grant and had not trained a single physician. I organized a panel of the doctors I had gotten to know at the Marina Hospital and arranged lunch-time trainings at hospitals for doctors' Continuing Medical Education. The program was effective, providing training to 500 physicians in one year, and my panel loved helping to involve more doctors.

I had read an NIMH study that found AIDS patients with spiritual support did better than those without, so I began contacting denominations to find out what materials they had in place for helping pastors respond to the pandemic. One person I spoke with was Cathie Lyons with the United Methodist Board of Global Ministries. She was working hard to develop materials and asked if I would write a booklet on HIV/AIDS Ministry. With her help I started lining up interviews with men and women with HIV or AIDS and with some concerned pastors. Most of them were Methodists but one I added was a long-time friend of ours, a Presbyterian clergyman in campus ministry. He had recently told me he was HIV+. He agreed to be interviewed. However, he was so fearful of retaliation if his status were known on the campus where he worked, that he didn't want to be interviewed in his office, preferring that we meet in the University parking lot in his little car. I think it was a VW bug. In any case, it was quite small. I conducted the taped interview with him in the driver's seat and me with my tape recorder on the passenger side. As he told his story of notifying the church where he had been teaching a Sunday adult class, he described meeting with the pastor and sharing about his illness. Soon after, he received a letter from the Session terminating his teaching at their church and reducing by 90% their support of his campus program. As he told this story, he wept. He had hoped for pastoral care and support but had received rejection.

His story was among the significant stories from the pandemic I shared to illustrate points in the booklet, "HIV/AIDS Ministry: A Practical Guide for Pastors," which the Methodists would publish in 1993.

I loved my job at Cal. State Long Beach, but missed regular direct contact with patients. One day, sitting in my office I picked up the phone and called Rev. Janet Humphreys, the Director of the Clinical Pastoral Education program at University of California at Los Angeles (UCLA). I knew her from Pacific Presbytery. I asked her, "Janet, if I were to get CPE training, what would be my chances of finding employment as a chaplain?" She told me, "Your chances as a lay woman are zero." I thanked her and put the idea out of my mind. Or at least I thought I did.

In Spring of 1991, I reluctantly left my Cal. State Long Beach job because Cecil and I were moving from Inglewood up the California coast to Ventura. Some of my friends at the Cal. State job made phone calls to Ventura to inquire about AIDS related jobs for me, but there wasn't much up there and what there was required a masters degree, which I didn't have. To make matters worse, 1991 was a period of major recession with nearly 10% unemployment in California. Jobs were hard to come by.

Once we got to Ventura I did different things: I coordinated a man's run for city council and when that was over, I started a fund development consulting business, writing funding proposals for nonprofits. It was all work I could do, but could never love. Perhaps God's Spirit was working through the dreariness of the jobs.

One day, sitting at home at my writing desk, going through our mail, I picked up the Pacific Presbytery newsletter. The Associate Director of the CPE program at UCLA had an article pitching their program and mentioning they accept laypeople. I think I had known that before, but that line leapt off the page and within the week I had applied. I wanted to do AIDS Ministry. I knew I needed training. Suddenly I had no doubt that I should go forward with this, in spite of all evidence to the contrary.

There were few Chaplaincy positions in the whole County and none in AIDS-serving agencies. In fact, there were basically only two AIDS-serving entities. One was a large weekly outpatient clinic, called the Immunology Clinic, at Ventura County Medical Center, and VCMC had never had a chaplain. The other was AIDS Care, a small, secular social service agency, with a director and a part-time secretary. I talked to the Director and she had no interest in ever hiring a chaplain.

So that was the outlook as I started my first extended unit of CPE in September, 1992, making the sixty mile commute twice a week from Ventura to UCLA and taking overnight on–call every other weekend. I got permission from my supervisor to do half my pastoral care hours in Ventura and Dr. John Pritchard, Medical Director of the Immunology Clinic at VCMC, that served patients with HIV and AIDS, agreed to have me at the weekly clinic as an unpaid chaplain intern. I became part of the HIV/AIDS team of home health nurses, social workers, a psychologist, and Dr. Pritchard. The Clinic operated out of two adjoining trailers on the Hospital grounds.

My sense of call was now morphing into ministry. On Tuesday mornings, I attended Case Conference to learn about the patients we would be seeing that day. When Clinic started, patients would be sitting in chairs lining the walls of the trailer's waiting room. This was the principle place where I operated. Cecil called it "doing ministry in a bus," although bus seating would have offered more privacy. But I got to know most of the men and the few women with HIV. Sometimes I was asked to visit someone back in an examining room. Dr. Pritchard also asked me to make home visits.

My first home visit was to John, who, because of his declining health, had moved back in with his parents near Ojai. I had met his mother at Clinic and would see her sometimes when she drove John down the hill for his clinic appointments. But neither of the parents were home the day I visited. I remember sitting in their sunny living room getting to know John. I learned he had a strained relationship with his father; they were just so different. His father loved to fix cars and John had no interest in auto repair.

A few months after that home visit, it was Clinic morning and Dr. Pritchard urgently told me that John was in ER and he wanted me to go see him. I went across the hospital grounds into the back door leading to the ER. John's mother was sitting alone in a waiting area. She told me her husband had come down with her and was around somewhere.

I went into an examining room to see John. He told me he wanted to talk with each of his parents, to thank them for everything. He asked if I would arrange for them each to come in. I said I would.

I hurried out and found his father and brought him in to see John, then left them alone and went back to where John's mother sat waiting. I told her John was speaking with his father and that he also wanted to speak with her. I took her in and then left to return to Clinic and the other patients.

I later learned that within a few hours John had slipped into a coma and that night he had died.

About a month after John's death, his mother came to Clinic to thank the staff for their good care of her son. She took me aside and told me how much it had meant to her husband to have those few minutes with John. John had thanked his father for all the times he had fixed his cars and had kept them running. Fixing the cars was a way this man had of showing love. At the end of John's life he let his father know he had received those acts of love. That was the gift John could give on his last day of life. God was moving in John's heart to offer that gift. And God was able to use me to get the gift delivered.

Frequently, on Clinic Day, staff from agencies like the County Drug and Alcohol program or AIDS Care would come over to talk to patients or to the clinic social workers. One day, AIDS Care's new Director, Doug Green, showed up. We hit it off right from the start. He had grown up in a Presbyterian Church. In the course of the next two years, Doug would be a person God sent to help me.

I was eager to try something I had learned in 1991, a small group form of *lectio divina*, an ancient meditative way of reading scripture. In November of that first year, with Dr. Pritchard's approval, I offered what I called a Spiritual Questing group. I set it up to run for the four weeks of Advent. I had fliers at Clinic, and advertised it at AIDS Care. Four men from Clinic committed to the four sessions. Scott had no religious background. Del had been raised in a fundamentalist church. Joseph, who was Latino, was a lapsed Roman Catholic. And Greg was a Presbyterian. They were there and on time each Tuesday evening for a month. At the conclusion of the last session I asked them to help me evaluate the experience. They all said they liked it, but it went too fast, maybe something could be added that would fill out the time. I took note

of their feedback, but was not in a position to offer Spiritual Questing again for two years.

After two extended units of CPE at UCLA, with the twice a week commute, and the demands of the Immunology Clinic, I was worn out. I applied to do my last two units, full-time at St. John's Medical Center in Oxnard, in their small program. My supervisor there would not allow me to continue ministry at the Immunology Clinic. But I was assigned to take over facilitation of an evening support group for family members of people with AIDS. This was a great opportunity to get a deep and detailed understanding of issues encountered by family members and sometimes partners.

During my last unit of CPE, as my Advanced Project, I had the chance to offer an eight week Spiritual Questing group. Remembering the advice I had gotten two years earlier from my first Spiritual Questing group, I asked my supervisor to help me think through what we could include in these small group meetings in addition to *lectio divina*. She suggested adding a weekly Reflection Question, something she had liked in her religious community when she had been a nun. I added an element of ceremony by opening with each person lighting a votive candle from the central Christ candle. I also decided to close each meeting with Passing the Peace. If there was anything most people with AIDS were needing at that time it was to be touched.

The first night there was a rain storm. I wondered if anyone would show up at this unfamiliar place, St. John's Hospital, to do this unfamiliar thing, with this lady they didn't know well, or didn't know at all. Doug Green had recruited the participants and wanted to be part of it himself, maybe to get a better idea what I was going to do. Doug and seven other men all showed up and we had our first session in a small conference room around a huge mahogany table.

The men showed up for every session and even asked to bring a couple more people. Their seriousness about spiritual questing made for a deep and memorable experience. When the last session concluded, the men did not want it to end. It was winter of 1995 and I was about to complete my fourth unit of CPE. Doug Green offered to pay me to continue facilitating a weekly Spiritual Questing group at AIDS Care.

gladly agreed. Then Doug contracted with Art McDermott to find some grant money to bring me on staff as the first AIDS Care Chaplain.

In 1995 I began that first job as a Chaplain. Significantly, it was the point at which researchers were introducing the cocktail that promised to extend the lives of people with AIDS. It was the year I turned sixty. And it coincided with publication by Eerdman's of the journal I kept in 1989–90, <u>AIDS and the Sleeping Church</u>. The Ventura County Star, of its own volition, carried a full page spread about the book. A heady time.

I was not prepared for what lay ahead, for the difficulties of developing a ministry for which there was no pattern anywhere in the country. Outpatient chaplaincy was a brand new field in 1995. I called my work at AIDS Care the exurbia of outpatient chaplaincy, way out beyond the suburbs. AIDS Care had about 150 clients spread over the whole County of Ventura. Most of the clients were between about twenty and forty and could no longer work, at least not a full-time job. AIDS Care offered a food pantry, assistance with housing, and other essential help. By the time I came on as Chaplain, they had just moved into a two-story Craftsman house in Downtown Ventura.

AIDS Care, under Doug Green, was growing rapidly and he was doing his best to put together a staff to meet the needs of clients. The staff was young and wanting to help, but some lacked specific training for their positions. Two of the staff were openly hostile toward me from my first day. They had never met me before. I don't know what their take on me was, but it made my first weeks pretty miserable. Fortunately, the one who was doing case work, had a change of heart and came to rely on me for support for clients and for herself.

After the initial weeks, I started focusing on questions of organization for my position. Here's an excerpt from an unpublished article I wrote at that time:

I've been on the job now for four months. The good news this past week was that I remembered enough of who I am as a chaplain to have a flood of questions. I felt strangely energized and empowered by the questions coming to mind.

During most of my first four months, I have felt overwhelmed by particularities: Where is the name of that woman I spoke with? I've got to remember to call her...Did I leave that blue spiritual support questionnaire with the guy's name on it out on my desk where it could be seen?...I left one message for the woman who marked that she wanted to speak with me. Should I keep pursuing it or is the ball in her court?

Last week I started seeing the larger questions of how chaplaincy might be structurally integrated into this setting. I long for the order I experienced in developed chaplain services departments. But AIDS ministry was my chaplaincy goal and here I am with who I am and what I know. God's gift to me is the chance to do this work.

One day, soon after I started the job, I was sitting at my donated computer (with no printer) trying to conceptualize goals and objectives for this chaplaincy position. The computer screen was blank. I looked up at my CPE certificates on the wall before me and thought of the supervisors who had helped me, trained and encouraged me. I wanted to call one of them up and ask, What do I do now? But they had done their job and now it was up to me. I sat looking at my certificates and wept. Then I told myself, you were trained and called to do this work, so pull yourself together and do it.

And with God's help, I did. I held the position for five years through three directors and two locations. Weekly Spiritual Questing groups, which Doug co-led with me, became the core of the AIDS Care Spiritual Support Program. Clients in those groups developed a close sense of community, and in the *lectio divina* portion clients listened for the voice of the Sacred coming to them and to each other.

We held twice a year spiritual support retreats at Casa de Maria in Montecito. Most of our clients had never heard of a retreat and were reticent to sign up. But after a couple of years, retreat spots were in demand. I canvassed Ventura County churches annually to cover the cost for each retreat participant. A list of supporting churches was given to every retreatant, and they were deeply appreciative that churches would

do that for them. And every church was sent a report after the retreat. I sometimes spoke at churches.

I visited with clients in the hospital and sometimes wrote prayers for them. And in my little office on the second floor of the Craftsman house, I met privately with clients, who grew comfortable sharing with me about their addictions, struggles with family members, and their fears. Partners and family members started coming to me to grieve after a loved ones death, so I sought more training and began offering grief groups.

And I had opportunities to conduct memorial services, which I never felt was my strong suit, but I had my copy of Services for Occasions of Pastoral Care and being there I was able to allow grievers to grieve while I put their loss, and sometimes my own, into Sacred Space.

Men and women I came to know allowed me to hear their stories, accompany them in finding hope, pray with them in both public and private settings, and send them forth with courage when AIDS Care closed in Jan. 2000.

In the Isaiah 49 reading this afternoon, we heard again the exile narrative of release and homecoming. As a Chaplain in AIDS Ministry, I believe it was my task to level out a pathway for our clients so they could find release and a sense of home, whatever that might mean for each person: acceptance of themselves; trustworthy community; comfort in the face of fear; hope as they walked the tightrope in those years between knowledge of their diagnosis and the reality that they were still living; and always, assurance that God was with them and in them.

The clients, their families and friends confirmed my call and I'll always be grateful for their trust in me.