



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

BY NORMA MARTINEZ

I am a widow

I live in Nezahualcoyotl City, Mexico, I am 32 years old and a widow with five children. I also have AIDS. Seven years ago, my husband found out that he had HIV, we didn't know what that was. They said he was going to die in three months.

He lived for five years without any kind of symptoms. Then he was sick for two years before he died. He became infected by donating blood, which was our income for a while. I got pregnant with my last child after I found out I had the virus. The truth is, I really didn't want to have him, so I told the doctors that I was infected, that my husband had AIDS. They told me that they would do a test to see if that was true, but either way I had to continue with my pregnancy because abortions were only performed in special cases.

When my new child was tested, he was found to be infected. He is now two years old. I had a child before him. He would be three-and-a-half years old now. He died and nobody could tell us why. I took him to the doctor because he had diarrhoea, and they told me he died of pneumonia. They scolded me, saying that I had neglected him.

The disease that my husband and I contracted has robbed my children of their childhood. My oldest son is responsible for bringing money home. My next, a daughter is responsible for the housework. I don't want to tell her teachers about my disease. I am afraid they will forbid her to go to school and will isolate her. She is a good student. She used to get "As" in school but now gets "Cs" because of her absences. I don't want my children, besides being poor, being marked.

We are poor, of course. We hardly have enough to eat. I need 90 capsules of AZT a month, but I can't afford to buy them. I should buy other medicines and should eat well. But I only buy beans. For me, knowing that I am going to die soon has made me stronger. I have to take care of a lot of things before I die. Who will want to take care of my children? How will they remember me? What will they be like when they grow up? Will it be a relief for them when I am not around?

I use my last strength to tell the story of my life, so that you would know it. I don't want your pity. I have lived, in spite of everything, differently during my last days. I learned a lot. I was with other women and people who helped me, gave me support and taught me not to feel guilty - and to live the last days of my life with dignity. I want you to do something. I want you to think as you listen to my story. What can you do in situation like this? Don't answer me because I can't hear you now. Say it to yourself and then tell other women. I leave you my voice for you to hear it. Maybe you will forget, maybe you won't. I did what I could. The rest is up to you.

I read, with little surprise, that Jody Wells the noted HIV/AIDS revisionist had died. The gleeful rumours that he was ill, receiving treatment and was succumbing to AIDS had been circulating in the HIV community for some time. The comments of those who were reassured to say "I told you so!" are still ringing in my ears. But this view of his death is superficial and has little understanding of the causes for which he fought.

The challenge of Jody's argumentative stance repelled many more than it attracted. Trying to convince his audience that HIV did not exist and that it could not cause AIDS was not his only motivation. Something drove him to confront every rational argument, every concerned question, with a fierce determination to deny the existence of the virus.

Yet, it was not just denial that I saw in this man. Jody fought all opposition with an intensity that was painful to experience. Often facing an angry crowd alone, and offering a message that was bound to be unwelcome. He must have had a strong source of courage to survive such opposition and make his concerns public property.

The obsessive determination that he displayed must surely have been shared by many great radicals and revolutionaries. I am sure that we shall all sleep more soundly in our beds, now that we know that the world is flat and that we could never have descended from the ape. He will not now discover whether the ideas for which he fought might come to be regarded as prophetic.

I saw in this man a courage to challenge an opposing world, to confront science, medicine and the hidden financial agendas, to speak the truth as he saw it and fight for what he knew to be right. This man may have been shot by a bullet from the AIDS gun, but he offered himself up for execution to every scientist, doctor and well meaning professional involved in the AIDS industry. It was no surprise to hear the hail of bullets which met his every opinion.

For us ordinary people, fear and anger is a reason to band together and protect those that we know. For Jody, fear and anger enabled him to confront a world of AIDS ideas and beliefs and to speak only that which he believed to be true.

ENTER MY HOUSE JUSTIFIED

BY MIKE O'DRISCOLL

At a time when death should be a distant prospect, many young men had to get used to the idea that death was a lot closer than they had thought. The cruel irony for many haemophiliacs is that in the early 1980s, the future looked better than it ever had before. With most of us on factor VIII home-treatment with government promises of self-sufficiency in blood products ringing in our ears, not to mention the possibility of synthetic blood products in the future, a complete victory over haemophilia seemed imminent.

Think of the 1200 haemophiliacs infected with HIV and imagine how hollow that victory sounds to them now. But it happened and nothing anyone can say or do will change that. What is perhaps surprising, and what many positive haemophiliacs draw strength from is that there are still more than five hundred of them defying the disease. Despite illness, loss of career, loss of wives and friends, and the constant awareness of their own vulnerability, they are still surviving.

But, and this is a question seldom asked, at what cost? Imagine carrying on a 'normal' life knowing that the next little illness or infection you get may be the one that kills you. Try putting on a brave face, just to let your family and friends know that you haven't given up the ghost. Most HIV positive haemophiliacs do just that because, as much as anything, it's the struggle itself that gives them the strength to go on. Each day spent resisting the wearying processes of the disease, each day you come through the struggle, is another small victory.

But is that really the case? Or are we just kidding ourselves because we still find it difficult to face the truth? Not just the truth of the inevitability of death, but the smaller, more poignant truth, that sometimes the struggle to live up to peoples' expectations, is simply too much.

Living with HIV, refusing to let a virus rob you of your humanity and dignity is a constant battle, a battle in which there is no ceasefire. Is it any wonder that people grow tired and their spirits weary? Is it any wonder that if you're forced, day in and day out, to acknowledge the truth of the old cliché about death being one of the few certainties in life, that it becomes difficult to sustain your strength and courage? What are you left with then? Anger, frustration, helplessness, fear and guilt. Yes, guilt, guilt that you haven't been strong enough, that there are people – family and friends – who rely on your strength and who you feel you are letting down. Do they resent your weakness? Is your illness an all too vivid reminder of their own mortality?

Maybe what's required is a different type of strength; the strength to recognise and accept that your part in the struggle is over; the strength to put your house in order; the courage to say your goodbyes. This sort of acceptance, and preparation for death can never be easy. It takes a rare dignity to acknowledge the imminence of death whilst maintaining your own humanity.

One could draw an analogy with a condemned man who, after years spent on death row, is told that he will be taken to the gallows at dawn. But such an analogy is inappropriate – no crime has been committed by the person dying from AIDS. A better comparison might be made with those unfortunate to be killed suddenly, in an accident. What chance have they had to prepare themselves for death? If they had known that a certain day was to be their last, isn't there a strong possibility that they might have wanted to put their affairs in order, and say their final farewells to friends and family?

In Sam Peckinpah's 1962 western, 'Ride The High Country', an aging cowboy is asked by his friend what he wants from the remainder of his life. "All I want is to enter my house justified," he answers. In other words, he would like the opportunity before he dies, to settle his affairs and make his peace with God. Whatever your religious beliefs – or lack of them – I think that there is a beautiful universality about that statement. Don't we all have an innate desire to settle our affairs, to say our goodbyes and leave no unfinished business behind us when we die? If it were possible for those who had died suddenly or unexpectedly to have the benefit of hindsight, isn't it certain that there are things they would have liked to have taken care of?

I think perhaps it's time for us to acknowledge that when illness gets too much for a friend or loved one, when we see that their perspective has changed from one of resistance to acceptance, then we too should accept the inevitable. Free of our expectations to keep up the fight, a person dying from an AIDS related illness, should have time to come to terms with death and, with our support, to take care of any unfinished business. We have to accept that there will come a time when, through pain and exhaustion, our friends and lovers, having fought the good fight, seek only the peace of death.

This is not to say that we shouldn't grieve, only that when we know that they are ready to go, we shouldn't impose our sense of loss, of guilt, or resentment upon them. Instead, we should accept their need to "enter their houses justified", and when they are gone, we should be strong enough to temper our grief with a celebration of their lives.

DEAR BOB

I'm a father of a PWA. I'm 60, my son is a heterosexual at 37 years (fact) with 2 beautiful children 3 and 6 and a wife of 15 years. The bastard, although I love him very much, was promiscuous and has his death sentence. My wife and I have taken in the children and the wife because of his violence. He has threatened my life because of this. His moods swings from love, to hate and to violence. This is not the son I nurtured.

He has had an MRI on his brain and swelling is indicated. His fingernails have been infected with a fungus for about 5 years and I suspect that the fungus has reached the brain which would account for the swelling and erratic behaviour. He is a smoker and a heavy drinker. He seldom keeps his doctors appointments. (His brother is a surgeon).

I'm tired of crying...please help!!! I don't really know how to use this internet, but I hope you can figure out how to get back.

Bob Salomone Prodigy: jfg130a

Dear Bob,

I read your posting with great concern for both your son and your family members. It is very difficult for loved ones to take such abuse, and I feel much empathy for you all. Your anger may seem justified, but anger can be a mask for fear and pain. Your son's irrational and frightening mood swings, are equally as distressing to him as they are to you. Can you separate the person you love, from the disease you hate?

You may find some comfort in knowing that there are those of us who watched, as you did, good and decent people, transformed into monsters who only seemed to have little conscience over their destructive behaviour. When the virus crosses the blood brain barrier (and it does), you can say that that individual has a diseased brain. Since you can't cut out a diseased brain, without causing severe damage or death, you helplessly and powerlessly sit by watching your son become a mere shadow of his former self. And yes, you are angry and you are afraid. Will knowing what to expect change the way you feel about your son? Will it enlighten you in developing coping skills throughout a progressive, and insidious illness?

I watched my spouse of 22 years, a gentle and kind man who reached out to help anyone who knocked on our door, turn into a raging, towering inferno who moved out of our bedroom a year before he became seriously ill. He closed off from me, then our son and daughter. I was filled with confusion, rage and sorrow. But, what I didn't understand then Bob, was that he was railing at the disease that was destroying everything he held dear to him. It robbed him of his job, his health, friends, financial security, control of his life, his sanity, and finally....his life. He died of PML, a viral infection that destroys the white matter of the brain, at the age of 40. What I wish I had known months

before his death, was that he was beginning that journey inward. It's that place inside one's soul that everyone in the dying experience goes to find that centre that is one with God and the universe. They turn away from all externals, and the first to go are those they love the most. It's an odd way of saying good-bye, isn't it?

But, I never heard the words when he was speaking them rationally. He thought that if he could push me away from him, it would hurt me a lot less when he made that final journey. I still remember him saying, "Let go of me, I'm dying!" But, I clung for dear life, seeing only my own insecurities and fears of my life without him. The more I demanded of him, the more distant he became. I needed to learn to let go with grace, to say, "It's your journey, you decide how and when you want to leave our planet, and I'll accept your choice". I lived with that regret for many months after his death. I lashed out at him for his behaviours, not understanding that he was no longer in control of his faculties. If your car doesn't have an engine, you can't expect it to run, can you?

And my husband, had a diseased brain, and it did not run. I needed to understand the sheer torment he was going through, and seek my solace elsewhere because he was no longer capable of being there for me, and God, I was still so dependent. I needed to forgive him for all the needles he stuck into his veins, especially the one that contained that virus. If I can't do that, then I am really no better than the person I condemn. I'm expecting them to do something that I myself cannot accomplish. Your son is filled with regrets, guilt, self-loathing, condemnation. What he most needs now that his life is nearing its end, is your compassion and your forgiveness. You wouldn't come across a fire and throw gasoline on it, would you? Your son is in grave emotional distress and pain, that's why he's acting out. In life, we learn to depend and derive our support from those who love us. It's a lonely, arduous down-hill spiral, when we find there is no one there. My husband made many poor choices "mistakes" in his life, but so did I. I never expected perfection, and I never got it.

But, what did I expect? That we would heal our wounds and make our amends before his final hours. We were granted that, because he transcended the human part of his being by living through his human spirit. A few months before he was hospitalised, he experienced an enlightenment, something ethereal, perhaps the power of God, but he emerged a beautiful and loving man, who was talking of things completely out of the realm of this world. It was then that I first understood, he was moving towards the death experience, and preparing himself to go on to a higher ground. I've witnessed this in all the five deaths I have been honoured to share in the past two years.

Do not despair Bob. Your son does not want to hurt anyone. The brain is an intriguing and delicate piece of master workmanship. Unfortunately, it is most difficult to be responsible when it's not functioning properly. Think of how the human body experiences exhaustion, aches and pains after a hard day's work and seeks to rest to repair itself; now think of what it would be like to have a brain that cannot be repaired, that finds little or no rest. Your son is punishing himself enough for his human failings, and we all have them. You may find, as I did, that when I could forgive, it provided me with the compassion and the strength I needed to mend our brokenness. You son no more wants to kill you, then he wants to die. He may be trying to kill the pain of your attitudes towards him, and the feelings of abandonment he's suffering when everyone left. If it were happening to you Bob, would you feel any different? We don't know what it's like to be that "other" person, unless we can walk around inside their skin and feel what they feel. So, the best we've got, is our own sense of conscience, because it is this that we will have to answer to.

This is a tragic situation for your whole family, and you must feel lost and enraged. When you can find a centre of calm inside yourself, go there and ask for help and empowerment. You will get what you need to see you through this. In the eye of the storm, emotions are whipped and tossed, sometimes rationality and reasoning leaves. It is only when we are quieted that our spirit finds the answers it needs. Love may not cure AIDS, but it can soothe and mend shattered lives. I wish your family peace and courage throughout your struggle. Don't despair, and if you can perhaps you could find some reading material that deals with the emotional and mental impact, as well.

My thoughts are with you, Annie *anne@uoguelph.*

The current editorial team have enjoyed working together on the last four issues of the Birchgrove newsletter. We have tried to broaden the horizons, if not the minds, of our readers. But, due to popular demand, we have been asked to let go the editorial reins and allow others to ride the steed of controversy and challenge. We wish the new team an equally exhilarating ride.

As usual, the views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group.

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USEFUL LAST WORDS

In the fight between you and the world,
bet on the world.

It's been lovely, but I have to scream now.

It's not a black or white thing... It's a death
thing!

Many are cold, few are frozen.

Life being what it is, I dream of revenge.

O rage! O despair!

One thing about pain: it proves you're
alive.

So I said to myself, 'Self,' I said...

What hope is there for the world if I die?

When the going gets tough... The tough
go drinking.

When things just can't get any worse, they
will.

You are terminally tired.

Practice random and senseless acts of
kindness.

All answers questioned here.

Abstain from wine, women, and song;
mostly song.

Alive, and simply delighted!

All I want is the chance to prove money
can't buy happiness.

Depression is merely anger without enthu-
siasm.

As your Doctor, I advise you to drink
heavily.

Don't take life too seriously, it's not
permanent. ...

For it is the doom of men that they forget

Either this man is dead or my watch has
stopped.

He's either dead or just very sleepy.

Everything I do is needlessly violent and
enormously irresponsible.

I'm sorry. Thank you for playing. Next
contestant.

A virus is a Daemon with an attitude
problem!

A cynic smells the flowers and looks for
the coffin.

A clear conscience is usually the result of
bad memory.

a natural death

BY MIKE O'DRISCOLL

Given that we all know we are going to die, should the grim diagnosis of AIDS and the realisation that the event is rather more imminent than one would have wished, make a difference to the way one lives, works and feels? Such a question preoccupied television playwright Dennis Potter after his diagnosis with terminal pancreatic cancer, as he has acknowledged in the introduction to his final two plays, *Cold Lazarus* and *Karaoke*. Whatever the answer to that question, for Potter at least, given a maximum of five months, everything felt different.

For those who have been given an HIV positive test result, most things do feel different. Death, for an asymptomatic HIV positive person, can still seem a rather vague and distant prospect. But after a few encounters with PCP, CMV, Toxoplasmosis, MAI or Lymphoma, one has no real choice but to accept the imminence of death. Part of the problem in trying to come to terms with this incontrovertible fact is that when faced with prognoses that may vary disconcertingly from a few weeks to six months or even a year, one may feel totally powerless. Perhaps one way to regain control over our lives is for us to assert that it is we who have made up our minds about when in the time left to us, we should pack up our bags and go. To be able to make a choice as to whether or not to receive treatment designed to prolong life, especially if the quality of the life prolonged is diminished in relation to its extension, is one of the most profound choices we can make.

When a person has lived for ten years or more with a potentially fatal diagnosis, and has experienced a number of 'AIDS defining illnesses,' one of which has come to be recognised as terminal, then other concerns may well assume more importance than the need to keep up the fight. Foremost among these would probably be the desire to 'put one's affairs in order'. The knowledge that you have settled any unfinished business, that you have left your wife, husband, partner and/or children as financially secure as you can, and that you have had the time to say your goodbyes, can be more empowering than many long days or weeks of painful struggle against the inexorable progress and inevitable outcome of the interaction between HIV and the human body.

THE NATURAL DEATH CENTRE

Set up in 1991, The Natural Death Centre has as its directors, three psychotherapists, and aims to help improve 'the quality of dying' for those with terminal illnesses. It attempts to do this in three main ways:

- 1 By breaking the taboo on freely discussing death and dying – through public meetings, media contact and a British Day of The Dead Festival, first held in April 1993.
- 2 By encouraging people to prepare for dying well in advance, through:
 - A series of one day workshops and seminars;
 - Promoting and distributing 'Living Wills';
 - Publicising accounts of dignified natural deaths;
 - Creating a network of people who have had Near-Death experiences, who may act as 'midwives for the dying,' to provide counselling and spiritual help to the dying person and the family.
- 3 Helping families to regain control of the process of dying from the big institutions, through:
 - Encouraging both Authority and neighbourhood support for those dying at home, so that more people can die in the familiar surroundings of their own home rather than in hospitals;
 - Researching into the alleviation of suffering for the dying, and into alternatives to euthanasia, such as fasting;
 - Publicising a 'Declaration of Rights of the person dying at home';
 - Campaigning with the Office of Fair Trading to ensure that the funeral trade do not breach the 1980 Competitions Act by refusing to sell coffins to the general public;
 - Acting as a consumer body to provide unbiased information, referrals and recommendations about helpful undertakers, funeral suppliers, crematoria and cemeteries, and on how to arrange a cheap, Green or D.I.Y. funeral.

The Natural Death Centre is an organisation that recognises the sense of empowerment that the process of preparing for death can give to a terminally ill person. Perhaps, by beginning to talk to each other about death and dying, we will understand that death can be both natural and dignified.

For more information on The Natural Death Centre, please contact them at: 20 Heber Road, Cricklewood, London, NW2 6AA.
Tel. N^o: 0181 208 2853

LIVING WILLS

A 'Living Will' is designed primarily to indicate how much high-tech, medical intervention, the signatory wants if they are suffering from a terminal illness. Basically the Living Will directs the person's family, GP or any other people involved, to inform the person of any illness from which he or she may be suffering, and about any possible treatments and likely outcomes.

This is followed by a declaration that if a number of listed circumstances arise – for instance, that the person has a terminal illness, such as AIDS or Cancer, or that they are unable to participate effectively in decisions about their own medical care – then that person is not to be subjected to any unwanted medical intervention, such as invasive drug therapies or forced feeding, which is aimed at prolonging or sustaining their life. It may also state that the person wishes to be allowed to spend their last days at home, if at all possible.

The Living Will is signed by the person with the terminal illness and another person is named as your appointed representative, to be contacted in the event that the person becomes unable to communicate their wishes, with the intention of representing the person's views. The Will is then witnessed and signed by two people, and finally, a copy is lodged with a doctor named in the will.

The Natural Death Centre, the Terrence Higgins Trust and the Voluntary Euthanasia Society all have their own versions of the Living Will. Though approved of by the British Medical Association, you would be well advised to discuss your Living Will with your GP, or with another doctor, as not all physicians are able to accept the patients views about their own treatment.

Give copies of your Living Will to both your doctor and to your relatives, and if you go into hospital, you should show it to your medical advisors and have a copy of the Will lodged in your notes. Remember too that if you appoint representatives, these should be people you trust absolutely, especially if they would benefit financially from your death.

An example of a Living Will has been enclosed with this newsletter, if you wish additional copies they are available from the Birchgrove Group.

BY PHILLIP HAWKINS

TAKING AN EARLY BATH

While recognising and accepting that everyone is different, and that the "quality of life" for one person isn't necessary the same for someone else, I have had the experience of seeing many people die from HIV&AIDS related illnesses. I believe that we all get to a stage when we no longer have a "quality of life".

Existence is such, that we are unable to do the simplest of tasks, and so are reliant on others for our every need. When "that time" comes we should be able to say enough is enough – it's time to take an early bath. Suicide seems the only option.

During the last couple of years we have seen a number of cases of patients asking to be allowed to die. One was of a man who was on a life support system, who decided that he did not have or that he would never have 'quality of life' again. Deciding he would rather die with dignity, he refused to take insulin for his diabetes. He died a few days later.

Patients cannot insist on doctors actively shortening their lives or "Euthanasia". However, they can refuse all medical treatment including being fed by gastro-nasal tube or intravenously, hence starving to death ("passive euthanasia"). Personally, I feel that this withdrawal is both immoral and in-human, as patients who have survived a comatose state, said that they were aware of pain and discomfort when nourishment had been withdrawn.

Although it is not against the law to take ones own life, it is however illegal for someone to assist an individual to do so, or to provide the means. A documentary on Euthanasia in the Netherlands was shown last year. It showed that, if safeguards are in place and followed, then patients can decide with the support of loved ones and their doctors, the appropriate time and place to die, and can achieve it with dignity.

I fear the reason that both the medical professions and societies refuse to either discuss or consider Euthanasia, could be one of seeing death as a failure, rather than as an inevitable part of life. Taking the step to assist in ending someone's life, is not easy. Even with the support of future legislation and in the knowledge that they are carrying out the wishes of the patient – it would never be easy.

A system of all encompassing support will be needed for everyone involved. Society's thinking evolves slowly and we still have a long way to go. I do believe however, that one day we will address the real needs of those who are totally dependent on others for their "quality of life". This will enable patients and those who care for them, to take the important steps that will enable them to move towards and achieve a "quality of death".

I WEAR A RED RIBBON

BY DEBBI HOOD JOHNSON

People often ask me why I wear a Red Ribbon. Some people ask the question simply to find out what the ribbon means, but other people are really asking a hidden question: they wonder what experience in life has moved me so that I would want to wear a Red Ribbon, a visible reminder to all who see me of the continuing battle against HIV and AIDS. They are asking why I, a white heterosexual female, would choose to take an often unpopular stand, instead of quietly going about my life. They are asking about my husband, BJ.

BJ made me his wife, but AIDS made me his widow. He died in my arms at 1:45 am on Monday, May 17, 1993, in the little white house we had moved into only two days earlier. Surrounded by packed boxes filled with our books, our music, our photographs, and other mementos of our life together, we lay in the dark on the hospital bed provided by Hospice. Consumed, at this point, by massive brain lesions caused by PML (Progressive Multifocal Leukoencephalopathy), Beej had lapsed into a coma hours before.

Earlier that day his wonderful parents and our supportive friends, our "family of choice," had come, encircling his bed to say their soft good-byes, kiss his cheek gently, and whisper final messages into his ears. The room began to fill with the loud, bone-chilling sound of fluids collecting in his lungs as he struggled to breathe. In our private final hours, I sang to him, prayed over him, and recited the 23rd Psalm over and over as I carefully brushed his long hair. I reminisced aloud about how we met and some of our favourite "heart snapshots" - those special memories and private jokes and tender moments we had shared for so long. I chose to believe BJ could still hear me through the curtains of his coma.

As I sang one of our most special songs to him, I suddenly noticed my voice was no longer competing with the loud gurgling "death rattle" of BJ's breathing. I sat up on the bed and saw that his eyes were open - he was looking at me. I knew he could really see me once again and that he could see that I was truly with him until the end. His face looked so serene, with a slightly lopsided grin.

"Go ahead, sweetie," I whispered hoarsely as I held him, "it's okay to let go now." As I kissed his lips for the last time and felt his life leave his body, my hand stayed on his chest, where his body heat remained the longest. I sobbed as I felt the chill spread; the warm spot over his heart grew smaller until it was no more. Another brave warrior in the fight against AIDS had fallen.

Why do I wear the Red Ribbon? I wear it because I can. I am still alive, still able to carry the message about the reality and urgency of AIDS and how HIV can be prevented. I carry this message for those whose voices can no longer be heard but whose presence can still be felt. What message is that? I carry the message - to all who will hear and listen - that HIV/AIDS is, at this point, 100% fatal... but it is also 100% preventable. I carry the message that Persons Living with AIDS are PEOPLE first and foremost. People who have families and loved ones, people who have dreams and hopes and fears, people who laugh and cry, people who deserve the same respect as you and I.

When I wear the Red Ribbon, I am demonstrating my compassion and care for people living with HIV/AIDS, my determination that those who have already died from AIDS-related causes will not be forgotten, my support for the ongoing efforts of all AIDS service organisations and researchers, my respect for the dedicated caregivers, and my desire to educate others about how to halt the spread of this obscene disease.

I can think of many other reasons to proudly wear the Red Ribbon, and these reasons have names and faces: Bill, the first PLWA I knowingly met and for whom I became an AIDS volunteer; David, the quiet man whose face had become a mask of cancer lesions; Daphne, the woman who fretted about who would care for her children after she had died; Tony, the entertainer who hung himself in desperation; Curtis, the proud African American who had such a big heart; Little Jessica, whose panel in The NAMES Project AIDS Memorial Quilt haunts me to this day; Ryan White, whose unyielding courage showed the world that AIDS might sap his strength but never bend his spirit; Ron, whose independent streak continued until he drew his last breath; and BJ, my sweet, gentle husband, who never passed up an opportunity to speak to groups to educate them and to "put a face on AIDS." AIDS finally robbed him of his speech, his mobility, his bodily functions, his smile - but never his dignity.

There are those who believe the Red Ribbon has lost its meaning, that it's only an empty symbol now. I disagree! As long as my Red Ribbon gives someone the opportunity to ask me a question about AIDS, or gives someone the strength to go through another day encouraged by this small sign of support and solidarity, then its message is very clear. The Red Ribbon simply means that I care.

Debbi lives in Charlotte, North Carolina, where she is an AIDS educator/counselor. She is currently writing a book about her husband and their fight against AIDS.