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Returning Home

*Fostering a Supportive and
Respectful Environment in the
Long-Term Care Setting*



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Respectful Environment in the
Long-Term Care Setting*

Our mission is to help the people of Canada
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Health Canada

*Returning Home: Fostering a Supportive and Respectful
Environment in the Long-Term Care Setting* was prepared
by **Jean Kozak** and **Teresa Lukawiecki** for the Family Violence
Prevention Unit, Health Canada.

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Favoriser un milieu de soutien respectueux dans les établisse-
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Introduction

Returning Home: Fostering a Supportive and Respectful Environment in the Long-Term Care Setting, and its companion monographs, *When Home Is Not a Home: Abuse and Neglect in Long-Term Care — A Resident's Perspective*, and *Stand by Me: Preventing Abuse and Neglect of Residents in Long-Term Care Settings* are a synthesis of the findings of two national projects known as Abuse Prevention in Long-Term Care (APL). The purpose of these monographs is to focus on improving the life of older adults in long-term care (LTC) by approaching the issue of abuse and neglect from their perspective. The aim of the three-part series is to stimulate discussion and action through sharing the experiences of residents, staff, families, volunteers and advocates from across the country. Questions are raised about perceptions and accepted practices in LTC and people are encouraged to explore ways of fostering a caring environment for all who reside, work or visit LTC.

This series of monographs was funded through the Family Violence Prevention Unit (FVPU) of Health Canada. Through the FVPU Health Canada leads the Family Violence Initiative (FVI), coordinating the relevant activities of 13 federal Departments and three central agencies that are formally involved in the Initiative. Under the current FVI, Health Canada remains committed to addressing family violence issues, including the abuse of older adults. In consultation with the Division of Aging and Seniors, the FVPU undertakes research on the consequences of abuse and neglect of older adults to enhance treatment and prevention. The FVPU has developed and revised a number of resources on the abuse of older adults for dissemination through the National Clearinghouse on Family Violence.

The audience for these monographs is anyone associated with LTC who wishes to address the issue of resident abuse and neglect, and foster a supportive and respectful environment in LTC. This includes both individuals within facilities, such as residents, staff, families and volunteers, as well as those external to facilities (e.g. advocates, government regulatory agencies and professional associations).

1.1 APL PROJECTS OVERVIEW

In December 1995, **New Horizons — Partners in Aging**, Health Canada, funded an 18-month national project to develop and evaluate a *resident*-focussed, educational package, with the goals of sensitizing people to abuse and neglect of older persons residing in institutional settings, and raising awareness of the need for a supportive and respectful environment in LTC. The project was overseen by a national steering committee of residents, staff, volunteers, advocates, administrators, family members and researchers.

In the second phase of the APL project (1997), funding was obtained from the Population Health Fund, Health Canada, to train trainers in the use of the educational package. Six hundred and sixty-five people across Canada were trained as trainers so they could return to their communities to train others on abuse and neglect prevention and intervention, and to lend their expertise in working toward solutions. A more in-depth discussion of these two phases may be found in the first monograph, *When Home Is Not a Home: Abuse and Neglect in Long Term Care — A Resident's Perspective*.

This monograph explores a major issue raised by all participants in the various phases of the APL project. Without a doubt, one of the core mechanisms that they felt individuals and facilities alike must develop to address the problem of abuse and neglect is through what they referred to as a supportive and respectful environment.

The importance of this issue can be seen in the fact that the APL Steering Committee, after reviewing the results of the cross-Canada interviews, felt that an educational package which discussed only abuse and neglect would not address the complexity of the problem or truly represent what residents and others were telling us.

The APL participants felt strongly that many incidences of abuse and neglect did not result from willful actions. Rather, the incidences were the end result of a process where the individual — resident, family and staff alike — was not respected; where people were seen as objects that had to be fed and moved according to schedules. The participants hoped and believed that, by fostering a supportive and respectful environment, one would ameliorate the factors that contribute to abuse and neglect while recognizing in everyday practice that the resident is a person. The following is a discussion of the factors and dynamics that APL participants identified as key to a supportive and respectful environment.

Defining a Supportive and Respectful Environment

A supportive and respectful environment is difficult to define, yet everyone agrees that most people want to make LTC a better place in which to live and work. Before presenting a model on a supportive and respectful environment, this section first presents a look at how residents perceive life in LTC. Quotes from the residents who participated in the focus groups provide a first-hand glimpse of what it means to live in LTC.

2.1 PERCEIVED LIFE IN LONG-TERM CARE

The APL focus group participants made as many negative as positive comments when asked what it meant to live in LTC. For some residents, entering LTC is a positive change. They have improvements in health, mobility and social life, and a rejuvenation of the spirit. Many residents are relieved to be in a facility because they feel that they are receiving good care for the first time in years. They also report that they do not feel like they are a burden on their families. The most common reason for entering LTC is that the required care was not available at home.

“To be quite honest, I came here to die; I couldn’t hack it at home, all my kids worked, I was all alone. With the treatment I got here, I perked up right away.” (resident)

“I’m contented here, this is my home.” (resident)

For many other residents, living in LTC is a painful experience. Moving into LTC is a time of great loss for many people. Adjusting to institutional life is difficult, with schedules and rules to follow, and space limitations and lengthy waits for personal care to contend with. In many of the focus groups, residents equated living in LTC to being in a prison.

“You think you’re coming to paradise and you end up in a room with one closet for two people.” (resident)

“The hard part for me when I first came, was going to bed at night. I felt as if I was in prison. It’s smaller quarters and at my age you’re back on rules and regulations again. The rules are not strict, but you’re still not your own person. You’re not in your own home. In my own home I was closer to my family and I went out more.”
(resident)

“We tell them when to get up and go to bed, what activity to do, when to go to the doctor — they have no choice. This person lives 24 hours a day, seven days a week, and there is always someone who will decide everything for them.” (staff)

When describing the move into LTC, residents talked primarily about two themes:

- the difficulty of the transition stage, and
- the many losses they were experiencing.

Transition

The transition stage when a resident first enters a facility is often difficult and stressful for both residents and families. Institutionalization requires great adjustment and many residents are not well prepared for institutional life. Nor are their families. Denial is common among newer residents with some thinking that they are going home when they get better. Other residents are simply resigned that LTC is the place to which they had come to die.

“My family is going to come and get me, and I’m going home.”
(resident)

“It broke my heart when I came here. I didn’t know what was facing me.” (resident)

“It wasn’t the day my husband died that was the worst in my life. It was the day I had to put him in the nursing home.” (family)

Many residents believe that acceptance is a key to successfully adapting to life in a facility. Mobility, choice and the ability to do some things for oneself are also important. Continued family involvement and supportive staff help ease the transition into LTC.

*“Well, I have to get adjusted, I’ve only been here for six months.”
(resident)*

“You just have to learn to live, it’s up to you to learn to adjust. Some people will complain ’til the day they die and some people adjust and make the best of it.” (resident)

“I think acceptance takes a long time. You’re taking these people out of mainstream society.” (staff)

Loss

Many participants described living in LTC as being a time filled with losses, such as the:

- loss of control over one’s daily life, independence and decision making,
- loss of community, friends, family, belongings, homes, rituals and habits developed over a lifetime,
- loss of health and being able to care for oneself,
- loss of intimacy with another person,
- loss of privacy because they have to share a room or bathing facilities and receive intimate care, and
- loss of being active and contributing to their communities.

As one resident said, she went from being very active to “spinning time”.

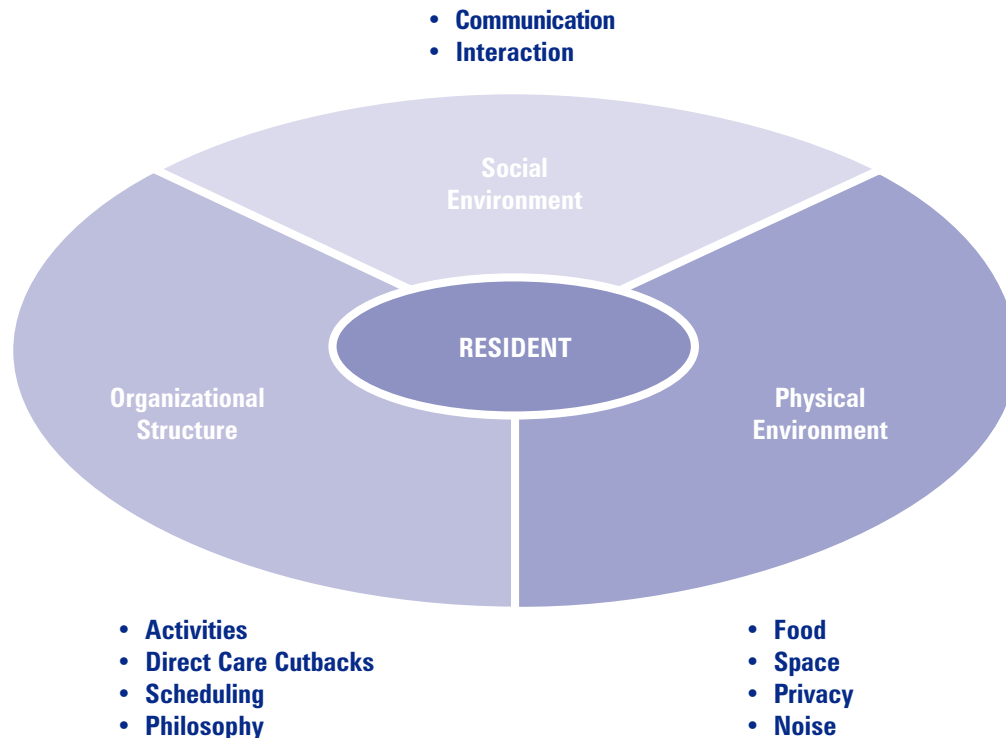
“It’s an awful feeling when you can’t even open your milk. You have to call someone to do it for you. Hard when you have been active all your life, done things for others.” (resident)

“They say it’s supposed to be your home, but then you can’t bring your things.” (resident)

“They know it is the end of the line and so with that goes permanent losses and the mourning... of facing death itself.” (staff)

A supportive and respectful environment was often described by participants as a home-like atmosphere that is resident-focussed, has adequate resources and staff, and is welcoming to families, volunteers and others alike. Often, what residents describe as supportive and respectful is defined as the quality of basic human interaction, such as a smile or a knock on the door before entering. Residents, staff,

FIGURE 1 — A SUPPORTIVE AND RESPECTFUL ENVIRONMENT



families and volunteers have similar visions of what constitutes a supportive and respectful environment although some differences exist in priorities (e.g. safety concerns versus making a room that is more comfortable).

Thus, a supportive and respectful environment is one that is resident-centred and is manifested in the social, physical and organizational contexts (see Figure 1). The following sections explore these factors and their role in contributing to a supportive and respectful environment.

What Is a Resident-centred Approach?

A resident-centred approach is at the heart of a supportive and respectful environment in LTC. To successfully integrate this approach into a facility requires elements that:

- promote resident empowerment,
- maintain resident rights and responsibilities, and
- provide good physical care and emotional support.

When the focus is on the resident, LTC becomes a much more supportive and respectful place for everyone because they are working toward a common goal.

3.1 PROMOTING RESIDENT EMPOWERMENT

The first element of a resident-centred approach is promoting resident empowerment. This means the environment builds on every resident's strengths and abilities. Residents enter LTC with different abilities; some have a physical disability, some have varying degrees of cognitive impairment, others have multiple disabilities. As well, a resident's level of functioning can vary from day to day. The environment must be conducive to supporting each resident's level of functioning for as long as possible.

The underlying theme in creating a supportive and respectful environment is providing residents with opportunities to have some control or power in their life, in whatever way possible. Power is simply the ability to carry out one's wishes and to meet one's needs. All people have personal needs that they try to fulfil. Some examples are:

Physical:	exercise, elimination, sexual expression
Emotional:	reassurance, a safe place to cry, humour
Social:	friendships, meaningful connection with others (e.g. family)
Intellectual:	reading, writing, playing card games
Spiritual:	moments of solitude, practising one's faith

We all have a basic responsibility to take care of our own needs to the best of our ability. The ability of residents to meet their needs can be limited by internal factors

such as cognitive impairment and low self-esteem, as well as external factors such as institutional policies.

Residents can continue to meet their needs as best they can with assistance from others. Some residents can ask for help themselves. We must recognize that even this “simple” action may take considerable courage because, depending on the response, they will either feel like a burden or a human being. Many residents are so incapacitated by communication difficulties or severe cognitive impairment that they cannot ask for help and must rely entirely on other people to identify and meet their needs. Everyone who interacts with these residents must be extra vigilant to correctly identify and then meet the needs in a timely manner. Moreover, decisions over treatment and personal care require the identification of appropriate decision makers in cases in which a resident has been legally deemed incapable of making decisions on her or his own behalf. Who can be a decision maker is defined by the provincial/territorial legislation in which the facility is geographically located.

Residents’ dependency on others to meet their needs and having their daily activities determined by a facility can lead to residents feeling powerless: that is, a lack of control and an inability to have any effect on what’s happening in their lives. Staff, family members and volunteers can also feel powerless.

Some of the signs that a resident is feeling powerless are:

- apologizing for requesting services (e.g. “I really hate to bother you, but...”);
- being unable to make decisions; or
- saying things such as, “All I can do is just sit” — which may indicate the person feels helpless to do what she or he really wants; or “*He’s* the doctor” — which may indicate that the resident believes her or his opinion is not important or not taken seriously. It may also reflect a belief of that age group: the “good” patient is a passive patient.

It is important for staff, family members, volunteers and the community to work together to build a supportive and respectful environment that provides residents with every opportunity to maintain control over their own life by encouraging them to:

- make decisions,
- express individuality,
- speak for self,
- care for self, and
- have a sense of purpose.

In every focus group, participants frequently discussed making decisions, expressing individuality, and speaking for themselves. Resident groups, however, placed more emphasis on caring for themselves and having a sense of purpose than did staff or family groups.

Make Decisions

For residents to make decisions for themselves as much as possible, they must be encouraged to make decisions congruent with their level of functioning. Moreover, although frequently reported by participants as forgotten or not offered, *choices* need to be made available to the resident regardless of the degree of cognitive impairment the person has.

A person may not be able to make certain health care decisions, but that does not mean that he or she cannot make *any* decisions. Some residents can make only simple decisions, such as which shoes to wear or whether to drink coffee or tea. Other residents who are able can be involved in larger decisions regarding the running of the facility. Whatever the level of decision-making ability, when residents make decisions, it is important that their wishes be respected.

Institutional living necessarily means that resident choices are limited because of such factors as space limitations, fire codes and government regulations. However, within these restrictions, facilities can alter institutional processes to facilitate more choices. For example, residents can have more choice in the following areas: bathing time, diet, when to eat, activities, time for bed, and staff caring for them. Choices can help make a facility more home-like.

“We are giving people back choices, like when you go to bed, when you get up. Let them have choices instead of us making up their plan of care.” (staff)

“They are not asked what they want, they are told what they want.” (family)

Express Individuality

Institutional living tends to be impersonal and there is not much opportunity for residents to express their individuality in their physical surroundings and the care they receive. Not only do residents have less space to call their own, they are also restricted by facility and provincial/territorial regulations (e.g. fire codes) and safety considerations. In institutions, people tend to be treated as a homogeneous group

instead of individuals, even though the latter is the intended and desired goal of staff. Care is standardized in order to be efficient and to ensure the delivery of effective care. However, standardized *routine* in care delivery may not meet the needs of individual residents. One staff member summed up the difficulties faced: “We need some way to operationalize focussing on patient and family needs. We talk about it, but actually putting it into practice falls down.”

One way in which institutions are becoming more supportive is by encouraging residents to personalize their living space by bringing in belongings, such as comforters and pictures, and decorating their rooms. Space limitation can be overcome by having family or friends periodically replace pictures or other personal articles with new ones. Common areas can also reflect residents’ individuality. For example, in one facility residents donate furniture to one of the lounges. This means that people can bring in favourite chairs or pictures, allowing them to maintain links with past memories.

It was evident from the various interviews and workshops conducted during the two phases of the APL project that staff and families are aware of the need to respect individual differences among residents when carrying out care planning, and that such considerations translate directly to recognizing the resident as a unique person.

“Instead of having people adapt to the institution, make the institution adapt to the individual. For example, someone who never had breakfast for the last 50 to 60 years, all of a sudden, we decide that breakfast is good, and that at all costs you have to have it. Who are we to decide? This is a small thing, but it makes a difference.”
(administrator)

“If you have your own room and put your own things up, then it becomes more like a home. I wanted my picture on the wall, but they wouldn’t let me because it wasn’t a private room.” (resident)

Speak for Self

Residents need more opportunities to speak for themselves in both their individual care plans and the functioning of the facility. All discussions regarding personal care need to include residents and families.

“Nurses will never stop and wait for a patient to finish up what they’re saying. We have some patients who talk very slowly, she decides that

she's heard enough and takes off. She should stop to listen. They don't communicate." (resident)

"I generally ride with the wind, and if there's something wrong, I'll mention it, and I get full cooperation from the staff." (resident)

"Learn assertiveness. Whoever has a bigger cane rules the elevator." (resident)

Resident input to how a facility runs is most often accomplished through resident councils. However, one drawback is that older residents may not be adequately represented on resident councils because their frailty means that many cannot participate.

"The majority of the issues in resident's council are resolved. Some things can't be because of money. Some residents are becoming less competent and are unable to run the council. The voice of the council comes from younger residents. Issues of older residents are not being addressed." (staff)

Other ways identified by the APL participants as to how residents can speak for themselves include:

- residents evaluating staff,
- residents (and/or) families writing information in the health chart, and
- residents and families filling out questionnaires about privacy, warmth, food, etc.

"What they do every few months is come around with a questionnaire. And you answer these questions about privacy and food and they end up by saying if there's one thing that you'd change, what would that be? That allows you to air your grievances, and I think that's a good thing to ask people." (resident)

Although surveys and questionnaires tend to be the most common method through which residents and others are asked to evaluate a facility and its staff, they are insufficient in themselves. It is necessary to communicate the results of these surveys to groups such as the residents' councils in order to "complete" the loop and allow residents to respond to survey results. Many residents noted that they are asked to comment on food, privacy, staff respect, etc., but they never hear what the results of the survey were. Of course, the reliability of any approach — whether survey, direct interview or discussions at a group level — is highly dependent upon the level of trust that the results will be confidential and anonymous.

Care for Self

The ability to care for oneself is extremely important to residents. Most residents want to continue to care for themselves as best they can. Therefore, staff, volunteers and family members should not do things for residents when they are capable of doing them themselves. This often requires patience, restraining desires to help and putting aside personal interests. For example, it may take a resident 10 minutes to brush her hair while a staff person could do the same task in two minutes. With a busy work schedule, staff may do the task instead of waiting for the resident. There is a fine line between caring for someone and fostering dependence. Mechanical tools are one way in which residents can exercise more control over their environment.

“I get to do everything, my wash, cleaning my room. There are places where you don’t have the right to do things, someone will ask to do a little cleaning, and they’ll answer no.” (resident)

“I like the idea of giving the patient some way of controlling his environment. Something like a remote-control gives esteem, control, choice, instead of having to rely on someone else to do things for them.” (family)

“They should have residents take more active roles in things that they can do physically. I get mad when they say I can’t do it when I really can do it. I want my independence. They don’t include us enough.” (resident)

Have a Sense of Purpose

Residents need to have a sense of meaning and purpose. The expression “soul pain” came up in the Train-the-Trainer workshops when discussing how residents may feel about their role in life at this time. The term refers to feeling hopeless and helpless. These feelings come up because after years of being active in caring for themselves and others, it is difficult for many residents to adjust to being only care recipients. They do not have an outlet to continue to give to others and their life does not have a sense of meaning or purpose anymore.

To address this highly personal and essential need, many facilities enable interested residents to have volunteer jobs or commitments. For example, residents deliver the mail, shovel snow, sit on a welcoming committee, do fund raising, offer

pastoral support or involve themselves in palliative care. In cases in which individuals have significant cognitive impairment, some sense of self might be achieved by allowing them to perform basic actions that were part of their everyday life. For example, in one facility women could fold towels in their rooms. In another, parts of an automobile (prepared to ensure safety) allowed residents to “tinker.” The need to feel a sense of purpose is a basic human trait that does not disappear with loss of cognition. Sadly, it is an aspect of institutional life that is typically not explored, provided, or recognized in provincial/territorial funding formulas.

“Most of those who are happy here have something to do, some responsibility.” (resident)

“Find something, a point of interest... if I didn’t have something, I’d go mad.” (resident)

“Spiritual needs, I think of meaning and purpose, my grandmother comes to mind. She’s severely cognitively deficient, and by accident, she ended up folding some laundry. We saw a great difference in her behaviour and peace of mind, because she folded laundry during a big part of her life. Finding some kind of purpose, rather than being looked after.” (staff)

3.2 MAINTAINING RESIDENT RIGHTS AND RESPONSIBILITIES

The second element of a resident-centred approach is maintaining resident rights and responsibilities. A right is a person’s established legal, moral or traditional claim to power. A person’s rights are no different in LTC than they were when he or she lived at home in the community. As with all adults, residents have the basic right to:

- make health care decisions,
- exercise independence,
- be treated with respect,
- vote,
- enjoy religious freedom, and
- participate in the community to the degree to which they wish or are able.

Similarly, people retain the same responsibilities to care for themselves to whatever extent possible; to treat others with respect; and to respect other’s rights to free speech, privacy and independence.

Residents typically lose personal control when they move into LTC, which, in turn, makes it difficult for them to maintain their rights and responsibilities. Moreover, when labelled as incapable or perceived as suffering from cognitive impairment, a person's rights can be easily dismissed. Such actions can lead to situations in which abuse occurs even though the intention is to protect the resident from harm. Implementing an operationalized residents' Bill of Rights is one mechanism for ensuring that the rights, autonomy and well-being of the resident are respected.

A Bill of Rights and Responsibilities can be a starting point for discussion among residents, families and staff. It can offer a basis for developing a common understanding of what to expect regarding care and living arrangements. A list of residents' rights serves as a reminder that:

- for the resident, the LTC facility is a residence and not just a care facility, and
- residents continue to be valued members of the community.

Although many LTC facilities report having a residents' Bill of Rights, the difficulty lies in practically implementing those rights. For example, the most common methods for facilities to inform people about their rights are to post them on a bulletin board or hand out copies at admission. By themselves, these two methods are not sufficient.

When rights are posted, they are often in small print, written in legal language, placed high on a wall and encased in glass. They are essentially inaccessible to most residents. Handing out a Bill of Rights with no back-up process at admission can be equally as ineffective. Admission is an emotional time and residents and families receive a surplus of new information all at once. They may, therefore, find it difficult to assimilate and remember information at that time.

While it is still important to continue to post a Bill of Rights in common areas and distribute copies to everyone, facilities need to focus on practical methods for implementing a Bill of Rights. To be successfully implemented, there must be:

- support from senior management,
- ongoing education that gives staff, residents, families and volunteers opportunities for discussion, and
- continual evaluations of how well the rights are being realized.

It was evident from the APL surveys and training sessions that some facilities work at integrating their Bill of Rights into the everyday functioning of the facility. For example, in one facility, every aspect of the resident's care plan is based on specific points in the Bill of Rights. Another facility posts one right every month on a poster

in the entrance. During every meeting held during that month, staff, residents and family members, Board members, senior management and others must discuss how well they are meeting that right.

“Most facilities do have the rights now. Every so often all the councils come together and give a report of the problems and successes they’ve had, and it’s a very valuable thing because we’re telling them what they’re doing and they’re telling us what we’re doing.” (resident)

“It’s on the wall down there, so I’m well aware I have rights as a resident.” (resident)

3.3 PROVIDING GOOD PHYSICAL CARE AND EMOTIONAL SUPPORT

The third element of a resident-centred approach involves providing good physical care and emotional support. APL participants indicated that good physical care is characterized by (but not limited to):

- efficient and timely meeting of physical needs,
- competency, and
- promoting of emotional support.

Efficient and Timely Meeting of Physical Needs

Residents within LTC typically require assistance to meet their most basic physical needs. These needs encompass a broad range of personal care, including bathing, eating, dressing and toileting. The process of care must be done in a respectful manner that is both efficient and timely. Residents in the APL projects reported that they felt neglected when having to wait for their basic needs to be met. APL participants, residents, staff, families and others all recognized that the delay in meeting these needs regardless of the reason (e.g. lack of staff) could be perceived as abuse and neglect.

“You ring the bell and you have to ring again 15 minutes later. When I get really angry I just pray that they come.” (resident)

Competency

In order to provide good physical care, staff need to be competent with respect to clinical skills, basic care techniques (e.g. bathing) and use of equipment. Although clinical competency can and is addressed through professional training and

accreditation processes, APL participants indicated that there is a lack of consistency in the use of appropriate care techniques such as bed transfers and use of equipment (e.g. lifts).

Training needs to be made available to teach staff appropriate techniques to reduce injury to both themselves and residents. Problematic funding levels within LTC reduce the likelihood that training on matters, such as how to bed transfer a resident, is available to LTC staff.

In addition to skills training, staff need to become more sensitive to what residents themselves may experience when care is being provided. To achieve this goal, some facilities, for example, seat new employees in a bathing lift to feel how frightening it can be to be left dangling off the floor.

“It is awfully hard on them [staff] too... it’s a two-way street. They don’t know you from a load of hay. At bath time I’m so nervous of that lift... I slip and slide all over.” (resident)

Providing Emotional Support

Along with good physical care, residents also require emotional support. Emotional support is shown by actions such as:

- listening attentively,
- taking time to talk with residents,
- holding a hand or hugging,
- smiling, or
- offering a kind word or a little reassurance.

Emotional support is facilitated by providing the individual with the opportunity and means to feel and express emotions. To do so requires the resident to have access to privacy when needed, to experience emotions without being rescued, and to have support when needed. Sometimes, the most powerful support that can be provided is simply being present.

*“All I could do was hold her hand to let her know that I cared.”
(staff)*

Residents need privacy to express their emotions without it being considered a clinical problem. For example, one resident in the APL project stated that she felt like she could not cry anymore because when she started crying staff would want to “give her a pill” to make her stop.

Emotional support is especially important during the transition period when a resident first enters LTC. LTC is where residents typically live out the last years of their lives. For many, it is a struggle to come to terms with the many losses they are experiencing at the same time: loss of their homes, health, community, friendships, independence and routines.

The key to coping with the emotions surrounding these personal losses is providing a safe and supportive environment. Permitting residents to grieve their losses acknowledges that they are more than just clients to whom care is provided. This goal can be obtained by adopting programs such as a resident or volunteer buddy system, orientation group sessions, and bereavement ceremonies and announcements for residents who die.

“Some nurses are so wonderful... they’re considerate. They deal with you as if they have a heart.” (resident)

“Admission needs an overhaul. More time should be put into it. I can’t overestimate the importance of humour, patience and goodwill.” (resident)

“People need to be flexible and compassionate, and the last five years there have been times when I’ve thought ‘what happened to flexibility, empathy, compassion?’” (resident)

Fostering a Supportive and Respectful Environment

A supportive and respectful environment is fostered through the social, physical and organizational environments. There are many details for staff (clinical and administrative) to consider and many avenues to explore. It is important that all three environments are addressed. It is also important to realize that the creation and maintenance of a supportive and respectful environment does not require extra time or money. It only requires greater awareness of how we interact with others. It requires the desire to change, and the means to promote such change.

4.1 SOCIAL ENVIRONMENT

The social environment is the cornerstone of a supportive and respectful environment. It is characterized by:

- the quality of interactions between people, and
- the type of interactions.

Quality of Interactions

The degree to which the social environment either fosters or hinders a supportive and respectful environment is determined by the quality of interactions between people. Interactions in LTC are affected by:

- conflicting needs
- power differences
- communication
- attitudes
- behaviours

Conflicting Needs

Residents, staff, families and volunteers have roles, needs and expectations which sometimes are in conflict with those of another group (e.g. residents want someone to speak with, staff need to get their work done, families or volunteers have other commitments). The conflict is a product of the division or tension

between work and home. For residents LTC is home; for staff it is their workplace; for families and volunteers it is a place to visit. There is also a strong contrast between busy staff and residents with time on their hands. Reconciling the conflicting needs and expectations in a manner acceptable to all parties is achieved through flexibility and openness in communication.

“The biggest change now is that we’re changing from ‘this is my job and these are my needs’ to ‘what are resident and family needs, and how are we going to organize our team around meeting them?’”(staff)

“We are dealing with all kinds of diversities and expectations, where staff, families or residents are concerned, and our ability to meet those concerns are something that we struggle with.” (administrator)

Power Difference

Within LTC, power differences exist among residents, staff and families and among staff themselves (e.g. direct care staff versus administration). These differences, in turn, affect an individual’s freedom to make decisions and act.

Because LTC is structured in a hierarchy of responsibility from that of the chief executive officer down to the care aide or volunteer, there will always be power differences. However, efforts can be made to mitigate the effects of the differences on individuals by recognizing that power differences do exist and promoting meaningful participation in shared decision making, with some of the control distributed among others. Sharing power does not mean that one group has to lose power.

“No, I don’t feel any abuse. What I find is that you’re under their power, and what you want doesn’t mean a bit of difference to anybody. You don’t have any say on where you go or what you do. I’m at a disadvantage because I don’t hear very well, so they just go and do things their own way. Well, they may try to talk to me, but they don’t make it so I can understand.” (resident)

“We have to recognize there is a power differential, but it does not have to be exercised, or it can be exercised in other ways. Our challenge is to try to neutralize, as much as possible, the power differentials.” (administrator)

Communication

How an interaction between individuals or groups of individuals is perceived depends on the quality of the communication between them. It is important that all communication be respectful. There is a need to increase communication and establish avenues that promote interaction. Good communication means listening to one another; being honest; having ongoing discussions among staff, resident and family; taking the time to talk with residents; and providing information, reassurance and support.

Respectful communication for staff includes not gossiping about residents, not discussing resident's care or body functions (e.g. bowel movements) in front of others, and not talking over residents (e.g. to another aide on the other side of the bed) while providing care.

For residents and family members, respectful communication involves speaking up about personal needs, keeping in contact with staff, and posting resident preferences.

Respectful language is an integral part of good communication and includes addressing residents by name, not using a resident's first name unless the person requests it, not calling residents "dear" or "honey," and not swearing or using other abusive language.

"Staff say, 'I'm going to do you now,' and that leaves a person feeling like a thing. You don't do a person, you do the dishes." (resident)

"A lot of my friends tell me that it's not in what is said, but it's in the tone and body language. For example, to be given instructions in a manner that does not allow discussion. This is a loss of self-esteem and my friends are losing their ability to be individuals. They say no, but after a while they get tired of fighting." (advocate)

"I don't like being shoved in the category, because I can't speak and walk, that there's anything wrong with my brain. I'm sharp as I've ever been. I don't have any memory loss, and I resent anybody that makes me feel like that. And some of them don't realize that you're normal." (resident)

Attitudes

Attitudes of staff, residents, families and volunteers play a large role in creating respectful interactions. People need to foster personal attitudes that are cooperative, trusting, caring and respectful. Often, the attitudes of management create a tone that affects the entire facility.

“Disrespect is not valuing the other person’s opinion. It is a two-way street with a lot of potholes that need to be repaired.” (resident)

“If the head nurse has a very caring attitude, it permeates the whole floor.” (resident)

Changing attitudes can be done only through a process involving awareness. Facilities need to explore the development of groups wherein staff (or within professional groups) discuss such matters as their feelings and beliefs surrounding life in an institution, what it means to become increasingly dependent upon others, and how the desire to provide care can clash with individual needs. In addition, educational sessions and workshops are needed to explore the understanding needed to address issues such as abuse and neglect, aggression and agitation in disease.

Behaviours

Respectful behaviours facilitate respectful interactions. People toward whom our behaviours are directed interpret the actions as reflecting what we think and feel about them regardless of what our actual intentions are. From the APL project, residents and others identified the following behaviours as actions which mean they are respected:

- knocking on doors before entering,
- more physical contact if desired (e.g. touching),
- closing the privacy curtain when dressing residents,
- bending down to talk with residents in wheelchairs,
- facing residents before pushing wheelchairs, and
- smiling.

“I hate it when they try to dress you when you are trying to go to the bathroom.” (resident)

“Sometimes it’s just an assembly line.” (resident)

Types of Interaction

APL participants identified three types of interactions in LTC as being important for the well-being of residents:

- social interactions among individuals,
- direct care practices, and
- activities.

Interactions Among Individuals

Within LTC, there are ongoing social interactions among individuals. They include:

- resident-staff interaction,
- resident-resident interaction, and
- family, volunteer and community interaction.

Resident-Staff Interaction

By far the most important component of the social environment is resident-staff interaction because of the high frequency of contact and its nature (provision of basic care). Of the comments mentioned by residents regarding what they perceived as abuse and neglect, the quality of the interaction between themselves and staff played a prominent role in determining whether the staff person was abusive. As such, staff must be aware of how their behaviour is perceived by residents and others.

“Who gets you up in the morning is how your day goes. If somebody comes in with a smile, it gets you up.” (resident)

“Among the host of people who take care of [residents], they anticipate at least one is having a bad day. They say, I knew when that nurse walked in, it was going to be a bad day. I wasn’t feeling too bad, but when I knew it was her, I was off for the day.” (staff)

“The nurses can’t be any better. They are better than my mother and father. They come to the door at night and ask if I’m all right.” (resident)

Resident-Resident Interaction

One area of the social environment that is limited is resident interaction. Some residents may not wish to socialize while others lack personal skills to develop social networks within the facility. Resident-to-resident interactions may be facilitated through the use of a buddy system, welcoming committees and matching of room-mates.

*“My roommates have Alzheimer’s disease, and they’re non-
loquacious. Neither of them talked at all in the eight months I’ve
been here. It’s very non-sociable.” (resident)*

“I don’t have anything to do with them [other residents].” (resident)

*“Well, you have to holler at them [Alzheimer’s patients] and go on.
I do.” (resident)*

Family, Volunteer and Community-Resident Interaction

Family involvement with residents is important for fostering a supportive and respectful environment. Families need to visit or take residents for outings as often as possible and get more involved in resident care. To increase involvement, relationships between staff and families have to be fostered and family input into their relative’s care optimized wherever possible. Moreover, discussions need to occur between staff and families regarding caregiver roles, as confusion over who provides care is a major source of conflict between informal and formal caregivers. It is important to understand that better family-staff interactions improve the quality of care provided to residents.

*“After a while, you get a name for yourself. When you come in, they’ll
say, ‘here comes the bitch.’ But what are you supposed to do?”
(family)*

*“Having my family around makes me feel safer. Someone to stand
up for me.” (resident)*

Volunteers are also an integral part of institutional life: serving meals, going for walks and talking to residents. Residents with no family would benefit from having a volunteer assigned to visit daily. High school students and children can be encouraged to volunteer. As well, an effort has to be made to address the negative stigma associated with LTC that leaves people reluctant to volunteer their time. More community involvement is also needed within the facility and residents can be encouraged to remain active in their community.

“There are a lot of people here who won’t have visitors from one end of the year to the other, and what would make this place a little more pleasant for those people, would be someone coming in to visit them — a visiting committee. Whether or not they are aware totally of what’s going on, it would mean a lot to them, to get in a car and go somewhere. They’re so appreciative.” (resident)

Direct Care Practices

Direct care practices are interactions that primarily involve providing care to residents. Although volunteers and family members may provide care, most often it is the responsibility of staff. APL participants identified the following four areas were identified as important for fostering a supportive and respectful environment:

- same-sex intimate care,
- consistent care,
- prompt care, and
- skilled/competent care.

Same-Sex Intimate Care

If residents are not comfortable with a person of the opposite sex providing intimate care (e.g. bathing, diapering), they should have the choice of being cared for by a staff person of the same sex. Although this was not mentioned by many participants, some — specifically women — felt extremely uncomfortable when receiving intimate care from someone of the opposite sex. Although this may raise issues requiring union involvement, facilities need to explore how this sensitive matter might be addressed.

“A lot of men and us have separate floors, and there aren’t a lot of men, and when a man does come to give us our bath, half the women don’t take their baths.” (resident)

Consistent Care

Consistent care is important to residents. It can be accomplished by reducing rotation and shift changes; having modular nursing; and employing fewer temporary, part-time staff. However, the need for consistency has to be balanced with staff concern about having to provide care to the same residents, especially if relations are strained. There is also the concern that professionalism could be lost if staff and residents become overly familiar.

“You’d be fine if all your patients were cooperative and pleasant, but you get someone who is difficult; how would you like to have the same patients all the time?” (staff)

“Recently the staff has been moved. I miss the steadiness of the staff, they were like family members. Some of them looked after me for 20 years. It’s like losing a member of your own family.” (resident)

Prompt Care

Waiting for staff to respond to call bells or provide services is a concern for most residents and family members. For residents, prompt service gives a sense of security and a feeling of being respected. However, residents need to have reasonable expectations about promptness as it has to be balanced with staff workload.

Skilled/Competent Care

Competent, skilled staff add to a supportive and respectful environment. Residents identified that staff who are knowledgeable about their care, who can use equipment correctly, and who are competent in their clinical skills provide the residents with a sense of security: security that their care is being adequately looked after and security in the knowledge that they will not be hurt.

“They [staff] go about their business quietly and they stay around to make sure the job is finished. They are competent, they talk to you, and they are respectful and listen to you.” (resident)

Activities

Activities are important to residents not only because they break up the monotony of the day, but because they also provide an opportunity for social interaction. A choice of activities that have meaning and purpose is important. Residents expressed the desire to have more than just bingo. As well, more variety in activities is needed to include people who have different levels of functioning. Activities need to be offered at different times, especially in the evenings and weekends when residents have little opportunity to interact with others. Resident schedules tend to be very busy between 8:00 a.m. and 6:00 p.m. during the work week but quite empty in the evenings and weekends.

“More activities, even wash the door a thousand times to keep us busy.” (resident)

Some ways that staff at various facilities reported that they are addressing this problem are: “hanging around” with residents to talk; a dream-time room with aromatherapy, music and lights; and a laughter room.

4.2 PHYSICAL ENVIRONMENT

Five specific components of the physical environment identified through the APL projects as important for fostering support and respect are:

- having adequate, tasteful food;
- efficient use of existing space;
- respecting privacy;
- reducing noise levels; and
- making the facility more personal.

Having Adequate, Tasteful Food

As would be expected, food is a major issue for many residents. Most want more variety in what is offered and better preparation that maintains or enhances its flavour. Moreover, APL participants commented on the need to ensure that meals are culturally appropriate.

“You can’t fuss about the tea, because sometimes it’s hot, and sometimes it’s cold. There’s nothing you can say about it.” (resident)

“It’s hard to get a bit of pie, I never had a bit of pie since I come here, so I buy it from one of the shops. And I go to a lawyer to see if I have to pay for what I can’t get here. I got a stomach as well as anyone else.” (resident)

“There’s plenty of food, no shortage. It’s the way it’s cooked, that’s the biggest problem.” (resident)

“They don’t listen to me very often about anything, I’ve been complaining about food for 30 years and still complain about the same thing.” (resident)

Staff also relayed how they have seen others mix the entire contents of a tray before starting to feed the individual. Some expressed the opinion that this should be done to staff and volunteers at orientation as an example of poor practice.

Efficient Use of Existing Space

Space limitation is a major problem for everyone in LTC. The lack of space has an impact on the staff's ability to work and on residents' ability to move freely or do things for themselves. Many facilities are not designed to accommodate the number of residents in wheelchairs. To address space problems, facilities need to look for ways to make better use of existing space and make the facility more accessible to residents (e.g. with wheelchair accessible washrooms and automatic doors). To ensure that such changes are made, funding to retrofit facilities is needed.

Another major issue raised during the APL project is providing the need for space for families to visit with their relatives other than the residents' own rooms. A lounge or private visiting room would be useful. Family visits can also be facilitated by improving access to the facility through such means as reduced parking fees after work hours. Although such rooms are available in larger care facilities, smaller ones do not have the budgets to construct such private areas.

Respecting Privacy

Privacy is a major requirement for ensuring a supportive and respectful environment. Personal privacy when bathing, dressing or receiving intimate care has to be protected even among residents who, because of cognitive impairment, may not be aware of a loss of privacy.

“We all need privacy. It's the basic tenet of human life. We all need our solitude.” (resident)

Residents expressed the need for more privacy, such as having individual rooms and private or semi-private washrooms, and having staff use privacy curtains when attending to residents or leaving them when rushing to another call. Residents also indicated the importance of privacy for conjugal visits and of the facility's acceptance of a resident's need for intimacy with a loved one. The need to be able to have some say over who shares a room with you was also raised under this topic of the need for privacy. The lack of compatibility translates directly to lack of privacy (roommates not respecting each other's needs, or not being aware of the need for privacy because of a cognitive problem).

“If I had to share a room, it would have to be with somebody I really like or respect. It must be hard for those people to be thrust together. Especially people who are here to die, if they have the wrong roommate, it would be more than difficult.” (resident)

“Couples who have been married 60 years have never had to ask permission for conjugal visits before.” (staff)

“I can’t share my feelings toward my girlfriend without everyone knowing. Staff would enter it in my chart.” (resident)

Reducing Noise Levels

Excessive noise is a problem in most LTC facilities. The noise is generated by residents calling out or shouting, many televisions on different stations, staff cleaning, the movement of equipment and meal trays, people not wearing soft-soled shoes and call bells ringing, to name but a few sources that were identified by APL participants.

Facility, managers and staff members should be aware that one way a supportive and respectful environment is defined is through the level of comfort it affords those who live or work there. It is important, therefore, that the level of noise be minimized and monitored on an ongoing basis.

Some of the ways facilities are responding to reduce the noise levels are requesting that all staff and visitors wear soft-soled shoes; encouraging residents to host a noise reduction day when they can fine anyone 25 cents for being excessively noisy; having a computerized pager system instead of call bells; having a quiet room for residents where they can retreat to find a peaceful and tranquil place for a moment’s reprieve.

“One of my roommates wakes me up at 2 in the morning all the time, every night. He bangs on my bed and yells, ‘wake up!’” (resident)

“The nights are terrible here. Very noisy. I haven’t had a good sleep for months now.” (resident)

Making the Facility More Personal

There are many ways to spruce up facilities to make them more personal and home-like. One way is through the use of plants. Even though there may be some concern regarding maintenance, such obstacles can be overcome through the use of volunteers or family members. If there is concern regarding the picking or eating of plants by certain residents, non-toxic and tasteful plants (e.g. herbs such as mint) could be used.

Attempts should also be made to provide furniture that has a non-institutional appearance (e.g. reduced use of chrome, as pointed out by APL participants). Corridors can be broken up visually by the use of plants or screens to reduce the sense of a hospital ward.

Depending upon available financial resources, skylights can be used to let in natural sunlight, or daylight lamps may be used. Residents can stroll in an enclosed garden. In one facility, residents in a special care unit eat in small units with a kitchen for each unit to keep food warm until it is served. In another site, there is agreement with a local museum to have special displays that resonate with residents (e.g. butter churns, old farm implements). Smaller facilities appear to have greater flexibility in creating a more home-like environment for residents, staff and visitors alike than do larger facilities.

“The larger the place, the more people have to be grounded to a common denominator in order to make this thing work. A large grouping is an abnormal way to live.” (staff)

4.3 ORGANIZATIONAL ENVIRONMENT

Within the organizational environment, there are four aspects that APL participants felt contribute to or detract from a supportive and respectful environment

- organizational philosophy,
- resource allocation (direct care cutbacks),
- scheduling, and
- meeting the needs of residents with cognitive impairments.

Organizational Philosophy

The organizational philosophy on institutional care that is held by senior management sets the tone as to how a facility functions and how its clients are perceived. If the underlying philosophy is one of respect, this is reflected in how senior management treats staff and, in turn, how residents are treated.

“There are several levels of administration. They usually tell you to see someone else.” (resident)

“Low morale starts with staff and moves to the resident.” (resident)

Resource Allocation (Direct Care Cutbacks)

Everyone in LTC expressed concern about the direct care cutbacks in LTC funding. Residents, staff and others perceive many of the cutbacks as drastic and negatively affecting direct care and the quality of life of residents and staff alike. APL participants, regardless of who they were, felt that it was extremely important that adequate funding and resources be allocated to the LTC sector.

*“The government cut off all our privileges, our outings, the staff.”
(resident)*

“When I started my career, the philosophy was that good care was measured in terms of reducing suffering. In the '90s, care, good or bad, is measured in terms of cost.” (staff)

“There should be no cutbacks in health care. Physical and mental health should be a top priority.” (resident)

Scheduling

Allowing for flexibility in scheduling is one way of making LTC more supportive and respectful. Facilities have to abandon the rigid structure and scheduling processes that have traditionally characterized institutional life. Although making this change is difficult because of the need to establish standards in care delivery, it is important that staff in facilities explore how flexibility can be introduced (e.g. a mid-morning snack for those who never ate breakfast before, steps taken to reduce the perception of being rushed, the need to waken residents throughout the evening when turning or changing them).

“I don’t think you can ever take the institutionalization out of it, you have to work with some kind of routine.” (staff)

“Activities are scheduled too close to meal times and there’s not enough time to brush your teeth.” (resident)

“Routine makes you feel more at home.” (resident)

Meeting the Needs of Cognitively Impaired Residents

At issue here is how to respect the rights of residents who are cognitively impaired while meeting the special challenges presented by such individuals. For example,

facilities need solutions for working with cognitively impaired residents who exhibit violent behaviour or who are abusive to other residents or staff. Facilities are responding to the needs of cognitively impaired residents in unique ways. For example, in one rural facility with a petting zoo for residents, a former farmer with dementia had been worrying about his horses being out and needing to be bedded down for the night. Staff brought in a pygmy stallion and tied it to his bedpost so he could reach out and reassure himself.

“You have to bring the [people with] Alzheimer’s to the activities, and I’m sure they can still find something in it, a renewal instead of doing the same thing all the time.” (resident)

Conclusion

Fostering and maintaining a supportive and respectful environment is one of the most effective ways in which we can safeguard against abuse and neglect in LTC facilities. Such an environment is defined by the quality of interactions among residents, staff, families and others. To reach the goal of creating a supportive and respectful environment, the following components are needed:

- management support,
- collaboration among the different groups associated with LTC,
- ongoing communication forums, and
- training opportunities.

Management Support

As with any new initiative, management support is crucial to foster a supportive and respectful environment. Boards of directors and administrators should recognize that a supportive and respectful environment is essential for the well-being of residents, staff, families and volunteers. Support is reflected in the mission statement and all policies. When an initiative is undertaken, progressive policies and administrative structures must be established or people will continue to face many obstacles.

Collaboration Among the Different Groups Associated with LTC

A supportive and respectful environment is achieved through the collaboration of all the groups associated with LTC — residents, staff, families, volunteers and the community at large. It requires time, effort and goodwill to ensure that the needs of everyone are considered.

Ongoing Communication Forums

People need a forum to share innovative ideas and experiences. During the life of the two projects, participants across the country expressed the desire to continue the discussion. Many felt relieved that the issue was being opened up, despite the

pain and difficult emotions that were generated and expressed. A formal mechanism to easily exchange information should be established (e.g. electronic media such as the Internet). During the Train-the-Trainer workshops, the site coordinators shared ideas as they travelled together. Participants often commented, orally and in the written evaluations, how much they appreciated the ideas that they could take back and try in their own facilities.

Training Opportunities

Training on how to achieve a supportive and respectful environment highlights positive aspects of LTC and gives people a forum through which to look for solutions. One of the most useful exercises in the workshops was the small group work that identified ways in which people contribute to a supportive and respectful environment. Many innovative ideas were shared with a great deal of enthusiasm. Training should include the topics of resident empowerment, communication, grieving and responding to losses.

By communicating these components as concrete goals and functions of each care setting, we will be able to achieve what everyone desires: a home for those we care about, a caring place in which to work and visit.

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