

Western Living, April 1993

IN VANCOUVER'S KERRISDALE district the horse chestnuts are in bloom; their cream and magenta blossoms float by on a morning breeze in early May. Two elderly women are walking a Westie. This is still a blue-rinse suburb, although a young Asian man passing in a white sportster portends the future. In front of an apartment building on West 39th Avenue a sandwich board advises passers-by of a rental opportunity. Gracious Living, the sign says.

In a sunny suite on the sixth floor of this building, a woman lies on a hospital bed. The room's sliding balcony doors are open, and the breeze gently lifts the gauze curtains. The woman's eyes are partly open, but her eyeballs are rolled up into her head so that only the whites, now yellow with jaundice, can be seen. The skin of her face has shrunk and tightened to the shape of her skull. The lips of her open mouth are drawn back over her teeth, and she looks very old. But her dark hair, spread out on the pillow, is still lustrous and thick.

The woman's hands rest on the sheet, the fingers waving about slightly. She is listening calmly to the voice of a companion, who is sitting on a chair beside the bed. Another friend, who has come from Toronto and is staying in a spare bedroom, is tidying up in the kitchen. Two of the woman's brothers are in the living room, talking quietly.

The figure on the bed is Shiane, my wife. She is 37 years old and close to death. After almost five years of battling cancer, she knows she's near the end. She has let go of many expectations. She will not bear children or raise a family. She will not finish her harp lessons, or see Florence, or find another bargain at a rummage sale. She will not grow old, or even welcome

in the 21st century. How touching it is, how human, to take so much for granted when so little is certain.

Out of the smoke of Shiane's hopes and dreams has emerged one last request: that she have some say in the manner of her death. Like most of us, she doesn't want to die in a hospital. What she does want is to spend her last weeks in a place she can call her own, with a few favourite things around her, and with many people—family, old friends and the new friends she has discovered in the long struggle—to comfort and support her.

Shiane's family and friends didn't know or consider that what we were helping to create at that time was a hospice. It was simply a pleasant, private apartment where she was able to die peacefully, with dignity and grace. The few weeks we all spent together, besides allowing Shiane to complete the preparations for her departure, had a powerful effect on us.

At first awkwardly and clumsily, then with increasing ability, those of us closest to Shiane formed a group. We evolved like a living organism: expanding and contracting, shuffling and stumbling, communicating internally. We tried to shift and change along with her needs, consoling her, being with her. It was a kind of miracle, really; as Shiane was dying, something else was coming alive.

Perhaps reading about how we die will make you uncomfortable. Perhaps you are wondering how anyone can write dispassionately about such an intimate experience. But consider. Most people have to deal at some time in their life with the death of someone they love. Death is such a painful subject in our society that, despite the fact that it is happening all around us, all the time, we rarely deal with it until it is imminent, and then it's often too late to do so completely. Urban Canadians have long since lost a world in which death was an everyday, familiar part of life. Now death happens somewhere else, behind closed doors, in special homes and hospitals.

Does it have to be this way? The huge baby-boom generation has reached an age where its members must deal—or not deal, as the case may be—with the deaths of their parents. And nearly everyone knows of someone who is dying of cancer or AIDS. These deaths can be planned for and given dignity, if we care to do so. The ability to face death directly is a milestone on the journey to human maturity; it reflects, ultimately, a willingness to consider one's own death. Will we fearfully shuffle our parents and friends off to institutions, or will we face our fear by becoming involved with the dying and enrich ourselves immeasurably in the process?

SHIANE AND I knew each other for 20 years, were together for seven, married for five. We owned a modest house in North Vancouver. She was a graphic artist at the hottest studio in town. I edited a magazine—this one, in fact. We had plenty of friends, lots of money. We travelled a fair bit. Life looked good. Six months after our wedding, when she was 33, Shiane was diagnosed with rectal cancer.

The lab results were confirmed on Christmas Eve, 1986. Shiane was devastated. We spent a somber holiday. Early in January, she went into hospital for surgery. She endured an abdominal-perineal resection and a colostomy: her rectum was removed, her bowel reattached to an artificial opening in the abdomen wall. She learned to excrete through this opening into a pouch—quite a lifestyle adjustment, especially if you're young and active. Especially if, three weeks before, one of your concerns had been whether the blue or the red ribbon looked better on the Christmas wreath.

After the surgery, Shiane was so long in the recovery room that her doctor let her family and me in to see her for a few moments. It was plain she was fighting for her life. She told me afterwards that she remembered floating above her body, watching it, trying to decide if she wanted to live

with these unwelcome physical changes (and with no guarantee that they would cure her), if she was willing to embrace the unexpected pain and humiliation that life apparently had in store for her. She decided to live.

She slowly recovered, and although the prognosis was good, a natural sense of urgency came over her. She began to think about how she might want to live her life if she didn't have much life left. I quit my job and we moved to Seattle, where I published an airline magazine and we had more freedom. Shiane became a student again, a searcher. Her quest was twofold: for self-awareness, to understand and accept what was happening to her, and for practical knowledge, to preserve her health, increase her survival chances and improve her ability to function in this new world.

And it was a new world. Her search led her to teachers and therapists with specializations I knew nothing of: energy-awareness, *chi quong*, herbal medicine. It led her to HOPE, a support organization run by cancer survivors. It led us both to China, where Shiane, a third-generation Chinese-Canadian, tracked down relatives in rural family villages, and saw for the first time the world of her ancestors. We became—compared to our former state, at least—very fit and outdoors oriented.

This new world endlessly challenged our preconceptions. Who were we? What was this life about? I went into therapy, too. My belief systems were being rapidly and alarmingly dismantled, with little to take their place. Life often felt like a struggle, but in retrospect I can also see that it was a period of vulnerability and invigorating change. At times we both felt that we were living more deeply than we had for years.

Finally, Shiane's spiritual restlessness brought her in touch with Nan, a Thai counsellor who applied her Buddhist way of life to her work with westerners, and whose clients met together as a group. This was a homecoming of sorts, for Nan could share deeply Shiane's cultural attitudes

and conflicts, and my wife dropped her other investigations. Nan and her group were the people who would help Shiane most when the going got tough.

After almost two years, a persistent cough led to the discovery that the cancer had spread to her lungs. We moved back to Vancouver. Who can afford to get ill in the States? At this time, science offered Shiane a terminal diagnosis, which she quite refused to accept. Nevertheless, she underwent two years of chemotherapy, which greatly helped her at first. Between medical treatments, she and I travelled widely, exploring, visiting family and friends. For work, I continued writing and editing from an office at home.

But Shiane grew weaker and the chemotherapy less effective. Finally, only radiation could help her, and only one treatment, at that. We made a last journey, to Costa Rica. In the spring of 1991, Shiane, fatigued and in chronic pain, decided it was time to prepare herself for death.

THE HOSPICE IS quiet in the morning; it's my favourite time to be here. Annie, the homemaker, has finished giving Shiane a sponge bath, and now it's time to help her get up so she can go to the washroom. Catherine, the home-care nurse, has taught me how best to do this: right arm behind her back, hand supporting her head, chin over her left shoulder, then swing to a sitting position on the count of three. She has become feather-light.

We rest a little while on the edge of the bed. Shiane is feeling stronger this morning; she tells me she dreamed about Freddy the tour guide again. She admires some recently arrived pink roses, latest in a stream of floral offerings. When she's ready to stand, she puts one arm around my neck and I put my arms under her armpits and around her back. One, two, three, again, and she's up. I make sure she's steady behind the walker.

Our group of volunteers has tapped into the hospice home-care program, available through the city health department. It was a surprise to me how much support was provided, and at what small cost. Increasing numbers of terminally ill Canadians are preferring to die at home or in a private hospice. As health-care costs skyrocket, and pressures on crowded hospitals grow, it makes sense to grant their wishes, especially the majority that doesn't need elaborate medical equipment.

Annie, who comes to us from the hospice program, has made a huge difference. She helps look after Shiane with great tenderness, bathing her, changing her clothes and assisting with her toilet. She does some cooking, cleaning and laundry. At first she came for four hours a day, now it's eight. She's as shy as a bird, but Shiane likes her a lot. We all do.

Margaret phones. She has today's volunteer options, which we talk about, then discuss with Shiane. Margaret, a friend with experience in palliative care, offered to co-ordinate Shiane's supporters. We've asked those who want to be with Shiane and help care for her to check in with Margaret, who then works out a rough schedule and goes over it with Shiane. People who don't know Shiane so well perform more of a background role, running errands, doing whatever is needed.

We've become pretty good as a group. Margaret's contribution has been a godsend for Shiane's brothers and me. We can come and go as we need, knowing at least one person is always there. The degree of care has been gradually increased as Shiane grows weaker, and now it's around the clock. Volunteers—many from Nan's circle of clients—take four-hour shifts during the day and 12 hours at night, when two people stay so they can spell each other and get some sleep, as Shiane is often restless.

(As the group's energy started to burn out, it eventually became necessary for me to hire some nursing assistance, which is quite expensive. I

had money set aside for this purpose, but sadly, I didn't need to go through much of it. In all, Shiane spent only six weeks in her hospice.)

With Margaret involved, Shiane has some control over who is with her. She is well loved, and people want to come from all over to see her and say goodbye, but she can only handle so much. We try to spread visitors out, as her energy is quickly drained when too many people are around. Some visitors cannot contain their emotion, and others are nervous or overly solicitous, which is human and understandable but not what Shiane needs.

Good humour and serenity are the best qualities to bring to a hospice, but failing that, honesty and openness will serve. Shiane prefers to be with people who know themselves well and are comfortable with their feelings. She sees instantly through pretense, and has sent several visitors packing, including me. Being her husband gives me no special claim on her here. I have to leave my guilt and emotional baggage outside her door like everyone else. The hospice is a test: if I want to be with her, I have to be real.

It's eleven o'clock, and Catherine, Shiane's cheerful home-care nurse, arrives, bringing a bedpan. Much of the equipment we need—commode, wheelchair, walker—comes from home care, although I did rent an adjustable hospital bed so that Shiane could rest more comfortably. Catherine calls every day, and so does Art, Shiane's family doctor. They console Shiane, check on her comfort and her medical needs, advise us about her constantly changing care requirements, supervise the medications and encourage us when our efforts flag. They have taught us, for instance, about morphine. Catherine and I go over the communication book, which is kept up to date with comments about Shiane's activities, condition and mood and, for the benefit of incoming volunteers, annotated with various care tips and medical bulletins. Catherine leaves, and soon Naomi shows up to take the afternoon shift. Naomi, Shiane's dearest friend, has come from Toronto

to be with her and is sleeping in the spare bedroom. I'll come back for a visit this evening.

It's strange how things have worked out. I was so afraid of what would happen when Shiane got really ill. But all these extraordinary people have gathered around to help her get through this last passage. It hasn't all been rosy, of course, especially for her. And I've taken some criticism over the unorthodox way that events have unfolded. But it's Shiane's death, and she calls the shots.

THIS STORY, HOWEVER, is about me as well as Shiane. I see no other way to tell it. "Your life is going to be turned upside down, too," Art told me when, right after Shiane's last diagnosis, I questioned him privately about her chances. He didn't think her chances were very good. I realize now that he was gently warning me both to loosen up if I could and to hold onto my hat. I thought at the time that I knew what life was all about. But I knew nothing.

Shiane was close to her family, especially to Jack, Bill, Dan and Peter, her four brothers. And she had a lot of friends—friends who were able to overcome their sadness and their fear of death in order to be with her when she needed them. There were many who wanted to help. At first I resisted letting all these people into our lives in this new and intimate way. I felt threatened. In the privacy of marriage it is all too easy to close oneself off from the world, from new encounters and new ways of doing things. To ask for help was to admit weakness, and the way of weakness was unknown to me. To do everything myself was to demonstrate strength.

I had to struggle to put some of Shiane's requirements ahead of my own. It was hard for me to accept, for instance, that her need to come to terms with her own death would eventually grow more important to her than her

need for me. I agonized over the idea of the hospice. My better part wished, as it had all along, to support her changes, ease her suffering and help her in every way I could, but I also rebelled against the prospect of our separation, and worried about how I would have to explain this apparent last-minute breakdown of our marriage to the world.

However, the decision to move Shiane to her own place, rather than have her stay at our home, was crucial. The apartment that we found for her became a neutral space, where each person could come to her equally, where she could decide whom she wanted to share these last days with. I didn't have to try to control things there as much as I would have at home. I began to welcome other people's help, which I required so desperately. All I had to do was ask. Soon I didn't even have to ask.

The neutrality of the hospice also helped with the anger. Can anyone get cancer, especially in their thirties, without also having to deal with a great amount of anger? Spouses, inevitably, will have that anger directed at them often, and may be wrestling with their own anger as well. Having the hospice meant that I didn't need to be there all the time. I could give Shiane a little space when she needed it. I could take a little space for myself. And other people were able to have a deeper connection and reconciliation with her than would have been possible at our home.

In truth, although I had changed somewhat and become a bit more flexible over the course of Shiane's illness, most of the changes I'd made up to those final weeks were ones that had been convenient for me. I'm pretty lazy, really, so working less was not a problem; fortunately, we were never pressed to the wall financially. The travel was right up my alley, and the therapy I could approach more as a curious observer than as a participant.

While I grieved for Shiane's pain and turmoil, some part of me enjoyed the drama of the situation. Through her openness and dedication, my wife

drew to herself a circle of loving and caring friends, and I basked in the reflected glory. What had not changed for me was my self-image: dutiful provider, model mate. I saw myself doing everything right, standing firm yet compassionate in the face of life's cruel gales.

Looking back, I think that the day we moved Shiane to her new apartment was more fearful and shattering for me than anything that came after. Sorting through the detritus of a human life immobilized me with misery and remorse. Shiane's brothers did all the work. It was the day I met the dragon, the day I had to choose between duty and love.

Each required a very different response. The former demanded only that I consider my acquired notions about how I should behave. The latter, that I consider only Shiane—what she wanted, what was best for her—and completely disregard the impact of those considerations on my own life. And at that moment of truth, it broke upon me in a great flash of relief and joy that *this* was love, not any of the things I'd thought before, and that I was capable of it.

After that weekend everything was clear. I became calm and focused. My life had purpose. Suddenly I was able to relinquish my need to control the situation. My fears of the unknown and of what other people would think subsided. Would it be too extreme to tell you that serving someone I loved—completely, and with no thought for tomorrow—became a kind of happiness that I had never known before? Rather than playing the brave husband, upon whose shoulders had fallen the entire burden of looking after a dying spouse, I simply became part of my wife's support team.

“THERE ARE SIX pieces left,” Shiane is telling me confidently, looking me straight in the eye and speaking quite clearly. I am being tested again, I know. Her tone says: are you able to penetrate beneath the misleading

surface of things—beneath that comfortable agreement you have with the world about the way things are—to see what’s really going on?

Some of what she has said to us over the past week could be called incoherent, the result of the toxins that are building up in her bloodstream and being pumped through her brain as her tumorous liver ceases to function. But if you pay careful attention, everything makes wonderful sense as metaphor. There is always a level at which even her strangest, most dreamlike comments can be interpreted.

I must appear confused because she rolls her eyes and turns away. “You don’t believe me,” she says.

“Yes, I do,” I say. “Where are they?”

“Underneath.”

“Underneath what, my love?”

“The stones, of course.”

Peaces, not pieces. One for Naomi, one for each of her brothers, one for me. And to find them we would have to become excavators, burrowing beneath the hard rock of our own minds.

Shiane smiles a secret smile.

She has adopted a rather fierce, no-nonsense attitude for these final days. She can be darkly humorous and often teases us. She knows she is not long for this world; its opinion means nothing to her. She has said goodbye to those she needs to say goodbye to; she has resolved what she needs to resolve. Now she is ready to die.

“Let’s go, Andrew,” Shiane is saying to me. “Let’s go, let’s go.” I look at her. The dark eyes seem huge, out of all proportion to her face. They glitter urgently. Her amazing hair is shot with premature grey; the purple tint she used to hide it with has long been neglected. Even wasted like this she is beautiful.

“Where do you want to go, sweetie?” I ask, as I’ve asked many times before. She has been in a “let’s go” mode for days, and each destination she announces—to grandpa’s, to the wedding, to join the people waiting outside—is a thinly disguised metaphor for death. There is no fear in her voice, only a childlike intensity. Her desire to leave is strong. Yesterday, despite her weakness (and to the doctor’s amazement), she persuaded two unsuspecting relatives to take her for a wheelchair ride around the block.

But her body, uncooperative from the beginning, now refuses to stop working. In our attempts to sooth her, we usually lift her to a sitting position on the edge of the bed, where her mania subsides and she returns to our realm. This last week, it seems, we have done little but shift her, every half-hour, from lying to sitting and back again.

Shiane has fixed today, Friday, as her last day in this world. She has even told us the hour of her departure: 11 p.m. Earlier, she had told Annie that she needn’t come in to work anymore, which upset Annie no end. And Friday, according to Nan, is numerically significant—“an easy day to die.” As evening draws on, Shiane’s breathing becomes very shallow. Death seems reasonable.

At the promised hour, just Naomi and Nan and I are with Shiane. We have been chanting Buddhist prayers. Although she appears to be in a trance, her eyes are moving under her partially closed eyelids, and her fingers are scratching the bedsheet. She can hear what we are saying.

Just past eleven we’re startled by a strange noise, an eerie kind of shriek that seems to come from just beyond the window.

“What’s that?” Naomi gasps.

“Sounds like a cat,” I say.

“That’s no cat,” says Nan, gesturing outside with her eyes. “That’s a bird.”

Shiane, meanwhile, has become quite agitated, thrashing around on the bed, tossing her head and groaning. The dark bird of death has finally come for her and is waiting outside on the balcony.

“*Sabbe satta sabbadukkha pamuccantu,*” we chant. “May all beings be free from suffering.”

Shiane’s frenzy gradually subsides. Death can be bargained with, evidently. She falls into a deep, deep sleep for the first time in days. And when she awakes at six the next morning, she is a different person: alert, bright, full of otherworldly stamina. It is as if, having let go, completely, of every fear and hope, she has been able to talk death into granting her some extra time. And Shiane, who can be very determined when she wants, is determined to enjoy this last freedom.

So began an amazing weekend: two days of laughter and clarity, insight and high spirits. “Shiane was my teacher those days,” said Nan. She taught us all. Her energy level was very high, but it was a hard energy, glittering and intense, like her eyes. Whatever fuel she was running on, it was not available to mere earthlings. She refused all drugs and painkillers. She didn’t sleep, she didn’t eat. She talked a lot, but her voice was strange and unfamiliar; it had an ancient tone, deep and knowing.

She seemed on a first-name basis with death, who visited her frequently. His form, though, was always benign: a child, a bird, a tour guide, grandpa, a wedding guest. And those who were with Shiane that weekend discovered that their own attitudes towards death were changing; he was not the black-cloaked skeleton with the scythe of their imagination, but an altogether gentler and more accommodating figure—one who, although he waited for them as well, could be negotiated with and faced.

By Monday, the fuel had run out. Shiane slipped into a coma; her breathing became more and more labored. By Tuesday afternoon it seemed

as if each inhalation would be her last. At 5 o'clock, Naomi, her brother Dan and I sat with her, holding her, waiting in vain for her next breath. Shiane left us so peacefully that the exact moment between her living and her dying was virtually indistinguishable.

We straightened her dead body, folded her arms over her breast and placed a bright, yellow daisy between her fingers. Each family member sat beside her one last time to say farewell. Art came and pronounced death, kissed her forehead and signed the death certificate. As the funeral home employees carried her away, I realized with grim finality that I would never see Shiane, or talk to her, or touch her, again. The calm and purposeful balance I'd known the past six weeks tipped off-centre, and I tumbled into a well of grief that now, 20 months later, I am just beginning to climb out of.

AS I LOOK BACK, though, I see that my wife's death, although tragic, was not horrible. The atmosphere of her hospice was light and very calm; there was much laughter and surprisingly few tears. There was grief, but also a great deal of joy, as those close to Shiane found useful, positive duties to perform and were able to see how their efforts helped the dying woman. The rewards of creating the hospice were many. Making the best of a bad situation must sometimes be all that we can accomplish.

The constant proximity to death gave those who attended Shiane a powerful sense of the preciousness of their own lives. Do we dull this sense by ignoring death? Is this dullness the price we pay for sending death off to conduct its business somewhere out of view? If one is open to death, one cannot help but be conscious of life's fragility and briefness, its wonder and joy. How ironic it is that acknowledging death and the presence of the dying heightens one's awareness of life and connection with the living.

Certainly, by facing her death so directly, Shiane had a profound and lasting effect on those who were with her. Her willingness to share her death with others, and her determination to know the naked truth about what happens at the end of this life, will keep her memory alive in many hearts for many years. Her courage and honesty made it more difficult for the ones who loved her to continue being weak and dishonest. Rather than advancing the powerful current of denial and fear and anger that already swirls around death, Shiane created opportunities to grow for those of us she left behind.