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The bearable unfairness of life

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free bus service for everyone in a wheelchair,
a group home with a fireplace and a cat.
And that is what he has.

I am thinking, once more, about Tracy Latimer. In October of this year, the courts will retry Robert Latimer, her father, who four years ago killed severely handicapped Tracy "out of love and compassion," because of the pain she endured in life. The state, not without a great deal of soul-searching, found him guilty of second-degree murder and sentenced him to life in prison with possible parole in ten years; they will soon be re-considering that decision.

We know that Tracy's body was terribly deformed by cerebral palsy. She couldn't feed herself, walk or speak, and had suffered a series of painful operations. We heard the agonized compassion with which her father says he viewed her struggles. What we will never know or hear is how Tracy, twelve-year-old Tracy, felt about her life.

I know a little how my friend Don feels about life. Don is nearly as "severely disabled" as Tracy was, so damaged by complications during his birth that his parents were advised to put him immediately into an institution, because caring for him at home would be too grueling. Don also cannot walk or feed himself. He needs to be lifted into bed, onto the toilet, back into his wheelchair; he has to be dressed, clothes stretched over his rigid, ungainly limbs. Don can talk, though his speech is so slurred it takes a long time to understand him. His parents were told he would live fifteen years, at most. His internal organs, crushed by the convolutions of his body, would simply give up.

This year, in his usual fashion - a Chinese banquet and a few stiff drinks - Don celebrated his forty-fifth birthday. Not only has he survived, he is a happy man, passionately attached to the world; he won't let his body defeat him. The success of Don's life is in every way a tribute to the limitless patience and love of his parents. What they have gone through to raise him cannot even be imagined, and they would be embarrassed to discuss it. They want no special credit. He is their son, to be cared for; that's all there is to it.

"A family with a handicapped child," goes the glum saying, "is a handicapped family." There is no doubt that Don's severe disabilities changed the course of his family's history. His father Edgar, retired from the gas station he ran for many years, unsentimentally points out a piece of land now worth a fortune and recalls that he was once offered it for a pittance. Even such a small amount, for a family with steep medical bills, was too much. Constant sacrifices were necessary to accommodate the family's most vulnerable and demanding member. Yet, despite the difficulties involved in raising Don at home, Edgar and his wife Connie only once considered putting him in an institution. They made the journey to the huge facility then serving the mentally and physically handicapped of the

province. "One look at that place," says Edgar, "and we just turned around and brought him home."

Don's four younger brothers, all hard-working men with good jobs and families, have special qualities because of their childhood with a sibling as helpless as their older brother. They are conscientious fathers, confident and tender with infants; they know how to look after themselves and others. Humorous, reliable, they're seldom discontented or restless. As one said, "We were never like other kids, whining 'I wish I had that toy.' We lived with a brother who had so little. The unfairness of it."

That brother, despite his blurred speech and contorted body, has always had a powerfully assertive personality. Furious when his slightly younger brother left home for university, he insisted that it was time that he, the oldest, leave home too. Once again, the family did a search through local institutions; the best they could find was the extended care wing of the local hospital, which holds mostly the very old and patients with degenerative diseases. Against his parents' wishes, determined to be independent, Don moved into the hospital, where he stayed for nearly twenty years.

He has always lived with chronic pain, as Tracy did. Once there was talk of an operation to straighten his spine, to give his compressed organs some room. The twelve-hour operation would have left him in a body cast for six months. At first eager, Don ultimately decided against the ordeal. He wanted to stay right where he was, in his new home.

After years of lobbying, phoning, writing letters, introducing their son to provincial representatives, Connie and Edgar finally persuaded the authorities to build a group home in the small B.C. town. The bungalow was designed to accommodate wheelchairs, with a central, low-slung kitchen and an extra-wide bathroom. Don has lived there for six years now, with three companions and their caregivers, in as normal a family atmosphere as is possible under the extraordinary circumstances. Don has his own room, crammed with family pictures, the walls covered with Baywatch posters. In the evening, when they are not barhopping in the Handy Dart wheelchair van, the housemates warm themselves by the fireplace. Friends drop in to visit. Don sits in his new wheelchair, the cat squeezed in beside him, his rye disappearing slowly. His face is blissful.

Though Don's life may look limited and pain-wracked to us, not once has he complained about the fate that assigned him his twisted body. He simply kept asking for what he needed: lots of time with family and friends, a free local bus service for everyone in a wheelchair, and a group home with a fireplace and a cat. And that is what he has.
