



# Birchgrove

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## death and dying....

I vividly recall a night late in December about a year ago. It was 6:00pm, very cold and getting dark. I was waiting for a bus to go home, standing behind a tree for protection from the wind. I had recently lost a friend to AIDS. From whatever measure of intuition God had given me, I knew suddenly and quite certainly that I also had AIDS.

I stood behind the tree and cried. I was afraid. I was alone and I thought I had lost everything that was ever dear to me. In that place, it was very easy to imagine losing my home, my family, my friends, and my job. The possibility of dying under that tree, in the cold, utterly cut off from any human love seemed very real. I prayed through my tears. But I knew. Several months later, in April, the doctor told me what I had discovered for myself.

Now, it's nearly a year later and I'm still here, still working, still living, still learning how to love. There are some inconveniences. This morning, just out of curiosity, I counted the number of pills I have to take during the course of a week. It came out to 112 assorted tablets and capsules. I go to the doctor once a month and find myself reassuring him that I feel quite well. He mutters to himself and rereads the latest laboratory results which show my immune system declining to zero.

My last T-Cell count was 10. I have been fighting painful sores in my mouth that make eating difficult. But, frankly, food has always been more important to me than a little pain. I have had Thrush for a year. It never quite goes away. Recently, the doctor discovered the herpes virus had gotten hold of my system. There have been strange fungal infections. One was on my tongue. A biopsy caused my tongue to swell and I couldn't talk for a week making many of my friends secretly thankful. A way had been found to shut me up and they all

revelled in the relative peace and quiet. Of course, there are night sweats, fevers, swollen lymph glands (no one told me they would be painful), and unbelievable fatigue.

When I was growing up, I literally detested grubby, down-in-the-dirt sorts of work like changing the oil, digging in the garden, and putting out the rubbish. Later on, a friend, who was a psychiatrist, suggested I should accept a summer job at a lumber camp. He chuckled with sinister glee and suggested it might be a constructive emotional experience. Well, this last year has been that constructive emotional experience that I had avoided. Parts of it have been grubby and down-in-the-dirt and parts have been life-changing. I cry more now, I laugh more now, too. I have come to realise that my story is not in any way unique, nor is the fact that I will most likely die within two or three years. Like many of my brothers and sisters, I have had to come to terms with my own death, and the deaths of many of those I love.

My death will not be extraordinary. It occurs daily to others, just like me. And I have realised that death is not really the

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In this newsletter, we look at the painful subjects of death and dying. These are topics which, for those of us who are directly affected by HIV and AIDS, eventually become impossible to avoid. It is not intended that any of the articles should cause grief or offense to any of our readers. But, whilst we recognise this possibility, we feel that this is too important a subject on which to remain silent.

# COMMENTARY

It seems that it was only a short time ago that I was sitting with the editorial team discussing the future plans for the Birchgrove newsletters. The Editor came up with the suggestion that we develop a range of themed issues. As we sat and laughed and joked, we asked ourselves what would appeal to the average Birchgrove member? In a flash it became blindingly clear that Sex, Drugs and Rock and Roll were the real topics that would interest any true Birchgrove member!

Well, we've tackled Sex, that seemed easy. The assumption that sex was something that haemophiliacs shouldn't do, or couldn't do, or didn't want to do, wasn't hard to challenge. It also suited our schoolboy sense of devilment, to say rude words and print dirty pictures.

And drugs too wasn't that difficult. Demonstrating that, for many haemophiliacs, drugs are an important issue, not just the pharmaceutical, doctor prescribed drugs, that have had such a devastating effect on our lives, but also recreational drugs, that many of us have chosen to become part of our way of coping.

At the time the rationale behind "Rock and Roll" escaped me. Try as I might, I could see no significance in the concept. I happened to be listening to the radio when I caught a piece about Johnny Rotten and the Sex Pistols. How appropriate! Johnny was talking about Sid Vicious who had committed suicide years ago, and he said, "the thing about Sid was that he bought into the whole bag, Sex, Drugs and Death!" and there it was, there was the answer. The final taboos, death and dying.

Now, as I lie here on my bed, with only a slight touch of AIDS and an even slighter chance of survival, it is with a grand sense of irony that I find that this is the issue that now faces me too. Your intrepid Birchgrove reporter is boldly willing to go where few journalists have investigated before. Are there no lengths to which we are willing to go to research an article?

Lying on my bed I can indulge in the pleasures of hindsight and think back to the many satisfactions that I have found. What stands out most clearly is the sense of pleasure that I take in having known so many haemophiliacs, so many people who have lived with this virus and died because of it. I am proud to remember their faces and remember their names. I am proud to have been part of bringing together many of those people who I feel closest to. There seems little more important in this Greek tragedy that has become our lives, than the friendship and companionship of those who truly understand life's little ironies.

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issue at all. The challenge of having AIDS is not dying of AIDS, but living with AIDS. I didn't come to these realisations easily and, unfortunately, wasted precious time in what I thought was the tragedy of my impending demise. I still have a difficult time when someone I love is sick, is in hospital, or dies. We have all been to far too many funerals and many of us don't know how we will be able to find any more tears for the ones that we continue to lose.

In a story about someone who had lost his partner to AIDS, the man said that after his partner had died, he thought, that just maybe, the horror was over. That somehow it would all go away and everything could get back to the way it once was. But, just as he starts to think the horror is over, the telephone rings. I am crying as I write this because I have a very vivid picture in my mind of my partner making those same telephone calls. We all know about the discrimination, fear, ignorance, hatred and cruelty attached to the AIDS epidemic.

There is a major myth I would like to dispel. When we approach the AIDS crisis our first inclination is to search about for money to throw at the problem. I don't underestimate the importance of funds for services and research. But money will not solve, by itself, the problems of suffering, isolation and fear. You don't need to write a cheque, you need to care. If you do care, and if you have some money in your account, the cheque will follow naturally enough. But, first, you have to care.

Back when I lost the first of my friends to AIDS, I knew that one friend, Don, had been sick. It seemed like he was in and out of the hospital with this and that and didn't seem to be getting any better. Finally, the doctors diagnosed AIDS. By the time he died, he had been affected with dementia and was blind. When his friends found out he had AIDS, many of us did not visit him while he was in the hospital. Yes, that included me. I was afraid - not of catching AIDS - but of death. I knew I was at risk and that in looking at Don I could be looking at my own future. I thought I could ignore it, deny it, and it would go away. It didn't. The next time I saw Don was at his funeral. I am ashamed and I know that none of us, even those with AIDS, are exempt from the sins of denial and fear. If I had just one wish, just one, it would be that none of you would have to experience the death of a loved one before you realise the extent and seriousness of this crisis. What a terrible, terrible price to pay.

"What happens", you may ask, "when I get involved and I come to care about someone and, then, they die?" I understand the question. The

wonderful part, though, is to understand the answer. At a recent meeting I was trying to listen to several threads of discussion all at the same time when a woman (and a dear friend) spoke up. She had recently lost her brother to AIDS. She said quite directly that she was always amazed to see me and to see how well I was doing. She had become convinced that I was doing so well because I had been open about my diagnosis and because of the support, love and care I had received from those around me. She turned to me and said she knew her brother would have lived longer if he'd been able to get that same support and care, if somehow he hadn't felt so isolated and alone. She was right and I have come to realise how precious that care and support, that love, is. It has literally kept me alive.

Soon after I had discovered I had AIDS, the most important person in my life brought home a small package of seeds. They were sunflowers. We lived in a small apartment with a tiny patio with a bare patch of earth – really more of a flower box than any sort of a garden. He said he was going to plant the sunflowers in the “garden”. Okay, I thought. Our luck with growing things had never been tremendous, especially such large plants as pictured on the package in such a small plot of ground. And I had much more important fish to fry. I was, after all, dying of AIDS and I had never paid much attention to anything as mundane as flowers in a flower box.

He planted the seeds and they took hold. By summertime, they stood at least seven feet high with glorious, bright yellow blooms. The blossoms followed the sun religiously and the patio became a hive of activity as bees of all descriptions hovered relentlessly around the sunflowers. Out of row upon row of apartments which were indistinguishable from one another, it was always easy for me to spot our patio with those great halos of yellow towering high above the fence. How precious those sunflowers became. I knew I was coming home: home to someone who loved me. When I saw those sunflowers, I knew that everything, in the end, would be alright.

For those of you who do care and find yourself ready to make this kind of commitment, I would like it very much if you could come to my house. We wouldn't do a whole lot. We would just sit on kitchen chairs, have some iced tea, and watch the bees in the sunflowers.

*Terry Boyd, age 38, was the father of a 14 year old son and was raised in Nebraska, Idaho.*

## MY EULOGY

by Terry L. Boyd

Before his death in 1993 from AIDS-related complications, Terry wrote My Eulogy, a portion of which is shared below.

There are a few things I would like to tell you that I think are very important. Let them be my legacy. At the doorway of death, I find myself very poor. I have only my faith in God and the love that many of you have given me. I have no idea what this new adventure of death will be like. Yet my faith tells me it is not the end.

Death from AIDS is a long, slow process. Painful, soul-wrenching, debilitating. I hope that you, having been with me during this time, will remember and offer your care and love to others who are suffering.

The greatest part of my legacy is a thing which a very special friend described to me as “The Embracing of Souls”. It is something that many of us only experience once or twice during our lifetimes. It describes those very special people who come into our lives at odd, unpredictable times. Love flows between them like water in a stream. It is a very special gift. I believe this ‘embracing of souls’ is the spirit of God working in our lives. To experience the ‘embracing of souls’ is to experience God.

It is this embrace of souls that will prepare you for whatever suffering you may have to experience. It will allow you to bear up and even to give thanks in the midst of suffering. I want you all to know that I will always love you and will think of you often. If it is possible, as I believe it is, I will pray for you and keep you in my heart always.

Until I see you again,  
all my love...

Terry