

leave staff gasping to cope with the demands. The average age of residents at admission is 80 and about 73 per cent have Alzheimer's or other dementia.

It can be overwhelming for front-line personal support workers just to meet the daily living needs of the majority of residents, leaving those more able to fend for themselves.

About 98 per cent of Ontario long-term care residents need help with toileting, 95 per cent with eating, 94 per cent with dressing and 88 per cent moving from bed to a wheelchair and back. Concern about lack of attention leads many families to rearrange their schedules to provide extra help, often at the cost of a job or family time.

A skeletal figure with sunken cheeks and large, animated eyes, Mr. LeLievre said he often had to change his own colostomy bag in the nursing home despite chronic back problems.

He continues to battle cancer and heart disease.

"When I needed help to change my colostomy bag, I'd say, 'Can I get some help to do that?' They'd say, 'With you in a minute.' Then it was, 'Oh, it's my smoke break.' Or it was, 'Oh, dinner hour, can't do it now.' I wind up changing it myself."

Ms Stipancic, the home administrator, said some residents choose to change their own colostomy bags.

For those who are physically and cognitively capable, "the staff will provide teaching in order for the residents to maintain their independence". Personal support workers assist those who need help with the procedure, she added.

#### REPUGNANT SIGHT

The sight of his fellow residents doing little other than sit in a TV room was repugnant to Mr. LeLievre.

"I couldn't stomach it," he said.

Victoria Gardens program manager Tracy Smoke makes efforts to keep residents active, although some are too sick to participate in a schedule of activities aimed at keeping residents busy and socially engaged.

And some elect not to participate, choosing to watch TV, read the newspaper or sit at the nurse's station watching people come and go.

"So, there are some residents who historically, they're not a people person, they never have been," Ms Smoke said. "So there are some people who have low levels of attendance, but it's by their choice."

Mr. LeLievre said the dead were neglected during his stay.

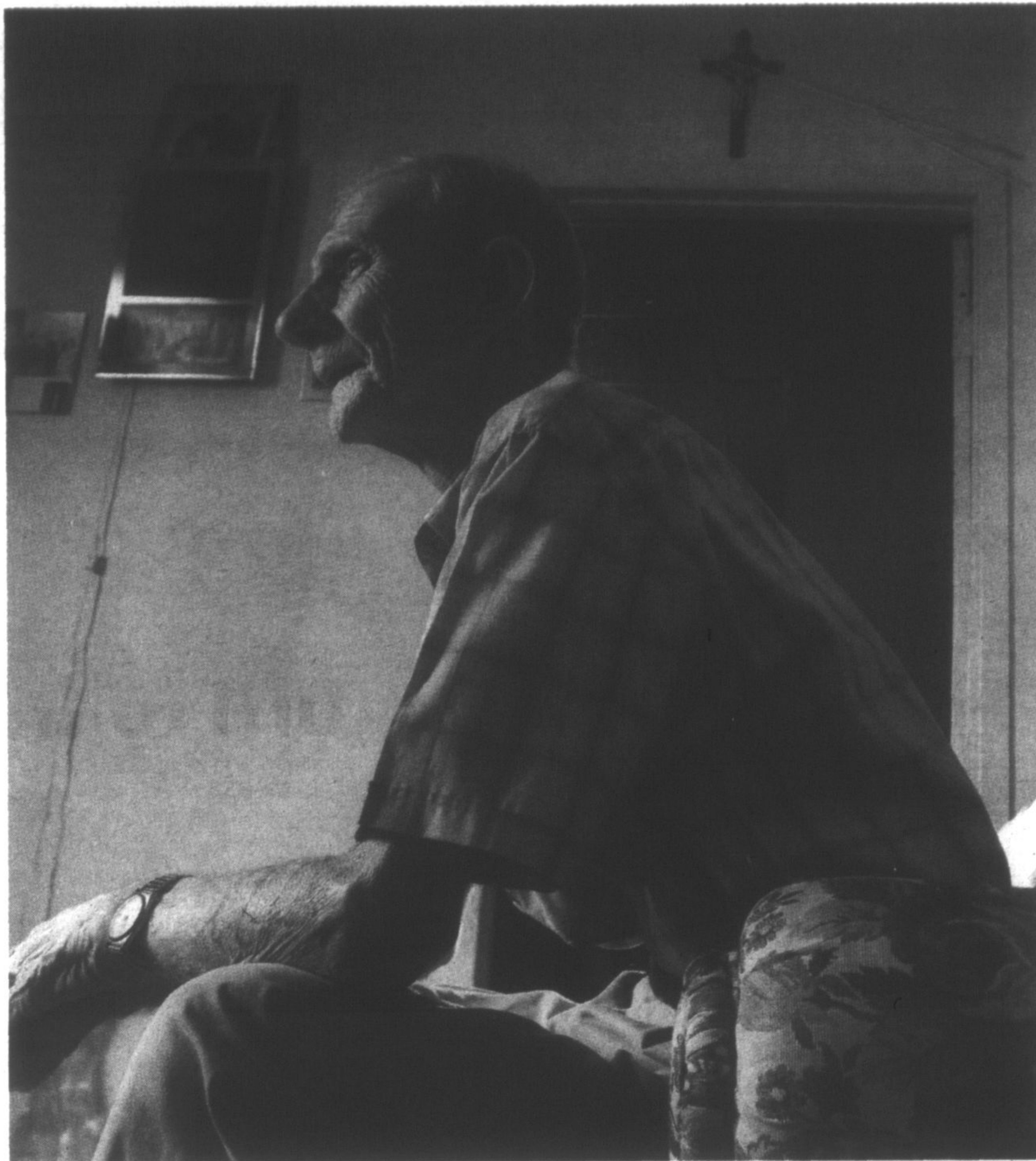
When a roommate passed away, the deceased man was left in his bed for hours.

"There's no courtesy there to pull the drape around him," he said. "He lay in that bed all night until maybe 11 o'clock in the morning ... That's not the only one I seen, I seen many of them go that way."

#### CORONER INVESTIGATION

Ms Stipancic said when a resident dies in a long-term care facility, a physician is notified to come to pronounce death. Every 10th death is investigated by a coroner.

"We can't move the body until either the physician or the coroner have been here," she explained,



METROLAND STAFF/SCOTT GARDNER

George LeLievre of Hamilton is an anomaly, one of only 11 per cent of residents who leave long-term care to return to the community. He tells a horror story about what he has seen in the seniors home in which he lived.

adding the body is always screened with privacy curtains as part of post-death care.

An end stage of the health care system, long-term care is generally acknowledged as the place where those who need 24-hour personal and medical assistance go to live out their last days. Despite the large number of people residing in homes, those who study long-term care say it remains largely an out-of-sight, out-of-mind sector.

"I think long-term care has been marginalized from mainstream health care," said Kevin Brazil, a professor in McMaster University's department of clinical epidemiology and biostatistics, an expert in long-term care and care of the dying. "It has been sort of bracketed and pushed aside."

Implicit ageism and a "sanitized culture" that distances itself from the realities of death and dying contribute to the marginalization, he added.

A Residents Bill of Rights (included in the Health Ministry's Long-Term Care Act) has long been in place to protect those living in long-term care settings and a new and expanded version of the bill, containing more than 25 rights, will be in place this summer. But those rights — the right to be properly clothed and groomed, to privacy, to

participate fully in care decisions, to engage in activities good for mind and body, and provision for family and residents' councils through which complaints can be made — are widely overlooked and often violated in homes across Ontario, advocates for the elderly say.

*A 2009 survey by the Ontario Health Quality Council found 60 per cent of families rated the care of their loved ones in nursing homes as good.*

Homes post the Bill of Rights for residents and families to see, but there is pervasive fear of repercussions for complaining.

"There are a few things about long-term care that are barriers to the enforcement of any standards or any rights," said Natalie Mehra, director, Ontario Health Coalition, "and one is that residents are afraid of repercussions for complaining, the same as their families."

First-hand accounts of the conditions and quality of nursing homes cover the exemplary as well as the questionable. A 2009 survey

by the Ontario Health Quality Council found 60 per cent of families rated the care of their loved ones in nursing homes as good.

Wendy Renault, whose mother, Janet, 86, lives in Willowgrove Long Term Care Residence in Ancaster (operated by Chartwell Seniors Housing REIT), is a representative case.

She said her mother trusts the workers, smiles at them, hugs them and holds their hands.

"I figure that's the best testament to the care she gets here," the daughter said.

Chartwell officials spoke of the absolute need for empathy and compassion in long-term care.

"Most of the people that work in this field are here because this is really what they want to do," said Linda Schertzberg, Willowgrove administrator. "You have to be a strong individual because we deal with death. They are here for eight hours a day with intense one-on-one with the people they are working with."

Administrators in long-term care homes plead lack of funding and staff as a root cause in cases when care is less than optimal.

The province is currently overseeing a review of funding, but there is no indication yet of what steps — if any — come next.

## ANOTHER ACCOUNT

Placing a small pen mark behind an ear, snipping a bit of hair at the nape of the neck, these were Grace Maltby's clandestine methods of testing a long-term care home's level of care for her father.

"Personal care was disgusting," said Ms Maltby, a retired nurse living in Cambridge.

Her father, John Hessels Sr., a Dutch war veteran who has advanced dementia, was a resident of King Nursing Home in Bolton before being moved to a facility closer to his daughter in Cambridge.

"It was a two-hour ride to go see my dad and I went up every third day," she said. "He was not washed, he was not shaved. He didn't even have a comb through his hair in those three days. His dentures, most times, had food caked on them, telling me they were not cleaned."

Ms Maltby said she set out a three-day wardrobe of clothes for her father to be changed into, but he was often wearing the same clothes when she returned.

Ministry of Health and Long-Term Care inspection records show King Nursing Home was placed under "enhanced monitoring" — the ministry's highest inspection level — as of Aug. 11, 2009.

According to the ministry, the home had 90 days to comply with regulations and reduce risk to residents.

If a home is unable to effect a turnaround to mitigate risk to residents, it is placed under enforcement status.

Feb. 19, 2010, King Nursing Home was placed under enforcement for 90 days, at which time it had to take immediate action to mitigate exposure of risk to residents.

A 2009 review of the home found 29 unmet criteria. The provincial average is 4.26. Eighteen of those unmet criteria were related to "cleanliness of resident's environment".

King Nursing Home administrator Janice King said those 18 violations of provincial standards of care were related more to physical-plant conditions than personal-hygiene care, things such as a dripping faucet, dust on a light cover, chipped paint or air temperature.

In principle, residents receive a bath or shower twice each week, she said in an e-mail correspondence. But in situations where a resident is physically aggressive, Ms King explained, staff is instructed to leave the resident and try again later.

Workers are often exposed to verbal and physical assault such as kicking, punching and scratching, she added.

But Maltby said her father is never violent.

"My dad is very quiet and docile — bothers no one," she said in an e-mail.

Ms King spoke of the mounting challenges associated with providing care to residents with increasingly complex medical conditions.