

Guidelines for Care:

Person-centred care of people with dementia living in care homes

FRAMEWORK

January 2011

"You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die."

Saunders, 1976.

Alzheimer *Society*

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ACKNOWLEDGEMENTS

While many individuals and organizations have assisted in the development of the Guidelines for Care: Person-centred care of people with dementia living in care homes framework, a very special “Thank you” goes to Jim Mann and Ann and Fred West for sharing their thoughts and providing support and guidance.

The Alzheimer Society would like to thank the organizations listed below for supporting this framework:

- Baycrest, Ontario
- Bayshore Home Health, Ontario
- Canadian Coalition for Senior's Mental Health
- Canadian Healthcare Association
- Clinic for Alzheimer's Disease and Related Disorders, University of British Columbia Hospital
- Division of Geriatric Medicine, Department of Medicine, University of British Columbia
- Faculty of Nursing, University of Alberta
- Institute for Life Course & Aging, Faculty of Social Work, University of Toronto, Ontario
- Mennonite Nursing Home Inc., Saskatchewan
- Murray Alzheimer Research and Education Program, University of Waterloo, Ontario
- Northwoodcare Inc., Nova Scotia
- Providence Health Care, British Columbia
- Regional Geriatric Program Central Ontario
- School of Nursing, Faculty of Health, York University, Ontario
- St. Joseph's Health Care, London, Ontario
- Vancouver Island Health Authority, British Columbia

PREAMBLE

The guidelines for care framework relies exclusively on a Rapid Evidence Assessment (REA).

Rapid Evidence Assessment

Through the lens of person-centred care, a REA (Appendix 1) was completed to systematically examine practice guidelines published in peer-reviewed journals regarding the care of people in advanced stages of Alzheimer's disease living in care homes.

In ensuring the health and well-being of people with dementia, it is critically important to continuously assess and take steps to improve their health from a holistic perspective. While the Guidelines for care: Person-centred care of people with dementia living in care homes framework does not include medical, nursing or other discipline-specific guidelines, it is understood that ongoing assessment of biomedical aspects of care is essential to the overall well-being of individuals with dementia.

There has been a recent surge of interest in the use of clinical practice guidelines, new reports about ineffective and inappropriate care of clients and a renewed focus on evidence-based practice. When clinical practice guidelines are systematically developed as statements to assist practitioners about appropriate care in specific clinical circumstances, it is believed that these practice guidelines can improve the quality, appropriateness, and cost-effectiveness of care.

The development of best practice guidelines within a framework of person-centred care acknowledges personhood, while promoting the quality of care based on the best available evidence. Although the personality of the individual with Alzheimer's disease can change with the severity of the disease, this best practice model recognizes that individual personhood remains intact. The guidelines cover a broad range of care approaches to include the many aspects of person-centred care and environment. This holistic approach addresses body, mind, and spirit to ensure people with Alzheimer's disease are receiving personalized and relevant care.

Method of the Rapid Evidence Assessment

Like systematic reviews, rapid evidence assessments are based on comprehensive electronic searches of appropriate databases. As a result, exhaustive database searching, hand searching of journals and textbooks, or searches of grey literature¹ are not immediately undertaken.

The functions of a rapid evidence assessment include:

- searching the electronic and print literature;
- collating descriptive outlines of the available evidence on a topic;
- critically appraising the evidence;
- sifting out studies of poor quality; and
- providing an overview of the current state of the evidence.

¹ Grey literature refers to material that is not formally published, such as institutional or technical reports, working papers, business documents, conference proceedings, or other documents not normally subject to editorial control or peer review. It may be widely available yet difficult to trace.

Information retrieval strategy

Ten electronic databases were searched for this review and search terms were modified according to the databases. The searches of all electronic databases, with no restrictions of date or location, were completed in January 2009. The total number of hits based on the information retrieval strategy was 2780 titles, resulting in 1830 titles and abstracts.

All 1830 titles were screened according to the inclusion criteria of whether the articles considered guidelines relevant to the care of people with Alzheimer's disease and whether the article systematically developed statements to assist practitioners about appropriate care in specific clinical circumstances.

Excluded articles covered diagnostic criteria or technical standards; guidelines on research methods; review articles; and secondary publications of the guidelines.

Based on the inclusion/exclusion of the first level of screening, 148 articles were passed to the second level of screening.

Once full text articles were retrieved and screened, 60 articles passed to the data extraction level. Twelve other articles were retrieved and included by searching grey literature and Google. Therefore, the total number of guidelines brought forward for data extraction was 72.

Assessment of the methodological quality of these practice guidelines was completed to determine the degree to which they used and documented methodological standards. Strict selection criteria for the guidelines set for the REA ensured that only high-standard evidence-based guidelines were included.

Framework - *Guidelines for Care: Person-centred care of people with dementia living in care homes*

Please note that the evidence-based guidelines included in this framework:

- involved high-standard methodology to identify and collect the evidence,
- were developed by eminent researchers, and
- were supported by a formal assessment of the strengths of evidence along with specific recommendations.

The content of the Guidelines for Care: Person-centred care of people with dementia living in care homes framework relies exclusively on the REA. The content of the REA was distilled into a guidelines framework for care home staff. Ultimately, this document will lead to the development of knowledge transfer tools to strengthen the capacity of care home staff to ensure a person-centred philosophy in care and to increase the potential for knowledge integration.

The Alzheimer Society of Canada recognizes that this framework is a “living document” with updates based on new and emerging research needed regularly. Additionally, many important aspects of care and areas of practice have not been included due to the lack of sufficiently strong evidence-based guidelines.

The Alzheimer Society of Canada challenges researchers to conduct investigations into the missing areas of practice. It has also called upon the expertise of the Alzheimer Society Guidelines for Care Expanded Working Group and Review Panel to bring their practice wisdom to bear in order to complement the guidelines outlined in this document.

Furthermore, the Alzheimer Society of Canada has developed an addendum to supplement this framework. It is articulated around the specific topics for which guidelines don't yet exist, but scientific evidence regarding good practice is available (Appendix 2).

A person-centred philosophy, coupled with additional scientific evidence, practice wisdom and user-friendly tools will combine to improve the care of people with dementia living in care homes in Canada.

BACKGROUND ON THE DISEASE

Dementia is a syndrome consisting of a number of symptoms that include a reduced ability to perform familiar tasks, impairment of memory, judgment and reasoning, and changes in mood and behaviour. Some dementias are caused by treatable conditions such as depression, thyroid disease, infections or drug interactions. However, treatments are not yet available for the progressive, irreversible, dementias in which nerve cells in the brain become sick and eventually die.

Currently over 500,000 people live with dementia in Canada, of which more than 60% have Alzheimer's disease. Other dementias include Vascular Dementia, Lewy body Dementia, Frontotemporal Dementia (including Pick's disease), Creutzfeldt-Jakob Disease and mixed dementia (usually Alzheimer's disease combined with vascular dementia).

The brain abnormalities that occur with Alzheimer's disease can start as early as one's 30's or 40's, however, the gradual onset of dementia symptoms usually begins in one's 60's or 70's. Until then, the brain's self-repair mechanisms seem to compensate for the ever-increasing nerve cell sickness. Improved testing techniques, plus the willingness of people to consult a doctor at the first signs of behavioural and memory impairment, are now leading to earlier diagnoses of Alzheimer's disease.

INTRODUCTION

The overarching goal of the Guidelines for Care is to improve the quality of care of people with dementia in care homes through a person-centred philosophy.

The Alzheimer Society believes that people with dementia have the right to enjoy the highest possible quality of life and quality of care by being engaged in meaningful relationships which are based on equality, understanding, sharing, participation, collaboration, dignity, trust and respect.

In order to reach this overarching goal, we need to reflect on the following:

- The first and most important objective is to ensure that a person-centred philosophy of care is well understood and put into practice;
- Interactions that enhance personhood are understood and demonstrated through respectful relationships and coordinated and proactive interventions;
- There is a focus on maintaining, supporting, and /or restoring the independence of the person living with dementia;
- Family members are actively engaged, maintaining strong bonds with their relative;
- Equal access to quality care is available to all residents with dementia with no discrimination based on diversity², especially age or mental health status;
- Risk reduction and therapeutic interventions for changes in mood and behaviour are implemented proactively throughout the progression of the disease, taking into consideration individual, social and environmental factors that might trigger behaviours;
- Persons with dementia are encouraged to, and supported in making choices. Ideally, care and support are offered in keeping with the person's lifelong values, preferences, and interests.

The Guidelines for Care: Person-centred care of people with dementia living in care homes framework consists of the following sections:

- I. What does a person-centred philosophy mean?
- II. What does person-centred care look like in a care home?
- III. Ensuring family inclusiveness.
- IV. Extending a person-centred philosophy through end of life.

² Diversity describes all aspects of difference, including, but not limited to, racial or ethnic classifications, age, gender, culture, religion, socioeconomic background, sexual orientation, physical health, mental health. Diversity also includes stages of dementia, comorbid conditions, behaviour and other mental health symptoms.

I. WHAT DOES A PERSON-CENTRED PHILOSOPHY MEAN?

Our most important objective is to ensure that a person-centred philosophy of care is well understood and put into practice in care homes in order to improve the quality of care and the quality of life for people with dementia.

A. WHAT ARE THE CORE CONCEPTS OF A PERSON-CENTRED PHILOSOPHY?

Person-centred care

Person-centred care is a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment. In this document, the term “environment” refers to both the social and physical environment. This includes the importance of the assumptions made about people with dementia, attitudes of care providers, care models and care practices implemented, organisational and cultural factors as well as structural elements such as flooring and lighting.

It is a holistic philosophy across the continuum of services which takes into account the specific needs of each person. It is grounded in mutually beneficial partnerships established between people with dementia and their caregivers.

Person-centred care is founded on an interactive process, in which people with dementia are active participants in their own care throughout the various stages of the disease and family members play a vital role in ensuring the health and well being of their relative.

The ultimate goal of person-centred care is to create partnerships among care home staff, people with dementia and their families that will lead to the best outcomes and enhance the quality of life and the quality of care of people with the disease. Services and supports are designed and delivered in a way that is integrated, collaborative, and mutually respectful of all persons involved, including the person with dementia, family members, caregivers and staff.

THE PERSON-CENTRED PHILOSOPHY FOCUSES ON THE INDIVIDUAL RATHER THAN ON THE CONDITION, AND ON THE PERSON'S STRENGTHS AND ABILITIES RATHER THAN LOSSES.

Core concepts:

Dignity and Respect: Like all individuals, people diagnosed with dementia are people first. Care staff listen to them and honour their perspectives and choices. They have an inherent dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times. The values, beliefs, cultural and spiritual backgrounds of people with dementia and their families are incorporated into the planning and delivery of care.

Information Sharing: Care home staff communicate and share complete and unbiased information with people with dementia and their families in ways that are affirming and useful. People with dementia and their families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation: People with dementia and families are encouraged and supported in participating in care and decision-making at the level they choose. This therapeutic relationship is based on the participation of the person with dementia, regardless of their level of cognitive or physical impairment. The goal is to focus the relationship on the person, without excluding family members.

Collaboration: People with dementia and families are also included on an organization-wide basis. Care home managers collaborate with people with dementia and families in policy and program development, implementation, and evaluation; in health care home design; and in professional education, as well as in care planning.

What does current available evidence say?

There are few studies that have assessed the implementation of person-centred care as most published work includes clinical experiences, personal opinions and anecdotal evidence (Edvardsson, et al., 2008). Qualitative studies suggest that health care staff's view of people with Alzheimer's disease has implications for health care and how care is provided. These studies suggest that if health care staff view people with Alzheimer's disease as "losing their personality" then there is a risk that the person will only be treated for physical symptoms while less effort is made by the health care staff to connect with the person in a meaningful and individual way (Logstrup, 1997). Conversely, a recent review of the interventions for caring for people with Alzheimer's disease concluded that creating and maintaining meaningful relationships between the person and their caregivers was essential (The Swedish Council on Technology Assessment in Health Care, 2006).

A randomized controlled trial of person-centred intervention for showering and bathing residents with moderate to severe dementia concluded that measures of discomfort, agitation and aggression among people with Alzheimer's disease in residence declined significantly in the group receiving person-centred care compared to the control group (Sloane, Hoeffler, Mitchell, et al., 2004).

In another randomized controlled trial of person-centred intervention for showering and bathing residents with moderate to severe dementia, Hoeffler, Talerico, Raisin, et al., (2006) found that staff in the intervention group were reported to be more gentle, more verbally supportive and felt more at ease (qtd in Edvardsson, et al., 2008).

Also, it is critical to ensure that caregivers communicate effectively and meaningfully with the person with dementia; they have to avoid using “elder speak” or “baby talk”, talking at a reduced cognitive level, or as if the person were absent. It has been shown that the use of infantilizing communication may result in resistiveness to care (Williams KN, Herman R, Gajewski B, Wilson K.).

In all guidelines, consensus statements and systematic reviews, there is a general focus on the need for people with Alzheimer’s disease to have meaningful relationships and social contact, predictable inviting rituals consistent with the person’s individual preferences (exercise, meals, and bedtime should be planned and punctual), quiet non-distracting environments, relaxed atmospheres with reduced stimulation and schedules that meet the unique needs of each person in care.

Person-centred, culturally, emotionally and spiritually sensitive approaches should be adopted to provide care that meets a resident’s changing needs and respects his or her preferences regarding end of life care.

A PERSON-CENTRED PHILOSOPHY CONSIDERS THE WHOLE PERSON, RATHER THAN JUST A SERIES OF TASKS TO BE COMPLETED.

B. WHAT DOES A PERSON-CENTRED CARE HOME LOOK LIKE?

Person-centred care homes offer an individualized plan of care and social and physical environments that support the resident's abilities, strengths and personal interests instead of generic programs and “cookie-cutter” activities suitable for the majority.

A care home that values a person-centred philosophy of care engages in the following activities:

1. Upholds the value of the person regardless of the level of functioning.
2. Works with staff to help them connect emotionally with people with dementia.
3. Places a high value on continuing staff education by providing staff with regular training opportunities.
4. Ensures adequate staffing levels necessary for person-centred care and organizes shifts to best respond to resident needs.
5. Recognizes that dementia does not diminish a person, but changes a person's capacity to interact with his/her environment.
6. Places importance on the individual's life history and uses it to plan their care and support at the same time respecting that the person's preferences may have changed.
7. Supports the person throughout the continuum of the disease including through end of life where a palliative approach is adopted.
8. Focuses efforts and resources to optimize the person's self worth and personal strengths.
9. Provides services and support in such a way as to maintain or enhance autonomy.
10. Recognizes and respects the right to privacy, dignity and confidentiality.
11. Values and fosters individual interests, customs, beliefs, as well as cultural, spiritual and ethnic backgrounds.
12. Focuses on an individual's holistic well-being.
13. Provides meaningful occupation and opportunities to help people with dementia remain engaged and active.
14. Provides comfort, a sense of belonging and a feeling of safety and emotional security.
15. Promotes the need for people to feel free and not controlled.
16. Values people who are living with dementia and is inclusive of the family and friends who care and support them.

17. Ensures that staff understand the hazards of using physical and chemical restraints and has in place a process for individualized assessment and care planning to meet each resident's needs.

What the current available evidence says:

Use of restraints

Effective care planning involves knowing a resident's remaining abilities and understanding how to make use of them to avoid conditions such as wandering and falls that can lead to inappropriate use of restraints.

Care planning staff are responsible for trying and documenting various options to avoid use of restraints. Staff at all levels need to understand the hazards of using restraints and the process of individualized assessment and care planning to meet each resident's unique needs. If at all, restraints should be used as a last resort. Every care home or agency should have a clearly stated protocol on the use of physical, chemical and environmental restraints.

18. Promotes and supports the appropriate expression of sexuality of persons living with dementia.
19. Has an environment that is adapted to make sense to the person.
20. Values, supports, integrates, includes and informs family members.
21. Provides a safe and comfortable environment consistent with the resident's care needs.
22. Has staff who adopt a person-centred philosophy (for more details, please refer to Section C - HOW DO STAFF PROVIDE PERSON-CENTRED CARE TO PEOPLE WITH DEMENTIA? on page 15).
23. Reflects diversity at all organizational levels, considers cultural appropriateness and endeavours to provide accessible materials and resources.
24. Ensures staff and contractors (janitorial services, cooks, drivers, etc.) understand their role in delivering good care and increasing the quality of life of residents. Ideally, contractors should receive a basic training on person-centred dementia care.

C. HOW DO STAFF PROVIDE PERSON-CENTRED CARE FOR PEOPLE WITH DEMENTIA?

In a person-centred care home, staff know exactly who residents are and how to accommodate their unique needs, preferences and strengths in ways that promote independence, self-esteem and quality of life. They show empathy, i.e. the ability to put themselves in the position of the person with dementia they are caring for and to think about decisions from the person's point of view.

Person-centred staff:

1. Understand and adopt a person-centred philosophy of care.
2. Respect culture change and philosophy of care.
3. Focus on people living with dementia first and foremost as individuals.
4. Strive to understand the experience of dementia and each person's reality.
5. Recognize that all behaviour has meaning and strive to understand the meaning behind behaviour.
6. Understand and master effective and meaningful communication, which is fundamental to all care approaches, and know how to adopt effective strategies when communicating.

What the current available evidence says:

Most guidelines address the importance of communication and it has been reported to be central to the interactions of persons, family members and service providers.

- *Use simple words and short sentences in a gentle, calm tone of voice.*
 - *Avoid talking to the person with Alzheimer's disease at a reduced cognitive level or discussing the person as if he or she were not there.*
 - *Minimize distractions and noise, such as the television or radio, to help the person focus on what you are saying.*
 - *Address the person by name, making sure you have his or her attention before speaking.*
 - *Allow time for the person to respond independently. Be careful not to interrupt.*
 - *If the person with Alzheimer's disease is struggling to find a word or communicate a thought, gently try to provide the word he or she is looking for. Try to frame questions and instructions in a positive way.*
 - *Explain all procedures and activities in simple and straightforward terms to the person before performing them.*
7. Recognize that every individual with dementia has the potential to engage socially and spiritually, and the right to live life to the fullest.

8. Respect and value the person with dementia by the way in which they talk to them and about them to others, using dignified, non-judgmental, and respectful language.
9. Take all opportunities for training which are offered to them.
10. Respect the right to self-determination of all persons with dementia no matter where they are in the disease progression. This means ensuring that choices are provided, the person's wishes are taken into consideration, and their consent obtained. As dementia progresses, it becomes increasingly difficult to obtain fully informed consent from people with dementia. However, it is always possible to involve them in the decision-making process to some extent, keeping them informed, asking and/or finding out from others about their preferences taking into account previously expressed wishes. Dissent must also be respected.
11. Understand the world from the perspective of the individual with dementia. Find the meaning behind their words and actions by speaking to the person, their family and friends and being attentive to non-verbal cues.
12. Recognise that the move to a care home can be frightening and confusing for some and provide support to residents when adjusting to life in the new environment and on an ongoing basis.
13. Consistently demonstrate empathy through actions and support.
14. Integrate, involve and support family and friends.
15. Value social interactions and focus on bringing out the best in the person.
16. Recognize that behaviour is meaningful and remains a way of communication. It is the responsibility of staff to interpret it and provide a supportive response.

D. HOW DO PEOPLE IN LEADERSHIP POSITIONS SUPPORT PERSON-CENTRED CARE?

In person-centred care homes, people in leadership positions motivate staff through empowerment and encourage creativity, active participation and sharing of solutions.

The leadership:

1. Understands the person-centred philosophy, culture change and philosophy of care.
2. Is strong, positive and draws on best care practices in order to produce culture change.
3. Models the actions expected of the direct care staff by treating staff in a person-centred way, promoting capacity building and ensuring policies and procedures are consistent with person-centred care and based on the guidelines.
4. Needs to involve staff in decision-making to make culture change happen.

What the current available evidence says:

Specialized training and education for caregivers

- *Staff should be treated in a person-centred way. Their training needs to be 'person-centred' and geared to their individual learning needs.*
 - *All health care providers should have access to training and education which will help them understand the disease process and assist them in their role as health care providers.*
 - *Staff need:*
 - *recognition for their use of problem-solving approaches to providing care, and*
 - *emotional support as they deal with their own emotional reactions to the decline of residents over time and their eventual death.*
 - *Guideline orientation should be provided for all health care providers involved in services for people with Alzheimer's disease.*
5. Ensures staff training is inclusive of all staff, even those who do not have a direct caregiving role (housekeepers, janitors, cooks, drivers, administrative staff, etc.) and promotes basic training on dementia signs and symptoms so they are better able to understand the behaviours and actions of persons with dementia, and know how to support the person with dementia.

6. Provides inspiring leadership whereby all staff have a clear understanding of the role they personally play in creating a person-centred, quality care experience for the person with dementia and their family members.

What the current available evidence says:

Inspired and inspiring leadership

- *Staffing patterns should ensure that residents with dementia have sufficient assistance to complete their health and personal care and to participate in the daily life of the residence.*
 - *Consistent staff assignments help to promote the quality of the relationships between staff and residents.*
 - *Direct care staff need education, support, and supervision that empowers them to tailor their care to the needs of residents.*
 - *Staff supervisors may need ongoing coaching to help them empower and support the direct care staff to be decision makers.*
 - *Administrators have the role of evaluating care home policies and procedures to ensure that they support direct care staff decision making during real-time interactions with residents.*
 - *Staff who understand the prognosis and symptoms of dementia and how these differ from normal aging and reversible forms of dementia are better prepared to care for and about people with dementia.*
 - *Staff should acknowledge and accept a resident's experience and should not ignore a resident's report of an event or his or her feelings and thoughts.*
7. Ensures appropriate and adequate staffing and resources necessary for person-centred care are available (staffing-resident ratio) to help reduce staff turnover and prevent decreased quality of care in care homes.
 8. Is sensitive to how the diversity of staff and residents impacts the delivery of care.
 9. Ensures that family members are recognized as integral to the team providing care to the person living with dementia.

The provision of dignified care must become part of the inherent culture of every long term care home. Such a transformation will require leaders in long term care to move beyond knowledge transfer and to move toward knowledge integration in the workplace.

IT IS IMPORTANT THAT STAFF HAVE AN OPPORTUNITY TO DISCUSS THEIR EXPERIENCE AND SHARE THEIR FEELINGS WITH THEIR LEADERSHIP.

II. WHAT DOES PERSON-CENTRED CARE LOOK LIKE IN A CARE HOME?

A. ENJOYING EVERY DAY

Daily life and inviting rituals

A person-centred care home recognizes that all persons with dementia have a future and aspirations. With input from the person with dementia and their family, it is important to strive for a perfect day.

Enjoying everyday is important regardless of the stage of the disease and it is critical to discuss the person's interests and lifelong habits, and enquire about what brings them joy and comfort.

The person-centred philosophy engages residents in meaningful activities and involves them in programs that stimulate them. This philosophy is even more relevant for those who have lost the ability to clearly express their needs, wants and desires. Person-centred care should be incorporated into all aspects of care regardless of the resident's condition or stage of the disease.

Care providers encourage the person's active participation; they get to know them and their tastes and understand the uniqueness of what the following means to every single person: comfortable personal hygiene (oral health, toileting, bathing, dressing, regular foot care, etc.), enjoyment of food/meals, meaningful activities (leisure, physical activities, mental exercise, opportunities to contribute to the home and others' lives) and satisfying social activities, interactions, and relationships.

What the current available evidence says:

Daily rituals have been found to help provide people with Alzheimer's disease with needed predictability. As well, this predictability has been found to reduce the anxiety of family members as they are provided with the steps in how their family member will be cared for. Guidelines for daily rituals also help to train new staff and guide senior staff for scheduling purposes. Most of the guidelines focus on everyday care, such as bathing, personal hygiene, dressing, toileting, eating, etc.

As soon as a diagnosis of Alzheimer's disease is made, it is essential to develop a daily ritual for the person's abilities to be maintained thereafter. In the early stages of the disease, persons are able to adapt to necessary changes. However, in more advanced stages, only those rituals which have been previously established are likely to be maintained and it is very difficult to expect people with dementia to adapt to any further changes.

Personal Hygiene

- *Complete bath or shower at a calm and agreeable time of the day. Ensure that you are consistent in following the time and ritual.*
- *To reduce stress, ensure you have all items required to complete the person's bathing on hand before you assist the person into the bathing area. Never leave the person alone in the bath or shower.*

- *Run the bath ahead of time, test the water and consider playing soothing music to create a calm environment.*
- *Be gentle and respectful. Be patient and calm. Be aware that bathing can make the person vulnerable, scared and confused.*
- *Communicate what will be done step by step, allowing the person to be as independent as possible.*
- *Ensure that safety features such as a handheld showerhead, shower bench, grab bars, and non-skid bath mats are installed properly.*
- *Consider a sponge bath on alternative days. This can reduce the daily stress and is effective for maintaining personal hygiene between showers or baths.*

Oral health and dental hygiene:

Experts in the field recommend ensuring oral hygiene care practices are in place. Persons with dementia may need prompting or someone to do their oral care. Twice per day oral care and routine dental appointments are essential to keeping the mouth and teeth healthy. A growing number of persons with dementia are retaining more teeth as they enter care settings and this is expected to increase.

For persons with dentures, they will need to have their mouths cleaned daily with a soft toothbrush and their dentures cleaned with an overnight soaking in water with some vinegar. Experts suggest avoiding the use of soaking tablets so to eliminate the risk of persons with dementia eating or swallowing them. Using special teeth wedges or toothbrush props during oral care will help prevent fingers being bitten. Poor oral hygiene can lead to oral diseases and pain and can be a cause of responsive behaviours and unintentional weight loss.

What the current available evidence says:

Dental hygiene

- *Ensure dental hygiene is in place. Daily oral health and dental appointments are essential to keep the mouth and teeth healthy. Persons may have dentures that need to be soaked.*

Dressing

- *Develop a dressing ritual that is to be performed at the same time daily, consistent with the preferences of the person.*
- *Allow the person as much independence as possible when dressing. Allow a reasonable amount of time for the person and a calm, relaxed environment to avoid time restrained interjections to speed the process up.*
- *Promote independent choice from a limited selection of outfits to ensure independence. If the person favours a type of clothing, it may be beneficial to have several items of similar clothing.*

- *Laying out the clothing in the order in which they should be put on provides a visual cue to help increase independence. Visual reminders as opposed to verbal cues may reduce agitation.*
- *Assist the person with clear, concise instructions to avoid confusion. You may need to repeat an instruction; however, ensure your tone is calm and patient.*
- *Loose, comfortable clothing with Velcro and elastic is easier to get on and off, and easy to care for. This also helps increase independence for the person.*

Toileting

- *A toileting schedule will help reduce incontinence and increase independence. Try to create this ritual in accordance with the person's bladder functioning. Their regularity will help determine their toileting schedule.*
- *Regardless of their toileting schedule, watch for signs that the person needs to use the bathroom and respond promptly.*
- *Prompt voiding to reduce urinary incontinence.*
- *Reassure individuals when accidents happen by reacting calmly and respectfully. Assist them to remove soiled clothing and to get redressed into clean clothing.*
- *Limiting fluid intake in the evening helps reduce overnight accidents. Chart when these accidents occur to try and determine a pattern to then insert a toileting ritual to accommodate this time.*
- *When going on an outing, encourage the person to use the toilet before heading out. Locate the washroom upon arrival at the destination. Make them wear clothing that allows for ease of toileting in unfamiliar locations and take an extra set of clothing along in case of an accident.*

Meals

- *Residents who have meals in public dining areas (rather than in their own rooms) and residents who have meals in dining areas with more home-like environments are less likely to have low food and fluid intake.*
- *Inadequate consumption or inappropriate food and fluid choices can contribute directly to a decline in a resident's health and well-being.*
- *Regular meal and snack time should be established. Keep in mind the person's preference and time in which they are hungry. As well, allow the proper duration of time for the person to eat at their pace.*
- *Persons should be provided a well-balanced diet, rich in protein, high in fibre, with adequate amount of calories depending on height and body weight. The total quantity of food can be calculated by a dietician, if necessary. Many persons have "sugar cravings" i.e. they love to eat sweet food products. Care should be taken that such persons do not gain excessive weight. The diet should take into account other medical illnesses which require diet modification, such as diabetes or high blood pressure.*
- *Mealtimes are opportunities for social interaction for the person with Alzheimer's disease.*

- *A person with Alzheimer's disease may experience increased confusion and anxiety during meal times so staff need to be aware of individual reactions to meal times and respond with both patience and sensitivity to the unique needs of the individual.*
- *Consider the use of low lighting levels, music, and simulated nature sounds to improve eating behaviours.*
- *Try to provide choice of food for the person keeping in mind to limit the choices to two. For example "Would you like carrots or peas?" or "Would you like carrots?" Choice should keep in mind preference, nutritional needs and independence. Keep in mind that the texture and colour of foods should provide variety.*
- *During the day several small meals, healthy snacks, finger foods, and shakes should be made available to a person if requested or if there are signs of hunger or a missed meal.*
- *Document what a person has eaten during the day to avoid overeating and promote proper nutrition.*
- *Use eating and drinking tools to assist with independence as recommended. For example, use a bowl instead of a plate or a straw to assist in drinking. Consider finger foods.*
- *Liquids during the day should not be limited. Fluid intake should be monitored to ensure the person does not get dehydrated.*
- *Choking becomes an increased risk as the disease progresses. Texture of food becomes important, as well as ability to chew and swallow.*

A PERSON-CENTRED APPROACH TO MEALS AND NUTRITION IS FOUNDED ON GETTING TO KNOW THE INDIVIDUAL, THEIR NEEDS AND PREFERENCES.

Pain management

Pain is recognized as an important concern in care homes and may be under-diagnosed and/or under-treated in people with dementia, particularly if they cannot communicate verbally. Staff need to be vigilant in watching for signs of pain through regular pain assessment and reduction measures.

Pain management is essential to the day-to-day care of people with dementia. Therefore, staff need to be trained to pay attention to signs and indicators (such as changes in breathing patterns, hyperventilating, moaning, crying, frowning, grimacing, clenching fists, pushing away caregivers, difficulty being comforted, etc.) to identify and assess pain or discomfort.

It is important to remember that people with dementia may have other health conditions that can cause pain or affect physical and/or mental abilities. This discomfort or pain can impact the person's capacity to function and therefore their quality of life.

Furthermore, individuals with dementia who have communication difficulties will use responsive behaviours (for example they will refuse to eat, become quiet or shout out, sit down when they usually wander, etc.) to express their pain.

Relieving suffering and managing pain are the best ways to enjoy every day and improve the quality of life for individuals living with dementia.

What the current available evidence says:

Pain management

- *Reducing a person's pain will help the resident enjoy an improved quality of life.*
- *Pain assessment should occur routinely, including when residents have conditions likely to result in pain and if residents indicate in any manner that they have pain.*

(Please refer to page 35 for further information on Pain management)

Palliative care

It should also be noted that residents should be entitled to residential palliative care when their condition requires it and that palliative care is an approach and a philosophy which can be adopted much earlier on in the course of the disease and not limited to the very last stage of life. For more information on palliative care and pain management, please refer to Section IV - EXTENDING A PERSON-CENTRED PHILOSOPHY THROUGH END OF LIFE on page 34.

B. FEELING SAFE AND “INDEPENDENT”

Safety

The goal is to find a balance between maintaining safety and ensuring resident autonomy and comfort. This will be different for each person and may evolve as the person’s needs and abilities change. The right balance of a person’s safety and autonomy must be established by means of an ongoing evaluation process that includes the person’s family and consideration of their lifelong values of personal autonomy and tolerance for risk.

Example: cleaning supplies are locked, yet residents who wish to help with tidying the unit have supervised access to the tools they need.

What the current available evidence says:

Safety

- *Install secure locks on all outside windows and doors, especially if the person is prone to becoming lost.*
- *Remove the locks on bathroom doors to prevent the person from accidentally locking himself or herself in.*
- *Use cabinet locks in the kitchen and any place where cleaning supplies or other chemicals are kept. Remember that cleaning and other toxic fluids can be mistaken for juices and other forms of beverage.*
- *Label medications and keep them locked up. Also make sure knives, lighters and matches are secured and out of reach.*
- *Remove scatter rugs and anything else that might contribute to a fall.*
- *Make sure lighting is good both inside and out – especially for aging eyes.*

Abuse prevention

According to the World Health Organization, elder abuse is “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person”. Elder abuse can take various forms such as physical, psychological or emotional, sexual and financial abuse. It can also be the result of intentional or unintentional neglect.

According to the Institute for Life Course and Aging (University of Toronto), at an institutional level, much of the abuse prevention work that has occurred to date has been in terms of protocols and policies focusing on the actions of staff, volunteers and others working in the care home environment. Increasingly, family advocacy groups and health unions have identified the need to also consider abuse and neglect in the context of systemic issues such as staffing levels and the types of training staff are receiving (e.g., dementia care).

Staff in homes stress the importance of training, but point out that there can be a significant "disconnect" between the best practices they are taught in school for providing care, and the way they are expected to provide care in practice. Similarly there can be a disconnect between stated health care policies and practice. People with dementia are at increased risk of different forms of abuse (e.g. verbal, physical, sexual, financial and psychological abuse as well as neglect) due to their progressive loss of capacity, communication difficulties and increasing dependence on others.

Staff often lack training and information about dementia and when asked to provide care that is beyond their capabilities, may unintentionally be abusive and/or neglect the person. Additionally, empowered staff will be more likely to adopt a person-centred approach in their care of people with dementia.

What the current available evidence says:

Prevention of and Response to Abuse

- *The emphasis should be on preventing abuse by identifying and alleviating circumstances which are likely to lead to physical, psychosocial or financial abuse or neglect.*
- *A protocol to deal with abuse should be in place.*
- *When abuse is suspected, the proper authorities should be contacted.*

Walking and wandering

Walking is an everyday activity that most people take for granted. It is not only the main form of transportation, but it is an excellent natural exercise often recommended as it helps people stay healthy and live longer, control weight, relax and be happy, enjoy time outdoors, or feel a sense of freedom.

People with dementia should not be deprived of their liberty to walk, and every effort should be made to make walking as safe as possible and less worrying for their families and caregivers. However, walking may result in wandering, which is a common behaviour for people with dementia and may be triggered by the desire to move about, search for someone or something, remove themselves from their current surroundings, or respond to a physical need, such as hunger or the need to use the washroom. In itself, wandering is not a bad or harmful behaviour and when done in a safe environment, can be a healthy outlet and a means of exploring the environment and making connections for a person with Alzheimer's disease or other related dementias. Helping to make wandering a safe activity involves looking at all the potential triggers of the behaviour. By determining what may be contributing to the behaviour, it may then be possible to find ways to make walking a safer and/or purposeful activity.

Offering meaningful activities and providing a safe place to walk both indoors and outdoors may reduce the occurrence of wandering and yet maximize the potential for independent living within the care home. Regarding the use of assisted technology, measures should be taken to ensure that ethical issues are always taken into consideration and that assisted technology is suited to the needs of each individual user. Restrictive or coercive measures should not be used and instead alternative means of ensuring safety or providing care need to be adopted.

What the current available evidence says:

Wandering

- *Make sure that the person carries some kind of identification or wears an identification bracelet. If the person gets lost and is unable to communicate adequately, identification will alert others to the person's medical condition.*
- *A picture or video of the person should be kept and up dated every 3 months to assist police if the person becomes lost.*
- *Ensure that all exits are secure and have alarms when exits are opened without consent.*
- *Ensure that all potentially harmful objects are stored safely, especially at night.*
- *The nearest police station should be informed of persons who have a tendency to wander.*

Maintaining social relationships and independence

The importance of maintaining the person's social networks should be recognised and creative measures taken to promote them, thus preventing social isolation. Residents are assisted to achieve maximum independence, maintain friendships, develop new relationships, and participate in the life of the community within and outside the residential care home.

Working with health professionals

A person diagnosed with dementia will have contact with a number of health professionals, usually over a long period of time. This will most likely include their family doctor, medical specialists, and therapists, among others.

The degenerative nature of dementia means that families and caregivers will also have a lot of contact with these health professionals. And as the disease progresses these contacts will almost certainly increase.

What the current available evidence says:

Attending the doctor

- *Scheduling appointments for the person's best time of day may help in a successful visit. Keep in mind that there may be a busy waiting room or a crowd. Ask the doctor's office when is the least busy time to visit or try to arrange care home visits.*
- *Inform the doctor's office staff of the client's diagnosis as they may be able to work something out so that the visit is less stressful.*
- *Informing the person of an upcoming appointment may cause stress for some. Inform the person as you are preparing to leave for the appointment.*
- *Bring along something enjoyable to do to pass the time. Sharing a snack can be a pleasant pastime.*

- *Consider inviting an additional staff or family member to the appointment as you may need to speak with the doctor separately. If this is not possible, set up a time to call the doctor after you have accompanied the person back to the care home.*
- *Outings such as medical, dental, optometry and other types of appointments that take the person out of the care home may cause stress and anxiety so guidelines should be followed to help reduce stress and confusion for the person and their families.*

Safe transportation

Ensure safe transportation is provided when needed.

What the current available evidence says:

Transportation

- *Vehicular transportation should be provided in a manner which ensures the safety and emotional comfort of the person with Alzheimer's disease.*
- *Whenever possible, the driver should be accompanied by another individual besides the person with dementia. If there is no one to accompany the person, an identification card should go with the person in case they lose their way. If at all possible, ensure staff is available to accompany the person.*
- *Persons should be assisted into and out of the vehicle and ensure that they are wearing their seat belt.*
- *Travel should be limited to the comfort level of the passenger. Trips may be shortened and/ or frequent stops may have to be made.*

To enhance the person's comfort and dignity, always ask if they need to use the washroom before going out.

SAFETY IS A SERIOUS RESPONSIBILITY

C. PARTICIPATING IN MEANINGFUL ACTIVITIES

Making meaningful activities and experiences possible is critical to a person-centred approach. Residents are encouraged and supported to participate in a wide range of interests and activities. It is important to consider one-on-one activities, as they can be just as meaningful to the person as group activities. It is also important to consider the person's abilities when choosing activities.

People should feel they are involved and there is meaningful and enjoyable activity for them to do.

Boredom or lack of engaging and meaningful activities can lead to the behaviours that challenge us and cause distress to the resident.

It is important to recognize that apparent boredom may result from a lack of initiative due to the disease. Individuals may need direction to undertake an activity, which they could not start on their own. Staff need training to know how to appropriately engage individuals and when to draw back.

Each resident (or representative) participates in decisions about the services offered, and is enabled to exercise choice and control while not infringing on the rights of other people.

Rather than solely focusing on offering activities, consider what the activity allows the person with dementia to experience. Experiences that are meaningful to persons with dementia are those that allow them to express themselves, to connect with others, to feel a sense of freedom and purpose and to have fun.

ACTIVITIES CAN BE AN IMPORTANT WAY OF HELPING A PERSON WITH DEMENTIA TO RETAIN THEIR INDEPENDENCE.

What the current available evidence says:

Studies have found that people with Alzheimer's disease benefit from physical activity. Physical activity improves overall physical health, mental, emotional and social wellbeing. Health care providers must follow guidelines to ensure activities are within levels of capabilities and within range of abilities.

Activities

- *Keeping physically active has been found to help minimize the physical and mental decline inherent in dementia.*
- *Simple activities are more successful.*
- *Staff should provide positive reinforcement when the person is performing an activity.*
- *Some individuals may need assistance in getting started or choosing an activity. When conducting an activity, give step by step instructions and remember to praise as a step is successfully completed. Also, use prompting and cues when needed.*

- *Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.*
- *As part of the person's day, incorporate activities of enjoyment and try to do them at a similar time each day.*

Physical activities have a positive impact on cognition, well-being, mood, sleep and functional ability of people with dementia. While encouraging residents to partake in physical activities every effort should be undertaken to prevent falls and fractures.

What the current available evidence says:

Physical Activity

- *There is good evidence to indicate that individualized exercise programs have an impact on functional performance.*
- *Individualized exercise programs should be tailored based on the person's ability and capabilities.*
- *Physical activities should reflect what the person enjoys. This physical activity should be incorporated into the day.*
- *Expectations of the person's physical ability should be considered when planning their day.*
- *When the person is partaking in physical activity, care providers should be watching for signs of strain and distress. Be aware of any discomfort or signs of overexertion. Talk to the person's doctor if this happens.*
- *Independence is very important when doing physical activity. Allow creativity even if that means a not-so perfect outcome.*
- *Spend time outside when the weather permits.*
- *Exercise often helps everyone sleep better.*
- *There is an association between greater involvement of families and greater resident participation in activities.*

Provide an environment that encourages spontaneous activities and supports persons in facilitating their own activities when they choose. Being able to maintain activities one enjoyed throughout one's life can help a person during the transition period helping the person adjust to the new home.

A change of scenery is important for some; consider involvement in activities both within the care home as well as the broader community.

Social Interaction

- *Social interaction is a consequential activity that is one of the critical elements of a person's care.*
- *Social interaction not only stimulates but helps maintain the person's functional abilities and can enhance quality of life.*

- *Offer many opportunities each day for providing a context with personal meaning, a sense of community, choices and fun.*
- *Interactions should reflect the person's values and interests.*
- *Scheduled social engagements like a card game or a sing along can create an activity that the person looks forward to. Although social engagement is important, staff must respect resident preferences to engage or disengage at anytime.*

STRUCTURE, ROUTINE AND FAMILIARITY ARE IMPORTANT TO PEOPLE WITH DEMENTIA.

Relationships and sexuality

It is important to recognize that a person with dementia has a right to maintain existing relationships with people who have been an important part of their life and to create new ones. All human beings are sexual beings from birth to death and dementia should not alter this perception.

As the disease progresses, some people may no longer recognize or remember their partners, and may seek companionship and physical intimacy with a new partner in a care home. Others may lose their inhibitions and act and behave in ways that they did not before, or in ways that others might consider “inappropriate”. However, staff need to consider all possible reasons for the “inappropriate” sexual behaviour, as the person may actually be trying to communicate a need or convey a message (i.e. the need to go to the toilet, discomfort, loneliness or boredom).

Everyone has a need for companionship and physical intimacy. People with dementia are no different. The needs for companionship and physical intimacy of people with dementia must be supported with respect and dignity. When appropriate, touch, holding hands and other warm gestures can help reaffirm a person's worth. Staff recognize the need for sexuality and intimacy; they support the residents to express their needs by providing adequate privacy. The needs of couples must always be considered and accommodated.

What the current available evidence says:

Sexuality

- *React to the behaviour in a calm manner.*
- *Gently discourage inappropriate behaviour such as removal of clothing in a public place and create a distraction. Consider re-directing the person to another activity.*
- *Persistently challenging behaviour may be discussed and problem solved with the person's medical doctor, care team and family.*

D. CHANGES IN MOOD AND BEHAVIOUR

Mood changes

Some people with dementia have abrupt changes in their moods and emotions. These changes can be unpredictable. Mood changes can be eased by keeping a calm environment with fixed daily rituals. The individual should not be questioned repeatedly or given too many choices.

Guidelines developed to help caregivers with changes in emotions allow for unpredictable emotions to be handled in a calm, consistent manner. Family members may be good resources in understanding behaviours and identifying potential triggers.

What the current available evidence says:

Moods and emotions

- *A calm, predictable environment that is set with fixed daily activities assists the person in feeling safe and happy.*
- *Persons should not be questioned repeatedly or given too many choices. (For example, limiting choice to two allows for personal choice but is not overwhelming or offering one option with yes or no response).*
- *Mood changes are also amenable to distraction, particularly if topics related to the past are discussed or favourite pieces of music played.*

Long-held holiday traditions may no longer be appropriate or enjoyable to both the person with dementia and his/her family. It is important to consider those aspects of the holiday which are truly meaningful so as to avoid overwhelming the person and his/her family caregivers. Simplifying traditions can be helpful.

For example, families may be encouraged to share frequent, shorter visits with their relative with dementia, rather than one long holiday meal. Reducing the number of visitors at one time (and associated noise levels and stimulation) may also be helpful.

Preparing for holidays can impact mood

- *A person's expectations for the holidays should be discussed, especially in that their expectations of the holiday may now be different. Realistic expectations should be discussed and new plans determined to best suit the person.*
- *Friends and family are encouraged to visit. Discuss with the family a schedule for visitors to avoid the person becoming overwhelmed due to too many visitors at once and none for long periods of time.*

Depression/anxiety

- *A cheerful and bright environment that promotes interaction instead of solitude will help decrease depression.*
- *Acknowledge feelings and comfort the person when they are feeling depressed or anxious.*
- *Redirect persons when they express persistent negative thoughts.*

Responsive and Protective Behaviours

Dementia can lead to responsive and protective behaviours that may challenge care providers. It is important to understand that behaviours are a form of communication and it is staff's responsibility to interpret them. What the person with dementia is expressing through their behaviours is always meaningful. Having specific guidelines to help with these responsive and protective behaviours can reduce and at times prevent them.

What the current available evidence says:

Aggression/agitation

- *Behaviours can become more challenging at dusk, a phenomenon known as “sundowning”. Additional care to proactively assess the person’s needs must be taken during the evening and at night.*
- *Behaviours perceived as disruptive may be reduced or eliminated by altering approaches to activities such as bathing and creating an environment to suit specific needs and/or concerns.*
- *Identify potential triggers of emotional outbursts and take steps to avoid them.*
- *A calm environment along with soothing music can help relax individuals and reduce agitation.*
- *Non-threatening and gentle approaches can reassure the person. Examples may include supporting and reassuring the person rather than arguing, confronting, or trying to reason with them.*
- *Distract a person from the trigger or cause of agitation.*

Repetitive Behaviours/ Perseveration

- *Be patient with the person. Distraction can help reduce the continuing or repeating behaviour.*
- *Offer the person something else to do as a distraction or remove the trigger.*
- *Touch and other forms of reassurance may help the person focus on a different thought and set of feelings. However, only use this approach if appropriate for the person.*

Clinging (or shadowing)

- *Provide something to occupy his/her attention while you step away; consider replacing yourself with an item that is known to be comforting to the person (such as a stuffed toy or soft blanket).*

III. ENSURING FAMILY INCLUSIVENESS

Staff need to ensure that family members are invited, encouraged and supported in being involved and engaged in the life of the person with dementia. Staff in a person-centred care home value and include family and friends, involving them actively in the support network and seeking them out, including them as valued members of the care team.

Family and friends play an integral role in helping the person with dementia to have a “good day” by maintaining normalcy and a sense of continuity for the person with dementia and familiarizing staff with the person’s likes and dislikes and prior ways of being.

It is critical for staff to receive training around working collaboratively with families and recognizing what a move to a long term care home represents for families. When sharing information with family members and friends about a resident, staff have an opportunity to engage in a collaborative process of positive problem solving in an effort to understand the meaning of behaviours. By inviting family and friends to share their experience of the person's life long values, wishes and personality, creative approaches to improving the person's day to day life are more likely to happen. Finally, staff need to be trained to work with families in various stages of grief.

What the current available evidence says:

Families with members who have been given a diagnosis of Alzheimer’s disease will experience a range of emotions and will have a number of decisions to make about the current and future care and support of the person living with Alzheimer’s disease. Health care service providers can help guide families to make decisions that they are comfortable with so that they feel their family member is well cared for.

For family members experiencing difficulties adjusting, it is best to refer them to counseling services.

Studies have found that interventions with a combination of social and cognitive components appear to be the most effective in improving psychological well-being of family members.

Working with the family

- *Encourage family members to ask the doctor any questions about Alzheimer’s disease, including information about medication, treatment options and the best ways to help alleviate symptoms or address behaviour they are concerned about.*
- *Caregivers need to be involved in care plan development.*
- *Caregiver input is obtained about whether any behaviour is perceived as a concern.*
- *Be prepared with a list of available support groups that family members may attend.*
- *Help families make future care plans.*
- *Family members should have access to training and education which will help them understand the disease process and assist them in their role as caregiver / support person.*

IV. EXTENDING A PERSON-CENTRED PHILOSOPHY THROUGH END OF LIFE

The overall goals of palliative and end of life care are to improve the quality of living and dying for people with dementia and to minimize unnecessary suffering through the provision of the following services:

- pain and symptom management;
- psychological, social, emotional and spiritual support;
- support for family members and caregivers; and
- bereavement support.

Working in partnership with the individual and their family to alleviate painful and traumatic processes and supporting them to make difficult decisions is central to palliative care.

Definitions³ :

Palliative care:

The Canadian Hospice Palliative Care Association (CHPCA) defines hospice palliative care as “the combination of active and compassionate therapies intended to comfort and support persons and families who are living with, or dying from, a progressive life-limiting illness, or are bereaved” (CHPCA, 1995). Hospice palliative care is “whole-person health care that aims to relieve suffering and improve the quality of living and dying” (CHPCA 2009).

The CHPCA definition is consistent with the definition established by the World Health Organization (WHO) 2005, which describes palliative care as “...an approach that improves quality of life of clients and their families facing the problem associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”

End of life care:

End of life care is designed to meet the physical, psychological, social, spiritual and practical needs of individuals and caregivers facing terminal illness.

Palliative care is an important consideration for end stage dementia in long term care homes⁴. It is important that palliative and end of life care planning is discussed and thought through early with the person with dementia and their family member. Discussions are encouraged as early as possible to ensure that appropriate end of life care is the goal for the end stage of dementia.

³ Source: Canadian Hospice Palliative Care Association - www.chpca.ca

⁴ Communities, the private sector and/or government may support the provision of palliative and end-of-life care services. Therefore, the services available and how they are funded may vary depending on the community in which you live.

It should also be noted that palliative care is an approach which can be adopted as early as possible in the course of the disease and is not limited to the very last days or weeks.

It is important to remember that people with dementia and their families should not be forced to accept various aspects of palliative or end of life care; these are personal choices. It has to be negotiated through education and interaction with staff, families and individuals with dementia.

"YOU MATTER BECAUSE YOU ARE YOU AND YOU MATTER TO THE LAST MOMENT OF YOUR LIFE. WE WILL DO ALL WE CAN TO HELP YOU, NOT ONLY TO DIE PEACEFULLY BUT TO LIVE UNTIL YOU DIE" (Saunders, 1976)

A. PAIN MANAGEMENT

What the current available evidence says:

Pain management

Providing effective pain management to people with Alzheimer's disease continues to be a challenge to healthcare professionals who practice in the long-term care setting. Good pain assessment technique involves looking at a comprehensive picture of the person upon admission or first complaint of pain and then following up with pain assessment on a regular basis.

Studies have shown a modest level of agreement between residents and supervisors about whether the resident had pain, and yet one third of residents with pain were not receiving any treatment for it.

- *Reducing a person's pain will help the resident enjoy an improved quality of life.*
- *Pain assessment should occur regularly, including when residents have conditions likely to result in pain and if residents indicate in any manner that they have pain.*
- *Pain should be treated as the "fifth vital sign" by regularly assessing and treating it in a formal, systematic way, as one would treat blood pressure, pulse, respiration and temperature.*
- *Pain management is unique to each resident's needs, circumstances, conditions and risks.*
- *Effective pain assessment addresses the following:*
 - *Site of pain*
 - *Type of pain*
 - *Effect of pain on the person*
 - *Pain triggers*

- *Whether pain is acute or chronic*
- *Positive and negative consequences of treatment*
- *For those residents who cannot verbally communicate, direct observation by staff consistently working with them can help identify pain and pain behaviours*
- *Suspicion or evidence of increased pain should be reported to and monitored by the nurse in charge of the unit or neighbourhood. Medical advice should be sought if it is drastically increased or persistent*

**FOCUS ON QUALITY OF LIFE AND COMFORT,
RATHER THAN ON LENGTH OF LIFE AND TREATMENT.**

B. END OF LIFE CARE

The person-centred philosophy of end of life care provides comprehensive comfort care to the person with dementia at a late stage as well as support to their family when attempts to cure the illness are not possible. It is crucial that care home staff work together with the person with dementia and the family to provide the medical, emotional, and spiritual support needed.

What the current available evidence says:

End of life

- *The goal is to use a person-centred, culturally and spiritually sensitive approach to providing care that meets a resident's changing needs and respects his or her preferences regarding end of life care.*
- *There is a need to minimize the resident's physical, emotional and spiritual distress, while maximizing comfort and well-being in a manner consistent with an individual's preferences regarding end of life care.*
- *It is important to ensure open and ongoing communication among the resident, proxy decision maker, family and care team so that all parties have a clear and common understanding of what constitutes optimal end of life care of the individual resident.*
- *Providing support to families, other residents and staff when an individual is dying and after death has occurred will help them to achieve meaningful closure.*
- *Care plans need to be flexible enough to adapt to daily changes in a resident's needs and wishes.*

Medical care decisions

There is a range of life-prolonging medical care available for people in the terminal stages of an illness. When and if to use these measures depends on the type of medical care that the person has specified or, if explicit directions have not been given, the best decision based on the person's values and desires.

The following are some of the measures that commonly need to be addressed.

- Cardiopulmonary resuscitation or CPR is a group of treatments used to restore function when a person's heart and/or breathing stops. CPR is not recommended by many experts when a person is terminally ill and is often not desired by persons when they are competent to make such decisions. A "Do not resuscitate" (DNR) or Do not attempt resuscitation (DNAR) order tells the medical professionals not to perform CPR if the person's breathing or heartbeat stops.
- Feeding tubes are sometimes suggested if a person has a difficult time eating or swallowing, which is common in the late stage of Alzheimer's disease. Tube feeding has not been proven to benefit or extend life and can result in infections and discomfort to the person. However, sometimes it is considered for a fixed time period. The health-care team should talk with the person's decision-maker about any specific plans for use of feeding tubes.

- Intravenous (IV) hydration is liquid administered to a person through a needle in a vein. Lack of hydration is a normal part of the dying process and allows for a more comfortable death over a period of days. Using IV hydration can draw out the dying process for weeks and physically burden the person. If IV use is being considered, there should be specific goals with a limited time period agreed to by the family and the health-care team.
- Antibiotics may be prescribed for common infections but may not improve the person's condition.

Spiritual Care

Spiritual care is relevant. Spirituality is about finding meaning, purpose and connection in life. A major misconception is equating spiritual care solely with organized religion. Religious care at its best will have spiritual dimensions, but not all spiritual care is religion based. Spiritual care is person-centred and makes no judgments about the individual's beliefs, illness, or lifestyle orientation.

Long-term care homes are communities of their own with strong bonds between residents and staff. In some homes a community of care has become so entrenched that when a resident dies, the event is akin to losing a member of one's own immediate family. This is not a bad thing. It is actually a positive cultural signal. But the resulting despair felt potentially by everyone in the community must be acknowledged, understood, and managed with sensitivity. Rituals that allow staff and families to acknowledge and share their loss with others can help them resolve their own grief.

HOW CAN WE HELP YOU SUPPORT INDIVIDUALS WITH DEMENTIA AND THEIR FAMILIES?

The Alzheimer Society is the leading not-for-profit health organization working nationwide to improve the quality of life for Canadians affected by Alzheimer's disease and related dementias and advance the search for the cause and cure. We are located in every province across Canada and in over 140 local communities.

Since 1978, we've been dedicated to providing help for people with Alzheimer's disease and related dementias and their caregivers. That help comes in many ways.

The Alzheimer Society provides support, information and education to people with Alzheimer's disease and related dementias, families, physicians and health-care providers.

For more information on our programs and services, please visit our national website www.alzheimer.ca or contact your local Alzheimer Society.

DISCLAIMER

The information provided in this document is for informational purposes; it is not a substitute for professional medical care or advice. This framework is intended to outline the current available research that has resulted in guidelines for optimum person-centred care of people with dementia living in care homes. This document does not include guidelines for care for specific health disciplines.

APPENDIX 1

Rapid Evidence Assessment of Guidelines for Care. Summary of Guidelines, 2009.

Introduction

Person-centred care is a framework advocated for the care for people with Alzheimer's disease. A central assumption of person-centred care is the notion of personhood, which values the quality and condition of being a person with Alzheimer's disease (Edvardsson, Winbold, & Sandman, 2008). It is a widely used concept for holistic and individual centres best –practice care of people with dementia (Edvardsson, et al., 2008). Within the lens of person-centred care for people with severe Alzheimer's disease, a Rapid Evidence Assessment (REA) was completed to systematically examine practice guidelines published in the peer-reviewed journals.

There has been a recent surge of interest in the use of clinical practice guidelines, largely because of the variation of clinical practice, new reports about ineffective and inappropriate care of clients, recent focus on evidence-based practice and a shift towards looking for more cost effective strategies (Shaneyfelt, Mayo-Smith, Rothwangl, 1999). When clinical practice guidelines are systematically developed as statements to assist clinicians and person decisions about appropriate care for specific clinical circumstances, it is believed that these practice guidelines can improve the quality, appropriateness, and cost-effectiveness of care (Institute of Medicine, 1990). In response to this increased interest, several major health care organizations have carefully formulated methodology for developing scientifically sound guidelines (American Medical Association, 1990; Canadian Medical Association, 1993; Eddy 1992; Woolf 1991).

The development of best practice guidelines within assumptions of person-centred care acknowledges personhood, while promoting the quality of care based on the best available evidence. This best practice model recognizes that the personality of the person with Alzheimer's disease is not lost but rather increasingly concealed with the severity of the disease. The guidelines cover a broad range of care to cover the many aspects of the personalization of the person's care and environment. Although the guidelines address basic prevention, management and elimination of physical discomfort (i.e. pain, constipation, malnutrition, etc), they also address psychosocial aspects (i.e. feeling safe, sense of belonging, etc). This holistic approach addresses body, mind, and spirit to ensure people with Alzheimer's disease are receiving personalized and relevant care.

Method

Rapid Evidence Assessment

Like systematic reviews, rapid evidence assessments are based on comprehensive electronic searches of appropriate databases, but concessions are made to complete the review within selected timeframes (Davies, 2004). As a result, exhaustive database searching, hand searching of journals and textbooks, or searches of 'grey' literature are not immediately undertaken.

The functions of a rapid evidence assessment include: 1) searching the electronic and print literature; 2) collating descriptive outlines of the available evidence on a topic; 3) critically appraising the evidence; 4) sifting studies of poor quality; and 5) providing an overview of the current state of the evidence (Davies, 2003).

Information Retrieval Strategy

Ten electronic databases were searched for this review (see appendix A) including PsychInfo, Ageline, ASSIA, Digital Dissertation, Medline (CSA), Social Science Abstracts, Science Service Abstracts, Medline (OVID), EMBASE (OVID), EBM (OVID). Search terms were modified according to the databases. For Medline (OVID), the following search strategy was used:

1. practice guidelines.mp.
2. exp Practice Guideline/
3. exp Practice Guidelines as Topic/
4. clinical guideline.mp.
5. practice parameter.mp.
6. consensus conference.mp.
7. evidence based guidelines.mp.
8. exp Clinical Protocols/
9. exp Decision Making/
10. practice policy.mp.
11. exp "Quality of Health Care"/
12. quality standards.mp.
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
14. exp Alzheimer Disease/
15. alzheimer.mp.
16. exp Dementia/
17. dementia.mp.
18. 14 or 15 or 16 or 17
19. 13 and 18

The searches of all electronic databases were completed in January 2009. The total number of hits based on the information retrieval strategy was 2780 titles. These were imported into Endnote, a bibliography software, and duplicates were removed, resulting in 1830 titles and abstracts. All 1830 titles were screened according to the inclusion criteria of whether the articles considered guidelines relevant to the care of people with Alzheimer's and whether the article systematically developed statements to assist practitioner and person decisions about appropriate care for specific clinical circumstances (Institute of Medicine, 1990). Excluded articles included articles that considered: 1) diagnostic criteria or technical standards; 2) guidelines on research methods 3) review articles; 4) any secondary publications of the guidelines.

Based on the inclusion/exclusion of the first level of screening, 148 articles were passed to the second level of screening. Once full text articles were retrieved and screened, 60 articles passed to the data extraction level. Twelve other articles were retrieved and included by searching grey literature and Google. Therefore, the total number of guidelines brought forward for data extraction was 72.

The methodological quality of practice guidelines was completed to assess the degree to which practice guidelines used and documented methodological standards. Assessment of the quality of guidelines considered: 1) the method used to identify and collect the evidence; 2) the individuals involved in developing the guidelines; and 3) whether formal assessment of the strengths of evidence were attached to specific recommendations (Penna, Grilli, Magrini, Mura, Liberati, 1998).

Results

Many published guidelines and consensus statements provide recommendations for identification, diagnosis and ongoing management of health issues such as cognitive decline and psychiatric symptoms. The focus of the current review of guidelines for care considers the quality of care for people with Alzheimer's disease to ensure they receive relevant and appropriate care based on the best available evidence. Guidelines reported here are relevant to nurses and health care providers in long-term health care facilities. Guidelines were selected from existing clinical guidelines, consensus statements and systematic reviews based on the credibility of the guideline, and the frequency of inclusion. Based on the criteria for assigning quality, higher quality guidelines were based on systematic review procedures and expert panel consensus models.

Person-Centred Care

There are few studies that have assessed the implementation of person-centred care as most published work includes clinical experiences, personal opinions and anecdotal evidence (Edvardsson, et al., 2008). Qualitative studies suggest that health care staff's view of people with Alzheimer's disease has implications for health care and how care is provided. These studies suggest that if health care staff view people with Alzheimer's disease 'losing their personality' then there is a risk that the person will only be treated for physical symptoms while less effort is made by the health care staff to connect with the person in a meaningful and individual way (Logstrup, 1997). Conversely, a recent review of the interventions for caring for people with Alzheimer's disease concluded that the relationship between the person and their carer was essential for creating and maintaining meaningful relationships (The Swedish Council on Technology Assessment in Health Care, 2006).

A randomized controlled trial of person-centred intervention for showering and bathing residents with moderate to severe dementia concluded that measures of discomfort, agitation and aggression among people with Alzheimer's disease in residence declined significantly in the group receiving person-centred care compared to the control group (Sloane, Hoeffter, Mitchell, et al., 2004).

In another randomized controlled trial of person-centred intervention for showering and bathing residents with moderate to severe dementia, Hoeffter, Talerico, Raisin, et al., (2006) found that staff in the intervention group were reported to be more gentle, more verbally supportive and felt more at ease (qtd in Edvardsson, et al., 2008)

In all guidelines, consensus statements and systematic reviews, there was a general focus on the need for people with Alzheimer's disease to have meaningful relationships and social contact, predictable routines (exercise, meals, and bedtime should be routine and punctual), quiet non-distracting environments, relaxed atmospheres with reduced stimulation and routines that meet the unique needs of each person in care.

Person-centered, culturally sensitive approaches should be adopted to provide care that meets a resident's changing needs and respects his or her preferences regarding end-of-life care.

Psychological Treatments

Non-pharmacological psychological treatments were not specifically considered in this review of guidelines but many reviews discussed treatments nevertheless. There was a general consensus of the benefit of using behavioural management for depression.

There was evidence supporting the effectiveness of behaviour problem-solving therapies and individualized progressive lowered stress interventions in combination with problem solving and environmental modification for the treatment of behavioural disturbances in dementia, but further research is required.

Music and multi-sensory intervention have also been considered as promising therapies for people with Alzheimer's disease, as these may help the person to be calm and relaxed. However, future studies should seek to replicate the findings.

The effectiveness of acupuncture for vascular dementia is uncertain. More evidence is required to show that vascular dementia can be treated effectively by acupuncture. There are no RCTs and high quality trials are few. Randomized double-blind placebo controlled trials are urgently needed. There was support for using caregivers and/or staff education programs to help deal with a variety of behaviours of people with Alzheimer's disease.

Communicating with Persons

Most guidelines addressed the importance of communication and it was reported to be central to the interactions of persons, family members and service providers.

- Use simple words and short sentences in a gentle, calm tone of voice.
- Avoid talking to the person with Alzheimer's disease at a reduced cognitive level or discussing the person as if he or she were not there.
- Minimize distractions and noise, such as the television or radio, to help the person focus on what you are saying.
- Address the person by name, making sure you have his or her attention before speaking.
- Allow time for the person to respond independently. Be careful not to interrupt.
- If the person with Alzheimer's disease is struggling to find a word or communicate a thought, gently try to provide the word he or she is looking for. Try to frame questions and instructions in a positive way.
- Explain all procedures and activities in simple and straightforward terms to the person before performing them.

Daily Routine

Daily routine has been found to help provide people with Alzheimer's disease with the needed predictability. As well, this predictability in daily routine has been found to reduce the anxiety of family members as they are provided with the steps in how their family member will be cared for. Guidelines for daily routine also help to train new staff and guide senior staff for scheduling purposes. Most of the guidelines focused on everyday care, such as bathing, personal hygiene, dressing, toileting, eating, cooking.

As soon as a diagnosis of Alzheimer's disease is made, it is essential to develop a daily routine for the person's abilities to be maintained thereafter. In the early stages of the disease, persons are able to adapt to necessary changes. However, in more advanced stages, only those routines which have been previously established are likely to be maintained and it is very difficult to expect people with dementia to adapt to any further changes.

Persons often deteriorate after dark, a phenomenon known as 'sundowning'. Additional care must be taken during the evening and at night.

Personal Hygiene

- Develop a bath or shower routine that considers the person's most calm and agreeable time of the day. Ensure that you are consistent in following the time and routine.
- To reduce stress, ensure you have all items required to complete the person's bathing routine on hand before you assist the person into the bathing area. Never leave the person alone in the bath or shower.
- Run the bath ahead of time, test the water and play soothing music to create a calm environment.
- Be gentle and respectful. Be patient and calm. Be aware that bathing can make the person vulnerable, scared and confused.
- Communicate the routine to the person step by step, allowing the person to be as independent as possible.
- Safety features such as a handheld showerhead, shower bench, grab bars, and nonskid bath mats are installed properly.
- Consider a sponge bath on alternative days. This can reduce the daily stress and is effective for maintaining personal hygiene between showers or baths.
- Ensure a dental routine is followed. Daily oral health and dental appointments are essential to keep the mouth and teeth healthy. Persons may have dentures that need to be soaked.

Dressing

- Develop a dressing routine that is to be preformed at the same time daily.
- Allow the person as much independence as possible when dressing. Allow a reasonable amount of time for this routine to allow the person a calm, relaxed environment to avoid time restrained interjections to speed the process up.
- Independent choice from a limited selection of outfits to ensure independence. If the person favours a type of clothing, it may be beneficial to have several items of similar clothing.
- Laying out the clothing in the order in which they should be put on provides a visual cue to help increase independence. Visual reminders as opposed to verbal cues may reduce agitation.
- Assist the person with clear, concise instructions to avoid confusion. You may need to repeat an instruction; however, ensure your tone is calm and patient.
- Loose comfortable clothing with Velcro and elastic is easier to get on and off, and easy to care for. This also helps increase independence for the person.

Toileting

- A toileting schedule will help reduce incontinence and increase independence. Try to create this routine in accordance with the person's bladder functioning. Their regularity will help determine their toileting schedule.
- Regardless of their toileting schedule, watch for signs that the person needs to use the bathroom and respond promptly.
- Prompt voiding to reduce urinary incontinence
- Reassure clients when accidents happen by reacting calmly and respectfully. Assist the client to removed soiled clothing and to get redressed into clean clothing, following the dressing routine.
- Limiting fluid intake in the evening helps reduce overnight accidents. Chart when these accidents occur to try and determine a pattern to then insert a toileting routine to accommodate this time.
- When going on an outing, encourage the person to use the toilet before heading out. Locate the washroom upon arrival at destination. Wear clothing that allows for ease of toileting in unfamiliar locations and take an extra set of clothing along in case of an accident.

Meals

- Residents who have meals in public dining areas (rather than in their own rooms) and residents who have meals in dining areas with more home-life environments are less likely to have low food and fluid intake.

- Inadequate consumption or inappropriate food and fluid choices can contribute directly to a decline in a resident's health and well-being.
- Meal and snack time routines should be established. Keep in mind the person's preference and time in which they are hungry. As well, allow the proper duration of time for the person to eat at their pace.
- Persons should be provided a well-balanced diet, rich in protein, high in fibre, with adequate amount of calories depending on height and body weight. The total quantity of food can be calculated by a dietician, if necessary. Many persons have "sugar craving" i.e. they love to eat sweet food products. Care should be taken that such persons do not gain weight. The diet should take into account other medical illnesses which require diet modification, such as diabetes or high blood pressure.
- Mealtimes are opportunities for social interaction for the person with Alzheimer's disease.
- A person with Alzheimer's disease may experience increased confusion and anxiety during meal times so staff need to be aware of individual reactions to meal times and respond with both patience and sensitivity to the unique needs of the individual.
- Low lighting levels, music, and simulated nature sounds to improve eating behaviours.
- Try to provide choice of food for the person keeping in mind to limit the choices to two. Choice should keep in mind preference, nutritional needs and independence. Keep in mind texture and colour of foods should provide variety.
- During the day several small meals, healthy snacks, finger foods, and shakes should be made available to a person if requested or if there are signs of hunger or a missed meal.
- Document what a person has eaten during the day to avoid over eating and proper nutrition.
- Eating and drinking tools to assist with independence as recommended. For example, a bowl instead of a plate or a straw to assist in drinking. Finger foods.
- Fluid liquid during the day is not limited. Fluid intake should be monitored to ensure the person does not get dehydrated.
- Choking becomes an increased risk as the disease progresses. Texture of food becomes important, as well as ability to chew and swallow.

Leisure/Recreation/Exercise/Outings

Studies have found that people with Alzheimer's disease benefit from physical activity. Physical activity improves overall physical health, mental, emotional and social wellbeing. Health care providers must follow guidelines to ensure activities are within levels of capabilities and within range of abilities.

Other types of outings, such as medical, dental, optometry and other types of appointments that take the person out of the long-term facility may cause stress and anxiety so guidelines should be followed to help reduce stress and confusion for the persons and their families.

Activities

- Keeping physically active has been found to help minimize the physical and mental decline inherent in dementia.
- Simple activities increase success rate.
- Staff should provide positive reinforcement when the person is performing an activity.
- Some person may need assistance in getting started or choosing an activity. Step by step instructions and praise as a step is successfully completed. Use of prompting and cues.
- Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.
- As part of the person's daily routine, incorporate activities of enjoyment and try to do them at a similar time each day.

Physical Activity

- There is good evidence to indicate that individualized exercise programs have an impact on functional performance. Individualized exercise programs should be tailored based on the person's ability and capabilities.
- Physical activities should reflect what the person with Alzheimer's disease enjoys. This physical activity should be incorporated into the daily routine.
- Expectations of the person's physical ability should be considered when creating their routine.
- When the person is partaking in physical activity, care providers should be watching for signs of strain and distress. Be aware of any discomfort or signs of overexertion. Talk to the person's doctor if this happens.
- Independence is very important when doing physical activity. Allow creativity even if that means a not-so perfect outcome.
- Spend time outside when the weather permits. Exercise often helps everyone sleep better.
- There is an association between greater involvement of families and greater resident participation in activities.

Attending the Doctor

- Scheduling appointments for the person's best time of day may help in a successful visit. Keep in mind that there may be a waiting room or a crowd. Ask the doctor's office when is the least busy time to visit or try to arrange house calls.

- Inform the doctor's office staff of the client's state as they may be able to work something out so that the visit is less stressful.
- Informing the person of an upcoming appointment may cause stress. Inform the person as you are preparing to leave for the appointment.
- Bring along distractions and nutrition for the person. This can help make the appointment more enjoyable.
- Consider inviting an additional staff or family member to the appointment as you may need to speak with the doctor separately. If this is not possible, set up a time to call the doctor after you have accompanied the person back to the facility.

Social Interaction

- Social interaction is a consequential activity that is one of the critical elements of a person's care.
- Social interaction not only stimulates but helps maintain their functional abilities and can enhance quality of life.
- Offer many opportunities each day for providing a context with personal meaning, a sense of community, choices and fun.
- Interactions should reflect the person.
- Scheduled social engagements like a card game or a sing along can create an activity that the person looks forwards to. Although social engagement is important staff must respect resident preferences to engage or disengage at anytime.

Transportation

- Vehicular transportation should be provided in a manner which ensures the safety and emotional comfort of the person with Alzheimer's disease.
- Whenever possible, the driver should be accompanied by another individual. If there is no one to accompany the person, an identification card should go with the person in case they lose their way. If at all possible, ensure staff is available to accompany the person.
- Persons should be assisted into the vehicle and out of the vehicle and ensure that they are wearing their seat belt.
- Travel should be limited to the comfort level of the passenger. Trips may be shortened and or frequent stops may have to be made.

Emotional

Some people with Alzheimer's disease have abrupt changes in their moods and emotions. These changes can be unpredictable. Mood changes are best controlled by keeping a calm environment with a fixed daily routine. The persons should not be questioned repeatedly or given too many choices. Guidelines developed to help caregivers deal with such emotions allows for unpredictable emotions to be handled in a calm, consistent manner.

Moods and emotions

- A calm, predictable environment that is set with a fixed daily routine assists in controlling moods.
- Persons should not be questioned repeatedly or given too many choices. Limiting choice to two allows for personal choice but is not overwhelming.
- Mood changes are also amenable to distraction, particularly if topics related to the past are discussed or favourite pieces of music played.

Dealing with Holidays

- A person's expectations for the holidays should be discussed and that things may be different. Realistic expectations should be discussed and new plans determined to best suit the person.
- Friends and family are encouraged to visit. Discuss with the family a schedule for visitors to avoid the person from becoming overwhelmed due to too many visitors at once and none for long periods of time.

Depression/anxiety

- A cheerful and bright environment that promotes interaction instead of solitude will help decrease depression.
- Mild to moderate exercise increases positive hormone circulation.
- Redirect persons when they express negative thoughts.
- Acknowledge feelings and comfort them when they are feeling depressed or anxious.

Behavioural

Alzheimer's disease can cause many behavioural issues. Having specific guidelines to help manage these behaviours can help regulate and cope with the behaviours and at times prevent them.

Aggression/agitation

- Disruptive behaviour may be reduced or eliminated by altering approaches to activities such as bathing, or environment to suit specific needs and/or concerns.
- Identify potential triggers of emotional outbursts and attempt prevention of outbursts
- A calm environment along with soothing music can help relax and reduce agitation.
- Nonthreatening and gentle approaches can reassure the person while avoiding arguing, confronting, or trying to reason with persons.
- Distract a person from what their trigger or focus of aggression is.

Repetitive Behaviour/ Perseverations

- Be patient with the person. Distraction can reduce perseveration.
- Offer the person something else to do as a distraction. Or remove the trigger.
- Touch and other forms of reassurance may help the person focus on a different thought and set of feelings. However only use this if appropriate for the person.

Clinging

- Provide something to occupy his/her attention while you step away or replace yourself with an item that is known to be comforting to the person.

Wandering

- Make sure that the person carries some kind of identification or wears an identification bracelet. If the person gets lost and is unable to communicate adequately, identification will alert others to the person's medical condition.
- A picture or video of the person should be kept and up dated every 3 months to assist police if the person becomes lost.
- Ensure that all exits are secure and have alarms when exits are opened without consent.
- Ensure that all potentially harmful objects are stored safely, especially at night.
- The nearest police station should be informed of persons that have a tendency to wander.

Misplacing things and accusations of theft

- Make discreet labels on personal items such as clothing.
- Become aware of favourite storage places the person has for missing items.
- If there are items such as eye glasses, keep a replacement pair.
- Check the garbage and laundry sacks for missing items.
- Respond calmly to the person's accusations and assist the person to locate missing items.
- Agree with the person that the item is lost and help find it.

Sexual

People with Alzheimer's disease continue to experience sexual desires in which they are entitled to. Health care practitioners can help assist persons with these situations by providing proper service providers to help deal with the person's sexuality and possible sexual inappropriateness.

Inappropriate/unwanted sexual behavior

- React to the behaviour in a calm manner.
- Redirect the person to another activity.
- Gently discourage sexually inappropriate behaviour such as removal of clothing and create a distraction.
- Persistently inappropriate behaviour may be discussed and problem solved with the person's medical doctor, care team and family.

Medical

It is important to recognize that person's with Alzheimer's disease may well have other medical conditions that require ongoing treatment.

Sleep Problems

- Exercise during the day and limiting daytime napping can improve the likelihood of a person being tired and sleeping at night.
- Schedule physically demanding activities earlier in the day so you are not stimulating the person right before bedtime.

- Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, and play soothing music if the person seems to enjoy it.
- Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.
- Reduce fluid intake in the evening especially drinks that contain caffeine.
- Night lights in a person's room, hall, and bathroom may reduce fear of the dark.

Hallucinations and Delusions

- Physical illness may be the cause of hallucinations and delusions. Medical opinion should be sought to rule this out. Document what the person is experiencing.
- Do not confront the person about what he or she sees or hears. Respond to the feelings he or she is expressing, and provide reassurance and comfort.
- Move the person from the trigger and attempt to distract them to a different topic.
- Televisions should be shut off when violent or other disturbing content is portrayed. The person with Alzheimer's disease may have difficulty distinguishing what is reality and what is fiction.
- Make sure the person is safe and does not have access to objects that he or she could use to harm anyone.

Alcohol and cigarettes

- Check with doctor to ensure they are cleared to consume alcohol and smoke.

Safety

- Install secure locks on all outside windows and doors, especially if the person is prone to wandering.
- Remove the locks on bathroom doors to prevent the person from accidentally locking himself or herself in.
- Use childproof latches on kitchen cabinets and any place where cleaning supplies or other chemicals are kept. Remember that cleaning and other toxic fluids can be mistaken for juices and other forms of beverage.
- Label medications and keep them locked up. Also make sure knives, lighters and matches are secured and out of reach.
- Remove scatter rugs and anything else that might contribute to a fall. Make sure lighting is good both inside and out – especially for aging eyes.

Pain Management

Providing effective pain management to people with Alzheimer's disease continues to be a challenge to healthcare professionals who practice in the long-term care setting. Good pain assessment technique involves looking at a comprehensive picture of the person upon admission or first complaint of pain and then following up with pain assessment on a routine basis. Studies have shown a modest level of agreement between residents and supervisors about whether the resident had pain, and yet one third of residents with pain were not receiving any treatment for it.

- Reducing a person's pain will help the resident enjoy an improved quality of life.
- Pain assessment should occur routinely, including when residents have conditions likely to result in pain and if residents indicate in any manner that they have pain.
- Pain should be treated as the "fifth vital sign" by routinely assessing and treating it in a formal, systematic way, as one would treat blood pressure, pulse, respiration and temperature.
- Pain management is unique to each resident's needs, circumstances, conditions and risks
- Effective pain assessment addresses:
 - o Site of pain
 - o Type of pain
 - o Effect of pain on the person
 - o Pain triggers
 - o Whether pain is acute or chronic
 - o Positive and negative consequences of treatment
- For those residents who cannot verbally communicate, direct observation by staff consistently working with them can help identify pain and pain behaviors.
- Increased pain should be monitored. Medical advice should be sought if it is drastically increased or persistent.

Prevention of and Response to Abuse

- The emphasis should be on preventing abuse by identifying and alleviating circumstances which are likely to lead to physical, psychosocial or financial abuse or neglect.
- Protocol to deal with abuse should already be in place.
- When abuse is suspected, the proper authorities should be contacted.

Use of restraints

- Effective care planning involves knowing a resident's remaining abilities and understanding how to make use of them to avoid conditions such as wandering and falls that can lead to inappropriate use of restraints. Care planning staff are responsible for trying and documenting various options to avoid use of restraints.
- Staff at all levels need to understand the hazards of using restraints and the process of individualized assessment and care planning to meet each resident's unique needs.
- Restraints should be used as a last resort.
- Every facility or agency should have a clearly stated protocol on the use of physical, chemical and environmental restraints.

End of Life Care

- To use a person-centered, culturally sensitive approach to providing care that meets a resident's changing needs and respects his or her preferences regarding end-of-life care.
- To minimize the resident's physical, emotional and spiritual distress, while maximizing comfort and well-being in a manner consistent with an individual's preferences regarding end-of-life care.
- To ensure open and ongoing communication among the resident, proxy decision maker, family and care team so that all parties have a clear and common understanding of what constitutes optimal end-of-life care for the individual resident.
- To provide support to families, other residents and staff when an individual is dying and after death has occurred to help them achieve meaningful closure.
- Care plans need to be flexible enough to adapt to daily changes in a resident's needs and wishes.

Staff/Supervisors/ Management:

Managers and supervisors help ensure guidelines are followed. As well, guidelines ensure that all staff are receiving adequate education and training to continue to provide care set out in the guidelines of care.

Inspired and inspiring leadership

- Staffing patterns should ensure that residents with dementia have sufficient assistance to complete their health and personal care routines and to participate in the daily life of the residence.
- Consistent staff assignments help to promote the quality of the relationships between staff and residents.

- Direct care staff need education, support, and supervision that empowers them to tailor their care to the needs of residents.
- Staff supervisors may need ongoing coaching to help them empower and support the direct care staff to be decision makers.
- Administrators have the role of evaluating facility policies and procedures to ensure that they support direct care staff decision making during real-time interactions with residents.
- Staff who understand the prognosis and symptoms of dementia and how this differs from normal aging and reversible forms of dementia are better prepared to care for people with dementia.
- Staff should acknowledge and accept a resident's experience and should not ignore a resident's report of an event or his or her feelings and thoughts.

Specialized training and education for caregivers

- Staff should be treated in a person-centred way. Their training needs to be 'person centred' and geared to their individual learning needs.
- All health care providers should have access to training and education which will help them understand the disease process and assist them in their role as health care providers.
- Staff need (1) recognition for their use of problem-solving approaches to providing care and (2) emotional support as they deal with their own emotional reactions to the decline of residents over time and eventual death.
- Guideline orientation should be provided for all health care providers involved in services for people with Alzheimer's disease.

Family Member Supports

- Family members are always welcome in the facility and are active members of the care team.
- Family members should be consulted before major decisions are made.
- All caregivers should have access to supports and resources.

Family

Families with members who have been given a diagnosis of Alzheimer's disease will experience a range of emotions and will have a number of decisions to make about the current and future care and support of the person living with Alzheimer's disease. Health care service providers can help guide families to make decisions that they are comfortable with so that they feel their family member is well cared for.

Studies show providing family members with information about the disease may improve their knowledge but this does not improved their psychological distress. For family members experiencing difficulties adjusting, it is best to refer them to counseling services. Studies have found that interventions with a combination of social and cognitive components appear to be the most effective in improving psychological well-being of family members.

Working with the family

- Encourage family members to ask the doctor any questions about Alzheimer's disease, including information about medication, treatment and the best ways to help alleviate symptoms or address behaviour problems.
- Caregiver involved in care plan development.
- Caregiver input obtained about whether any behaviour symptom is perceived as a problem.
- Caregiver perception of adequacy of health care providers' time, clarity and respect in discussing the person's care.
- Be prepared with a list of available support groups that family members may attend.
- Help families make future care plans.
- Family members should have access to training and education which will help them understand the disease process and assist them in their role as caregiver / support person.

Visiting a Person with Alzheimer's disease

- Schedule a visiting time of day that best suits the person. Visiting is encouraging for the person with Alzheimer's disease.
- Family members are to remain calm and quiet and ensure they avoid using a loud tone of voice or talking to the person as if he or she were a child. Ensure family members respect the person's personal space.
- It may be difficult for visitors to realize that their family member may not remember their name and exact identity although they may well recognize them as a familiar person. Staff will assist with the visit if required.

Implications

The purpose of the project was to collect relevant practice guidelines, rate and assess the guidelines' methodological qualities and then to convene a group of national experts to review, sift and sort the guidelines based on scientific merit, relevance and applicability to their local context. These activities are performed within the framework of person-centred care.

Although person-centred care is advocated for the care of people with Alzheimer's disease, it is important to point out that there remains a gap in evidence regarding its clinical efficacy as an approach for care. Consequently, there remains a number of important and unanswered questions, such as which part of a person-centred intervention is effective? For whom is a person-centred intervention effective? For which type and at what stage of dementia is it effective? What kind of staff should be caring for the person? (Edvardsson, et al., 2008).

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Electronic Database Results

Electronic Database	Search Term Strategy	Hits
PsychInfo (Jan 13 2009)	((AB= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (DE= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (TI= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) and((AB= (Alzheimer* or dementia)) or (TI= (Alzheimer* or dementia)) or (DE= (Alzheimer* or dementia))))	158
Ageline (Jan 13 2009)	((AB= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (DE= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (TI= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) and((AB= (Alzheimer* or dementia)) or (TI= (Alzheimer* or dementia)) or (DE= (Alzheimer* or dementia))))	109
Assia (Jan 13 2009)	((AB= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (DE= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (TI= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) and((AB= (Alzheimer* or dementia)) or (TI= (Alzheimer* or dementia)) or (DE= (Alzheimer* or dementia))))	20

Electronic Database	Search Term Strategy	Hits
Digital Dissertation (Jan 13 2009)	((AB= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (DE= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (TI= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*)))) and((AB= (Alzheimer* or dementia)) or (TI= (Alzheimer* or dementia)) or (DE= (Alzheimer* or dementia))))	1
Medline (Jan 13 2009)	((AB= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (DE= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (TI= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*)))) and((AB= (Alzheimer* or dementia)) or (TI= (Alzheimer* or dementia)) or (DE= (Alzheimer* or dementia))))	549
Social Science Abstracts (Jan 13 2009)	((AB= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (DE= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*))) or (TI= ((practice within 1 guideline*) or (clinical within 1 guideline*) or (practice within 1 parameter*) or (consensus within 1 conference*) or (practice within 1 polic*) or (evidence within 2 guideline*) or (quality within 1 standard*)))) and((AB= (Alzheimer* or dementia)) or (TI= (Alzheimer* or dementia)) or (DE= (Alzheimer* or dementia))))	18

Electronic Database	Search Term Strategy	Hits
Medline (OVID)	<p>practice guidelines.mp. or exp Practice Guideline/ exp Practice Guidelines as Topic/ or clinical guideline.mp. practice parameter.mp. or exp Practice Guidelines as Topic/ consensus conference.mp. evidence based guidelines.mp. exp Clinical Protocols/ or exp Decision Making/ or practice policy.mp. exp "Quality of Health Care"/ or quality standards.mp. exp Alzheimer's disease/ or alzheimer.mp. exp Dementia/ or dementia.mp. 8 or 6 or 4 or 1 or 3 or 2 or 5 8 or 9 11 and 10 clinical protocol.mp. or exp Clinical Protocols/ 4 or 1 or 3 or 13 or 2 or 5 11 and 14</p>	804
EMBASE (OVID)	<p>practice guidelines.mp. or exp Practice Guideline/ exp Practice Guidelines as Topic/ or clinical guideline.mp. practice parameter.mp. or exp Practice Guidelines as Topic/ consensus conference.mp. evidence based guidelines.mp. exp Clinical Protocols/ or exp Decision Making/ or practice policy.mp. exp "Quality of Health Care"/ or quality standards.mp. exp Alzheimer Disease / or alzheimer.mp. exp Dementia/ or dementia.mp. 8 or 6 or 4 or 1 or 3 or 2 or 5 8 or 9 11 and 10 clinical protocol.mp. or exp Clinical Protocols/ 4 or 1 or 3 or 13 or 2 or 5 11 and 14</p>	915
EMBASE (OVID)	<p>practice guidelines.mp. or exp Practice Guideline/ exp Practice Guidelines as Topic/ or clinical guideline.mp. practice parameter.mp. or exp Practice Guidelines as Topic/ consensus conference.mp. evidence based guidelines.mp. exp Clinical Protocols/ or exp Decision Making/ or practice policy.mp. exp "Quality of Health Care"/ or quality standards.mp. exp Alzheimer's disease/ or alzheimer.mp. exp Dementia/ or dementia.mp. 8 or 6 or 4 or 1 or 3 or 2 or 5 8 or 9 11 and 10 clinical protocol.mp. or exp Clinical Protocols/ 4 or 1 or 3 or 13 or 2 or 5 11 and 14</p>	59
		2780 1830 after duplicates removed

APPENDIX 2

Rapid Additional topics requiring further evidence-based research and/or development of optimal practice guidelines and recommendations

Introduction:

The guidelines for care of people with dementia who live in care homes are founded on evidence-based guidelines compiled in a Rapid Evidence Assessment (REA) conducted in 2009. The REA examined practice guidelines for people with advanced Alzheimer's disease published in peer-reviewed journals.

The purpose of the Guidelines for Care: Person-centred care of people with dementia living in care homes framework is to create the foundation for knowledge transfer tools aimed at strengthening the capacity of care home staff in order to ensure that a person centred approach to care is in place. The framework is not intended to be used as training material by care homes; however, it provides an inventory of identified training needs for which specific knowledge transfer tools will be ultimately developed.

Missing areas of practice:

The Alzheimer Society of Canada recognizes many important aspects of care and areas of practice have not been included in the framework due to the lack of sufficiently strong evidence-based guidelines.

This document includes a list of additional topics where, while strong evidence may exist to support them, guidelines or recommendations for optimal care in care homes are not readily available.

These research questions are important as they will supplement the guidelines outlined in the Guidelines for care.

The questions (next page) are articulated around the specific topics for which guidelines don't yet exist, but scientific evidence regarding good practice is available.

ASC Call:

The Alzheimer Society of Canada invites researchers and university students to play a role in helping to improve the way dementia care is delivered in Canadian homes. Specifically the Alzheimer Society has called upon students to conduct systematic review searches into the missing areas of practice identified in the Guidelines for care.

The Alzheimer Society will:

- Provide guidance to students interested in completing this work.
- Review the work as appropriate.
- Engage students as student members of project team.

Guidelines for Care:
Person-centred care of people with dementia living in care homes

**Additional topics requiring further evidence-based research
and/or development of optimal practice guidelines and recommendations**

1. Fall prevention interventions to decrease fractures in people with dementia living in care homes.
2. Dental and oral care strategies that improve oral health in people with dementia living in care homes.
3. End-of-life / palliative care interventions to improve quality of life of people with dementia living in care homes.
4. The effectiveness of music therapy in improving quality of life in people with dementia living in care homes.
5. The effectiveness of art and creative expression in enhancing quality of life in people with dementia living in care homes.
6. Effective approaches in enhancing spiritual wellbeing in people with dementia living in care homes.
7. Successful measures in implementing culture change towards person-centred care in homes.
8. Effective measures involving the person with dementia in their own care to enhance feelings of autonomy and independence.
9. The effect of dementia-specific environmental design on enhancing the abilities of people with dementia living in care homes.
10. Personalizing the individual's environment in a care home as a way to improve the quality of life of people with dementia.
11. The impact of social programs for people with dementia living in care homes to enhance feelings of companionship and peer support.
12. Effective approaches for staff to understand and normalise expressions of sexuality and intimacy among people with dementia living in care homes.
13. Factors and characteristics associated with effective leadership in implementing a person-centred approach in homes caring for people with dementia.

