"Coming to Terms with Dying"
Remarks at AIDS Conference, April 24, 1987

I'd like to start out in the garden with a little report. On April the 23rd the grapes have sent out promising new growth, with many buds. The newest leaves are still edged with deep pink. The strawberries are blooming and setting fruit. Some collards that wintered over have burst out with pale yellow flowers. The weeping cherry has delighted us with its riotous display and now is sober green. The sweet Williams come thronging forth amidst the last of the narcissus. The obedient plant that the old woman down the street gave us is up and thriving alongside the volunteer nicotianas. The little seedlings, all lined up tidy in their egg-cartons,are doing fine.

It's disconcerting to have to talk about death in the springtime. Last year my friend Gloria was angry to be dying in the Spring. And for me there was considerable sorrow during that season as Carl's tulips and hyacinths came right on up and bloomed as if the gardener were still watching over them, as if nothing had changed.

This Spring I'm less inclined to mourn. As I wander among the raised beds that Carl shored up with railway ties he filched from along the tracks beyond the back fence, I ponder his work and his friendships. Carl <u>was</u> a gardener. He cultivated friends and nurtured great interests. I wonder that coming to terms with dying is not so perplexing or frighteneing for gardeners.

For old Mrs. Hartel down the street each peony, each iris and each bridal wreath bush was a friend or a relation: "This one here's from Glady's sister in Swansboro"; "I got that there from Mrs. Rigsbee use to stay on Carden's Lane." She knew about perpetuity in her old bones,bent from stooping in the garden for eighty years.

First time we saw her she came around to the back door in her garden bonnet to offer us some cuttings. She trusted deeply in sharing and in gardening, and she still lives out in our garden.

Now and then Mrs. Hartel would say how she wanted to die in her garden, out with the corn and zinnias. Instead, because her relatives didn't understand, she died lashed to a bed in the Intensive Care Unit at Durham County General. Carl, on the other hand, did die in his garden, in a sense. He died surrounded by the life he had tended -- the friends, the interests and the yellow crocuses which saw fit to bloom in January last year.

Before proceeding, let me say that our experience during those few weeks was somewhat unusual, but it's all I know of "coming to terms with dying" and it's what I have to share.

You all have with you the handout I prepared. Perhaps you'll take it home and look it over. I've chosen passages from letters which I hope will give you an idea, beyond my remarks now, of this man I speak of, and his friends and what we went through. The first entry is a story Carl wrote me from London in 1984, about his encounter with another resourceful gardener, this one from Wales and on his eventful way home. For me it captures Carl's fascination with people and how they tick, his optimism about sex and his belief in gay brotherhood. I share this with you because Carl's spirit in living was not much changed in dying.

When we got word, conclusively, that Carl had AIDS, I cried and he comforted me. Then the first thing he said was, "There are two things I want to do: get what it takes to end my life when I want to, and to try and finish my book."

Dancing, especially English and Scottish folkdancing, was Carl's greatest love, and is the beating heart of our community of friends. Carl was in the midst of a definitive, visionary volume on country dancing and he knew that none of us could easily take over that work. That, and his concern for the emotional and spiritual wellbeing of his close friends and his family, kept him going for the next month.

For all of us dance became the central sustaining metaphor during that time and a source of valuable experience with cooperating and problem-solving. In my handout, Patricia's letter and Dorothy's song are testament of the importance of dance in the lives we've shared.

When I first met Carl, in 1973, he was mighty proud about having just rebuilt the engine in his old slant-6 Dodge truck. In the intervening years he tended his vegetable garden, planted 200 fruit trees, built himself a house, and took the introductory sewing class at the community college, proceeding to piece together his own shirts and overalls. When we moved to Durham, he got the zoning changed when the housing in our neighborhood was threatened and then he master-minded the campaign to get rid of the chemical dump down the street. In short, Carl took care of himself; he was an imminently responsible man.

Confronted by death he proceeded responsibly. Or at least with all the autonomy he could reclaim from a hospital. First off, Carl was blessed with the help of a gay doctor and fine nurses who took time to answer questions, to explain procedures and to share the frustrating work of helping someone to die. Two of the excerpts in the flier are from letters written by nurse friends and they illuminate some of the dilemmas faced daily by principled people working in the hospital setting.

Carl had no patience with all the small, significant ways in which hospital protocol infantalizes clients. A couple of anecdotes: With the mixture of indignation and glee so familiar to to those of us who knew him, Carl recounted a trip down to X-Ray. They had sent up an orderly with a wheelchair. Carl marched down the long hall to the elevator, waltzing his IV pole with him. The hapless orderly followed behind, pushing a very empty wheelchair.

Then there was the flap one evening over the Amphoterycin. This was during a brief stretch when Carl was an out-patient and reporting in every couple of days for medication. Earlier on, when he was a fulltime patient, he learned how to disconnect the tube when the solution was all dripped through. He was a quick study and had it down cold. That evening, with a friend waiting around to drive him home, long after the bag was empty and after repeated requests for someone to come unhook him, Carl clamped his catheter, cleaned up carefully and checked out. When he arrived home and reported his escape, with great flourishes, my

heart sank. We were in the midst of negotiating a volunteer home-IV arrangement (the hospital bureaucracy was balking) and I figured the jig was up. Needless to say, we got a grave lecture from our doctor friend.

I am tremendously grateful to the nurses and doctors who accepted the challenge of such a participatory client. It was only after Carl came home for good that I realized how very close we had come to losing our chance for death with integrity.

All along Carl questioned the procedures and tests ordained by the doctors. "Why?" he would ask. "What will you learn from that?" "What difference will that make?"

When there seemed, indeed, to be some justification, he would consent. Often though, he would decline.

I remember one conference with an earnest young doctor who had the habit of wearing one of those Christian fish pins. Theology was of only anthropological interest to Carl; much less Christianity, with its unforgiveable history of persecuting homosexuals. We were a little wary. The late afternoon light bathed them as they sat facing each other. He had come to announce an impending lumbar puncture and Carl, having got wind beforehand, was ready. He had had a couple of awful experiences with spinal taps before and I rather expected him to stonewall flat out, maybe to start hollering.

Instead, he proceeded very carefully to explain how he felt about the time he had left, and his priorities. I was amazed, as they conversed, by the respect he showed this doctor who, of course, had no answers ultimately. They spoke quietly, for a long time. The light moved across the wall and then faded. When the doctor finally rose to leave, they were in shadows. The door clicked shut. There would be no spinal tap after all.

In spite of Carl's misgivings about a medical system that becomes a universe to itself, where therapy assumes such self-importance, even a meaning of its own, in spite of his wariness, he almost didn't escape.

It's nobody's fault, I guess. You really want to believe the doctors who plead with you to stay and try one more drug. They dangle "quality time" before you. "If you'd just stay on Septra

for one week, we can probably give you some quality time." But Carl had been up all night with a high fever, vomiting, in reaction to this latest chemical.

Still, I begged silently, "Oh Carl, Carl, please try. We might have another month. Oh, please." I dreamed of the kindness I could show him to make up for all the hard times over the last fourteen years -- all my fuck-ups, all the disappointments. Visions of "quality time" glowed before my tear-filled eyes. The doctor pressed his case more urgently.

It's only with hindsight now that I appreciate deeply that somehow, in spite of the numbing medication, Carl could see what I had forgot, and what the doctor never knew. At that moment Carl was strong enough to transcend the panic sounding in the doctor's voice and written across my face, to accept that his life was pretty much over and that all in all it had been good.

He smiled sweetly, tolerantly, and shook his head. His life had had plenty of quality time.

When I wheeled him out the front door of Memorial Hospital for the last time, it seemed that both of his final goals were attainable. He had been able to work fairly steadily on his book during hospitalization, and we were on the trail of drugs with which he could end his own life.

For the person with AIDS, coming to terms with dying in April 1987 is a different matter than it was in January of 1986. I wonder sometimes what Carl would have done with AZT as an option. He was shocked when he read, somewhere, figures to the effect that the medical bill for the last 60 days of the average American's life is some huge precentage of one's total life medical expenses. Like 60 or 70 percent.

I remember, too, his keen interest in a book that chronicled the gradual weakening of resolve between the author and her dying husband, as they did, after all, opt for one desperate and expensive life-support measure after another,when they had vowed not to.

Of course I can't say for sure, but I suspect Carl might have foregone AZT. As it was, he spent precious energy after his diagnosis hustling SSI and Medicaid applications so his family and friends would be spared unconscionable medical bills.

The last four days of Carl's life were a magical transformation that I certainly had not foreseen from his room on the sixth floor. It was pure serendipity that the sun shone in warmly at the window and that the Breath-of-Spring bush bloomed, on the eighteenth of January.

Much less a matter of luck was how the twinkle returned to Carl's eye. Although we had hauled a big oxygen cannister up the narrow stairs, it was the only reminder of the weeks of high-tech hospitalization , and five days later it got hauled back down, unused.

There, back home in his own bed or propped in his rundown easy chair, was old caustic Carl, working furiously to delegate chores for his book and visiting with his folks, mine and our closest friends.

There's not much to say about that time that wouldn't seem sentimental and euphemistic. He had had the wisdom and gumption to excuse himself from the enticements of quality time and now he headed towards death with unnerving nonchalance. Regularly, solemn visitors ascended the stairs to Carl's room only to descend before long smiling, and perhaps chuckling over a manila folder containing some editorial responsibility or other.

Humor was a loud and vibrant note in the music for Carl's life dance, and in his death too. After each of us overcame the initial uneasiness with death we quickly learned again to laugh.

That last afternoon of his life, Carl cracked up when my sister Nancy arrived from the mountains to admit, through her tears, that the only other death so close for her thus far had been her old hound dog, Flea Bag.

For me, that last afternoon was the first time in several weeks that I could quit the desperate search for the pills for Carl to kill himself. Several close doctor friends were unwilling to help us out. Someone -- someone who could have helped -- I don't remember who -- had actually suggested that I take to the streets and try to score drugs there. I was furious and exhausted by the time things finally fell into place.

If I could change anything about the experience of Carl's death it might well be in finding ready access to a pill or two, or a simple glass of chemicals, for Carl's suicide. The quality of our time together would have been different, or rather I would have had time -- the time wasted on the phone, enquiring and pleading. The time I spent waiting in faraway drugstores while the pharmacist hunched over the phone, mumbling to the SBI.

As it was, in spite of that, our last evening went well. Supper, a few goodbyes and then our housemates, Carl's aunt and several friends retired next door to keep vigil.

Carl and I had agreed how to spend those few remaining hours. First, we would finish the last chapters of the Trollope novel that had afforded many charmed afternoons of reading aloud. (One will stay with me always: Carl in his armchair, Daddy sitting by the window where birds jostled at the feeder he had built, I on the edge of the bed, swinging my legs, as Mama read with measured delight of the downfall of the Reverend Mr. Slope, and the sun glowed among us.) Then we would listen to a favorite record, chat and proceed with the pills.

After a few pages from Barchester Towers I asked, "How you doing?" "I'm okay. A little distracted, but keep reading."

When the penultimate chapter was done, Carl said "Let's stop there." I smiled at a rare note of sentimentality. Then we sat beside each other in bed as we had most nights for fourteen years and talked.

This past February, over a year after Carl's death, I walked across town to Duke one icy, crunchy night for a concert of baroque chamber music. My flutist sister was in the ensemble performing a suite of little portraits and sketches by Rameau, the music we listened to on Carl's last night. In the safe and loving dark my hands and feet warmed, my face thawed and the graceful, social music conjured him up. French baroque music is dance, all turning toward and away, bowing and nodding -- a distillation of nature (the arc of birds, the twitch and surge of dragonflies, the majesty of weather) and style (sometimes a sort of ironic dignity, sometimes poignant fients and longing, sometimes exuberant release).

I saw Carl smile, tilt his head and wink. How wonderful that we can so delight in each other, I thought. What, after all, is more profound than the simple joy of human company? In this curving and curling to each other and in this music is the essence of our humanity, and our kinship to sea birds, butterflies and cats. Carl will always be here for me in this music.

We sat together in bed and after a while we were quiet, listening. "Did you ever notice, in that last movement, how in the next to last bar, it's as if there's an extra beat?" Carl asked.

We had not been able to find sure information about what constituted a lethal dose of drugs, or how to administer it. A doctor friend suggested an order for taking the pills we'd collected -- alcohol first, wait thirty minutes, so many pills, wait fifteen minutes, then more pills. And so we began this ritual, having to trust that it would work.

First, since none of us are drinkers, the kirsch that Carl had bought for making Christmas cookies like his Austrian grandmother's. Then another favorite recording, the Bach Goldberg Variations. The harpsichord played in and out of awareness, ordering, reassuring, making familiar this strange experience. As he downed the first batch of pills Carl said, "I'm doing the easy part."

Perhaps so. Carl always travelled light. No extraneous baggage, no unresolved business, no guilt. Death was not a time for frantic catching up or remorse.

On New Year's Eve we had smuggled him out of the hospital to join us for dancing. It's come to be a tradition for seventy or eighty of us to transcend all the hoopla and boozing by dancing, sharing a potluck meal, then dancing some more and then going home wrapped in goodwill and quietness.

This was Carl's last dancing and he told me later that he wept as "In the Fields in Frost and Snow" started up -- advance a double, turn single, turn, cast, circle. Then he got to thinking how folks had danced those same gentle figures to that haunting tune for hundreds of years and that others would continue to, and then tears seemed inappropriate.

I sat on the edge of the bed, holding his hand, watching the clock. "The one thing I regret," he said, "is not being able to see what you'll do."

Counting out the next pills I thought of his boundless encouragement and faith over the years for my halting pursuit of art, writing and music, too often at the expense of his own work and peace of mind.

Soon, his eyes began to falter. I hurried to feed him the last of the drugs. "Carl, just a few more. Carl. Carl."

Panic rose in me when his mouth and throat stopped working and my hand still cradled a dozen pills.

I wonder now what I'll do if the time comes to kill myself. Whether Carl was doing the easy part or not, I know that the rest is demanding. As his body gradually relented and his breathing slowed I remembered the friend downstairs, knitting, and the friends next door. He had believed deeply in the community of lovers and friends and now here they were, waiting, pausing, before they started up again to help, learn, love, grow.

Finally Carl's body was still and cool and pale. I stopped the clock, turned off the music and knelt at the foot of the bed. After a while I studied his face one last time and walked downstairs.

One of the lessons we learned on that month-long journey was that dying on one's own terms is a bold and political act in this fearful, pain-addicted culture. Just as one dispossessed people after another has studied its dilemma and then demanded justice, we all are due a reconsideration of dying. For most of us it has been kept a degrading experience, robbed of both its reverberation and its ordinariness by powerful, often faceless forces -- the medical profession, the law, the church and the insurance industry. Death is the ace up their sleeve. It is the ultimate threat.

Some of us know now that it is not, after all.

In order to be discharged more-or-less honorably from the hospital Carl had had to present and defend his decision to discontinue treatment to three different doctors, one at a time. Already they had been humbled by this plague -- no more breezy promises, no more beating the odds, no more odds.

Now they sat, in turn, like tired, sulky wizards flummoxed by by this clear-headed client who accepted death matter-of-factly. Each admitted that he respected Carl's decision although he didn't

concur and wouldn't prescribe any drugs to help Carl end his life.

After Carl died I wrote a long letter to one of them describing how it had gone after we left the hospital, encouraging him to think of us as allies in ministeringfully to clients and friends with AIDS. I never heard back from him. Maybe it didn't make any sense.

Later that night some of our friends gathered quietly around Carl's bed. They stood and sat and pondered, carefully feeling out the sharp edge between dying and being gone.

Then we hauled his body down to the greenhouse and put it on the stretcher that had been sewn out in the sun that afternoon. A doctor friend filled out a death certificate.

The rest was mercifully uneventful. Next morning we hoisted the stretcher into Geoff's old VW van and drove over to Duke, to the crematorium. Then we waited, holding our breath whenever the phone rang. But each time it was someone asking if there was anything they could help with, or if Thursday night dancing was still on. Finally they called from the crematorium saying we could pick up the ashes. There had been no incriminating post mortem.

That night the dance hall overflowed.

I'd like to end out in the garden with one last story.

Last week, in preparing the brochure you have with you, I had spread letters and photos across my work table. There was a familiar knock at the door; it was Munchie, who moved to Vale Street with his mother and brothers after Carl died.

I told him I couldn't play since I was in the middle of a project and that he'd have to amuse himself. He dawdled in and looked quietly over the pictures of Carl, lingering over one of him dancing and smiling. It was my friend Carl and he was dead, I told him. Munchie studied and studied. "Where is he now?"

It's hard, explaining cremation to a five-year-old Jehovah's Witness, but I did my best and told him that the ashes were still upstairs in an old cookie jar and I hadn't decided yet what to do with them. Might put them in the garden.

"Put 'em in the garden," he said to himself.

After a while, Munchie's thoughts took their inevitable course. "You got a tomato?"

I started to explain for the zillionth time how tomatoes aren't worth buying except in the summer, but caught myself and said, "Munchie, let's go get us some tomato plants."

At the FCX we picked out several and then asked a round, affable man, who appeared to be of the same mind, just what we should feed our tomatoes. "Oh, a little lime, a little 5-10-10, a little wood ash," he opined, smiling down at the little gardener.

Back home, we dug and worked in compost and a little 5-10-10 and lime, put in our plants and watered.

Waiting until July for ripe tomatoes was an abstract concept for Munchie. "A long, long time," I said dramatically. "Next week?"

The more I tried to explicate, the more mysterious it got for both of us. We put the tools away and turned off the hose and then Munchie went on home.

My hands smelled of dirt and tomato leaves. Somewhere a cardinal sang its bright red song.

I went inside and climbed the stairs to Carl's study. Stacks of file folders and books waited for the next round of editorial work on the dance manual. I hunkered down in the corner, lifted the lid off the cookie jar and scooped out a handful of ashes.

Back out in the clear spring light I scattered them around our three hopeful little tomato plants.

Allan Troxler