

# No Asylum

Mentally ill people die young. Not just from overdose or suicide, but from heart disease and cancer—the same sicknesses that hit us all. Who will care for those least able to care for themselves?

By Frances Bula

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**E**VERYONE could see that something was wrong with Ben Williams. His girlfriend, his mother, his two sisters. Once a muscular guy who cycled up and down the slopes of North and West Vancouver, he'd bloated to 350 pounds and was constantly short of breath. He stopped dressing every day. Sometimes he didn't get to the bathroom in time. His fingernails turned blue. He had chest pains. He should have gone to the doctor and been sent to hospital for tests. He should have been put on heart medication and a diet. But Williams didn't believe he was sick, didn't like doctors, and refused medical help.

"Ben was his own man," says his girlfriend of 20 years, Carol Mathiesen, flipping through photos: Williams as a teenager in West Vancouver; at family dinners; with friends in North Van. But it wasn't just that he was stubborn. He'd been diagnosed as a teenager with paranoid schizophrenia. In his final six months, his family tried repeatedly to get help. They wanted someone to commit him to hospital. Earlier that year, they'd been successful—for six days, at least—when he bolted from hospital after treatment for a mild heart attack (doctors having determined his delusions prevented him from understanding his condition or making logical decisions). Six months later, in December 2009, a health team visited his apartment on the upper reaches of North Van to assess whether he should be

committed again. His suite was clean. He was not noticeably delusional. In fact, he told the psychiatrist and caseworker, he was just tired—tired of his family bugging him. He could take care of himself.

Twelve days later, Williams put on some new Christmas clothes. Heading out on errands, he collapsed on Lonsdale Avenue. A passing off-duty firefighter tried to revive him, but by the time an ambulance got him to emergency at Lions Gate Hospital, he was dead. He was 52.

His case is not uncommon. Earlier this year, a British study tracking 30,000 people established that the mentally ill die 10 to 15 years earlier than average. Those with schizophrenia fare worst: men live to an average of only 63, compared to 77 in the general population. An American study published in 2006 painted an even grimmer picture: those with psychiatric problems die 25 years earlier than others. They don't kill themselves or get into lethal fights or overdose on illegal drugs. They die of cancer and diabetes and, especially, heart disease. One factor in their early deaths is the antipsychotic drugs they take, which are hard on their bodies; another is that people with psychiatric illnesses seem susceptible to physical malfunction. But perhaps the biggest reason is that they aren't good at taking care of themselves. And as Williams's case proved, the health-care system isn't able to do it for them.

AT THE REQUEST of the North Shore Schizophrenia Society, coroner Scott Fleming investigated Williams's death. He concluded that the regional health

authority needs a new approach. "It became apparent that the issues illustrated by Mr. Williams' death are becoming increasingly common as a greater number of psychiatric patients, often with accompanying chronic and/or acute physical illness, are managed in the community."

The community-care model is a recent, and controversial, development. Until the 1960s, people like Williams were often committed to long-term psychiatric facilities where decisions were made for them. But scathing stories about those institutions' conditions, rising costs, and popular movements demanding that mentally ill people be allowed to live in the regular world convinced governments to shift care to group homes and to emphasize integration. At the same time, new laws restricted involuntary commitment, and the medical establishment began espousing the idea that even psychiatric patients with serious problems should be given a say in their treatment. As Dr. Paul Termansen, the psychiatrist with Community Psychiatric Services who visited Williams, told the coroner, "We were trying to follow a more trusting, autonomous view of treatment."

Families and advocates, fighting that libertarian view, say it does a profound disservice to the mentally ill. In Vancouver, the fight has been taken up in recent years by the families of mentally ill people who are also drug addicted. For years, doctors and hospitals would refuse to commit someone who was mentally ill, even if families begged them. For those willing to get help, psychiatrists would argue they needed to get off drugs

first; addiction specialists would counter that they needed psychiatric help before they could be admitted to rehab. Slowly, Vancouver's health-care system has responded with more programs for the "dual-diagnosed," and acted more aggressively on involuntary commitments.

But cases like Williams's—involving psychiatric patients who ignore physical health problems—represent a syndrome only now emerging. At the Atira Women's Resource Society, one of many B.C. housing nonprofits that have become refuges for the mentally ill, CEO Janice Abbott sees this issue more and more, citing the example of a client who has liver cancer but refuses to get treatment, partly due to poverty and addiction, but largely due to mental illness. The B.C. Schizophrenia Society, too, increasingly deals not with people's mental-health problems but with their chronic physical problems: tuberculosis, AIDS, hepatitis C.

Fraser Health, addressing this new challenge, started a pilot program to track certain metabolic indicators so health staff could rely on data rather than patients' self-assessment to see if someone is developing a health problem. It's a small move, but one that at least acknowledges the possibility that even psychiatric patients who seem to be functioning may not be good judges of their own health.

The Vancouver Coastal Health review of Williams's death, which the coroner had asked for, found that coordination mistakes had been made, but confirmed the basic philosophy that keeps people from being committed against their will. When Williams was discharged from Lions Gate after his involuntary 30 days that spring of 2009, his files were sent not to his family doctor but to another doctor. "It was a tragic mistake," says Dr. Lance Patrick, Coastal Health's North Shore medical director of mental health and addiction services. The review also concluded there needs to be a better management system for people with "complex" psychiatric conditions living on their own. "We need some kind of reminder system when patients don't go to follow-up."

Williams's case prompted a massive round of training at Coastal Health to educate staff about what power the Mental Health Act gives doctors to force people into treatment. But, says Patrick, there are

limits. "We can't use force to require them to attend medical appointments." And he sounded as reluctant as the psychiatrist Termansen to say that someone like Williams, who sounded lucid and appeared to be doing well, should be committed. "If he was starting to slur his words, if he was disoriented—some additional mental signs—then I think the staff could act. But it looked like he was functioning."

Dr. Bill MacEwan, a St. Paul's Hospital psychiatrist who works in the Downtown Eastside, disagrees. He argues forcefully that health-care workers misunderstand the powers of the act. People don't need to be dangling off the Second Narrows Bridge before they can be understood to be endangering their lives; the act allows

**Ben Williams, at his mother's home in West Van. "He didn't like people telling him what to do," says his partner, Carol Mathiesen**



those having persistent relapses or demonstrating that they are unable to take care of themselves to be committed.

Advocates say families often don't know there are other options: under the Health Care and Care Facility Act, doctors can choose a family member or other adult to act as a substitute decision maker if the patient is unable to understand their illness. Hospitals don't routinely share that information, which leaves families believing their only choices are to accept the doctor's decision on committal or go to court.

Herschel Hardin, the dogged leader of the North Shore Schizophrenia Society, is also critical of the Williams findings. "Focusing on the GP not getting the discharge summary the previous spring. Diverts attention to a side issue," he says (Williams had vociferously claimed he didn't have a serious heart condition, and

he'd been avoiding doctors.) "What is most disquieting are the reasons given by the psychiatrist himself for not certifying Ben," says Hardin. "He explained, as the coroner described it, that 'It would be inhumane to have Mr. Williams apprehended by police against his will.' That's just silly. The whole purpose of police intervention is to help people who are deteriorating but don't have insight into their own condition. The real inhumanity is leaving someone to die."

**W**hen Ben Williams's psychiatric troubles started, at age 16, his family was bewildered. His father, John, worked at the CBC as a design director; mother Paula took care of four lively kids. Ben ended up doing three stints at Riverview and another seven in the psychiatric ward of Lions Gate Hospital. In between: drinking, trouble with the law, working at Woodward's, a bout of life on the Downtown Eastside.

In his late 20s, he managed to claw his way back. He took olanzapine to stay on an even keel. He made friends at the group homes where he lived. (He met Carol when she was living at a group home nearby; her own mild schizophrenia had emerged in her late 20s.) He turned into someone who liked to cook and to draw. He and Carol went for long walks around the North Shore. They loved movies. *A Beautiful Mind* was one of her favourites: "Mental-health issues were brought out in a nice light."

When they met, Carol says, Ben was outgoing and had a lot of friends. Visions of red dogs plagued him, "But we helped each other." Over the years, she watched him withdraw. Once he went on olanzapine, he started gaining weight. In the last months, she tried to help but couldn't get Williams or any of his doctors to listen.

His death remains puzzling and sad. "The day he died, I was trying to call him," she remembers, in the small, crowded living room of her basement suite a few blocks from Williams's old place. "I tried to get him to the doctor so many times, but you couldn't push Ben."

"I miss him," she says, putting on "There You'll Be," the theme from the film *Pearl Harbor*. For a few minutes we sit and listen to Faith Hill. "I dedicated this song to him. It reminds me of Ben because he was my strength." ❖

Courtesy Carol Mathiesen