

# Girl's death inspires try for hostel

## Family donating home as haven for terminally ill

By Dave Haynes

**T**HE VIEW from the dining room window sweeps down through trees and shrubs to the bush and rock that obscure the winding Seine River.

Looking out, in the first months of 1980, 17-year-old Jocelyn Hutton spent some quiet moments, enjoying the scenery and accepting the fact she would soon die of bone cancer.

More than four years after her death, the young girl's spirit has been kept alive through her family's efforts to establish Jocelyn House, a home care hospice for the dying made by converting the home where she died. Such a hospice would be the first of its kind in Winnipeg, and one of only a handful in Canada.

Bill and Miriam Hutton have donated their Egerton Road home, a custom-built cottage-style split-level on an acre of heavily wooded property just 10 minutes from downtown, for the project. Eventually, the Huttons hope as many as six terminally ill patients can be moved in to spend their last weeks in an emotional and spiritual atmosphere not possible on busy hospital wards.

The family had been hoping to win approval for operating funds from the Manitoba Health Services Commission, but a decision isn't expected for several months. The province told Bill Hutton after a recent meeting that they wanted to further study the hospice concept.

Hutton isn't discouraged. He isn't a real believer in things metaphysical, but he can't help thinking his late daughter is somehow guiding the family towards the start of the hospice.

"When we found out Joc was going to die, there was no question about it. She was going to die at home," says Bill Hutton, thinking back to October, 1979.

Jocelyn, a bright, popular girl with a talent for sketching and a love of dancing, had noticed a pain above her right knee months earlier. At first, doctors wrote it off as a dancing injury. But X-rays eventually showed a large, growing tumor.

### Spread to lungs

The leg was amputate and therapy started, but by fall, the cancer had spread to her lungs. On Halloween, the Huttons were told further treatment was pointless.

It was a shock, but Jocelyn managed to retain her spirit, determined to make the best of the time she had. She wouldn't allow her family and friends to grieve for her, so Jocelyn came home from the hospital for good and the Huttons returned family life to normal. Always active, Jocelyn grew more involved — writing, drawing, talking to people about her situation. "She just lived with such intensity it was mind-boggling," Hutton says.

In January, 1980 a local CBC producer approached the Huttons about doing a piece for 24 Hours. Camera

crews filmed Jocelyn at home, and one night she got out of bed to hobble on crutches through the airport to meet her best friend, who had flown home from Amsterdam to see Jocelyn one last time.

She was weak, not really strong enough to walk. But she insisted, managing smiles and bursting into tears when her friend came in sight. She collapsed as soon as the cameras were switched off. "There is only so much you can do with pain control," recalls Hutton. "The next morning, the pain was so bad she just lay in bed screaming."

### Cameras return

The film was shown on 24 Hours, and noticed by CBC's Man Alive producers. Weeks later, the camera crews were back. Jocelyn's story was televised nationally on April 1, 1980. She died 17 days later.

A blending of grief, relief, and in some ways, happiness, swept through the family and close friends, who had spent six months on an emotional roller-coaster. Paul Edwards, a 23-year-old law student, recalls spending hours with his friend Jocelyn, sitting by her bed and talking if she wanted. Like her other friends, he says he just wanted to be around if she needed help. "She had incredible spirit," says Edwards. "Out of necessity, it became everything. I was just so impressed by impressed by her will."

Her death took a personal toll on Bill Hutton. At one time a teacher at Kelvin High School, and an Anglican minister, Hutton was bed-ridden in the months that followed by a heart condition that was aggravated in the strain of Jocelyn's last year. With Miriam Hutton still working as a social work professor, taking care of the house and its huge lot proved impossible. She suggested that, along with son John, they move to a smaller home.

"I agreed to move, but only on the understanding that we couldn't sell it," Hutton says.

The house was rented for two years, "and then someone came up with the idea of having a hospice."

An architect said conversion was possible, zoning was approved with little neighbourhood opposition, the Manitoba Hospice Association was formed and Jocelyn House incorporated. In the final plans, a registered nurse will be in the house at all times, and other care will be provided through normal visiting Home Care Services. The medical care will be semi-institutional, the patients sleeping in proper hospital beds and on full pain-control programs. But that's where any similarities to other local palliative care programs will end, says Hutton.

"This is a very particular approach to a hospice. It's evolving from home care rather than devolving from hospital care... Instead of traumatizing the patients by putting them in a hospital, put them in a house where there is a very conscious emphasis on living."



William Hutton stands in front of his home holding a portrait of his daughter, Jocelyn.

The yard, he says, offers a retreat for the patients and families. Hutton envisions families coming over to visit, walk, even barbecue on the deck. "Even if he (the patient) can't eat the food, he'd probably just enjoy something like that."

"I'd like to see people do all these family things. Bring their dogs and cats around, even bring them into the house."

Converting the home to a house, with an elevator, ramps, rearranged walls and equipment, could cost \$70,000. If the money is there, Hutton would also like to erect a small chapel in one basement corner.

John Hutton, a 24-year-old student, has a provincial grant to work out of the home this summer, running the foundation and starting to look into fund-raising possibilities.

That part should prove relatively easy. Already, \$2,000 has been donated by church groups and another \$10,000 raised, without prompting, by school and church groups. "I really think that's indicative of the effect Joc seemed to have on people," says Hutton. "We haven't gone out to raise money, but the friends of Jocelyn Hutton have given us \$10,000."

Hutton, who can only work a few hours a week because of his weakened heart, has been speaking to service

groups and lobbying for operating and grant money from the city and province. He has been hesitant to start major fund-raising, he says, because there has always been a chance the province would decide not to provide operating funds.

### Resource centre

But now that the Manitoba Health Services Commission has delayed any decision, the Huttons are talking about opening the hospice in two phases. Until operating funds are approved, Hutton says the home can be used for such things as a resource centre and as a daytime respite for the dying and their families.

It may be a scrap getting the first ones started, but Hutton says opening hospices has to be considered inevitable. Within the next decade, the baby boom generation will be moving into a high incidence age group for cancer. Hospitals will be jammed.

It costs roughly \$300 per day to care for a cancer patient at a conventional hospital. Jocelyn House

could provide the same medical care at half the cost, in a much more attractive setting.

Hutton and other organizers hope to keep costs down through donations of equipment and volunteer time.

In the last few weeks, the house has been slowly brought back to life. Students, friends of Jocelyn's are living in the house, putting things in order. John is using a bedroom as a temporary office.

Outside, Hutton looks over the property he had to leave after his daughter's death. He remembers planting shrubs with his two children. He marvels at how some of them have grown, and how others have withered away. Mostly, he recalls the happy times. "I hope you can get a sense of this place," he says, wandering down to the riverbank. "I think this is a special place."

His face isn't easily read. He misses her. But deep religious convictions have tempered much of Jocelyn's loss. He knows she is now happy. More than anything, Hutton seems in awe of his daughter.

"She told me before she died, 'I always felt that God had a very special purpose for me.'"