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# We Were There

*Irene Burns*

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*Irene Burns and Robin Macdonald are friends. Neither knew Mitchell Holsman or Gretta Wren. And neither did Mitchell or Gretta know each other. All four live and work in New York City — Irene as a telecommunications consultant; Robin as a paralegal; Gretta as an office administrator; and Mitchell as a fashion designer — and all four were friends of John Krieter. It was the love inspired by that friendship that brought them together to care for him. He died of AIDS on January 24, 1988.*

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**J**ohn Krieter was as close to me as my brothers (though my parents never had the opportunity to meet him). John was one of those wonderful souls you take immediately into your heart. John died of AIDS three weeks ago. I loved him very much.

I learned a great deal caring for John. I want to tell you some of what I learned because you'll need it. Every day the profile of the person with AIDS (PWA) looks more and more like someone you know. Some of your colleagues, friends, and family may be a part of the vast reservoir of HIV-infected persons. Just as you and I may be. We can't pretend this happens only in Africa, or Hollywood. John nearly died in my apartment. My neighbors are dying in theirs and so are yours.

John started to lose his sparkle about six months ago, shortly after the death of a good friend of his. I tried to talk to John about his health several times and each time he changed the subject. AIDS was not going to be discussed as a possibility by John. We'd both known people who had died of this disease. We'd seen only deterioration, dementia, and tortured souls. This was just not an option for John. I'd heard him say many times, "If I got AIDS I'd kill myself before I'd have you watch me be eaten alive — wondering what it was you used to love about me."

On December 12, John attempted suicide. He hadn't been to a doctor but he knew he had AIDS. We all knew. But no one else did. Even the woman who regularly gave John massages and who saw him shortly before his suicide attempt did not detect the ravaging changes taking place in his body.

*Irene Burns is a telecommunications consultant in New York City and serves as a member of the board for the Writers' Theatre.*

Before I go further, let me introduce the rest of the cast of characters: Mitchell, Gretta, and Robin. We call ourselves the FN's (Florence Nightingales).

I knew Robin, though I had only met Gretta and Mitchell. Robin and I are like sisters. I knew just what to expect from Robin. When my older sister had an accident that resulted in brain surgery, I learned from Robin's care for her what it means to be a care giver. Robin's mother worries about the deer every time there is a storm in Maine, and Robin is a chip off that beautiful old block. I expected her to be sad, solicitous (of John and the FN's), and soul-searching — reaching deep down into her soul and ours to pull up knowledge and nerve endings we didn't know were there. Yes, I knew just what to expect from Robin, and I am so happy for John (and for me) that we got just what I'd expected.

Mitchell and Gretta were enigmas. I guess I expected Mitchell to wilt. I knew of her history with agoraphobia. It was John's strength and determination that had pulled her through her roommate's death and her separation from her husband — all in the last six months. He couldn't pull her through this one, and I didn't see how she could possibly make it. I couldn't have withstood what she had and then added this to it.

I guess I expected Gretta's participation to be sporadic, at best. After all, her grandmother, aunt, and uncle had all died within the last three months. How much could a person take? No, I wasn't counting on any support from Mitchell and Gretta.

Fortunately, I was right about Robin and couldn't have been more wrong about Mitchell and Gretta. I wasn't the only one with low expectations, though. We four FN's have talked many times about our preconceived notions of one another. Sometimes it's great to be wrong.

We proved the whole *is* greater than the sum of its parts.

Ordinarily, the folks on twenty-four-hour duty are members of the patient's family. Well, we became an instant family. There is nothing like forced intimacy to strip one of safety shields and expose strengths and weaknesses with flashing neon signs. We read one another's signals as if we'd been doing it all our lives. One person's weakness would be instantly offset and overshadowed by another's strength. The balancing act was like nothing I'd ever experienced before . . . let alone with strangers.

Among many things that made this group unique, we were all self-employed. Our consultancies included law, telecommunications, fashion, and office administration. Though none of us is financially independent, we were each in the very fortunate position of being able to tell our clients that we were unavailable, circumstances dictated a higher priority. When I said that we were on twenty-four-hour duty, I meant just that. None of us got more than a few days' work done in six weeks. Every one of us borrowed money to live on while we worked for John.

We had new jobs now. Gretta was in charge of research. Mitchell kept John focused on the game plan and ran interference with all the friends and family. Robin kept us tuned in to the power centers within us waiting to be tapped. My job was to keep in touch with the medical and social services staff.

We were all in charge of comic relief.

Comedy was always important to John. Discussing tragic topics like AIDS was not. Only after the suicide attempt could we talk AIDS. Finally! But not with finality. The day after he tried to kill himself, John moved into my apartment. He was there for two days. I can't describe adequately what it was like to have him there. In the daytime, we talked about AZT, about extending life a little longer, about going to Trinidad and getting a tan. We talked about doing a few more things on borrowed time. We had hope.

But there are some things I just can't describe. Like the nights — the coughing, the fevers, the chills, the nightmares. I can't do it. I lack the control over language to make it clear, and I don't have enough control over my emotions to look back on that horror clearly.

We knew we had to hurry up, but we did think there was still time. Within forty-eight hours after John's suicide attempt, the doctor said he thought the pneumonia, clearly evidenced on John's x-ray, was PCP. The drugs for treating PCP would be rough on John's system if that wasn't what he had, so the doctor wanted a confirmed diagnosis before starting him on so severe a protocol. A mixed blessing, uncertainty is.

My studio apartment is also my office. I had business meetings scheduled there, and John felt too uncomfortable to stay. He left my apartment and moved in with Mitchell and Robin. He wasn't leaving there, he said, till he and Mitchell were on their way to Trinidad.

Despite his rapid deterioration, John insisted on not going to the hospital. Two days after moving in with Mitchell and Robin — and with two of us struggling to hold him down on the bed to control his convulsing — he looked at us and asked, "I'm not shaking badly, am I?" John had gotten slowly sicker over four days, but in only an hour and a half he had gone from quite sick to very nearly dead. We called an ambulance.

When you live in New York, you are never surprised at being treated like a nonperson. When I called 911, I expected to wait a long while, then have the folks in blue arrive with gloved paramedics and display overt aggression toward this obvious AIDS patient and us lepers who were with him. I was very wrong. Again.

The police and ambulance arrived within ten minutes. And these people were wonderful! They couldn't take John to the private hospital his doctor was affiliated with because it was not one of the nearby hospitals. That was a policy I'd forgotten about. I asked them to carry John downstairs and put him in our car so that we could drive him to the hospital. God bless these guys, they didn't treat me like the lunatic I was for even suggesting that. Very calmly, they explained that he wouldn't make it without immediate oxygen. We called the doctor to arrange for a private ambulance, and the paramedics asked to speak with him so they could report on John's vital signs before he was moved. The police and paramedics stayed with us till the other ambulance arrived. The police repeatedly apologized, saying they all wished they could do more for these guys (PWAs). The cops took each of us aside just to make sure we were coping. They were just amazing.

Their support and concern came from their AIDS experience. They knew what John's fate was likely to be; they had seen this many times before. Rather than distance themselves, they were right there with us on the most human and humane level. They'd sure earned the title "New York's finest." That they were.

I can't imagine what horrors would have been in store for us had that first contact outside our close-knit group been with people whose only exposure to AIDS was the TV commercials even I find frightening, and I'm well schooled in this disease. What happens in small towns where they think AIDS is transmitted like a cold? When someone you love is dying in your arms, the very last thing you need is a medical professional who is afraid to pick him up.

We were so very lucky.

The rollercoaster ride began in the Emergency Room. Mitchell came out and told us that John had been asked for permission to intubate him, should that become necessary, and he

had refused. I went in and asked John if he understood what the doctor had said. I said, “They want your permission to bring the oxygen closer to where it is needed. If you don’t get enough oxygen through the mask, because your lungs are clogged by the pneumonia, they want to put a tube of oxygen directly in your lungs until the medication can clear them enough to get oxygen normally. Did you understand that that is what they were asking you?” He said, “Get the doctor.” When the doctor came in, John said, “I didn’t understand.” I looked at the doctor, who said nothing, then at John. I said, “Doctor, John is telling you that he did not understand the request for permission to intubate him. He is giving you permission to do that whenever you deem it necessary. Is that right, John, is that what you mean?” He just said, “Yeah, I didn’t understand.” Of course he didn’t — he wasn’t getting enough oxygen to his brain.

I’ve replayed that conversation in my mind I don’t know how many times. It seems direct and straightforward enough on the surface. But where is the acknowledgement that this “tube of oxygen” is external life support — that it is extraordinary means? Where is the acknowledgement of the conversations we’d had months before about not living by machine? The text seems direct and nonjudgmental, but text doesn’t have a tone of voice. I did. I obviously thought a tube of oxygen was a good idea. Did I owe John mention of external life support? This was the man who had said he’d rather take his own life than rot away in a hospital.

That was the beginning of what became a recurring question. When do you turn the machines on? And how, after that, do you decide to turn them off?

The first five days John was in the hospital, he was on a breathing machine. When he was taken off it, we were so excited we could barely contain ourselves. As we were walking out of the hospital, Mitchell took one look at the empty, shiny marble hallway, dropped her bags and did an Olympic-caliber cartwheel, complete with the royal wave finish. All she wanted to know was whether her legs were straight. Now, one of the things a person learns about me within minutes of meeting me is that I have a very loud belly laugh. Seeing Mitchell’s spontaneous cartwheels tickled my funnybone so much I was afraid they were going to admit me to the psychiatric ward.

When we got out of the building and went to cross the street, Mitch gave a devilish grin, dropped her bags again, and did six continuous cartwheels across York Avenue. Oh, how I wish I could communicate to you the absolute joy that gushed out of me at the sight of her perfect performance. Remember, this public display, public spectacle, came from an agoraphobic. One who just couldn’t reign in her happiness. From then on, all good news was judged by whether it warranted one cartwheel or more — and if more, how many.

There was a lot that was funny. The FN’s kept the jokes coming, and even when the breathing machines forced John to write what he wanted to say on the back of computer printouts, his wit kept sparking us on.

Forty-eight hours after John was admitted to the hospital the first time, we all had to deal with being told he had a 15 to 40 percent chance of living through this bout with PCP (still the unconfirmed diagnosis). Forty-eight hours after that, he was off the breathing machine and out of intensive care, and we were told the *Pneumocystis* was 90 percent gone.

Rollercoaster? You bet.

AZT. Hope. We made new flight reservations for Trinidad. We brought John bathing suits that were gifts from my sister and another of his friends and had a map of Trinidad framed and perched it on his table.

Gretta, the head of the FN research department, had done her homework. We'd started reading wonderful stories of PWAs "Surviving and Thriving with AIDS." (That is a great publication put out by the PWA Coalition and available through the New York City Gay Men's Health Crisis, and it ought to be required reading for everyone! Okay, "everyone" is too much. Just people over the age of sixteen.)

It took the four of us working full-time to "manage" John's illness. We had to pay his bills, get him on Medicaid, give away his fish, make and receive hundreds of phone calls, keep people from visiting when he didn't want anyone to see a machine breathing for him, get people to visit when our jokes couldn't get a laugh out of him, clean his house of dirt and pre-suicide depression, and do so many other things.

We never minded cleaning his spit or bedpans or missed bedpans, because we loved him. I can't imagine how that gets done by a stranger. It's a loving act that requires real family. What happens to the PWAs who don't have someone who loves them right there when these things need attending? John had a hard time accepting our help. He needed it and he took it. But it wasn't easy for him to accept his dependency. Even when he couldn't eat by himself, he wouldn't let a nurse feed him. We could do it as long as it was no big deal. His willingness to fight was tied to his image of himself. He needed constant support from people who knew what his self-image was and who fed it the right food at the right time.

After twenty-one days in the hospital, John was told he could go home. Waiting in the lounge for John's discharge papers, we all laughed about Mitchell's now-legendary cartwheels and how they had begun. We told John about strangers walking up to Mitch and saying, "Thank you. I really enjoyed that!" and he wanted a command performance. She did a cartwheel for him right there in the lounge and he shook his head and said, "Slower, Mitchell, your skirt didn't have time to fall and show your panties." She actually did a cartwheel in slow motion (showing off the black, lace-trimmed dance pants I'd given her especially for the occasion).

Twelve hours, four sets of blood work, and two x-rays later, John was discharged.

Life and death. Such extremes.

Last summer, a very dear friend of mine came alarmingly close to dying of cancer. John hated how that affected me. He kept saying, "Deal with it!! If the bitch dies, she dies. That's it now. Go on." Neither of us could say, "If he dies, he dies," when it came to John's turn. It wasn't that easy. We *had* to "deal with it!"

Before John died, I thought I would exercise the same choices he did. That included a preference for suicide if I learned I had AIDS. Most people I know say they would never want to be kept alive by machine. I've changed my mind about AIDS, suicide, and life-support machines. Our survival instinct can't be summoned in the abstract. My feelings about "living wills" (legal instructions to next of kin regarding life-support systems) are very different now. I don't want to be Karen Ann Quinlan, but I don't want to miss a chance at more quality time either.

John had been out of the hospital just six days before we took him back to the Emergency Room. He died twelve days later. We didn't know that the first stay in the hospital was just our warm-up exercise for this one. Now it really got tough.

He understood the question about the tube of oxygen all too well this time, and he wanted no part of it. DNR (Do not resuscitate) instructions were reaffirmed daily — when the medical team could find John lucid for a few moments.

I can't begin to really describe what this time was like. This was hell.

The virus had gone to his brain. Some of his hallucinations seemed fun and inviting. Then there were the others. We tried not to think about what he must have been seeing when he twisted his face muscles so as to be unrecognizable and shook his head — and everything else — and whispered, “No! No!” The first day he probably had two hours, all told, of being consciously with us. That number decreased daily. The coughing now brought up blood the size and consistency of golf balls.

Once, after filling a spit cup of blood balls, he said, “Save that. I want to give it to Troop and Patty.” Then he looked at me with abject horror on his face and whispered, “I know.” He'd heard himself ask for a gift of blood for his friends, and he was horrified that this had happened to him. I just smiled and rubbed his feet and told him a story.

My worst nightmares are the ones that include him saying, “I know,” with that tortured look on his face. That was the hardest moment for me. I was glad that I had majored in theater and was able to look as though nothing had happened when, in fact, I was as horrified by his unwelcomed knowledge as he was.

I left town three days before John died. A few days before that, John had given me a hard time for not being better prepared for this business trip. I had to go. I knew I was saying goodbye to him before I left.

What could be harder than what we had just been through? Leaving. Being with people who didn't understand at all and didn't want to hear about it. Abandoning Robin, Mitchell, and Gretta. Needing them.

As Robin says, “The hits just kept on coming.”

Now what?

Some of us fear, late some nights — before the nightmares start — that we may have contracted AIDS from cleaning spit cups, or from other, less elegant caretaker duties. Gloves aren't always available, or convenient. We weren't careless, certainly, but we weren't always following the strictest of standards either. Irrespective of that fear, none of us, given the chance, would have done anything differently. No, that's not true. We can each think of instances where we would have done more.

Preparing for this article, we all discovered something terribly important. We're still a family. When John died, the force that had brought us together, the goal we had had in common, went too. None of us knew if the FN's needed to be a group anymore. As we talked of writing about our experiences, we found ourselves back in the automatic pilot mode — picking each other up, filling in the holes — finding that delicate balance. John's legacy holds something very different for each one of us. And something very much the same. He left us each other.

We've learned wonderful things . . . about each other and about ourselves. We've learned horrible things . . . about AIDS, certainly, but also about “the system.”

AZT costs \$800 a month. It takes several months to get a Medicaid application approved. Many PWAs don't have months! John died just five and a half weeks after visiting a doctor who couldn't make a definite diagnosis of AIDS. Five and a half weeks!

When John's doctor prescribed AZT, John's Medicaid had not yet come through. He didn't have \$800 to pay for the drug. Neither did we.

But we did have Maryann, the system's greatest gift. Maryann called us four hours after we left the Emergency Room. She introduced herself as a social worker on staff at the hospital, then said, “Now, tell me what can I do for you.” I told her that the first question John had asked from behind his oxygen mask was, “Who is going to pay for all of this?”

She said, “I know, I’ve already seen him.”

When John was released from the hospital after his first stay, Maryann stressed that her job wasn’t over just because he was no longer a patient there. She insisted that we call her if she could help in any way. When the doctor handed me the AZT prescription, I called Maryann. She had already submitted the appropriate forms for Medicaid. She had researched city and state programs that would cover medical expenses until Medicaid kicked in. Her preparations for the AZT prescription began two weeks before the doctor wrote it. She told me one day that in the preceding two days she had made forty phone calls about funding just for John (and he was not the first PWA she had supported). Forty phone calls!

I bet you think that’s an exaggeration. She told me about the calls. These weren’t repeated messages to the same folks. She had initiated and completed forty *different* phone conversations on John’s behalf. Just in the preceding two days.

She uncovered a program that allowed the manufacturer of AZT to provide the drug at no cost until government funding was available. But they needed a letter from her and one from the doctor. John needed AZT. Now! How were we going to get through the two weeks till the paperwork was processed?

She said, “I’ll ask the hospital to pay for it. I’m going upstairs right now with the request in one hand and my resignation in the other. They’ll have to accept one of them. Call me back in ten minutes.”

She didn’t have to resign. The hospital gave us the AZT.

This woman is obviously quite extraordinary. How many social workers would — or even could — place forty phone calls in two days and put their job in jeopardy to get medication for a stranger?

Every PWA needs a Maryann. We got one. What in hell do other people do? Why is it that this woman *had* to work that hard to find ways to help one man when thousands are in the same situation?

I’m as deeply angry for needing Maryann as I am grateful for having her.

Maryann succeeded in allaying John’s fears about being thrown out of the hospital because he couldn’t pay the bill, but nobody came to talk to him about any other fears he might have. It’s probably safe to assume that someone who has attempted suicide and then winds up on a toboggan ride to hell needs professional counseling. But, that isn’t part of the program.

We were lucky. Again. John had a client who is a psychologist. We called and asked her to please visit him in the hospital. She was more than glad to do it. He could talk to a friend. He would never have requested of the hospital staff that they send in a psychiatrist. What do PWAs do without friends who are mental health professionals?

Friends pulled through on so many fronts.

Another friend helped us get around a policy that probably makes a lot of sense — unless it backfires, as it did on us. The Gay Men’s Health Crisis does an exemplary job in providing information about and support for PWAs. Twenty pages of praise would still be inadequate recognition (so just send them your money so they can keep it up). But even this wonderful organization suffers from imperfections.

In order to arrange for John to be visited by someone who had firsthand experience with AIDS, the request had to come from him — the PWA — not from friends. John was scared. The only people he’d known with AIDS were dead or dying. All had suffered horribly, and he was afraid to see someone else with the disease. He desperately needed to replace those perceptions if he was going to be able to continue the fight. Those were the



notions which went along with suicide. They had to be replaced by the image of someone surviving and thriving with AIDS, and there are a lot more of those people around than any of us had realized.

We couldn't arrange a visit, and he wouldn't arrange one.

Thankfully, a friend told us about someone visiting from LA who had gone to the Gay Men's Health Crisis and said, "I have AIDS and I'm happier and healthier than I've ever been in my life. I'd like to spread some sunshine. How can I visit some PWAs in the hospital? They know the 'before' picture, I'd like to show them what happens after the make-over." He was told that wouldn't be possible until after he had taken some training to qualify as a counselor. When our mutual friend heard that one, he sent this imported ray of sunshine our way. We needed his mind and his heart, not a certificate.

John was visited by that PWA and his psychologist friend on the same day. (Mitchell's arms got pretty tired from the cartwheels this occasion warranted.) These two visits made a tremendous difference to John . . . to all of us.

What happens to PWAs who don't have these strokes of luck? Why do we call it "luck" when some attention is paid to the nonmedical effects of AIDS?

The FN's did extensive research. Considering how much is not known about AIDS, we were quite surprised to find that a vast amount of information is available. We read studies on numerous drugs and treatment programs. We read about many PWAs surviving and thriving. We read those things and were then shocked to discover that the physicians treating John had not. They were anxious to do so once we brought the data to their attention.

When John was in the Emergency Room the second time, we had to insist upon seeing the attending physician. We couldn't get the nurse, head nurse, or resident to acknowledge the interaction that possibly might result from administering aspirin to reduce John's fever. I talked to them about the possible effects on his blood work or the diminished efficacy of the AZT, or both, were he to be given aspirin or acetaminophen. When the attending arrived, he was, understandably, annoyed at being summoned. When we explained why, he looked at me and said sarcastically, "Where did you hear that?" I said simply, "I read it here, in the insert that came with the AZT. You'll find it under the heading 'Contraindications.'" He read it. His demeanor changed immediately. He thanked us and changed the order to Tylenol, knowing now what to watch out for.

I'm sorry to say that this is just one of our examples.

We learned a great deal that goes beyond our personal experience. We learned about patient advocacy. In this case, it took four full-time FN's to support the medical, financial, psychological, and mundane needs of one PWA.

Regrettably, we fear that this knowledge will be more than character building. We know we will need to call upon it again. 🐻

*The dignity of this article belongs to Pdraig O'Malley; the precision of its expression belongs to Toni Jean Rosenberg; and the indignity of AIDS death belongs to us all.*