

FOREWORD

WHO CARES ABOUT HOME CARE?

SENIORS CARE, because their quality of life, their ability to remain in their own homes, may well depend upon whether the public home care system is functioning adequately. Staying in familiar surroundings, holding on to the identity that one's own chosen ambience sustains, this may loom as the most emotionally-weighted aspiration in a senior's life.

FAMILIES CARE. Estimates of the amount of eldercare performed by families range between 80% and 90%, with most, though not all, such service performed by women. For the vast majority of families, it is natural and satisfying to take care of their elder members – for children and grandchildren (and often nieces and nephews) to care for their parents or their aunts and uncles, for elderly mates to care for one another.

It is not always possible, however, for families to provide all the care an older person needs. Adult children do not always work and reside in the same place their parents do. If parents are fortunate enough to have children close by, their daughters and daughters-in-law most often belong to two-earner families, whose standard of living depends on their earnings and who can, therefore, offer only limited help. It must be noted also that children are sometimes estranged from their parents and for this, or other reasons, may refuse to care for their parents. Elderly wives and husbands may not, of course, be physically capable of providing the care needed by their mates.

And our society provides neither recognition nor compensation for eldercare. The Canada Pension Plan allows pension-year credits for years when a mother drops out of the workforce to care for children under the age of seven. No such drop-out provision applies for a daughter who drops out to care for her mother or father. The Employment Insurance system provides for six months maternity leave, with the guaranteed right to return to one's former job. There is no such compensation or guarantee for those taking time out for eldercare – or, as it is now often

referred to, “eternity leave” to care for dying parents. Recently an Ontario woman was fired from her job for requesting **unpaid leave** to care for her dying mother.

If the publicly funded home care system fails to provide adequate care for their parents, it is usually the children who must pick up the pieces. And most of them will try their best to do so, whatever the cost to their own health or their own economic security.

Just as the parents of chronically ill or disabled children are at serious risk if the public system of care lets them down, the children of today’s seniors, the “baby-boom” generation, are at risk if the home care system for their parents fails them.. That is why our PhoneLine receives more calls from family caregivers and from concerned family members and others than from clients themselves. Adequate and high quality in-home care will, increasingly, be the concern of “baby boomers,” as more and more of them have to deal with the problems of their aging parents.

DOES ANYONE ELSE CARE? Since government policy decisions have such a profound influence on what the home care system is designed to do and funded to do, we need to know how much the government cares. The end of the first year of Care Watch PhoneLine operations coincides, fortuitously, with the month that Ontario citizens are preparing to elect a new provincial legislature.

Our challenge, to ALL PARTIES and to ALL CANDIDATES is: Do **YOU** care enough about the frail elderly to build a home care system that supports them when they need help with the activities of daily living? Or do you think home care is primarily for acutely ill post-hospital patients, with nursing home beds for seniors who can’t take care of themselves?

Of the COMMUNITY CARE ACCESS CENTRES, who now arrange for all publicly-funded in-home care, we ask: Do you care enough about the quality of your service to pay serious attention to **all** the stories in this report? They did not all happen in your area, but the calls were from so many areas and the concerns from all areas were so similar that no one should think complacently, “It can’t happen here.” Any of the gaps, inadequacies and failures that you read about here could happen anywhere.

May 1999

CARE WATCH TORONTO

This report is produced under the auspices of Care Watch Toronto, a network of organizations and individuals dedicated to improving the quality of life for those who receive care in their own homes. Formed originally in 1995 as Metro Consumers for Community-based Long Term Care, its aim was to monitor how consumers were faring as a new system of home care was becoming established. Our name was changed in December 1997 to Care Watch.

Care Watch Toronto works to influence public policy with regard to in-home care. We reach out to the community, distributing literature, speaking at community meetings and conducting workshops and forums to spread the word about how the home care system works and how it can be improved. We have also developed an experiential professional development workshop, called “The Caring Game”, which has been facilitated with a number of service provider groups and is available for any group that is interested in becoming more sensitised to how it feels to be a recipient of in-home care.

Another Care Watch Toronto project, the PhoneLine, was a project begun in 1997 with three-year funding from the Trillium Foundation. Its purpose is to collect information about the experiences of in-home care recipients and use the information to draw a clear picture of how the system is working, identifying where there are gaps and inadequacies.

THE PURPOSE OF THE CARE WATCH PHONELINE

Home care is a service that is delivered behind closed doors, by one worker attending the needs of a family or an individual. **Invisibility** characterises all aspects of in-home care. Who is more invisible in our youth-worshipping culture than the elderly – particularly women, who are the majority of the elderly? Or the chronically ill or disabled, in a world where strength, agility, speed and physical perfection are idealised? And what work is more invisible than the work done by health care workers, almost all women, in the privacy of clients’ homes?

Care recipients, their families, the staffs and boards of Community Care Access Centres, many of the government officials responsible for these Access Centres: all hope that the home care services will

be of the highest quality. But we know that high quality service never comes about automatically, that it has to be monitored and controlled.¹

How, then, do we establish quality control in a situation where actual performance is observed only by the care giver and the care recipient? The **life-blood of quality control** in such a situation is **communication** received from care recipients. Complaints are the only way that the invisible weaknesses and gaps in the system can be discovered. Of course, all Access Centres assure their clients that if they experience any problems with the service, the client need only call them and report it. Some clients do call, of course.

Will everyone who has a problem call to complain, however? The answer, we have found, is an unqualified “No.” Clients receiving care in their homes **need** the service: to avoid going into or staying in hospital or to avoid permanent transfer to a nursing home. Their **need**, coupled with their poor health, insecurity and deep desire to remain in their own homes, **makes them vulnerable and afraid**. They fear losing what care they have, being labelled as whiners, being treated with indifference or hostility by a worker or an agency they have complained about. They may, in fact, feel so lucky to have any service at all that they will do nothing to jeopardise it.

The dread of “biting the hand that feeds you” runs very deep for seniors and other vulnerable adults. The power imbalance between the individual care recipient and the “system” that provides their care can be overwhelming. There are always some who are confident enough and assertive enough to speak up for themselves.² But there are many more who, particularly if they have no family backing, will keep silent – **unless there is a way to complain that they feel is completely safe**.

Could the home care system be modified to reduce this fear, so as to actually receive honest communication about the quality of service? Seniors’ and other community organisations

¹ The Auditor-General, in his last report noted that, while the Long Term Care Act requires CCACs and other long term care community organisations to establish formal processes for the receiving and reviewing of complaints, “regional offices had not formally reviewed the adequacy of the complaint resolution processes developed.

² We receive many calls, however, from seniors and their families who have complained to their CCACs, but have given up after receiving no satisfaction.

have been lobbying for years for the government to set up an arm's length, ombuds-type complaints agency, which would not only **be independent of the CCACs and the provider agencies**, but would also be **perceived to be safe** by the vulnerable recipients of in-home care. No one in government has presented any arguments against such an agency, aside from the, nowadays, familiar one of "it will cost money." They have simply sat still and done nothing about it.

The **absence** of such an avenue for **complaining without fear of reprisal** impelled Care Watch Toronto to establish its PhoneLine. We are doing our best to fill an abhorrent vacuum, though we would prefer to see an effective, independent government agency, which could investigate and act on the complaints they received.

Our purpose is more modest. We can encourage clients or their care givers to tell us their experiences, anonymously if they wish,³ and this is what the vast majority choose to do. We can't and don't offer to solve the problems callers describe. We do encourage them to speak to their Access Centres and, if they are at all interested in doing so, we offer suggestions about how they might present the matter. If we can give them any useful information, refer them to any source of help, we do. (We keep resource lists of all kinds for the use of our volunteers). Our primary purpose is, however, to **collect information about how the system is working and use the information to help improve it.**

³ It is strongly indicative of the prevalent fear of reprisal that so many of the callers prefer anonymity.

THE PHONELINE REPORT

1.0 INTRODUCTION

The actual operation of the line began in May 1998, and this document represents an interim report, based on the information received in our first year of operations. Our phones are staffed by trained volunteers, with the whole operation supervised by a half-time staff co-ordinator.

Though the total number of calls may seem small, they clearly indicate the nature of the current problems in the delivery of in-home care. Active knowledge of our operation is still so limited that even two hundred calls suggests fairly widespread concern about how the home care system is working. Since even calling a “safe”, confidential line like ours requires considerable initiative, we consider each of our calls to reflect issues shared by of many others.

Our report focuses on the quality of the service provided by the public home care system. Quality is, of course, the combined result of many kinds of decisions:

- ✓ **policy decisions** (about funding, eligibility criteria, priority, service maximums);
- ✓ **administrative decisions** (about how eligibility criteria are applied, how priority of need is judged, how case loads are managed within a given budget);
- ✓ **organizational decisions** (about how the agency work force is trained, directed and monitored), and
- ✓ **individual decisions** (about how to deal with each individual client, how to manage the assigned schedule of clients).

By reporting the stories of those on the receiving end of home care, we trust that the decision-makers will be led to remedy the revealed problems and formulate strategies to avoid similar problems in the future.

As the number of persons receiving care in their homes continues to grow (due to earlier discharges and a steadily aging population), the calls we have received indicate that **we need to be doing better**. Poor quality or inadequate service, service that is initiated too late or terminated too soon, inappropriately scheduled services or inappropriate denial of service: all result in a loss of client dignity. In the long run, unmet needs at home also result in higher rates of more expensive institutional care.

We trust this report from the people who receive care and those who care for them will reach the ears of those making the decisions and that they will be listened to with respect and attention.

1.1 DATA COLLECTION

The calls or “stories” as we have been calling them were recorded on Caller Intake Sheets, which we designed to obtain two kinds of information:

- ✓ **demographic details** about the caller (care recipient, caregiver, concerned family member or other) and about the care recipient (age, living status, mobility status, area of the city, services received, need for service)
- ✓ the story of the care recipient’s experience, including their **main concerns** about the service they have received, are receiving or feel that they need.

Demographic data is recorded by number, for data entry purposes. Stories are written up in narrative form by the volunteers who take the calls, with common concerns highlighted as key words. A list, with definitions of each key word, appears in a column at the side of the page on which narratives are written.

For example, the key word **Hours** is defined as “enough/not enough hours of service.” **Attitude** means the client “likes/does not like the way the worker talks to me, touches me, listens to me, complies with my wishes.” **Promptness** means “services started/did not start promptly when needed.” Other key words are Costs, Dependability, Continuity, Competence, Safety, Language, Decision-making, Organisation, Isolation, Information and Referral, Transportation. Transferring and Respite.

2.0 THE STORIES

While we have tabulated the number of times each of our listed concerns has been reported by a caller, we found, as we expected, that many callers had more than one concern. One category of concern that overlapped frequently was **Information/Referral**. Some callers wanted only to learn how to access the services they needed, but many of those with stories to tell also lacked sufficient information about the system.

We did not anticipate the degree to which this would exist, but we now know that **the lack of adequate public education about the home care system is a major flaw in its operation**. Much, much more needs to be done to raise awareness of the existence of Community Care Access Centres and their function, as well as of the other community support agencies providing long-term care. Eligibility criteria should also be public knowledge.

One caller, for example, a 79-year-old wife caring for an 86-year-old husband, wanted to know how she could get some help. Her husband is a veteran and they get a small amount of home care through Sunnybrook, but it is not enough because she is now experiencing her own health problems.. She sounds just worn out. (Story #39)

Another caller, a retired nurse, did not know about CCACs. Her husband was in hospital with pneumonia following a stroke. She wanted to know what services she could get for him when he comes home from the hospital. Evidently no discharge planner was in the picture. (Story 74)

We feel that the providing of essential information about the home care system is an appropriate part of the function of our PhoneLine and we are continuing to expand the collection of information, which our volunteers use in answering caller's questions.

I have a yearly evaluation from the CCAC but have already had service cut several times.

Somebody is coming again to tell me how much they are cutting now. I am already down to an hour a day.
Story 128

I was getting two hours of homemaking a day and that was adequate. The hours have now been split into four half-hours at unspecified times.

Different home-makers come each time and none are able to complete any task in the time allotted.

This was done before, but they had so many complaints that they cut it out. Now, they have reinstated it.
Story 66

In presenting the exemplary stories that follow, we have clustered them according to the level where decisions are made that lead to particular kinds of concerns.

2.1 HOURS and COSTS

We found that not only did caller's concerns overlap, in that many callers had multiple concerns; but the levels of responsibility tended to overlap as well. **Hours** of service provided to each client, for example, are determined by the CCAC care co-ordinators. CCACs must, however, work within guidelines provided by the Ministry and within the budgets set by the Ministry, a fact of life that conditions their choices.

But even under-funded CCACs have choices and may make some ill-judged ones. "It's because of the cutbacks" is a too easy explanation of inadequate care, and it may be heard too frequently throughout the health care system. If under-funded hospitals choose to lay off nurses, for example, rather than forego purchase of the latest available piece of medical technology, we have to recognise that this is their choice, not an inevitability.

Similarly, though all CCACs face funding constraints, they each respond to these constraints in their own way. And while each care co-ordinator may know that she must assign the minimum possible number of hours, so as to serve a maximum number of people, she still must make a judgement call when she decides to tell Mrs. Smith she can have only two hours of service a week, instead of the four she has been receiving.

"Not enough hours of care" is, therefore, a category of complaint affected both by the policy decisions made at the **Ministry** level and by the administrative decisions made by the **CCACs**.

The same applies to concerns about **Costs**, which we define as the client **"can/can not afford to pay for supplementary service."** Supplementary

One caller had a fall and was in hospital for ten days with fractures of leg, ankle and ribs.

She lives alone in a three-story house and has no family. When she asked about home care she was told she was "over-reacting," but if she wanted help she could look in the Yellow Pages. She got no service. *Story 5*

A couple, in their eighties, live in a seniors' residence. It takes all their money to pay the rent and buy the necessities. The husband is blind.

He gets no service, which was fine until his wife fell. She received two hours a day for personal care and Physiotherapy. It takes 1½ hours to get the wife ready for the half-hour of physiotherapy.

Then the CCAC cancelled one of the two hours because it appears that they can afford it (*which they can't*). "We feel we are being forced to purchase the other hour because it looks like we can afford it".
Story 71

service comes into the picture only when the hours provided by the public system are inadequate to the patient's perceived need. There may, of course, be clients with an exaggerated perception of what they need. But this can not be presumed always to be the case. We hear too frequently from callers that the care co-ordinator has suggested the client "top up" services by hiring a private care-provider. "Just look in the Yellow Pages," as the client in Story 5 was told.

If a client **"can not afford to pay for supplementary service"** that she believes she needs, this is only another and stronger way of saying that the hours provided by the public system are inadequate. The decision-making responsibility is again divided between the Ministry's funding decisions and the CCACs chosen way of responding to these decisions.

Formally, there is no "means testing" for in-home service. Many of our callers have, however, been convinced that care co-ordinators' assumptions about their apparent financial status were silently, and occasionally even vocally, taken into account in deciding how much care they would receive. It need hardly be pointed out that an elderly couple may live in a well furnished home but be living on a very limited income. (See Story 71 as an example.)

Another client, for example, who had lost one leg and the use of one arm, received home care five days a week for one year, was cut to two days a week in the second year and had just been told that her service was to be **cut off altogether because her husband had money in an RRSP**. She cannot afford the rates of private agencies but she must have help because she has two young children and her husband is often away.

Lack of **information** is a concern that overlaps with concern about **costs**. We find that callers frequently have not been told by their CCAC that community support agencies may offer supplementary home health care at rates applied on a sliding scale, according to ability to pay. A disturbing

Caller's mother, who has Parkinson's and Osteoporosis is very unsteady. Daughter worries constantly that her mother, alone most of the day, will fall and not be able to get up. No service is being received. Her mother won't go into a nursing home and daughter can't afford the \$10-\$12 an hour charged by private agencies.

Story 108

"My daughter needs medications and that restricts the number of homemakers qualified to help her. Even then I have to train the home makers on how to give her particular medications. Some times no one who is qualified is available, so no one comes. It has been a real struggle to access the system. I worry about those living alone. I worry about the future."

Story 119

number of callers were unaware of such possibilities and thought their only alternative was to pay the full charge of private home care agencies.

That much depends on administrative decisions is shown by the story of Olive, in her late eighties, who is quite frail and lives with her wheelchair-bound husband in a seniors' apartment building. She had an accident two years ago that left her with a mobility problem in her shoulder. One consequence is that she is unable to push her husband's wheelchair or give him other assistance. He has had several strokes and a heart attack. While they lived at Yonge and Eglinton they had excellent help. Since they have moved to Mississauga they have had serious problems. They had no service at all for the first three months. When they finally got a homemaker she said that she was "not allowed" to push the husband's wheelchair. (Story 95)

We heard from another caller, a 64-year-old handicapped caregiver for a father in his late 80s, that she herself was disqualified for homemaking services because she can get into the shower without help.. But, as she pointed out to us, she is unable to vacuum or do laundry due to her shoulder injury. (Story 97)

2.2 COMPETENCE, DEPENDABILITY, ATTITUDE

Competence is defined as **"the worker does/does not appear to know what to do."** Dependability means **"the worker comes on time/is sometimes late, sometimes does not come."** Attitude means the client **"likes/does not like the way the worker talks to me, touches me, listens to me, complies with my wishes."**

These are all concerns which seem to be more personal than systemic; i.e. they stem from the competence, dependability and attitude of the individual care-provider who is sent into the client's home. Whether the client **feels safe** in her hands and whether she feels **less isolated** because of her visits are closely related to the care-provider's abilities and attitude.

"The homemaker was reluctant to do the vacuuming because it made a noise and was unwilling to do dishes in the sink because they had not been used while she (*the homemaker*) was in the house."

Story 15

"My friend, who is confined to a wheelchair, had a homemaker who did no work at all, but spent her afternoon in front of the TV, keeping the remote control so she could watch her favourite programs. When my friend protested, the young woman replied sternly, "You're NOT going to report me!" The next day she brought her six-foot-tall boyfriend, who repeated the warning and stayed for an afternoon of TV entertainment. My friend told no one but me and I could not persuade her to tell anyone in charge."

Story 209

But responsibility for the competence and caring qualities of the worker is more than simply a matter of personal responsibility. The hiring policies and personnel practices of the provider agency come into play. There are some personal care workers who are so **dedicated to caring** that they will give high quality care and attention to the client's needs, even if they themselves are poorly paid and working under stressful conditions.

But if workers are underpaid, kept in a casual employment status, forced to hurry with each client in order to get in enough paid-for hours to make some kind of a living – everyone employed under such conditions will not prove adequate to the needs of their frail clients.

Are personal care workers so badly treated? Clients, themselves, even as they complain about unsatisfactory care, are aware that this is often the case. We know that some private agencies are paying sub-standard wages and insisting on casual status for their workers, the better to control their own costs and their own profits.

It can not be expected that the employment they offer will be attractive to anyone who has any other opportunities. It is already becoming a worry in the service community that the opening of new nursing home beds will draw personal care workers out of home care and into institutions that offer better pay and better conditions for the same qualifications. (There are similar fears about home care nurses, who are also paid less than hospital nurses.)

Many non-profit agencies have union contracts and are meeting the requirements of earlier pay equity legislation. They fear, with good reason, that in the “managed competition” process which the CCACs are mandated to enforce, they will lose out to for-profit agencies. While everyone connected with the CCACs protests loudly that they will never allow cost to determine which agencies are awarded contracts, the pressures of scarce funding, if it continues, will inevitably push them in this direction.

Caregiver was five months pregnant and was constantly out of breath, so she needed many rests. She asked me to help her!
Story 177

Mother, 81, was admitted to hospital with congestive heart failure in January. Her husband has Alzheimer's and is in nursing home. She was given homemaking indefinitely but was not comfortable or satisfied with the service. Different people were sent and they often shouted at her and did not do any cleaning.
Story 90

The caregiver used the same pair of gloves for my hygiene, skin dressings, bed-making and food preparation and saw nothing wrong with this
Story 189

The homemaker refuses to clean the toilet because some- one used to do that for her in her country of origin.
Story 38

The competence, dependability and caring attitude of home care workers results, therefore, from both their nature as individuals and from the policies of those who hire them. Our stories speak to the effect on the care recipients of receiving care from those, individuals or agencies, who **don't care enough.**

2.3 CONTINUITY, ORGANIZATION, PROMPTNESS

We define continuity as **"the same person/a different person comes every time."** Organisation means **"the service is/is not well organized, coordinated."** Promptness is defined as **"service started/did not start promptly when needed."**

Decision-making that results in lack of continuity is primarily at the level of the provider agency. The agency may or may not consider that it matters whether the same or a different person comes to a client. Some agencies, for their own reasons, prefer to keep their employees on a casual basis, telling them each day whether and how many hours they are to be employed and which clients they are to visit.

This is a stressful system for the employees involved, who have been known to sign with more than one agency to be sure of a full day's pay. They may have to rush through whatever tasks they are performing, with no time at all to interact with the client. As a consequence their job satisfaction decreases greatly and turnover becomes a large factor. Not long ago, home care nurses in Kingston went on strike against just this aspect of their working conditions.

From the care recipient's point of view, continuity looms as a large component in the quality of service. If the same person comes each time, a relationship, often deepening to friendship, develops between care recipient and caregiver.

The chiropodist who called was treating a 63-year-old diabetic man for an abscess on his foot. He broke his toe, had surgery at the hospital and was sent home, with arrangements for a nurse to come daily to change the dressing.

The nurse came one day and then did not come for two days. He did not have regular treatment. The result was that the wound became infected and the toe had to be amputated.

Story 106

The client feels **more safe** and **less lonely** because someone she knows and has come to trust visits her on a regular basis. The care-giver may be performing intimate tasks like helping with a bath. It is hard enough to reach the point where you require such help; it is even harder if the person helping you is always a stranger.

Continuity is a value and should be seen as a value by agencies and by the CCACs as they award contracts for service. It is not, perhaps as “efficient” from the viewpoint of the scheduler deploying a casual labour workforce. But research has shown that health outcomes are better, both in hospitals and in homes, when the same caregiver serves a patient on an ongoing basis. Whatever continuity may cost, should be considered a **necessary cost in the provision of high quality service.**

Lack of effective **organisation and co-ordination** may and often does occur in the provision of in-home service. One caller told us about her mother’s experience after hip surgery. The mother stayed at the daughter’s home for a while after discharge from the hospital and received homemaking services there (daughter at work all day). When the mother returned to her own home, the service followed her but, but the first week no one came for the first two days. On the third day, the homemaker got lost, the next week a different person came, then the next week another person came. The last one was dependable and after that they got good service. (Story 106)

Another caller, Martha, told about her in-laws, both 85 years old who live together independently. Her father-in-law is almost bedridden by a heart condition; her mother-in-law is almost blind. They have been receiving homemaking care three times a week for two hours each visit for more than six months.

90-year-old mother has middle-stage Alzheimer’s; father also demented. Each receives homemaking services from two different agencies. Scheduling by the two companies is not co-ordinated. Sometimes two come at the same time; sometimes no one comes. Caller feels that the CCAC wants her to put her parents into a nursing home and this is why there is so little consideration for the family’s needs.
Story 69

Caller’s friend, who had broken her arm, needed service only from Meals on Wheels. Caller ad-vised her to call her CCAC for the famous one-stop shopping? At first she was shunted from one line to another, with long waits. Finally she was told to call the Scott Mission, whose catchment area, it turned out, was east of where she lived (*in the High Park area*). The CCAC were not helpful at all.
Story 100

She feels the care is inconsistent and minimal. Different people come all the time. The mother-in-law is afraid to open the door because she doesn't know who it is; it's always a new person.

Some of the workers don't speak English very well and the mother-in-law (who is almost blind) has to try to show them what to do. Some refuse to do things. Some of the workers complain of sore backs, and feeling sick. Martha's in-laws tried to speak to Home Care but there was no change. Martha is having trouble even getting the Coordinator on the phone.

Lack of co-ordination is most serious when it appears in the transition of a patient from hospital back to the community. CCAC care co-ordinators are stationed at all hospitals. Whether or not a sufficient number are so employed is an open question. We do know that no system is in place to guarantee that the CCAC co-ordinator will know the time and post-discharge needs of every patient. This is particularly complicated in the downtown Toronto teaching hospitals, where patients may be going home to anywhere in the Greater Toronto area or beyond it.

While home care services for caller's husband were generally good, there were breakdowns every 3 or 4 months. Whenever a staff member was absent, clients were expected to just get along without service or accept an un-trained replacement. One of the replacement workers was both rude and threatening.
Story 148

Client sent home from hospital with terminal cancer. Home care coordinator did not make contact with CCAC in time for service to be arranged. Demerol was to be administered through IV, but IV was not sent home with her and she was without Demerol for many hours. Ventilator machine was sent without personnel or instructions for use. After many attempts to get proper care, patient was finally sent back to hospital where she died peacefully after proper pain management.
Story 110

2.4 RESPITE, TRANSFERRING, TRANSPORTATION

Some of the most disturbing stories we hear are from family caregivers, struggling to keep their loved ones as comfortable and healthy as possible, but staggering under the load because they are unable to access adequate respite.

Respite care no longer exists as a category of in-home service. Instead all forms of service are considered as respite for the care giver, whether it be a professional visit or the visit of a personal care/homemaker. The family care giver, in other words, is deemed to be relieved if anyone else is in the home. (She can slip out to the bank or to pick up a few groceries.) This policy determination by the present government's Ministry of Health has resulted in what amounts to denial of the support to care givers contemplated by the Long- Term Care Act.

The policy has far-reaching implications. It assumes that anyone going into the home for any reason is capable of dealing with the patient's problems on her own. What apparently has not occurred to the policy makers is that when a family member takes on the job of full-time care giver, the **patient's needs are usually extensive and complex.**

Alzheimer's disease, acquired brain injuries, post-stroke disabilities and, in children, birth anomalies and developmental handicaps: these are among the most common problems family care givers deal with. These conditions not only make for heavy demands; they also require special training and skill development. Any family care giver will tell you that the biggest problem is getting **competent** respite workers, who will take **as good care** of the care recipient as the family member routinely does.

Most family care givers could easily free themselves from their burdens by placing their loved one in an institution. They have **chosen** not to do so. For the same reason that they made this choice, they are unwilling, most would

My husband acquired a brain injury when he was knocked off a bicycle. I also have school-age children. My husband needs to be supervised for all aspects of personal care and daily living. He also has to be supervised at meal times. His brain injury has created behaviour problems which are, at times, disruptive to the family environment. He will never return to his job; therefore he is dependent on me to provide ongoing support and supervision...At this time I do not have any respite. One day a week would give me a break that would allow me to. We are a young family and this is a life-long commitment.
Story 208

When Rose's story was told in an article in *The Toronto Star*, we received a call from Olga, who said that her situation was just like Rose's. Her father, who is 86, has Alzheimer's disease. Her mother has recently been operated on for colon cancer and is not strong enough to help. Olga gets no respite, only 1 ½ hours a day of homemaking support. She gave up her career as a chemist to become the family caregiver.
Story 112

say unable, to leave the person they care for in anything less than capable hands.

One of the first callers to our PhoneLine was Rose Giglio, who told us, as a few others have done, that she had no objection to putting her name to her story. Rose is a full-time family caregiver for, first her father, and now for both her mother and her father. Rose has been in this position for four years and has kept a diary of her experiences in getting support and respite care. She shared her diary with us and has kept us updated on her experiences this year.

Rose's father, who suffers from advanced Parkinson's disease, was in a nursing home when Rose, coming home for a visit, discovered that his experience there was intolerable. She left her own career to bring her father home and devote herself to his care.

By 1996, Rose's mother was having severe, incapacitating back pain and Rose's responsibilities increased accordingly. In the years that Rose has functioned as the family caregiver, she has had many disappointments in the home-making support and respite she has been promised. The biggest problems have been connected with **transferring** Mr. Giglio, who needs to be moved from the bed to the toilet and to his chair. If he is left lying in bed all day, pressure sores emerge very quickly on his fragile skin. The only times Rose has had any comfortable, uninterrupted time off have been when a male home-maker was available, which has not been often. She has a Hoyer lift for the use of workers coming in, though she herself never uses it and has learned to handle the transfers herself. The women workers who come in are either afraid of injuring themselves, or do actually injure themselves and have on occasion injured the patient in their attempts to transfer him.

After 20 years with a head injury a man of 53 is still relying on one person for all his needs. He needs trained ABI Personal Care workers to take on some of his care so that his wife does not burn out and need hospitalization herself... The CCAC has not addressed these needs. Other agencies do not have trained on-line workers and his wife can not risk leaving them alone
Story 206

Husband has suffered a minor head injury which left him in a condition where he can't be left alone with the children due to anger outbursts and inability to make appropriate decisions. Wife had to leave her job for this reason. Feels she needs help with regular home maintenance, counselling for family and more respite for herself.
Story 204

Rose feels that the CCAC wants her to place her father in a nursing home again. They seem to think that she is expecting too much in asking for a whole day off once a week, with her father receiving the same quality of care that she provides for him on the other six days.

It is now approaching five years that Rose has been wrestling with this problem and it has still not been solved.

Another correspondent with our PhoneLine has been Elizabeth Dilley, whose brother sustained a severe brain injury in 1989. She and her husband brought her brother to live in their home a year later and have been caring for him ever since. Elizabeth writes:

At the time I thought that when I could put him in a loving environment he would progress. He did progress but, very slowly. I had expected to have home support from the various agencies and, surely, someone other than family to give me a break. After all I had relieved the system of this very expensive patient. There turned out to be very little sympathy or support from the system outside the hospital. Home care physiotherapists and occupational therapists were not trained to deal with the level my brother required.

We hired privately using all our financial resources, to give me 3 ½ hours respite twice a week. I found that the staff sent to relieve me were not adequately trained or informed about their client; most times they did not even know he was in a wheelchair. Most staff did not know how to deal with him; some thought he was retarded or mentally ill and treated him accordingly, causing him great frustration.

At this time I am able (due to a well-fought litigation) to provide for his ongoing needs, as well as help for me for 6 ½ hours three times a week. This, however, takes most of his monthly income, the rest provides for wheelchair repairs, transportation, dentist, etc.

To this point, my husband and I have not had a break from my brother for nine years.

My son was severely brain injured in 1988 in a motor vehicle accident. He requires 24-hour a day care. My husband and I have been caring for him for the past ten years. Recently my husband had major surgery for lung cancer. At this time I am looking after both my husband and my son. I need respite care for Michael. There are no congregate living arrangements for ABI clients in York Region and no transportation from Thornhill to Richmond Hill.
Story 207

Elaine's main concern is that they are not receiving enough care for her brain damaged daughter. Daughter had been on an Acquired Brain Injury program. Now, however, she receives 21 hours a week of care from the March of Dimes. For the past two months they have had no home-making support. Mother feels no one is listening to them.
Story 81

Our callers have also cited **transportation** as a concern. Problems include those of spouses with mates in nursing homes too far away, like the caller in Story 59, and also those of patients who have to travel to hospitals for

Our clients have also cited **transportation** problems. These include spouses with mates in nursing homes too far away, like the caller in Story 59, and also patients who have to travel to hospitals for radiation or other essential treatment. Another caller, in Story 29, is too weak for chemotherapy, but could have radiation following her second mastectomy, if she could get to Sunnybrook hospital five days a week for three weeks.

Caller said that her husband, whom she had cared for for many years, was finally placed in a nursing home. Although there are two nursing homes close to where she lives in Mississauga, her husband was placed so far away that it takes three buses for her to travel to see him.
Story 59

IS THERE A LONG-TERM PLAN FOR LONG TERM CARE?

We have to question whether or not there is a plan after listening to the calls we have received and observing government funding and policy decisions regarding the Community Care Access Centres. What we have seen in the past four years appears to be mainly *ad-hocery*.

Proposals to reform long term care go back almost fifteen years, through the terms of office of all three Ontario political parties. Drafted and re-drafted, debated and consulted over, reform was always aimed at helping seniors to “age in place” and the chronically ill or disabled to live at home. **Supportive care, delivered to clients in their own homes**, remained **the core** of all the various versions that finally eventuated in the Long Term Care Act passed in early 1995.

Unfortunately, the government that passed this legislation had not yet, when it left office, prepared the necessary regulations to make it operational. The new government did not rescind the Act, nor amend it, nor issue any regulations under it. What they did, after some deliberation, was to announce the establishment of **Community Care Access Centres** in areas corresponding to the areas of the district Health Councils. (The exception was Toronto, where, shortly after the decree amalgamating the old cities into one new city, the decision was made to establish six Access Centres, one in each of the six old jurisdictions.)

Many people assumed that, sooner or later, there would be amendments or regulations to the Long Term Care Act to provide a legal basis for these Access Centres. When no such action was forthcoming, the Access Centres themselves began to ask questions about their legal status and were told that they were “**creatures of government policy,**” not subject to the Long Term Care Act. It continued, nevertheless, to be widely assumed that this was a temporary situation and that the necessary regulations were being drawn up and would soon be announced, so that the legal status of the CCACs would be regularised.

It was not until, in January of this year, the case of a Niagara CCAC client reached the Health Services Appeal Board that the intentions of the Ministry of Health became clear. Through its attorneys, the Ministry argued that the Niagara CCAC was **not an approved agency** under the Long Term Care Act and that, therefore, **no right of appeal** existed. In other words, they maintained their

previous assertions that CCACs were simply “creatures of government policy” and, by implication, that the Long Term Care Act was not in operation.

The Ministry’s position was overruled by the Appeals Board. They declared that the Niagara CCAC (which had been totally funded by the Ministry since its inception) was, indeed, an approved agency under the Long Term Care Act; and that the client, Ian Strathern, had the right to appeal for the amount of service he needed, as opposed to the amount of service the Access Centre deemed they could afford to give him. The government chose not to go into court to challenge this ruling and lawyers tell us that it now stands, with the legal implication that all Access Centres are operating under the Act, and that the right of appeal and the Bill of Rights are available to all clients.

Despite this ruling and its clear legal implications, the Ministry of Health and the Ministry of Long Term Care appear still to be operating on the assumption that the Long Term Care Act does not apply to the Community Care Access Centres. While they draft and redraft a document called “Service Directions for CCACs and other LTC Community Agencies,” they are already imposing their chosen prioritization criteria and, in doing so, **changing** totally **the meaning of long-term care** as understood by most Ontarians.

Their aim, according to the document, is to see that “resources are targeted to those most in need of service.” **First priority goes to persons “who are at risk of dying or suffering the breakdown of an essential bodily function.”** Until recently, of course, anyone would assume that patients at risk of dying would be in hospital, where medical attention is available around the clock. But we live in the world of hospital restructuring, where acutely ill persons are no longer to be kept in acute-care hospitals once they are stabilized. The second priority are persons “with acute health care problems,” those who “require supervision,” or are “at risk of abuse or crisis,” or “who have mobility impairments that require assistance with transferring and toileting.”

These priorities, though contained in what is labeled a draft document, are already in operation. All CCACs have been told that they must care for cases that fall into these first two priorities **before** anyone else receives care. For many CCACs the level of funding they receive is being largely and sometimes totally absorbed by these high-acuity cases. Those who need supportive care to remain in their own homes may have to wait or do without it altogether.

Since there is no sign of a major transfer of resources to the Access Centres, the whole thrust of government policy appears to be to move the CCACs towards **meeting the crunch created by hospital restructuring**. Those who are disabled by age-related or chronic conditions are largely being left to fend for themselves. They can get help from family members if they are available. Or from paid caregivers if they can afford it. For those who have neither family nor money, the alternative is unnecessary deterioration, with possible admission or re-admission to acute care or to what is now called a “long term care facility.”

The term, “long term care facility” was introduced by the present government and is now the preferred way to refer to what we used to call nursing homes and homes for the aged. This change in terms has been followed by the establishment of a Ministry of Long Term Care, which now presides over 1) a home care system dealing more and more exclusively with post-hospital needs and 2) the establishing of 20,000 new beds in “long-term care facilities.” Long-term supportive care, delivered in clients’ homes, is falling out of the publicly funded home care system. The present long-term plan for long-term care is beginning to look like **warehousing instead of aging in place**.

RECOMMENDATIONS

1. **Sub-acute beds**, recommended by the Health Services Restructuring Commission in every jurisdiction, should be established without delay. These beds would eliminate the need to send patients home when they are still in danger of dying or losing some essential bodily function, as is now being done. It is worth noting that our hospitals are now assessing the end of the acute stage for each patient according to an American assessment tool. But the American tool is based on the widespread existence of sub-acute care facilities in the USA.. Sub-acute care is currently, in fact, the fastest-growing segment of health care there.
2. Funding for the Access Centres must be substantially increased to allow them to **provide supportive care to the frail elderly**. as well as taking care of patients discharged too soon. For seniors, as well as the younger chronically ill, to maintain optimum well-being in their own homes, they must have basic cleanliness and order. If they can not maintain this for themselves, home care services must do it for them. The current downgrading and reduction of home-making services should be brought to an end.
3. An arm's length, **ombuds-like complaints office**, for recipients of in-home care, should be established by the government, widely publicized, with confidentiality guaranteed. The proper investigation of complaints is the most effective means of controlling the quality of service being provided. At the same time, the Access Centres themselves must increase their efforts to make clients feel that calling them with complaints is safe and that proper attention will be paid to their calls.
4. **Public education** about the Access Centres must be greatly increased. Their location, the services they provide and the eligibility criteria for obtaining service must be better known to Ontarians than is the case today.
5. The *ad hoc* status of the Access Centres must be brought to an end by the establishment, after full public consultation, of the necessary regulations to **make the Long Term Care Act operational**.

6. The Access Centres must make more diligent efforts to **monitor the quality of care** they provide. The situations described by our callers should not occur anywhere and we are confident that the Centres are as anxious to prevent them as we are. They will not necessarily hear directly about these gaps and inadequacies, because, as we have pointed out and as our experience with the PhoneLine has demonstrated, many care recipients are afraid to complain to the system that dispenses their care. Each Access Centre should assume that the stories in this report occurred in their own catchment area and act appropriately to prevent their reoccurrence.

7. **Adequate respite** must be provided, particularly for families caring for members with acquired brain injuries, Alzheimer's disease, Parkinson's disease and other conditions that require heavy, round-the-clock care. Respite is equally necessary for elderly spouses caring for their mates. **Special training for respite workers** must be established so that an adequate number of competent respite workers are available.

CONCLUSION

We opened this report with a question. **Who cares about Home Care?** The answer should be, **Everyone must care.** We are living at a time when an increasingly large and still growing proportion of the population are seniors. And while seniors are in better health until later in life than in the past, they still need a larger proportion of health care resources than do most younger members of society.

But with seniors, as with all age groups, population health depends on many factors besides doctors, hospitals and pharmaceuticals. The well-known determinants of health and the promotion of health education and other preventive measures are at least as important as medical services. That is one reason why the present trend towards the medicalization of home care is so disturbing.

The wellbeing of seniors is best fostered by making it possible for them to remain in their homes and among their neighbors as long as possible. The lack of supportive care to enable people to **age in place** can be only a negative determinant of their health. Morale and confidence are significant factors; being able to count on the help necessary to maintain your accustomed way of life can improve the wellbeing of seniors and prevent their premature decline. In the long run, premature decline leads to higher costs to the health care system. This is what long-term care reform was all about and this is what is being lost as the Home Care system is increasingly pushed towards taking up the slack for downsized hospitals and earlier discharges.

Seniors are not the only ones affected by the adequacy or inadequacy of the Home Care system. Their younger family members are deeply affected, because they have to take the brunt of any and all inadequacies in the public system. Younger adults with acquired brain injuries or other chronic illnesses or disabilities, and those family members who care for them, also depend on the public system for support and respite.

As the number of persons needing care in their homes continues to grow (due to earlier discharges and a steadily aging population), the calls we have received indicate that **we should be doing better.** Everyone involved in the current Provincial Elections, candidates and voters, should give serious heed to the concerns documented in this report. Ontario needs a more effective and a fully-funded Home Care system, now and for the future.