Families Allied to Influence Responsible Eldercare

Protecting the entitlement of elderly people in care to the same rights, freedoms, privileges and necessities of life as other citizens

Creating Protections for Better Lives Of Vulnerable Seniors in Care Today and in The Future

Presentation to the
Standing Policy Committee on Health and Community Living

June 17, 2003

by
Families Allied to Influence Responsible Eldercare (FAIRE)

Box 969 Cochrane, Alberta, T4C 1B1
Tel: (403) 932-5557
Email: bevmckay@telus.net

Presenters:
Bev McKay, Founder/President
Stan Henderson, Family Member

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Introduction

Families Allied to Influence Responsible Eldercare (FAIRE) was founded in 1998 by a small group of families in response to their loved ones' experiences of abuse, neglect and poor care in an Alberta nursing home and to their own feelings of helplessness and fear to speak out. It is in this context that FAIRE formalized to educate and support families and to work alongside them to protect their loved ones' fundamental rights and improve their quality of life and care.

FAIRE is very honoured to be recognized provincially and nationally for its contributions to the work being done across the country to raise public and government awareness to the mistreatment of frail older persons in publicly-funded care facilities and to press for a plan of government action to combat elder abuse in these settings. Examples of FAIRE's work include:

- November 2002: FAIRE was selected to give a presentation on institutional abuse and neglect of older persons at the Ontario Elder Abuse Conference co-sponsored by the Ontario Network For the Prevention of Elder Abuse and the Ontario Seniors' Secretariat.
- May 2002: Sponsored a public forum to launch our researched-based report, *The Shame of Canada's Nursing Homes,* which was distributed nationally. The report examines nursing home abuse and neglect from a national perspective. Our guest speaker was lawyer/researcher Charmaine Spencer, Gerontology Research Centre, Simon Fraser University. More than 125 people attended the event.
- March 2002: Launched our educational/informational website which was made possible by a donation from the South Calgary Rotary Club.
- 2002 and 2003: Received grants from Imperial Oil's Volunteer Involvement Program for the maintenance of our website which is being used as a resource by families, students, researchers, health care professionals and seniors' organizations
- 2001-2003: Gave presentations to seniors' organizations, inter-agency homecare workers, CARP Calgary Chapter, the Calgary Kiwanis Club, Kerby Centre and L'Arche staff, students enrolled in the University of Calgary Vulnerable Adults Education Program and the Victorian Order of Nurses Personal Careaide Program
- March 2001: Made a submission to the Romanow Commission
- 2000 – 2003: Gave media interviews to CBC Radio and Television, QR77, CKNW, A Channel, Calgary Herald, Edmonton Journal, Cochrane Times, Cochrane Eagle, Western Producer and Reader's Digest
- September 2000: Sponsored a public forum featuring Dr. Kenneth Rockwood, Professor of Geriatric Medicine, Dalhousie University
- March 2000: Co-sponsored a community consultation on the *Protection for Persons In Care Act*
- July 1999: Hosted guest speaker, Michael Kendrick who is known internationally for his advocacy and lectures and work in the areas of mental health, disability and ageing.
- June 1999: Initiated an analysis by the University of Calgary of the Health Facilities Review Committee routine investigation reports; conducted our own review of the inspection rate of Alberta's nursing homes
- From 1999: Continue to advise the Alberta government, its Ministers and MLAs of the issues facing seniors in care and the pressing need for remedial action (See Appendix A).

Background

Since late 1999, FAIRE has documented 189 anecdotal experiences of elderly residents, reported to us by concerned families and, increasingly, by concerned health care professionals. More than seventy-three percent (73%) of these anecdotes involve residents who suffered harm or were placed at risk of serious injury. Over nine percent (9%) relate to possible preventable deaths. Additionally, approximately 3000 abuse allegations have been reported under Alberta's *Protection For Persons In Care Act*. Of the 542 allegations reported in the Act's 2001/2002 fiscal year alone, more than fifty-seven percent (57%) potentially held some criminal law elements (Spencer C. 2002). While these numbers are alarming in themselves, research indicates incidents of abuse, neglect and crimes committed against nursing home residents are grossly under-reported.

In 2001, FAIRE conducted an extensive literature review to examine institutional abuse and neglect of older persons from a national perspective and the many factors that facilitate and permit this unconscionable social problem in our health care system. Our findings, published in a report called *The Shame of Canada's Nursing Homes,* suggest abuse and neglect is a widespread regular aspect of institutional life. They also show research is lagging in this area and provincial governments are slow – even reluctant - to acknowledge the existence of the problem and their part in creating it. For years, short-sighted government policies regarding our nursing homes have resulted in chronic underfunding, under-regulation, lax inspections, lax enforcement of standards and the lack of sanctions against facilities that cause residents harm or place them at serious risk. The report concludes that without the political will to effect change, the situation in our nursing homes will likely worsen.

Recent media reports on mistreatment and wrongful deaths of the elderly in nursing homes in Alberta and other provinces are awakening the general public to the realization that our nursing homes are not the safe havens they believed them to be. Indeed, people are now learning that our long-term care system is so seriously flawed and under-resourced that even the basic care requirements of many residents are not being met. As a result, more and more families are hiring private caregivers to help feed, dress, toilet, bathe, groom, change incontinent wear, walk and give mouth care to their loved ones. For those families who cannot afford to hire help, many are providing the care themselves, often on a daily basis and at considerable cost to their physical and emotional well-being. What the media are truly revealing to the general population is that provincial governments have no comprehensive strategy for dealing with the long-term care needs and vulnerability of nursing home citizens and our aging population or the criminal acts perpetrated against them. This oversight is significant considering there is an estimated one-quarter million seniors living in care institutions in this country and that Canada's population of people over 65 is expected to reach 5 million in less than a decade.

Proposals

We offer the following 5 proposals which we hope this Standing Policy Committee will consider and support. The first three proposals relate to Alberta Health & Wellness and the last two to Alberta Justice.

Legislative Standards

1) FAIRE proposes that the Alberta government take immediate steps to reform the Nursing Homes Act and Regulations so as to set out precise comprehensive standards. Specifically, we call for standards that: ◙ relate directly to residents' individual care needs and levels of acuity ◙ include a Residents' Bill of Rights ◙ specify the responsibilities of direct-care staff and the nursing and personal care services and supports to be provided ◙ set out best care practices ◙ specify minimum staff-to-resident ratios and the mandated training/education levels for nurses and aides (See Appendix C) ◙ require each nursing home to have a nurse practitioner on staff to provide assessment of and direct care to residents ◙ specify strict parameters around the use of chemical and physical restraints ◙ require facilities to develop abuse protocols, procedures and guiding principles and to routinely assess for, and address risk factors that contribute to the occurrence of abuse ◙ require nursing home owners/operators to give a resident and/or his or her substitute decision-maker, upon request, access to the resident's personal record, meaning all recorded information relating to that resident, for the purpose of reviewing the record or copying it at the person's expense ◙ require each facility to support the establishment of an Autonomous Family Council (See Appendix D)

Increasingly, families are reporting abuse, neglect and poor care of their loved ones, as well as marked differences in the level and quality of care from one facility to another and from one shift to another within the same facility**.** We believe these conditions are directly associated with the scant and vague standards set in Alberta's *Nursing Homes Act and Regulations* which have remained virtually unchanged for more than 17 years. These outdated pieces of legislation are failing to address the complex needs and illnesses of people currently in care - 68% of whom assess as requiring a high level of service and care (Alberta Health & Wellness Resident Classification 2001/2002). The impact of deficient standards in this province is clearly conveyed in the disturbing personal testimonies and photographs in this submission.

Inspections/Enforcement

2) We propose that the Alberta government dissolve the Health Facilities Review Committee and replace it with a body of independent, highly trained and qualified inspectors, including nurse practitioners, mandated to: ◙ conduct annual inspections of every nursing home based on standards set out in the reformed Nursing Homes Act and Regulations ◙ monitor for and enforce compliance of standards ◙ cite violations and take strong and swift enforcement action against nursing homes that violate health and safety standards or that cause residents harm or place them at risk of serious injury or death

Alberta's Health Facilities Review Committee, established in 1973, consists of two Members of the Alberta Legislative Assembly and ten citizens. It is not a requirement that members of the

HFRC have professional health credentials (Minister of Health & Wellness correspondence to FAIRE). The mandate of the Committee is to monitor and investigate the quality of care, treatment and standards of accommodation provided to patients and residents in health care facilities throughout Alberta (1998 Committee brochure). Astonishingly, however, the Committee is not mandated to investigate whether a facility is in contravention of the standards set out in the *Nursing Homes Act and Regulations*, nor is it mandated to enforce the standards or impose sanctions in relation to these pieces of legislation and, it cannot address general nursing practice issues as they pertain to the professional conduct or competency of nurses (Committee correspondence to FAIRE). This information from the Committee allows us to see that the health, safety and well-being of nursing home residents in this province are not, and have never been monitored or investigated to legislative standards or best care practices. At the same time, it allows us to understand why residents in this province are so vulnerable to neglect and poor care --- why no resident care issues are reported in Committee routine investigation reports, and --- why no sanctions have ever been levied against nursing homes for violating regulatory standards or jeopardizing residents' health, safety and very lives. While well-intentioned, we believe this Committee, "*constituted to provide the Minister and Albertans with an ordinary citizen's perspective of the quality of care being provide*" (Minister of Health & Wellness correspondence to FAIRE) is inadequate to the task of identifying, assessing and investigating the many issues impacting residents quality of care and quality of life.

Funding

3) We propose that the Alberta government provide funding that meets the individual needs and levels of acuity of citizens in Alberta's nursing homes, and that additional funding go directly toward higher wages and increased benefits for direct-care staff.

Chronic underfunding of Alberta's nursing homes seriously undermines the ability of owners/operators to deliver the level of care and protection that residents desperately need and so rightfully deserve. It also speaks to government policy that fails to recognize the relationship between low dollar allocations to the nursing home sector and the far-reaching negative effects, including:

a) The deterioration of residents' health, functioning and quality of life due to inadequate or non-existent rehabilitative/therapeutic/medical services and supports;
b) Low staff-to-resident ratios which result in heavy workloads, staff burnout and low staff morale which contribute to poor care and increase the potential for abuse and neglect;
c) The hiring of untrained unskilled personal care staff which is a key factor in resident injury and neglect which, in turn, results in costly hospital admissions;
d) Low staff wages which result in high staff turnover, an inadequate pool of available skilled staff, and the indiscriminate hiring of people who are inappropriate for this field of work.

Alberta's 2001/2002 expenditures for facility-based continuing care services totaled approximately $575 million (Health Authorities Audited Financial Statement) --- an increase of about $120 million since 1996/1997. Despite these increased funds, the critical staffing issues noted above remain unaddressed.

Canadian Criminal Code

4. We propose that Alberta Justice be diligent in enforcing the following sections of the Canada Criminal Code (Part VIII) with respect to crimes committed against citizens living in nursing homes and other care settings in Alberta.

- Duty of persons to provide the necessaries of life: S 215 (1)(c)(i)(ii); 215(2)
- Duty of persons undertaking acts dangerous to life: S 216
- Duty of persons undertaking acts: S 217
- Criminal negligence: S 219
- Causing death by criminal negligence: S 220
- Causing bodily harm by criminal negligence: S 221
- Homicide: S 222
- Death that might have been prevented: S 224
- Death from treatment of injury: S 225

In 1986, Criminologist Birthe Jorgensen published a research paper, *Crimes Against the Elderly In Institutional Care.* The paper is based on Dr. Jorgensen's analysis of complaints about treatment of residents in nursing care facilities brought to the attention of Concerned Friends of Ontario Citizens in Care Facilities. Her findings revealed that approximately 46 percent of 56 detailed complaints received held sufficient grounds for the laying of criminal charges of theft, assault or breach of the legal duty to provide the necessaries of life or proper medical care established by certain sections of the Canadian Criminal Code. Although Dr. Jorgensen acknowledged there are obstacles to criminal prosecutions, including the vulnerability of elderly victims to retaliation and the unfamiliarity of much of the general public, including the police and crown prosecutors, she nevertheless concludes that such prosecutions can and should be initiated. FAIRE strongly supports this view.

Vulnerable Adults Protection Commission

5. FAIRE proposes that the Alberta government dissolve the Protection for Persons in Care Act and create an Act that establishes a Vulnerable Adults Protection Commission to operate as an independent agency under Alberta Justice. This Commission would comprise experts in the fields of medicine, gerontology, criminology, law enforcement, rehabilitation, mental health and forensic pathology mandated to identify and investigate incidents of abuse, neglect and wrongful deaths of vulnerable adults in publicly-funded care settings in Alberta with the aim of affording victims protection, treatment, continuity of care and equal access to the criminal justice system. The commission would also routinely assess for, and address systemic factors that may contribute or lead to abuse, neglect and wrongful deaths.

Alberta's *Protection for Persons In Care Act,* enforced in 1998*,* is currently undergoing a five year review. This law, while well-intentioned, has been strongly criticized in the community on several different grounds, including its failure to ensure alleged victims protection and access to the criminal justice system. Indeed, as government statistics show, only 5.1% of the 542 cases in 2001/2002 were referred to the police yet, as previously stated, over 57% potentially held some criminal law elements (Spencer C.) Spencer explains that while, "*the specific actions in*

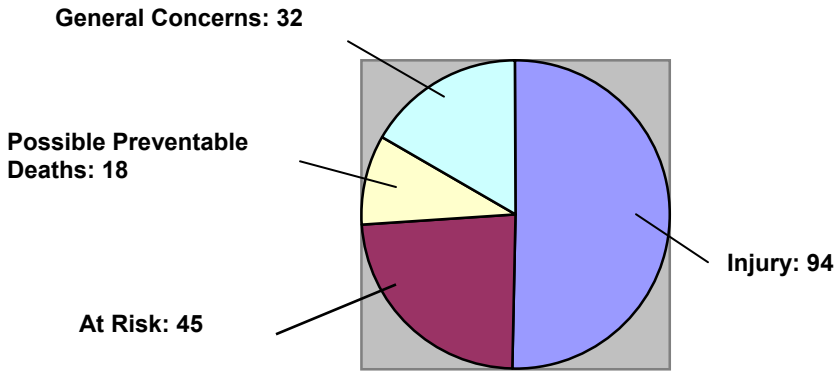
the cases might not reach the level of criminal intent, or serious harm to warrant a criminal charge … often those determinations are being made by consultants doing the investigation, not the police." Furthermore, government policy in this province allows Regional Health Authorities to make similar determinations based on their own investigations of potential crimes in care facilities (e.g. March 2002 Calgary Health Region investigation into the alleged sexual abuse of an 88-year-old stroke patient of a Calgary hospital; December 2002 Capital Health Authority investigation into the preventable death of a paralyzed 72-year-old respirator-dependent resident of an Edmonton nursing home). The victimizations of the sort described in these two cases and in the majority of PPIC allegations are similar to those examined in Dr. Jorgensen's 1986 report mentioned above. In the final analysis, Jorgensen concludes, "*Criminal prosecutions probably will be more likely to effect positive changes in conditions in nursing homes than the current enforcement mechanisms of the Ministry of Health*." Today, a growing number of prosecutors, coroners, medical examiners and law enforcement officers in the United States are expressing this same view and are working collaboratively to pursue some form of justice for nursing home victims (Special Report 2002: St. Louis Post-Dispatch).

Conclusion

FAIRE views this submission as important for several reasons. First, it provides an opportunity for concerned families to be heard at the government level, and for this government to learn what nursing home life is like for increasing numbers of our most vulnerable citizens in care. Secondly, it speaks to the need for government and policy makers to involve knowledgeable families and other informed stakeholders in policy-decisions that affect the lives of long-term care residents. Moreover, it enables our elected officials and the general public to realize that nursing home citizens in this province have been left seriously vulnerable by deficient regulation, inspection, investigation and funding. At the same time, it offers solutions for bringing about changes that would make a difference in the lives of people who live and work in care facilities. Finally, it calls for a political response that commits to ensuring nursing home residents the best possible quality of care and quality of life.

We believe our proposals are consistent with the vision of this government – providing effective protection and quality care to our frail elderly while honouring their right to a secure environment and equal access to the criminal justice system. We look forward to the opportunity to work collaboratively with government and to be part of an expert advisory committee which we suggest be established to address this pressing issue.

Summary of Anecdotes
Recorded in FAIRE's Confidential Database



Total Anecdotes Recorded: 189

Examples of residents' experiences that resulted in injury, illness, trauma and health decline

- Physical and sexual assault
- Life-threatening pressure sores associated with infrequent or no repositioning
- Undetected/untreated urinary tract infection, pain, fractures, pneumonia, sepsis, malnutrition and dehydration
- Life-threatening bowel obstruction caused by fecal impaction associated with inadequate fluid and poor nutrition
- Drug-induced toxicity, falls causing fractures and bruising, neurological disorders, swallowing difficulties, coma and loss of functioning
- Muscle contraction and atrophy attributed to the use of physical restraints and/or inadequate or no exercise or physiotherapy
- Mouth thrush, gum disease and full-tooth extraction caused by inadequate or no mouth care
- Unskilled/inappropriate handling of mechanical lifts and wheelchairs resulting in residents suffering serious injury
- Residents requiring toileting assistance are being put in diapers and told to use them – and, to their humiliation , they do.

Examples of residents being placed at risk of injury, illness, abuse or death

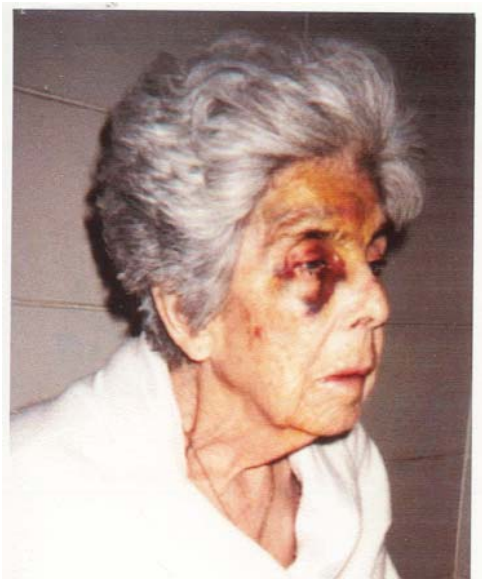
- Units are left unsupervised; call bells for assistance go unanswered; staff are unaware of fire drill procedures
- Residents are left in their waste for hours at a time
- Colostomies rupture and catheter tubes plug due to inadequate monitoring
- Residents are not given adequate assistance or time to finish their meals; meals are taken away untouched
- Residents suffer weight loss and health decline due to inadequate food intake, undetected swallowing difficulties or medical condition
- Residents suffer adverse drug reactions due to being administered wrong or multiple medications; nurses dispense medication but do not ensure residents take it; medication carts are left unlocked and unsupervised
- Residents are hospitalized in diabetic coma caused by inadequate monitoring of blood sugar levels
- Residents wander out of the facility unnoticed and are found lost and injured in the community
- Ambulatory residents are restrained in wheelchairs or are tied down in their beds
- Residents' oxygen tanks run empty or are not turned on
- Residents are made to stay in their beds for hours and even days at a time.

Examples of premature deaths

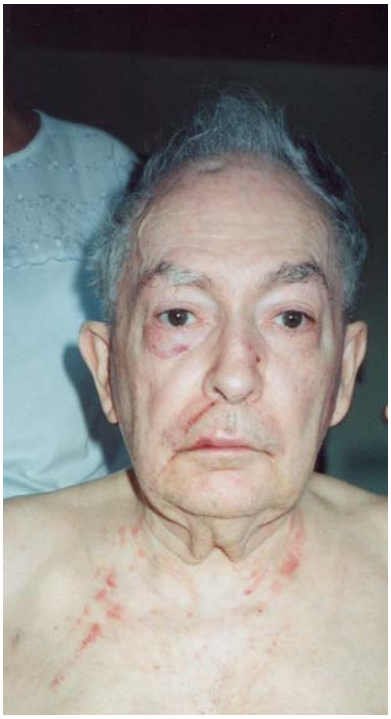
- A paralyzed respirator-dependent resident died when staff failed to respond to alarm monitors indicating the respirator had failed
- A resident wandered unnoticed out of the nursing home and was later found dead in a nearby field.
- A resident died of asphyxiation after becoming trapped between her mattress and a support pole.
- A resident died after being dropped from a mechanical lift.
- A resident died after being hurled out of her wheelchair when it rolled down an indoor ramp and impacted a wall.
- A resident fell, his head hitting the floor. Two unassessed falls followed. The resident subsequently died.
- A resident died after failing to receive treatment for a gangrenous foot.
- Two residents died after failing to receive treatment for 1) a reported gastrointestinal bleed 2) reported symptoms of pneumonia.
- A resident died from 3rd degree burns caused when his clothes caught fire in a smoking incident
- A resident was left unattended in the bathroom. He fell to the floor and suffered a broken hip. He died within 10 days of the incident.

A Portrayal of Abuse, Neglect and Poor Care of Vulnerable Seniors In Alberta's Nursing Homes

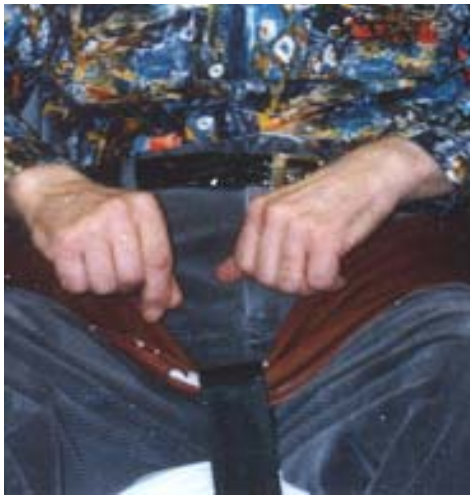
The following photographs portray some of the tragic nursing home experiences of Alberta's elderly citizens identified in the previous summary and following testimonies.



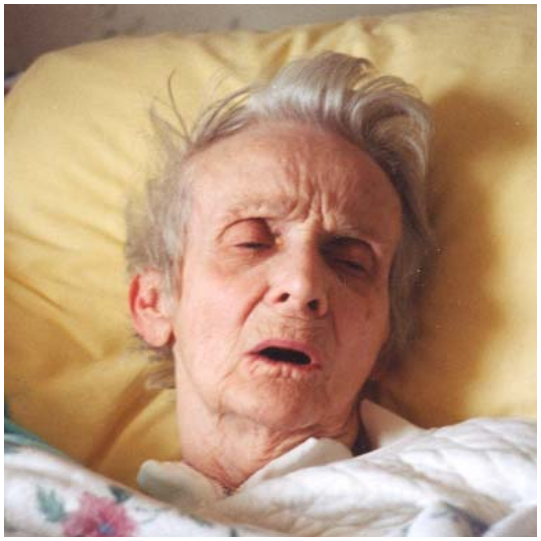
The overuse of antipsychotic drugs on this woman with dementia caused heavy sedation, resulting in falls that led to these injuries and a broken hip.



The injuries of this gentleman with dementia were the result of a beating by his roommate who suffered the same illness. There was no staff supervision on the Unit at the time of the attack.

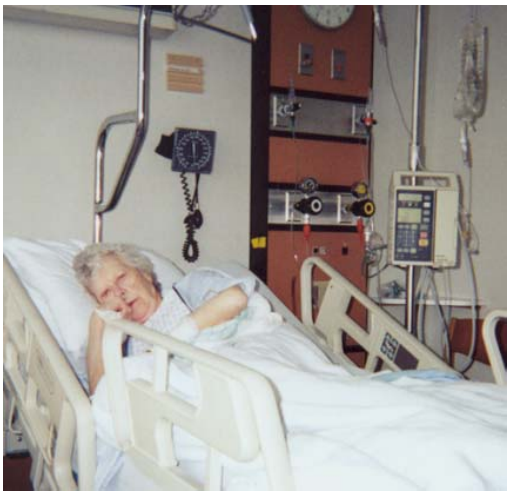


This gentleman with dementia suffered the trauma and indignity of being routinely confined to a wheelchair under a three-way restraint.



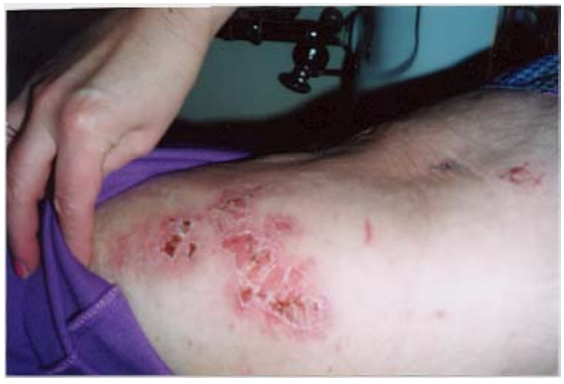
This woman with dementia suffered prolonged untreated pain due to staff's failure to detect her obvious symptoms.

A Portrayal of Abuse, Neglect and Poor Care of Vulnerable Seniors In Alberta's Nursing Homes … continued

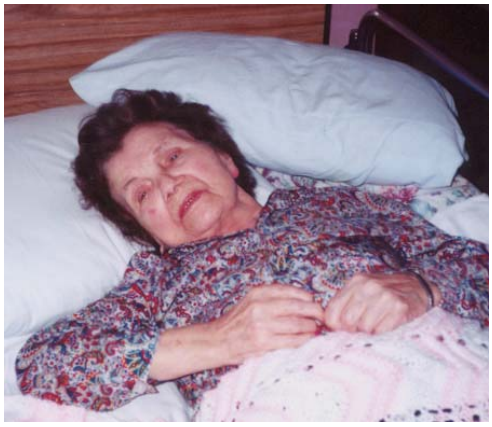


When the nursing home failed to address this woman's declining health, the family took her to the hospital. Lab results confirmed malnourishment, severe dehydration and pneumonia.

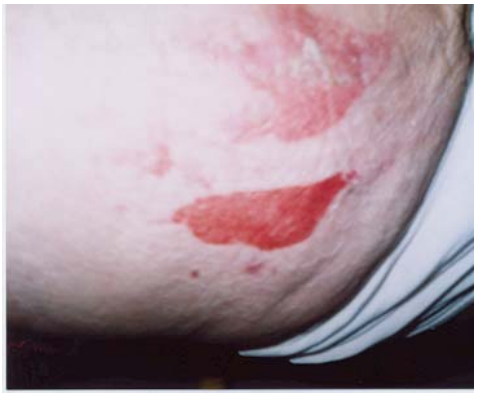
This woman's protruding tongue is a symptom of an irreversible neurological disorder caused by the overuse of antipsychotic drugs.



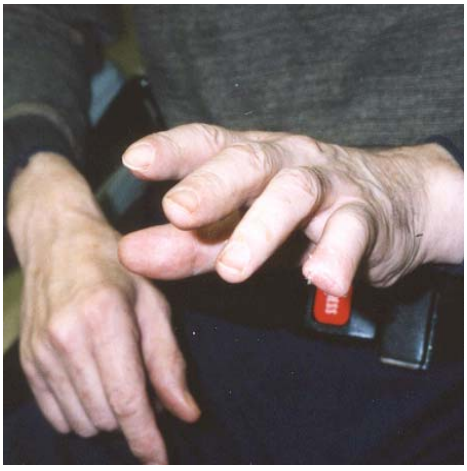
When the nursing home failed to treat this woman's skin condition, the family took her to a specialist who diagnosed staph infection.



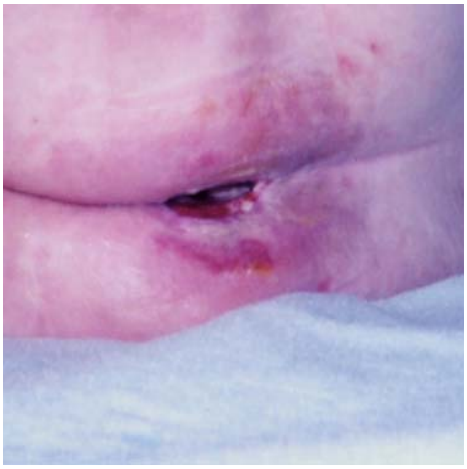
This woman was diagnosed as suffering from dehydration due to inadequate fluids



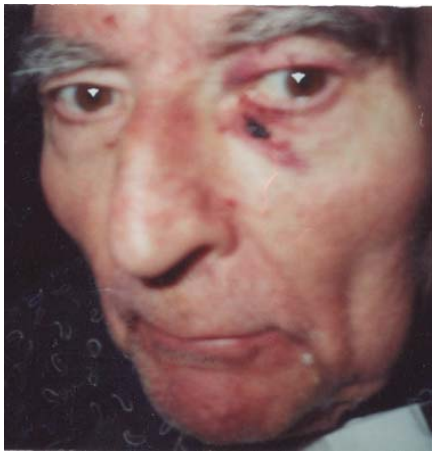
These injuries of unconfirmed cause were discovered by the family.



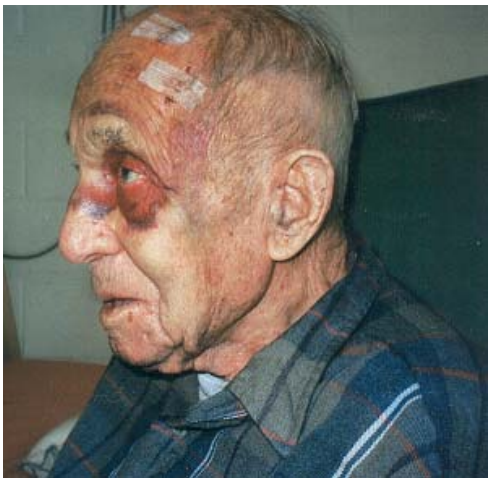
While trying to maneuver this man out of a room, staff inadvertently shut the door on his hand, severing the fingertip.



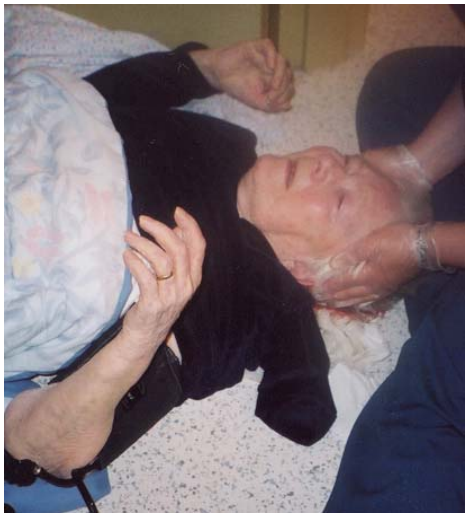
A pressure sore open to the spine and surrounded by dying skin tissue



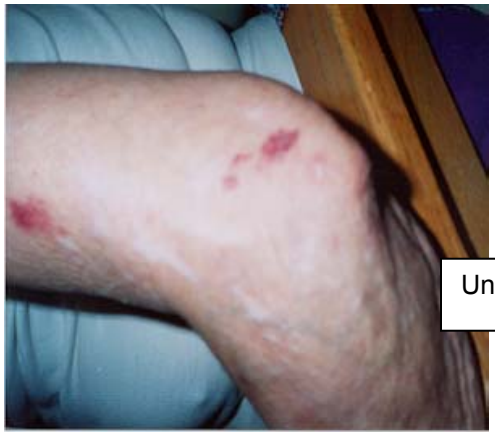
This gentleman's injuries are believed by the family to be the result of a physical attack by his roommate – but claimed as self-inflicted by a government investigator.



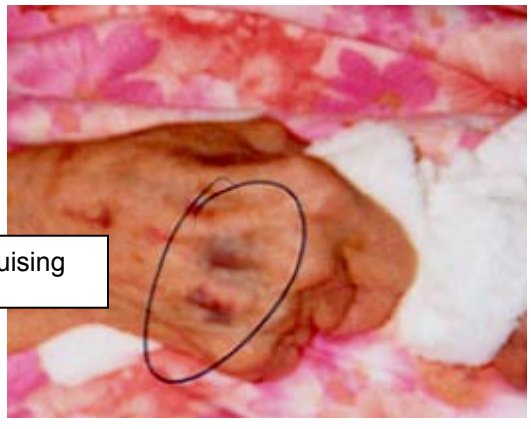
The overuse of major tranquilizers caused this gentleman several falls resulting in a broken nose and heavy bruising and cuts to his face and hands. Staph infection in the cuts went untreated until the family intervened.

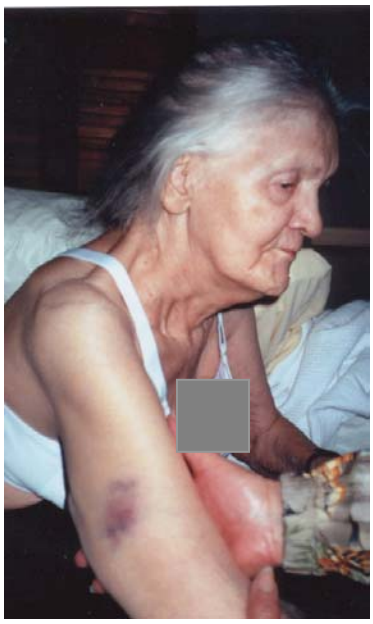


Unskilled handling of a mechanical lift resulted in this woman falling to the floor, causing a severe head concussion.

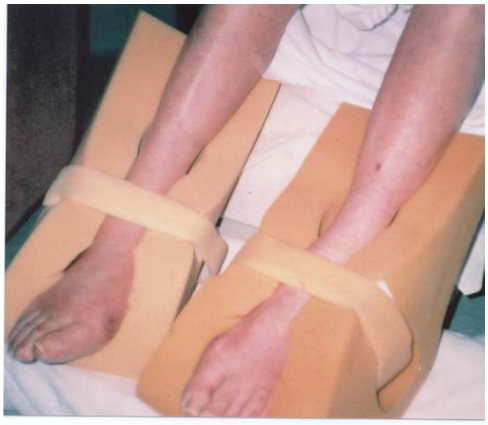


Unexplained bruising

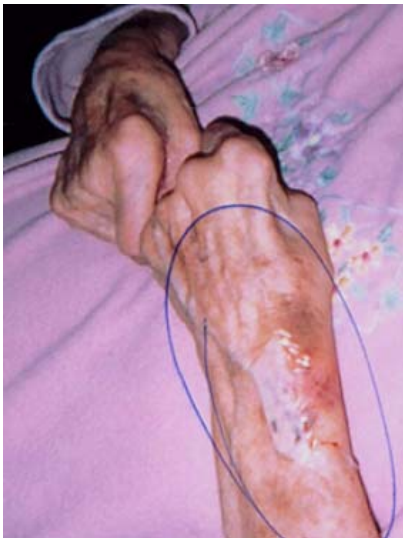




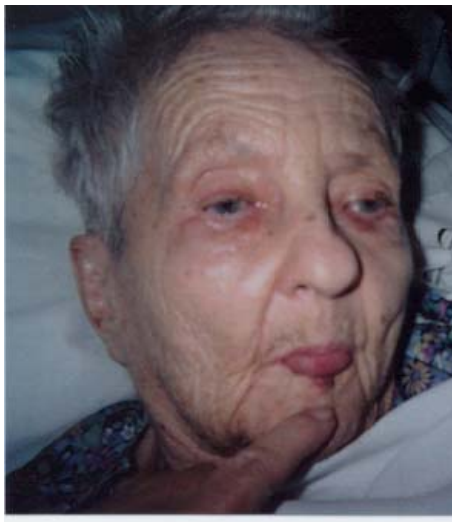
The details of the alleged assault of this woman by her roommate's son and the results of a government investigation into the incident were never revealed to her family. However, the family suspects the heavy bruising on their mother's arm and the injury to her right toe (opposite) were inflicted by the alleged abuser.



This same woman suffered blisters and bruising on the bottoms of her feet caused by staff allowing her feet to drag along the floor as they pushed her wheelchair rather than supporting them on the footrests.



Unexplained bruising and broken skin

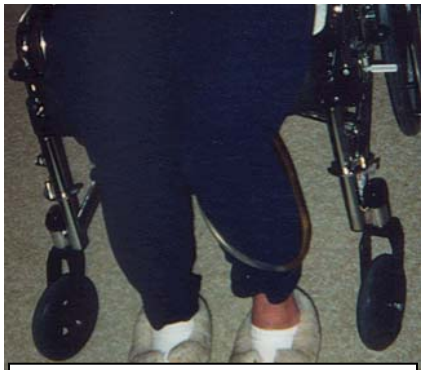


Unexplained bruising below left eye and lower lip

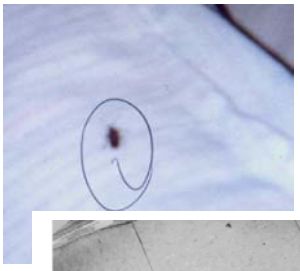
A Portrayal of Abuse, Neglect and Poor Care of Vulnerable Seniors In Alberta's Nursing Homes … continued

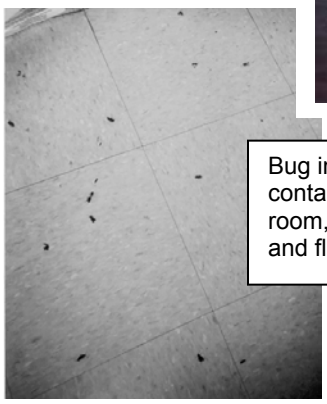
In a letter to this woman's son, the facility administrator assures "*we will endeavour to meet the comprehensive needs of (your mother) in a quality and caring fashion*." These words fly in the face of the mother's true experiences as shown below.

Suffering the indignity of being left exposed

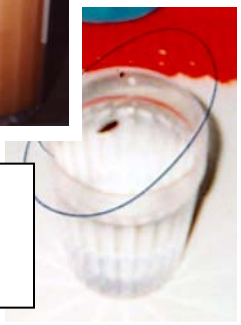


Bad nursing practice demonstrated by the hazardous position of catheter tube



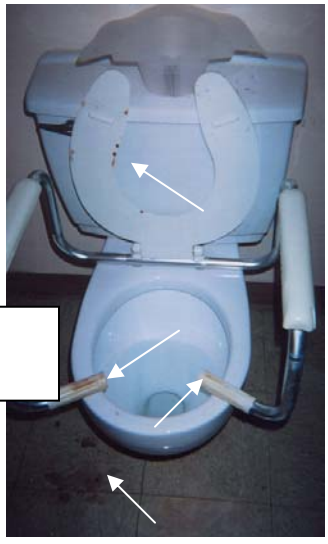


Bug infestation contaminates her room, bed linens and fluids



Left shamefully exposed with catheter tube wound beneath her

Feces contaminates her personal space.



Personal Testimonies of Families

A Daughter's Testimony

My father, Frank Gardner, suffered from dementia. He entered a nursing home in Calgary in January 1997and lived there until his death, in April 1999 at age 74.

My Dad was abused while in care.
Put on the antipsychotic drug Haldol, when he wasn't psychotic. It is a "chemical restraint". It quickly made him immobile, in a wheelchair, drooling and nonverbal. Unexplained bruises were observed by us. While sleeping, Dad was beaten up by his roommate, who also had dementia.

My Dad was neglected while in care.
His hygiene was very poor. One shower per week. Urine soaked. Unsupervised, he ate soap and had an allergic reaction. Unable to feed himself, he wasn't fed well by staff, and Mom had to go at least once a day, to feed Dad one good meal. Not taken to recreational activities, because he wandered. Falls that nobody saw. Because he was nonverbal, the staff didn't talk to Dad.

Why was my Dad's care in the nursing home so bad? Why were the last years of his life so miserable? Why was there no respect for his humanity? Why did Dad work so hard for his country and city, and receive so little when he most needed care?

Why doesn't our government address this terrible state in our province's nursing homes, and change things to make them better?

Thank you for listening, but I hope that you will really hear, and then do what is right.

A Wife's Testimony

Recently, while spending time in a waiting room, I picked up a Reader's Digest containing an article on nursing homes, called *Canada's Hidden Crimes.* It brought back the horror of my husband's experience of care and death in an Alberta long-term care facility.

It is five years since my husband died and I continue to feel rage and guilt. Rage at our Health Care System and guilt that I did not know how to fight effectively for his welfare.

My husband had Alzheimer's but apart from that he was a healthy man. Two weeks after admission to a Calgary hospital in August of 1996 he could not feed himself, he could not stand or walk. He was secured in a chair. He engaged in uncontrolled pounding on the tray. The drug was Haldol, administered to keep him from wandering - a drug banned in the U.S. and, according to drug books not recommended for the elderly or those with a history of depression. My husband was 83 with life-long depression.

He was transferred to a Continuing Care Centre and taken off the drug. There he experienced gentle concerned care. They worked hard at helping him to walk and slowly he recovered. Finally he could walk with me and carry on a conversation. A book of his poetry had been published recently and he was able to enjoy it with his friends.

Just before Christmas he was transferred to another facility. Initially, I was pleased with the bright atmosphere so necessary for a person with depression. The staff wanted to know everything about him and an assessment meeting was held to share the information for effective care. At this meeting my statement was loud and clear that no change in medication should be made without consultation with me. I understood there was agreement. What a cruel farce. They paid no attention. There was no continuity of care. Twelve hour shifts for three days and off for three days and then an assignment elsewhere. For most of the staff it was just a job. My husband's lifelong apprehension of strangers put him in a fear situation. When I objected to this parade, the response was, "Oh our patients get used to us all in the course of time." WE ARE TALKING ABOUT ALZHEIMER PATIENTS HERE! From one day to the next I never knew who was responsible for his care ... and I was there five days a week.

When he responded in his fear he was termed violent. He did not strike out at me or his friends or relatives including two young children.

Soon he was walking with tiny steps which I recognized as a forerunner of the Haldol treatment. When I challenged the staff about his drug situation they denied any change. When I persisted they admitted the doctor who had prescribed a new drug. My strong impression was that THIS WAS THE WAY IT WAS GOING TO BE! I was pacified with assurance that it was mild and a low dose. In no time he was once again in the same state that Haldol had produced.

Now, this recently healthy man looked like a victim of a concentration camp. His skin hung on his bones. And in this weakened emaciated state he picked up a hospital infection and died. This was accomplished in the short time between mid-December and the end of February.

I have some questions!

1. What deficiencies within Alberta's health care system are responsible for the persistent use of potentially dangerous antipsychotic drugs when humane non-pharmacological alternatives are being practiced elsewhere?
2. In my opinion, failing to withdraw a patient from antipsychotic drugs when he or she presents with adverse drug reactions and deteriorating health, constitutes abuse and unethical practice. When treatment proves not in the best interests of the patient, what allows medical professionals to continue to inflict harm, or worse, to hasten death through bad practice?
3. Medical professionals treated my mentally incompetent husband without my informed consent. More to the point, they ignored and overrode my decisions regarding his treatment. According to the law, these practices constitute unlawful behaviour. What allows medical professionals immunity from the law?

A Daughter's and Grandson's Testimony

Our frail 85-year-old beloved mother /grandmother entered Alberta's long-term care system at the age of 85. She suffered severe osteoporosis, violent headaches resulting from two unsuccessful eye surgeries and short-term memory loss caused by a stroke. At this most vulnerable and needy time in her life, our loved one found herself caught in a so-called "care" system that caused her intolerable suffering and harm, robbed her of every dignity, and violated her fundamental human rights.

<u>In Alberta's long term care system, the mother/grandmother whom we dearly love was</u>…

- Physically assaulted by her roommate's son
- Subjected to multiple psychotropic drugs which took a terrible toll on her health
- Deprived of her ability to walk by being restrained in a wheelchair; she was given no exercise or physiotherapy
- Put in a small dark room because she called out for help; we often found her there soaked in urine and sitting in feces; her diapers had no fasteners
- Often left without the use of her dentures, either because they weren't put in or were lost; during these times she was given a regular diet making it impossible for her to chew her food; to our knowledge, no assessment was done to determine food appropriateness or adequacy of food intake
- Bruised on the bottoms of her feet … the bruising and blisters on the soles of her feet were caused by staff allowing her feet to drag along the floor as they pushed her wheelchair, rather than supporting them on the footrests.
- Made to suffer the indignity and trauma of being hoisted naked in a mechanical lift up under the cold air vents in the ceiling; When we walked in and found her in this awful state, staff said they were cleaning her and told us to leave.
- Found by hospital staff to be suffering a pressure sore at the base of her spine; to our knowledge no wound care was previously given by the nursing home
- Deprived of the right – at our request - to be moved to a more compassionate competent care setting

When our loved one died, we told her story to the CEO of the Regional Health Authority and showed our photographs of the unconscionable harm caused to her. The CEO agreed our loved one suffered an intolerable experience and promised to check into the situation and report back to us. The CEO failed to keep his promise – nothing was done. Our experience suggests there is no accountability in this system – that there is no will among the powers-that-be to take responsible parties to task – that elderly people like our loved one can suffer miserably at the hands of health care professionals and no one of authority cares enough to right the wrongs. The question we ask this government is: "What are you prepared to do to stop the needless harm and suffering in our nursing homes?"

A Son's Testimony

My experience with my mother, so far has been fairly positive. On the other hand, I have observed several incidences where a resident has been allowed to stay long in wet incontinent wear. Also individuals are not properly washed and then develop a rash and other times worse complications like urinary tract infection. Sometimes medication is not administered properly because staff is switched and they are inadequately instructed and with no clear direction they become frustrated and inattentive to a sense of urgency and following procedures. In cases where oxygen is required, the resident often will be without oxygen for hours due to lack of adequate staff or sense of urgency and necessity. The ultimate question for government officials, nursing home owners and workers is, "If it were you, right now, would you appreciate this kind of care?"

The resignation on the part of the family is ' what can we do about it?' I feel that adequate standards are missing or not implemented consistently as deriguer.

My question to this government is: Are you committed to help the elderly in nursing homes have a quality of life they deserve and have a right to?

Sincerely,
Rocco Angelozzi

A Daughter's Testimony

Two words that sum up me experiences with Long Term Care Facilities in the past six (6) years are UNSATISFACTORY AND SCAREY.

1) OVERWORKED STAFF

   Nursing Aides had 70 residents to care for with 4 or 5 staff on evening shift. Half of these residents were wheelchair reliant, perhaps 8-10 were complete bed care with feeding etc., 10 relied on a walker and the remainder were mobile. If it was flu season or someone returned from hospital, the number of caregivers did not change.

2) MINIMAL TRAINING REQUIREMENT FOR CARE WORKERS
   Some new staff would ask my mother (97 yrs) how to operate the mechanical lift. One staff member dropped her in the bath tub by neglecting to place her seat belt on when she was on the tub lift. There are too many falls that take up too much Emergency Room time to say nothing of the stress to the residents. My mother fell and spent 24 hours in the ER and another 7 days on a busy Surgery Unit to discover that the fracture in her hip was an old one!!!!!! Isn't that a surprise. Many many letters were written at that time with very pat answers.

3) VALUE OF OUR ELDERLY – STANDARDS AND ABUSE
   There is a very thin line between abuse and poor care. One young hard working caregiver told me about her first day on the job at another facility in Calgary. She did not return after day 1 because of the poor treatment of the elderly there by the staff. She did not complain to management because according too many of these workers, "it falls on deaf ears."

The 2 latest studies on the Healthcare System have echoed my sentiments. They totally ignored the elderly in our Long Term Care System.

A Daughter's Testimony

My Mother is an 88 year old stroke victim who has been in nursing home care and unable to walk since 1997. Many disturbing occurrences in her life have us questioning the 'Alberta Advantage', however this one was life threatening.

On April 18, 2002, the day before Mom's 88th birthday, a telephone call about 8:30 in the morning alerted me to the fact that an accident had happened to my Mother. My Mother had suffered two falls recently (March 20 and April 1) therefore I rushed to her residence to see for myself what had happened. I arrived within 10 minutes of the call and made sure, this time, to take a camera with me. As the photos show, Mom was laying on the floor, her head being stabilized by a staff person. Mom lay on the floor until 10:30 when paramedics arrived to transport her to emergency for treatment.

To date, no administrative explanation or apology has been given to our family.

HOWEVER -- Attendant and care-giving staff (including the senior care-giver at the occurrence) have told me that Mom was in the sole care of an inexperienced new staff person. This person, by herself, was attempting to move my Mother in the lift while the senior staff person was attending to the needs of another resident. My Mother slid out of the lift and fell fully backwards with such force that her head required staples to close the bleeding wound.

My Mother's safety was placed at risk because of this decision and this action.

Further --

My Mother suffered a severe concussion that has left her more noticeably confused and frustrated. She becomes extremely emotional and weepy. She has a difficult time trusting any caregiver unless she sees them and can relate to them consistently. She reacts with extreme fear whenever she sees a lift, and we have instructed staff that a lift should not be used with her. She lost about 20 pounds (she now weighs about 115 pounds) in a very short time, and we discovered that she could not even feed herself because of weakness - thus necessitating hiring of feeders when family cannot attend to ensure that adequate nutrition is a daily guarantee.

A Wife's Testimony

EVENTS CONCERNING MY HUSBAND'S CARE

In care since January, 2001

(1) Dehydration.

(2) Gland infection due to lack of oral hygiene.

These two problems led to 3 weeks hospitalization with several days when he was semi-conscious.

(3) Physical attack – . Injuries to face. Refusal of senior staff to report this to PPIC. I reported the incident and an investigator was appointed to the case. Photographs were taken as evidence, although the investigator would not take a copy of the photos with her. The final report from PPIC stated that there was a lack of evidence.

(4) Physiotherapist cancelled walking program over 1 year ago. After 14 months he is still walking with me, assisted by the Director of Care at the facility.

(5) After allegations of his being aggressive I was requested to give permission for him to be given Risperdal, an anti-psychotic drug. I disagreed, and said that I would not agree to any medication being given until the RN investigated the reason for the so called "aggression". This was done, and malfunctioning equipment was found to be the main cause of the problem. Arrangements were made for this equipment to be avoided. Staff had no further wish to administer Risperdal.

More staff would obviously eliminate some of the problems, but also determination by senior staff to investigate and resolve difficulties before using drugs could bring a quicker and better result.

There are so many residents who have no one to speak for them, so I feel it is also essential that there should be inspections carried out at facilities, without previous notice being given.

A Daughter's Testimony - Tina's Story

In August 1995, my mother was placed into a long-term care facility. They immediately changed all her medications, and began to administer Prozac to calm her. In January 1996 she suffered a bleeding ulcer and was found on the floor. The blood loss and transfusion caused a stroke that paralyzed her.

Her health & quality of life after the stroke deteriorated - any concerns that I voiced were dismissed or ignored. She received more medications and less care. A senior nurse once told me that these old fogies are only here waiting to die anyway.

Mom was near death and rushed into the hospital two more times over 2 years, the last time in a diabetic coma with blood sugar levels over 80 and infected bed sores.

What gives the right to these care facilities to drug their residents needlessly? I was often told it was because they were understaffed and the drugging made it easier for the staff. Our health care system pays for the unnecessary, over-medication of seniors in care facilities when this money could go toward hiring quality staff and better policing of these facilities to ensure the proper care of the residents. Where is the care, respect and dignity our elderly deserve – have they not earned it?

Thank you.

A Daughter's Testimony

My Father Arnold Kauppila passed away Nov 9th 2001. I, with the help of my husband and daughters, looked after my father for the last ten years. My father had Alzheimer's. In the last ten years my experiences with hospitals and nursing homes have been horrifying. The first nursing home was Glenmore where my father packed his bags and paid some guy on the street $5.00 to drive him from Glenmore Trail to Forest Lawn. Thank God he wasn't found in a ditch somewhere. Over an hour later when the nursing home was contacted, we were told he was down the hall playing cards. They had no idea he was gone! He packed his suitcases and left. Some years later, I mistakenly entrusted the care of my father to the system again at Forest Grove where I got three phone calls a day. They had no idea of how to work with an Alzheimer's patient. They withheld vital pain medication which, to me, was cruel, and tried to chemically restrain him with Risperdal. Medication was not written down and blood tests weren't given when they were supposed to. I constantly had to argue with Forest Grove. It was more stressful and dangerous to have him in this nursing home than to have him at home. After thirty days and a hospital stay, I brought him back home. I am still arguing with Forest Grove because they are trying to over- charge us. Seniors have built this country and deserve to be looked after and safe. It's our obligation to make this happen. If it was not for them, Canada would not be what it is today and we owe it to them. Someday we may be seniors too.

Sherry Lester

A Daughter's Testimony

ABUSE OF MY ELDERLY MOTHER

My Mother was a resident in a Calgary nursing home. In one year she had sixteen falls resulting in cuts, bruises, a possible broken rib and, on one occasion, was too hurt to walk. She was never x-rayed, and a doctor examined her for these injuries only twice.

Mom told us that she had been beaten by a staff member. Her nurse was later fired after being observed knocking an elderly resident to the floor. I saw a nurse grab Mom's face and yell at her.

When Mom developed raw, painful sores on her back and my requests for a physician assessment were ignored, I took her to a dermatologist who diagnosed an untreated staph infection.

On another occasion, a rapid decline in Mom's health was minimized by nursing staff as the flu, when in fact she was suffering life-threatening dehydration due to a lack of fluids, as diagnosed by her physician.

She sometimes was not fed, and she was often soaked in urine.

Mom passed away from pneumonia after her blatant symptoms of lung congestion and depleted oxygen levels were deemed by nurses to be only the sniffles. When I challenged their observations, I was admonished for being over-protective.

I have concluded that despite my heroic efforts, I could not protect my Mother from the inadequacies of this facility.

A Daughter-in-law's Testimony

Muriel Freeman (my mother-in-law) entered Mayfair Nursing Home at the end of August 2001. She was moved to the Vulcan Nursing Home on November 26, 2001. Muriel passed away two months later on January 22, 2002 from dehydration and pneumonia.

The four months in Mayfair, I witnessed:

- Over medication
- At times staff would not take Muriel to the bathroom when she asked.
- She become so weak and hunched over and left sitting in one position for long periods.
- She became dehydrated.
- Toenails were uncut. They started to curl under.
- Staff used hoists and handled her roughly. They ignored her pain.
- They lost personal items.
- Muriel was given only one bath a week.
- Staff lifted her skirt and checked if she was wet in front of visitors.

It does not cost more to treat a human being with respect and compassion. Homes need to be held accountable for their treatment of our elderly.

A Daughter and Son-in-law's Testimony

After two years at our home Anna went to a nursing home. In the four years that she has been there she has been hospitalized twice suffering from pneumonia, dehydration and lack of nutrition. During her nursing home care she has had three fractures (pelvis (twice) and ribs).

We have witnessed people unable to feed themselves and not being helped, people without teeth given regular food, drinks placed beyond the reach of the residents, full drinks replaced with new drinks with no concern that the previous drinks were untouched. Plus we have seen and experienced much, much more.

Our deepest wish is that these nearly helpless seniors would someday receive at least as much concern and protection as children in a day care. In many ways they are the same as children but lack the ability to complain and speak on their own behalf.

Testimony of The Hamel Family

The Experiences of Margaret Hamel, while a resident of the Bethany Care Centre, Calgary.

Mother of 12, Grandmother of 30.

My mom lived with a family member for three years after being diagnosed with Alzheimer's disease. Then we placed Mom into a facility. I would love to say my mom was placed in a home, but Bethany Care Calgary is a facility. We documented daily, not to find fault with the facility, but to keep our family informed about changes in mom's condition and aspects of care. What we have now is a well-documented journal of the facility. It starts with the staff and administrators. We need a **Governing Accountable Body**. Nothing changes - incident reports are handed in and no results ever communicated to family members; staff are transient, ill-trained and unmotivated to do more than what they MUST do ; staffing ratio to patients are only sufficient when V.I.P.s are on their way. This facility would hire or allow more hours when someone important was coming around. Did you know staff are given a quota of diapers allowed to be used on a patient. 2 to 3 a day is the allotted amount?

Our critical overview of the facility

Suppertime –Residents are herded to a dining area where they sit and wait up to an hour for dinner. Well functioning patients are made to sit with residents that scream or do not want to sit at the table. Residents are made to sit through meals with soiled diapers. Each resident is put in a bib, even if they are able to feed themselves (where is the dignity here).

Toileting. I had to get staff to help a resident who was walking the corridor with her depends to her ankles... no one was paying attention. On several occasions we would come in to find my mom soaked and embarrassed. When we addressed the obvious, the staff would blame the disease, " you know your mom is progressing she will need diapers."

We purchased the store-bought variety of depends because they were better fitting than the ones provided by the facility. We advised the nursing desk and the team leader that we had purchased them. It took over two weeks for the staff to use them. We came in nearly every day to find my mom in her regular undergarments soaked. No communication. When the diapers were incorporated into my mom's daily attire, then no one would toilet her because she was in diapers. So then we come in and find her sitting in soiled diapers.

Accountability - On more than one occasion that we know of my mom was given medication that was not prescribed for her, but you could never find out why or who was responsible.

Once when we arrived to take Mom on a zoo outing, we were informed that she needed a suppository because she hadn't had a bowel movement for x amount of days. When we phoned her daily private caregiver to find out if this was true, she informed us that Mom is very regular and that she had informed staff so they could chart it. However they didn't chart it, so the suppository would have resulted in unnecessary physical discomfort and no outing. Apparently it is mandatory to keep track of such things, however there is simply no point in rules that are not followed and no one is held accountable.

The restaurant business is inspected by random visits from health inspectors. If the establishment doesn't meet code they are shut down for a day, a week, or until the requirements are met. The inspectors visit unannounced, and sometimes at the busiest times of the day. We want to see unannounced visits to all facilities at least yearly. We want satisfaction surveys sent to the guardians not the Alzheimer's patients. (this actually happened). We want the inspectors to have the authority to make demands for changes and revisit to see that changes have been made. Residents are a lot more vulnerable than the average person eating a meal in a restaurant. Maybe if a facility was closed down for a day and the residents had to be moved, or the facility's subsidy was based on some aspect of these inspections and surveys - someone might listen. I think the media would listen.

A Daughter's Testimony

My name is Angie Murray. I had a Father who lived in a care centre 8 ½ years. This dear man was placed into the nursing home with severe depression and a thyroid problem.

Unknowing to the family, he was put on Haldol, an antipsychotic. He was on this drug for 6 ½ years. There was no documentation in the clinical records concerning any significant side effects from this medication. It was family that witnessed severe drowsiness, drooling and hand tremors for over three years and discussed their concerns to staff.

It was I that demanded he be taken off this drug after I was put wise that something was going on here. He suffered terrible adverse side affects, including involuntary muscle movements, tongue darting, rocking and difficulty speaking. These side affects are irreversible.

We feel this is a criminal offence. It's no different than a drug-pusher in a schoolground pushing drugs destroying young lives. The same applies in the nursing homes. What gives them the power to destroy the elderly and tear the hearts out of families?

A Daughter's Testimony

My name is Beverley Mann. My mother lived in a nursing home for approximately four years, during which time 1 was a constant visitor as 1 had many concerns with regards to the physical and emotional care given to my mother.

This is one example: visit October 13, 2001

- Failure of staff to follow doctor's order of offering a food supplement, the staff didn't know where the supplement was kept. My mother would have gone to bed hungry had I not been there.
- Failure of staff to safely handle a one -person transfer resulting in my mother becoming frightened and agitated and at risk of falling.
- Failure of staff to provide needed skin care even though I mentioned to staff that my mother had a rash on her bottom.
- Failure of staff to provide a thorough evening wash, including pericare.

Administration's solution to the problem: To move staff member to another resident, or I could move my mother to another facility.

Final Comment: My mother died in the hospital on October 31, 2001 with a scalding rash to her bottom and groin --- an indication of no improvement since October 13th.
I've come to the conclusion that I hope not to live long enough to endure life in a nursing home.

A Daughter's Testimony

My mother is 98 years old and has been a resident in a nursing home in Lacombe for the past 8 years. She spends all day in her wheelchair, and over the years with the budget cuts we have seen a deterioration in the care the staff give her. Family members have seen her not warmly wrapped, with her knees covered with an afghan and the back of her legs bare and cold. A lot of the time the staff neglect to place her call bell where she can reach it, and many a time she has not a supply of water where she can reach it (and this in the middle of July)

Mom is one of the few residents who reads, yet they do not always have her curtains pulled and the reading lights on. Many a time they wheel her in and leave her in the middle of the room where she cannot reach anything. My sister and I who visit the most regularly have spoken to the staff time and time again about her neglected care. Once in awhile we will visit and find all things done as they should be. But why do family members always have to harp about her care?
To our government officials, I say, you may be a resident some day in a nursing home. See what you have to look forward to.

Marion Wooden, Calgary

A Son's Testimony

The care of our seniors today is a serious problem due to the fact that the institutions that care for them are very understaffed and have very little training in eldercare.

To look after children in daycare, you must have proper training and adequate staff. When it comes to the elderly, it almost seems the attitude is: Who cares, these people are at the end of the life and are no longer productive, so why waste time and money on them? Why do the elderly have to be treated like the leftovers of society?

I think government has a responsibility to ensure that seniors' rights and living conditions are protected.

Funding is an issue that has been talked about a lot. The homes that care for the elderly always say that there is not enough funding. Let's have the homes tell the public where the money spent. Make them accountable for the funds they receive from the governments and the funds paid by the seniors.

Financial statements are public knowledge. Approximately $4000.00 per person is paid to homes from the governments and the person residing there. I believe there is a lot of money that is not accounted for after the homes or institutions receive it.

The home my parent is in has 80 residents. That means the institution receives about $320,000.00 a month which works out to about $3,840,000.00 a year. You would think that a sum of money such as that would ensure proper care, but as we've seen time and time again, it has not.

There needs to be a better accountable system that utilizes the funds for proper training, better meals, proper equipment and overall better care of our elderly.

Murray Carson

A Sister-in-law's Testimony

Hospital Care

My name is Linda Iverson. On May 23, 2002, my brother-in-law, Fred Iverson was released from the Peter Lougheed Centre. Before I got him out the front door, he coded. I took him around to the E.R. where they worked on him to get him stabilized. But they would not readmit him. The "Doctor" said to take him home. He said how I got him there was not his problem. Fred was taken by ambulance to the Crossbow Transition Unit where the head nurse told me that he was much too sick to be released. Fred was in the Crossbow for seven days. While he was there, his oxygen tubes came undone twice. They said that he disconnected them himself. My husband could not pull these tubes apart, so how could a man as weak as Fred pull them apart? In conclusion, it is my opinion that the Alberta Medicare System does not care if you live or die, as long as you don't die on their premises.

A Family Testimony

The base of our concerns as experienced with our parent is as follows:

- inadequate care
- not enough care givers
- many staff, if not most, are not trained in the disease they are administering to
- staff morale is very low
- unrealistic job descriptions
- no obvious valuing of these jobs by administration and/or society
- cuts in middle management have created unrealistic job duties which cannot be performed properly
- staff has been intimidated into negative advocating role that encourages no voicing of problems for fear of personal disciplinary repercussion and/or further funding cuts
- not enough supplies and equipment to allow for safety of patients, cleanliness to ensure healthy environment or basic needs which guarantee a degree of comfort and dignity

Most, if not all, of this can be blamed on inadequate amount of money being given and directed towards the frontline problem areas, such as more care givers and proper training.

Our parent homesteaded literally to help build this province. She spent a lifetime raising a family that has contributed to and been proud of Alberta and Canada. It is shocking that we spend more per day on a prisoner in a jail, than on our elders in our care facilities. Maybe it is time for some militant action to be taken in the form of a civil suit against the government, in order to protect our parents, and make old age decent for our generation and for you and your family.

CONCERNS OF FAMILIES WITH LOVED ONES IN RIVERCREST NURSING HOME

RESIDENT CARE

1. Weekly baths not adequate
2. Pericare not sufficient (Use rolled-up wet toilet paper for personal cleanup)
3. Residents sometimes smell of urine and feces
4. Toileting routines not appropriate
5. Residents encouraged to use incontinent supplies rather than toilet
6. Some residents left in soiled incontinent supplies for too long (e.g. some wheelchair cushions are soaked with urine)
7. Some residents wait on toilet for help for 45 minutes
8. Bladder training every two hours is not consistently observed by staff
9. Improve mouth care – not all residents can manage to brush their own teeth or to clean dentures; frequently mouth care is not provided
10. Staff do not clean residents appropriately after meals (e.g. soiled clothing)

RESIDENT COMFORT, SAFETY, MOBILIZATION

1. Some residents wait for call bell to be answered for 1 hour +
2. Inadequate help for residents to dress appropriately and comfortably (e.g. the right shoes, hair care)
3. Family felt staff did not notify them in a timely manner re incident of falling, resident missing, etc.
4. Family felt some residents inappropriately put in wheelchairs and restrained and not mobilized enough
5. Gloves infrequently used by staff
6. Inadequate staff hand washing between resident care
7. Rinsing of bed pans in sinks, subsequent sinks are not disinfected or properly cleaned prior to resident use
8. Care plans are posted but not consistently adhered to or changed in accordance with resident's changing needs

NUTRITION /HYDRATION

1. Inadequate hydration is a major problem
2. Poor hydration of residents has sometimes resulted in the need for residents to attend hospital
3. not all residents receive fluids or snacks (eg diabetics) on a consistent basis

NUTRITION /HYDRATION … continued

4. Inconsistent assistance for those who can't manage to drink on their own
5. If fluids are spilled by a resident, not reoffered or replaced
6. Poor quality of food
7. Poorly balanced meals (e.g. no vegetables at lunch)
8. Special diets not observed
9. Residents may not be able to eat the meal (eg: not ground for residents with no teeth, sandwiches for residents who have difficulty swallowing)
10. Some residents refuse to eat due to poor taste, poor presentation and meal unappetizing
11. Food is too cold and coffee too hot
12. Some residents have missed their meals if they are not in the dining room
13. Staff have been observed to finger feed two residents simultaneously/or use same utensils for both'
14. Poor hand-washing technique in the kitchen (staff smoke outside and do not wash hands upon return)
15. Dietician not responsive to expressions of concern

STAFFING AND RELATED ISSUES

1. Families feel inadequate staff (Re: Ratio to residents – not enough staff to feed, toilet, bath, mobilize)
2. Staff require more training
3. Proper transfers not being done:
   - do not use transfer belts appropriately
   - do not use 2 person transfer when necessary
   - not all staff appear to be appropriately trained to feed
4. Some staff are rough and do nor give compassionate care (eg. When moving residents)
5. Good staff who are competent are stretched "too thin" and "run ragged"
6. Some families hire private individuals to feed their family member
7. Some families do nor feel confident in staff's ability to manage residents' care when family members are away (e.g. vacations, business trips, etc.) and, in fact, would not go away on vacation without hiring someone to assist with resident's care

STAFFING AND RELATED ISSUES .. cont'd

8. Families are expected to provide an increasing amount of care for residents
9. Staff take inappropriate breaks during busy times (eg. Before and after meal times, during actual lunch and supper hours, staff sometimes go offsite for meals or to pick up food)
10. Some staff not trained to give medications properly
    - on occasion medication mistakes corrected by residents
    - medications suspended and changed?? Doctors orders??
    - Medications removed from floor if dropped and given to residents
11. Families feel inadequate supervision re restraints in wheelchairs and residents who have mobility problems; residents wandering outside facility
12. Lack of walking program or appropriate exercise program
13. Lack of supervision to ensure client care is adequate
14. Families' request for crushed/liquid meds not met
15. Staff take extended breaks in evenings in meeting room with lights out when management not around
16. Recreation staff and activities not adequate
17. Staff socializing with each other during residents' meal rather than with residents
18. Staff do not appear to be diligent about the care of residents' belongings
    (eg. Hearing aides, glasses, clothing, dentures, and staff not particularly helpful in finding lost items)
19. Family feel inappropriate medication used for control of resident behaviour – and also disagree with staff perception of what constitutes aggressive tendencies
20. Some families feel physician visits and coverage not acceptable

THE FOLLOWING PERCEPTIONS OF STAFF WITHIN THE FACILITY WERE EXPRESSED

1. Lack of supervision and leadership
2. Poor morale generally
3. Plotting, back stabbing
4. Insecure – feel job repercussions if they voice concerns
5. Inadequate training and educational opportunities

PERCEPTIONS OF STAFF … continued

6. Feel management does not support/listen to staff concerns (Re workplace issues)
7. Lack of communication between shifts
8. High turnover of staff
9. Too many good staff have left

ORGANIZATION OF LAUNDRY

1. Clothing frequently missing even when labeled
2. Nor sorted/delivered appropriately; residents frequently have on each other's clothing

ADMINISTRATION

1. Families do not feel local management listens/respects concerns
2. Families fear repercussions to residents if concerns are voiced
   (eg. Increase of personal injury to resident,; threats of transfer or eviction)
3. Some families feel local management is dictating direction of client care to the detriment of residents and family support

MATERIALS MANAGEMENT

1. No dishwasher – dishes done by hand
2. Insulated cups are old and are not sanitary
3. Plastic water glasses washed and reused
4. Plastic medication cups washed and reused
5. No straws available
6. No spill-proof cups for residents who require them
7. Mattresses not replaced appropriately; families told to buy foam mattresses
8. Inadequate/archaic physio equipment

BUILDING MAINTENANCE

1. Smoking area is not contained or vented
2. Smoke filters through hallways and throughout facility
3. Air quality is poor
4. Poor ventilation in summer; no air conditioning in common areas
5. Exhaust fans in hallway not working

Appendices

Appendix A

Following is a small sample of FAIRE's efforts to advise the Alberta government of residents' experiences of abuse, neglect and poor care, and the urgent need to address the root causes.

1. FAIRE's 1999 Report:
An Initiative Addressing The Needs and Rights of Alberta's Nursing Home Residents

This report draws attention to Alberta's appallingly lax Nursing Homes Act and Regulations through a comparison of regulatory standards and legislated residents' rights from other jurisdictions, including Ontario, British Columbia and New South Wales. FAIRE called on Alberta Health and 3 MLAs to use the content of this report as a framework for reforming Alberta's Nursing Home legislation. **There was no response**.

2. **FAIRE's January 2000 letter to the Premier**

This letter called for a meeting to discuss the growing reports of residents' experiences of abuse and neglect, and an action plan to address the contributing factors. **The Minister of Health responded in the Premier's stead, saying the Premier's schedule did not allow for him to meet with us.**

3. **FAIRE's October 2000 Meeting with the Associate Minister of Health**

This meeting drew awareness to systemic flaws that are endangering the health, safety and lives of nursing home residents. FAIRE called on the Minister to respond to our recommendations that included: I) the development of effective legislative safeguards for nursing home residents; 2) increased numbers of skilled front-line staff 3) the development of policies and standards for strengthening the mandate of the Health Facilities Review Committee. **There was no response.**

4. **FAIRE's October 2000 Meeting with the Calgary Conservative Caucus**

This meeting involved two family members who used personal photographs to relate their loved ones' experiences of nursing home abuse and neglect. FAIRE presented a summary of regulatory deficiencies that contribute to the problem, and called on Caucus to work with the Associate Minister to address these longstanding flaws. **There was no response.**

5. **FAIRE's September 2001 Report:** *The Shame of Canada's Nursing Homes*

This research-based report examines abuse and neglect of nursing home residents from a national perspective. Distribution of the report included Premiers and Ministers of Health of the Provinces and Territories. **There was no response from Alberta's Premier. The Minister of Health & Wellness sent a letter of appreciation.**

6. **FAIRE's March 2002 Letter to the Minister of Health & Wellness**

This letter provides a detailed account of deficiencies plaguing Alberta's long-term care system and the serious ramifications for residents. FAIRE's recommendations focused on 4 key contributing factors: 1) lax regulatory standards 2) chronic underfunding 3) lax inspections and enforcement of standards 4) lack of sanctions. **The Minister's response showed no discernible understanding of the seriousness of the problem or the urgent need for immediate remedial action.**

7. **FAIRE's May 2002 Forum:** *Speaking Out Against Abuse and Neglect in Our Nursing Homes*

FAIRE's report, *The Shame of Canada's Nursing Homes*, was launched at this public awareness event which drew more than 125 people. Our guest speaker was Charmaine Spencer, lawyer and researcher of vulnerable populations at Simon Fraser University. Invitations were sent to the Premier, every Minister and MLA. **None attended.**

Appendix B … Current Minimum Staffing Standards in Alberta

Under Sections 14(5)(6) of Alberta's Nursing Homes Operation Regulation, an operator is required to provide an average of at least 1.90 paid hours of combined nursing and personal services to each resident per day with at least 22% of combined services provided by nurses. These non-specific minimum standards translate into dangerously-low staffing levels as reflected in the following information provided by Extendicare administration at the request of a family member.

EXTENDICARE CEDARS VILLA
STAFFING PATTERNS – as of August 10, 1998

Unit	Census	Days	Eves	Nights
Primrose	35	1RN 2PCA	1RN/LPN 1.9PCA	1/3RN 1PCA
Willow	33	1RN 2PCA	1RN 1.9 PCA	1/3RN 1PCA
Larkspur	47	1RN 3.7PCA	1RN 3.3PCA	1/3RN 2PCA
Clover	54	1RN 1LPN 4PCA	1RN .4LPN 3.3 PCA	1/3RN 2PCA
Maple	40	1RN 1LPN 3.7PCA	1RN 3PCA 3PCA	1/3RN 1PCA
Poplar	39	1RN 1LPN 3.7PCA	1RN 3PCA	1/3RN 2PCA

Formula for Determining Compliance with the Required 22% RN Component

- 248 residents X 1.9 hours = 471 total care hours per day
- 22% of 471 total hours = 103.6 required hours of **RN** care = 0.42 hr care per resident per day divided by 3 shifts = approx. 14 minutes of RN care per resident per shift
- 103.6 RN hours divided by 7.5 hour shifts = **13.8 RNs** in a 24 hr. period
- Extendicare has 14 RNs indicating the facility is complying with Section 14(6) of the Nursing Homes Act.

Average Staff-to-Resident Ratios:

Days:	1 RN for 41 residents	(248 divided by 6 RNs)
	1 LPN/PCA for 11 residents	(248 divided by 22.7 LPN/PCA staff)
Evenings:	1 RN/LPN for 39 residents	(248 divided by 6.4 RNs/LPNs)
	I PCA for 12 residents	(248 divided by 19.4 PCAs)
Nights:	1 RN for 124 residents	(248 divided by 2 RNs)
	1 PCA for 28 residents	(248 divided by 9 PCAs)

Appendix C

Following are recommendations from a research paper developed by a panel of experts in response to the need for improved staffing standards to accommodate the increased acuity of residents in nursing homes in the United States. These recommended standards specify the amount and type of nursing staff and education /training levels considered as essential to meet minimum daily standard. **As shown in Appendix B, Alberta's staffing levels fall well below these recommended minimum standards**.

Administration Standard

- Full-time RN with a bachelor's degree as director of nursing (a provision for grandfathering current RN directors would be allowed for a specified period)
- Part-time RN assistant director of nursing (full-time in facilities of 100 beds or more; this person may also be the MDS coordinator)
- Part-time RN director of in-service education (preferably with gerontology training; full-time in facilities of 100 or more)
- Full-time RN nursing facility supervisor on duty at all times, 24 hr/day, 7days/week

Direct Care Staffing Standard

The minimum number of direct care staff must be distributed as follows:

Minimum level direct care staff (RN, LVN/LPN or CNA)

Day shift	1FTE for each 5 residents	(1.60 hr per resident day)
Evening shift	1FTE for each 10 residents	(0.80 hr per residents day)
Night shift	1FTE for each 15 residents	(0.53 hr per resident day)

Minimum licensed nurses (RN and LVN/LPN) providing direct care, treatment and medications, planning, coordination, and supervision at the unit level:

Day shift	1FTE for each 15 residents	(0.53 hr per resident day)
Evening shift	1FTE for each 20 residents	(0.40 hr per resident day)
Night shift	1FTE for each 30 residents	(0.27 hr per resident day)

Minimum total number of direct nursing staff is 4.13 hr per resident day. Total administrative and direct and indirect nursing hours is 4.55 hr per resident day. Staffing must be ADJUSTED UPWARD for residents with higher nursing care needs.

Mealtime Nursing Staff

Direct care staff standards will take into account specific needs of residents at mealtimes. At all mealtimes there will be:

- 1 nursing FTE for each 2-3 residents who are entirely dependent on assistance
- 1 nursing FTE for each 2-4 residents who are partially dependent on assistance

Nursing staff who assist with feeding should be CNAs who are adequately trained in feeding procedures and they should be supervised by licensed nurses.

Education and Training

All licensed nurses in nursing homes must have continuing education in care of the chronically ill and disabled and/or gerontological nursing (at least 30 hr every 2 years)

NAs should have a minimum of 160 hr of training, including training in appropriate feeding techniques.

Nurse Practitioners

Each nursing home is strongly urged (but not required) to have a part-time geriatric or adult nurse practitioner and/or a geriatric clinical nurse specialist on staff (full-time for 100 beds or more).

Note: RN = registered nurse; MDS = minimum data set; LVN/LPN = licensed vocational nurse/licensed practical nurse; CNA = certified nurse assistant; FTE = full-time employee; NA= nursing assistant
Builds on the Nurse Staffing Standards accepted by the National Citizen's Coalition for Nursing Home Reform (1995).

Resource: Experts Recommend Minimum Nurse Staffing Standards for Nursing Facilities
Harrington C. PhD,RN, FAAN - Kover C. PHD,RN,FAAN - Mezey M. PhD, RN, FAAN - Kayser-Jones J. PhD, RN, FAAN - Burger S. RN, MPH - Mohler M. RN, MN, MHSA - Burke R. PhD - Zimmerman D. PhD

What's an autonomous family council?

An autonomous family council is an organized, self-led, self-determining, democratic, consumer group composed of families and friends of residents living in long-term care facilities.

A family council usually has a staff advisor who supports and assists the council, but is not considered a council member. However, councils are free to operate without a staff advisor if they choose.

The emphasis of all family councils is mutual support, empowerment and advocacy.

A family council has two main goals:

- To protect and improve the quality of life of residents
- To give families a voice in actions and decisions that affect them and the residents of the facility

Each council will be unique. There are no hard and fast rules about how a council should organize or operate, or how it should meet the needs of its members, residents and the facility.

Common to all family councils is the commitment to provide families a forum in which to openly express their concerns and ideas, and a way work together for positive change.

Produced by Families Allied to Influence Responsible Eldercare (FAIRE)