



**IMPROVING BC'S CARE  
FOR PERSONS WITH DEMENTIA  
IN EMERGENCY DEPARTMENTS  
AND ACUTE CARE HOSPITALS**

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*The fast-paced environment, the perpetual relocation of patients, the orientation to acute episodic and curative episodes, and lack of recognition of the needs of persons with dementia can significantly compromise the care of such persons in the acute care environment.*

*BC Dementia Service Framework (2007)  
page 65*

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## Executive Summary

### EXECUTIVE SUMMARY

*Improving BC's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals: Findings and Recommendations* is the final report of a project that examined the care received by persons with dementia in two particular areas of BC's health system – emergency departments and acute care hospitals.

As the over-65 population in BC grows, so too will the number of people with dementia. Emergency departments and acute care hospitals are designed to care for patients with specific acute health problems and are not equipped to manage the often complex health issues and behaviour of people with dementia. Health care professionals, as well as families, have recognized that changes to the overall health care system could improve care for people with dementia. Research confirms that the primary issue is that when patients with dementia are admitted to acute care, they often have prolonged stays and worse outcomes than patients with intact cognition.<sup>1</sup>

This report is the result of a project which included a literature review and ten focus groups – two with family caregivers and six with health care providers – who responded to questions around emergency and acute care for person with dementia. The Improving BC's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals Advisory Committee provided ongoing advice and feedback in the development of the report recommendations. Data from the project research literature and focus groups and the expertise of the Advisory Committee members indicates that researchers, families, and health care professionals recognize common problems and know what is needed to improve both the experience and health outcomes of emergency and acute care services for people with dementia. While some of the report findings may appear critical of the current situation, it is important to remember that the identification and analysis of problems is a necessary first step in correcting them and that the focus of the report is on improving care and outcomes for patients with dementia.

Health needs of persons with dementia are complex and interrelated. Improving care for persons with dementia is equally complex with no single or simple answer. Thus, this report offers ten specific recommendations based on project information, selected from the many actions possible to improve care for person with dementia in emergency and acute care settings. These actions were considered achievable in the current economic situation, likely to

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<sup>1</sup> Morrison and Siu 2000, Sampson et al. 2009.

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produce rapid and obvious improvements in care, and their implementation would provide the foundation for further actions.

The five recommendations for improving care for persons with dementia in emergency departments:

1. Screen all patients for delirium who show indications of cognitive impairment.
2. Provide appropriate triage for patients with dementia and involve specially-trained geriatric emergency nurses where possible.
3. Focus on working closely with caregivers as partners in care.
4. Follow appropriate guidelines for managing behaviour problems in dementia, starting with non-pharmacological approaches and adding medications as needed.
5. Improve training of all personnel in emergency regarding appropriate care for persons with dementia.

The five recommendations with associated strategies for enhancing care for patients with dementia for acute care hospitals are:

1. Focus on who the person is by following a person-centered care approach.
2. Implement the 48/5 protocol.
3. Follow appropriate behavioural protocols for patients demonstrating behavioural or psychological symptoms of dementia.
4. Have a policy of minimal restraints.
5. Get consumer feedback and consumer involvement in care on the acute care units.

Receiving and providing appropriate care for persons with dementia in emergency and acute care settings is challenging for vulnerable patients and their families and for busy, often unprepared staff. It is hoped that the information and recommendations in this report will clarify these challenges and contribute to improvements that are necessary to ensure that appropriate care is available for persons with dementia when they need emergency or acute care services in British Columbia.



## PART I: Introduction

*Improving BC's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals: Findings and Recommendations* is the final report of a project that examined the care received by persons with dementia in two particular areas of BC's health system – emergency departments and acute care hospitals.

This report is organized in two major parts. Part I, the Introduction, briefly describes the context, mandate, and methodology of the project, while Part II provides a brief summary of findings and ten recommendations with their associated implementation strategies. Following the main body of the report are multiple appendices that contain the detailed project findings on which the recommendations are based; Appendix B contains the literature review, while Appendices C, D, M, and N document the results of the focus groups in both summary form and in the form of direct quotations from their participants. Also contained in the appendices are two papers – one on delirium and one describing an approach to care called 48/5 – and a variety of tools and program descriptions pertinent to providing care to persons with dementia in an emergency or acute care setting.

### Context

Dementia is a chronic condition marked by progressive and irreversible mental deterioration, memory loss, and disorientation.<sup>2</sup> In 2011, approximately 61,000 British Columbians suffered from dementia, of which approximately 57,000 were over 65. Like the rest of Canada, this number is increasing and it is expected that by the year 2021, 81,000 people in BC will have a dementia, a projected increase of 33% in that ten-year period.<sup>3</sup> Both current and projected numbers of persons with dementia encourage the exploration of how well our health care system now serves these individuals and how prepared it will be to serve increasing numbers of them in the future.

This report, along with many others in this and other provinces and worldwide, is a result of an examination of health care provided to persons with dementia. In addition to the demographic imperative, the impetus for this report was BC health care providers' and other stakeholders' concerns about the care that persons with dementia currently receive in the province's emergency departments and acute care hospitals.

<sup>2</sup> See Appendix A for a glossary of terms used in this report.

<sup>3</sup> "Dementia Projections for British Columbia," Centre for Applied Research in Mental Health and Addiction, Simon Fraser University, September 2006.

## Part I

This report takes its cue from other key British Columbia documents. In 2007, the *BC Dementia Service Framework* identified seven critical gaps in the system of dementia care including “a gap in the capacity and ability of acute care settings to meet the needs of people with dementia” and observed that this gap results in emergency and hospital responses to patients with dementia that are “suboptimal.” The Framework also identified a gap in “the formal integration, collaboration and communication across care settings between health care providers and across health authorities,” as well as gaps in health care providers’ knowledge about dementia and in the system’s ability to address the clinical and support needs of family caregivers.<sup>4</sup>

In 2009, the *BC Dementia Education Framework* recommended education on advance care planning, delirium, understanding behavioural and psychological problems associated with dementia, and individualizing care for persons with dementia for those providing acute care. Last year (2010), the BC Ministries of Health and Children and Family Development released *Healthy Minds, Healthy People: A 10-Year Plan to Address Mental Health and Substance Use In British Columbia*. This plan establishes a decade-long vision for action on mental health and psychoactive substance use in BC and recognizes that aging poses particular challenges for seniors’ mental health including those resulting from Alzheimer’s disease and other forms of dementia. Within this broader context of seniors’ mental health and dementia care, the project focused specifically on the care provided to persons with dementia in emergency department and acute care hospital settings.

### Mandate

In 2010, the BC Mental Health Foundation funded the work on which this report is based. An advisory committee was charged with examining the care received by persons with dementia in emergency departments and acute care hospitals and reporting on ways in which improvements in this care could be made.

### Methodology

*Improving BC’s Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals: Findings and Recommendations* is the result of work that was guided by an expert advisory committee. The project used a mixed methodology to obtain information – a literature

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<sup>4</sup> BC Dementia Service Framework (September 2007), [http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework\\_PDF.aspx](http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework_PDF.aspx)

review, a multi-phase consultation with stakeholders, and the identification of key clinical and administrative tools that could be disseminated via this final report. The information gathered from these sources was then considered, distilled, and used as the basis for this report's findings and recommendations.

Improving BC's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals Advisory Committee (the Advisory Committee) envisioned "an enhanced quality of care in emergency department and acute care for persons with dementia." The goal of the Advisory Committee was to review the care provided to persons with dementia in acute care hospitals and emergency departments and identify improvements that could be made.

The literature review focused primarily on three associated areas: preventing the need for admitting patients with dementia to emergency departments (and thus in some cases to acute care), the care provided to patients with dementia in emergency departments, and the care provided to that same group in acute care hospitals. The results of that literature review are summarized prior to the appropriate sections in Part II of this report. The complete literature review is included as Appendix B.

**Consultation:** In the interests of hearing from a wide spectrum of stakeholders, the project hosted ten focus groups to solicit and document first-hand perceptions and experiences. Two focus groups were held with twelve caregivers of patients with dementia chosen by the Alzheimer Society of BC; six individuals came from the Lower Mainland and six from other areas in BC. The participating caregivers were asked if they or their family members had been in an emergency department or an acute care hospital in the past five years and, if so, to describe positive or negative experiences and what they would have hoped for in terms of care and communication in these settings. This report includes the caregivers' stories and their recommendations for better care in the future as Appendices C, D, and M.

Two focus groups were held with seventeen specialized geriatric nurses coming from the Vancouver Coastal Health Authority, Vancouver Island Health Authority, and Fraser Health Authority. As most participants were either familiar with or worked in emergency departments, they were asked questions about their experiences and perceptions of care for patients with dementia in emergency departments.

Three additional focus groups were brought together and included twenty-five health care providers representing all disciplines active in emergency departments from BC's five geographic health authorities. Of these, five worked in Vancouver Coastal, three in Fraser, six on Vancouver Island, five in the Interior, and six in the North. The group included three urban and two rural emergency doctors, five geriatric psychiatrists, three geriatricians, one

## Part I

family physician, one internist, five nurses, three managers, one educator, and one home and community care case manager.

Finally, three more focus groups of health care providers from all disciplines from the five health authorities came together to discuss acute care. Of the thirty participants, six were from Vancouver Coastal, nine were from Fraser, seven were from the Interior, five were from the North, and three were from Vancouver Island. Of the eleven physicians, one was a geriatric psychiatry fellow, five were geriatric psychiatrists, two were geriatricians, one was an internist, one a family physician, and one a family practice researcher. Nine nurses included one educator, two clinical nurse specialists and six direct care RNs. In addition, one occupational therapist, four physiotherapists, one pharmacist, one manager, and three social workers participated in the groups. Participants' roles included: a Medical Director Transitional Care Unit, Tertiary Care Leader, Integrated Health Network Worker, Priority Access, Educator, Hospital Liaison with Home and Community Care, Home and Community Care Case Manager, Hospital Worker, Regional Dementia Consultant, Practice Leader Home and Community Care, and Medical Director in Acute Care.

In all the focus groups, health care providers were asked for the common reasons patients with dementia are in emergency departments and acute care hospitals, how patients are identified as having dementia, what tools or protocols are used, what helps or hinders health care providers in providing appropriate care to patients with dementia in these settings, what guidelines or protocols would be useful, and suggestions for improving the care of patients with dementia in these care settings. See Appendices C, D, and N for documentation of the results of the health care provider focus groups.

Information from the literature review and consultation data from family caregivers and health care providers who participated in the ten focus groups was compiled and analyzed by the report writer and reviewed by the Advisory Committee's membership of caregivers, provincial and regional representatives of the health care system, and clinical experts. The information gathered for this report represents a balance between research and experience and it is notable that researchers, family caregivers, and health care providers identified many of the same issues and proposed similar approaches to improving care for persons with dementia in emergency departments and acute care hospitals.

Readers are strongly encouraged to take time to read the full accounts of the information on which this project's results are based. The research literature in Appendix B, but particularly the stories and informed observations of caregivers and health care providers included in Appendices C, D, M, N, O, P, and Q, create a vivid picture of how dementia patients are cared for in emergency and acute care settings and how that care could be improved.

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In addition to information directly relevant to the subject of this report, the literature review and results of the focus groups contain valuable information about how other sectors of the health care system (e.g., primary care, residential care, home care) interact with emergency and acute care and how gaps in service in these sectors may trigger unnecessary hospital admissions. Although community resources were considered outside the scope of this project, the project proposal called for attention to be paid to the goal of reducing unnecessary trips to the hospital for persons with dementia as a lens to be applied through the course of the project. Therefore, some information and focus group comments are directed at how to achieve such purposes.

Part II of this report contains a summary of the project's findings, and recommendations on the prevention of unnecessary admissions to emergency departments or acute care hospitals for persons with dementia. It also contains recommendations and strategies for improving care for patients with dementia in emergency departments and acute care settings.

## Part II

# PART II: Findings, Recommendations, and Strategies

Health needs of persons with dementia are complex and interrelated; improving care for persons with dementia is equally complex with no single, isolated, or simple answers.

Based on project information and selected from the many actions possible to improve care for persons with dementia in emergency and acute care settings, these ten recommendations were chosen as they were considered achievable in the current economic situation, likely to produce rapid and obvious improvements in care, and able to provide the foundation for further actions. It is important to note that while some of the report findings may appear critical of the current situation, the identification and analysis of problems is a necessary first step in correcting them.

## General Findings

A visit to an emergency department or a stay in hospital can be a disorientating experience for anyone. How much more so for someone with dementia? In addition to requiring medical attention for acute or chronic illness, patients with dementia are frail, easily frustrated and frightened, prone to behavioural and psychological symptoms when they are stressed, and often unable to communicate their needs. Transitions and change are particularly difficult for persons with dementia. Caring for people in this situation requires time and patience.

From the perspective of the health care provider, the project findings are a reminder of the complexity of acute and chronic medical conditions in later life which often makes diagnosis and treatment more difficult and thus time consuming. As well, providing appropriate care for older patients with dementia is different than providing care to other individuals, particularly in emergency and acute care settings.

This juxtaposition of the need for unhurried patient care for persons with dementia and the “fast-paced environment, the perpetual relocation of patients, the orientation to acute episodic and curative episodes”<sup>5</sup> that are the hallmarks of emergency and acute care, suggests just some of the reasons that care of persons with dementia in these settings is often sub-optimal.

The literature review identified many concerns about the adequacy of care given to patients with dementia, both in the emergency department and in acute care. The most compelling fact which serves as the point of departure for many research studies, is that when patients with

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<sup>5</sup> BC Dementia Service Framework (2007) page 65

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dementia are admitted to acute care, they often have prolonged stays and worse outcomes than patients with intact cognition (Morrison and Siu 2000, Sampson et al. 2009). Research also indicates that preventing admissions to emergency or acute care, is the best possible care for patients with dementia and their families. However, in spite of efforts to prevent admission, there will still be patients with dementia coming into the emergency and needing admission to acute care.

As behavioural and psychological symptoms are a hallmark of dementias, the issue of the use of restraints has a place in the discussion of emergency and acute care provided to these patients. In the literature, Evans and Cotter (2008) argue against the use of restraints for patients with dementia and emphasize the importance of identifying the unmet needs of the patient with dementia which may be triggering behavioural problems. There is evidence that physical restraints inevitably lead to a decline in physical activity and thus have a detrimental effect on both cognition and behaviour (Scherder et al. 2010) and that they should be avoided. With respect to chemical restraint, Mott (2005) argues that medication should never be used to manage difficult behaviour.

In all situations, once a behaviour has been identified, it is essential to try non-pharmacological approaches first. If non-pharmacological approaches don't work, then medications are considered, depending on the individual circumstance, the origins of the behaviour, the nature of the threat to others and the particular health problems of the patient.

In the focus groups, caregivers were consistent in their message about the kind of care that is most appropriate for persons with dementia. Most important was the point that successfully managing, treating, and caring for persons with dementia depends upon knowing that person as an individual, whether as a family member or as a regular caregiver. As people with dementia may be unable to communicate their own individuality or express their needs and preferences, family and caregiver knowledge and the communication of that knowledge is central to quality care. The concept of person-centeredness was noted repeatedly; as was the importance of continuity of care to ensure that all carers understand the patient. Family caregivers emphasized the need for gentle, patient, routine, and consistent care of persons with dementia, particularly in situations where there is change, such as illness or moving from one care environment to another. Taking time with patients and working in partnership with family caregivers and their knowledge, emerged as a common theme and a necessary component to providing person-centred care.

Families clearly want to be involved and believe that care will improve if they are able to communicate with health care providers and give direction (and consent) based on their

## Part II

knowledge of the patient and on their family members' wishes expressed for health care decisions while they were competent. Health care providers who participated in the focus groups reported that the most common primary diagnosis for persons with dementia admitted to emergency or acute care is a medical problem, sometimes signalled by a behavioural change related to an underlying medical problem; it was also observed that medical problems may be masked by unsettled challenging behaviours or overlooked because of behaviour.

The primary reasons for admission reported in focus groups were falls and fractures, medication errors and mix-ups, infections (urinary tract infections, pneumonia), cardiovascular problems, failure to thrive and dehydration, and delirium that may be caused by these medical problems. Another reason that patients with dementia may be brought to the emergency department is because of acute changes or deterioration in behavioural and psychological symptoms of dementia which may or may not be related to medical problems.

Medical problems are often complicated by their interaction with social, behavioural, and system problems such as caregiver burn-out, unrealistic family expectations for improvements in their family member's health, lack of a caregiver or conflict among caregivers, self-neglect, aggression and/or wandering, facility staff unable to manage challenging behaviour, lack of supports for patients waiting for facility care or community services, and transfers to emergency without assessment by primary care providers.

Additional system problems contributing to inappropriate or suboptimal care for persons with dementia which were identified by focus group participants, included: a lack of education in dementia care for those providing care; inconsistency or lack of continuity in care (hospitalists changing and family and patient not really knowing who their doctor is); an over-stimulating environment that is cluttered, noisy, and overcrowded and thus confusing for persons with dementia; inappropriate rooms (with no windows, no toilets, no place for family to be); no timely geriatric assessment; lack of rehabilitation services, and poor communication systems before and during hospital stays; medication problems; precipitous discharge planning because of the first appropriate bed policy, and poor connection/communication between mental health teams and community health services.

Focus group participants also identified problems in approaches to caring for patients with dementia in these settings. Nurses may fail to mobilize patients for fear of potential falls, there may be no appropriate and timely assessment for key factors that effect frail elderly persons with dementia – delirium/cognition, medications, functional mobility, nutrition/hydration, and bladder/bowel – and physical or chemical restraints may be used inappropriately to manage patient behaviour.



The appropriateness of treatment and families' treatment expectations were also raised as issues with respect to consent to health care and advance care planning. When there has been no advance care planning, family members may not know what the patient would have wanted or understand the likely scope for improvement. Similarly, both family and health care providers may not be aware of proper procedures and rules governing consent to health care on behalf of an incapable adult.

## **Preventing Unnecessary Emergency and Acute Care Admissions**

Research literature and best practices in dementia care assert that an initial step in improving quality of life, maintaining function and decreasing mortality in dementia patients is to prevent unnecessary visits to the emergency department and admissions to hospitals. It has already been noted, emergency departments are not designed in a way that facilitates care of patients with dementia and that when patients with dementia are admitted to acute care wards, they often have prolonged stays and poorer outcomes than patients with intact cognition.

Health care providers in project focus groups noted that they thought that perhaps a quarter or perhaps even up to half of the admissions to emergency departments could be prevented through earlier interventions. Participants recognized barriers to early intervention, such as lack of appropriate levels of staff and/or lack of supports in residential care facilities and the community, as related issues. Some participants were concerned that although residential facilities care for people with complex care needs, staff may be insufficient or not have the necessary expertise, knowledge, skills, abilities, and attitudes to meet these needs.

Both caregivers and health care providers who contributed to this project agreed with the findings in the research literature and would like to see a greater emphasis on building community services to prevent crises and unnecessary admissions to emergency departments. An important factor in the decision to transfer a person with dementia to emergency or acute care is the identification and communication of the patients' goals of care. A transfer to hospital may not be in the patient's best interest and highlights the need for discussions regarding goals of care and education for proxy decision makers about the likely outcomes of hospitalization and the course of dementia as a disease. If there are discussions with patients prior to, or early in their dementias, or with their family (or appropriate health care decision-makers) including documentation, such information may either prevent the patient from being moved to another care setting or allow for stabilization and comfort care only in emergency and acute care without the imposition of unwanted or inappropriate treatment.

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Research literature identified *preventable visits* to emergency as visits for events that may have been avoided if an existing condition had been adequately managed through primary care services at an earlier stage (Grunier et al. 2010). These conditions included angina pectoris, asthma, pneumonia, cellulitis, congestive heart failure, chronic obstructive pulmonary disease (COPD), dehydration, diabetes, gastroenteritis, seizure, hypertension, hypoglycemia and urinary tract infections. The literature also noted that when patients were acutely ill at the time of the emergency department visit, opportunities for intervention needed to occur much earlier in the illness trajectory. These authors also suggest that policy changes may be necessary in the form of better funding for long-term care facilities and primary care physicians to improve early management of preventable conditions.

Health care professionals echoed these views when they suggested that patients should be seen and assessed by a primary care physician or a nurse practitioner prior to being transported to an emergency department and that this may reduce unnecessary stress and risk of iatrogenic<sup>6</sup> illness for patients, especially those with dementia, by reducing inappropriate transfers.

### Emergency Departments

While the literature was clear that preventable admission to emergency or acute care is a first consideration, it was also clear that not all admissions can be prevented. From the start of emergency care, patients with dementia are at risk as their transfer from home (or residential care) can be confusing and disorienting and there can be complications resulting from poor communication. The research literature emphasized that emergency departments are focused on treating and diagnosing acute and life-threatening illness quickly, and that given the need for speed and busy staff, patients with cognitive impairment are often left confused, disoriented, and only partially diagnosed and treated. As noted, emergency care of older adults requires more resources and is often significantly different from the management of younger patients because of complex medical issues and atypical presentations and responses to therapy. A common problem reported by all sources of project information and faced by patients, families, and emergency department physicians is poor communication and the lack of reliable patient medical histories.

Complicating the lack of patient information is the rapid style of triaging and assessing patients in the emergency department which may leave patients' cognitive impairments unrecognized. It is vital that emergency staff be aware of a diagnosis of dementia. Screening for delirium that can result from acute medial problems was also identified as an important approach to all frail

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<sup>6</sup> Induced inadvertently by a physician or by medical treatment or diagnostic procedures.

elderly patients whose risk of and those with a diagnosis of dementia. As Maureen Shaw notes in her paper, *Delirium*, included in this report as Appendix F, “due to its variable course and subtle symptoms, delirium is often unrecognized and misdiagnosed. Untreated, delirium leads to functional and cognitive decline, increased hospital stay, long-term care placement, and early death.” More practical problems associated with emergency admissions were also noted in the literature and in the focus groups – patients may arrive without dentures, corrective eye wear, hearing aids, or assistive devices such as canes and walkers.

This project identified and recommends the implementation of the 48/5 approach to care. 48/5 means that within 48 hours of emergency or hospital admission, care plans are developed to address the needs of older patients in the following five key areas: delirium/cognition, medications, functional mobility, nutrition/hydration, and bladder/bowel. This approach to care includes interprofessional practice statements as key strategies to ensuring high quality seniors’ care in acute care settings. As a person-centered approach, 48/5 includes strategies for home care and family caregivers to prevent hospital admission, where possible, and facilitate transitions through acute care when hospital admission is needed to minimize the risk of disability in older patients. A fuller description of the 48/5 approach to care is provided in the paper by the same name authored by Drs. McElhaney and Donnelly and David Thompson which is included in this report as Appendix G.

## Recommendations and Strategies for Improving Emergency Care

1. Screen all patients for delirium who show indications of cognitive impairment.
  - Patient assessment using tools such as the Confusion Assessment Method (CAM) that includes 1) screening for overall cognitive impairment and 2) screening for only those four features that have the greatest ability to distinguish delirium or reversible confusion from other types of cognitive impairment, description and collateral information from family, community physician, residential care facility, nurse, and advance care plan (documentation of previously-expressed wishes for future health care).
2. Provide appropriate triage for patients with dementia and involve specially-trained geriatric emergency nurses where possible.
  - Environmental manipulation including specialized geriatric pods/areas, clear signage, and accessible washrooms.

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- Patient information and medical records including standardized documentation and emergency medical records (with alerts concerning dementia as a diagnosis) that accompany patients who are transferred in and out of facilities.
3. Focus on working well with caregivers as partners in care.
    - Educate health care providers and other staff to involve caregivers as partners in care and planning, as communication conduits, and as proxy decision makers who need to be fully informed in order to give or refuse consent to health care on behalf of patients who may be incapable of making these decisions such as those with dementia.
  4. Follow appropriate guidelines for managing behaviour problems in dementia, starting with non-pharmacological approaches and adding medications as needed.
    - Care approaches including having and complying with a least restraint policy, following non-pharmacological approaches to managing behaviour, using medication as a last resort, and implementing the 48/5 approach (see description above).
  5. Improve training of all personnel in emergency regarding appropriate care for persons with dementia.
    - Education regarding patient-centred approach to caring for patients with dementia that features a positive, caring, slow approach, using family caregivers to facilitate communication with and treatment of patients.
    - Staffing changes to include geriatric-specialized nurses, trained care aides to provide assistance to dementia patients, guidelines that establish care ratios 1:1, and security guards who have been trained to deal with dementia patients appropriately.
    - Education including basic training for all staff in the care of patients with dementia, and knowledge of the 48/5 approach.

### Acute Care Hospitals

The *BC Dementia Service Framework* makes the following succinct observations about how the major features of the acute care system are a poor match for the complex needs of persons with dementia:

Additionally, there may be a lack of knowledge or a lack of a dementia-sensitive care approach by providers. Because the physical environment can be unsafe and overstimulating, the result can be inappropriate care results that cause further decline

in the health and quality of life for patients with dementia. Families, caregivers, and other health care providers who know the patients and their needs may often find that they are ineffective in advocating for people with dementia. As a result, patients with dementia have longer lengths of stay in acute care compared with cognitively intact patients, and the acute care stay will often trigger premature admission to residential care.<sup>7</sup>

As McElhaney, Donnelly, and Thompson observe in their paper 48/5 included in Appendix G:

...hospitals' inability to recognize and effectively meet older Canadians' health needs is the general lack of any recognition that a comprehensive assessment, treatment and care framework is essential to maintain function (Palmer 1995). Acute care services focus on the identification and management of a patient's most acute episodic illness (i.e., "one thing wrong at a time"). This is a limited perspective given that it is well known that older adults typically present with multiple, interacting medical and social problems (i.e., "many things wrong, all at once").

Thus, on the one hand we have a system that is not designed to accommodate the particular and unique needs of patients with dementia and, on the other, the vulnerability of those same patients to increased distress or diminished health when those needs are not addressed.

Research has found that the results of this mismatch is that persons with dementia suffer more distress due to the change in daily patterns and the variety of treatments and tests while in hospital (Miller and Campbell 2004). Some of the complications that arise as a result of the gap between patient needs and service provided are delirium that may increase hospital stay by contributing to a functional decline and preventing the patient from participating in rehabilitation, inadequate rehabilitation services, and poor nutrition as a result of fasting for certain tests, inadequate staff time to help with feeding, and the anorexic effect of certain types of medications. These problems may further contribute to muscle loss and decreased mobility and function (Lang et al. 2010).

Research literature aligned closely with project focus group participants' identification of problems in emergency and acute care of persons with dementia and with many of their suggestions to improve that care. These suggestions ranged from clinical imperatives related to assessment and treatment to practical considerations regarding environment and routines of personal care to address patients' difficulty adapting to new environments. Clinical recommendations included assessing mental status initially, asking family members or

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<sup>7</sup> BC Dementia Service Framework (2007), p. 65.

## Part II

caregivers about health history, daily routines and food preferences, encouraging family members to bring in familiar objects and to accompany patients for tests and procedures, assessing fall likelihood, putting the patient in a room close to the nursing station, and assessing the patient more frequently if they were unable to use the call system. Practical suggestions included leaving a night light on in the bathroom, keeping small items, toxic substances and medications out of reach, avoiding placing a patient in a room near an exit or elevator, keeping the patient busy with supervised activities, using a kind approach rather than confrontation when the patient wanders, trying to maintain similar daily routines, making sure hearing aids are available and working, scheduling a rest in the afternoon to reduce sundowning, avoiding over-stimulation, and expecting and planning for occasional behavioural outbursts (Halduk and Shellenbarger 2004).

### **Recommendations and Strategies for Improving Acute Hospital Care**

1. Focus on who the person is by following a person-centered care approach.
  - Education for health care providers and other staff to de-stigmatize dementia and encourage clinical culture of caring.
  - Education for health care providers to support their compliance with requirements for seeking valid consent to health care from appropriate substitute decision makers and their ability to recognize and interpret/respond to legal agreements in support of patient autonomy (pre-expressed wishes for future health care, advance directives, representation agreements)
  - Provide support to family caregivers through linking them with the Alzheimer's Society and its caregivers' support groups, involving them in goal setting for acute hospitalization and care transitions, ensuring that family expectations are understood and discussed, and ensuring that proxy decision makers are aware of their powers and duties with respect to consent to health care.
2. Implement the 48/5 protocol.
  - Institute procedures and train staff in the 48/5 protocol of care; that is, within 48 hours of emergency or hospital admission, care plans are developed to address the needs of older patients in the following five key areas: delirium/cognition, medications, functional mobility, nutrition/hydration, and bladder/bowel.
3. Follow appropriate behavioural protocols for patients demonstrating behavioural or psychological symptoms of dementia.

Part II

- Education for staff (all new hires) in dementia care including communication approaches and approaches to behavioural issues, with code white protocols taught by geriatric specialty nurses, and the provision of access to further public education.
  - Train staff (care aides or LPNs working in transitional units, security staff) in appropriate approaches to dementia patients and in assisting patients to reduce incidence and severity of behavioural or psychological symptoms of dementia.
  - Provide for flexible nurse ratios to accommodate patients demonstrating behavioural or psychological symptoms of dementia.
4. Have a policy of minimal restraints.
- Educate staff in least restraints policy and the rationale for it.
  - Link least restraint policy and education with education in appropriate medication protocols and non-pharmacological approaches to management of behaviour problems.
  - Introduce more transitional care units, Acute Care of Elders (ACE) units as model, and secure acute units to enable safe wandering.
5. Get consumer feedback and consumer involvement in care on the acute care units.
- Include family satisfaction surveys in quality improvement process with an emphasis on quality of life in hospital, rather than length of stay or ALC.
  - Assess compliance with dementia-care-specific protocols such as least restraints, 48/5, and care ratios.

## Conclusion

### CONCLUSION

Both research and experience confirm that concerns about the adequacy of care given to patients with dementia in the emergency department and in acute care hospitals are well founded. There is also good evidence to support the concept that preventing emergencies is the best care possible for patients with dementia and their families. However, in spite of preventive efforts, there will continue to be patients with dementia coming into emergency departments and needing admission to an acute care hospital. Families clearly want to be involved and believe care can be improved through their ongoing communication with health care providers, a key to the patient/person-centred care that is so important to persons with dementia. As well, families can play an important role by guiding health care providers in the provision of appropriate care that is consistent with the requirements of valid consent and with patients' pre-expressed wishes.

Receiving and providing appropriate care for persons with dementia in emergency and acute care settings is challenging for vulnerable patients and their families and for busy, often unprepared staff. The combination of dementia, delirium and the medical conditions that require visits to emergency and acute care hospitals are often exacerbated by over-stimulating and unfamiliar environments that are not conducive to good dementia care. Adequate and appropriate resources (e.g., educated staff, staff mix) within emergency departments and hospitals as well as in community and residential care facilities are also necessary to provide the consistency of care required by these patients. All professional and non-professional health care personnel require specialized knowledge, skills, abilities and attitudes to facilitate timely and appropriate dementia care. It is hoped that the information and recommendations provided in this report will help clarify some of these challenges and contribute to implementing improvements that are necessary to ensure that appropriate care is available for persons with dementia when they need emergency or acute care services in British Columbia.



## APPENDIX A: Glossary of Terms and Abbreviations

**3MS** – Modified Mini Mental State Exam

**ACE** – Acute Care of Elders

**ADLS** – Activities of Daily Living - Primarily self-care activities such as personal hygiene and grooming, feeding oneself, etc.

**ALC** – Alternate Level of Care

**ALS 5** – An occupational therapy of function

**Behave AD** – A behavioral assessment tool

**BPSD** – Behavioral and Psychological Symptoms of Dementia

**CNS** – Clinical Nurse Specialist

**Code White** – A trained team response to a disturbance that is a behavioral emergency

**Cohen Mansfield Agitation Inventory** – A seven point rating scale for assessing the frequency with which people show certain behaviours

**Confusion Assessment Method (CAM)** – The Confusion Assessment Method (CAM) includes two parts. Part one screens for overall cognitive impairment. Part two includes only those four features that were found to have the greatest ability to distinguish delirium or reversible confusion from other types of cognitive impairment.

**Cornell Scale for depression and dementia** – Assesses signs and symptoms of major depression in patients with dementia.

**Delirium Rating Scale** – Measures and tracks mental status in adults with cognitive impairment

**ED** – Emergency Department

**Geriatric Depression Scale 15 (GDS 15)** – Shortened 15-item form of the Geriatric Depression Scale

**HEART teams** – a VCH project to assist care planning transitions out of hospital to residential care

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**IADLS** – Instrumental Activities of Daily Living: activities related to independent living such as preparing food, managing money, shopping, etc.

**ISAR-SEISAR by McCusker** – This is a screening tool for detecting severe functional impairment and depression and predicting increased depressive symptoms and increased utilization of health services. The tool is a six-item self-administered questionnaire to be used in an emergency department to identify seniors at a high risk of subsequent functional decline including institutionalization or death. (McCusker et al. 1999 Detection of Older People at Increased Risk of Adverse Health Outcomes after an Emergency Visit: the ISAR Screening Tool. Journal of the American Geriatrics Society. 1999;47(10)1229-37)

**Lawton and Brody ADL and IADL scale** – Assesses Activities of Daily Living and Instrumental Activities of Daily Living

**LPN** – Licensed Practical Nurse

**Mini Cog** – 3-minute instrument to screen for cognitive impairment using a 3-item recall test for memory and a clock-drawing test.

**Montreal Cognitive Assessment (MoCA)** – 30-point test to assess cognitive functioning especially for mild cognitive impairment.

**OT** – Occupational Therapist

**Patient Health Questionnaire 2 (PHQ2)** – Inquires about the frequency of depressed mood and anhedonia over the past two weeks.

**Patient Health Questionnaire 9 (PHQ 9)** – 9-item form to assess depression

**QI** – Quality Improvement

**River Mead Functional and Behavioural Memory Assessment** – predicts everyday memory problems in those with acquired, nonprogressive brain injury and can also be used to monitor change over time. The test is comprised of tasks which are comparable to everyday situations that seem problematic for memory impaired patients.

**SAEM** – Society for Academic Emergency Medicine

**SORT Team** – Special Operations Response Team - Specialized tactical and emergency response unit.

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**Standardized Mini Mental Status Examination (SMMSE)** – Screening tool for cognitive impairment.

**VGH** – Vancouver General Hospital

**VIHA** – Vancouver Island Health Authority

## Appendix B

### APPENDIX B: Literature Review

The purpose of this literature review was to look at research in the areas of preventing hospital visits of patients with dementia, when appropriate, as well as to define problems and potential solutions in emergency care and acute care for patients with dementia.

#### Prevention

An initial step in improving quality of life, maintaining function and decreasing mortality in dementia patients is to prevent visits to the emergency department and admissions to hospitals. It is widely recognized that emergency departments are not designed in a way that facilitates care of patients with dementia (Hustey et al. 2003, Wilber et al. 2006, Terrell et al. 2009). It has also been found that when patients with dementia are admitted to acute care wards, they often have prolonged stays and worse outcomes than patients with intact cognition (Morrison and Siu 2000, Sampson et al. 2009).

Several guidelines have been designed for primary care physicians to optimize dementia care; however a comprehensive review of such guidelines is beyond the scope of this report. That said, there are specific recommendations and studies that should be mentioned about the role primary care physicians can play in preventing transfers of patients with dementia to emergency departments and admission to acute care wards in the hospital.

The Guidelines and Protocols Advisory Committee of BC has published a guideline entitled *Cognitive Impairment in the Elderly – Recognition, Diagnosis and Management* with recommendations for primary care physicians treating patients with dementia. This Guideline recommends that dementia be treated as a chronic disease with regular monitoring and follow-up visits dedicated specifically to dementia care (GPAC 2008). Regular monitoring would likely reduce rates of acute deterioration requiring hospital admission in dementia patients. As well there is a recommendation within the Guidelines for primary care physicians to discuss care goals such as do not resuscitate orders with patients and caregivers (GPAC 2008). If primary care physicians had this discussion and then made the information available to emergency and acute care physicians, the suffering of patients with dementia from unwanted procedures in acute care hospitals and emergency departments might decrease. The guideline also recommends – in the interest of potentially reducing hospital visits – that primary care physicians provide educational resources to patients and their caregivers or send them to the Alzheimer Society to get further information (GPAC 2008). Caregivers who have a better understanding of dementia will likely be able to provide better care and address risks

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before problems become acute enough to require hospital admission. Education may also decrease caregiver burden by connecting caregivers with respite services.

These recommendations correspond closely with recommendations made by Villars and others in their international position paper on the role of the primary care physician in managing Alzheimer's disease and the conclusions from the Canadian Consensus Conference on Dementia (Patterson et al. 1999, Villars et al. 2010). In addition, Villars and others recommend that follow-up should occur approximately once every 1-3 months (Villars et al. 2010). At each visit the primary care physician should monitor the patient's cognitive, functional and nutritional status and evaluate behavioural changes, gait and balance disorders, co-morbid diseases and the tolerance/efficacy of drugs (Villars et al. 2010).

Within the aforementioned guidelines and recommendations there are no references made to educating patients and caregivers about when to see the primary care physician and when to take the patient to the emergency department. Encouraging primary care physicians to develop an action plan with caregivers and patients for how to respond to symptom changes may help caregivers recognize early symptoms that need assessment by a primary care physician. Another aspect of care not included in these recommendations is a method for communication between primary care providers and emergency or acute care physicians. When patients with dementia go to the emergency department, they often have difficulty remembering or communicating information on medications, allergies, co-morbid conditions, DNR orders, etc. An established method in place for transferring this information would likely lead to more appropriate care (Jones et al. 1997, Scott et al. 2006).

Many nursing home residents have some level of dementia and studies have shown that nurses and primary care physicians play an important role in preventing unnecessary hospital transfers for these patients (Jones et al. 1997, Natalwala et al. 2008, Grunier et al. 2010). In a study on nursing home transfers to the emergency department, Jones and others found that 12% of patients were transferred from nursing homes to the emergency department without any consultation with the on-call primary care physician (Jones et al. 1997). Another 68% of patients were transferred after the on-call primary care physician was contacted by telephone but without the patient being seen by the physician (Jones et al. 1997).

Emergency department transfers were assessed as being either appropriate, i.e., the patient required services not available in the nursing home, or inappropriate (Jones et al. 1997). In this study 77% of transfers were considered appropriate (Jones et al. 1997). The authors suggest that if policy changes were made to make it more likely that a patient will be seen and assessed by a primary care physician or a nurse practitioner prior to transport to an emergency department, it might reduce unnecessary stress and risk of iatrogenic illness for patients, especially

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those with dementia, by reducing inappropriate transfers (Jones et al. 1997). Similar results were found in a recent study conducted in Ontario (Grunier et al. 2010). In this study, the researchers classified visits made by long term care residents as preventable, low acuity and other (Grunier et al. 2010).

Preventable visits were defined as visits for events that may have been avoided if an existing condition had been adequately managed through primary care services at an earlier stage (Grunier et al. 2010). These conditions included angina pectoris, asthma, pneumonia, cellulitis, congestive heart failure, chronic obstructive pulmonary disease (COPD), dehydration, diabetes, gastroenteritis, seizure, hypertension, hypoglycemia and urinary tract infections (Grunier et al. 2010). Low acuity visits were defined as visits that resulted in the resident returning directly to the nursing home without inpatient hospital care (Grunier et al. 2010).

Of all the visits to the emergency department, 25.4% were classified as preventable and 10.6% as low acuity (Grunier et al. 2010). Of the patients making visits for potentially preventable reasons, 62.4% were hospitalized and 23.6% died within 30 days of their arrival at the emergency department (Grunier et al. 2010). This indicates that many of these patients were acutely ill at the time of the emergency department visit and that opportunities for intervention needed to occur much earlier in the illness trajectory. These authors also suggest that policy changes may be necessary in the form of better funding for long-term care facilities and primary care physicians to improve early management of preventable conditions (Grunier et al. 2010). The high prevalence of low acuity visits also indicates a need for greater access to assessments for non-critical incidents in the long-term care facility.

The effect of access to primary care physicians and more highly trained nursing staff in nursing homes was also addressed in a study by Carter and Porell 2005. Specifically, they looked at whether the quality of care in nursing homes affected the likelihood of nursing home residents with and without Alzheimer's disease and related dementias being admitted to hospital with medical conditions that are considered avoidable with timely access to appropriate medical care. In this study the most common conditions in this category were urinary tract infections, kidney infections and gastroenteritis. Results showed that having an on-site nurse practitioner significantly reduced the odds of residents with and without Alzheimer's disease and related dementias being hospitalized for medical conditions that may not have needed hospitalization if they had been diagnosed and treated promptly. However, the reduction in hospitalizations for avoidable causes was greater in patients with dementia.

In facilities with more registered nursing staff members compared to licensed practical nursing staff members, the hospitalizations for avoidable medical conditions were also reduced. The researchers suggested that more highly-trained nursing staff are better able to recognize

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subtle changes in symptoms of patients with dementia, thus allowing for prompt medical interventions that may prevent hospitalization (Carter and Porell 2005). This study further highlights the importance of access to timely and appropriate nursing and primary care services for dementia patients in order to prevent hospitalizations.

INTERACT II (Ouslander 2011) is a quality improvement intervention technique to reduce acute care transfers from nursing homes. It uses a set of tools and strategies to assist nursing home staff in early identification assessment, communication and documentation about changes in resident status. In Ouslander's study, there was a 17% reduction in self-reported hospital admissions in the 25 nursing homes over a six month period .

One of the reasons patients with dementia may be brought to the emergency department is because of acute changes or deterioration in behavioural and psychological symptoms of dementia (BPSD) (Nourhashémi 2001, Andrieu et al. 2002). In an effort to improve care of patients with BPSD, the Nova Scotia Health Authority created a committee to make recommendations for improving education and awareness of BPSD and access to resources and coordination of services for patients with BPSD and their caregivers. The committee recommended developing a public education campaign to improve the ability of caregivers to better navigate health care resources and options for patients with dementia and thereby potentially avoid visits to the emergency department (Delva et al. 2010). The committee also recommended the development of models for acute stabilization and crisis intervention for BPSD in the community (Delva et al. 2010). This strategy might involve specialized care teams in long term care facilities, challenging behaviours assessment and stabilization units, mobile crisis BPSD teams for long term care and the community, and a mobile nurse practitioner model for immediate consultations for urgent/emergent BPSD (Delva et al. 2010).

Like BPSD, some conditions affecting people with dementia could be managed outside the hospital if supports and equipment were available. Scott and others in the Society for Academic Emergency Medicine Geriatrics Task Force report on the emergency care of older patients recommend increasing supports for home care of selected conditions such as pneumonia, heart failure, chronic obstructive pulmonary disease, etc. (Wilber et al. 2006). Home care may result in improved patient satisfaction and decreased iatrogenic illness and deconditioning.

Another aspect of preventing hospitalizations for patients with dementia requires the discussion of care goals at the end of life. In a study by Lamberg and others, researchers attempted to describe the factors associated with decisions not to hospitalize nursing home residents with advanced dementia who were dying (Lamberg et al. 2005). At the time of death, 83.8% of subjects had a DNH (do not hospitalize) order (Lamberg et al. 2005). The prevalence of DNH

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orders was 50% and 34.4%, 30 and 180 days before death respectively (Lamberg et al. 2005). Factors independently associated with having a DNH order before death included having a surrogate decision maker that was not the subject's child, eating problems, aged 92 and older and length of stay in the nursing facility 2 years or longer (Lamberg et al. 2005). This research showed that a decision to forgo hospitalization is usually not made until death is imminent, making transfers to hospital more frequent near the end of life. A transfer to hospital may not be in the patient's best interest and highlights the need for earlier discussions regarding goals of care and education for surrogate decision makers about the likely outcomes of hospitalization and the course of dementia as a disease.

Caregivers experience many stresses and may become overburdened by the care they provide; this level of stress can potentially lead to hospitalizations or potentially premature institutionalizations of their loved ones with dementia. A Nova Scotia study (Neman, et al. 2007) found that "about 20% of caregiver survey respondents reported a range of physical and mental health challenges, including physical injury, sleep deprivation and high blood pressure, as well as stress and feelings of hopelessness. Four themes arose from their qualitative study, including the need for care navigators throughout the system, the need for a wide range of education, health and respite resources, including improvements in home care and finally, economic supports. Providing needed resources before caregivers are burned out follows a health rather than a sickness model and was suggested by Lilly (Lilly, M. 2011). Reporting on a case study in the Interior Region of British Columbia, the question pursued was how to better support the health and wellness of family caregivers to persons with dementia. In their review on caregiving in dementia, Sörensen and Conwell (2011) noted that interventions involving education need to have active participation and behaviour management skills building for the caregiver in order to be effective.

### Emergency Department Care

A prospective observational study of 297 patients 70 years or older, presenting to an urban teaching hospital emergency department over a twelve month period (Hustey & Meldon, 2002), showed that 78 individuals had mental status impairment, 30 had delirium diagnosed by the CAM, 48 had cognitive impairment without delirium, 17 screened positive on both the CAM and an orientation, memory, concentration examination for dementia. Only 22 of the 78 who had mental status impairment had documentation of a problem by the emergency physician, and 16 of the 23 patients with cognitive impairment who were discharged home had no prior history of dementia.



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The authors highlight the lack of documentation and lack of recognition by the emergency doctors as important issues (Hustey, Meldon, 2020). Transfer of residents between nursing homes and emergency departments can be difficult, and complications can arise from poor communications. McCloskey's qualitative study (2011) on the transfer of residents between the nursing home and emergency department found that many practitioners "expressed guilt over how resident transfers occurred and under what conditions. Nursing home practitioners acknowledged that, despite having no expectations of residents receiving quality care or hearing about events that transpired in the emergency department, including diagnoses, appointments for diagnostic investigations and medical consultations, they continue to send residents to ED." Also, "Although practitioners felt guilty about how residents were treated when they were transferred between the ED and the nursing home, they did not accept responsibility for their actions or inactions." (McClosky, 2011). Somehow, there needs to be better communication between residential care facilities and emergency departments.

Emergency departments are focused on treating and diagnosing acute and life threatening illness quickly and consulting other services when patients need more complex or long term care. But given the rapid assessments and busy staff, patients with cognitive impairment are often left confused, disoriented and only partially diagnosed and treated (Hustey et al. 2003, Wilber et al. 2006). Due to poor communication, there is also a risk of unnecessary tests leading to increased stress and iatrogenic illness (Jones et al. 1997).

Recognizing that emergency departments were not meeting the needs of the growing elderly population, the Society for Academic Emergency Medicine (SAEM) Geriatric Task Force created a list of quality of care indicators based on a systematic review of the literature, supplemented with expert opinion when necessary (Terrell et al. 2009). The objective of the project was to develop emergency-department-specific indicators to help practitioners identify gaps and to focus improvement efforts.

Six of these indicators focused specifically on the care of patients with cognitive impairment. The first indicator recommended that a cognitive assessment be carried out on all older patients arriving in the emergency department. The second indicator required that if an older patient was found to have cognitive impairment, the care provider should assess and document whether there had been an acute change from baseline. The third and fourth indicators stated that if there had been a change in baseline mental status, the care provider should make sure necessary home supports were set up and that there was a plan for follow-up when the patient was discharged. The fifth indicator stipulated that if a patient was found to have cognitive impairment that was not a change from baseline, the care provider should determine whether there had been a previous diagnosis or not. If the cognitive impairment had not been previously diagnosed, the sixth indicator required that the emergency department care

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provider make a referral for outpatient evaluation of cognitive impairment upon discharge. The Task Force recommended that emergency departments or researchers measure the extent to which each quality indicator is successfully being met in current emergency practice (Terrell et al. 2009). These indicators represent an ideal scenario, and the Task Force recognized that they are not all being implemented.

The SEAM Geriatrics Task Force also prepared a report on the general emergency care of older patients (Wilber et al. 2006). In this report they discussed several ways emergency department design, management and staff education could be changed to better support the needs of older patients. Many of these changes would also improve care for patients with dementia. The report highlighted how emergency care of older adults requires more resources and is often significantly different from the management of younger patients because of complex medical issues and atypical presentations and responses to therapy. Plans for additional staff, equipment and space may be needed to accommodate the increased need for emergency department care by older patients.

Older people are also at increased risk during disasters; emergency medicine planning for disaster relief should thus also take the needs of older adults into account. Current emergency department physicians have not generally received special training in geriatric care; education would thus improve understanding and care of older adults. One hospital in the United States attempted to address the issue by creating an emergency unit staffed by geriatricians while another hired geriatric nurse practitioners to work in the emergency department. The SEAM Geriatrics Task Force compared the special needs of geriatric patients to other groups such as pediatrics and advocated for specialized training for all members of the care team as well as changes in protocols, policies, procedures and the emergency department design and environment (Wilber et al. 2006).

Since many of the older patients transferred from nursing homes have some degree of cognitive impairment, a common problem facing both patients and emergency department physicians is the poor communication skills and the lack of a reliable medical history. In their report, the SEAM Task Force also highlighted clear communication between the emergency department physician, the nursing home and the patient's primary care physician as vital to providing quality and cost effective care in the emergency department (Wilber et al. 2006).

In a study by Jones and others on transfers of patients from nursing homes to emergency departments, it was found that 10% of patients were transferred to the emergency department without any documentation (Jones et al. 1997). Even if patients were transferred with some documentation, less than 50% were transferred with documentation of advance directives, immunizations, baseline mental status or functional abilities, diet and recent vital signs.

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The authors recommend that the development of a universal transfer form would provide emergency department physicians with access to information that would likely improve quality of care and patient outcomes (Jones et al. 1997).

Due to the rapid style of triaging and assessing patients in the emergency department, patients may not be recognized as cognitively impaired, and even if cognitive impairment is recognized, there may not be sufficient time or resources to address it. A study by Hustley and others found that emergency physicians recognized impaired mental status in only 38% of patients who screened positive for cognitive impairment (Hustley et al. 2003).

The two screening tools used were the Orientation Memory Concentration examination for cognitive impairment and the Confusion Assessment Method for delirium. When emergency physicians were informed of the screening results, they altered management in none of the study patients. This seems to indicate that screening and awareness of impaired mental status are not enough to improve care. 84% of the patients that screened positive for dementia did not have a prior diagnosis of dementia. This also indicates that screening in the emergency department represents a good opportunity for earlier recognition and diagnosis of dementia.

Nolan (2009), in her paper on older patients in the emergency department, reports on many problems that seniors experience because of their own deficits, including difficulties because of eye glasses and hearing aids not being sent in, mobility problems because canes or walkers were not brought with the patients and difficulty eating because dentures were not brought in. She concludes with a suggestion that hospital staff develop strategies which will decrease the risks for seniors in emergency departments, including such things as the need for all staff to have education about how to deal with older patients and patients with dementia, having more elderly friendly areas, having more assistance by nurses' aides, by improving communication, as well as decreasing wait times for inpatient beds and providing geriatric specific triage at the door (Nolan 2009).

Andrews and Christie (2009) discussed six recommendations from the Scottish government to help patients who suffer from dementia in the emergency department. These recommendations include: urgent physical and psychological assessments; training for all staff about people with dementia in the emergency department; a flag system to raise awareness about these patients' needs; avoiding admission where possible; having a dementia care trained nurse in every hospital and avoid moving patients with dementia between care settings (Andrews and Christie 2009).

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### Acute Care Hospitals

Many studies have identified dementia as a risk factor for prolonged hospital stays (Lyketsos et al. 2000) and higher rates of mortality when patients are admitted to acute care wards (Morrison and Siu 2000, Sampson et al. 2009). There have also been attempts made to determine which aspects of dementia and related co-morbidities put people at greater risk for longer stays and increased mortality (Lang et al. 2010). This information may make it possible to improve certain aspects of care and to determine if it is in the patients' best interests to be admitted to hospital. It is also recognized that patients with dementia suffer more distress due to the change in daily patterns and the variety of treatments and tests while in hospital (Miller and Campbell 2004). Some research has been conducted by nurses on ways to improve the care and comfort of patients with dementia. This information may also lead to better quality care and better outcomes in terms of decreased morbidity and mortality and shorter hospital stays.

In a study by Lang and others, researchers attempted to identify markers of prolonged hospital stay in patients with dementia (Lang et al. 2010). Multifactor analysis demonstrated that demographic variables had no influence on the length of stay, while diagnosis of delirium, walking difficulties and reports by the informal caregiver of moderate to severe burden or low caregiver social quality-of-life score, according to the Zarit's Burden Inventory short scale and the Duke's Health Profile respectively, were identified as early markers for prolonged hospital stays. Other variables in the analysis included: level of disability in activities of daily living (ADL's), gender, age, living situation, marital status, type of caregiver, mood disorders, gait and balance disorders, malnutrition risk, bedridden status, pressure sores risk, incontinence and comorbidity index level.

Researchers suggested that delirium may increase hospital stay by contributing to a functional decline and by preventing the patient from participating in rehabilitation. Patients who develop delirium are also more likely to be transferred to a nursing home and therefore may remain in hospital longer as they wait for a bed to become available. In order to decrease hospital stays, it is necessary to try to prevent delirium or to treat it early on. In the Lang study, walking difficulties were also associated with increased length of stay, and the authors propose that early rehabilitation and mobilization may reduce length of stay. During hospital stays, fasting in connection with certain tests, inadequate help with feeding and the anorexic effect of certain types of medications, may lead to decreased protein and caloric intake. These problems may further contribute to muscle loss and decreased mobility and function. Therefore, monitoring caloric intake and weight may help to maintain strength and mobility. The third marker of prolonged hospital stay identified in the study was increased burden of care on caregivers.

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This burden of care may contribute to increased length of stay in a variety of ways. It may lead to more frequent crisis situations requiring visits to the emergency department and hospital admissions. It may also make caregivers more reluctant about patient discharge. A multidisciplinary approach to care of patients with dementia in the community is recommended to decrease the burden of care on family members. This approach would include involving the primary care physician, nurses and care aids that can visit the patient at home as well as access to respite programs. Communication between the hospital care team and community care teams may also facilitate the discharge process (Lang et al. 2010).

Patients with dementia are at higher risk of developing delirium when they are admitted to hospital. Voyer, et al. (2006) found that the severity of cognitive impairment was correlated with the likelihood of a patient developing delirium. In patients with mild prior cognitive impairment, 50% developed delirium; 82% of patients with moderate cognitive impairment developed delirium; and in patients with severe impairment, 86% developed delirium. These differences were statistically significant (Voyer et al. 2006). Delirium significantly increases a patient's risk of mortality and prolonged hospital stay; therefore, diagnosing dementia and recognizing it as a risk factor for delirium may allow care providers to prevent or treat delirium earlier (Han et al. 2010, Lang et al. 2010).

In some studies it has been found that rates of mortality are higher in patients with dementia compared to cognitively intact patients who are admitted to acute care hospital wards (Morrison and Siu 2000, Sampson et al. 2009). Morrison and Siu compared the outcomes and care for patients with end-stage dementia and patients who were cognitively intact who were admitted to acute care for pneumonia or hip fracture. Six-month mortality for patients with end-stage dementia and pneumonia was 53% compared with 13% for cognitively intact patients. Six-month mortality for patients with end-stage dementia and hip fracture was 55% compared with 12% for cognitively intact patients. There were no significant differences in the care received by end stage dementia patients compared with cognitively intact patients in terms of the number of burdensome procedures, and all patients with pneumonia were treated with IV antibiotics. There was also no evidence that palliative care was undertaken instead of life-prolonging measures for patients with end-stage dementia. However, dementia patients were more likely to be restrained, and dementia patients with hip fracture received a mean of 1.7 mg/d of morphine sulphate equivalents while cognitively intact patients received a mean of 4.1 mg/d.

The authors suggest that the increased rates of mortality for end-stage dementia patients and the potentially higher burden of care due to lack of understanding of tests and treatments, lack of analgesia and lack of ability to make choices regarding treatment, may make it appropriate to discuss goals of care early on in the admission, and in some cases, to have a more palliative

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approach to care focusing on patient comfort (Morrison and Siu 2000). Sampson and others looked at rates of dementia in patients over 70 who were admitted to hospital as well as mortality rates of patients admitted with dementia compared to cognitively intact patients. There were no significant differences between the group of patients with dementia and the group of patients who were cognitively intact in terms of chronic health status, but the patients with dementia had more severe acute illnesses on average (Sampson et al. 2009). The risk of mortality during hospital admission was much higher in the group of patients with dementia. Of the patients admitted with dementia, 18.1% died during hospital admission whereas only 7.5% of the patients with a MMSE score of 24 or greater died during hospital admission. Mortality risk increased with the level of cognitive impairment. The authors suggest that patients with dementia may receive poorer quality of care or that the combination of dementia and acute illness may be particularly damaging. They also suggest that mental health liaison services for older people in hospitals may improve care and outcomes (Sampson et al. 2009).

Zekry and others (2009) found that although a diagnosis of dementia was significantly associated with a longer hospital stay and institutionalization following the hospital stay, it was not significantly associated with mortality while in hospital. Mortality was, however, significantly associated with a high Charlson Comorbidity Index and poor nutritional status. The authors suggest that the reason their study may have had unique results was because they used a diagnosis of dementia rather than an MMSE score to differentiate patients. In their study, Sampson and others found rates of dementia based on DSM IV criteria to account for 42% of the patients over 70 who were admitted (Sampson et al. 2009). The DSM IV criteria include an MMSE score of less than 24. Fewer than half (21.1%) of patients diagnosed with dementia had received a previous diagnosis of dementia (Sampson et al. 2009). Therefore, using a previous diagnosis of dementia versus a MMSE score to differentiate patients likely selects for patients with more severe cognitive impairment and affects results of a study.

Patients with dementia often have difficulty adapting to new environments and may find hospital admissions more stressful because they cannot fully understand why they are in hospital and why certain tests and treatments are necessary. The Elder Care Supportive Interventions Protocol (ECSIP) is a set of nursing and family support interventions designed to reduce discomfort, rates and severity of delirium, reduction in function and the need for post-hospital care in patients with dementia admitted to the hospital (Miller and Campbell 2004).

Miller and Campbell published a study which attempted to test this protocol to determine if there were differences in length of hospital stay, level of required post-hospital care, family caregiver involvement, discomfort, severity of delirium, physical function and activities of daily living between patients who were treated with this protocol and those who were not. Elements of the protocol included a client profile, an individualized care protocol and an elder

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guide. The client profile had information on routines of rest and physical activity, preferences for foods and diversional activities, personal history including preferred name, and particular manifestations of discomfort. Personal information from the caregivers of patients was gathered within 24 hours of hospitalization in order to complete the client profile. The individualized care protocol included two types of interventions; the prevention and control of discomfort, using data from client profiles, and maintaining a familiar environment with meaningful communication and sensory input.

The Elder Guide included the following three components in a booklet: 1) the family as valued members of the health-care team; 2) explanation of the physical environment with descriptions of common equipment and treatment devices; and 3) financial and transportation assistance (e.g., meal and parking vouchers). Although 181 patients were initially enrolled in the study, researchers had significant difficulty completing all stages of the research due to not being informed of discharge plans and the consequent loss of more than 50% of the patients. This made it difficult to find any significant differences between the intervention and baseline treatment in terms of outcome measures. The study was also impaired by nurses' low implementation of many of the basic interventions despite efforts and education.

One unexpected outcome of the study was that the hospital hired the elderly care aides that had been involved in implementing the study because of the high rates of satisfaction by both family members and nursing staff (Miller and Campbell 2004). Although this study was unable to report any significant differences between the group of patients receiving care under the protocol and those who were not, it does provide some suggestions as to which aspects of acute care might be modified to improve care of patients with dementia.

Similar, yet more specific suggestions for nursing care of patients with dementia, were provided in an article by Halduk and Shellenbarger. Recommendations included: initially assessing mental status, asking family members or caregivers about health history, daily routines and food preferences, encouraging family members to bring in familiar objects and to accompany patients for tests and procedures, assessing fall likelihood, putting the patient in a room close to the nursing station, assessing the patient more frequently if they are unable to use the call system, leaving a night light on in the bathroom, keeping small items, toxic substances and medications out of reach, avoid placing a patient in a room near an exit or elevator, keeping the patient busy with supervised activities, using a kind approach rather than confrontation when the patient wanders, trying to maintain similar daily routines, making sure hearing aids are available and working, scheduling a rest in the afternoon to reduce sundowning, avoiding over stimulation, expecting behavioural outbursts and involving caregivers in early discharge planning (Halduk and Shellenbarger 2004).

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It is often difficult for patients with dementia to communicate what aspects of hospital care could be improved. However, informal care providers often continue to spend time with and care for the patient while they are in hospital. Douglas-Dunbar and Gardiner interviewed informal care providers of people with dementia to determine how they thought dementia care could be improved (Douglas-Dunbar and Gardiner 2007). The care providers described six areas which needed improvement in terms of nursing care: communication, nurses' understanding of dementia, care provider vulnerability, the need for advocacy, long term effects of being in hospital and the therapeutic relationship. Care providers found that communication was poor in both directions; they were often not informed of treatment plans and health status changes, and when they tried to explain individual aspects of the patient and the patient's vulnerabilities, the nurses failed to listen to them. There was also a general impression that nurses had a poor understanding of dementia and how to care for patients with dementia. The care providers described feeling vulnerable and disempowered in the hospital setting and wished the nurses would consider that when communicating with them. Care providers felt the need to stay with the patient to provide a voice for the patient and to make sure their needs were met and their concerns voiced. The care providers also felt they were able to see the long term effects of patients being in hospital because having seen them before they were in hospital; they could detect changes separate from the acute illness, changes such as weight loss and decrease in functional capacity. The care providers thought that a better therapeutic relationship with the health care staff would have facilitated communication and improved overall care.

Based on the concerns expressed by care providers, the authors came up with some suggestions for changing clinical practice. One suggestion was having a letter introducing the dementia specialist nurse to be given to the care providers at the time of admission. They also suggested having posters to inform care providers and nurses about the letter and to have workshops on dementia for nurses (Douglas-Dunbar and Gardiner 2007).

### Care Transitions

Seniors with dementia are frail and are easily frustrated, frightened, and are at risk of having their needs forgotten, particularly during transitions, i.e., home to emergency department, emergency department to acute care hospital, acute care to sub-acute care, to home. All transitions are potentially problematic. Eric Coleman's work speaks about four pillars in transitions: the patient-centered record, medication reconciliation and management, primary care and specialist follow-up, and a knowledge of red flags by staff and caregivers (i.e., weight gain in a patient with congestive heart failure). He developed the concept of transition coaches to communicate over the gap between sites of service and also developed tools to assist in smooth transitions. His program is called BOOST, Better Outcomes for Older Adults Through Safe Transitions (Coleman, E).



## Restraints and Approach to Behaviour Disorders in Dementia

Mott (2005) describes a chemical restraint as:

...the deliberate and incidental use of pharmaceutical products to control behaviour and/or restrict movement, but which is not required to treat a medically identified condition. These drugs may be purposefully administered to sedate a patient as a means of convenience. Convenience is any action not in the patient's best interest to control or manage behaviour. Medication should never be used according to that definition. However, there are many instances where sedating medication needs to be used therapeutically.

Hughes (2008) describes three conditions for using medications appropriately. First, the underlying causes of the person's behaviour that requires some sort of restraint need to be understood. Second, the best interests of the individual should be put at the centre of any decision to proceed with restraint. Third, restraint should only be used when there is a serious risk of harm to the older person. Decisions should be recorded and the least restrictive technique justified (Hughes 2008). It is important to add that it is not only for the protection of the patient with dementia, but protection of staff who are caring for that patient and for other seniors around them who are frail and may also be hurt.

Physical restraints may be as detrimental, or more so, than chemical restraints in management of patients with dementia who are severely agitated. Scherder et al. (2010) argued that physical restraints inevitably lead to a decline in physical activity and thus have a detrimental effect on both cognition and behaviour. Behaviour may get worse and, in fact, exercise may actually reduce stress and agitation and therefore should be encouraged (Scherder et al. 2010). A physical restraint is defined "as a device that is attached and cannot be easily removed by the resident, which restricts freedom of movement and/or normal access to his/her body (Castel 2006).

The Cochran Collaboration reviewed five randomized controlled studies on educational approaches to reduction in the use of physical restraints. Unfortunately, there was insufficient evidence to support the effectiveness of educational interventions targeting nursing staff for preventing or reducing the use of physical restraints in geriatric long-term care (Mohler et al. 2010). Further work needs to be done in this area and in particular, studies with more intensive educational interventions.

Evans and Cotter (2008) wrote on avoiding restraints in patients with dementia. They emphasized the need to identify the unmet needs within the patient with dementia which is at the base of their behavioural problem. They also emphasized the need for individualized care

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focusing on the following needs: communication consistency, surveillance and appropriate environments, a flexible team approach based on dialogue amongst staff members and respect for patients' needs and rights (Evans and Cotter 2008). They also wrote a two-page summary for nurses on how to avoid restraints in older adults with dementia as part of the "Try This" series from the John A. Hartford Institute for Geriatric Nurses and the Alzheimer's Association ([www.ConsultGeriRN.org](http://www.ConsultGeriRN.org)).

There are many behavioural rating scales for assessment of behavioural disturbances associated with dementia. Geon reviewed nine and in the end suggested that the behavioural pathology in Alzheimer's disease rating scale (Behave-AD) and the Neuropsychiatric Inventory (NPI) were the most appropriate measures for both clinical and research situations (Geon 2011). In all situations, once a behaviour has been identified, it is essential to try non-pharmacological approaches first. If non-pharmacological approaches don't work, then medications are considered, depending on the individual circumstance, the origins of the behaviour, the nature of the threat to others and the particular health problems of the patient (Geon 2011).

Passmore, et al., reviewed alternatives to atypical antipsychotics for the management of dementia related agitation including the conventional antipsychotics, cholinesterase inhibitors, memantine, antidepressants, antiepileptics, lithium, anxiolytics, analgesics, b-Adrenoceptor Antagonists (propranolol), cannabinoid receptor agonists and hormonal agents (Passmore et al. 2008). They noted "there is a wide variability in the level of evidence supporting the use of non-antipsychotic medications for the treatment of dementia-related agitation." They concluded that "patients with severe dementia-related agitation might benefit from short-term treatment with antipsychotics, plus long-term treatment with cholinesterase inhibitors and/or antidepressants and possibly memantine, or a less well established alternative." (Passmore et al. 2008)

The use of antipsychotic and other psychotropic medications for older nursing home residents to treat behavioural problems associated with dementia, is complicated no matter how it is approached. Polak and Mulsant report that psychotropic medications may increase the risk of death in older nursing home residents and that the risk-to-benefit ratio of any medication must be carefully evaluated on an individual basis for older patients. They note that there is an urgent need for evidence-based pharmacologic and non-pharmacologic treatments for the behavioural and psychological symptoms of dementia (Pollock and Mulsant 2011).

Despite the lack of good evidence in general, for treatment of behavioural disorders with medications, senior practitioners in mental health are all aware of the need to use medications, albeit carefully and thoughtfully.

## Conclusion

Dementia is increasing in prevalence as the population over age 65 increases (Evans 2009). Studies have shown there are options for improving dementia care: at the level of preventing hospital visits, in the emergency department and when patients are admitted to acute care wards. Implementing some of the recommendations from these studies will decrease the morbidity and mortality of patients with dementia.

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## Appendix C

# APPENDIX C: Results of Emergency Department Focus Groups

## Caregivers' Focus Groups

The following questions were asked of the caregivers in their focus groups:

1. Have you or your loved one been in an Emergency Department of a hospital in the past five years?
2. Please mention any positive or negative experiences and what would you have hoped for in the emergency department in terms of care and communication?

### **Suggestions from caregivers about improving care of patients with dementia in the emergency department:**

- Slow down when approaching a patient with dementia and watch the body language.
- Have a positive, caring attitude.
- Demonstrate respectful, non-judgemental listening, communication and collaborative with both the patient and the caregiver. This includes acknowledging the caregiver's role – (giving collateral information, discussing goals of care, helping their loved one communicate with health care professionals and receiving prompt, clear communication from the health care professionals about what is happening).
- Explain to the patient what is going on when anything is being planned for or to be done, (e.g. tests, diagnosis) and allow time for questions.
- Please "do with" rather than "do to" the patient and/or caregiver.
- Involve family physicians in care planning.



## Health Care Professionals' Focus Groups

### **Questions asked of the health care professionals in all focus groups:**

1. *What do you see as the common reasons for patients with dementia coming to your emergency department? Are they triaged with a primary diagnosis of dementia or with the underlying symptoms or illness?*
2. *In your emergency department how are patients identified as having a dementia?*
3. *What tools or protocols are being used?*
4. *What are the enablers for emergency department patients with dementia being provided with appropriate dementia care.*
5. *What are the barriers and/or challenges for patients with dementia being provided with appropriate care?*
6. *What guidelines and protocols would you want developed, and what suggestions do you have that would improve the care of patients with dementia who come into the emergency department?*

The following is a summary of the questions, answers, and suggestions provided by the health care professionals.

1. ***What do you see as the common reasons for patients with dementia coming to your emergency department? Are they triaged with a primary diagnosis of dementia or with the underlying symptoms or illness?***

The diagnosis of dementia itself is most often not the primary reason for coming to emergency departments. Dementia is usually a secondary diagnosis, and the most common primary diagnosis is a medical problem, sometimes because there has been a behavioural change related to an underlying medical problem. When the primary reason for referral is dementia, it is because of a social problem, a behavioural problem or systems issues.

Medical problems were frequently cited as being the most common reasons patients with dementia end up in emergency departments. Primary medical problems were often masked by unsettled challenging behaviours or in fact, overlooked because of behaviours. The following were the most common reasons cited:

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- ✓ delirium
- ✓ falls and fractures
- ✓ medication errors and mix-ups
- ✓ infections (urinary tract infections, pneumonia)
- ✓ cardiovascular problems
- ✓ failure to thrive and needing a medical workup
- ✓ dehydration

Social problems reported in the literature and from professionals include caregiver burn-out, fatigue and exhaustion. The underlying problems observed were:

- ✓ the family cannot cope any longer
- ✓ the family expectations could have been or were unrealistic
- ✓ the caregiver thought that the patient could be “fixed” in the emergency department
- ✓ there was no caregiver, or there was conflict between the family caregivers
- ✓ there were inappropriate living conditions

Behavioural problems include:

- ✓ issues of self-neglect
- ✓ escalating unsettled behaviours, including aggression and/or wandering
- ✓ the care staff not being able to manage these challenging behaviours at the care facility level
- ✓ behavioural crises happening with no resources to help stabilize either community or residential care facility

Systems issues include:

- ✓ waitlists in the community being too long for residential care facility beds
- ✓ family supports falling apart
- ✓ lack of community resources to stabilize patients in the community while they are waiting for appropriate care facility or services
- ✓ families believing that if they took their loved one to the emergency department, that they will get their relative into a facility faster

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- ✓ families not knowing what services are available in the community to help before the crisis happens
- ✓ families taking their loved one to emergency departments without first being seen by their primary health care team

Additional systems problems include a lack of education within the community for trained professional and non-professional staff. Also mentioned was the trend towards more LPNs and fewer RNs in facilities, a trend that may lead to more emergency department transfers because patients' needs exceed the capabilities of the facility. Communication breakdowns were another systems problem described. A failure to communicate between the doctor and the nurse in the facility may lead to patients being sent without the physician seeing them first, and a failure to work collaboratively in the community between the family physicians and home and community care to keep the patient in the community also occurred.

Health care professionals within these groups mentioned that they thought that perhaps a quarter or perhaps even up to half of the admissions could be prevented by having earlier interventions. However, barriers to early intervention, such as lack of appropriate levels of staff and/or lack of supports in both residential care facilities and the community, were acknowledged. Residential care equates to complex care needs that are expected to be provided by staff who do not have the expertise, knowledge, skills, abilities and attitudes.

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### Suggestions For Improvement

- Patient Assessment:
  - Get a precise description of what the problem is according to the referring source (long-term care facility, nurse, family physician, family member) and what specifically is being asked to be achieved.
  - It is important to get collateral information about the history of the present problem and the overall patient functioning, both cognitively and with respect to ADLS, either from family or the community (family physician or home and community care), or old charts.
  - The patient needs a thorough examination to understand what medical problems underlie the behavioural issues.
  - A CAM should be done to screen for delirium whenever cognitive problems are suspected.
  - Families or family physicians should be asked about advance care directives in order to understand how to develop goals of care with the family, even in the emergency department.

#### 2. *In your emergency department how are patients identified as having a dementia?*

- ✓ interview by physician of the patient/family
- ✓ family collateral information, either verbal or written
- ✓ facility communication, either written or nurse-to-nurse or doctor-to-doctor
- ✓ “emergency paramedics” notes
- ✓ electronic medical records – when available
- ✓ old paper charts
- ✓ liaison with home and community care case managers
- ✓ talking with family physicians
- ✓ experienced emergency department staff just knowing “something is up”
- ✓ geriatric emergency nurse assessments

Both the caregivers and the professionals mentioned the importance of specialized geriatric emergency nurses in emergency departments and generally agreed that care improves

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significantly with the presence of geriatric trained emergency nurses. These specialized staff are seldom there 24-hours a day, seven days a week, leaving gaps in the provision of care. There was no stronger recommendation than having specialized geriatric emergency nurses.

When participants were asked about identifying dementia in the emergency department, many felt that delirium and dementia were difficult to differentiate, especially without a good past history of functioning. Many suggested that delirium be screened whenever there is any concern about cognition. Many also felt that a new diagnosis of dementia was unwise in the emergency department when the patient is there because they are usually medically sick and may perform cognitively much better when they are well. The professionals therefore suggested that for clarification of the diagnosis of dementia, the patient should be identified on the acute care unit when they are medically stable. It was recommended that dementia assessments and work-ups be completed when back in the community and the patient's condition had stabilized closer to their norm. There was great concern about misdiagnoses of dementia or “?Dementia” noted on the chart when cognitive deficits could have been due to delirium or depression. Furthermore, without good collateral information about mental health history, patients with major psychiatric illness were also labelled as dementia because of their presenting behaviours.

### Suggestions For Improvement

- Medical Records:
  - Health authorities should be encouraged to have emergency medical records which include alerts about dementia as a diagnosis and access to recent assessments for function.
  - There should be standardized approaches to assessment throughout the system for patients with dementia regarding screening for delirium, depression and cognitive impairment, as well as for function (IADLS, ADLS) and mobility.
  - There should be standardized, written transitional care documents used by the entire region for transfer in and out of facilities.

### 3. *What tools or protocols are being used?*

- Screening for Delirium:
  - ✓ Confusion Assessment Method (CAM)
  - ✓ Delirium Rating Scale

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- Cognition:
  - ✓ Mini Cog
  - ✓ Standardized Mini Mental Status Examination (SMMSE)
  - ✓ Montreal Cognitive Assessment (MoCA) for early cognitive impairment
- Depression:
  - ✓ Geriatric Depression Scale 15 (GDS 15)
  - ✓ Patient Health Questionnaire 9 (PHQ 9)
  - ✓ Patient Health Questionnaire 2 (PHQ2)
- Function:
  - ✓ Lawton and Brody ADL and IADL scale (filled in by caregiver)
- At Risk in Community:
  - ✓ ISAR-SEISAR by McCusker: This is a screening tool for detecting severe functional impairment and depression and predicting increased depressive symptoms and increased utilization of health services. The tool is a six-item self-administered questionnaire used in emergency departments to identify seniors at high risk of subsequent functional decline, including institutionalization or death.
- At Risk for ALC:
  - ✓ InterRAI ED Screener (Dr. John Hordes): The M.O.P.E.D. Study included sites at the Royal Jubilee Hospital in Victoria and Nanaimo Regional General Hospital using the InterRAI ED Screener. The performance of this screener was very good and was a good predictor of ALC. Dr. Andrew Costa, Department of Health Studies in Gerontology, University of Waterloo.

There was general recognition that it is essential to understand the patient's functioning within the community prior to coming to the emergency department in order to have an understanding of their overall change in functioning with their acute presentations. Because time is of the essence in assessment, caregivers' reports are probably the most likely to be used in determining pre-hospital functioning.

### Suggestions For Improvement

- Pay Attention to the Caregivers:
  - Caregivers need to be listened to, involved in all aspects of care and communicated with regarding goals of care, results of tests and transitional planning.
  - There should be information in the emergency department for caregivers such as Alzheimer Society pamphlets to connect those who may not be connected, or social workers available to give caregivers information about community resources.
  - Physicians and nurses should assist caregivers to understand what can reasonably be expected to be accomplished within the emergency department and acute care hospital for their relative.
  - Ask family caregivers to stay with the patient as long as possible or get other family members in to spell them off.

4. ***What are the enablers for emergency department patients with dementia being provided with appropriate dementia care?***

Geriatric triage nurses who work collaboratively with all the RN staff in emergency departments with the community and with the nurses in the inpatient units in hospital.

5. ***What are the barriers and/or challenges for patients with dementia being provided with appropriate care?***

- Lack of time for proper history
- An inappropriate environment:
  - ✓ over-stimulating
  - ✓ noise
  - ✓ lack of privacy
  - ✓ sleep deprivation
  - ✓ no chairs beside the bed for caregivers
- beds don't go down low to allow the patients to get up easily
- poor access to toilets

## Appendix C

- inappropriate lighting
- signage too small to read or understand
- Communication problems from the emergency department to the community, from the emergency department to facilities
- The inappropriate use of restraints, physical and/or chemical
- The lack of mobilization
- A negative attitude or prejudice about patients with dementia not being “acute care”
- Lack of specialized staff (specialized geriatric nurses, geriatric psychiatrists, geriatricians)
- Inappropriate use of catheters
- English not a first language for many of the patients
- Lack of general education about care for patients with dementia in the emergency department and more specifically about management of behavioural problems with dementia with both non-pharmacological and pharmacological approaches
- Advance directives may not have been done in the community, so when patients come in to the emergency department, it is difficult to define goals of care
- The wait time for a bed in acute care hospitals is too long and patients get sicker waiting in the emergency department
- Pay for performance may sometimes interfere so that there is not time to assess a patient properly in emergency department



### Suggestions For Improvement

#### Environmental Manipulation:

- If it is possible to have specialized geriatric areas or pods in the emergency department, it would be advisable to create them, especially for patients with dementia.
- It is ideal to have the nurses be able to see patients with dementia from the nursing stations.
- Make the emergency department elderly friendly:
  - signs in the emergency should be bigger and clearer for both the patients and the families.
  - there should be good access to washrooms.
  - patients should be up and out of their beds, sitting in a chair, to eat.
  - bed should be able to be lowered so that the patient can get up.

#### Care Approaches:

- Staff in emergency departments should follow a least restraint policy with respect to both physical and chemical restraints.
- A minimalist approach should be taken for patients with dementia in that unnecessary tests should be avoided and catheters or IVs should be used only when absolutely necessary.
- All emergency departments should implement a non-pharmacological approach to manage behaviour problems associated with dementia first, whenever possible, before medications. If medications are used, there should be a standardized approach to the use of medications for BPSDs prescribing the least amount of medication necessary, with the fewest side effects and best evidence.
- A 48/5 approach should be introduced into emergency departments whereby patients are: screened for delirium; minimal use of catheters; hydration and nutrition should be assessed and supported; patients' mobilization should be understood prior to admission to emergency departments; and patients should be mobilized as much as possible in the emergency department.

## Appendix C

### Suggestions For Improvement *cont'd*

- Finally, there should be an exact medication reconciliation (knowledge of what medications the patient was taking prior to admittance to the emergency department). Medications that are necessary should be administered on time and medications that may cause problems must be identified and discussed with the community family physician if the patient is to be discharged.
- The number of patient moves from one bed to another within the emergency department should be minimized because every bed move may lead to increased confusion.

#### **A Patient-Centred Approach:**

- All staff should approach patients with dementia with a positive, caring, unhurried manner.
- Staff should use caregivers to facilitate communication with their loved one who has dementia.
- Translators should be used as needed, especially when the patient is suffering from a dementia and therefore not able to communicate as easily as those who are cognitively intact.

#### **Staffing:**

- Geriatric, specialized nurses are a proven asset to improving care with people with dementia in the emergency department and acute care hospital. All hospitals should strive to have some staff with this expert education.
- Trained acute care aides can be useful in the emergency departments to assist the patients with dementia eat meals properly, use the washroom, go for walks, watch that they don't wander off and offer emotional support to the patient.
- 1:1 may be needed occasionally, and there should be guidelines to help staff decide when 1:1s are considered appropriate for a particular emergency department.
- Consideration should be given to have physiotherapists and occupational therapists available to see patients in the emergency department to assess and assist mobility and function.
- If security guards are used, they must be trained in dealing with patients with dementia appropriately.

### Suggestions For Improvement *cont'd*

- Where possible, consults from Geriatric Medicine and Geriatric Psychiatry should be encouraged in the emergency department.
- All staff in the emergency department must know the basic principles of good care for people with dementia.

#### Education:

- All staff in emergency departments should have basic education in the care of patients with dementia. This training would include communication with patients and understanding of BPSDs, including non-pharmacological approaches as well as pharmacological approaches. They should also know how to differentiate delirium, dementia and depression.
- The 48/5 approach to seniors' care.
- All new staff in emergency departments should have orientation about care for patients with dementia in the emergency department.
- If security guards are to be used in emergency departments, they should be educated in a standardized, appropriate approach to dementia patients.

6. ***What guidelines or protocols would you want developed, and what suggestions do you have that would improve the care of patients with dementia who come into the emergency department?***

- Emergency Paramedical:
  - ✓ Emergency paramedics (and/or family members) should be asked to bring the patient's medications, eye glasses, hearing aids and dentures when possible, in order to maximize the function of the patient and to ensure updated knowledge regarding medications.
- Follow-up:
  - ✓ When patients are discharged from the emergency department to home, it should be clear who will follow the patient and when: the family physician, the home and community care case manager, home and community care nurse, physios or OT's, specialized clinics for Geriatric Medicine or Geriatric Psychiatry, and/or home care services. Plans should be set up before the patient leaves.

## Appendix C

- Good Transitional Care:
  - ✓ Emergency departments should encourage community family physicians to develop advanced care directives and goals of care with caregivers for all patients with dementia.
  - ✓ There should be communication between the emergency department and the family physician regarding overall patient functioning and plans for care.
  - ✓ When the patient is discharged from emergency departments to the unit or to home, it should be clear what happened in the emergency department and what the immediate plans for care are. All care transitions should follow the best practice of what happened (e.g., diagnosis, tests and results), medication reconciliation, follow-up to be done and red alerts (what should trigger seeking assistance and by whom). This should be given to a family caregiver as well as to the referral source.
  - ✓ Hospitals within a region should work towards one standardized transitional form.
  - ✓ On discharge from the emergency department to home or to a facility, families should understand if there are any suggested medication changes or prescriptions.
  
- Community Support:
  - ✓ Hospital staff in general should support better communication between the hospital and the community sector.
  - ✓ Hospital staff should know what community supports are available and be part of an advocacy process to support better community resources in order to avoid hospitalization wherever possible for patients with dementia.
  - ✓ Emergency staff should be part of an education process for family physicians within their communities to understand the need for having appropriate advanced care discussions and goals of care discussions with the family caregivers of patients with dementia prior to arrival in the emergency department so that the emergency department can be used in the most appropriate way possible and the care for the individual patient can be individualized to support their own goals of care.

## **APPENDIX D: Results of Acute Care Hospital Focus Groups**

### **Caregivers' Focus Groups**

The following questions were asked of the caregivers in their focus groups:

1. Have you or your loved one been in an acute care hospital in the past five years?
2. Please mention any positive or negative experiences and what you have hoped for in the acute care hospitals in terms of care and communication?

### **Suggestions from caregivers about improving the care of patients with dementia in acute care hospitals:**

#### **Approach to Patient**

- Positive attitudes towards your loved ones even if the staff had not planned to deal with dementia patients in the first place
- Affection
- Hugging and giving pats on the shoulder to make her smile
- Same sex caregivers for intimate things like bathing
- Same people doing care
- Person-centred care where someone tries to get to know the patient and shows him some respect for the person he is and was, including the caregivers making sure that caregivers are respected as well
- Continuity of care
- Including patient in as much of their care planning as possible
- Not talking about the person in front of them as if they did not exist

## Appendix D

### **Involve Caregivers**

- Family members recognized as being important and included
- Recognizing that family members have a clear role in advocacy
- An admissions protocol which involved family members giving collateral
- Respecting caregiver's opinions
- Seeking consent
- Asking up front what the family can help with (e.g., call if the loved one is having difficulty settling)

### **Improved Communication**

- Better transfer of information at shift change
- Better communication in general
- Liaison with home and community care
- *"We have here and I support integrated care that communicates with people right in hospital, both in emergency and acute care with interdisciplinary teams. They made a big difference for my mom who needed home support after her stroke when she came home"*
- Good communication is number one.

### **Training**

- Better training for the staff
- Education by the staff of the caregivers on how to provide care, like putting compression stocking on, how to bathe her with comfort, how to give back rubs. I found that to be very, very helpful and I was very appreciative of it.

## Health Care Professionals' Focus Groups

### **Questions asked of the health care professionals in all focus groups:**

1. *What are the common reasons for patients with dementia being in acute care hospitals?*
2. *How are patients identified as having dementia?*
3. *What tools or protocols are used?*
4. *What are the enablers for acute care patients with dementia being provided with appropriate dementia care?*
5. *What are the barriers or challenges for patients with dementia being provided with appropriate care?*
6. *What guidelines or protocols would you want developed, and what suggestions do you have that would improve the care of patients with dementia who come into an acute care unit?*

The following is a summary of the questions (as stated above), answers and suggestions provided by the health care professionals:

### 1. ***What are the common reasons for patients with dementia being in acute care hospitals?***

#### **Medical Problems:**

- Acute medical problems, falls, infection, congestive heart failure, failure to thrive, fractures, adverse effects of medications
- Delirium with co-morbid medical problems

#### **Social Problems:**

- Caregiver burnout
- Facility unable to cope
- Sudden death of a caregiver
- Living alone with decreased function and mobility with no connection to services available

## Appendix D

- Abuse, neglect or self-neglect
- Unattached patient (no family physician) who uses walk-in clinics with no continuity of care

### Psychiatric Problems:

- Behavioural and Psychological Symptoms of Dementia (BPSD, i.e. agitation, aggression, wandering, hoarding)

### Suggestions for Improvement:

#### Understanding Who the Person Is:

- Do person-centred care.
- Find out who this person was before they came into hospital and how he or she has been functioning so you have some understanding and expectations for post-hospital functioning.
- Find out who was involved, which members of the team, so that you can include them in care planning or discharge planning.
- Identify who this patient is and what the goals are within the first 48-hours.
- Make sure you have assessment of behaviour and behavioural support planning.
- Clarify what patients really want in hospital.
- Give clear directions on what the goals of care are.
- Start early identification at primary care, even before going into the emergency department.
- Focus on function and maximizing function at all times.

### 2. *How are patients identified as having dementia?*

#### Collateral information:

- ✓ from caregivers
- ✓ from geriatric triage nurses in emergency departments
- ✓ from hospital charts or outpatient clients
- ✓ from family physicians (hopefully with a past MMSE)



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**Comprehensive Interdisciplinary Assessment:**

- ✓ family physician/hospitalist, RN, OT, SW, neuropsychologist as needed
- ✓ screening for delirium and organic causes of delirium
- ✓ 'The case of the disappearing Question Mark' Misdiagnosis of dementia, due to charting, starts off with Dementia ?, as the chart gets copied the ? gets dropped

**Consultations:**

- ✓ Neurology, geriatric medicine, geriatric psychiatry, specialized geriatric nurses when available

**Suggestions for Improvement**

**Families:**

- Ask families what they want and what the goals of care should be.
- Encourage families to keep their own health records along with a list of medications.

3. ***What tools or protocols are used?***

**Cognitive:**

- Mini Mental Status Exam (MMSE)
  - ✓ repeated over time
  - ✓ misses delirium
- Montreal Cognitive Assessment test (MoCA)
- 3MS
- CAM for delirium
- OT cognitive assessment
- Verbal reasoning test

**Behavioural:**

- Behavioural Assessment Tool
- Cohen Mansfield Agitation Inventory
  - ✓ A sleep log

## Appendix D

### **Depression:**

- Geriatric Depression Scale 15 item
- PHQ 9
- Cornell Scale for depression and dementia

### **Functional Assessment:**

- Lawton and Brody (IADLs and ADLs)
- Kitchen assessment
- River Mead Functional and Behavioural Memory Assessment (developed first for traumatic brain injury)
- ALS 5

### **Executive Functioning:**

- Exec 25 Assessment of Executive Functioning

### **Frailty:**

- CSHA Clinical Frailty Scale (Rockwood et al. CMAJ August 2005)

### **Suggestions for Improvement**

- Comprehensive interdisciplinary assessments. Standardized approaches to assessment with specific tools to screen for delirium to assess cognition, to screen for and assess the level of depression, to measure function and mobility and pain.
- Follow the principles of 48/5 assessment.

#### 4. ***What are the enablers for acute care patients with dementia being provided with appropriate dementia care?***

### **Special Units:**

- ACE Units
  - Group patients with dementia into a certain area of the hospital and develop staff interest in those areas so that they are akin to ACE Units.
  - ACE Unit team huddles.

## Appendix D

### Programs:

- Have family photos at the bedside.
- Group programs that are either about orientation or discussion of events.
- Taking care of patients' personal comfort, things like sorting out bowel protocols so they are comfortable and that may prevent behavioural problems.
- Have a white board next to the bed so everybody knows what's going on with the client.
- Getting family to bring in hearing aids, shoes, walking aids.
- Distraction boxes on the units as a non-pharmacological approach to manage behaviour.
- Exercise classes in the geriatric psychiatry area.

### Family:

- Referring people to caregiver groups like the Alzheimer Society.
- Support the family so they feel in the loop and they have been given appropriate information.
- Families keeping diaries about the hospital care and tests being done so they truly understand what is going on.
- Families keeping guest registries so that when people come to visit they know who they are so they can discuss that with their loved one when they come in.
- Understand what the wishes are of the family and creating care plans around that.
- Openness of acute care and utilizing the family when necessary or when the family wishes.

### Personnel:

- Staff who are willing to meet these patient's needs and understand what the needs are.
- The geriatric triage nurse in the emergency department was a huge step forward and fundamentally changed the care in the emergency department. The Gerontology CNS.
- Case manager leaders "to have the pulse of what is going on." "I guess I've been around enough to remember the days of the Head Nurse. You go to one person and they kind of knew all the patients. These case manager leaders from a clinical standpoint know these patients usually pretty well and I think that's really helpful on the ACE Unit.
- Implementation of senior specialty teams like GEM teams or senior nurse consultants.
- Geriatric interdisciplinary teams with nurses, OT's, PT's, and geriatricians.

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- Seniors' nurse consultant working in the emergency department helping ease their transition from the emergency department to the ward to promote best practices right at the beginning, as far as the use of restraints is concerned.
- Nurse liaison or case manager inside the hospital who can transition the patient in the emergency department to be discharged home and not be admitted and to sort out community services.
- Geriatric Evaluation Management Teams, Quick Response Team, and the SORT Team that connect with the community.
- Also as far as planning goes, "The geriatrician is usually the first person that goes to see the patient and then the team gets involved." We have a physio, an OT, a rehab assistant and a nurse and we go anywhere in the hospital we'd been requested to help with geriatric management.
- Proper staffing ratios.
- Recreational therapists.
- Hospitalists instead of just having doctor of the day.
- Pockets of good care, but short on resources. Underserved to be honest.
- Geriatrics and dementia care education and ongoing specialty support is necessary at all levels of care and throughout all health care delivery services.

### **Policies:**

- Big work on restraint reduction and restraint free environments BUT also need investment in elder-friendly environment for this to be enabled.
- Medication practices which follow standardized treatment.
- An integrated approach that starts out with primary care may include neighbours as well as primary caregivers. A common care plan approach across the continuum of care should be used. Reinforce education so the whole notion of the culture of care and the elements of personhood are supported.
- Protocols for when to use 1:1 to avoid the use of antipsychotics.
- Environments with lower stimulation.
- Easy access to washrooms.
- Daily rounds to talk about patients we are involved with.

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### **Discharge Planning and Transitions:**

- Post-discharge follow-up within two weeks, especially if there was a delirium, by a geriatrician when possible, or a family physician.
- Home assessments being involved to assess discharge planning.
- Communication with the family on an ongoing basis and especially around discharge planning.
- Take a bit more time to prepare and plan for discharges.

### **Education:**

- Family education groups.
- Education of front line staff and family too.
- Active academic geriatric medicine teaching units.
- Six-month mandatory geriatric psychiatry experience.
- Specialty R3 Programs in Family Practice Geriatrics.

## Appendix D

### Suggestions for Improvement

#### **Group patients together as in transitional care units.**

- Create ACE Units.
- Secure acute units to enable safe wandering.

#### **Explore options for specialized units, specialized staff and specialized programming for patients with dementia:**

- Explore the use of cohorted units like Acute Care of the Elderly (ACE) Units or transitional units within the hospital.
- Consider geriatric specialist floating inter-professional teams that would go to any ward in the hospital to assist the unit team with specific geriatric and dementia care.
- Minimize moves within the hospital, making each move criteria-based.
- Consider increasing use of specialty trained geriatric nurses, especially for education and policy development if not for direct service provision.
- Train unregulated care providers (i.e., care aides) in dementia care.
- Make sure the model of staffing is congruent with the person-centred model of care so that the needs of the patient will define the staffing needs.

#### **5. *What are the barriers or challenges for patients with dementia being provided with appropriate care?***

##### **Inconsistency or Lack of Continuity**

- Inconsistent care. There are pockets which are good, but there is inconsistency overall.
- Hospitalists changing and family and patient not really knowing who their doctor is.
- Lack of continuity of care.

##### **Poor Environment**

- The environment being over-stimulating, dementia unfriendly, confusing, noisy, overcrowded.
- Over-capacity rooms with no windows, no toilets and confused patients with no real place for family to visit.

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- Cluttered spaces, busy rooms.
- Not normalizing environments to a typical day

### **Lack of Training**

### **Lack of Education**

### **Lack of Active Dducation**

**Not knowing what you don't know is as dangerous as trying to apply something that you think you know**

### **Inappropriate Staffing**

- Lack of rehab assistance.
- Not an early enough geriatrician assessment.
- The design of acute care staffing, not only nurses, but occupational therapy and social work, geriatricians and geriatric psychiatry.

### **Inadequate Communication**

- Lack of communication and understanding of communication approaches.

### **Gaps in the Community Services**

- There is a gap in home and community care. If people have variable ADL's, they may not meet the mandate for home and community care, but end up in hospital because they did need it.
- Lack of ability to provide appropriate care in the community leads to earlier admissions.
- An unwillingness to involve home and community care on discharge.

### **Medication Problems**

- Wrong medications.
- Too much medication or inappropriate medication.

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### **Inappropriate Days/Place**

- Mandated precipitous discharge planning because of our first available bed policy. We cannot connect in a proper way with our mental health teams and with the health units.
- Acute care hospitals holding onto patients when they are ready to go.
- The wrong client in the wrong unit.

### **Poor Family Involvement**

- Not seeing that families are partners.
- Not collaborating with family.

### **Care Approaches**

- Nurses' fears of mobilizing patients for fear of falling.
- 48/5 needs to be embedded into all care plans.
- A lot of our care is reactive, not proactive, and we should be thinking of proactive and anticipating potential harms.
- Patients in four point restraints because of behaviours.

### **Advance Care Planning**

- When there has been no advance care planning and you don't know what the patient wants when they are in a critical situation.
- If you don't know who is legally able to give consent to health care on behalf of an incapable adult, it's difficult. It really needs to be clear who is the legally-appropriate person within the family or community that can speak [i.e., consent] for this person.
- Acute care hospitals wanting to discharge people before they are ready to go home.

### **Lack of Engagement**

- Lack of engagement in work.



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**Suggestions for Improvement**

**Communication:**

- Work on having electronic medical records, which would include these things, since communication is one of the biggest drawbacks in providing good care, and facilitating medication will improve care.

**Education:**

- Set up educational programs for family members where they learn about behavioural management training or having a family support group within the hospital connecting with the community.
- Have public forums on dementia and delirium so that there is better education all around.
- Create more abilities to train staff.
- Create seniors' health education teams. Teach about the ABC's of communicating respectfully with persons who have dementia and the dos and don'ts of communication.
- Create one page cheat-sheets differentiating between delirium, dementia and depression.
- Increase knowledge translation.

**Work on smooth transitional care:**

- Consider direct admits to the unit instead of going through emergency departments where possible.
- Have OT do home assessments when necessary.
- Involve primary care (family physicians and home and community care) or mental health as needed.
- Discuss medical alert bracelets with families or Life Line if they haven't been introduced yet.
- Make a plan for follow-up and make sure the family is aware of it.
- Make sure family is educated about the use of medications and has the prescriptions for the medications at discharge.

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- Create simple transfer forms for families and facilities.
- If the patient is to be discharged to a facility, have the facility be clearly aware of the discharge recommendations, including medications and care approaches, either by a visit to the facility nurse or a phone call nurse-to-nurse, hospital nurse-to-facility nurse.

### **Work on continuity of care from the community to the hospital:**

- Inform the family physician about the admission. Ask for collateral information and have them involved in the care planning.
- Have community primary care (family physicians and home and community care) involved in care transitions home or into facility care.

### **Work on elder and dementia-friendly environments:**

- Make signage more easily visible.
- Work on reducing noise and use appropriate lighting.
- Encourage the family to make the patient's space more personal for a greater sense of identity.
- Work on having a quiet area and/or a designated program or eating area.
- Make sure the unit is uncluttered.
- Have controlled access where possible.
- Ensure easy access to washrooms.
- Have very low beds for ease and mobility.
- Create bulletin boards above the bed for families to bring in photos or to support life histories.

### **Create a culture of caring where dementia is destigmatized and where a person-centered approach is standard:**

- Follow the advanced care decision plans made by families and ensure that if there is no representative or written advanced care plan, then appropriate health care consent with substitute decision making must be pursued.
- If a family has not yet been involved with advanced care planning, then make a suggestion that they do so with the patient's family physician upon discharge.
- Recognize, respect and support family caregivers:

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- ✓ Suggest First Link with the Alzheimer Society, or caregivers' support groups.
- ✓ Ensure family expectations are understood and discussed regarding how realistic they are with respect to the present functioning of the patient.
- ✓ Ensure family members give collateral information on admission.
- ✓ Involve family in goal setting for the acute hospitalization.
- ✓ Support families in their day-to-day presence on the hospital unit.
- ✓ Involve families in all care transitions.

6. ***What guidelines or protocols would you want developed, and what suggestions do you have that would improve the care of patients with dementia who come into an acute care unit?***

### **Policy**

- Guidelines around consistent types of assessment.
- Use a 48/5 approach.
- Make sure you have assessment of behaviour and behavioural support planning.
- Set up preadmission clinics into the hospital when patients are having elective surgeries.
- Build mandatory geriatric practices into all hospital units where older patients will be.
- Have a more efficient way to get patients into safe, complex long-term care beds.
- Plan for and deal with the very sick, young, mobile people with advanced dementia, anticipating that there will be problems and finding proactive solutions.
- Focus on physical rehabilitation of older patients in the hospital consistently, including on the weekends and over shift changes.
- Encourage the development of HEART teams.
- Do case reviews.

### **Discharge Planning**

- Find out who was involved, which members of the team, so that you can include them in care planning or discharge planning.

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- Create transitional tools that go from the community, to emergency departments, to the medical unit, back to the community, which include a snapshot of the client, include medications on it, diagnoses, function – as in mobility and continence.
- Make sure patients have medic alert bracelets on discharge if they don't have them on admission.
- Improve a discharge planning system and involve the primary care physician in the community in the discharge planning.

### **Include dementia care within quality improvement processes**

- Look at quality of life within the hospital, not just length of stay or ALC.
- Review protocols as in least restraints, 48/5, BPSD, use of 1:1.
- Continually perform family satisfaction surveys and encourage families to have 1:1 discussions with the social worker or primary nurse regarding either their concerns or their positive comments regarding care.
- Involve family members in QI projects.

### **Personnel**

- Have administration recognize that patients with dementia do take a lot of time to take care of so that staffing ratios need to be considered in terms of the amount of time for personal care.
- Have care aides or LPNs working in transitional units who understand dementia care and whose job it is to get people up, dressed, active and assist them with eating.
- Organized earlier referral to the geriatric team.
- Have correct staffing.
- Have flexible nurse ratios and working with care aides to be able to look after people 1:1 when there is delirium or dementia.

### **Make education regarding dementia care a priority**

- Ensure families understand how to access public education.
- Connect families to the Alzheimer Society.
- Provide pamphlets or website information available on the units.

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- All new hires on the units should have specific education about dementia care, particularly about communication approaches and approaches to behavioural issues, as well as understanding the differential diagnosis of delirium, depression and dementia.
- Make sure security staff are educated with respect to appropriate approaches to patients with dementia.
- Have Code White protocols taught by geriatric specialty nurses where possible.

### **Develop dementia appropriate care protocols**

- Maintain a “least restraints” policy.
- Always try use of non-pharmacological approaches to management of behaviour problems prior to any use of medications.
  - recognition of behaviour problems
  - understanding the reasons for behaviour problems (biopsychosocial, environment)
  - use of behavioural logs
- Use appropriate medication protocols for managing behaviours.
  - what to use
  - when
  - how much
  - for how long
  - monitoring process
- Follow a 48/5 protocol for care.
- Review the effect of an over-capacity protocol on the behaviours and/or the infection rates within the unit.
- Create and follow dementia palliative care protocols when appropriate.
- Maximize functioning on the unit by ensuring eye glasses, hearing aids, dentures, personal canes or walkers are on hand.

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- Create meaningful activity programs so that patients who stay for more than a few days have routines.
  - exercise classes
  - walking programs
  - music therapy
  - discussion group
  - family education programs
  - getting up to eat
- Have daily rounds to do updates and care planning.

### **Programming**

- Provide more structure on the unit for the patient's day so that they don't spend time in bed and making sure that the patients are getting up and activated.
- Provide meaningful activities to keep these patients busy during the day and active mentally.
- Get up in the chair for every meal.
- Have a common dining area.
- Normalize what a typical day looks like.
- "Consider an ADL suite (like in Ontario)," an apartment-like setting in the hospital where people are placed for a couple of days and monitored by the staff to see how they would function to determine whether or not that individual needs to go home or could go home.
- Encourage proper sleep hygiene.

## APPENDIX E: The ABCs of Communicating Respectfully with Persons who have Dementia



### The ABC's of Communicating Respectfully With Persons Who Have Dementia

#### ✓ "A" APPROACH

- It is counter-productive to try and rush a person with dementia.
- Use a friendly, gentle, non-controlling manner – "ask" rather than "tell".
- Remember that expectations *must not* exceed abilities – this causes frustration.
- Approach slowly from the front, get the person's attention before you speak and introduce yourself by name – you may be a stranger again, five minutes later.
- Be flexible and give choices that the person can make successfully. Break tasks down into smaller steps.
- Be careful with touch – sometimes it helps, sometimes not.
- Remember that the "person" is more important than the "task" and - it is easier to change the environment than to change a person with dementia.
- Be patient and kind - to them, it's the first time they've asked that question!

#### ✓ "B" BODY LANGUAGE

- Our mood is contagious. Be aware of how you are presenting yourself – stay relaxed, smile and look friendly – speak at eye level.
- Use non-verbal communication such as smiling, nodding, gestures, holding out your hand, visual cues and demonstrations.
- Respect the elder's space (usually much bigger than yours and mine) and never confront or overwhelm the person.
- "They won't resist if you don't insist" (Peter Wiebe, 2007) – meet the elder where he or she is at – abilities can change from hour to hour.
- Remember that in dementia, all behavior has meaning and purpose.

#### ✓ "C" COMMUNICATION TIPS

- Speak slowly and clearly – allow time for the person to answer or act.
- Try not to start sentences with "Don't ..." or "No, ...".
- Never argue with, tease, criticize or scold a person with dementia and use humour cautiously. Distract rather than confront.
- Ask one question at a time and avoid questions that rely on short term memory.
- Use short, simple sentences, speak in concrete terms and avoid use of pronouns as abilities related to abstract thinking may be lost.
- Talk about things that provoke positive memories.
- Remember that needs are communicated through behavior when words are lost.
- Most important of all, focus on creating "Moments of Joy" (J. Brackey, 2007).



## Appendix F

**APPENDIX F: Delirium**

1. A link to a national guideline on assessment and management of delirium: [www.ccsmh.ca](http://www.ccsmh.ca)
2. Vancouver Island Health Authority's delirium tools including the CAM, a chart which helps to differentiate delirium from dementia from depression, and a description of the VIHA Delirium Watch Program: [www.viha.ca/mhas/resources/delirium/tools.htm](http://www.viha.ca/mhas/resources/delirium/tools.htm)
3. This site includes an interactive case about delirium adapted by Dr. Peter Chan from a Care for Elders Interprofessional Educational Module: [www.careforelders.ca](http://www.careforelders.ca)
4. *Delirium* by Maureen Shaw, CNS which follows.

**DELIRIUM**

by Maureen Shaw (April 2011)

Delirium (acute confusional state) is a **very** common and potentially avoidable cognitive impairment in older adults. Considered to be a geriatric emergency, delirium is a transient and non-specific organic syndrome characterized by a disturbance in attention, consciousness, cognition, memory, and orientation. Perceptual disturbances can be accompanied by suspiciousness which further contributes to emotional and behavioural manifestations. Due to its variable course and subtle symptoms, delirium is often unrecognized and misdiagnosed. Untreated, delirium leads to functional and cognitive decline, increased hospital stay, long-term care placement, and early death.

**Is It Delirium or Dementia or Both?**

Because of its effect on cognition, delirium can be difficult to distinguish from dementia and depression. However, the pathophysiology and prognosis of dementia and delirium are very different diagnoses. Delirium is characterized by a rapid onset and fluctuating symptoms over 24 hours time frame with symptoms often worsening at night. The failure to recognize the etiology compounds the prognosis and outcomes associated with delirium.

**Clinical Presentation**

Commonly referred to as features, symptoms of delirium are unique to each patient and may include disturbances in attention span, thought processing, and LOC. In addition, the patient



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may have impaired memory, perception, orientation, sleep patterns (frequently reversed), speech, affect, psychomotor activity (increased or decreased) and function.

**Hallmarks of Delirium**

**Inattention:** Essential to maintain safety, attentiveness is the ability to concentrate for as long as needed to process information or complete a task. An abnormally short and limited attention span is a cardinal symptom/feature of delirium. The loss of attentiveness with an inability to focus, shift and sustain attention is a hallmark of delirium.

**Fluctuating Level of Consciousness:** Level of consciousness (LOC) almost always fluctuates, making a retrospective observation of cognition over a 24-hour period essential, especially during the change from day to night or twilight. The fluctuating course of the diagnosis of delirium makes identification and diagnosis more challenging.

**Incidence**

There is wide variation in the reported incidence of delirium in acute care settings due to differences in populations and diagnostic criteria. Currently, delirium occurs in 25-60% of older hospitalized patients, with associated mortality rates of 25-33%. Up to 85% of terminally ill patients may experience delirium before they die. Delirium is the second most common psychiatric diagnosis in patients with advanced cancer and should be considered a palliative care emergency.

**Etiology**

Delirium is a multifactorial syndrome with a complex etiology that involves changes in cerebral metabolism and neurotransmission. The main causes of delirium include:

- metabolic disturbances
- nutritional deficiencies
- reduced renal function
- hyper/hypoglycemia
- hypoxia
- untreated pain
- fluid disturbance
  - dehydration
  - electrolyte imbalance
- infection
- medications

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### Risk Factors for Delirium

Delirium arises from a combination of individual risk factors and the etiology and severity of the acute illness or event. Risk factors fall into 3 general categories:

Patient/Environment	Medical/Health	Medications of Risk
<ul style="list-style-type: none"> <li>▪ Age &gt;75</li> <li>▪ Cognitive impairment</li> <li>▪ Prior delirium, depression</li> <li>▪ Withdrawal (ETOH &amp; drugs)</li> <li>▪ Sleep disturbance</li> <li>▪ Vision/hearing loss</li> <li>▪ Immobility</li> <li>▪ Restraints</li> <li>▪ Unplanned admission</li> <li>▪ Frequent admissions in last 2 years</li> <li>▪ Frequent relocations</li> <li>▪ Sensory overload/stress</li> </ul>	<ul style="list-style-type: none"> <li>▪ Acute &amp; chronic illnesses</li> <li>▪ Surgery &amp; anaesthesia</li> <li>▪ Noncardiac thoracic</li> <li>▪ Aortic aneurysm</li> <li>▪ Fractures</li> <li>▪ Electrolyte imbalance</li> <li>▪ Hypoxia</li> <li>▪ Fever</li> <li>▪ Unrelieved pain</li> <li>▪ Hypotension</li> <li>▪ Infection (UTI/chest)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Multiple medications or polypharmacy</li> <li>▪ Benzodiazepines</li> <li>▪ Lorazepam</li> <li>▪ Diazepam</li> <li>▪ Analgesics</li> <li>▪ Meperidine</li> <li>▪ Morphine</li> <li>▪ Antidepressants</li> <li>▪ Neuroleptics</li> <li>▪ Cardiac Drugs</li> <li>▪ Antiemetics</li> </ul>

### Types of Delirium

Three clinical subtypes of delirium have been identified:

Subtype	Symptoms/Features
<p>1. <b>Hyperalert, hyperactive (15%)</b></p> <ul style="list-style-type: none"> <li>▪ Increased psychomotor activity</li> </ul>	<ul style="list-style-type: none"> <li>▪ Agitation, restlessness, aggression, irritability</li> <li>▪ Rapid speech, calling out</li> <li>▪ Disrupt medical treatments</li> <li>▪ Easier to identify</li> </ul>
<p>2. <b>Hypoalert, hypoactive (19%)</b></p> <ul style="list-style-type: none"> <li>▪ Decreased psychomotor activity</li> </ul>	<ul style="list-style-type: none"> <li>▪ Decreased alertness, apathy, lethargy</li> <li>▪ Slow speech</li> <li>▪ Overlooked or misdiagnosed as depressed</li> </ul>
<p>3. <b>Mixed (52%)</b></p> <ul style="list-style-type: none"> <li>▪ Shift between hyper- and hypoactive states</li> </ul>	<ul style="list-style-type: none"> <li>▪ Fluctuation between agitation and apathy.</li> </ul>

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## Appendix G

### APPENDIX G: 48/5

by Dr. J. McElhanev, Dr. Martha Donnelly, and David Thompson

#### Problem Statement

In Canada, a large percent of acute care hospital beds are currently occupied by seniors (persons aged 65 years and older) on any particular day. Moreover, one third of older persons admitted to acute care will be discharged at a significantly reduced level of functional ability and most will never recover to their previous level of independence (Covinsky, Eng et al. 2003). While hospitalization offers older patients the benefits of high-level care during episodes of acute illness, it also exposes them to the risks of iatrogenic illness (i.e. adverse events) and functional decline. Without swift and appropriate targeted clinical interventions, the general functional ability of older patients can decline rapidly. The repercussions can be costly: for hospitals, the cost of avoidable complications associated with hospital care; prolonged lengths of stay; and access and flow issues in the system due to bed shortages; for patients, recurrent admissions, premature admission to residential care homes, and permanent loss of independence and diminished quality of life.

#### Dorothy's Story: Putting a Face to the Problem

An 86 year old woman, Dorothy, is brought to the emergency department after a fall in the assisted living facility into which she moved one month earlier due to increasing physical limitations and the inability to maintain a large home. She spends 10 hours on a stretcher in the emergency department (ED) with all oral fluids and nutrition withheld until investigations can be completed to rule out a fracture and possible surgery. A catheter is inserted as she is not permitted to move off the stretcher during this time. A very supportive daughter is at her bedside. She denies pain but is given Tylenol #2 in spite of her initial attempts to resist taking the medication. Dorothy stated that she does not take Tylenol. During the course of her stay in the emergency department, she asks her daughter why the various staff members keep asking the same set of questions. Within the first 48 hours of her admission to the emergency department and subsequent admission to hospital, her daughter notes periods of confusion. She also notes that the staff is now behaving as if her mother has dementia. No fracture is identified but the patient's condition continues to deteriorate and the patient eventually dies in hospital seven days later.

Our anecdote is depicted in the video that can be found at the link below. The video, *Dorothy's Story*, includes an interview with her daughter. [http://www.vch.ca/your\\_health/seniors/](http://www.vch.ca/your_health/seniors/)

## The Context

Based on Canadian census data, Canada is undergoing an unprecedented demographic shift: in 2000, 12.5% of the population of British Columbia was aged 65 years and by 2026 it is estimated to increase to 21%; aging is thus at the forefront of the health and social policy agenda. Patients aged 65 and older now account for 37% of inpatient discharges and over 50% of inpatient days (Siu, Spragens et al. 2009).

Despite the high utilization by older adults of the health care system, the care that many frail older adults receive may be ineffective and even harmful because we are unable to assess the risk-benefit of different treatment options. A balance needs to be struck between the level of frailty of seniors and the impact of a particular intervention aimed at providing good outcomes for the patient. A comprehensive American study, using a home care database, suggested that one in three people over the age of 70 was discharged from acute care at a reduced level of functional ability (than at admission), and most never regained their previous level of independence (Covinsky, Newcomer et al. 2003). In addition to catastrophic disability, other potential adverse outcomes of illnesses that arise from hospitalization include mobility issues and cognitive impairment, long term institutionalization and death. The extent to which these adverse outcomes happen to older adults in Canada today and the extent to which they might be mutable are not clear. We believe that both patient and hospital factors are related to the risk of adverse outcomes. In essence, the formal insouciance about hospital care of older adults arises because physical and mental deterioration is seen as inevitable and thus neglected. In fact, older adults have an innate capacity for rehabilitation (Strawbridge, Cohen et al. 1996); at almost any given level of frailty, some improvement remains possible (Mitnitski and Rockwood 2006). Importantly, increases in life expectancy are not necessarily accompanied by increases in disability and disease (Hubbard, Fallah et al. 2009).

At the root of hospitals' inability to recognize and effectively meet older Canadians' health needs, is the general lack of any recognition that a comprehensive assessment, treatment and care framework is essential to maintain function (Palmer 1995). Acute care services focus on the identification and management of a patient's most acute episodic illness (i.e., "one thing wrong at a time"). This is a limited perspective given that it is well known that older adults typically present with multiple, interacting medical and social problems (i.e., "many things wrong, all at once"). Over two thirds of older adults suffer two or more chronic morbidities (Wolff, Starfield et al. 2002), the most common being cardiovascular/respiratory disease and mental illnesses (Marengoni, Winblad et al. 2008). However, most problems of older adults in hospital are not captured by the classic "co-morbidity count." For example, the prevalence of malnutrition among older hospitalized adults is also disproportionately high and often goes undetected (Babineau, Villalon et al. 2008). Delirium, which often has multi-factorial

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etiology (e.g. dehydration, urinary tract infection) affects many hospitalized older adults, either commonly goes unrecognized and unrecorded in usual inventories of disease or is misdiagnosed (e.g. as stroke) (McNicoll, Pisani et al. 2003).

Without swift and well-integrated, evidence-based and interdisciplinary interventions, the health of older patients can decline rapidly in hospital. Specifically, prolonged periods of inactivity and bed rest during hospitalization can generally cause irreversible loss of function and mobility specifically (Callen, Mahoney et al. 2004). Between 44% and 70% of older adults have been documented as experiencing their initial episode of delirium during a hospital stay (McNicoll, Pisani et al. 2003) from which, many never recover (Bhat and Rockwood 2007; Cole, Ciampi et al. 2009). Indwelling urinary catheters are frequently used in hospitalized older adults without specific medical indication (Holroyd-Leduc, Sen et al. 2007), and can give rise to urinary tract infections resulting in delirium, and urethral trauma, perforation and fistulae (Hart 2008; Wald, Ma et al. 2008). Poor continuity of care, flawed communication and lack of feedback mechanisms in the hospital context have led to significant medication-related adverse events among older adults; in Vancouver, 46% of older adults in hospital missed their regular medications, placing them at risk for moderate/severe discomfort and health deterioration (Cornish, Knowles et al. 2005). While not formally studied, there is a concern that frail older adults commonly receive all of their hospital meals in bed, contributing to the risk of poor nutritional intake, aspiration and immobility – all leading to general functional decline. In short, several hospital-related factors may increase the risk of an adverse event in hospital among frail older adults.

Five key areas for care improvement have been identified including medication reconciliation; delirium; mobility; catheter use and nutrition/hydration. These key areas needing improvement are the main factors contributing to the decrease in level of function that frequently occurs over the course of a hospital admission, increasing the complexity of the transition back to the community (Dedhia, Kravet et al. 2009; DeJonge, Taler et al. 2009).

For hospitals, the repercussions of the status quo can be costly, as previously mentioned, resulting in the further need for complex medical services, increased lengths of stay and recurrent admissions (Reuben 2000). For the patient, an increase in disability affects quality of life and may require premature admission to residential care homes. Staff may become demoralized and frustrated when they see that the longer the patient stays in hospital, the more care the patient requires and the weaker they become. Taxpayers are faced with the burden of providing resources for older patients requiring more services in their home, increased demands for funding for residential care homes, home support services and longer waits in the emergency departments as beds are occupied by seniors who are medically stable but unable to manage at home due to the functional decline induced by hospitalization.



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Over the last two decades, growing evidence has emerged for specific 'elder friendly' (in other words, care that is appropriate and sensible) interventions and models of care in single care locations of a hospital, such as the emergency department (McCusker, Cole et al. 2001; Mion, Palmer et al. 2003), and inpatient settings (Landefeld, Palmer et al. 1995; Naylor, Brooten et al. 1999; Inouye, Kishi et al. 2000). These studies have demonstrated clinical, economic and social benefits such as reductions in both lengths of stay and readmissions as well as inappropriate resource utilization. Even so, many successful interventions have yet to be widely accepted and adopted across the majority of acute care facilities in spite of sound evidence to support their development and broad implementation (Rockwood 2006). Given financial and human resource constraints, effective interventions from clinical studies cannot be cost-effectively implemented into routine hospital care (Reuben 2000). To date, there have been no clear solutions identified that address these problems.

The implementation of new acute care models directed at the care of older adults is largely influenced by evidence of effectiveness, organizational culture and structure, and financial costs and benefits (Bradley, Schlesinger et al. 2004). However, program effectiveness is often too poorly described in the literature to allow potential adopters to understand which components of a given program are necessary. Importantly, the implementation of new models of care is especially challenging to current acute care practices because it requires the commitment of teams of highly qualified personnel, and senior management across organizations and within organizations (Siu, Spragens et al. 2009). This calls for the adoption of a model of transformational change as opposed to incremental change that has failed in previous attempts to implement care guidelines. The studies published to date on strategies to improve acute care for older patients including Nurses Improving Care for Healthsystem Elders (NICHE) (Mezey, Kobayashi et al. 2004) and the Hospital Elder Life Program (HELP) to reduce functional decline (Bradley, Webster et al. 2006) and rates of delirium (Inouye, Baker et al. 2006) have yet to report any changes in functional outcomes or demonstrate how these interventions could be implemented in the absence of a strong volunteer program.

## The Intervention

"48/5" means that within 48 hours of hospital admission, care plans will be developed to address the needs of older patients in five key areas including: delirium/cognition, medications, functional mobility, nutrition/hydration, and bladder/bowel. For this purpose, interprofessional practice statements have been developed as key strategies to ensure high quality care to seniors in hospital settings and for achieving the goals of the intervention. As a person-centered approach, 48/5 will also include strategies for home care and family caregivers to help prevent hospital admissions, where possible, and facilitate the transitions through acute care when hospital admission is necessary to minimize the risk of disability in older patients. This strategy

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will improve health outcomes for seniors and increase the system capacity to provide care for everyone.

We will take a *bundled* approach to implementation whereby we identify a particular setting, process of care to be changed and the staff's readiness for implementation. While the interprofessional team will be supported in implementing practice statements in each of the five key areas, staff will be asked to focus on functional mobility. A key strategy underlying this approach is that mobility (measured by the Heirarchical Assessment of Balance and Mobility – HABAM) (Rockwood, Rockwood et al. 2008) is to be viewed as the fifth vital sign, in addition to blood pressure, pulse, respiratory rate and temperature. Some would identify pain as the fifth vital sign; we would submit that pain is a symptom and that changes in mobility would be a much more appropriate sign of pain control. Further, understanding changes in mobility provides the care team with an overall assessment of the patient's response to treatment. As noted above, reduced mobility, or lack of support for mobilization, is often the catalyst that results in the functional decline of seniors in acute care settings. Improving functional mobility can be achieved by the patient going to the toilet rather than using a bedside commode or by walking down the hallway to the dining room. Through implementation, we will demonstrate that a focus on changes in mobility will immediately trigger an assessment of medications, nutrition/hydration, bowel/bladder, and the presence of delirium by a member of the interprofessional care team.

## Conclusion

To say that it is timely to focus on the implementation of interventions for older patients in the acute care setting is a huge understatement due to the increasing number of seniors in the general population and their utilization rates of hospital-based services. If seniors continue to experience a loss of independence at the current rate, it will be difficult for our health and social care system to recover from the increased burden of illness and the concomitant care needs of older Canadians and it will be very, and unnecessarily, costly. While over the next 50 years the baby boomer generation will die out, the next generation may likely be healthier and live longer than current elders, consequently the problem will not completely go away. On the eve of this demographic shift, the appropriateness and quality of hospital care for older adults remains grossly inadequate. We cannot accept that loss of independence following acute care is just a part of normal aging. The common cascade of both physical and cognitive decline is frequently preventable and is therefore unacceptable. However, an extensively researched strategy will be necessary in order to provide convincing evidence to challenge deeply ingrained traditional ways of providing poor and inappropriate care (Rockwood 2006). At no other point in the history of Canada has there ever been such an urgent demographic imperative to step up to the challenge of improving acute care for older adults.

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## Appendix H

### APPENDIX H: Tools

- [www.hospitalmedicine.org/geriresource/toolbox/resources](http://www.hospitalmedicine.org/geriresource/toolbox/resources)  
This includes mental status, functional assessment and mobility assessment tests.
- [www.caretransitions.org](http://www.caretransitions.org)  
This is Eric Coleman's work
- [www.ntocc.org/Home/HealthCareProfessionals/www\\_HCP\\_Tools](http://www.ntocc.org/Home/HealthCareProfessionals/www_HCP_Tools)  
NTOCC has created information to help health care professionals understand how poor transitions impact care delivery and how you can help improve transitions in your facility.
- CSHA Clinical Frailty Scale: "A global clinical measure of fitness and frailty in elderly people" from CMAJ 30-Aug-05; 173(5), pp 489-495  
Very fit – robust, active, energetic, well-motivated fit: These people commonly exercise regularly and are in the most fit group for their age.
  1. WELL – without active disease, but less fit than people in category one.
  2. WELL – with treated co-morbid disease – disease symptoms are well controlled compared to those in category four.
  3. APPARENTLY VULNERABLE – although not frankly dependent, these people commonly complain of being "slowed up" or have disease symptoms.
  4. MILDLY FRAIL – with limited dependence on others for instrumental activities of daily living.
  5. MODERATELY FRAIL – help needed with both instrumental and non-instrumental activities of daily living.
  6. SEVERELY FRAIL – completely dependent on others for the activities of daily living, or terminally ill.

## Appendix I

### APPENDIX I: Behaviour Management

- A. Behavioural Log by Maureen Shaw
- B. Sleep and Agitation Record
- C. Fraser Health – Look At Me
- D. Extra reading, a good reference:
  - Serge Gauthier, Jeffrey Cummings, Clive Ballard, Henry Brodaty, George Grossberg, Philippe Robert and Constantine Lyketsos, Management of Behavioural Problems in Alzheimer's Disease, *International Psychogeriatrics*, May 2010, 346-372.

Appendix I

**A: Behaviour Assessment Log**

**INSTRUCTIONS:** Please check (✓) the time when and location where each behaviour(s) occurred.

<b>TYPE OF VERBAL &amp;/OR DISRUPTIVE BEHAVIOUR</b>	DATE									
	TIME									
	Calling Out									
	Crying									
	Screaming									
	Banging									
	Verbal Abuse									
	Swearing									
	Trying to Leave									
Other (state)										
<b>TYPE OF AGGRESSIVE &amp;/OR RESISTIVE BEHAVIOUR</b>	Striking									
	Punching									
	Grabbing									
	Pushing Away									
	Slapping									
	Biting									
	Resists care									
	Other (state)									



Appendix I

<b>PERSON(S) AFFECTED</b>	Staff									
	Other Patient									
	Visitor/Family									
<b>LOCATION</b>	(See Key)									
<b>RELATED FACTORS</b>	Personal Care									
	Transfers									
	Taking VS, Tests									
	When Alone									
	With Others									
	Other (state)									
<b>INITIALS</b>										

**Location Key:** PR: Patient's Room BR: Bathroom H: Hallway O: Other (state)

M. Shaw, 2010R

Appendix I

**B: Ace Units: Sleep and Agitation Record**

PCIS Label

INSTRUCTIONS: Each hour, check (✓) the appropriate box.

TIME	Date:	Agitated	Calm	Asleep	Date:	Agitated	Calm	Asleep	Date:	Agitated	Calm	Asleep	Date:	Agitated	Calm	Asleep
06																
05																
04																
03																
02																
01																
24																
23																
22																
21																
20																
19																
18																
17																
16																
15																
14																
13																
12																
11																
10																
09																
08																
07																

C: Ace Units: Look at Me



**LOOK at Me**

HELP ME CONNECT WITH MY FAMILY

<p>REDIRECT ME</p> <p>DO A PAIN ASSESSMENT</p> <p>ASSIST ME TO THE TOILET</p> <p>ENCOURAGE ME</p> <p>SPEAK MORE CLEARLY</p> <p>ASK ME WHAT I NEED</p> <p>WRITE A CARE PLAN JUST FOR ME</p> <p>CHECK TO SEE IF MY SLEEP NEEDS ARE MET</p> <p>REDUCE PHYSICAL IRRITATIONS</p> <p>USE A BEHAVIOUR PATTERN RECORD TO IDENTIFY A PATTERN TO MY BEHAVIOUR</p>	<p>CONSIDER I MIGHT BE DEPRESSED</p> <p>TAPPING</p> <p>WANDERING</p> <p>CALLING OUT</p> <p>FALLING</p> <p>GRABBING</p> <p>WITHDRAWING</p> <p>HITTING</p> <p>PACING</p> <p>INVADING OTHERS' SPACE</p>	<p>RESPECT ME AND TREAT ME AS AN UNIQUE INDIVIDUAL</p> <p>BANGING ON THE TABLE</p> <p>SEXUALLY EXPRESSIVE BEHAVIOUR</p> <p>TIED</p> <p>OVERWHELMED</p> <p>IN PAIN</p> <p>BORED</p> <p>HUNGRY</p> <p>CONFUSED</p> <p>IRRITATED</p> <p>ITCHY</p> <p>THIRSTY</p> <p>SINGING</p> <p>RESISTING CARE</p> <p>WHAT AM I DOING</p> <p>KNOW MY TRIGGERS FOR AGITATION</p>	<p>REPEAT ME AS AN UNIQUE INDIVIDUAL</p> <p>BANGING ON THE TABLE</p> <p>SEXUALLY EXPRESSIVE BEHAVIOUR</p> <p>TIED</p> <p>OVERWHELMED</p> <p>IN PAIN</p> <p>BORED</p> <p>HUNGRY</p> <p>CONFUSED</p> <p>IRRITATED</p> <p>ITCHY</p> <p>THIRSTY</p> <p>SINGING</p> <p>RESISTING CARE</p> <p>WHAT AM I DOING</p> <p>KNOW MY TRIGGERS FOR AGITATION</p>	<p>REPEAT MYSELF</p> <p>NOT SLEEPING</p> <p>CRYING</p> <p>HOARDING</p> <p>SCREAMING</p> <p>BITING</p> <p>SHOUTING</p> <p>FIDGETING</p> <p>TEST FOR A UTI</p> <p>WHAT YOU CAN DO FOR ME</p>	<p>ASSESS ME FOR DELIRIUM</p> <p>PROMOTE A CALM, SOOTHING, SAFE ENVIRONMENT</p> <p>HELP ME FEEL NEEDED</p> <p>ASK ME ABOUT MYSELF</p> <p>GIVE ME AN ACTIVITY TO DO THAT I WILL ENJOY</p> <p>VALIDATE MY FEELINGS</p> <p>REVIEW MY MEDICATIONS</p> <p>SEEK SUPPORT FROM OTHER TEAM MEMBERS</p>
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**WHAT I FEEL**

LONELY, VULNERABLE, SCARED, SAD, FEARFUL, LOST, FRUSTRATED, ANGRY

Adapted version (2011). Fraser Health Residential Care and Assisted Living

## Appendix J

### APPENDIX J: Other Resources


1. Emergency Older Adult Assessment VCH.
2. The HEART Program helping elders adapt in residential transitions, My Daily Care Routine. Updated GPEP Model
3. [www.acgnn.ca](http://www.acgnn.ca): In this website there is educational material on delirium, falls, the geriatric emergency nurse network, incontinence medications, psychosis, and wandering and elopement.
4. [www.alzheimerbc.org](http://www.alzheimerbc.org): Click "We Can Help" and use "Resources for Health Care Providers" from the menu. This site is particularly helpful for education for health care providers.
5. [www.niceprogram.org](http://www.niceprogram.org): NICE is a leading organization designed to help health care professionals in hospitals improve the care in older adults. It offers assessment tools, education benchmarking methodologies and platform connecting with peers and experts.
6. [www.hospitalelderlifeprogram.org](http://www.hospitalelderlifeprogram.org): This site called HELP is an approach to improving the hospital care for older adults.
7. Avoiding Restraints in Older Adults with Dementia, Cotter and Evans, AGN, March 2008, Vol 108:3, 45-46. This is part of the "Try This" series of educational materials by the John A. Hartford Institute for Geriatric Nursing and the Alzheimer's Association. This material may be downloaded from [www.ConsultGeriRN.org](http://www.ConsultGeriRN.org)
8. [www.InteriorHealth.ca](http://www.InteriorHealth.ca): The Interior Health Website includes the Interior Health Phased Pathway for Dementia, which is an excellent resource for all levels of care.



Appendix K

<p><b>MOBILITY &amp; ADL AIDES:</b></p> <p><input type="checkbox"/> Walker <input type="checkbox"/> Cane(s) <input type="checkbox"/> Crutches <input type="checkbox"/> Wheelchair <input type="checkbox"/> Scooter</p> <p><input type="checkbox"/> Toilet Seat/Commode <input type="checkbox"/> Bathing Aides <input type="checkbox"/> Grab Bars <input type="checkbox"/> Other: _____</p>	<p><b>DISCHARGE OTHER:</b></p> <p><input type="checkbox"/> Equipment Arranged <input type="checkbox"/> Transportation Arranged <input type="checkbox"/> Prescriptions Arranged <input type="checkbox"/> Patient/Family Education <input type="checkbox"/> Other: _____</p>
<p><b>LIVING ARRANGEMENTS:</b></p> <p><input type="checkbox"/> Alone <input type="checkbox"/> Spouse <input type="checkbox"/> Adult Children <input type="checkbox"/> Grandchildren <input type="checkbox"/> Pets <input type="checkbox"/> Other _____</p> <p><b>ACCOMMODATION:</b></p> <p><input type="checkbox"/> Apartment <input type="checkbox"/> House <input type="checkbox"/> Facility: _____</p> <p><b>DESCRIPTION:</b></p> <p><input type="checkbox"/> 1, 2, or 3 Level(s) <input type="checkbox"/> Stairs to Home Entrance <input type="checkbox"/> Elevator <input type="checkbox"/> Stairs to Bedroom/Toilet <input type="checkbox"/> Assisted Living <input type="checkbox"/> Intermediate <input type="checkbox"/> Extended <input type="checkbox"/> Discharge Concerns: _____</p>	<p><b>DISCHARGE PLANNING:</b></p> <p><b>ED REFERRALS:</b></p> <p><input type="checkbox"/> Case Manager <input type="checkbox"/> Social Worker <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Physician (Geriatrics, Family Doctor, Palliative Care) <input type="checkbox"/> Geriatric ONS <input type="checkbox"/> Other: _____</p> <p><b>DISCHARGE REFERRALS:</b></p> <p><input type="checkbox"/> Home Care/Hospice <input type="checkbox"/> Health Service Agency <input type="checkbox"/> Falls Clinic <input type="checkbox"/> Geriatric Assessment Clinic <input type="checkbox"/> Geriatric Day Program <input type="checkbox"/> Family Physician <input type="checkbox"/> Respite/Caregiver Support Group <input type="checkbox"/> Mental Health/GPOT <input type="checkbox"/> Other: _____</p>
<p><b>INSTRUMENTAL ADL (IADL) NEEDS HELP WITH:</b></p> <p><input type="checkbox"/> Banking <input type="checkbox"/> Shopping <input type="checkbox"/> Cleaning <input type="checkbox"/> Laundry <input type="checkbox"/> PCA <input type="checkbox"/> Meal Preparation <input type="checkbox"/> Yard Work <input type="checkbox"/> Public Transit <input type="checkbox"/> Transportation <input type="checkbox"/> Filling Prescriptions</p>	<p><b>DISCHARGE PLANNING:</b></p> <p><b>DISCHARGE REFERRALS:</b></p> <p><input type="checkbox"/> Home Care/Hospice <input type="checkbox"/> Health Service Agency <input type="checkbox"/> Falls Clinic <input type="checkbox"/> Geriatric Assessment Clinic <input type="checkbox"/> Geriatric Day Program <input type="checkbox"/> Family Physician <input type="checkbox"/> Respite/Caregiver Support Group <input type="checkbox"/> Mental Health/GPOT <input type="checkbox"/> Other: _____</p>
<p><b>GERIATRIC ASSESSMENT:</b></p> <p><input type="checkbox"/> Mobility: _____</p> <p><input type="checkbox"/> Fall Risk: Indoor fall in last 6 months? <input type="checkbox"/> Yes <input type="checkbox"/> No _____</p> <p><input type="checkbox"/> ADL: <input type="checkbox"/> Bathing/Dressing <input type="checkbox"/> Eating <input type="checkbox"/> Toileting _____</p> <p><input type="checkbox"/> Hobbies/Activities: _____</p> <p><input type="checkbox"/> Bladder/Bowel: <input type="checkbox"/> Incontinent of Urine/Stool <input type="checkbox"/> Diarrhea/Constipation _____</p> <p><input type="checkbox"/> Assistive Devices: <input type="checkbox"/> Hearing Aid(s) <input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Glasses <input type="checkbox"/> Dentures _____</p> <p><input type="checkbox"/> Language: <input type="checkbox"/> English <input type="checkbox"/> Aphasia <input type="checkbox"/> Fluent &amp; coherent speech <input type="checkbox"/> Other: _____</p> <p><input type="checkbox"/> Sleep: <input type="checkbox"/> Disturbed Sleep <input type="checkbox"/> Daytime Naps <input type="checkbox"/> Daytime Fatigue <input type="checkbox"/> Sleep Apnea/Snoring <input type="checkbox"/> Unusual Nighttime Behavior (restless, agitated, paranoid, hallucinations, vivid dreams) <input type="checkbox"/> Other: _____</p> <p><input type="checkbox"/> Behaviors: <input type="checkbox"/> Calm/Cooperative <input type="checkbox"/> Fearful <input type="checkbox"/> Wandering <input type="checkbox"/> Impulsive <input type="checkbox"/> Restless/Agitated <input type="checkbox"/> Uncooperative <input type="checkbox"/> Physically aggressive <input type="checkbox"/> Verbally aggressive <input type="checkbox"/> Mechanically restraint needed <input type="checkbox"/> Other: _____</p> <p><input type="checkbox"/> Cognition: <input type="checkbox"/> Unable to assess <input type="checkbox"/> Deferred <input type="checkbox"/> Level of consciousness: <input type="checkbox"/> Alert <input type="checkbox"/> Hypervigilant <input type="checkbox"/> Lethargic <input type="checkbox"/> Obtunded <input type="checkbox"/> Comatose</p> <p><input type="checkbox"/> Short-term memory: <input type="checkbox"/> Intact <input type="checkbox"/> Impaired</p> <p><input type="checkbox"/> Long-term memory: <input type="checkbox"/> Intact <input type="checkbox"/> Impaired</p> <p><input type="checkbox"/> Insight &amp; judgment: <input type="checkbox"/> Intact <input type="checkbox"/> Impaired</p> <p><input type="checkbox"/> Concentration/attention: <input type="checkbox"/> Intact <input type="checkbox"/> Impaired</p> <p><input type="checkbox"/> Thought content: <input type="checkbox"/> Intact <input type="checkbox"/> Impaired</p> <p><input type="checkbox"/> Other (ie hallucinations, orientation): _____</p> <p><b>Delirium Screen (CAM)</b></p> <p>Does the patient have:</p> <p>1. Acute onset &amp; fluctuating course</p> <p>2. Inattention</p> <p>3. Disorganized thinking</p> <p>4. Altered level of consciousness</p> <p><b>Key:</b> Delirium present if features #1 &amp; 2 present plus 3 and/or 4</p> <p><b>Delirium Screen (CAM):</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative</p> <p>If positive, initiate Delirium PROS</p> <p><input type="checkbox"/> Mood: <input type="checkbox"/> Appropriate to Situation <input type="checkbox"/> Sad <input type="checkbox"/> Anxious <input type="checkbox"/> Irritable <input type="checkbox"/> Elevated <input type="checkbox"/> Labile <input type="checkbox"/> Other: _____</p>	<p><b>OUTCOME:</b> <input type="checkbox"/> Admitted <input type="checkbox"/> Discharged Home/Facility <input type="checkbox"/> Family/Facility Aware of Plan</p> <p><b>CARE PLAN ISSUES</b> <b>RECOMMENDATIONS</b> <b>ACTIONS TAKEN</b></p> <p><b>Medical/Health</b></p> <p><b>Mobility/Function</b></p> <p><b>Cognition</b></p> <p><b>Mood</b></p> <p><b>Social</b></p> <p><b>Other</b></p> <p><b>Date:</b> _____ <b>Time:</b> _____ <b>Signature:</b> _____</p> <p><b>PROGRESS NOTES:</b></p>

# APPENDIX L: Heart Program

 <p><b>HEART PROGRAM</b> Helping Elders Adapt In Residential Transitions Phone: 604-708-5344</p>	
<p><b>MY DAILY CARE ROUTINE</b></p>	
Client Initials	Client PHN #
Client PID # (Internal Use Only)	
Date Completed (dd/mm/yyyy)	
Completed By	
<p><b>MY THINKING CHALLENGES AND ABILITIES:</b></p> <p>? Dementia, which type</p> <p>Does this cause decreased problem-solving, aphasia, frustration, feelings of being overwhelmed</p> <p>? disinhibitions</p>	
<p><b>MY TRANSFER &amp; MOBILITY:</b></p> <p>? independent</p> <p>? walking aids/walker/ wheelchair/pivot transfer</p> <p>? weight bearing</p> <p>? any falls</p> <p>? up @ night</p> <p>? elopement risk/wanderer</p> <p>Does he/she need redirection/? Intrusive into other's rooms/space</p>	
<p><b>HOW I LIKE TO COMMUNICATE:</b></p> <p>? speech – word salad, aphasia</p> <p>Languages spoken, non-verbals</p> <p>Pictures @ bedside, cue cards, simple phrases from caregivers</p> <p>? hearing impaired</p>	
<p><b>PERSONAL AIDE DEVICES I NEED:</b></p> <p>? hearing aids</p> <p>Dentures</p> <p>Walker</p> <p>Pocket talker</p> <p>Eating utensils</p> <p>Glasses</p> <p>Prosthetic eye/limb</p>	
<p><b>MY DRESSING HABITS/MY PERSONAL HYGIENE NEEDS (INCLUDING ORAL HEALTH):</b></p> <p>? 1-2 ppl for care</p> <p>How are they with pericare?</p> <p>Need to go quickly or slow with lots of direction??</p> <p>?simple phrases</p> <p>?brushes own teeth- cues- dentures</p> <p>AM or PM better for care</p> <p>Dresses self/ helps/ total assistance</p> <p>VHCA</p> <p>Vancouver Community Mental Health Service</p> <p>HEART 21 C: 13/11/2008</p>	
<p><b>MY DINING/DIET ROUTINE:</b></p> <p>Diet texture</p> <p>How much assistance is needed/ cut up/ total feed</p> <p>Food/ drink likes and dislikes</p> <p>Snacks/ fluids</p> <p>Sits alone or with others</p> <p>Eats off other's trays?</p> <p>Finger foods</p> <p>? hoards food to room</p>	

## Appendix M

**APPENDIX M: Caregivers' Quotes About  
Emergency Departments**

"My husband collapsed and was taken to hospital by ambulance, and the Fire Department and the paramedics were absolutely fantastic and wonderful and understood everything. We got to Emerg and there was a great deal of slamming on of the brakes. The paramedics didn't leave us until somebody came over to take a history, which I really appreciated. They ordered CT Scans. My husband was in the hallway for eight hours in Emerg. In that time we asked just twice for him to go to the bathroom. He was groggy. He was unable to walk. He wasn't communicating very well. The first time they took him into an empty room and I guess there was a chair or something and they helped him. However, it took over half an hour before anyone came to help. The second time it happened it was a long wait. He was getting agitated when my friend went up to a nurse to ask if we could take him into the empty room and they said we had to wait. They tried to stop us, but we said you couldn't stop somebody who wanted to have their dignity and go to the bathroom, especially when they were stuck in a hallway. It was terrible. There was very little care in Emerg. Nobody came to take his temperature or blood pressure or ask how he was doing. We were just waiting and waiting and not knowing. Eventually after the difficulty with going to the bathroom he got very violent because they were telling him what to do and he doesn't respond too well to that and they had to force him and tie him down. The doctor just before that had talked to me and said that he could be released and my friend, who was behind the door, was violently shaking her head at me because she knew we couldn't cope at home. So the doctor finally said, "Well I guess we should admit him." He was put into a special acute area in the Emergency to be kept there until the next afternoon when he could be admitted to an acute care ward. In the acute care part of the Emergency he had much better care. They were much more aware of what was going on and what medications he was on. However, when my daughter went in the next morning, she found her father in chest restraints, naked with no covering and I was appalled because he was a very proud man and there was no dignity at all. Just observing the Emergency I know that there are people who are quite violent and there were policemen there. I wondered if they ever tried to diffuse a situation before the security guards come in and grab people. It's frightening to watch. I wondered if there was any possibility, if there were enough nurses in the Emergency area, to get him out of the hallways. Could he not at least be checked on the hour? We just didn't feel comfortable leaving him because nobody cared. They wouldn't have taken time to try to calm him down or anything. So that's my story."

"They were taking him to be examined out of the waiting room and his wife wanted to come in and they said, "No, you may not go." She said, "Well my husband has Alzheimer's disease." I think this is the third or fourth time they mentioned it. He was agitated and was not going to



## Appendix M

remember and she needed to be with him and they were adamant she could not come with him. He said, "I'm frightened to go without my wife because I don't know if I can remember anything or I can remember to tell you the things I need to tell you." The doctor said, "We know what dementia is and you don't have it." He said, "No I have my bracelet here that says I have Alzheimer's disease." They still wouldn't let his wife go in with him. When we got home he wrote a letter to the Minister of Health, but he was still disturbed about it. He said, "I don't present like a typical person with dementia because I'm quite an early stage, but when I'm sick I'm not at my best and I needed that help."

"They don't know how to listen to what she's actually saying. They don't know how to speak to her and they just have the caregiver insert what's needed. It's like they treat the person with dementia as if they are not there."

"They are in such a hurry that they don't read the body language they are giving off and the body language they are giving back."

"The major problem, when we have to access Emergency, is that there is a basic language barrier. They don't seem to have any idea how to speak to someone who has some kind of mental disability."

"They would always speak to me as if she was not there. "She doesn't understand anyway so there was no point in talking to her" seems to be their attitude."

"My experience was my mother was very, very unhappy. She was strapped to a gurney and I asked a nurse if I could please just walk her because restraining her was what was agitating her and the nurse said no. Another nurse overheard my request and came over immediately and said, "of course you can" and got my mom off the gurney and we walked for three hours because the waits were just horrific in the Emergency. I found it so amazing that one nurse could hear a very clear request that was going to help everybody because my mother was just bellowing, and I was just given a no. I think there should be better training protocols so that when family members provide their time and support, we get to be heard and responded to appropriately."

"I've been in Emerg with three people with dementia and they only ask physical things. They don't seem to see mental health issues as equally as acute physical. I think they really need to triage better to be aware that issues are equally difficult, both physical and psychological. It happened that my husband got through Emerg very quickly, but if he hadn't, I would have had to take him home. I had to qualify what other people said. I really did make sure that they at least gave him eye contact and then I could offer information."

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"A few times people come in with dementia with acute problems and the assumption is made that you're just another old person with dementia. And you know drugs are used and that's the end of it, and ultimately the fate of these few people I am referring to is not good."

"It's very confusing when you're a caregiver to know how does this fit into the system and where is the system? How big is the system? How limited is the system? You just don't really understand and I think there is not a lot of help to explain, so there are a lot of misunderstandings."

"I guess I can only repeat my experience with them misdiagnosing her. It was a terrible experience."

"My mom had vascular dementia but she wasn't acutely affected by it. She was held in the Emergency in the overrun area for 4-5 days without a proper place, really uncomfortable place to sleep and that kind of thing, and a very stressful environment. Ideally, there should have been some provision to help her be more at rest. I appreciate the overflow in Emergency, but I'm sure that has to be something that can be done."

"Staff needs to be educated, including security staff, regarding how to communicate and effectively deal with patients who suffer from a dementia in the Emergency Department, and that includes an approach which would involve the caregiver whenever possible."

"There should be admission protocols designed specifically for people who exhibit symptoms of dementia which would include families as much as possible."

## **APPENDIX N: Health Care Professionals' Quotes About Reasons for Admissions through Emergency Departments**

"Sometimes there is a miscommunication or a lack of communication between the nursing team and the physician, and my personal soap box is that if the physician is serving well in the facility and is on top of it and he and the nurses are working together, most admissions from facility can be avoided and headed off better. So I'm disappointed when patients come to the Emergency Department, especially if there is no communication with attending physician about what the problem is or how the Emergency Department is going to solve the problem. The attending physician must have a clear picture of what is going on and get good information from the nurses so that we can use the Emergency Department effectively and either keep them out of acute care, or if an admission is truly needed, deal with it quickly."

"Often times what's happening is the resident's needs have exceeded the ability of the level of care that they are in to provide, and rather than case management happening proactively and moving, often times it takes a crisis and then you catch up with the patient living in acute care while we figure it out instead of adequate case management at the outset that provides for that increased level of care before we come to a crisis."

"Pay for performance may actually accentuate admissions if the person is not from a facility but is admitted from home into acute care. I want to clear the emergency room faster, but may end up admitting to acute care, not dealing with the issues in the Emergency."

"In residential care there may often be medical crises needing IVs that are beyond the level of abilities of the staff of the facility. Maybe nurse practitioners helping doctors could help, or just making certain that people are assessed at the facility before being sent into Emerg."

## Appendix O

### **APPENDIX O: Health Care Professionals' Quotes About Improved Care in Emergency Departments**

"In larger places, the question would be are there some environments that are better suited to deal with the older person than the major trauma hospitals? Or could one design part of an emergency, you know, just a smaller area for people who need the quieter environment? So some of it would be physical. Some of it would be staffing. I think overall if people had a really good common understanding of dementia itself and why people generally present to the Emergency Room, with good training."

"Just to follow up with that issue on the practical side, around the demented patient who is spending some time in the ED. With our last renovation about five years ago, we added individual cubicles that had previously been curtained, they had glass walls, and what that did was reduce the level of delirium that was induced by the sensory overload for these patients. The second issue that we have found that has been quite helpful, is to promote family presence whenever possible so that these individuals are not left isolated and it helps reassure them; so just again a couple of practical considerations."

"Any structural things that people can do to an environment, keeping the curtains closed, keeping a person unless they need telemetry or something very close in terms of monitoring, keeping them in a quiet area, having family orient them as much as possible, trying to keep the lighting dim at night and bright during the day, all those basic things, which are almost impossible in an Emergency. The biggest risk our demented folks have is over-sedation if they become agitated or disorientated. Emerg staff with support should have alternatives other than sedation and helping them in terms of strategies and trying to mobilize as much support for the nurses as possible; bringing in 1:1 care if required and advocating for that despite financial pressures."

"One of the studies that was done in one of the hospitals showed that increasing clients with dementia that come into the ER Department, getting them up and moving as soon as possible and not tying them down or over-medicating them actually increased the likelihood of them going back to either their home environment wherever that was, or reducing the length of stay. We bring in sitters so that they are not tied to a bed in the ER Department that they can get up and mobilize."

"I was speaking with some of the Emerg docs this morning and they said that they know that either leaving them in Emerg or shipping them to a medical unit is not helpful because the

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atmosphere in both places is often very challenging for those folks and it's almost like they suggested a half-way place where they could get the medical care with a dementia lens. They don't know where that is. They understand there are no resources, but that would be most helpful for the patient and then the rest of the workup could be done. My concern and what I see happening is that people assume that long-term care has the same level of staffing and expertise as the hospital, and I think there are patients that are being discharge back to long-term care with the assumption that they are going to get the support there and they are not. So, whether that is physio or OT or some sort of rehab, the assumption is out there and they have come from that setting and so they should have that in that setting where they are going and it's not happening."

"Part of the education is to have understanding from different parts of the system, for long-term care to understand the pressures in Emerg and Emerg to understand the pressures in long-term care."

"I reiterate the world being what it is, as many resources as possible to avoid hurting these patients while in our department would be helpful, and in my department what we really use is a small array of care aides to just get patients out of bed, to move, to eat, to toilet and to actually do that. The nurses don't have the time or the education or the ability to do this; the physicians don't and you see them decay in front of your eyes. If they are in the Emergency Department for 72 hours, the horse is out of the barn and we've lost it, so I really see there needs to be a recognition that these services are vitally important the moment they walk in the door."

"We do have to understand that we may have increasing numbers of people living at home with maximal supports, living at high levels of risk."

"We need to have something for families who are close to the end of their rope in terms of caregiver burnout for appropriate respite care. "

"I think with the tsunami of the elderly coming, I think we're going to have to look at a better way of dealing with them. They are just going to flood the Emergency otherwise and really people will still be looking at the other emergencies as the priority and the elderly shunted off to the side unless we have an Emergency that is primarily interested in the elderly and primarily has their needs in focus."

"We need to have family physicians have open spaces to that caregivers don't have to wait 2-3 weeks to see patients who are falling apart."

## Appendix O

"We should have units where we can admit patients, not through the Emergency, but straight to the units for short-term assessments and managements to improve their functions. This might be able to be done in respite beds in long-term care facilities."

"Geriatric triage nurses have been quite an improvement. They work collaboratively with all the RN staff in Emerg, they connect with the community and they connect with the nurses on the inpatient units in hospital."

"I find there are still some gaps in trying to get access to resources in the community for the patient to go home. I would like more of a connection between the community and the hospital."

## APPENDIX P: Caregivers' Quotes About Experiences in Acute Care Hospitals

"One problem is that people have to bring their information, like their health cards and keep answering the same questions. It feels like no one is communicating with each other and it just adds stress."

"A big issue is restraints in acute care. And the issue of consent. Is consent actually always sought? It needs to be."

"When she was on the geriatric ward I brought my power of attorney. [It was apparent that many did not understand the difference between a power of attorney and a representation agreement and the fact that power of attorney over finances does not give the relative the authority to act as the decision maker for health. Rather, it is the *Acute Care Consent Act* or a representation agreement.] So there are some things that may be more education through doctors and patients to let us know about this for the future."

"One group of security guards in the medical unit were wonderful. They calmed him down and everything was quiet and they didn't have to restrain him. There was no problem. Another time he was beginning to act up and I was just coming into the room and the security guards were just coming to find me. I went over to him and at that point he grabbed my daughter and he also grabbed me and I wasn't afraid because I knew that if I could get him to hear me I could get him calm, but the security guard came right over and shoved him, told him to release us and he couldn't do that. I just became this spitting bear of a mother, to get that man out of my sight and I just started to talk to my husband and he calmed down right away. He let go of my daughter and he allowed the security guard to put restraints on him. But the security guard made me angry. There is another incident too where a lab person came in and she said she had to put an IV in. We understood that he didn't need an IV and were saying that, and the lab tech became annoyed because she was really busy and she had an order and she wanted to do it. We got it clarified and indeed there was a mistake and no IV was ordered."

"My mother was in hospital for 10 days. I spent a lot of time there during the day. One day she said she was hungry and so I asked the nurse if she'd had breakfast, and she said, "No, she can't have anything, she chokes." I said, "Excuse me, are you telling me that you are just going to let her lie here and starve to death?" She quickly left and came back with water that had been thickened with a thickener and a dish of pudding. I gave her little bits on a spoon. She never choked while I was feeding her. They brought her a tray at noon. I fed her again, very slowly, very small amounts and I found that she didn't choke. I feel that they were just shoving

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food into her mouth. Perhaps were busy and had more than one person they had to deal with and they were just trying to get the food into her and she was choking. But I couldn't believe that they would just let her lie there without having had anything to eat or drink."

"Mom was in hospital but she couldn't open her beverages because she'd had a small stroke, or get a spoon to her mouth without dropping the food. They didn't offer any help so I had to arrange for a group of people that would alternate to help her with meals."

"You basically have to commit to being there and taking care of them and that is almost as if the hospital staff are there for big ticket items at Emergency and anything else falls onto the family. I have no idea what happens to people without a family nearby, but I know that none of my family members go into a hospital without almost 24/7 care being arranged by family members. You have to be there when physicians visit to ask questions and clarify what their instructions are. The nursing staff are usually excellent about that."

"The first place she went was into a hospital. It was called long-term care within the hospital. But where she is now is in a dementia facility and there are only twelve on the unit and they are very good. They know who needs help and spend the time to look after that."

"I think that we as part of the system don't know what to expect and we have to trust the people around us and we don't know what is next. Will he be released or will he go to another ward, or will he be going to a care facility? Which care facility? Do we get a say in it? Will it be a private room or a room with another person? Well what exactly is happening? Is the doctor caring for him a psychiatrist? Who is responsible? I think we need to be told about the system. The health care providers have to be understanding, but they have to give us the information that we need for decision-making."



## APPENDIX Q: Health Care Professionals' Quotes About Suggestions for Improved Care in Acute Care Hospitals

"I sort of went more general but really the admission for somebody is because their illness overwhelms their ability to be cared for at home. So a lot of the time these people come in and they may be, if they did not have dementia and had a more capable caregiver and had more support, they'd be able to go home. But those systems aren't allowing this person to be discharged safely and that's one of the big reasons."

"Okay, the one that I've seen the most is the behavioural stuff. It's like, you know, people are bumping along; they're doing pretty good. They might even have fairly advanced dementia, but when the behavioural stuff comes up, that's often what pushes people over the edge. And then all the other stuff is pretty much the same; you know the client's diseases popping up. From my experience it's mainly been the behaviour stuff and the caregiver is not having the capacity to deal with it and just saying, 'Forget it. I'm done.'"

"And it isn't everything everyone else has said, and especially tying in to the piece with people who have a bit of delirium, something that we've noticed here is what we call 'The Case of the Disappearing Question Mark.' On someone's chart someone will write query dementia, so question mark dementia and then as things get copied over and sometimes the question mark gets missed and then suddenly someone's labelled with the diagnosis of dementia when maybe there wasn't a previous diagnosis. So, sometimes we see things going both ways. Being questioned maybe for having dementia, like we go through the whole history. We talk to the GP, there is no history, so maybe it's the case of the disappearing question mark versus people who are just being mistaken for having dementia, but they are really in a delirium state."

"We don't have a lot of Geriatric Psychiatry Support, nor do we have a lot of geriatricians out here either. So that's another factor that comes into play for us as well."

"The OTs here use the Verbal Reasoning Test. It's a smaller component of one of the larger OT tests, and it's basically a 20-point test that tests for common sense, like if your door was open and there was a burglar and what would you do? What would you do if you see smoke under the door and that kind of stuff? We find that's really handy, especially if people live in a residence where there are other people around. You know if you burn down your own house and there is nobody there, it's not a big deal, but if you live in an apartment building with twenty other people and you burn the place down, we are more concerned about safety."

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*“At hospital- two things tend to get used, you know, sort of more intensive behavioural support needs and those would be the ‘Maureen Shaw Behavioural Assessment Tool’ with Maureen as a CNS at VGH and she kind of took the Cohen Mansfield Agitation Inventory and broke it into a kind of very succinct box strategy rather than this kind of a, b, c, thing that no one will ever fill in. And we really have good support from the nurse in the sub acute units at VGH doing this. And the other one is the ‘24-hour Sleep Awake and Agitation Chart’ that is again very simple and just simply is a tic at a time of the 24-hour day. So, when you’re trying to see where patterns are in the behaviour that can be really helpful.”*

*“The OT contribution is getting more of a background history by going out to the home and seeing the environment; getting an assessment of that. That person, the way they interact with their environment, is very telling if you know thinking processes and coping and functioning processes. And I think in more recent years we’ve really liked using the Assessment of Living Skills, the ALS, the Instrumental Assessment of Living Skills, and the ILS. It covers a lot of different domains and it is very functional from money, to house management, to personal management, to safety, to problem solving. It takes a while to do but we do like that assessment. It breaks it down very categorically what the person’s strengths and deficits are and it helps advise whether we should be pursuing discharge home with added support or if a transition to more supported living in residential care is indicated.”*

*“Well I think things that are within our older adult program are working well and that includes our Geriatric Emergency Nurses, our Seniors Clinic and their continuity of information in the inpatient setting. And then our ACE Unit. We have a 14 bed ACE Unit, so when patients are properly connected to these services I think we do a pretty good job of having people in their routines, getting them settled in the environment, and involving the family in all of their transitions. I think we don’t do a great job when patients are in other places of the hospital or when the Geriatric Emergency Nurses are not involved. We have a Clinical Nurse Specialist who was with us for a while to debrief with complex patients on other wards, and to try to get the team coordinated around these complex patients. That’s no longer the case, so we don’t have an outreach program to other wards, and I think there are a lot of patients that are not being served well because of that. One of the enablers is that the family doctors in the community most often follow their patients in hospital, and I think that makes a big difference in terms of families being heard because the families can meet with the family doctor in the office and get information that way and the family doctor has a good sense of the background. There are a lot of barriers, however. We need to do a lot of work ensuring that the patients who have dementia are properly linked up to us. There are major gaps with the patient care coordinators (PCC’s) on all of the wards sending referrals to us and connecting patients to our program.”*

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“Okay, I think that one of the things that works really well is on our ACE Unit. Everybody gets up to eat meals if they are able to physically, and they’ve got clothes and you know, not too sick, they also get dressed during the day. So, that helps orient them to day and night and socializing during the day and then they also are active as much as possible. We encourage them to walk around the ward and stuff rather than just staying in their room. So I think that’s a really key part in helping people not decondition. That’s one of the big challenges in Acute Care.”

“Well, I think I have two points to make about what is going well in acute care with our demented clients and usually it’s revolving around people who are in acute care typically waiting placement and that can be weeks, if not months in duration, and that is in one of our medical units we’ve been able to shift to essentially an ALC placement unit where we move these people into the unit. Their day-to-day routines are normalized. It’s no longer acute care where you stay in your hospital gown. We expect them to get up and get dressed for the day and get out of their beds, and I think that’s really good, because people when they sit for long periods of time in acute care can very quickly deteriorate when the expectation is that they essentially stay in their beds and wait their turn.”

“At one point we actually had a unit where most of the folks with dementia were cared for, and when that happened the care was much smoother and we actually had a body of expertise. Unfortunately, with changes in the hospital, that has gone by the wayside, and I must say that I don’t actually think the care is as good as it once was.”

“People who are waiting in hospital for placement because it is already deemed that they are unable to have a further trial at home, can go to our rehab unit and there is some expertise with the nurses and rehab assistants and OT’s and PT’s to deal with some of the dementia issues. This is a rehab unit for all ages, but it has a designated area for patients waiting for placement.”

“One of the biggest enablers we see are patients who have really strong advocates, be it friends, be it family being supportive. We have people being supported by their neighbours or by their community. Those people always seem to get through the system well when they have a strong voice speaking for them.”

“We have in acute care some nurses who are real nurse champions who have a lot of buy-in with geriatrics, and I find that if you are lucky enough to have one of those nurses, quite often everything has been done.”

“Geriatric Evaluation Management Teams that floats, going around the hospital. Something that we can do is provide some consistency, so because we are here five days a week and we can

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be a continuous support to staff. And a lot of it is sort of the education piece that starts with the seniors' nurse in Emergency and education of staff who care for those people who have been admitted for surgery electively. Showing staff how good dementia care can not only benefit the patient, but can actually benefit the staff as well in the way if you get to know that person and provide the care that works the best for them, that can also save nursing time. So there's that education and support piece as well. Also, as far as planning goes, we have some great resources as well in things like the Quick Response Team and the SORT Team and that that we can really connect with in the community. But as far as the hospital, a lot of that is that education piece that good dementia care looks like."

"I think from a physician's point of view, having very active academic geriatric medicine teaching units, not teaching units, but teaching teams. By the time people have done the internal medicine residency, probably 60-70% of them have spent at least a month on geriatric medicine and that's been hugely powerful in shifting attitudes among the physician staff, hugely powerful."

"Well it would be very good if we had some guidelines that we actually used around consistent types of assessment and how we approach the care of people who have behavioural support needs. So, from the perspective of making sure we have as optimal a physical environment as is possible, making sure that we are avoiding Code Whites where we can by being proactive, not being reactive; anticipating who is likely to develop a delirium and, you know, sort of really working intensively up front with that person to prevent it where it's possible."

"I think the behavioural protocol thing, trying to find other ways of dealing with people who are agitated and either over-medicated or having security sit outside their room. It seems like a tremendous waste of resource to have somebody who is paid outside the room and really not interact with the person. But if we spent that money differently, would we be able to, you know, would we be able to overcome their problems and settle them more easily. And working with families to help them know what to do because it's fine to say families, we really need your help, but if they don't get instruction on how to spend time with their loved one and what's going to make a difference, they are as lost as the security man."

"I think we have to sort of think outside the box. When somebody who is ill needs to come in to hospital, they should not have to endure the Emergency unless necessary. There should be direct admits. We have to think of more innovative models."

"The Heart Team is a psychiatrist and nurse who will take referrals for older adults with BPSD who we know for a fact are going to be a challenge in adjusting to residential care living. We make a referral to the team. They go out and do an assessment, develop a care plan and

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follow that client and family into care throughout the transition. We at Priority Access use them to get very comprehensive assessments and to determine what facility could receive them and what added care planning or special knowledge and teaching and training of staff are needed to help them with behavioural problems.”

“Make sure there is someone like a primary care physician doing the connections from the community and the post-discharge follow-up if there is a surgical ward. It would nice if they could work on the hospital ward as well, like old family physicians used to do to create that continuity.”

“Have staff who want to know them as people as opposed to bed blockers (someone who is just ‘using up a very vital bed’). I think the attitudinal shift needs also to be addressed. Part of that is cohorting and helping people see who that person is and what they were doing in their life before they came to hospital. If they come in with a rip-roaring delirium, you can’t really see that they were serving as a volunteer or working in a church community before. So it’s a lot about who is this person and what are we trying to get them back to.”

“I cover nine units in this hospital and as I walk around and see all these isolated seniors in their own rooms or in four bedrooms, and still isolated in a four bedroom. We have no rec therapy. These people just sit and rock all day and it’s terrible. And I think if we co-warded them, I think the good ones would help out the not so good ones, and you know, you just get a rec therapist in there and you could really improve the quality of life while people are waiting perhaps 3-4 months to go a facility, or maybe get better, activate and go home.”

