Housing Options For People Living With Dementia

Volume 2

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Housing Options for People Living with Dementia

Volume 2

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Chapter 8.0 Managing "Home" provides guidance on planning, establishing, managing and operating supportive/community-based housing for persons living with dementia.

Chapter 9.0 Models of Care examines four models that have been developed to address the health and well-being of persons living with dementia

7.0 Supporting "Home"

7.1 Principles of Good Support

As previously mentioned, the recommendations in this guide are based on a person-centred approach, which focuses on the individual rather than the condition, and the person's strengths rather than losses. Person-centred care is based on an interactive process in which persons living with dementia are active participants in their own care throughout the various stages of dementia. In addition, family members and caregivers play an important role in ensuring the health and well-being of persons living with dementia. Services and supports are designed and delivered in a way that is integrated, collaborative and mutually respectful of all persons involved, including persons living with dementia, their family members and caregivers, as well as health care staff.

When caregivers view persons living with dementia as "losing their personality," there is a risk that these persons will only be treated for physical symptoms and that less effort will be made to connect with them in a meaningful and individual way. It is also important for caregivers and staff to communicate effectively and meaningfully, avoiding 'elder speak' or 'baby talk' or talking as if the persons were absent.

In a person-centred environment, staff members know their residents and how to accommodate their unique needs, preferences and strengths in ways that promote independence, self-esteem and quality of life. They show empathy for persons living with dementia and they think about decisions from the persons' point of view. A person-centred home offers an individualized plan of care and social and physical environments that support residents' abilities, strengths and interests instead of generic programs and cookie-cutter activities that are suitable for the majority.[1]

Persons living with dementia, through focus groups, expressed the importance of having flexibility in their care. Having options that respond to the 'needs of the day' were identified as important as well as having the option for privacy and opportunities for socializing based on what the individual needed or wanted.

7.2 Supports to Better Engage People Living with Dementia

7.2.1 Daily Rituals

Daily rituals help provide persons living with dementia the predictability they need. This predictability also helps reduce the anxiety of family members as they know how to care for their loved one or how their loved one will be cared for in the assisted living/long-term care facility.

As soon as a diagnosis of dementia is made, it is important to develop a daily ritual for the persons' abilities to be maintained. These rituals include those related to behaviour and habits as well as their home. In more advanced stages, it may be very difficult for persons living with dementia to adapt to changes so the daily rituals that have been established are the only rituals that are likely to be maintained.[2]

7.2.2 Meaningful Engagement

Persons with dementia, regardless of the stage of their progression, wish to be active participants in their own lives and feel a sense of belonging in their home and community. Boredom or lack of engaging and meaningful activities can lead to behaviours that are often described as challenging for caregivers and cause distress to persons living with dementia. Such behaviours are referred to as "responsive behaviours" because they are a response to an unmet need and the behaviour is a form of communicating such need. It is important for caregivers to take the time to really get to know the persons behind the dementia to help create opportunities to engage in activities that are meaningful to the individuals themselves. This requires understanding their likes and dislikes and present abilities and past interests. Caregivers must also consider the relationship between the person with dementia, the environment, the activity and their approach.[3]

Engaging in meaningful or purposeful activities connect persons with dementia with others and their community. It reminds them that they are worthwhile regardless of what they can or can no longer do. Providing opportunities to engage in something that is meaningful to persons with dementia (for example, food drives, gardening advice and follow-up program, helping or contributing in some way) promotes a sense of purpose, promotes health, improves quality of life and contributes to a sense of control, dignity, self-worth and achievement when they often feel their sense of control slipping away. In some cases meaningful engagement is considered as having the potential to actually delay the progression of a dementia. Active social, physical and mental engagement prior to a diagnosis of dementia is also noted to have a preventative effect on the brain and helps to delay (not prevent) the onset of a dementia.[4]

When planning activities for persons with dementia, rather than focusing solely on a host of different options to provide based on typical symptoms of a dementia, it is important to also consider how best to engage individuals in the creation of their own activities—both planned and spontaneous. Experiences that are often meaningful to persons with dementia are those that allow them to express themselves, to connect with others, to have fun, and to feel a sense of freedom and purpose. For example, staff members in some supportive housing facilities encourage persons with dementia to participate in planning and making meals, and some also encourage staff and residents to eat meals together to foster a greater sense of normalcy and home-like environment.

Meaningful engagement sets the stage for understanding and fulfills a need of the individual. For persons living with dementia, living in a care setting other than home can create a sense of disorientation, loss, isolation and boredom. Studies have found that engaging in meaningful and satisfying experiences can greatly add to the well-being of persons living with dementia. Thus, it is important to ensure that the design of the care setting and the visual cues employed (for example, signage, landmarks) all help to direct and create opportunities for the persons living with dementia to engage in both informal/spontaneous and more formal/planned yet meaningful experiences.[5]

For more information on creating meaningful activities, please see the guides developed by the Murray Alzheimer Research and Education Program (MAREP): https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides/living-celebrating-life-through-leisure

7.2.3 Mood and Behaviour

Some people with dementia experience abrupt changes in their moods and emotions and these changes can be unpredictable. Mood changes can be eased by understanding the individual needs of the person and managing, accommodating for, and if possible eliminating known triggers for negative changes in mood and behaviour. Persons living with dementia often benefit from having fixed daily rituals and a well-designed environment. A well-designed environment can reduce confusion, agitation and promote independence by providing a balance of familiarity and appropriate stimulation. Disruptive behaviours can be reduced or eliminated by altering approaches to activities that trigger this behaviour and creating an environment that suits an individual's specific needs and preferences. Having access to a garden where a person living with dementia can dig and plant or a walking program to help address listless wandering and encourage purposeful walking or wheeling are examples of decreasing disruptive behaviours.[6]

Caregivers of persons living with dementia can benefit greatly from learning coping strategies to manage and accommodate for the changing needs, including changing behaviour, of the people they are caring for and how to engage them in meaningful activities to redirect or avoid negative responsive behaviour. There are several approaches that have been shown to help with mood and behavioural changes, including GENTLECARE®, the Eden Alternative, Montessori Methods for Dementia™ and the Reitman Centre CARERS Program. Descriptions of these approaches as well as some case studies can be found in other sections of this guide.

Behavioural Supports Ontario (BSO) provides coping advice and strategies to caregivers. Information can be found at http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Behavioural-Supports-Ontario.aspx

Mount Sinai Hospital has also prepared a guide for caregivers, "How to Handle Challenging Behaviours in People with Dementia" (2013). It can be found at http://www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/prc-dementia-resources-for-primary-care/dementia-toolkit-for-primary-care/caregiver-support/how-to-handle-challenging-behaviours-in-people-with-dementia

In addition, caregivers can find local resources in communities across Canada at http://www.alzheimer.ca/en

The Murray Alzheimer Research and Education Program also provides helpful strategies and tools for persons living with dementia and caregivers. The By Us for Us© Guides can be found at https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides

In particular, Managing Triggers, the second guide in the above series, offers solutions for how persons living with dementia and their caregivers can manage various behaviours and triggers.
https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides/managing-triggers

7.2.4 End-of-Life Care

The experience of dying is different for each person. It comes in its own time and its own way. The overall goals of palliative and End-of-life care are to relieve suffering and improve the quality of living and dying for persons experiencing a life-threatening disease, including people living with dementia. This can be achieved by minimizing unnecessary suffering through the provision of pain and symptom management; psychological, social, emotional, spiritual and practical support; support for family members and caregivers and bereavement support.

While the majority of individuals would like to age at home, most people living with dementia will receive end-of-life care in an assisted living or long-term care facility due to the high level of care they require as dementia progresses. If a decision has been made to have the person living with dementia die at home, it is important to obtain home support services, such as a community nurse who can help the family figure out what care is needed and how to provide this care. Under the best circumstances, the family will be assisted by a palliative care team made up of professionals, para-professionals and volunteers. Palliative care is a more holistic approach to care than a medical intervention approach. Palliative care principles will apply to persons at the end stage of dementia both at home through home care and in a long-term care facility.

Quality of life

While providing palliative care in a person's own home is helpful to the caregivers, it can also be difficult for both caregivers and the person living with dementia to have a number of different people coming in and out of their home. The end stage of dementia can last from months to years, which can take a physical and emotional toll on caregivers if the end-of-life care is provided in their home.

Many provinces in Canada have eligibility criteria to qualify for end-of-life care. Often, this is provided in the last three to six months of life. However, with dementia, this is more unpredictable and can last much longer. Ideally, the decisions related to advanced care and end-of-life care will be discussed in the early stages of dementia while the person living with dementia can still participate in the decision-making process. The focus of end-of-life care or palliative care should be on the quality of life and comfort rather than on length of life and treatment.[7]

For more information on end-o-life care for persons living with dementia, including what to expect, please refer to the Alzheimer Society of Canada's brochure: http://www.alzheimer.ca/~/media/Files/national/Progression-series/progression_endoflife_e.pdf.

7.3 Supports for Caregivers

7.3.1 Supporting Informal Caregivers

Informal caregivers are family and/or friends who provide often unpaid care to a person. Caring for a person living with dementia can be demanding and stressful, even if it is a loved one. In general, caregivers of persons living with dementia provide 75-per-cent more care than other caregivers and experience 20-per-cent higher levels of stress. In addition, the demands on the caregiver tend to increase as dementia progresses.[8] Most informal caregivers are seniors and may be managing their own health issues in addition to providing care to a loved one.

For more information on caregiver statistics please refer to http://www.alzheimertoronto.org/ad_Statistics.htm#three and http://www.statcan.gc.ca/pub/82-003-x/2012003/article/11694-eng.pdf

Many caregivers experience difficulty coping with the multiple losses that occur not only in the life of the persons with dementia, but also in their own. Normal emotions identified with grief are identified as a response to care, rather than as a response to loss. Caregivers for persons living with dementia often experience latent grief, which differs from ordinary grief in that the person is still alive however caregivers experience symbolic loss (psychosocial death) of the person as the dementia progresses. They will also experience a loss of their former identity prior to the caregiving role. Latent grief is a major factor in caregiver stress and burnout.[9] While evidence-based literature on this topic is limited, it stands to reason that by improving the quality of life of persons living with dementia through the provision of a positive living environment, the quality of life of their caregiver will also improve.

The current shift to aging at home and providing care at home puts greater pressure on informal caregivers. While there are options to receive formal or professional care services to support informal caregivers, the availability of these supports is limited and varies by province. Providing information on improving the housing environment of persons living with dementia by making it more supportive and safe helps ease the burden on informal caregivers.[10]

In addition, there are strategies that can help ease the burden on informal caregivers while delaying moving a person living with dementia to a long-term care home. One of these strategies is to provide a program of occupational therapy to persons living with dementia and their informal caregivers. This results in a reduction in the hours spent on care and an increase in the caregiver's competence, skills and communication strategies. It also helps delay admission to long-term care by about 18 months.[11]

Another strategy to support informal caregivers is to have a system navigator or case manager. This helps persons living with dementia to stay in their own homes longer, reduces the burden on informal caregivers and reduces overall costs.[12]

The Murray Alzheimer Research and Education Program (MAREP) has a series of guides created by persons living with dementia and/or caregivers. The guides provide useful tools to enhance the well-being of persons living with dementia and managing daily challenges. https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides#wellness

7.3.2 Supporting Formal Caregivers

The role of formal caregivers is changing. The shift to person-centred care requires additional capacities and skills, including enhanced dementia-specific social and communication skills, compared with more task-oriented care. In addition, the shift to creating a 'home' environment as opposed to an institutional environment requires staff to create a 'household,' which may be an intensive and complex process. Training, particularly dementia-specific training, is of paramount importance. In addition, staff members need to receive training on working collaboratively with families and informal caregivers. The use of technology may also provide support to staff and increase job satisfaction.[13] It is important for staff to recognize the effect of moving to a long-term care home on both persons living with dementia and their families. Staff training should include working with families in various stages of grief and sadness associated with dementia-related losses and death.[14]

7.3.3 Financial Support for Caregivers and Individuals

There are several resources that may help caregivers and their loved one, either through income support or incentives for undertaking home modifications. Some such resources include:

Caregiver tax credit: Caregivers may be eligible for a credit if they maintained a dwelling where both they and a dependent lived during any time in the tax year. http://www.cra-arc.gc.ca/familycaregiver/

Compassionate Care Benefits: Employment Insurance Compassionate Care Benefits are available to employed family members caring for a gravely ill relative at risk of dying within 26 weeks. These benefits are offered through Employment and Social Development Canada (ESDC). http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Infirm dependant deduction: Caregivers may claim a deduction for each infirm relative dependent. http://www.cra-arc.gc.ca

Personal disability credit: A person with a disability may claim a credit if a qualified professional certifies that 1) a severe mental or physical impairment markedly restricted all, or almost all, of the person's basic activities of daily living during the year and 2) the impairment was prolonged, which means it lasted, or is expected to last, at least 12 months. Only doctors, optometrists, psychologists, occupational therapists, and audiologists are qualified to certify impairment. http://www.cra-arc.gc.ca/disability/

Medical expenses credit: Caregivers may claim a credit for medical expenses paid for themselves or their spouse, children, grandchildren, parents, grandparents, brothers, sisters, uncles, aunts, nieces, or nephews who depended on them for support. http://www.cra-arc.gc.ca

Provinces may also have financial supports for caregivers such as:

Manitoba Primary Caregiver Tax Credit

Manitobans who act as the primary caregivers for family members or others are eligible for a refundable tax credit of $1,275. http://www.manitoba.ca/finance/tao/caregiver.html
Caregiver Recognition Act http://web2.gov.mb.ca/bills/39-5/b042e.php.

Quebec respite tax credit

The maximum tax credit is $1,560 per year. The credit equals 30 per cent of the total expenses incurred during the year to obtain specialized respite services for the care and supervision of a person, up to $5,200. http://www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/aines/Pages/credit-impot-repit-aidant.aspx

Nova Scotia Caregiver Benefit

The program is targeted at low-income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of $400 per month. http://www.gov.ns.ca/health/ccs/caregiver_benefit.asp

Ontario home renovation tax credit

http://www.ontario.ca/taxes-and-benefits/healthy-homes-renovation-tax-credit

Ontario Senior Homeowners' Property Tax Grant

http://www.fin.gov.on.ca/en/credit/shptg/index.html

British Columbia Seniors Home Renovation Credit

http://www.cra-arc.gc.ca/E/pbg/tf/5010-s12/

Home Renovation Tax Credit

http://www.cra-arc.gc.ca/gncy/bdgt/2009/fqhmrnvtn-eng.html

8.0 Managing "Home"

8.1 Principles of Good Operation

8.1.1 Planning and Establishing Supportive/ Community-Based Housing

Designing and operating housing with supports for persons living with dementia, including assisted living and long-term care homes/nursing homes, will involve a number of key considerations. Some initial questions to be considered:

1. **Who is the housing for?** For example, will eligibility be set by stage in the progression of dementia of individuals looking for housing? Will the site be dementia-specific or will it accommodate individuals needing some support but who do not have dementia?
2. **Will it be a larger or smaller facility?** Larger buildings are more likely to be able to provide a wider range of amenities and facilities, while smaller developments allow staff to have greater contact with fewer residents and get to know them more intimately, creating a sense of community.
3. **What 'extras' will be included?** For example, extras may include more staff time, training and supervision or specialized activities and resources.
4. **How seamless is the service?** For example, integrated local strategies for housing, health and social care services, including appropriate support from community health and specialist care services, leads to a better quality of care and life experience for persons living with dementia compared to piecemeal offerings.[15]

Once a decision has been made with regard to the four questions outlined above, there are a number of steps to undertake in planning housing for persons living with dementia. Establishing clear values and principles for the service is one of the important tasks in setting up a new assisted living facility for persons living with dementia.

These values and principles are in part home-specific as well as dementia-specific, but also reflect the values and principles of the organization. Other considerations include the following:

- Deciding who the home is for (for example, dementia-specific or mixed populations, level or degree of impairment accepted.
- What and how services will be provided (for example, linked models where service provision and housing are offered by the same organization or delinked models where housing and care are provided by two separate entities).
- Developing a clear service model or approach from an early stage.
- Ensuring that plans take full account of what persons living with dementia and their families want (for example, developing family councils for regular ongoing advice and feedback).
- Comprehensive assessment and individualized care planning by dementia-trained staff.
- Ensuring good building design (for example, it is easier to start with good design from the beginning than retrofit—learn from successful models).
- Developing good partnerships with local services and community groups (for example, this is beneficial to help keep persons living with dementia engaged with their community and enhance their sense of normalcy).
- Considering the importance of getting the best managers and staff (for example, dementia-trained staff, ongoing professional development, safe working conditions, fair pay and benefits, high staff to resident ratios).[16]
- Enhancing an individual's experience of independence, empowerment and accessibility (for example, ensuring personhood is respected, celebrated and valued by all members of the care team).

The service model will depend on the organization's values and principles. For example, some organizations believe in having nursing and/or medical staff while others believe in a social care model where the environment is as ordinary as possible and where nursing staff may not be necessary.

Considering that the quality of life and sense of well-being and independence of persons with dementia are closely related to the quality of care they receive, relationships with staff and other residents, and the surrounding environment, the decision for a service model is very important.

A planning framework and tool kit, developed in Ontario by the *Roundtable on Future Planning for People Affected by Alzheimer's Disease and Related Dementias* (ADRD), addresses the impact of ADRD on government programs, communities, and Ontario as a whole. The overall aim of the framework is to help all those involved in dementia care enhance their effectiveness in supporting people living with ADRD and their families, and to promote cross-sector linkages and the development of strong partnerships in dementia care. These resources can be helpful in the development and ongoing evaluation of housing models for persons living with dementia and can be accessed at the following addresses:

ADRD Planning Framework (PDF) Roundtable on Future Planning For People Affected by Alzheimer Disease and Related Dementias.
http://brainxchange.ca/Public/Files/Age-Friendly-Communities/ADRD-Planning-Framework-English.aspx

ADRD Planning Framework Brochure (PDF)
http://brainxchange.ca/Public/Files/Age-Friendly-Communities/Brochure.aspx

ADRD Planning Framework Toolkit (PDF) (To accompany the ADRD Planning Framework) – A self-assessment tool for individuals and organizations to evaluate and improve their responsiveness to the needs of persons with ADRD and their families.
http://brainxchange.ca/Public/Files/Age-Friendly-Communities/ADRD-Toolkit.aspx

Size of the home

In terms of size, a smaller home would be ideal for persons living with dementia. 'Small scale' may refer to the size of the home overall or to the size of the units within a larger home. In general, a philosophy of 'ordinary living' points to keeping the overall size of the facility as small as possible. There are several advantages to having a smaller home:

- Persons living with dementia experience less stress as they are not overloaded with stimuli from noise, activity and too many people. For example, housing providers noted that people with dementia may have trouble eating in large groups, so smaller group settings are ideal.
- Activities can be designed specifically to meet the needs of each individual.
- The design of a smaller home can be more like a 'home' rather than an institution. For example, the atmosphere and arrangement of communal areas can be made to look like someone's house.
- It is easier for persons living with dementia to participate in activities without having to travel.
- It is easier to develop good relationships between residents and staff, and for staff to get to know individual residents in a smaller home. This also helps to avoid loneliness, social isolation and feelings of discrimination.
- Unit-based staff groups develop a team spirit and result in good care.[17]

Providing long- and short-term/respite accommodation

Another decision to be made by an organization planning to develop housing for persons living with dementia is whether they will provide both long- and short-term/respite accommodation. Combining these two services has challenges as it may be difficult for short-term residents

and disruptive for long-term residents. On the other hand, this arrangement also has benefits. First, staff members can get to know persons living with dementia and their families at an early stage, before they become long-term residents of the home. Second, the home becomes familiar to persons living with dementia even before they move in as full-time residents.

If an organization decides to provide respite or adult day-care services, it must be clear about the type of service offered and the goal of providing this service. For example, is the service meant to provide regular breaks for informal caregivers or is it for emergency care, such as when a caregiver is taken ill? One more thing to consider is the range of needs that can be accommodated in the facility and the implications of having people at different stages of dementia.[18]

T. Roy Adams

Who will the residents be?

The affinity between residents is important in shaping the atmosphere and quality of life in homes for persons living with dementia. It is therefore important for organizations to consider the type of resident group they will provide services to. Resident characteristics to consider would include levels of care required, age, gender, social background, religious background and cultural and ethnic origins.[19] For example, one of the case studies in this report had a large population of Mennonites so such things as activities, food and the type of care provided catered to this group.

Heimstead Senior's Lodge

Success of a home

There are a number of ways to measure the success of supportive/assisted housing for persons living with dementia. The following are some important factors that contribute to the success of a home:

- **Providing person-centred care** – Providing care that is tailored to the needs, interests and strengths of individuals.
- **Developing knowledge and expertise in dementia** – Having well-trained staff not only improves the quality of life for residents, it also encourages job satisfaction, high staff morale and less staff turnover.
- **Partnerships** – A successful operation includes integrated care from local social care agencies, health and housing departments, and care and supports from cultural, spiritual and ethnic organizations/associations within the community.

Success for residents

Providing person-centred care is one of the factors that determine a successful care environment for persons living with dementia. Residents perceive their quality of life as better when staff members are more involved in planning their care and when they express a positive attitude and good understanding about dementia.

As previously discussed in the design section, effective buildings can help compensate for physical and sensory disability. For persons living with dementia, understanding and adjusting to a building should be made easy. Strategies such as signs, landmarks, memory boxes, and colours all help residents find their own front door and other areas in the building. Adequate spaces for gatherings of both large and small resident groups should be provided. Proper lighting can improve appetite, health and self-confidence and decrease incidence of loneliness, poor temper, anxiety and falls.

A stimulating environment is also highly beneficial for persons living with dementia. Having opportunities for social interaction and a range of activities is important. Involving residents in the design of activities is one way

to accommodate different preferences. Another way to accommodate individual preferences is to involve families in planning activities.

Assistive technology can benefit both residents and staff greatly although they should be given information on what is available and how to use it. Assistive technology should be tailored to individual needs, and residents and their family members should be given control over when and how these are used.[20]

For further information on success factors and measuring success, please refer to *Living Beyond Dementia: A Guide to Dementia and Housing with Care* at http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/Living_Beyond_Dementia.pdf

8.1.2 Management

There are several types of management systems for homes for persons living with dementia. For example, some homes choose a formal system while others do not but, rather, use a range of techniques to ensure high standards of care. **Whatever type of management system is chosen, some strategies to achieve high quality management in homes for persons living with dementia are the following:**

- Have a clear philosophy and ensure that all staff members understand the philosophy and work toward it.
- Ensure good management and staff communication.
- Keep in mind that there is always room for improvement and be willing to respond positively to criticisms and suggestions.
- Ensure that management has strong expectations and standards and communicates these to staff.
- Promote staff education and training, including dementia-specific training.
- Ensure that perspectives of persons living with dementia are incorporated into quality management.
- Ensure that managers and staff have ownership of quality systems.
- Use quality systems that involve realistic time commitments and avoid volumes of paperwork.

Organizations should also note that while main services and supports have to be provided by staff in the home, there is an opportunity for partnership with other organizations and community agencies to provide additional services. These services can be provided within the home or residents can go into the community to receive these services. As noted in the previous section, these partnerships are one of the main factors to ensure the success of a home.[21]

8.1.3 Staffing and Training

Adequate staffing has a direct and positive impact on the well-being of persons living with dementia in supportive housing or long-term care homes. Quality person-centred dementia care is dependent on all staff feeling supported and valued as members of the care team. Therefore, managers need to ensure that any potential role confusion and frustration are avoided by having appropriate, and not necessarily traditional, role definitions accepted by all the staff. In addition, positive working conditions including adequate pay and benefits are important to overall staff satisfaction.

A system of supervision is the heart of a training and development strategy and the key to maintenance of high standards in the long term. Supervision includes monthly sessions with all staff members, the appropriate person supervising staff and a cascade of supervision. **Instead of a focus on disciplinary policies and procedures, an approach to maintaining high standards of conduct among staff should be characterized by the following:**

- Ensuring staff members internalize the high standards of the home.
- Managers having an approachable style that encourages staff members to come forward if they have problems.

- Managers using their own personal 'antennae' to pick up on any problems.
- Having a high level of staff respect for managers' and supervisors' authority.[22]

Unfortunately, not all staff members in retirement homes, supportive housing, assisted living or long-term care homes, particularly those which are not dementia-specific, may have specialized knowledge or dementia-specific training. This poses a challenge for providing the best quality of care. As part of the training provided by the Alzheimer Society, staff go through an aging simulation where they put beans in shoes, wear earplugs and wear goggles that simulate various conditions of the eye. This training is meant to help them better understand what residents are going through. The Registered Nurses' Association of Ontario also provides resources and educational material to prevent elder abuse through programs such as the PEACE program.

> *"The humility that comes with it [training] allows you to be more patient and compassionate."*

Additional information can be found at
http://rnao.ca/bpg/initiatives/promoting-awareness-elder-abuse-longterm-care
http://www.nicenet.ca/tools-elder-abuse

Staff recruitment and retention

Selection of staff involves assessing the suitability of the individual but also ensuring a good balance of personal attributes, skills and experience in the staff group as a whole. There should also be sufficient diversity, such as in terms of age, gender and ethnic background, to match staff with residents' needs and to allow residents to have a choice about who provides their personal care. Quality of care is dependent on having staff with positive attitudes and, therefore, some managers focus on an individual's values and attitudes rather than on qualifications and experience, as the latter can be developed but attitudes are very hard to change.

Staff turnover is not entirely negative. It contributes to bringing new ideas into a home and helps counter institutionalizing tendencies. Turnover can, however, have a negative impact on the quality of care. An ongoing concern is having high staff turnover, which creates significant disruption for persons living with dementia as well as their informal caregivers.

Some factors that contribute to good levels of staff retention:

- Lack of competition from other homes or other employment opportunities.
- Good initial selection.
- Good induction and support for staff while they 'find their feet' in a new setting.
- A good match between the reality of the work and the expectation of new staff.
- High staff morale and work satisfaction.
- Good team spirit.
- Good terms and conditions.
- A management style that fosters a sense of belonging and commitment.
- A sympathetic approach to staff personal circumstances.
- Good ongoing support, training and development.[23]

Most community-based agencies providing hands-on care to persons living with dementia require their staff to have minimum training requirements (diploma or certificate in personal care support work) as well as dementia-specific training. In addition, most care staff at these agencies will undergo a criminal reference check prior to being hired. This is important as individuals can become quite vulnerable with progressive declines related to dementia. Therefore, these basic qualifications and reference checks are also important considerations when hiring private caregivers (live-in or otherwise) to help persons living with dementia to remain safely and independently in their own home. Other important considerations may include hiring staff members who speak the mother tongue of the person living with dementia, as second languages are often lost with the progression of a dementia. In addition, persons living with dementia may also relate more easily to someone who understands or shares similar customs or cultural practices as their reliance on the familiar increases.

Volunteers

Volunteers can include family members of residents, students and people from the community. One innovative model that was suggested includes having volunteers reside in the home along with persons living with dementia. These volunteers are provided with some compensation, training and housing in exchange for providing care to their fellow residents who are living with dementia.

There are strategies that can be used if an organization decides to use volunteers to provide services:

- Asking staff what volunteers can do and when it is more appropriate to have them in the home.
- Being clear about expectations of volunteers.
- Matching volunteers with tasks that fit their interests and skills.
- Recognizing that it can be difficult to involve volunteers in extensive one-on-one contact with residents living with dementia.
- Providing volunteers with training and support.
- Making sure volunteers are appreciated.[24]

8.2 Financial Resources

Most organizations will require external financing to design, build and operate a housing development, including housing for persons living with dementia. To secure this financing, the organization has to demonstrate that the project is feasible. In addition to banks and other lending institutions, there are a number of government programs that may provide funding for a proposed project. These include funding programs through CMHC as well as programs from each provincial government. Additional information on these programs, including programs for individual provinces, can be found on the CMHC website: https://www.cmhc-schl.gc.ca/en/co/prfinas/.

9.0 Models of Care

There are a number of models of care that have been developed to address the holistic health and well-being of persons living with dementia. These models look beyond biomedical models of care that operate based on brain dysfunction and look toward engaging persons with dementia in a manner that purposefully capitalizes on their remaining capabilities, interests and desires. Four examples of such models of care are provided below.

9.1 The Green House®

This model is based on the work of Dr. William Thomas and aims to replace the institutional skilled nursing model. Each home is designed for 10 to 12 residents and private rooms and bathrooms are combined with open common areas. This model focuses on the quality of life of persons living with dementia. The model combines small homes with the full range of personal care and medical services expected in high quality nursing homes.

An innovative staffing model gives residents four times more contact with staff compared to a typical long-term care home and reduces staff turnover. Each Green House is staffed by a universal worker called the elder assistant who is responsible for the care of the seniors and their environment. The elder assistant also helps with the delivery of some of the therapeutic activities that are part of the treatment plan for residents. Clinical treatment is delivered by a clinical support team made up of a physician, registered nurse, licensed practical nurse, occupational therapist, physical therapist, social worker, dietician, speech therapist and any other professionals required. This team assesses and designs a plan to meet the clinical treatment needs of residents in co-operation with the elder assistant but these professionals are not based in the Green House. They visit based on the needs of the residents as well as in compliance with regulations.[25] The Sherbrooke Community Centre in Saskatchewan is an example of this approach.

For more information on Sherbrooke Community Centre, see *Housing Options for People Living with Dementia - Volume 3.*

9.2 Planetree Model®

This model is based on an approach that is holistic, focusing on the person's mental, emotional, spiritual, social and physical needs. Healing partnerships are created among persons living with dementia, families and caregivers, and conventional medicine is integrated with complementary therapies. One of the cornerstones of the Planetree Model is that people are involved in their own care. This model also recognizes the importance of architecture and design as a complementary therapy; design is one of the ten components of the Planetree Model. Planetree uses architecture to bring together the design concepts of the healing environment with a patient-centred approach of providing care.

There are 10 elements of the Planetree Model of patient-centred care:

- Human interaction
- Healing partnerships: the importance of family, friends and social support
- Empowering through information and patient education
- Nutrition
- Spirituality
- Human touch: communicating caring through massage
- Healing arts
- Complementary therapies
- Architectural design conducive to health and healing: healing environment is welcoming, accessible and promotes positive experiences that engage the senses.
- Healthy communities: expanding the boundaries of healthcare

The Donald Berman Maimonides Geriatric Centre in Quebec is Planetree-affiliated.

For more information on Donald Berman Maimonides Geriatric Centre Centre, see *Housing Options for People Living with Dementia - Volume 3*.

For further information on this model: http://planetree.org/.

9.3 Montessori Methods

Montessori Methods for Dementia are an innovative method for working with people with cognitive and/or physical impairments. It is based on the educational philosophies of Dr. Maria Montessori. Dr. Cameron Camp discovered that these philosophies and principles could be effectively adapted to dementia programming. The use of this method for persons living with dementia has resulted in increased levels of engagement and participation in activities. Grandview Lodge in Dunnville Ontario is an example of the Montessori approach.

For more information on Grandview Lodge, see *Housing Options for People Living with Dementia - Volume 3*.

9.4 GENTLECARE®

GENTLECARE is a comprehensive program of care for people with Alzheimer's disease that maximizes client skills and abilities for longer periods, compensates for the dysfunction caused by the disease, and protects the health of family and professional care providers. GENTLECARE is considered "prosthetic in nature" in that much like a person using a prosthetic limb to better manage life and one's environment, this approach seeks to arrange an environmental fit between the person with dementing illness and the physical space, the programs and the significant people with whom the person must interact. As such, this model of care accommodates and supports existing levels of function and development, rather than challenging the person with dementia to adapt and perform in ways no longer possible. In particular it looks toward the assessment of the physical, social and cultural environment using the filter through which the person with dementia experiences the world and the impact these components have upon the person's ability to function.

The GENTLECARE approach integrates strategies for many facets of living with a dementing illness:

- The relationship between disease pathology and client behaviour.
- Environmental design concepts.
- Stress identification, prevention and reduction that eliminates catastrophic incidents.
- Assessment tools that provide for individualized care plans.
- Strategies for programming, nutritional concerns, and development of therapeutic partnerships with families, communities and volunteers.

GENTLECARE has specifically adopted the butterfly as its logo in an effort to depict the gentle and complex approach advocated in the care of people with dementing illnesses.[26]

An example of GENTLECARE is Delta View Adult Day Program, Assisted Living and Life Enrichment Centre in British Columbia.

For more information on Delta View, see *Housing Options for People Living with Dementia - Volume 3*.

Endnotes

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