An Inside Look At
The Continuing Care Experience in Alberta

An Analysis of Family Feedback

By:

The Citizens' Watch Network, Continuing Care in Alberta

www.continuingcarewatch.com

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Contact Bev McKay
Email feedback@continuingcarewatch.com

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Acknowledgement

This analysis would not have been possible without those families who offered Citizen Watch their testimonies of a loved one's experience within Alberta's continuing care system. Their thoughtful comments, perspectives, shared observations and knowledge provided an insightful look into life inside some of the province's care facilities. The Citizens' Network extends thanks and gratitude to all those who contributed.

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I. Introduction

At the February 2006 media launch of this website, the *Citizens' Watch Network* called on families to send us confidential feedback on their loved one's experiences in a continuing care setting in Alberta for review and analysis. The first testimony arrived within two days of the press release. By mid July 2006, we had received reports from 22 families (and friends assuming a family role) and 4 front-line staff.

Although the number of responses was small in comparison to the number of families with a loved one in a continuing/long term care setting, this feedback contained sufficient pertinent information to develop a framework and database for the analysis. The reports we received from both families and care staff provided an opportunity to examine the quality and adequacy of resident care across a number of facilities as well as the standards, practices and conditions under which the care centres operate. It also enabled us to explore the involvement of family members and what they experienced when they brought concerns to the attention of nursing staff, facility management, regional health authorities and/or provincial government officials and agencies. In addition, it allowed for a look at some of the broad-system issues.

Given the small sample size, our findings cannot be considered an accurate reflection of the day-to-day experiences of all individuals residing in continuing care settings throughout Alberta. None-the-less, information gleaned from this feedback is instructive and revealed a number of common themes and issues. It further reinforces the urgent need for far more corrective measures by all parties concerned to protect the rights and well being of dependent and vulnerable individuals in care settings.

II. Preparation

Submissions from families were sorted and filed according to the relevant Regional Health Authority. Feedback from front-line staff was separated out, reviewed and logged. Information in the reports was scanned for the care centre's name, the type of setting (e.g. traditional long-term care facility, assisted living, public lodge, group home, etc.) and ownership status – i.e. private, voluntary and public. Reported experiences of residents were identified, categorized and summarized along with reported care outcomes. Incidents described as causing harm or posing risks to residents were flagged. Contributing factors, identified directly by families and/or in official investigative reports provided by some families, were summarized in point form. Themes or trends were colour-coded and compiled as part of the overall findings. Another scan was conducted to identify personal sentiments, perspectives, advocacy efforts and relevant experiences of the contributing families. Information was then reviewed and analyzed by an ad hoc Working Committee of the *Citizens' Watch Network.*

III. Summary of Analysis and Findings

- The 22 testimonies by families dealt with residents in 21 continuing care settings within the jurisdiction of 4 Regional Health Authorities.

- 13 of the care centres (60%) were owned and operated by private for-profit companies (private enterprise); 6 by non-profit charities (private voluntary); and 2 by Regional Health Authorities (public).

- The majority of these testimonies (18) described experiences of residents in traditional long-term care facilities (i.e. nursing homes and auxiliary hospitals), 1 related to experiences in a group home, 1 to a personal care home and 2 related to "assisted living" settings.

- 53 reported experiences of deficits in care were identified in the 22 submissions, as well as a number of case related care outcomes and contributing factors reported by families. These deficits related to ten different aspects or categories of care:

    - Medication management (10)
    - Oxygen therapy management (3)
    - Changing health status (6)
    - Hydration (5)
    - Nutrition, including feeding practices (5)
    - Toileting assistance and incontinence care (7)
    - Personal hygiene (2)
    - Care plan and care planning (3)
    - Call bell system (3)
    - Safety and security (9)

- **Common themes identified in our sample of family feedback were:**

    1) A range of unaddressed care deficiencies seriously compromised the health, safety and well being of identified residents.

    2) A consistent critical shortage of qualified professional and non-professional care staff on site was perceived by families as the key issue impacting the quality of care and quality of life of residents.

    3) Reported experiences often reflected a complete departure from identified appropriate or responsible care practices.

    4) Family monitoring and intervention were critical to residents receiving necessary medical, nursing, or acute care services.

    5) Families' reported observations of health decline in a loved one were often not taken seriously or acted on, particularly in a timely manner.

    6) Families' advocacy efforts to protect or improve the quality of care of a loved one or other residents were often futile.

7) There often appeared to be no effective authority or process that families could turn to for resolving care deficiencies that posed risks to residents.

8) In general, nursing staff were perceived as doing their best to fulfill their responsibilities under very difficult circumstances..

9) The facilities' attending physicians and Medical Directors appeared to have a minor role in the care and assessment of residents.

10) The majority of stories reflected a tragic breach of trust by those charged with the care and protection of residents in continuing care settings.

- **Other relevant findings were:**

1) Many families/friends assumed new and unexpected responsibilities

Many family members and friends had taken on a wide range of new and unexpected responsibilities during a loved one's stay in the facility in order to compensate for gaps in hands-on care and oversight. (A list of some of these responsibilities can be found on pages19 and20.)

2) Feedback from front-line workers echoed feedback from family/friends

While not the primary focus of this analysis, feedback also was received from 4 front-line workers in 3 traditional long term care facilities in 3 RHAs: 2 facilities were owned and run by private companies and 1 by a charitable organization. Submissions from these workers echoed many of the experiences and issues reported by family members, identifying both site specific and broader system issues affecting the quality of care and quality of life of residents. These included:

1) Unreasonably high workloads given the complex and high care needs of residents, too few and/or unsuitable or unskilled staff and high staff turnover;

2) Site or care organization specific policies and practices (e.g. rationing supplies such as diapers, financial incentives);

3) Manager and management attitudes and practices (e.g. tolerating misconduct, ignoring reports of abuse/neglect); and

4) The inadequacy and ineffectiveness of current regulations, oversight and inspection processes.[1]

[1] Some of the actual comments by front-line workers can be found on the Citizen Watch on Continuing Care web-site at www.continuingcarewatch.com under section "Feedback" entitled Quotable Quotes from Front-Line Workers.

IV. Summary Chart of Case Examples

The following chart summarizes reported resident experiences with deficits in care, care outcomes and contributing factors reported by families to Citizen Watch Network. It is organized based on 10 aspects of care identified in submissions by families.

1. MEDICATION MANAGEMENT (10 identified cases)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1 Long-term care facility	**DOSE ERROR** At admission to the facility, the resident was taking **6 tablets of methotrexate once a week** to treat her rheumatoid arthritis. **The family writes**: "She had been on this drug for years." Within 5 days of admission**,** the resident developed a sore throat and was prescribed an antibiotic. However, "the sore throat worsened to the point where she could hardly swallow, and within a day or two had also developed a rash which spread to her entire body." At that time, an RN mentioned a possible reaction to the methotrexate, but didn't follow through on her suspicion. By the 9th day, the resident "was extremely weak, could hardly talk, was in a lot of pain, hadn't eaten for days, nor drank much." The RN on duty asked the family "why she was on methotrexate and what the dosage was." When the family provided the information, **the RN indicated the resident had been given 6 pills <u>every</u> day for 9 days instead of 6 pills one day a week.** The family called the doctor-on-call who advised immediate hospitalization. Because of resident's critical condition, the family slept on the floor of her hospital room for several days. **The family writes**: "She was passing blood and tissue in her stool, her mouth was a mass of ulcerated flesh, she was in a near coma-like state. We almost lost her."	This incident led to an investigation. **The family writes**: "It was an oversight on the part of everyone involved – her MD, the pharmacist, nursing staff at the facility. The dosage had been recorded and confirmed incorrectly by her physician on admission and no one caught it. All of these professionals should have been fully aware of how this chemotherapy drug is used when treating rheumatoid arthritis, and known that it was the wrong dosage."

2 Long-term care facility	**OVER MEDICATION** (The use of psychotropic drugs as a chemical restraint) The resident went from walking independently on the day of admission to being physically restrained in a geri-chair by the 3rd day and unsteady on her feet by day 4 with physician orders for increased sedation. Continued use of these sedating drugs over time led to numerous falls resulting in serious injury requiring admission to acute care.	**An investigation report provided by the family includes these findings:** "It is evident that the resident was very sedated for a period of time and that, rather than nursing care, sedation was being used to manage the resident." "Staffing in this facility is not at a level to provide the direct supervision that this resident needed." "Registered nurses informed investigating members that they do not have time to check residents on a daily basis." "Restraining the resident through chemical and physical restraint appears to have weakened the resident and increased her number of falls."
3 Long-term care facility	**OVER MEDICATION** A family member made friends with many of the residents in the facility where her own mother lived. **The family writes**: "A lady my mother's age liked to visit with us and chat." One day, the family found the woman "slumped over in her wheelchair in what appeared to be a very sedated condition." When she expressed concern to nursing staff, "I was told that medication was given because, 'she was too much trouble to bother with'." A few days later, the family member observed the head nurse standing over the woman saying, "She is way, way too medicated". **The family writes**: "The following week, she was almost comatose in appearance with a large, nasty-looking black bruise on one side of her face. Alarmed, I asked staff if they had notified her family about the bruise and was told, 'Yes.' I was not able to learn what caused the bruise and could not get the family's address or telephone number. A short while later, the woman died."	The casual attitude and seeming lack of appropriate response by staff to the resident's reaction to the medication, as well as the possible lack of awareness by the resident's family of the significant change in her condition

4 Long-term care facility	**FORCED FEEDING OF ORAL MEDICATION** The forced feeding of an oral medication by a personal care aide (witnessed by the resident's family) caused the resident to choke and aspirate resulting in life-threatening complications	**An investigation report provided by the family includes these findings:** "There are few professional staff available (at this facility) to carry out professional nursing duties. Nursing duties are being delegated to untrained and poorly prepared non-professional staff." "The team leaders at the facility are personal support aides who only have a day and half of training in the administration of medications." "These staff members have very limited knowledge about the medications, their names and their correct use." "A staff member was not assigned to remain with the Resident in her room to ensure that she would have no further problems related to the aspiration experience." "The Resident did experience further problems related to the aspiration of medications: 1 ½ hours later, staff found her in respiratory distress, very diaphoretic (sweating) with mottled extremities and a pulse of 152." "Once contacted by staff, the family had to insist that a physician be called and, once staff contacted the physician, medication and treatment were ordered."
5 Long-term care facility	**NO MEDICATION** The resident's repeated requests to staff for pain medication to treat her headaches were reportedly disregarded. The family's requests of nursing staff to inform the doctor of the resident's constant pain were also "ignored." Finally, at the family's insistence, the nurse on duty called the doctor who ordered a daily pain medication. The family observed the medication was not consistently provided as directed by the resident's physician.	The family member felt her requests were ignored because she wasn't the legal representative of her loved one.

6 Long-term care facility	**NO MEDICATION** The family hired a private companion for the resident. During a phone call to the companion, the family heard the resident "shrieking in pain." The family called the nursing desk to request the resident be given "an injection of pain medication." **The family writes**: "They said they had no order from the doctor. I knew it was there but they would not look." The companion also went to the desk several times to request pain medication for the resident, but "the nurse said he needed to finish his paper work." The family goes on to say, "In the same incident, the day nurse asked (the resident) if she was in pain. Since she could not speak, this was a ridiculous question."	Staff on duty appeared unfamiliar with the resident's medication profile and her medical condition that made verbal communication impossible.
7 Long-term care facility	**MEDICATION NOT TAKEN** The family found the resident's pills under the bed.	Not identified
8 Long-term care facility	**MEDICATION NOT CONSISTENTLY ACCESSIBLE** A terminally ill patient was placed in a long-term care facility. **The family writes**: "My loved one's need for care and pain management, I am sure, put an added strain on the understaffed facility. I stayed in my loved one's room for the last 12 nights of his life. His mental condition made it impossible for him to use the call bell if he needed pain medication. I frequently had to wander the halls in search of a staff member."	**The family writes:** "Staffing levels of both professional nurses and personal care attendants did not allow for the frequent checks required to see if more pain medication was needed."
9-10 Long-term care facility	**MEDICATION ADMINISTERED WITHOUT CONSENT** In 2 separate cases, mentally-incompetent residents were administered psychotropic drugs without the knowledge or informed consent of the residents' legal guardian /substitute decision-maker	Attending physician did not adhere to the requirement of obtaining informed consent prior to treatment. NOTE: "*In the absence of a medical emergency, a doctor cannot treat someone without first obtaining consent*." [Source: Seniors and the Law: A Resource Guide, Alberta Civil Liberties Research Centre]

2. OXYGEN THERAPY MANAGEMENT (3 identified cases)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1 Long-term care facility	**DEPLETED OXYGEN SUPPLY** The family found the resident's oxygen tank empty on numerous occasions. Sometimes, the family found the canula had not been placed on the resident's face – or the oxygen had not been turned on – or the equipment had broken down. On one occasion, the family observed an RN replace the tank, then leave the room without ensuring the equipment was functioning. When the family checked, no oxygen was flowing to the resident. Although the family reported each incident to the charge nurse and facility management, the problem continued to occur.	No one seemed to take responsibility for monitoring the resident's oxygen supply, or ensuring continuous supply of oxygen or proper functioning of equipment.
2 Long-term care facility	**DEPLETED OXYGEN SUPPLY** The family reported finding the resident without oxygen "several times."	Not identified
3 Long-term care facility	**NON-RESPONSE TO ALARM** A family twice heard a high-pitched alarm that had been ringing for about five minutes. Concerned, the family "went to investigate - both times it was the same resident gasping for breath as her oxygen was not working, and she begged me to help her." **The family writes**: "When I went to get help, the answer was the same both times, 'yes we heard it' – and then they did nothing. So each time I created a loud enough conversation that I believe they went just to shut me up."	Care staff appeared to have little motivation to provide care.

3. CHANGING HEALTH STATUS (6 identified cases)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1 Long-term care facility	**UNDETECTED/DELAYED RESPONSE** The family alerted nursing staff to the resident's "odd" behaviours as a	Not identified

	symptom of recurring urinary tract infection. **Two days later**, the resident was transferred to acute care; the family described her condition on admission as "so bad she vibrated on the bed" and "she couldn't swallow." The resident remained in hospital for one month.	
2 Long-term care facility	**UNDETECTED/DELAYED RESPONSE** The family alerted nursing staff to traces of pus in the resident's dark-coloured urine as symptoms of recurring urinary tract infection. **One week later**, a urinalysis was ordered. Test results confirmed urinary tract infection.	The family felt the untimely response to the resident's condition and delayed treatment contributed to unnecessary risks. **The family writes:** "How do we bring these things to their attention so they are addressed in less time than a week or a week and a half?"
3 Long-term care facility	**UNDETECTED/DELAYED RESPONSE** The family observed the resident "grimace as if in pain and grab weakly at his lower abdomen." The family repeatedly alerted nursing staff to their suspicion of a urinary tract infection. **Approximately 9 days after the family reported their observation**, the resident's condition had deteriorated to the point where "he wasn't eating" – "his breathing was very shallow and rapid" – "his tongue and mouth were covered in sores." At about this time, the attending physician told the family he suspected a bladder infection; he ordered antibiotics, oxygen and a urinalysis "which came back completely foul." On inquiring whether the resident needed to be hospitalized, the family was reportedly told the care would be the same at the hospital as at the facility. The resident died at the care centre within 11 days of the family reporting their observation … and within 67 days of entering the facility at which time "he was a walking, talking, self-feeding, happy individual."	The family felt their concerns, observations or suggestions were often dismissed, ignored, or considered unimportant.
4 Long-term care facility	**UNDETECTED/NON-RESPONSE** The resident had "two SEVERE falls within a month." **The family writes:** "No one recognized the serious change in him after his second fall - incapable of speech - drooping head - unable to	Perceived lack of skilled, knowledgeable or motivated staff

	walk. . . And no one saw anything seriously wrong when he started to have small seizure-like movements, accompanied by CONSTANT twitching, almost constant sleeping, no response."	
5 Long-term care facility	**DELAYED/NON- RESPONSE** One day the family found the resident "scrambled" – "out of it" – "almost hallucinatory." **Almost two weeks later**, the resident was admitted to acute care at the family's request. Laboratory results confirmed an infection in the resident's foot had spread to the bone. At the time of hospital admission, the facility had not informed the family of the infection.	Not identified
6 Personal care home	**EVICTION / INABILITY TO "AGE IN PLACE" AS HOME CARE NEEDS INCREASED** Increasing care needs of the resident triggered a decision by Home Care to transfer her from the personal care home to a nursing home. However, the family member refused to place her mother in a nursing home. **The family writes**: "Upon being evicted, mom was hauled off to a hospital in an ambulance. The hospital tried everything to bully and coerce me, including threats, to commit her." When the family member finally took her mother home to care for her, "the doctor refused to give me any medication or prescription for her."	In the family's opinion: "Home Care controls everything and pretty much serves as the warehouse for seniors. They know seniors are too poor to fight them."

4. HYDRATION (5 case examples)

Identified Cases **Care Setting**	**Care Experiences and Outcomes** (Reported by Families)	**Contributing Factors** (Reported by Families or in Official Reports Provided by Families)
1-2-3-4 Long-term care facilities	**DEHYDRATION** Four submissions revealed residents had suffered dehydration. The following are some excerpts from the families' stories. 1. "During his time in the holding unit, he was taken to hospital due to dehydration."	One family member identified the failure of staff to respond to her concerns related to the need for more fluids. **The family writes:** "Intravenous [for hydration] was only given at night. Why does it take two weeks of questioning to get it given round the clock?"

	2. "It was a struggle to get him to eat, but he sucked juice boxes dry. Was he dehydrated again?" 3. "I feel medications administered without consent, dehydration and lack of attention to her thyroid brought on the crisis that led to removal of her gallbladder." 4. "The dehydration worries us as we have lost an uncle to dehydration in care. He died when they attempted to rehydrate for the second time and it caused a heart attack."	
5 Long-term care facility	**REHYDRATION** A close friend described many problems she observed with a resident's experience with "hypodermaclysis" - a procedure used for rehydration. This entails infusing IV fluids directly into tissue. **Examples included**: When the friend reported "redness" at the site, an RN reinserted the clysis in the resident's leg then left the room. Within 10 minutes, "a large bubble" had developed on the leg causing discomfort. The family reported the problem to the RN who then changed the site. Sites of insertion were often not rotated as recommended: "The clysis had been in her abdominal region for a couple of weeks. She had bruising due to this. There was definitely discomfort." "The night nurse came in to check the site. It was extremely red and the date on the site was past due for changing." "We found another [new] site on her body. The day nurse had not removed the old site or switched the IV bag." Another time, the clysis bag ran out of fluid, causing air in the tubing that needed to be corrected. The RN had a great deal of difficulty trying to fix the problem and had to call another RN to assist her.	The friend indicated there seemed to be a lack of policies and procedures and/or staff were not familiar with clysis management and/or policies.

5. NUTRITION …FEEDING PRACTICES (5 case examples)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1-2-3-4 Long-term care facility	**INADEQUATE ASSISTANCE / INAPPROPRIATE FEEDING / INAPPROPRIATE FOOD** **Two families reported these** 4 **mealtime practices at the <u>same</u> facility:** 1. "Most of the residents were given no assistance at all because there were not enough care attendants available. Again and again, I watched residents being rolled away from uneaten meals." 2. "I saw them (personal care aides) shoveling in food with a big spoon. There was no patience to allow for the residents to eat at a normal pace. Scoop shovel, scoop shovel without letting them finish their first mouthful." 3. A resident refused to eat the rest of her meal after nearly choking on "an overlarge spoonful of food that had been put in her mouth." 4. A resident put aside the ham served with his meal because pork is forbidden in his culture. This "left him with almost nothing to eat." No alternative food was served.	Families identified understaffing and inadequate staff training and supervision related to feeding methods as possible contributing factors. The facility was unable or unwilling to accommodate cultural requirements related to food.
5 Assisted living facility	**RISK OF NOT BEING FED** **The family writes**: "Our loved one often has to remind staff that his GI (gastro-intestinal) feed hasn't been given."	Family noted the facility is understaffed.

6. TOILETING ASSISTANCE AND INCONTINENCE CARE (7 case examples)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1-2-3-4-5-6-7 6 Long-term care facilities	**UNTIMELY OR NO ASSISTANCE WITH TOILETING / INAPPROPRIATE INCONTINENCE CARE**	

1 Assisted living facility	**Seven submissions identified the following experiences of residents:** 1. Having to wait "far too long to get help with toileting or a change in underwear." 2. "Not making it to the bathroom in time and the humiliation and frustration that comes with that." 3. Being told by staff to "go ahead and go, you've got Depends on." 4. Being left in a feces-soiled diaper "for two hours." 5. Being told by staff "they have to wait 'til the meal is over before they can be taken to the bathroom." 6. Being found by the family or the hired companions "at least five times in the last two weeks soaked in urine and covered in dried feces." 7. Staff having "to use paper towels on residents' buttocks when the resident doesn't have the funds to buy the appropriate products and the care facility does not provide them."	Families identified understaffing and the use of diapers for the sake of staff convenience (as opposed to resident need) as possible contributing factors.

7. PERSONAL HYGIENE (2 case examples)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1 Long-term care facility	**SERIOUSLY INADEQUATE** **The family writes:** "Her basic hygiene was not good. Her teeth were not brushed … her hair not combed. She often wore the same clothes for days until I asked the PCA to put them in the wash."	The family identified "inadequate staffing" as a key deficiency.
2 Long-term care facility	**SERIOUSLY INADEQUATE** **The family writes:** "He is often not shaved which tells me his face was not washed and teeth not brushed. Towels in his bathroom do not appear to be used. On one occasion, he didn't have a shower for	The family said the facility is understaffed.

	9 days. I called the head nurse on day 9 and demanded he be showered."	

8. CARE PLANS AND CARE PLANNING (3 case examples)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1 Long-term care facility	**NOT READ** The resident suffered macular degeneration causing significant vision loss. A PCA admitted to the residents' family that she was not aware of the resident's vision problem. When the family indicated this information should be documented in the resident's care plan, the PCA indicated "she didn't have time to read all the Care Plans."	Not identified
2 Long-term care facility	**UNTIMELY PREPARATION** "The timeframe for setting up a care plan for (the resident) was six weeks."	According to the family, "there is a lack of [appropriate] policy and procedure - or if polices are in place, the follow-up is inadequate."
3 Long-term care facility	**NO CARE PLAN** The resident moved from one facility to another. The care plan that had been developed by the previous care centre for the resident was placed in her file at the new facility. During the resident's three-month stay at the new facility, no new care plan was developed.	**An investigation report provided by the family noted:** "Investigators were unable to find evidence that any plan was being used to guide the care being provided to the resident. They were also advised by staff that they were having difficulty establishing and adjusting care plans as the residents' needs changed and they had no time to do so."

9. CALL BELL SYSTEM (3 case examples)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1-2-3 All long-term care facilities	**DIFFICULT TO USE /UNRELIABLE** **Three submissions** noted the following: 1. The resident had difficulty using the call bell, would become frustrated and call out for help; was reportedly "deemed a nuisance for doing so."	

	2. The facility had an "ongoing problem with the call system" requiring the family to walk the halls to find staff. 3. The facility's call bell system "seemed to have a mind of its own."	

10. SAFETY / SECURITY (9 case examples)

Identified Cases Care Setting	Care Experiences and Outcomes (Reported by Families)	Contributing Factors (Reported by Families or in Official Reports Provided by Families)
1 Long-term care facility	The resident wandered out of the facility unnoticed on numerous occasions. Twice the resident was found by the river about ½ km. from the facility.	The family said the facility is understaffed.
2 Long-term care facility	A family member heard a resident call out for help. "Staff members were too far away to hear her calls." **The family writes**: "She would have died had I not been there to summon staff."	The family identified understaffing as a significant risk to the safety of the resident.
3 Long-term care facility	A family member heard a resident "yelling for help for some time." On looking in on the resident, the family found her "tangled up in her bedding and hanging upside down over the side of her bed."	The family reported the facility is understaffed.
4 Long-term care facility	The family found the resident with "multiple bruises on her knees, shoulders, chest, arms and face." The resident was transferred to acute care for assessment at the family's request. Facility staff and administration could not explain the cause of the injuries. Although the facility undertook an investigation at the family's request, no definitive conclusions could be drawn as to the cause of the unwitnessed event.	**The facility's investigation report provided by the family concludes:** "*While it is impossible to know what exactly occurred, the most likely possibilities are that (the resident) either experienced an interaction with another resident which resulted in her bruises, or she may have turned abruptly in her sleep and struck the protective side rails of her bed.*"
5 Long-term care facility	The family observed a new staff member use unsafe methods to transfer the resident from a chair to her bed. The improper maneuver of the mechanical lift hurt the resident enough to cry out.	The family noted the new staff member did not follow the facility policy or the two-person transfer instructions on a chart posted above the resident's bed suggesting he did not receive adequate training or orientation.
6	A resident fell in her room in the early morning. No staff member checked "to	The facility was perceived as not providing the services it promised.

Assisted living facility	see why she was not at breakfast which she never missed." Following another fall, the resident "lay in her room far too long" before being found.	
7 Long-term care facility	The family found the resident "half way out of bed. Due to the resident's physical impairment, "it would have taken her a long time to move that far." From the family's perspective, "it was obvious no one had looked in on her for some time." The family was asked to buy a bed alarm. "It was used once then disappeared within two weeks of purchase."	The family reported the facility was understaffed to the point of being unsafe for residents requiring a high level of care.
8 Long-term care facility	**The family writes:** "My daughter found her grandfather lying in his bed with his intravenous pole across his neck and his catheter tube pulled out. This left her to wonder how long he would have been left like that had she not been there to notify staff."	The family identified "minimum staffing standards" as a contributing factor.
9 Group home	**The family writes**: "I am never sure if there will be enough staff to monitor the residents, let alone take care of them."	The family identified the lack of adequate qualified staff as a potential risk to the residents.

V. Chart of Identified Responsibilities Assumed by Families

Responsibilities Assumed by Families

- Overseeing the health and care of a loved one and reporting problems; diarizing deficiencies in the care and services; keeping track of medications and monitoring for symptoms of adverse effects; challenging the overuse of high-risk psychotropic drugs;
- Assisting with the care; exercising a loved one in the absence of a physiotherapist; purchasing equipment, supplies or medications not provided by the facility; hiring private care to compensate for the inadequate services of the facility;
- Checking the working order of facility equipment and reporting problems;
- Checking on residents who call out for help and summoning staff to respond; reporting concerns about the health and safety of other residents to nursing staff; portering residents to the dining room and serving meals;
- Informing the physician about the resident's medical condition;
- Finding their way through the process of moving a loved one out of the facility when it proved incapable of providing safe, adequate or appropriate care;
- Maintaining bedside vigilance in a crisis situation; being the voice and decision-maker for a dependent loved one;

- ► Documenting incidents and reporting them to facility administration; requesting and reviewing a loved one's medical records;
- ► Calling for an investigation when things went wrong; taking additional steps if investigative decisions, processes or results were perceived inadequate, flawed or unfair; and
- ► Writing letters of concern to the Premier, responsible Ministers and their MLA.

VI. Concluding Comments

The common themes and key findings derived from our analysis of feedback to Citizen Watch (gathered between February 2006 and July 2006) reinforce and add substance to concerns and issues identified in many other testimonials, consultations and reports. These findings emphasize the urgent need for effective remedial measures to protect the rights and well being of dependent and vulnerable individuals "in care" and their families. We hope this report based on feedback from families, friends and front-line workers will help overcome the societal blinders, prejudices and practices which appear to be allowing the current situation to go uncorrected.