

*Alzheimer Society*

**ALZHEIMER SOCIETY OF CANADA**

**OLDER ADULT ABUSE AND DEMENTIA**

***A LITERATURE REVIEW***

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## TABLE OF CONTENTS

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<b>ACKNOWLEDGEMENTS.....</b>	<b>3</b>
<b>INTRODUCTION .....</b>	<b>4</b>
<b>DEFINITIONS AND THEORIES.....</b>	<b>12</b>
<b>ABUSE AND DEMENTIA .....</b>	<b>15</b>
<b>SCREENING FOR ABUSE .....</b>	<b>25</b>
<b>LEGAL CONSIDERATIONS .....</b>	<b>29</b>
<b>ETHICAL PERSPECTIVES .....</b>	<b>36</b>
<b>ISSUES AND CHALLENGES.....</b>	<b>38</b>
<b>MOVING FORWARD.....</b>	<b>41</b>
<b>PROMISING APPROACHES.....</b>	<b>45</b>
<b>RECOMMENDATIONS.....</b>	<b>52</b>
<b>APPENDIX.....</b>	<b>54</b>

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## INTRODUCTION

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### AGING AND AGEISM

Two major themes provide the backdrop to inform the discussion of abuse of persons with dementia. The first relates to increased longevity and the increased proportion of older adults in Canada. The second relates to the challenges arising from ageism.

Over the past 30 years, the proportion of the population made up of those aged 65 years and older has increased from 9% to 14%, and it is estimated they will make up more than one-quarter (27%) of the population by the year 2050.<sup>1</sup> Aging of the population is currently one of the most discussed topics in Canada.<sup>2</sup> On the one hand, this is seen as a dramatic success story, with a growing percentage of people living into later life. On the other hand, there are concerns related to this "social and demographic phenomenon" such as increased services to support the physical, mental and social wellbeing of these older adults.

Our Western culture places significant value on reason, cognition and financial productivity. "We live in a culture that is, at least in large segments, dominated by heightened expectations of rationalism and economic productivity, so clarity of mind and productivity inevitably influence our sense of the worth of a human life."<sup>3</sup> This in turn places a particular lens on aging. Butler coined the term "ageism" in 1968, contending that old age is equated by society as powerlessness, as a result of disease, disability or uselessness.<sup>4</sup> Ageism results in prejudices and stereotypes that are applied to older people sheerly on the basis of their age. This negative attitude toward older adults, results in the belief that older adults cannot or should not participate in societal activities or be given equal opportunities afforded others.<sup>5</sup> Ageism and stereotypes are at the root of many myths and misunderstandings about older adults. Stereotypes set older adults apart based on supposed characteristic qualities, even though they comprise the most diverse and individualized age group in the population.<sup>6</sup> Stereotypes held by young, middle-aged, and elderly adults about the elderly vary significantly and become more complex as individuals age. In other words, the older one becomes, the more likely one is to view old age as complex, with many more facets than viewed by younger persons.<sup>7</sup>

The consequences of negative stereotypes of aging are significant: services may be limited for rehabilitation and health promotion in the older population, and older adults can be segregated from

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<sup>1</sup> Canada (2010). *The Chief Public Health Officer's Report on the State of Public Health in Canada 2010*. Retrieved November 8, 2010 from <http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php>.

<sup>2</sup> Turcotte, M. & Schellenberg, G. (2007, p. 7). *A Portrait of Seniors in Canada: 2006*. Ottawa, ON: Statistics Canada, Social and Aboriginal Statistics Division.

<sup>3</sup> Post, S. G. (2000, p. 5). *The moral challenge of Alzheimer disease: Ethical issues from diagnosis to dying, Second edition*. Baltimore and London: The Johns Hopkins University Press.

<sup>4</sup> Butler, R. N. (1989, p. 138). Dispelling ageism: The cross cutting intervention. *Annals of American Academy of Political and Social Science*, 503: 138-147.

<sup>5</sup> Wallace, M. (2008, p. 10). *The Essentials of Gerontological Nursing*. New York: Springer Publishing.

<sup>6</sup> Eliopoulos, C. (2010, p. 34). *Gerontological Nursing (7th ed.)*. Philadelphia: Wolters Kluwer Health / Lippincott Williams & Wilkins.

<sup>7</sup> Ebersole, P. & Hess, P. (2001, p. 2). *Geriatric Nursing and Healthy Aging*. St. Louis, MO: Mosby, Inc.

mainstream society.<sup>8</sup> Ageism is as unacceptable as any other prejudice, and often leads to older adults being treated with lack of dignity and respect.<sup>9</sup>

**Discrimination** is the differential treatment of others because they are a member of a particular group or identified as being negatively different.<sup>10</sup>

**Implicit ageism**—thoughts, feelings, behaviours toward old persons—without conscious awareness can form the basis for negative interactions.<sup>11</sup>

## DEMENTIA: AN OVERVIEW

The word dementia comes from the Latin *de mentis*, meaning “out of the mind.” The term was coined by Philippe Pinel in 1801 when he wrote about mental illness in the asylums of Paris. When used medically, the term “dementia” is very specific—it means brain failure, the inability of the brain to function normally, and it refers to a loss of intellectual ability sufficient to interfere with the person’s daily activities and social or occupational life.<sup>12</sup>

Dementia is the term given to a syndrome characterized by progressive and persistent decline in both cognition and function, and applies to a group of signs and symptoms seen in a variety of diseases affecting the brain. “For the most part it is a chronic or progressive disease of older people resulting in impairment of higher brain functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function to a degree sufficient to affect daily activities.”<sup>13</sup> Dementia is central in many people’s fears of old age, particularly fears of loss of independence and dignity.

The dementias most commonly seen in older adults are best classified as neurodegenerative disorders. That is to say, they cause deterioration of the brain tissue. The precise pattern of decline of function will vary from individual to individual and from disease to disease; however, the overall course always moves towards an increasing impairment of function and, eventually, death. Dementia is the primary cause of long-term disability in older adults and is the fifth leading cause of death.

Globally, dementia is an emerging epidemic, with an estimated 24.3 million people worldwide and 4.6 million new cases expected every year.<sup>14</sup> Canada is experiencing significant population aging and, although dementia is not a normal part of aging, the likelihood of developing dementia increases with age. Over the next decade, as the general population ages, the prevalence of dementia is expected to rise. Alzheimer’s disease, the most common type of dementia, generally affects those over the age of 65 years; however, people in their 40s and 50s can also be affected.

<sup>8</sup> Tabloski, P.A. (2010, p. 3). *Clinical Handbook for Gerontological Nursing* (2nd ed). Upper Saddle River, NJ: Pearson Prentice Hall.

<sup>9</sup> British Medical Association (2009, p. 8). *The Ethics of Caring for Older People* (2nd Ed.). Chichester, West Sussex, UK: John Wiley & Sons Ltd.

<sup>10</sup> Kent-Wilkinson, A. (2010). The context of mental health care: Cultural, socioeconomic, and legal. In W. Austin & M. A. Boyd. (Eds.). *Psychiatric and mental health nursing for Canadian practice* (2nd Ed.) (pp. 29-44). Philadelphia: Lippincott, Williams, & Wilkins, Inc.

<sup>11</sup> Miller, C. A. (2009, p. 5). *Nursing for Wellness in Older Adults* (5th Ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

<sup>12</sup> Molloy, W. & Caldwell, P. (1998, p. 5). *Alzheimer's Disease*. Toronto, ON: Key Porter Books Limited.

<sup>13</sup> British Columbia: Provincial Dementia Service Framework Working Group (2007, p. 3). *BC Dementia Service Framework*. Retrieved August 18, 2010 from [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).

<sup>14</sup> Ferri, C. P. et al. (2005, p. 2112). Global prevalence of dementia: A Delphi consensus study. *Lancet*, 366(9503): 2112-2117.

### A CANADIAN SNAPSHOT: *THE RISING TIDE*

- 1 in 11 Canadians over the age of 65 has Alzheimer's disease or a related dementia.
- Of the 500,000 Canadians affected by dementia, more than 71,000 of them are under the age of 65, and approximately 50,000 of them are under the age of 60.
- In just five years, as many as 50% more Canadians and their families could be facing Alzheimer's disease or another form of dementia.
- As it stands today, the number of Canadians living with Alzheimer's disease or a related dementia will more than double within a generation (25 years).

—Alzheimer Society of Canada (2009).

Retrieved September 2, 2010 from:

<http://www.alzheimer.ca/english/media/putyourmind09-release.htm>.

The greatest risk factor for dementia is age:

- Dementia affects five to ten percent of all individuals aged 65 years or older in Europe and North America at any given time.
- Beginning at age 65, the rate of dementia doubles every five years.
- Approximately one percent of 60 year olds manifest a dementia syndrome, two percent of those aged 65 to 70, four percent of those 71 to 74, eight percent of those 75 to 79, 16 percent of those 80 to 84, and 30 to 40 percent of those aged 85 and over.

The social and economic implications of dementia are far-reaching:

- The personal and economic implications of dementia are significant for persons with dementia, their families and friends who support their care, and society.
- The irreversible nature and the progressive deteriorating course can have devastating effects on affected individuals and their families.<sup>15</sup>
- Research identifies increasing issues of caregiver stress and elder abuse.
- In Canada, the economic cost of dementia is estimated to double every decade, increasing from \$15 billion in 2008 to \$153 billion in 2038. In addition, \$56 billion in annual opportunity costs (foregone wages) of informal caregivers will represent a substantial societal burden by 2038.<sup>16</sup>

A variety of pathologies are responsible for dementia. Alzheimer's disease (AD) is the most common form of dementia—approximately 64% of all Canadians who have dementia have Alzheimer's disease. Vascular dementia (VD) is the second leading form of dementia, accounting for up to 20% of all cases. Lewy body dementia (LBD) can occur by itself, or together with Alzheimer's disease or Parkinson's,

<sup>15</sup> Eliopoulos, C. (2010, p. 416). *Gerontological Nursing (7th ed.)*. Philadelphia: Wolters Kluwer Health / Lippincott Williams & Wilkins.

<sup>16</sup> Alzheimer Society of Canada. (2010, p. 8). *Rising Tide: The Impact of Dementia on Canadian Society: Executive Summary*. Toronto, ON: Alzheimer Society of Canada.

accounting for 5-15% of all dementias. Frontal lobe dementia accounts for 2-5% of all dementia cases.<sup>17</sup>

Dementia is a clinical diagnosis, thus complete geriatric assessment helps to ensure accuracy of diagnosis. Because of the difficulty in obtaining direct pathological evidence of AD, a diagnosis is based on history and course, as well as by excluding other causes for the cognitive decline.<sup>18</sup> In addition to the history of symptoms from the person and family members or significant others, diagnosis is aided by brain scans that can reveal changes in the brain's structure that are consistent with the disease, neurological testing that evaluates cognitive functioning, laboratory tests and neurological examinations.<sup>19</sup>

An accurate assessment is vital and, wherever possible, draws upon the expertise of an interdisciplinary team for assessment and plans for treatment and ongoing care. The interdisciplinary team may include psychiatrists, geriatricians, neurologists, physicians, psychologists, nurses, pharmacists, social workers, dietitians, occupational therapists, physiotherapists, rehabilitation professionals, and spiritual care workers.

Dementia is a degenerative terminal condition, thus, people with dementia tend to move through clinical stages as they progress through their disease. As dementia progresses, so does the need for caregiver support. The stages of Alzheimer's disease are commonly referred to as:<sup>20</sup>

**Early:** The term "early stage" refers to individuals of any age who have mild impairment due to symptoms of Alzheimer's disease. Common symptoms include forgetfulness, communication difficulties, and changes in mood and behaviour. People in this stage retain many of their capabilities and require minimal assistance. They may have insight into their changing abilities, and, therefore, can inform others of their experience of living with the disease and help to plan and direct their future care. Please note that the term "early stage" refers to people of any age who have mild impairments as a result of Alzheimer's disease. This differs from the term "early onset" which refers to people who have been diagnosed with Alzheimer's disease at a younger age than usual.

**Middle:** This stage brings a greater decline in the person's cognitive and functional abilities. Memory and other cognitive abilities will continue to deteriorate although people at this stage may still have some awareness of their condition. Assistance with many daily tasks will become necessary.

**Late:** In this stage, the person eventually becomes unable to communicate verbally or look after themselves. Care is required 24 hours a day. The goal of care at this stage is to continue to support the person to ensure the highest quality of life possible.

**End of life:** As the person nears death, comfort measures become the focus. As in the care of any person living with a terminal illness, physical as well as emotional and spiritual needs must

<sup>17</sup> Alzheimer Society of Canada. *Alzheimer's Disease: Related Dementias*. Retrieved September 7, 2010 from <http://www.alzheimer.ca/english/disease/dementias-intro.htm>.

<sup>18</sup> Duffy, E. G. (2010, p. 746). The neurologic system. In P. A. Tabloski. *Gerontological Nursing: The Essential Guide to Clinical Practice* (pp. 735-782). 2nd Ed. Saddle River, NJ: Pearson Prentice Hall.

<sup>19</sup> Eliopoulos, C. (2010, p. 414). *Gerontological Nursing (7th ed.)*. Philadelphia: Wolters Kluwer Health / Lippincott Williams & Wilkins.

<sup>20</sup> Alzheimer Society of Canada. (2010). *Overview: What is Alzheimer's disease?* Retrieved November 17, 2010 from <http://www.alzheimer.ca/english/disease/progression-intro.htm><http://www.alzheimer.ca/english/disease/progression-intro.htm>.

be carefully considered and attended to. Providing supportive care focuses on quality of life and comfort.

### **Behavioural and Psychological Symptoms of Dementia (BPSD): An Overview**

*In the past persons with Alzheimer's disease and other dementias were often labeled as having "problem behaviors" or "behavioral disturbances." ... A consensus group of International Psychogeriatric Association (IPA, 2002), however, has recommended the term "behavioral and psychological symptoms of dementia" or BPSD be used instead, emphasizing that such symptoms are disease related.*<sup>21</sup>

The frequency of BPSD tends to peak in the middle stages of dementia. Symptoms of BPSD include delusions, hallucinations, depressive symptoms, agitation and hostility.<sup>22</sup> Some types of BPSD are more common in certain types of dementia, such as visual hallucinations with Lewy body dementia and sexual disinhibition with frontotemporal lobe dementia. **Caring for persons with BPSD requires education regarding strategies and particular approaches for the various behaviours and symptoms.**

Dementia significantly increases the likelihood of an individual needing to move to a long term care home. Family caregivers help people with dementia remain at home, although they vary considerably in their ability to do so.<sup>23 24 25</sup>

### **A PHILOSOPHY OF PERSON-CENTRED CARE**

Caring for persons with neurodegenerative illnesses is inherently challenging for all caregivers. Clinicians, researchers, philosophers and ethicists have contributed to the current philosophy of care that recognizes dementia as a condition that needs to be understood from several perspectives—biological, psychological, sociological, functional and cultural. These perspectives are inherent in the person's experience of the condition.<sup>26</sup>

Kitwood contributed significantly to this broader understanding of dementia. Much of his early work focused on demonstrating how personhood was eroded by caregivers, even if not intentional. He describes personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust." Personhood includes all the dimensions of a person that makes one feel whole, including life history and family.<sup>27</sup>

<sup>21</sup> Schwartzkopf, C. E. & Twigg, P. (2010, p. 544). Nursing management of dementia. In K. L. Mauk (Ed.). *Chapter 15, Gerontological Nursing: Competencies for Care* (pp. 530-557). (2nd ed.). Mississauga, ON: Jones and Bartlett Publishers Canada.

<sup>22</sup> Schwartzkopf, C. E. & Twigg, P. (2010, p. 545). Nursing management of dementia. In K. L. Mauk (Ed.). *Chapter 15, Gerontological Nursing: Competencies for Care* (pp. 530-557). (2nd ed.). Mississauga, ON: Jones and Bartlett Publishers Canada.

<sup>23</sup> Mittelman, M. S., Haley, W. E., Clay, O. J. & Roth, D. L. (2006, p. 1592). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67: 1592-1599.

<sup>24</sup> Eaker, E. D., Vierkant, R. A. & Mickel, S. F. (2002). Predictors of nursing home admission and/or death in incident Alzheimer's disease and other dementia cases compared to controls: A population-based study. *Journal of Clinical Epidemiology*, 55: 462-468.

<sup>25</sup> Stevens, A., Owen, J., Roth, D., Clay, O., Bartolucci, A. & Haley, W. (2004). Predictors of time to nursing home placement in White and African American individuals with dementia. *Journal of Aging and Health*, 16(3): 375-397.

<sup>26</sup> Brooker, D. (2007). *Person-centred Care*. London: Jessica Kingsley Publishers.

<sup>27</sup> Kitwood, T. M. (1997, p. 8). *Dementia Reconsidered: The Person Comes First*. Buckingham, UK: Open University Press.



*We are called to recognise these life stories and witness to them in ways that are fitting. Depending on their impairments, vulnerabilities and dependencies, we can seek ways of helping the individuals involved to enact those stories in new contexts and in the face of challenges which they did not choose to confront.*<sup>28</sup>

One way to understand personhood is as a narrative process—to which all contribute. We are all narrative beings<sup>29 30</sup> and, simply put, we are our stories. This perspective helps us recognize the value of learning the history of the person with dementia and to recognize more fully "fragments" of the life story that a person with dementia is able to share.<sup>31</sup> "Ultimately, the narrative has ethical content because it impacts on the body and what the body must endure."<sup>32</sup>

Threats to personhood in later years include dementia, end of life issues, physical illness, hospitalization, labels and language, and institutional models of residential care.

### Person-centred Care

Person-centred care provides integrated care, being respectful of and responsive to the person with dementia, family, significant others, and network of support—their perspectives, needs, values and choices. This approach involves the person with dementia and family as partners in decision-making processes, and ensures integration of persons with dementia and families into the care team in order to maintain optimal, evolving care.

The Alzheimer Society of Canada summarizes the core concepts of person-centred care as the following:

- **Dignity and Respect:** Like all individuals, people diagnosed with dementia are people *first*. Their caregivers listen to them and respect their wishes, concerns, values, priorities, perspectives and choices. They have dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times. The values, beliefs and cultural backgrounds of people with dementia and families are incorporated into the planning and delivery of care.
- **Information Sharing:** Caregivers and health professionals communicate and share complete and unbiased information with people with dementia and their families in ways that are affirming and useful. People with dementia and their families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation:** People with dementia and families are given choices and make decisions. They are encouraged and supported to participate in care and decision-making at the level they choose. This therapeutic relationship is based on the participation of the person with dementia, regardless of their level of mental or physical impairment. The goal is to put the person at the centre of any decision, without excluding family members.
- **Collaboration:** Caregivers and people with dementia collaborate through mutual sharing and work together to achieve common goals to improve the quality of care and the quality life for the person with dementia. Caregivers are flexible to accommodate the person's preferences. In care facilities,

<sup>28</sup> Harrigan, M. L. & Gillett, G. (2009, p. 52). Hunting good will in the wilderness. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 47-57). London: Jessica Kingsley Publishers.

<sup>29</sup> MacIntyre, A. (1984). *After virtue: A study in moral theory* (2nd ed.). Notre Dame, IN: University of Notre Dame Press.

<sup>30</sup> Taylor, C. (1989). *The sources of self*. Cambridge, MA: Harvard University Press.

<sup>31</sup> Baldwin, C. (2009, p. 26). Narrative and decision-making. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface*. (pp. 25-36). London: Jessica Kingsley Publishers.

<sup>32</sup> Gillett, G. R. (2004, p. 26). *Bioethics in the clinic: Hippocratic reflections*. Baltimore: The Johns Hopkins University Press.

managers collaborate with people with dementia and families in policy and program development, implementation, and evaluation as well as in the delivery of care. Staff are empowered with relevant knowledge and decision-making authority, enabling them to alter work routines to adapt to the person's needs and preferences.

### DEMENTIA AND ABUSE: A HIDDEN PROBLEM

*There are inherent difficulties in studying elder abuse since it is a hidden offence, often perpetrated against vulnerable people, many with memory impairment, by those on whom they depend. Since the concept of elder abuse was first raised in the seminal paper about 'granny battering', numerous studies have attempted to measure its prevalence. Existing studies have used several different methodologies, including a variety of definitions of elder abuse, making comparisons difficult and internationally, prevalence estimates have varied considerably.<sup>33</sup>*

Dementia and abuse of older adults are geriatric syndromes, each relatively common and under-diagnosed. When the two entities coexist, a unique relationship is observed. "Special issues can confound the care of the dementia patient suspected of being abused. Impaired language or motor abilities to communicate abusive situations to a third party, lack of decisional capacity to address the abusive situation, disinhibited behavior that contributes to a cycle of violence, and coincident depression of the abused older adult complicate the diagnosis and management of elder abuse."<sup>34</sup>

Abuse and neglect among older adults is often described as a "hidden problem", in that the signs may be non-specific or ambiguous, and older adults may not be able to or want to identify themselves to others as being abused or neglected. Abuse and neglect in later life is often a multifaceted and complex problem which manifests in a various ways: in family settings from a spouse or partner, and from family members or others involved with the person. The abuse may be caused by a single person or several people may be involved. The abuse may be a recent phenomenon or may be a continuation of years of emotional, physical, financial or sexual abuse or neglect within a relationship. The range of varying situations and perpetrators has significant implications for screening and assessment as well as decision-making process and interventions.<sup>35</sup> Thus, abuse of vulnerable older adults with dementia must be explored from different perspectives.

### Demographic Imperative

The 2010 Report of the Chief Public Health Officer of Canada emphasizes: "One particularly concerning issue for the well-being of seniors is the potential for physical, psychological and financial abuse or neglect. It is difficult to know the extent of this problem in Canada since the data are extremely limited, outdated and, due to the nature of the issue, most likely under-reported. Research estimates, however, that between 4% and 10% of Canadian seniors experience some form of abuse or neglect from someone they trust or rely on. ... Just as the abuse and neglect of seniors can take many forms, the resulting effects of the abuse can have an impact on many aspects of their health and well-being."<sup>36</sup>

<sup>33</sup> Selwood, A., Cooper, C. & Livingston, G. (2007, p. 1009). What is elder abuse—who decides? *International Journal of Geriatric Psychiatry*, 22: 1009-1012.

<sup>34</sup> Hansberry, M. R., Chen, E. & Gorbien, M. J. (2005). Dementia and elder abuse. *Clinics in Geriatric Medicine*, 21(2): 315-332.

<sup>35</sup> Edwards, P. (2009). Elder abuse in Canada: a gender-based analysis. Division of Aging and Seniors Public Health Agency of Canada.

<sup>36</sup> Canada (2010). *The Chief Public Health Officer's Report on the State of Public Health in Canada 2010*. Retrieved November 8, 2010 from <http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php>.

"The 'demographic imperative' that has fueled the awareness of the needs of older adults has a major impact on issues related to social welfare, justice, and economics. ... All health care professionals working with older adults need to become familiar with the recognition, treatment, and prevention of elder abuse and neglect."<sup>37</sup>

Over the past twenty years, abuse of older adults has emerged as an area of concern. Canadian health care providers and others desire effective ways to identify this problem and appropriately meet the older adult's needs, as well as society's broader goals of social security and community well-being.<sup>38</sup>

### Protection and Prevention

Protection can be both preventive and reactive. One way to categorize is the following:<sup>39</sup>

- Primary prevention refers to policy and actions undertaken before situations become problematic. For example, "the security and wellbeing of older adults in the 'grey zone'—not incapable but more vulnerable—is a key area of concern among practitioners and legislators."<sup>40</sup> Policy concerns about the increasing proportions of older people with dementia have fostered an emphasis on later life planning, assessment of capacity and substitute decision-making.<sup>41</sup> This may also include development of regulations and legislation at the societal level.
- Secondary prevention refers to people who could be identified as possibly in need of protection. This includes periods of respite care to reduce caregiver stress, before acts of mistreatment occur.
- Tertiary prevention refers to providing services and interventions after an actual issue concerning protection has been identified. The objective here is to take action in order to reduce the risk of harm occurring again.

<sup>37</sup> Gorbien, M. J. & Eisenstein, A. R. (2005). Elder abuse and neglect: An overview. *Clinics in Geriatric Medicine*, 21(2): 279-292.

<sup>38</sup> Spencer, C. (2009, p. 5). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>39</sup> Browne, K. & Herbert, M. (1997). *Preventing family violence*. Chichester, UK: John Wiley & Sons.

<sup>40</sup> Hall, M. (2006). Equitable fraud: Material exploitation in domestic settings. *Elder Law Review*, Article 7.

<sup>41</sup> Tilse, C., Wilson, J. & Setterland, D. (2009, p. 134). Personhood, financial decision-making and dementia. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 133-143). London, UK: Jessica Kingsley Publishers.

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## DEFINITIONS AND THEORIES

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### Definitions of Abuse

Abuse includes physical, psychological, financial, or sexual harms to older adults, as well as intentional (active) and unintentional (passive) neglect. It may also take other forms such as spiritual abuse, rights violations, and broader systemic harms. "Regardless of the type of abuse, it will certainly result in unnecessary suffering, injury or pain, the loss or violation of human rights, and a decreased quality of life for the older person."<sup>42</sup>

The term "abuse" in the context of older adults has been defined by the World Health Organization as: "a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person"<sup>43</sup>

The World Health Organization defines the following categories of abuse:

- "Physical abuse—the infliction of pain or injury, physical coercion, or physical or drug induced restraint.
- Psychological or emotional abuse—the infliction of mental anguish.
- Financial or material abuse—the illegal or improper exploitation or use of funds or resources of the older person.
- Sexual abuse—non-consensual sexual contact of any kind with the older person.
- Neglect—the refusal or failure to fulfil a caregiving obligation. This may or may not involve a conscious and intentional attempt to inflict physical or emotional distress on the older person."<sup>44</sup>

The terms "elder abuse," "elder mistreatment," and "abuse of the older adult" have been used throughout the literature, with "elder abuse" used most frequently in the studies reviewed.

### Caregivers

Family caregivers, also referred to as carers, are defined as individuals who provide care and assistance for their family members and friends in need of support because of physical, cognitive or mental health conditions. Studies reviewed included both adult children and spouses as caregivers. There is some evidence that risk factors for abuse and abusive behaviours differ between those two groups.<sup>45</sup> Research studies reviewed did not usually provide a definition of family caregivers or differentiate between caregiving and co-residency, thus, in many instances; the abuse may have been inflicted by someone in the home who is not in a caregiving role.

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<sup>42</sup> Hudson, M. F. (1991). Elder mistreatment: A taxonomy with definitions by Delphi. *Journal of Elder Abuse and Neglect*, 3: 1-20.

<sup>43</sup> World Health Organization. Prevention of elder abuse. Online: [www.who.int/ageing/projects/elder\\_abuse/en/](http://www.who.int/ageing/projects/elder_abuse/en/) Accessed August 30, 2009.

<sup>44</sup> World Health Organization (2002, p. 127). Abuse of the elderly. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi & R. Lozano (Eds.). *World Report on Violence and Health* (pp. 123-146). Retrieved September 3, 2010 from [http://whqlibdoc.who.int/publications/2002/9241545615\\_eng.pdf](http://whqlibdoc.who.int/publications/2002/9241545615_eng.pdf).

<sup>45</sup> Peri, K., Fanslow, J. & Parsons, J. (2008, p. 15). Elder Abuse and Neglect: Exploration of Risk and Protective Factors. New Zealand: Families Commission. Retrieved November 11, 2010 from <http://www.inpea.net/images/abuseneglect.pdf>.

## Recipients of Care

Persons receiving care are referred to in the literature as "care receivers," "patients," "care recipients" or "victims."

## THEORIES OF ELDER ABUSE

*In some cases, abuse and/or neglect of older adults is thought to be a continuation of previous and long-term existing abuse against a person who has become an older adult; it is also understood at times to be a result of caregiver stress. Abuse also may be a transfer of abusive behaviors to a parent, learned by a child who was abused by that person who is now an older adult; or it may be a sign of intergenerational conflicts.*<sup>46</sup>

The theories of elder abuse refer to abuse of older adults generally, not specifically to those with dementia. Research in this area of older adult abuse has been criticized as largely atheoretical;<sup>47</sup> perspectives have only limited empirical support.<sup>48</sup> More recently, critical feminist theory entered the older adult abuse literature providing another lens for conceptualizing the dynamics of abuse that draws attention to two aspects of abuse, namely gender and power,<sup>49</sup> contending that abuse is generally about power inequities both within the relationship and society at large. As well, the feminist lens suggests that men and women may differ dramatically in terms of the meanings and interpretations that they accord the abuse.<sup>50</sup>

The complex nature of elder abuse—encompassing various forms and domains—makes it difficult to construct one theory to decisively explain the causes of elder abuse or specifically of elder abuse and dementia. As well, the various communities—including medical, judicial, and social service—bring different perspectives regarding assessments and interventions for the victim and the abuser, which adds to the challenge of finding a common theoretical framework.<sup>51 52 53</sup>

The literature describes a number of hypotheses of elder abuse<sup>54 55</sup> using these categories:

<sup>46</sup> Roger, K. S. & Ursel, J. (2009, p. 117). Public opinion on mandatory reporting of abuse and/or neglect of older adults in Manitoba, Canada. *Journal of Elder Abuse & Neglect*, 21: 115-140.

<sup>47</sup> Biggs, S. (2003). Negotiating aging identity surface, depth, and masquerade. In J. Hendricks (series ed.) and S. Biggs, A. Lowenstein & J. Hendricks (vol eds.). *The Need for Theory: Critical Approaches to Social Gerontology*. Amityville, NY: Baywood Publishing.

<sup>48</sup> Lachs, M. S. & Pillemer, K. (2004). Elder Abuse. *The Lancet*, 364(9441): 1263-1272; Penhale, B. (2003). Older women, domestic violence and elder abuse: A review of commonalities, differences and shared approaches. *Journal of Elder Abuse and Neglect: An International Journal*, 15(3-4): 163-183.

<sup>49</sup> Yllo, K. A. (2005, p. 20). Through a feminist lens: Gender diversity and violence. Extending the feminist framework. In D. Loseke, R. J. Gelles & M. M. Cavanaugh. (Eds.). *Current Controversies on Family Violence*. (2nd ed.). (pp. 19-34). Thousand Oaks, CA: Sage.

<sup>50</sup> O'Connor, D. & Donnelly, M. (2009, p. 109). Confronting the challenges of assessing capacity: Dementia in the context of abuse. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 106-118). London, UK: Jessica Kingsley Publishers.

<sup>51</sup> Centre for Substance Abuse Prevention Pathways (2010). Module 2: The basics of elder abuse. *Out of the Shadows: Uncovering Substance Use and Elder Abuse*. Retrieved December 13, 2010 from [http://pathwayscourses.kitsolutions.net/elab/elab\\_2\\_pg12.htm](http://pathwayscourses.kitsolutions.net/elab/elab_2_pg12.htm).

<sup>52</sup> Alberta Elder Abuse Network. (2010). Retrieved December 13, 2010 from <http://www.albertaelderabuse.ca/>.

<sup>53</sup> Aging and Senior Health Issues. (2010). *Elder Abuse and Neglect*. Retrieved December 13, 2010 from <http://www.easylifegas.com/elder-abuse-and-neglect/>.

<sup>54</sup> Fulmer, T. (2008). Screening for mistreatment of older adults. *American Journal of Nursing*, 108(12): 52-59.

<sup>55</sup> Fulmer, T., Guadagno, L., Dyer, C. & Connolly, J. D. (2004). Progress in elder abuse screening and assessment instruments. *Journal of the American Geriatrics Society*, 52: 297-304.

**Psychopathology of the Abuser:** Considers mental illness or alcohol dependency as factors in abuse of older adults.<sup>56</sup>

**Transgenerational Violence:** Considers elder abuse to be part of a family violence continuum. There is little empirical evidence, but case studies suggest further research could be valuable (related to a social learning theory).

**Situational Theory or Caregiver Stress:** Contends that caregiver burdens multiply and supersede the caregiver's capacity to meet the needs of the older adult, and caregiver stress ultimately overtakes the situation.

**Isolation Theory:** Posits that a dwindling social net may ultimately result in elder mistreatment.<sup>57</sup>

**Political Economic Theory:** Addresses the challenges faced by older adults when they lose their role in society—including issues of ageism.

Wolf contends that the critical issue is the lack of rigorous studies to test the theories.<sup>58</sup> "The lack of clarity reflects an overarching uncertainty about how elder abuse" and particularly dementia-related abuse, "fits within other theoretical frameworks related to violence. Parallels have been drawn between elder abuse and child abuse and between elder abuse and domestic violence. Many elder abuse cases fit the paradigm of family violence—that is, acts of abuse or misuse of power that may result in harm to a family member."<sup>59</sup> However, not all cases involve spouses or family members. "Practitioners stress the need to understand the entire range of elder abuse and the underlying causes—including self-neglect..."<sup>60</sup>

A number of authors such as VandeWeerd, Paveza and Fulmer describe a *vulnerability* of persons as a result of Alzheimer's dementia (AD): problems in cognition that span memory, language, attention, perception, and motor skills, including loss of attention, communication skills, and perceptual skills, which can hinder driving, reading, and dressing; often includes depression, agitation, suspiciousness, delusions, and hallucinations.<sup>61</sup>

<sup>56</sup> Lachs, M. S. & Pillemer, K. (2004). Elder Abuse. *The Lancet*, 364(9441): 1263-1272.

<sup>57</sup> Tabloski, P. A. (2010, p. 292). Violence and elder mistreatment. In P. A. Tabloski. *Clinical Handbook for Gerontological Nursing* (2nd ed). (pp. 287-307). Upper Saddle River, NJ: Pearson Prentice Hall.

<sup>58</sup> Wolf, R. S. (1997). Elder abuse and neglect: Causes and consequences. *Journal of Geriatric Psychiatry*, 30(11): 155-159.

<sup>59</sup> American Psychological Association (1996). *Report of the American Psychological Association Task Force on Violence and the Family*. Washington, DC: Author.

<sup>60</sup> Centre for Substance Abuse Prevention Pathways (2010). Module 2: The basics of elder abuse. *Out of the Shadows: Uncovering Substance Use and Elder Abuse*. Retrieved November 11, 2010 from [http://pathwayscourses.kitsolutions.net/elab/elab\\_2\\_pg12.htm](http://pathwayscourses.kitsolutions.net/elab/elab_2_pg12.htm).

<sup>61</sup> VandeWeerd, C., Paveza, G. J. & Fulmer, T. (2005, p. 44). Abuse and neglect in older adults with Alzheimer's disease. *Nursing Clinics of North America*, 41:43-55.

## ABUSE AND DEMENTIA

*People with dementia are more vulnerable to situations of abuse and neglect. On the one hand, increasing dependency on others and deteriorating social networks leave the person more isolated, creating a context that is ripe for becoming abusive. Simultaneously, cognitive difficulties interfere with the ability to take action—for example the person may have difficulty organizing to leave or seek support.*<sup>62</sup>

The literature emphasizes that abuse of older adults is a complex social, legal and ethical issue, with multiple dimensions. "In community settings the perpetrators may be the person's spouse, one or more family members, paid care providers, or casual acquaintances. The abuse may be recent or long standing... The response to preventing or addressing abuse and neglect in later life does not easily fit within one type of legal or social approach."<sup>63</sup>

### Prevalence

"Elder abuse is associated with distress and increased mortality in older people and caregiver psychological morbidity. Discovering the prevalence of abuse, perpetrated against vulnerable people by those they rely on, is inherently difficult."<sup>64</sup>

In an international review of the literature, Lysne summarized that the prevalence rate of elder abuse of persons with dementia is considerably higher than the prevalence rate for elder abuse in general,<sup>65</sup> which, in Canada, is recognized as 4% to 10%.<sup>66</sup> For example, in the United Kingdom, a recent study concluded that abusive behaviour by family carers towards people with dementia is common: a third reported important levels of abuse and half reported some abusive behaviour.<sup>67</sup>

A study using structured interview data from 142 caregivers (98 wives, 44 husbands) indicated that "more depressed caregivers are more likely to treat their spouses in potentially harmful ways. However, consistent with hypotheses derived from communal relationships theory, when the pre-illness relationship between caregiver and care recipient was characterized by mutual responsiveness to each other's needs (i.e., was more communal), caregivers were less depressed and less frequently engaged in

<sup>62</sup> O'Connor, D. & Donnelly, M. (2009, p. 107). Confronting the challenges of assessing capacity: Dementia in the context of abuse. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 106-118). London, UK: Jessica Kingsley Publishers.

<sup>63</sup> Spencer, C. & Soden, A. (2007, p. 18). A softly greying nation: Law, Ageing and Policy in Canada. *The Journal of International Aging, Law and Policy, Vol. 2 (Summer):* 1-32.

<sup>64</sup> Cooper, C., Selwood, A. & Livingston, G. (2008, p. 151). The prevalence of elder abuse and neglect: A systematic review. *Age and Ageing, 37:* 151-160.

<sup>65</sup> Lysne, L. (2010, p. 16). *Elder Care, Elder Abuse and Neglect: An International Literature Review*. Ottawa, ON: Division of Aging and Seniors, Public Health Agency of Canada.

<sup>66</sup> Bain, P. & Spencer, C. for Federal/Provincial/Territorial Ministers Responsible for Seniors in Canada (2009, p. 2). *Fact Sheet 2: What is Abuse of Older Adults?* Retrieved November 11, 2010 from [http://www.cnpea.ca/Fact2\\_WEAD-EN\\_2009.pdf](http://www.cnpea.ca/Fact2_WEAD-EN_2009.pdf).

<sup>67</sup> Cooper, C., Selwood, A., Blanchard, M., Walker, Z., & Blizard, R. (2009). Abuse of people with dementia by family carers: Representative cross sectional survey. *British Medical Journal, 338:* b155. Retrieved September 2, 2010 from <http://www.bmj.com/content/338/bmj.b155.full.pdf>.

potentially harmful behaviors."<sup>68</sup> Thus, the "pre-illness experiences with care recipients serve as a lens through which caregivers view and react to their current caregiving circumstances."<sup>69</sup>

A survey of family violence in Canada found that 7% of older people had experienced some form of emotional abuse, 1% financial abuse, and 1% physical abuse or sexual assault, at the hands of children, caregivers or partners during the previous 5 years.<sup>70</sup> Men (9%) were more likely than women (6%) to report suffering emotional or financial abuse. Because of differences in the survey questions and time frame, these findings cannot be compared with the earlier study in Canada which had found a much smaller proportion of emotional abuse (1.4%) and a larger rate of financial abuse (2.5%).<sup>71" 72</sup>

"The Statistics Canada (2005) report indicates that there were 4,000 incidents of abuse reported to the police in Canada in 2003 that included older adults. Common assault was the most frequently reported form of violence against older adults, however, these assaults were considered to be serious because older adults are more physically fragile and more easily injured. ... Other forms of abuse and/or neglect are less well documented. Financial dependence on an older adult has been found to lead to abuse by a dependent younger family member."<sup>73</sup>

Recognition of various forms of abuse is not always easy:<sup>74</sup>

- Physical and psychological abuse may mimic health problems.
- Physical neglect may be harder to recognize than physical abuse.
- Emotional abuse may be hard to distinguish from "ordinary family tensions."<sup>75</sup>
- Sexual abuse may not even be considered by some health care providers.

### Impact of Abuse

*...Because older victims usually have fewer support systems and reserves—physical, psychological, and economic—the impact of abuse and neglect is magnified, and a single incident of mistreatment is more likely to trigger a downward spiral leading to loss of independence, serious complicating illness, and even death.*<sup>76</sup>

<sup>68</sup> Williamson, G. M., Shaffer, D. R. & The Family Relationships in Late Life Project, University of Georgia (2001, p. 217). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychology and Aging*, 16(2): 217-226.

<sup>69</sup> Williamson, G. M., Shaffer, D. R. & The Family Relationships in Late Life Project, University of Georgia (2001, p. 224). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychology and Aging*, 16(2): 217-226.

<sup>70</sup> Canadian Centre for Justice Statistics. (2000). *Family Violence in Canada: A Statistical Profile*. Ottawa: Health Canada.

<sup>71</sup> Podnieks, E. (1992). National survey on abuse of the elderly in Canada. *Journal of Elder Abuse and Neglect*, 4(5): 58.

<sup>72</sup> World Health Organization (2002, p. 129). Abuse of the elderly. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi & R. Lozano (Eds.). *World Report on Violence and Health* (pp. 123-146). Retrieved September 3, 2010 from [http://whqlibdoc.who.int/publications/2002/9241545615\\_eng.pdf](http://whqlibdoc.who.int/publications/2002/9241545615_eng.pdf).

<sup>73</sup> Roger, K. S. & Ursel, J. (2009, p. 117). Public opinion on mandatory reporting of abuse and/or neglect of older adults in Manitoba, Canada. *Journal of Elder Abuse & Neglect*, 21: 115-140.

<sup>74</sup> Banerjee, A. K. (2008, p. 408). The abuse of older people: The English scenario. *Indian Journal of Gerontology*, 22(3-4): 405-410.

<sup>75</sup> Spencer, C. (2009, p. 5). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>76</sup> Dyer, C. B., Connolly, M.-T. & McFeeley, P. (2003, p. 340). The clinical and medical forensics of elder abuse and neglect. In R. J. Bonnie & R. B. Wallace, R. B. (Eds.). (pp. 339-380). *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: National Academy of Sciences.



Abuse may be immediately life threatening and also influence longer-term survival. A seminal study by Lachs et al. identified, after a 13 year follow-up period, the survival rate for those who had experienced elder abuse was 9% compared to 17% for those seen for neglect and 40% for those not abused.<sup>77</sup>

The abuse and neglect of older adults has major impacts on emotional and social wellbeing:<sup>78</sup>

- Both older men and women who are abused have higher rates of depression and anxiety than those who do not experience abuse.
- Resulting depression can, in turn, increase seniors' isolation.
- Abuse and neglect perpetrated by family members or others close to the victim can cause shame, guilt or embarrassment.
- Financial abuse of seniors can impact their health and well-being by reducing the resources necessary to maintain good health such as proper nutrition, physical activity, medications and care.
- For some victims of abuse and neglect, coping with the effects may lead to problems with alcohol or substance abuse.

## Values

The literature explores reasons why persons with dementia are at risk for abuse. One perspective relates to how they are valued. The personhood literature<sup>79 80 81 82 83</sup> proposes that older adults with dementia are undervalued as people.<sup>84</sup> Kitwood described a paradigm of dementia including a "malignant social psychology" which depersonalized persons with dementia by labelling, infantilization, and banishment.<sup>85</sup> Current Australian research provides an example, indicating that prevailing attitudes to older people who require assistance with managing their assets allow some people to think that it is acceptable to "help yourself" to their assets even though this can result in severe detriment to the older person.<sup>86</sup>

Education and training are recognized as a significant area for research. "Health care personnel are generally not aware of the special vulnerabilities of the dementia patient and fail to recognize elder abuse. Education of caregivers regarding the clinical course of dementia and the anticipated needs of the care recipient is critical to successful care of the dementia patient and presumption of abuse

<sup>77</sup> Lachs, M. S., Williams, C. S., O'Brien, S., Pillemer, K. A. & Charlson, M. E. (1998). The mortality of elder mistreatment. *Journal of the American Medical Association*, 280(5): 428-432.

<sup>78</sup> Canada (2010). *The Chief Public Health Officer's Report on the State of Public Health in Canada 2010*. Retrieved November 11, 2010 from <http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php>.

<sup>79</sup> Jaworska, A. (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philosophy and Public Affairs*, 28(2): 105-138.

<sup>80</sup> Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.

<sup>81</sup> Post, S. G. (2000). *The moral challenge of Alzheimer disease: Ethical issues from diagnosis to dying, Second edition*. Baltimore and London: The Johns Hopkins University Press.

<sup>82</sup> Sabat, S. (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, 19(11-12): 1030-1035.

<sup>83</sup> O'Connor, D. & Purves, B. (Eds.). (2009). *Decision-making, personhood and dementia: Exploring the interface* (pp. 11-21). London, UK: Jessica Kingsley Publishers.

<sup>84</sup> Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.

<sup>85</sup> Kitwood, T. (2007). The dialectic of dementia: With particular reference to Alzheimer's disease. In C. Baldwin & A. Capstick (Eds.). (pp. 34-51). *Tom Kitwood on Dementia: A Reader and Critical Commentary*. Maidenhead, UK: Open University Press.

<sup>86</sup> Tilse, C., Wilson, J. & Setterland, D. (2009, p. 138). Personhood, financial decision-making and dementia. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 133-143). London, UK: Jessica Kingsley Publishers.

precipitants. Support of caregivers, including treatment of caregiver depression and referral to community resources, may help prevent or stop abuse."<sup>87</sup>

### Cultural Considerations

*Markers of cultural difference—the norms, values, beliefs, traditions and practices that signal membership in a particular social group—subtly shape our day-to-day actions and profoundly influence interactions between the providers and the recipients of services in dementia care, as in any other health or social service encounter.*<sup>88</sup>

Research explores issues of cultural awareness and competency. Mackenzie et al. contend that within the United Kingdom, "the evidence base available to guide professionals working with people with dementia from diverse ethnic and cultural groups is limited, and beliefs about dementia and the type of treatment and support needed have received little attention. Consequently this creates problems for service providers faced with appropriately supporting people with dementia and their families..."<sup>89</sup> Research also includes a related focus on "cultural safety," a term "developed in the 1980s in New Zealand in response to the indigenous Maori people's discontent with nursing care. ... Cultural safety moves beyond the concept of cultural sensitivity to analyzing power imbalances, institutional discrimination, colonization and relationships with colonizers, as they apply to health care."<sup>90</sup>

Hulko and Stern explore cultural safety within the context of decision-making and dementia and note that within the First Nations culture, "ensuring the inclusion of aboriginal older adults with memory loss in decision-making requires viewing them as embedded within a collective, retaining a focus on the community as a whole, and attending to their physical, spiritual, mental and emotional health and well-being."<sup>91</sup>

***Being Least Intrusive*** is a guide "developed to support front-line clinicians and service providers who are in the position of having to respond to, investigate and intervene in situations of abuse and neglect of vulnerable First Nation adults." It assists practitioners through "complex terrain of adult vulnerability, abuse and neglect in ways that honour cultural and spiritual diversity, ensures safety for individuals, families and communities..."<sup>92</sup>

### Issues of Competency and Capacity

The moral, ethical and social, as well as the clinical dimensions of capacity or competency assessments are increasingly recognized. For example, competency judgements are ultimately moral judgements insofar as the clinician or the judge acts as a proxy for society in determining whether an individual

<sup>87</sup> Hansberry, M., Chen, E. & Gorbien, M. J. (2005). Dementia and elder abuse. *Clinics in Geriatric Medicine*, 21: 315-332.

<sup>88</sup> Hulko, W. & Stern, L. (2009, p. 70). Cultural safety, decision-making and dementia: Troubling notions of autonomy and personhood. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 70-87). London, UK: Jessica Kingsley Publishers.

<sup>89</sup> Mackenzie, J., Bartlett, R. & Downs, M. (2005, p. 39). Moving towards culturally competent dementia care: Have we been barking up the wrong tree? *Reviews in Clinical Gerontology*, 15(1): 39-46.

<sup>90</sup> National Aboriginal Health Organization (NAHO). (2006). *Fact Sheet: Cultural Safety*. Retrieved November 26, 2010 from <http://www.naho.ca/english/documents/Culturalsafetyfactsheet.pdf>.

<sup>91</sup> Hulko, W. & Stern, L. (2009, p. 75). Cultural safety, decision-making and dementia: Troubling notions of autonomy and personhood. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 70-87). London, UK: Jessica Kingsley Publishers.

<sup>92</sup> Struthers, A. & Neufeld, L. (2010 [Draft], p. 4). *Being Least Intrusive: An Orientation to Practice for Front Line Workers Offering Services to First Nations Communities*. Victoria, BC: BC Community Response Network; WiT Works Ltd.; Vancouver Island Health Authority.

should retain autonomy in a set of activities.<sup>93</sup> Decision-making with or for people living with dementia is not a neutral act but one entwined with ethics.<sup>94</sup>

"As practitioners working with elderly clients in abusive and neglectful circumstances, it is our challenge to balance our duty to protect the safety of the vulnerable elder with the client's right to confidentiality and self-determination. Like many ethical dilemmas the goal will essentially be to respectfully come to a conclusion which is the least harmful to the vulnerable client."<sup>95</sup>

O'Connor and Purves emphasize the need to examine decision-making within the context of a personhood lens.<sup>96</sup> "Attempting to understand the behaviours of and actions of someone within the context of abuse can be challenging."<sup>97</sup> Questions invariably emerge regarding the person's capacity to make decisions. When the person has dementia, it can be even easier to slide into an acceptance of incapacity rather than query difference. O'Connor and Donnelly emphasize how different tests of capacity draw on different standards, depending upon the province. Further, they suggest that there may be incongruence between actual practice and standards.<sup>98</sup>

### Barriers to Disclosure

Older adults who experience abuse, especially those who have a form of dementia, encounter many barriers to disclosure:<sup>99</sup>

- Diminished capacity to comprehend.
- Ignorance of the law.
- Cultural differences.
- Shame and fear when the perpetrator is a family caregiver.
- Fear of placement in a care facility.
- A socio-culture norm that discourages involvement of outsiders in family matters.
- Belief that there is little that police or social agencies can do to help.

<sup>93</sup> Tilse, C., Wilson, J. & Setterland, D. (2009, p. 137). Personhood, financial decision-making and dementia. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 133-143). London, UK: Jessica Kingsley Publishers.

<sup>94</sup> Baldwin, C. (2009, p. 34). Narrative and decision-making. In D. O'Connor & B. Purves (Eds.). *Decision-making, personhood and dementia: Exploring the interface*. (pp. 25-36). London: Jessica Kingsley Publishers.

<sup>95</sup> Donovan, K. & Regehr, C. (2010, p. 181). Elder abuse: Clinical, ethical, and legal considerations in social work practice. *Clinical Social Work Journal*, 38: 174-182.

<sup>96</sup> O'Connor, D. & Purves, B. (2009, p. 15). Decision-making, personhood and dementia: Mapping the terrain. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 11-21). London, UK: Jessica Kingsley Publishers.

<sup>97</sup> O'Connor, D. & Donnelly, M. (2009, p. 116). Confronting the challenges of assessing capacity: Dementia in the context of abuse. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 106-118). London, UK: Jessica Kingsley Publishers.

<sup>98</sup> O'Connor, D. & Donnelly, M. (2009, p. 116). Confronting the challenges of assessing capacity: Dementia in the context of abuse. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 106-118). London, UK: Jessica Kingsley Publishers.

<sup>99</sup> Donovan, K. & Regehr, C. (2010, p. 175). Elder abuse: Clinical, ethical, and legal considerations in social work practice. *Clinical Social Work Journal*, 38: 174-182.

## Risk Factors

*Early research on elder abuse/neglect focused on the care receiver in the belief that the combination of his/her dependency on the caregiver and caregiver stress led to abuse or neglect. The solution was often to simply remove the victim from the home. More recently, however, attention has shifted to risk factors associated with the caregiver as well as the vulnerability of care receivers due to functional or cognitive impairment.<sup>100</sup>*

"...Health and social care professionals who work with older people will frequently come into contact with people who are abused whether they are aware of it." Only a small proportion of this abuse is currently disclosed.<sup>101</sup> Chronic disease and a progressive decline in activities of daily living and cognitive function heighten the risk of older adult abuse. Diminishing cognitive function has a significant impact since it may lead to disruptive behaviour on the part of the care receiver.<sup>102</sup>

Although physical abuse is believed to be the least common form of elder abuse, it is common among those with dementia. Lachs and Pillemer suggest this may be due to disruptive behaviours demonstrated by the person with dementia.<sup>103</sup> Living alone increases the risk of financial abuse and decreases the risk of physical abuse.<sup>104</sup>

A nine-year longitudinal US study of risk factors for reported and verified abuse discovered that existing functional disability, cognitive impairment, new or worsening cognitive impairment were risk factors for elder abuse.<sup>105</sup>

A study of severe family violence and Alzheimer's disease—of 184 Alzheimer's patients and their primary caregivers—found that two variables were significantly associated with violence in the care receiver/caregiver dyad: care receivers living with family members other than a spouse and caregiver depression. Caregivers who abuse and caregivers who are abused were found to be providing more hours of care, caring for more functionally impaired individuals and were more likely to be depressed.<sup>106</sup>

Fulmer et al., proposing a risk-and-vulnerability model, contend that elder abuse can result from a combination of: risk factors in the caregiver's background, vulnerability from the care receiver, and the dynamics of the relationship between the two.<sup>107</sup> Relevant factors include the care receiver's personality, cognitive and functional status, social support network and history of childhood trauma; the caregiver's functional status, childhood trauma and personality. Talley and Crews have proposed a similar model of caregiving, a triadic relationship between the family caregiver, the care receiver and the

<sup>100</sup> Lysne, L. (2010, p. 10). *Elder Care, Elder Abuse and Neglect: An International Literature Review*. Ottawa, ON: Division of Aging and Seniors, Public Health Agency of Canada.

<sup>101</sup> Cooper, C., Selwood, A. & Livingston, G. (2009, p. 827). Knowledge, detection, and reporting of abuse by health and social care professionals: A systematic review. *American Journal of Geriatric Psychiatry*, 17(10): 826-838.

<sup>102</sup> Lachs, M. S. et al. (1997). Risk factors for reported elder abuse and neglect: A nine-year observational study. *The Gerontologist*, 37(4): 469-477; Coyne, A. C., Reichman, M.D. & Berbig, L. J. (1993). The relationship between dementia and elder abuse. *American Journal of Psychiatry*, 150(4): 643-646; Coyne, A. C. (2005). The relationship between dementia and elder abuse. *Geriatric Times*, II (4). Retrieved October 28, 2010 from <http://www.cmellc.com/geriatrictimes/g010715.html>.

<sup>103</sup> Lachs, M. S. & Pillemer, K. (2004). Elder abuse. *Lancet*, 364: 1263-1272.

<sup>104</sup> Levine, J. M. (2003). Elder neglect and abuse: A primer for primary care physicians. *Geriatrics*, 58: 37-44.

<sup>105</sup> Lachs, M. S. et al. (1997). Risk factors for reported elder abuse and neglect: A nine-year observational study. *The Gerontologist*, 37(4): 469-477.

<sup>106</sup> Paveza, G. J. et al. (1992). Severe family violence and Alzheimer's disease: Prevalence and risk factors. *The Gerontologist*, 32(4): 493-497.

<sup>107</sup> Fulmer, T. T. et al. (2005). Dyadic vulnerability and risk profiling for elder neglect. *The Gerontologist*, 45(4): 525-534.

professional caregiver(s) which exists within a larger framework of variables that can affect the health and well-being of all three participants in the relationship<sup>108</sup>.

"More research is needed on the role of stress among caregivers, originally considered a primary cause of elder abuse. With the increasing prevalence of Alzheimer disease worldwide and the greater level of abusive behaviour found in families where a family member suffers from the disease, more attention should be given to the relationship between the caregiver and the care recipient. While it may be obvious that social isolation or lack of support can contribute to abuse or neglect, the sufferers of abuse in these situations are generally unwilling to join programmes that encourage social interaction, such as centre for the elderly or day-care activities. Research on who these victims are and on their situations might produce better solutions."<sup>109</sup>

The New Zealand Families Commission Research Report on Elder Abuse and Neglect identified risk and protective factors for individuals and for families. For the individual, risk factors were identified as isolation, poor physical health, mental competency, housing/living arrangements, ongoing partner violence, personal characteristics, and personal shame or guilt. For the family, risk factors were identified as family member with mental health issues and/or substance abuse, dysfunctional families (ongoing intimate partner violence; children abusing parents), overburdened families (time constraints, lack of money, lack of capacity to cope with caring needs), overbearing families who take total control, family greed, families that are geographically separated, and suspected sexual abuse by husband with wife who is not mentally competent.<sup>110</sup>

### Perspectives on Caregiving

*Caregiver stress has significant repercussions for patients and families, such as early patient institutionalization, substandard care, and neglect or abuse of patients. Signs such as depression, anxiety, irritability, and poor physical health can indicate that caregivers are in need of evaluation and psychosocial support.*<sup>111</sup>

"...Seniors caring for seniors are more likely to report psychological than physical health consequences. Senior women, in particular, are more likely than senior men to report that they sometimes or nearly always feel stressed between helping others, trying to meet other responsibilities and finding time for themselves (31% of women compared to 19% of men)."<sup>112</sup>

Cooper et al. identified determinants of family caregiver abusive behaviour to persons with dementia. They determined that more anxious and depressed caregivers reported more abuse; this relationship was mediated by dysfunctional coping strategies and higher burden. Abuse was predicated by spending more hours in caregiving. Caregivers for people with dementia experience more stress, anxiety and depression than the general population of caregivers for people with other disorders. "The particularly distressing nature of dementia caring is unsurprising, given the inevitability of increasing dependence,

<sup>108</sup> Talley, R. C. & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health, 97*(2): 224-228.

<sup>109</sup> World Health Organization (2002, p. 141). Abuse of the elderly. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi & R. Lozano (Eds.). *World Report on Violence and Health* (pp. 123-146). Retrieved September 3, 2010 from [http://whqlibdoc.who.int/publications/2002/9241545615\\_eng.pdf](http://whqlibdoc.who.int/publications/2002/9241545615_eng.pdf).

<sup>110</sup> Peri, K., Fanslow, J. & Parsons, J. (2008, p. 64). Elder Abuse and Neglect: Exploration of Risk and Protective Factors. New Zealand: Families Commission. Retrieved November 11, 2010 from <http://www.inpea.net/images/abuseneglect.pdf>.

<sup>111</sup> Kalapatapu, R. K. & Neugroschl, J. A. (2009, p. 25). Update on neuropsychiatric symptoms of dementia: Evaluation and management. *Geriatrics, 64*(4): 20-26.

<sup>112</sup> Canada (2010). *The Chief Public Health Officer's Report on the State of Public Health in Canada 2010*. Retrieved November 8, 2010 from <http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php>.

and high frequency of personality changes, loss of insight and behavioural problems including aggression."<sup>113</sup>

An earlier Canadian study by Jutras and Lavoie examined health indicators of co-residents/family caregivers (n=292) aged 55 and older with either a physical or cognitive impairment, and compared them to those of two non-caregiving groups. The research found that psychological health is adversely affected by caregiving, as evidenced by higher incidence of depression, anxiety, relationship problems with their family member, and lowered quality of life. The researchers suggested that "informal caregivers should be regarded as a target population for which health and social services should be carefully planned."<sup>114</sup>

Caregiving for a person with dementia may make significant physical, psychological and time demands on the family caregiver due to the care receiver's dependency on the caregiver and behavioural and psychological symptoms of dementia (BPSD). Research continues to examine caregiver wellbeing.

Over a third of family caregivers reported significant abuse from the people they cared for. Caregivers who reported a greater deterioration in their relationship with the person with dementia also reported more abuse. The use of dysfunctional coping strategies by the caregivers partially explained this, suggesting that interventions to change their coping styles might alleviate the impact of abusive behaviour.<sup>115</sup>

A Canadian research team recently studied the health consequences of caregiving on women who were caring for a family member who had been abusive to them in the past, or women who accepted their responsibilities only out of a sense of filial obligation. They theorized that such women will have poorer health outcomes than caregivers who accepted their responsibilities out of love and affection. Negative outcomes included fatigue, burnout, depression, sleeplessness, hostility, emotional distress, hypertension, back pain and increased arthritic pain. Analysis of the data from a survey of 236 female caregivers (average age 54 years), 64% of whom were daughters and 16% of whom were spouses, caring for a family member with a mean age of 77 years, supports the influence of the pre-morbid relationship and sense of obligation on health outcomes and health promotion activities by the caregiver.<sup>116</sup>

A study by Macneil et al. examined the ability of anger to mediate and moderate the relations of depression, resentment, and anxiety with potentially harmful behaviour (PHB) of caregivers of community-dwelling elderly care recipients with whom they co-reside. Anger was found to mediate the relation between anxiety and PHB. This suggests that "identifying anger levels among caregivers who report symptoms of depression is warranted. Reducing depression in caregivers who report high levels of anger may result in reductions of PHB. Screening for resentment is warranted, as the relation between resentment and anger is similar to that between depression and anger."<sup>117</sup>

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<sup>113</sup> Cooper, C., Selwood, A., Blanchard, M. & Livingston, G. (2010, p. 592). Abusive behaviour experienced by family carers from people with dementia: The CARD (caring for relatives with dementia) study. *Journal of Neurology, Neurosurgery & Psychiatry*, 81(6): 592-596.

<sup>114</sup> Jutras, S. & Lavoie, J.-P. (1995, p. 46). Living with an impaired elderly person: The informal caregiver's physical and mental health. *Journal of Aging and Health*, 7(1): 46-73.

<sup>115</sup> Cooper, C., Selwood, A., Blanchard, M. & Livingston, G. (2010, p. 596). Abusive behaviour experienced by family carers from people with dementia: The CARD (caring for relatives with dementia) study. *Journal of Neurology, Neurosurgery & Psychiatry*, 81(6): 592-596.

<sup>116</sup> Wuest, J., Hodgins, M. J., Malcolm, J., Merrit-Gray, M. & Seaman, P. (2007). Effects of past relationship and obligation on health and health promotion in women caregivers of adult family members. *Advances in Nursing Science*, 30(3): 206-220.

<sup>117</sup> Macneil, G., Kosberg, J. I., Durkin, D. W., Dooley, W. K., Decoster, J. & Williamson, G. M. (2009, p. 76). Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. *Gerontologist*, 50(1): 76-86.

Cooney, Howard and Lawlor explored "possible associations between characteristics of carers, dementia sufferers and the caring situation and the presence of abuse that was acknowledged by carers. ... Eighty-two carers of dementia sufferers were interviewed in their homes about three types of abuse (verbal abuse, physical abuse and neglect) using a structured questionnaire. ... Fifty-two percent (n = 43) carers admitted to having carried out some form of abuse. Verbal abuse was the most common form. ... Significant associations were found between verbal abuse and psychological ill health in the carer and behavioural problems in the dementia sufferer. Physical abuse was significantly associated with higher levels of self-reported good health by the carer." The researchers concluded that, "It is possible to identify situations where people with dementia may be at high risk of abuse from their carers. Any effective intervention strategy should address psychological health problems in the carer, behavioural problems in the dementia sufferer and a strategy to manage high levels of expressed emotion in these situations."<sup>118</sup>

Gainey and Payne state that caregiver burden is among the most cited explanations for elder abuse in the literature but, despite its popularity, the explanation is rarely tested empirically. They considered the role of caregiver burden in 751 suspected cases of elder abuse. "The results suggest that the role of burden has been misstated in past research."<sup>119</sup> "Caregiver burden is not a primary cause of abuse in Alzheimer's cases any more than it is a primary cause in other kinds of elder abuse cases. Essentially, it's not the situational context (e.g., providing care to an older person with dementia) that necessarily causes burden, but something else. ...Indeed, the stress explanation may be an 'oversimplification,' meaning that a lot of individuals experience stress, but not everyone commits abuse as a result of the stress."<sup>120</sup>

### Models of Interventions

Podnieks provides a comprehensive view of models of intervention for elder abuse:

#### *Domestic Violence Programs*

This model for program delivery is adapted from those that target abuse of women. It does not violate people's civil rights and does not discriminate on the basis of age. The domestic violence response to elder abuse involves crisis intervention services including telephone hotlines, a strong role for police, court orders for protection, the use of legal clinics, emergency and secondary sheltering, support groups, and health services. To date, however, the services have been "scant and sporadic," and questionable as to whether this is an effective model for elder abuse intervention.<sup>121</sup>

#### *Advocacy Programs*

Formal and informal advocacy programs occur in a number of provinces in Canada and operate in the community or in institutions. Examples include the Advocacy Centre for the Elderly (ACE), a community-based legal clinic for low income senior citizens in Toronto and the British Columbia Centre for Elder Advocacy and Support whose services include supportive programs for older adults who have been abused.<sup>122</sup> Some social scientists have argued that, in practice, it can be quite intrusive, as might not

<sup>118</sup> Cooney, C., Howard, R. & Lawlor, B. (2006, p. 564). Abuse of vulnerable people with dementia by their carers: Can we identify those most at risk? *International Journal of Geriatric Psychiatry*, 21(6): 564-571.

<sup>119</sup> Gainey, R. R. & Payne, B. K. (2006, p. 245). Caregiver burden, elder abuse and Alzheimer's disease: Testing the relationship. *Journal of Health and Human Services Administration*, 29(2): 245-259.

<sup>120</sup> Gainey, R. R. & Payne, B. K. (2006, p. 254). Caregiver burden, elder abuse and Alzheimer's disease: Testing the relationship. *Journal of Health and Human Services Administration*, 29(2): 245-259.

<sup>121</sup> Podnieks, E. (2008, p. 132). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>122</sup> BC Centre for Elder Advocacy and Support (2010). Retrieved November 15, 2010 from <http://site.bcceas.ca/>.

initially appear. "Older people are asking for a shift in the emphasis of responding to "elder abuse" from protection laws to a "rights" model involving collaboration between the older person and those who are offering services or support."<sup>123</sup>

#### *The Multidisciplinary Approach: An Integrated Model*

The integrated model is a coordinated community approach. Examples of this approach occur in communities that have formed community response networks (CRNs): British Columbia, Ontario, Alberta, Manitoba, and with First Nation Peoples. The Elder Abuse Consultation Team developed by the Family Service Association of Toronto is another example of an interdisciplinary model.<sup>124</sup>

#### *Restorative Justice*

The restorative justice approach frames elder abuse as primarily a violation of people and relationships, rather than a violation of the law. It aims to support older adults whose rights have been violated by a person in a position of trust and create processes that resolve conflict, and work respectfully toward restoring relationships while respecting the rights of all people involved in the conflict. This approach includes mediation, family conferencing and dispute resolution. This method is being piloted in several sites. There is, however, "some concern that it is easy for the abused to be re-victimized and the process may be another way that abuse of elder adults is defined as something less than a crime."<sup>125</sup>

#### *Networking*

A further framework which supports multiple aspects of prevention and intervention is the network. Regional networks in some jurisdictions, as well as national networks, have developed in Canada to help communities work together to better understand and address the underlying causes of abuse and neglect of older adults. Examples of networking programs are the Ontario Network for the Prevention of Elder Abuse (ONPEA),<sup>126</sup> the Canadian Network for the Prevention of Elder Abuse (CNPEA),<sup>127</sup> and the International Network for the Prevention of Elder Abuse (INPEA),<sup>128</sup> ONPEA was formed in 1989 and, over the years, "has spearheaded many creative and innovative projects that have been replicated in other areas of Canada." CNPEA is a "national nongovernment network whose focus is to help Canadian communities build their capacity for preventing and addressing elder abuse and neglect." In 1997, INPEA "was generated with representatives from six continents and has an active Canadian membership."<sup>129</sup>

<sup>123</sup> Podnieks, E. (2008, p. 133). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>124</sup> Podnieks, E. (2008, p. 134). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>125</sup> Podnieks, E. (2008, p. 135). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>126</sup> <http://www.onpea.org/>

<sup>127</sup> <http://www.cnpea.ca/>

<sup>128</sup> <http://www.inpea.net/>

<sup>129</sup> Podnieks, E. (2008, pp. 144-145). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.



## SCREENING FOR ABUSE

*The critical point in screening is that it is a first step, not an end in itself, and the language used needs to be understood by all professionals involved.*<sup>130</sup>

In a comprehensive review of the screening and assessment literature, Spencer discusses that screening can be broadly understood from three different perspectives:<sup>131</sup>

- Enquiry: An informal process of becoming aware of (and alert to) certain common indicators and knowing how to ask patients or clients about the issue
- Questions: A question or group of questions which are applied to all persons or select groups of persons that the health care provider comes in contact with; and
- Process: A systematic process of inquiry with the person and others.

The latter two may be referred to as formal screening. Enquiry and “screening for abuse” are both important, but they are not the same.

### Awareness Building, Communication and Confidence

Enquiry involves asking older adults questions about their wellbeing generally or more specifically about feeling safe, having control over their lives, or experiencing harm. A general awareness building process is used to facilitate enquiry by the health care provider and others working with older adults to recognize the signs of existing or potential abuse or neglect in later life, and be encouraged to “ask the question.”<sup>132</sup>

In some cases, screening tools have developed as a way to aid communication, and build the confidence in an uncharted territory. Currently many working with older adults have had minimal opportunities, if any, to learn about abuse or neglect in later life and its dynamics.

The Ontario Network for the Prevention of Elder Abuse (ONPEA), for example, in their core curriculum guide recommends the use of open-ended questions to give the person the opportunity to talk and elaborate on concerns.<sup>133</sup> ONPEA also stresses the need to respect the 3 A’s when older adults acknowledge there is a problem occurring, which involves:

- Active listening and reassurance.
- Ask the older person what he or she wants.
- Action according to wishes and follow-up.<sup>134</sup>

130 Perel-Levin, S. (2008, p. 19). *Discussing Screening for Elder Abuse at Primary Health Care Level*. London: World Health Organization.

<sup>131</sup> Spencer, C. (2009, p. 8). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>132</sup> Spencer, C. (2009, p. 8). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>133</sup> Ontario Network for the Prevention of Elder Abuse. Core Curriculum and Guide. Chapter 4. Retrieved November 15, 2010 from [www.onpea.org/english/download.php?name=CoreCurriculum.pdf](http://www.onpea.org/english/download.php?name=CoreCurriculum.pdf).

<sup>134</sup> ONPEA, Chapter 5, p.75.

## Assessment

"Screening and assessment" are commonly linked, but the line between the two may be grey. The general purpose of assessment is to further identify or clarify the situation, ascertain whether the suspicious circumstances might reflect abuse or neglect, and develop some understanding of the degree of the harm and context so as to promote safety and wellbeing of the person.<sup>135</sup> The purpose of screening and assessment is to pilot the health care providers and others through a systematic process of observation and documentation to ensure that the signs and symptoms of abuse are not missed, and appropriate assistance is offered.

Having considerable experience working on abuse issues with older adults, the Family Services Association of Toronto emphasizes that a well rounded assessment should be conducted from a strengths-based approach, focussing on how a person has managed in a situation, and identifying the degree of risk with which a person may be living. For example, the Chinese study by Dong and Simon found that older adults with a strong social support system may have a significantly lower risk of mistreatment.<sup>136</sup>

## Screening Tools

There are several purposes of screening tools. Fulmer et al. emphasize the need for consensus on various tools. Some instruments screen for existing abuse.<sup>137</sup> Others assess *future risk of abuse*, and have been developed to evaluate likelihood of a person becoming abusive or the likelihood of a person experiencing abuse in the future.<sup>138</sup> The objective of screening for future risk is to reduce the incidence of abuse or neglect, by detecting early preclinical forms when treatment or offering help may be easier and more effective than for advanced cases showing up after the symptoms occur. Both types of screening measures are integral to the development of intervention strategies and management plans for both the victim and the perpetrator.<sup>139 140</sup>

## Types of Tools

Screening tools may be divided into three types:

- Those that use direct questions ("Has anyone hit, threatened you?");
- Those based on indicators of abuse (identification of evident signs of abuse); and
- Those based on risk factors.<sup>141</sup>

<sup>135</sup> Spencer, C. (2009, pp. 8-9). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>136</sup> Dong, X. Q. & Simon, M.A. (2008). Is greater social support a protective factor against elder mistreatment? *Gerontology*, 54, 381-388.

<sup>137</sup> Fulmer, T., Guadagno, L., Bitondo-Dyer, C. & Connolly, M. T. (2004). Progress in elder abuse screening and assessment instruments. *Journal of the American Geriatrics Society*, 52(2): 297-304.

<sup>138</sup> Goodrich, C. S. (1997). Results of a national survey of state protective services programs: Assessing risk and defining victim outcomes. *Journal of Elder Abuse and Neglect*, 9, 69-86.

<sup>139</sup> Fulmer, T., Guadagno, L., Bitondo-Dyer, C. & Connolly, M. T. (2004). Progress in elder abuse screening and assessment instruments. *Journal of the American Geriatrics Society*, 52(2): 297-304.

<sup>140</sup> Spencer, C. (2009, pp. 8-10). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>141</sup> Cohen, M., Halevy Levin, S. L., Gagin, R. & Friedman, G. (2007). Elder abuse: Disparities between older people's disclosure of abuse, evident signs of abuse, and high risk of abuse. *Journal of the American Geriatrics Society*, 55(8): 1224-1230.

"The National Initiative for the Care of the Elderly (NICE) is an international network of researchers, practitioners, students and seniors dedicated to improving the care of older adults, both in Canada and abroad. NICE received funding from the New Horizons for Seniors Program to launch the NICE "Elder Abuse Theme Team: Knowledge to Action" project. This project disseminates evidence-based tools for the detection, management and prevention of elder abuse."<sup>142</sup> Screening tools to date include:

- Elder Abuse Suspicion Index (EASI), developed by Dr. Yaffe, McGill University, and colleagues, for use by family physicians to gauge suspicion regarding senior patients who may be at risk. Yaffe et al. argue that family physicians are well placed to detect and report abuse and require rapid screening tools to support this. They developed and validated a physician friendly tool, the EASI, for use in office settings to elicit suspicion of abuse in cognitively intact older adults.<sup>143</sup> This tool is now being trialled successfully by social workers and nurses. A further area of research includes application in long term care facilities, including residents with earlier stage dementia.
- Indicators of Abuse (IOA) and Caregiver Abuse Screen (CASE), developed by Drs. Myrna Reis and Daphne Nahmiash, for use by various allied health professionals for identifying risk and assisting with working toward prevention.
- Elder Abuse Assessment and Intervention Reference Guide, developed by community organizations and police services in Hamilton, Ottawa and Toronto, for use by police in intervening in situations involving elder abuse.
- *En Mains/In Hands*, developed by Dr. Marie Beaulieu, Université de Sherbrooke, is an ethical decision-making resource to assist a wide variety of professionals with thinking through their own values and triggers as they work to intervene in the most complex situations.

The other published validated instruments are summarized by Perel-Levin:

- *The Hwalek-Sengstock Elder Abuse Screening Test (HSEAST)*, which addresses the various types of elder abuse and is a self-report measure. The instrument has 15 items in three domains: violation of personal rights or direct abuse, characteristics of vulnerability, and potentially abusive situations.
- *The Brief Abuse Screen for the Elderly (BASE)* is a simple tool comprising five brief questions. The respondent here is the practitioner following an assessment of the patient.

Perel-Levin emphasizes that, "Elder abuse takes place within a context and, without a comprehensive assessment of the bio/psycho-social context of elder abuse, any screening or assessment instrument has significant limitations." She contends that, "The more disciplines, and the more older people are involved in the design and refinement of a tool, the better the tool will be accepted by both professionals and patients. It will also improve the interprofessional practice on referrals and interventions."<sup>144</sup>

In her research paper, Spencer "highlights questions that have arisen in this area generally and more specific issues for older adults and health care providers. Some questions include 'Should we actively

<sup>142</sup> Public Health Agency of Canada. (February 2010). *Elder Abuse Screening and Assessment: Elder Abuse E-Bulletin*. Retrieved November 12, 2010 from <http://www.phac-aspc.gc.ca/ea-ma/EB/eb-eng.php>.

<sup>143</sup> Yaffe, M. J., Wolfson, C. & Lithwick, M. (2009). Professions show different enquiry strategies for elder abuse detection: Implications for training and interprofessional care. *Journal of Interprofessional Care*, 23(6): 646-654.

<sup>144</sup> Perel-Levin, S. (2008, p. 15). *Discussing Screening for Elder Abuse at Primary Health Care Level*. London: World Health Organization.

screen for abuse and neglect (as opposed to simply being alert to signs), and if so, why?' and 'Do we have the necessary training, skills and tools to do this well?'<sup>145</sup>

Cooper et al. emphasize the need for a screening tool "to detect efficiently those cases of abuse where harm has occurred or where there is a high risk of harm, so that these can be managed urgently." These researchers contend that current abuse screening tools have low specificity for such cases and are therefore of limited use to health professionals.<sup>146</sup> Their study found that the Modified Conflict Tactics Scale (MCTS) is a brief instrument with good sensitivity and specificity when used as a screening instrument for clinically concerning abuse. This research suggests that this tool could be used routinely in clinical practice with caregivers of people with dementia "to detect clinically concerning cases of abuse, many of which are currently being missed."<sup>147</sup>

The Aging in America Elder Mistreatment Report emphasizes that the utility of screening instruments is an important area for research and recommends studies to track samples of individuals.<sup>148</sup> Recent research investigated characteristics of people with dementia and their caregivers to inform clinicians screening for abuse. The findings suggest significant characteristics of older adults with dementia and their caregivers that have potential for use in a clinical screening tool for elder abuse and potential screening questions to ask the caregivers of people with dementia.<sup>149</sup>

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<sup>145</sup> Public Health Agency of Canada. (February 2010). *Elder Abuse Screening and Assessment: Elder Abuse E-Bulletin*. Retrieved November 12, 2010 from <http://www.phac-aspc.gc.ca/ea-ma/EB/eb-eng.php>.

<sup>146</sup> Cooper, C., Maxmin, K., Selwood, A., Blanchard, M. & Livingston, G. (2009, p. 775). The sensitivity and specificity of the Modified Conflict Tactics Scale for detecting clinically significant elder abuse. *International Psychogeriatrics*, 21(4): 774-778.

<sup>147</sup> Cooper, C., Maxmin, K., Selwood, A., Blanchard, M. & Livingston, G. (2009, p. 778). The sensitivity and specificity of the Modified Conflict Tactics Scale for detecting clinically significant elder abuse. *International Psychogeriatrics*, 21(4): 774-778.

<sup>148</sup> Bonnie, R. J. & Wallace, R. B. (Eds.). (2003, p. 124). *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: National Academy of Sciences.

<sup>149</sup> Wigglesworth, A., Mosqueda, L., Mulnard, R., Liao, S. & Fitzgerald, W. (2010, p. 493). Screening for abuse and neglect of people with dementia. *Journal of the American Geriatrics Society*, 58(3): 493-500.

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## LEGAL CONSIDERATIONS

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### AN INTRODUCTION

A number of legal remedies exist in Canada to deal with elder abuse and neglect. Certain categories of abuse are prohibited under the *Criminal Code* while, for other types of abuse as well as neglect, provincial and territorial legislation set out procedures for investigation and intervention.

Most Canadian jurisdictions integrate the protection and legal interventions for abused or neglected older persons through the use of:

- Family violence protection laws (e.g., protective orders, restraining orders, peace bonds);
- Mental health, adult guardianship and substitute decision-making laws (for cases involving financial abuse and mental incapability [to make decisions]);
- In Quebec, into its human rights law.

Provinces and territories are responsible for public legal education, legal aid, poverty law, advocacy or victim services.

### Federal Legislation

*Criminal Code* provisions apply to various forms of elder abuse:<sup>150</sup>

- Provisions may apply in cases of **financial abuse**, for example, theft by a person holding power of attorney, misappropriation of money, extortion, forgery or fraud;
- Provisions that may apply in cases of **physical and sexual abuse** include unlawfully causing bodily harm, manslaughter, murder, assault, sexual assault and forcible confinement;
- Provisions that may apply in cases of **psychological/emotional abuse** include criminal harassment, uttering threats, harassing telephone calls, intimidation, and counselling suicide;
- Provisions that may apply in cases of **neglect** include failure to provide the necessities of life and criminal negligence causing death or bodily harm.

Laws are constantly under revision; organizations and service providers are encouraged to refer to the actual legislation for detailed and current information. Criminal law, however, is infrequently used to address abuse and neglect in later life. "Compared to domestic violence for other age groups, there are fewer criminal charges laid for abuse of older women and older men, and it can be difficult to get a prosecution."<sup>151</sup> Issues include:

- Older adults may be reluctant to pursue justice system intervention if they believe a close relative (who is often an adult child) will be convicted and punished.

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<sup>150</sup> Canada: Department of Justice. (2010). *Abuse of Older Adults: Department of Justice Canada Overview Paper*. Retrieved December 13, 2010 from <http://canada.justice.gc.ca/eng/pi/fv-vf/facts-info/old-age/index.html>.

<sup>151</sup> Canadian Network for the Prevention of Elder Abuse. (2010). *Canadian Laws on Abuse and Neglect*. Retrieved October 14, 2010 from [http://www.cnpea.ca/canadian\\_laws\\_on\\_abuse\\_and\\_negle.htm](http://www.cnpea.ca/canadian_laws_on_abuse_and_negle.htm).

- In some criminal cases, the senior's health may deteriorate in the time between the charge and the court case, making them unavailable as a witness. In other instances, the primary witness (the victim) may experience mental incapacity<sup>152</sup>

### **Provincial/Territorial Legislation**

Provincial and territorial frameworks sometimes include adult protection legislation, adult guardianship, family violence statutes, human rights statutes and long-term care facilities regulation. As well, the provinces and territories have jurisdiction in many areas that affect older adults, such as family law, consumer protection and housing. For example, some jurisdictions in Canada have adult protection legislation, but not all jurisdictions have mandatory reporting requirements related to instances of elder abuse. Thus, powers and responsibilities vary in each jurisdiction.

The following chart <sup>153</sup> summarizes the laws in each province and territory.

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<sup>152</sup> Gordon, R. M. & Verdun-Jones, S. N. (1992). *Adult Guardianship Law in Canada*. Toronto: Carswell.

<sup>153</sup> Canadian Centre for Elder Law Studies. (2010). *The Counterpoint Project Discussion Paper: Moving from Scrutiny to Strategy*.

## Responding to Elder Abuse & Neglect Summary of the Law in each Province & Territory

	Law	Where	When	Who
BC	<i>Adult Guardianship Act</i> , R.S.B.C., 1996, c. 6.	Adult is living anywhere (except in a prison).	An adult is being abused or neglected and is unable to seek support or assistance.	Any person may notify a designated agency.
			A report of abuse or neglect has been received, there are reasons to believe an adult is abused or neglected, or a representative, decision maker, guardian or monitor is hindered from visiting or speaking with the older adult.	An employee of a designated agency must: refer to health care, social, legal accommodation, or other services; assist older adult in obtaining services; inform public guardian and trustee; investigate abuse or neglect; or report criminal offence to police.
	<i>Community Care and Assisted Living Act</i> , R.S.B.C. 2002, c. 75.	Adult is residing in a community care facility or assisted living residence.	A person in care witnesses or experiences elder abuse or neglect.	Licensee of the facility must notify: the parent or representative, or contact person of the person in care; medical practitioner or nurse practitioner responsible for the care of the person in care; medical health officer; and funding program.
AB	<i>Protection for Persons in Care Act</i> , S.A. 2009, c. P-29.1.	Adult receives care or support services from a lodge accommodation, hospital, mental health facility, nursing home, social care facility, or other service provider.	An adult who receives care or support services is being abused, or has been abused.	Every person must report to a complaints officer, a police service, or a committee, body or person authorized under another enactment to investigate abuse.
SK	<i>Victims of Domestic Violence Act</i> , S.S. 1994, c. V-6.02.	Adult is living in the community (i.e. not in care).	Domestic violence has occurred.	A victim, a person on behalf of the victim who has the victim's consent, or a person on behalf of the victim with leave of the court or designated justice of the peace may apply for an <i>ex parte</i> order or restraining order from the court.

**Please be aware: This material contains information and guidance for practice. The information is not legal advice. Elder abuse and neglect can have serious consequences. It will be your obligation to seek legal advice and ensure that you are in compliance with the law.**

**The law is always changing. Legislative reform and legal precedents continuously revise how the law applies to a situation. All material provided is up to date as of August 31, 2010. Any substantive changes to the law after August 31, 2010 are not included in these materials.**

	Law	Where	When	Who
<b>SK</b>	<i>Personal Care Homes Regulations</i> , R.R.S. c. P-6.01 Reg. 2.	Adult is a resident in a personal care home.	Serious incident has occurred.	Licensee must inform the resident's supporter or a member of the resident's family, resident's personal physician, the department and the regional health authority.
<b>MB</b>	<i>Protection for Persons in Care Act</i> , C.C.S.M. c. P144.	Adult is a resident, in-patient or person receiving respite care in a health facility.	A resident, in-patient or person receiving respite care in a health facility is being abused, or is likely to be abused.	<b>Employee or service provider at a health facility</b> must promptly report to the Minister.
	<i>Vulnerable Persons Living with a Mental Disability Act</i> , C.C.S.M. c. V90.	Adult has had a mental disability since childhood and is in need of assistance.	An adult who has had a mental disability since childhood is being abused or neglected, or is likely to be abused or neglected.	<b>A person who provides care, support services or related assistance, a substitute decision maker, or a committee</b> must report to the executive director appointed by the Minister.
<b>Ont</b>	<i>Long Term Care Homes Act 2007</i> , S.O. 2007, c. 8.	Adult is residing in a long-term care home.	Harm, abuse or neglect has occurred or may occur.	<b>A staff member, any person who provides professional services</b> (i.e. health, social services) and licensee must report to the Director appointed by the Minister.
<b>Que</b>	<i>Chartre des droits et libertés de la personne</i> , L.R.Q., c. C-12.	Adult is living anywhere.	Older adult is the victim of exploitation.	<b>Victims, group of victims, or advocacy organization</b> may apply to human rights commission. Commission may initiate investigation.
<b>NB</b>	<i>Family Services Act</i> , S.N.B. 1980, c. F-2.2	Adult is living anywhere.	Adult is being abused or is at risk of abuse.	<b>Professional person</b> (i.e. care worker, physician, nurse, or other health or mental health professional, social worker, etc.) may report to the Minister.
<b>NS</b>	<i>Protection for Persons in Care Act</i> , S.N.S. 2004, c. 33.	Adult is a patient of a hospital or a resident of a health facility (i.e. special care home).	Adult is being abused or is likely to be abused.	<b>Employees and service providers of a health facility</b> must promptly report to the Minister.

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The law is always changing. Legislative reform and legal precedents continuously revise how the law applies to a situation. All material provided is up to date as of August 31, 2010. Any substantive changes to the law after August 31, 2010 are not included in these materials.



	Law	Where	When	Who
NS	<i>Adult Protection Act</i> , R.S., c. 2.	Adult is living anywhere.	Adult is the victim of abuse or is not receiving adequate care, is incapable of protecting himself or herself and refuses, delays or is unable to protect himself or herself.	Any person must report to the Minister of Community Services.
PEI	<i>Adult Protection Act</i> , R.S.P.E.I. 1988, c. A-5.	Adult is living anywhere.	Adult is in need of assistance or protection, or is at serious risk.	Any person may report to the Minister.
Nfld	<i>Neglected Adults Welfare Act</i> , R.S.N.L. 1990, c. N-3.	Adult is living anywhere (except a mental health facility).	An adult is incapable of caring properly for himself or herself, not suitable to be in a mental health facility, not receiving proper care and attention and refuses, delays or is unable to make provision for proper care and attention for himself or herself.	Any person must give information to Director of Neglected Adults, or to a social worker (who must report the matter to the Director).
Nu	<i>Family Abuse Intervention Act</i> , S.Nu. 2006, c. 18.	Adult is living in the community (i.e. not in care).	Family abuse has occurred.	A victim, a person on behalf of the victim who has the victim's consent, or a person on behalf of the victim with leave of the court or designated justice of the peace may apply for an <i>ex parte</i> or restraining order from the court.
NWT	<i>Protection Against Family Violence Act</i> , S.N.W.T. 2003, c. 24.	Adult is living in the community (i.e. not in care).	Family violence has occurred.	A victim, a person on behalf of the victim who has the victim's consent, or a person on behalf of the victim with leave of the court or designated justice of the peace may apply for an <i>ex parte</i> or restraining order from the court.
YK	<i>Adult Protection and Decision Making Act</i> , S.Y. 2003, c. 21, Sch. A.	Adult is living anywhere (except a prison).	An adult is abused or neglected and unable to seek support or assistance.	Any person may report to the Seniors' Services/Adult Protection Unit, currently the only designated agency in the Yukon.

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**The law is always changing. Legislative reform and legal precedents continuously revise how the law applies to a situation. All material provided is up to date as of August 31, 2010. Any substantive changes to the law after August 31, 2010 are not included in these materials.**

## Effectiveness of Canadian Laws

When looking at whether or not particular laws are effective in preventing abuse and neglect of older adults or addressing abuse if it has occurred, it is important to look at the scope (what the laws cover and what are they intended to do), what needs that they are serving, whether they are used, how they are used, and whether they respect the rights of the abused.<sup>154</sup>

Currently there are challenges in the Canadian legal system. Adult protection laws can be limited in scope and some are considered paternalistic. Some adult protection laws may lack procedural safeguards.<sup>155</sup>

There is concern that appropriate assistance and support services may not be available after authorities have intervened in an abuse case. Many communities have seen a lack of services or reductions in health and social services budgets which can make response challenging.<sup>156</sup> Adequate community resources are key in order for responses to be effective. In recent years, some provinces have seen major reductions (and, in some cases, elimination of services) for victim services, legal aid and lawyers who cover poverty law (which can be important in helping low income older adults have their rights respected). These service cuts affect vulnerable people in all age groups, but also especially harm abused older adults.

## Abused Older Adults and Use of the Justice System

It is common to hear statements like “abused or neglected seniors won’t use the legal system,” or “they don’t want to lay criminal charges against their children,” or “they won’t sue the person if they have been financially abused.” This is sometimes accurate, and these are very difficult decisions for people who have been harmed, no matter what their age.<sup>157</sup> (For further information, see the Abuse of Older Adults: Department of Justice Canada Overview Paper.)<sup>158</sup>

## Barriers and Opportunities

Throughout Canada, policy and attitudinal barriers in the justice system can “shut out” many abused or neglected older adults from having their situations treated as crimes. These barriers are heightened when one has a form of dementia. These include:<sup>159</sup>

- Police may lack training to recognize and appropriately respond to abuse of seniors;
- Ageism and paternalism (such as when people in authority do not believe older adults or do not consider the harms as serious);
- Police and community service agencies may not have training in appropriate interviewing techniques to help draw the best and most reliable information from older adults;

<sup>154</sup> Canadian Network for the Prevention of Elder Abuse. (2010). *Canadian Laws on Abuse and Neglect*. Retrieved October 14, 2010 from [http://www.cnpea.ca/canadian\\_laws\\_on\\_abuse\\_and\\_negle.htm](http://www.cnpea.ca/canadian_laws_on_abuse_and_negle.htm).

<sup>155</sup> Macdonald, M. & Collins, A. (1998). *Abuse and Neglect of Older Adults: A Discussion Paper*. Ottawa: Health Canada Family Violence Prevention Unit. Online at: [www.hc-sc.gc.ca/hppb/familyviolence/html/agediscussion\\_e.html](http://www.hc-sc.gc.ca/hppb/familyviolence/html/agediscussion_e.html).

<sup>156</sup> Harbison, J., Coughlan, S. G., Downe-Warmboldt, B., Elgie, R., Melanson, P. & Morrow, M. (1995). *Mistreating Elderly People: Questioning the Legal Response to Elder Abuse and Neglect*. Halifax, NS: Dalhousie University Health Law Institute.

<sup>157</sup> Canadian Network for the Prevention of Elder Abuse. (2010). *Canadian Laws on Abuse and Neglect*. Retrieved October 14, 2010 from [http://www.cnpea.ca/canadian\\_laws\\_on\\_abuse\\_and\\_negle.htm](http://www.cnpea.ca/canadian_laws_on_abuse_and_negle.htm).

<sup>158</sup> Canada: Department of Justice. (2010). *Abuse of Older Adults: Department of Justice Canada Overview Paper*. Retrieved December 13, 2010 from <http://canada.justice.gc.ca/eng/pi/fv-vf/facts-info/old-age/index.html>.

<sup>159</sup> Canadian Network for the Prevention of Elder Abuse. (2010). *Canadian Laws on Abuse and Neglect*. Retrieved October 14, 2010 from [http://www.cnpea.ca/canadian\\_laws\\_on\\_abuse\\_and\\_negle.htm](http://www.cnpea.ca/canadian_laws_on_abuse_and_negle.htm).

- Police and community services agencies may not document and utilize the available collateral information from people who have direct knowledge of abuse;
- There are limited lawyers with special skills to recognize and address the needs of older clients and aging issues;
- The legal environment may be unsupportive (e.g., where abused older adults are ignored or treated in a paternalistic way; a lack of appropriate victim services to help older adults in the legal process);
- Policies of the police or community services may divert later life abuse cases into the health system. (As a result, staff are told to use all other tools, which may include those that are available under mental health acts, as a result focusing more on the health or mental condition of the abused person than on the fact that they are being abused);
- Crown and judges are often not trained on abuse issue issues affecting older adults and the impact of the abuse on their lives.<sup>160</sup>

Many of these barriers can be reduced through training, education, and policy development through ongoing efforts by community agencies and the justice system, but progress to date has been slow.

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<sup>160</sup> Beaulieu, M. & Spencer, C. (1999). *Older Adults' Personal Relationships and the Law in Canada*. Ottawa, ON: Law Commission of Canada Online at: [www.lcc.gc.ca/en/themes/pr/oa/spencer/spencer.asp#ftnref88](http://www.lcc.gc.ca/en/themes/pr/oa/spencer/spencer.asp#ftnref88).

## ETHICAL PERSPECTIVES

*Abuse and neglect of older adults in society breaches a widely embraced moral commitment to protect vulnerable people from harm and to ensure their well-being and security.*<sup>161</sup>

Professionals struggle with complex ethical dilemmas created by elder abuse, particularly when the victim does not want an investigation and when faced with complex family and contextual factors.<sup>162</sup>

### Research and Practice

A study by Beaulieu and Leclerc<sup>163</sup> examined interventions regarding elder abuse and raised questions for practitioners. Five themes emerged, with a focus on psychosocial and ethical issues:

1. Practitioners need to be aware of their own perspectives on aging, older adults and violence, and what personal values they put forward with the intervention.
2. Practitioners need to understand the victim's capacity, and appreciate grey areas (capacity is determined by the specific decision at hand).
3. Practitioners need to be aware of issues of information sharing between practitioners and agencies (duty of confidentiality, rights to privacy).
4. Practitioners need to consider ways to address the problem of violence within the family.
5. Practitioners need to understand the competing values that arise between autonomy and ensuring protective measures.

Beaulieu and Leclerc developed a framework for ethical decision-making to support psychosocial practitioners in their ethical reflection, leading to decision-making during the intervention process in senior abuse situations. They intend to adapt the framework to be used in various socio-legal settings. The framework, *In Hand*, targets various competing values arising in a senior abuse situation and provides various suggestions for practice. This process facilitates the identification of psychosocial and ethical situations raised in practice.<sup>164</sup>

This *In Hand* framework can be applied in particular to dementia abuse issues:

- "The starting point for this decision-making tool is decision-making capacity. It inquires whether the person has capacity to make decisions and defend his or her rights. If the answer is 'yes', then the next step focuses on whether or not the person accepts the intervention. If the answer is 'no', the

<sup>161</sup> Bonnie, R. J. & Wallace, R. B. (Eds.). (2003, p. xiv). *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: National Academy of Sciences.

<sup>162</sup> Killick, C. & Taylor, B. J. (2009). Professional decision making on elder abuse: Systematic narrative review. *Journal of Elder Abuse & Neglect*, 21(3): 211-238.

<sup>163</sup> Beaulieu, M. & Leclerc, N. (2006). Ethical and psychosocial issues raised by the practice in cases of mistreatment of older adults. *Journal of Gerontological Social Work*, 46(3/4): 161-186.

<sup>164</sup> Beaulieu, M. & Leclerc, N. (2006). Ethical and psychosocial issues raised by the practice in cases of mistreatment of older adults. *Journal of Gerontological Social Work*, 46(3/4): 161-186.

practitioner should cease the intervention, and the practitioner then considers how he or she feels about this action."<sup>165</sup>

- Part of the purpose of this decision-making tool is to summarize the abuse situation with facts; to identify all players in the situation "(abused person, abuser, close relations); to identify all active partners in the case from public, private, community networks, and to identify past and present interventions (what has worked, or not worked, and why."<sup>166</sup>
- Practitioners need to be aware of their own perspective towards persons with loss of cognition (e.g., dementiaism) and the relationships within family settings.
- "Abuse should never be condoned whatever the mitigating circumstances. What may not be considered abusive towards a healthy, competent person may be so in a vulnerable older adult."<sup>167</sup>
- When dealing with older adults with cognitive losses, practitioners need to be particularly aware of the grey areas of capacity. O'Connor and Donnelly discuss the challenges of assessing capacity within the arena of abuse and dementia, and the need for health professionals to consider the importance of context in both undertaking assessments and making determinations about capacity. They suggest broadening the scope of the assessment process to ensure "that the assessment moves beyond a focus on intellect to the entire person."<sup>168</sup> Efforts must be made to talk with people when they are at their best, especially when fluctuating capacity is a consideration.<sup>169</sup> Further, capacity for decision-making is a function of the person and the decision at hand.<sup>170</sup>

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<sup>165</sup> Beaulieu, M. (2010). *In Hand: An Ethical Decision-making Framework*. Canada: New Horizons for Seniors Program, Human Resources and Skills Development Canada. Retrieved November 15, 2010 from [http://www.nicenet.ca/files/IN\\_HAND.pdf](http://www.nicenet.ca/files/IN_HAND.pdf).

<sup>166</sup> Beaulieu, M. (2010). *In Hand: An Ethical Decision-making Framework*. Canada: New Horizons for Seniors Program, Human Resources and Skills Development Canada. Retrieved November 15, 2010 from [http://www.nicenet.ca/files/IN\\_HAND.pdf](http://www.nicenet.ca/files/IN_HAND.pdf).

<sup>167</sup> Katona, C., et al. (2009, p. 1321). World Psychiatric Association section of old age psychiatry consensus statement on ethics and capacity in older people with mental disorders. *International Journal of Geriatric Psychiatry*, 24: 1319-1324.

<sup>168</sup> O'Connor, D. & Donnelly, M. (2009, p. 116). Confronting the challenges of assessing capacity: Dementia in the context of abuse. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 106-118). London, UK: Jessica Kingsley Publishers.

<sup>169</sup> British Medical Association (2009, p. 36). *The Ethics of Caring for Older People (2nd Ed.)*. Chichester, West Sussex, UK: John Wiley & Sons Ltd.

<sup>170</sup> Flegel, K. M. & MacDonald, N. (2008, p. 127). Editorial: Decision-making capacity in an age of control. *Canadian Medical Association Journal*, 178(2): 127.

## ISSUES AND CHALLENGES

*Abuse and neglect of older adults occurs in all Canadian communities and solutions require the coordinated efforts of society at large. Amelioration entails more than a legislative approach. Prevention of this growing problem is a social responsibility that requires networking and collaboration between different disciplines in all sectors of the community.*<sup>171</sup>

A central theme from the literature is that abuse and neglect are complex areas to explore and, as a result, there have been difficulties in establishing a theoretical base.<sup>172 173 174 175</sup> Internationally, the issues abound. Summarizing the UK situation, Penhale describes elder abuse as the most recent form of interpersonal violence to have been recognized as a problem that needs attention. Until recently, it has been hidden from public concern and regarded as a "taboo" topic. Much mistreatment happens behind closed doors whether in homes or institutions.<sup>176</sup> Likewise in New Zealand, "although significant research and intervention activities have been undertaken to reduce family violence in general, less is known about the nature of elder abuse and neglect, and appropriate and effective prevention strategies."<sup>177</sup>

There are different types of mistreatment, different settings and a range of participants involved in abusive situations. A change of setting (e.g., from home to institutional setting) does not necessarily result in the abuse ceasing altogether, but rather a different type of abuse occurs. Societal ageism and ambivalence toward older adults and their care are a part of the challenge. Naming the situation is vital—abusive situations that occur in private are not discussed and often not recognized.<sup>178</sup>

"Professionals and carers reported significantly different views from each other and guidelines about what constituted elder abuse. This may be because abuse remains unacknowledged if people feel there are no better management options," and disclosing sometimes leads to "punitive action for the carer perhaps coupled with institutionalization for the person with dementia. Successful guidelines require societal agreement about what constitutes abuse and that prevention leads to better outcomes."<sup>179</sup>

The challenges are global. Killick and Taylor confirm that, internationally, social work and health care professionals recognize the need to better understand and respond to the abuse of older people. In an

<sup>171</sup> Podnieks, E. (2008, p. 126). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>172</sup> Penhale, B. (2008). Elder abuse in the United Kingdom. *Journal of Elder Abuse & Neglect*, 20(2): 151-168

<sup>173</sup> Podnieks, E., Anetzberger, G. J., Wilson, S. J., Teaster, P. B. & Wangmo, T. (2010). WorldView Environmental Scan on Elder Abuse. *Journal of Elder Abuse and Neglect*, 22(1-2): 164-179.

<sup>174</sup> Podnieks, E., Penhale, B. Goergen, T., Biggs, S. & Han, D. (2010). Elder mistreatment: An international narrative. *Journal of Elder Abuse and Neglect*, 22(1-2): 131-163.

<sup>175</sup> Quinn, K. & Zielke, H. (2005). Elder abuse, neglect, and exploitation : Policy issues. *Clinics in Geriatric Medicine*, 21(2): 449-457.

<sup>176</sup> Penhale, B. (2008, p. 153). Elder abuse in the United Kingdom. *Journal of Elder Abuse & Neglect*, 20(2): 151-168.

<sup>177</sup> Peri, K., Fanslow, J., Hand, J. & Parsons, J. (2010). Keeping older people safe by preventing elder abuse and neglect. New Zealand: Ministry of Social Development. Retrieved October 17, 2010 from <http://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj35/35-keeping-older-people-safe.html>.

<sup>178</sup> Penhale, B. (2008, pp. 153-154). Elder abuse in the United Kingdom. *Journal of Elder Abuse & Neglect*, 20(2): 151-168

<sup>179</sup> Selwood, A., Cooper, C. & Livingston, G. (2007, p. 1009). What is elder abuse—who decides? *International Journal of Geriatric Psychiatry*, 22: 1009-1012.

extensive literature review of nine bibliographic databases, they found that policy and guidance have identified processes; however, definitions of key concepts remain problematic, and the literature suggests that practitioners and agencies have little insight or guidance for decision making.<sup>180</sup>

There is not one particular picture of "an abuser"—rather this person looks different depending upon the type and context of abuse. For example, spouses (husbands in particular) are more likely to abuse physically, and adult children are more likely to perpetuate financial or resource abuse.<sup>181</sup>

Podnieks provides an overview of efforts within Canada during the past decades. In the 1980s adult protection legislation and mandatory reporting came under scrutiny. The 1990s included publication of the first national scope survey that helped to understand the extent of the problem of elder abuse in Canada. During this decade the federal government funded research programs and education, and there was a growth of community-based elder abuse networks to raise awareness and to try to define the issue. "Research in Canada continues to grow and explore various areas related to the development of theory."<sup>182</sup> Harbison and colleagues' empirical interdisciplinary research (including social work, sociology and law) has focused on the interrelationship between legislation and social delivery in response to mistreatment and neglect of older persons.<sup>183 184</sup>

Podnieks' review emphasized that all Canadian provinces and territories have legislation providing for the appointment of a guardian on behalf of individuals who are mentally incapable of managing their own financial affairs. The court-appointed guardian has the power to make decisions with respect to that individual's person or property or both.<sup>185</sup> However, a recent review by Harbison et al. of adult protection legislation in three Canadian provinces indicates that "there are considerable issues with regard to respecting the rights and autonomy of older people."<sup>186</sup> "Many of these laws have been criticised for inadequacies in responding to elder abuse and neglect... In addition, it is an expensive and convoluted process."<sup>187</sup>

A recent study by Spencer highlights sensitivities in the area of elder abuse screening and assessment. "...Early identification and appropriate assistance has the potential for improving health care and quality of life for older victims. However, determining the value of screening involves balancing potential benefits against potential harms. Many of the existing tools try to predict the risk of abuse or neglect occurring in the future, in contrast to screening for abuse currently happening." Spencer suggests that universal screening of older adults may lead to individuals being labeled as victims and family members labeled as abusers.<sup>188</sup>

<sup>180</sup> Killick, C. & Taylor, B. J. (2009, p. 211). Professional decision making on elder abuse: Systematic narrative review. *Journal of Elder Abuse and Neglect*, 21(3): 211-236.

<sup>181</sup> O'Connor, D. & Donnelly, M. (2009, p. 108). Confronting the challenges of assessing capacity: Dementia in the context of abuse. In D. O'Connor & B. Purves. (Eds.). *Decision-making, personhood and dementia: Exploring the interface* (pp. 106-118). London, UK: Jessica Kingsley Publishers.

<sup>182</sup> Podnieks, E. (2008, p. 136). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>183</sup> Harbison, J., Coughlan, S. G., Downe-Wariboldt, B., Elgie, R., Melanson, P. & Morrow, M. (1995). *Mistreating Elderly People: Questioning the Legal Response to Elder Abuse and Neglect*. Halifax, NS: Dalhousie University Health Law Institute.

<sup>184</sup> Harbison, J., McKinley, P. & Pettipas, D. (2006). Older people as objects, not subjects: Theory and practice in situations of elder abuse. In R. Alaggia & C. Vine (Eds.). *Cruel but not Unusual*. (pp. 467-502). Waterloo, ON: Wilfrid Laurier.

<sup>185</sup> Podnieks, E. (2008, pp. 130-131). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>186</sup> Harbison, J. et al. (2008, p. 307). Adult protection legislation: From intent to practice in three Canadian provinces. *Indian Journal of Gerontology*, 22(3-4): 307-319.

<sup>187</sup> Podnieks, E. (2008, p. 131). Elder abuse: The Canadian experience. *Journal of Elder Abuse & Neglect*, 20(2): 126-150.

<sup>188</sup> Public Health Agency of Canada. (February 2010). *Elder Abuse Screening and Assessment: Elder Abuse E-Bulletin*. Retrieved November 12, 2010 from <http://www.phac-aspc.gc.ca/ea-ma/EB/eb-eng.php>.

Penhale emphasizes that, "In order to increase much needed awareness and knowledge of the problem, including at the level of the general public, systems and approaches to education and training must be further developed. This will then act as the framework from which appropriate responses to mistreatment, including prevention, can evolve. There is also a critical need for more research into this whole area to improve both our knowledge and understanding of mistreatment and ultimately, how to prevent it. Commitment and action are needed on the part of both individuals and government to pursue this agenda as far as is necessary."<sup>189</sup>

Ploeg et al. conducted a rigorous systematic review in order to summarize the effectiveness of interventions for elder abuse. Only eight studies met the inclusion criteria. They concluded that, "Elder abuse interventions had no significant effect on case resolution and at-risk caregiver outcomes, and had mixed results regarding professional knowledge and behavior related to elder abuse."<sup>190</sup> "...There is currently insufficient evidence to support any particular intervention related to elder abuse targeting clients, perpetrators, or health care professionals."<sup>191</sup>

Subsequently, these researchers emphasized the need for high-quality research in the areas of case management, home-based geriatric assessment, support groups, adult protective services, multiservice programs, partnerships with faith communities, and professional education. They recommend that mixed-methods studies include both quantitative and qualitative components to help to determine not only the effectiveness of interventions but also to understand why some interventions are successful or not and the perspectives of recipients who receive those interventions.<sup>192</sup>

A number of "promising approaches," those that practitioners and researchers in the field believe are effective but which have not been evaluated, will be discussed in the final section of this report.

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<sup>189</sup> Penhale, B. (2008, p. 167) Elder abuse in the United Kingdom. *Journal of Elder Abuse & Neglect*, 20: 2: 151-168.

<sup>190</sup> Ploeg, J., Fear, J., Hutchison, B., MacMillan, H. & Bolan, G. (2009, p. 187). A systematic review of interventions for elder abuse. *Journal of Elder Abuse & Neglect*, 21(3):187-210.

<sup>191</sup> Ploeg, J., Fear, J., Hutchison, B., MacMillan, H. & Bolan, G. (2009, p. 206). A systematic review of interventions for elder abuse. *Journal of Elder Abuse & Neglect*, 21(3):187-210.

<sup>192</sup> Ploeg, J., Fear, J., Hutchison, B., MacMillan, H. & Bolan, G. (2009, p. 207). A systematic review of interventions for elder abuse. *Journal of Elder Abuse & Neglect*, 21(3):187-210.



## MOVING FORWARD

*At the most basic level, greater importance must be attached to primary prevention. This requires building a society in which older people are allowed to live out their lives in dignity, adequately provided with the necessities of life and with genuine opportunities for self-fulfilment. For those societies overwhelmed by poverty, the challenge is enormous.*<sup>193</sup>

Supporting community and societal change that reduces ageism and promotes positive and valued roles for older people is a cornerstone to moving forward. "Practical strategies—such as the provision of information for older people, family and carers—that support the empowerment of older people may also help to minimise the risks of elder abuse and neglect."<sup>194</sup>

### Prevention Starts with Awareness

One important way to raise awareness—both among the public and concerned professionals—is through education and training. Those providing health care and social services at all levels, both in the community and in institutional settings, require basic training on the detection of elder abuse. To reduce barriers to the disclosure of elder abuse, Halpen et al. propose clinician education that includes familiarity with a simple approach to screening and identification of cases, awareness of risk factors and warning signs, and awareness of appropriate interventions.<sup>195</sup> Both community and acute care settings are opportunities for identifying elderly persons at risk of abuse.<sup>196</sup> Family physicians and emergency room physicians are "ideally situated" to see mistreated older adults and "to refer suspected abuse and neglect for appropriate action."<sup>197</sup> The media are a second powerful tool for raising awareness of the problem and its possible solutions, among the general public as well as the authorities.<sup>198</sup>

A general awareness building process is necessary to facilitate enquiry by the health care provider and others such as Alzheimer Society staff and volunteers. This includes raising awareness of risk factors specific and unique to those living with dementia. Through training, they learn to recognize the signs of existing or potential abuse or neglect in later life, and are encouraged to "ask the question." The purpose of awareness building is not necessarily to introduce a formal screening method, but to give health care providers a basic knowledge about abuse and neglect in later life as well as about

<sup>193</sup> World Health Organization (2002, p. 142). Abuse of the elderly. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi & R. Lozano (Eds.). *World Report on Violence and Health* (pp. 123-146). Retrieved September 3, 2010 from [http://whqlibdoc.who.int/publications/2002/9241545615\\_eng.pdf](http://whqlibdoc.who.int/publications/2002/9241545615_eng.pdf).

<sup>194</sup> Peri, K., Fanslow, J. & Parsons, J. (2010). Keeping older people safe by preventing elder abuse and neglect. New Zealand: Ministry of Social Development. Retrieved October 17, 2010 from <http://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj35/35-keeping-older-people-safe.html>.

<sup>195</sup> Halphen, J. M., Varas, G. M. & Sadowsky, J. M. (2009). Recognizing and reporting elder abuse and neglect. *Geriatrics*, 64(7): 13-8.

<sup>196</sup> Cohen, M., Levin, S. H., Gaglin, R. & Friedman, G. (2007, p. 1224). Elder abuse: Disparities between older people's disclosure of abuse, evident signs of abuse, and high risk of abuse. *Journal of the American Geriatric Society*, 55(8): 1224-1230.

<sup>197</sup> Bonnie, R. J. & Wallace, R. B. (Eds.). (2003, p. 127). *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: National Academy of Sciences.

<sup>198</sup> World Health Organization (2002, p. 142). Abuse of the elderly. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi & R. Lozano (Eds.). *World Report on Violence and Health* (pp. 123-146). Retrieved September 3, 2010 from [http://whqlibdoc.who.int/publications/2002/9241545615\\_eng.pdf](http://whqlibdoc.who.int/publications/2002/9241545615_eng.pdf).

community resources, along with communication skills to ask about abuse or neglect in a safe, respectful and trust building manner.<sup>199</sup>

### Select Screening Tools

Screening and assessment tools serve a number of diverse purposes and functions. For example, the tool may be used to aid detection and identification, assessment, and intervention in abuse cases involving older adults. While screening tools are used to identify potential instances of abuse, they do not by themselves differentiate between types of abuse or substantiate that abuse has occurred.<sup>200</sup> Nevertheless, screening measures are seen as integral to the development of intervention strategies and management plans for both the person being abused (victim) and the person causing the harm (perpetrator).<sup>201</sup>

"Research on the effects of training health care professionals in responding to family violence indicates that the best practices are based on adult learning theory—that is those in which the curriculum is attached to screening instruments and the ability to practice the skills."<sup>202</sup> Adult learners are intrinsically motivated and learn more permanently when knowledge has direct and early application to practice. Consequently, adult learning theory emphasizes strategies that support self-directed learning, reflection, and applicability to practice.<sup>203 204 205 206</sup>

### Interventions: Continued Research

A variety of interventions have been developed, including interventions related to reporting and response, protective service units, social service protocols, emergency shelters, support and self-help programs, and consultation teams. "Very few of these, however, have been evaluated using an experimental or quasi-experimental research design, and evaluative research of a high standard is urgently required. Unfortunately, the topic of elder abuse has not attracted the attention of many established researchers, whose expertise is nonetheless much needed. A greater investment of resources in studies on elder abuse would encourage such research."<sup>207</sup>

"One promising recent study showed that community service providers can be trained to deliver effective, evidence-based caregiver intervention in caregivers' homes, and intervention improved caregiver depression, burden, and stress appraisal, while also improving patient quality of life and behavioral problems. Further efforts to extend residence-based caregiver interventions beyond

<sup>199</sup> Spencer, C. (2009, p. 8). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>200</sup> Family Service Toronto. (2004). Breaking the silence: Best practices for responding to the abuse of older adults. Retrieved November 15, 2010 from <http://www.familyserVICEToronto.org/programs/seniors/manual.html>.

<sup>201</sup> Spencer, C. (2009, pp. 8-10). *Environmental Scan and Critical Analysis of Elder Abuse Screening, Assessment and Intervention Tools for Canadian Health Care Providers*. Ottawa, ON: Public Health Agency of Canada.

<sup>202</sup> Bonnie, R. J. & Wallace, R. B. (Eds.). (2003, p. 127). *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: National Academy of Sciences.

<sup>203</sup> Knowles, M. (1990). *The adult learner: A neglected species* (4th ed.). Houston, TX: Gulf.

<sup>204</sup> Jarvis, P. (1995). *Adult and continuing education: Theory and practice* (2nd ed.). London: Routledge.

<sup>205</sup> Kolb, D. (1984). *Experiential learning: Experience as the source of learning and development*. Englewood Cliffs, NJ: Prentice-Hall.

<sup>206</sup> Benner, P. (1994). The role of articulation in understanding practice and experience as sources of knowledge in clinical nursing. In J. Tully (Ed.), *Philosophy in an age of pluralism: The philosophy of Charles Taylor in question*. Cambridge, UK: Cambridge University Press.

<sup>207</sup> World Health Organization (2002, p. 142). Abuse of the elderly. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi & R. Lozano (Eds.). *World Report on Violence and Health* (pp. 123-146). Retrieved September 3, 2010 from [http://whqlibdoc.who.int/publications/2002/9241545615\\_eng.pdf](http://whqlibdoc.who.int/publications/2002/9241545615_eng.pdf).

research settings should be a high priority, given their potential benefit to caregivers" of persons with dementia, patients with dementia, and society.<sup>208</sup>

"The prevalence and seriousness of elder abuse and neglect require the collaboration of health care professionals with many other disciplines for adequate assessment and intervention. The home visit provides a unique opportunity for the visitor to evaluate risk factors." Interventions and response depend on available resources, expertise and local legislative frameworks. Domestic violence sometimes persists into late life and requires different approaches than dealing with caregiver burnout or self-neglect. Involvement of health professionals in educating others in the community about elder abuse and neglect may allow isolated at-risk older adults to be identified.<sup>209</sup> Therefore, a key step in addressing the problem of elder abuse is to educate clinicians about the risk factors for elder abuse and to have a high index of suspicion for abuse in dementia patients.<sup>210</sup>

### Caregiver Perspectives

In a study by Selwood et al., caregivers were asked what might or does prevent abuse, and their priorities were:

- "Medications for memory,
- Good communication from professionals,
- Written advice on memory problems,
- Home care,
- Residential respite and sitting services."<sup>211</sup>

These researchers suggest that because interventions to reduce abuse by family caregivers have not been formally evaluated, a starting point is their expressed wishes. Intervention should incorporate both written and verbal advice from professionals such as coping with dementia behaviours and respite care.<sup>212</sup>

### General Public Perspectives

A survey of 500 respondents in Manitoba investigated the general public's knowledge and level of awareness regarding legislation, mandatory reporting, and older adult abuse and/or neglect. Recommendations from the survey include:

- "Use the term *older adult* rather than *senior*.
- Define the types of abuse, types of perpetrators, and those at risk.
- Implement mandatory reporting for all older adults who have a diagnosis of incompetence or dementia and appear to be at risk of abuse and/or neglect. Provide more education and information on voluntary reporting for older adults.

<sup>208</sup> Mittelman, M. S., Haley, W. E., Clay, O. J. & Roth, D. L. (2006, p. 1598). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67: 1592-1599.

<sup>209</sup> Abbey, L. (2009, p. 47). Elder abuse and neglect: When home is not safe. *Clinics in Geriatric Medicine [Case Reports Review]*, 25(1): 47-60.

<sup>210</sup> Hansberry, M., Chen, E. & Gorbien, M. J. (2005). Dementia and elder abuse. *Clinics in Geriatric Medicine*, 21: 315-332.

<sup>211</sup> Selwood, A., Cooper, C., Owens, C., Blanchard, M. & Livingston, G. (2009, p. 312). What would help me stop abusing? The family carer's perspective. *International Psychogeriatrics*, 21(2): 309-313.

<sup>212</sup> Selwood, A., Cooper, C., Owens, C., Blanchard, M. & Livingston, G. (2009, p. 312). What would help me stop abusing? The family carer's perspective. *International Psychogeriatrics*, 21(2): 309-313.

- Educate professionals and community members.
- Develop alternatives for at-risk older adults."<sup>213</sup>

### **Knowledge Mobilization**

Knowledge mobilization supports further exploration and evaluation of the current promising approaches. The literature review provides a foundation for moving forward—identifying issues, challenges, and new knowledge emerging from research. Moving research into practice is vital to harness potential and bridge gaps.<sup>214</sup>

*...Knowledge translation is the adaptation of research findings into effective treatments, services, and products; knowledge exchange is collaborative information sharing and problem-solving between researchers, caregivers, and policy makers—it is the process of connecting and linking people, ideas, and resources.*<sup>215</sup>

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<sup>213</sup> Roger, K. S. & Ursel, J. (2009, p. 129). Public opinion on mandatory reporting of abuse and/or neglect of older adults in Manitoba, Canada. *Journal of Elder Abuse & Neglect*, 21(2): 115-140.

<sup>214</sup> Canadian Institutes of Health Research (2010). *Knowledge to Action: An End-of-Grant Knowledge Translation Casebook*. Retrieved November 23, 2010 from <http://www.cihr-irsc.gc.ca/e/41594.html>.

<sup>215</sup> Dalhousie University Faculty of Medicine Communications Office. (2008). *Background: The Canadian Dementia Knowledge Translation Network (CDKTN)*. Retrieved November 23, 2010 from <http://communications.medicine.dal.ca/newsroom/cdktn.htm>.

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## PROMISING APPROACHES

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“Promising approaches are those that practitioners and researchers in the field feel are effective, but which have not been evaluated.”<sup>216</sup>

“Snapshot 2009”<sup>217</sup> provides the most current picture. To date, there are a variety of promising approaches in the prevention of abuse/neglect of older adults in Canadian community settings, building on previous findings from “*Outlook 2007: Promising Approaches in the Prevention of Abuse and Neglect of Older Adults in Community Settings in Canada*” and the “*Draft Framework for a National Strategy to Prevent Abuse and Neglect of Older Adults in Canada*”, both produced by the Canadian Network for the Prevention of Elder Abuse (CNPEA).

According to the World Health Organization Guidelines to the Implementation of Recommendations in Prevention of Violence Report, the following types of initiatives are considered promising:

- Community policing
- Coordinated community initiatives for prevention
- Prevention and educational campaigns
- Public information campaigns to promote pro-social norms
- Training health-care professionals to detect and refer abuse victims
- Shelters for abuse victims

Many such programs exist across Canada, which suggests that much of what is happening in Canada seems promising. There are several overarching national approaches that are having, or could potentially have, a huge impact on the field across Canada, including the Federal Elder Abuse Initiative, the Multiple Intervention Program, the First Nations Wholistic Policy and Planning Model, and the Nuluaq Strategy.<sup>218</sup>

As discussed in the introduction, there are three levels of prevention. Examples of promising approaches occur at each level.

### Primary Prevention

Aimed at preventing abuse from occurring in the first place; activities include community/social/agency development, addressing root causes, education to change systemic or social norms, ongoing outreach, and keeping track of the response. Examples include:

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<sup>216</sup> Canadian Network for the Prevention of Elder Abuse (CNPEA). (2007). *Outlook 2007: Promising Approaches in the Prevention of Abuse and Neglect of Older Adults in Community Settings in Canada*. Retrieved December 13, 2010 from <http://www.cnpea.ca/Promising%20Approaches%20Final%20%202007.pdf>.

<sup>217</sup> BC Association of Community Response Networks. (2010). *SNAPSHOT 2009: Promising Approaches in the Prevention of Abuse and Neglect of Older Adults in Community Settings in Canada*. Ottawa, ON: Public Health Agency of Canada.

<sup>218</sup> BC Association of Community Response Networks. (2010). *SNAPSHOT 2009: Promising Approaches in the Prevention of Abuse and Neglect of Older Adults in Community Settings in Canada*. Ottawa, ON: Public Health Agency of Canada.

- National: Canadian Network for the Prevention of Elder Abuse, National Seniors Council, Native Women's Association of Canada and the Fédération des aînées et aînés francophones au Canada
- Provincial/Territorial: provincial government strategies, awareness networks and committees, primary care networks, the Prevention of Elder Abuse Policy Lens
- Local: whole community approaches such as Community Response Networks which operate according to community development principles

### Secondary Prevention

Aimed at early intervention in potential or actual abuse situations before they become more serious and entrenched; these activities include developing referral systems, creating agency, interagency and community protocols and improving existing support and assistance generally. Examples include:

- National: detection tools disseminated by the National Initiative for the Care of the Elderly, Family Service Association of Toronto's "If I'd Only Known Project"
- Provincial/Territorial: phone lines for information and referral and New Brunswick's intergovernmental response protocol
- Local: various local seniors' organizations providing peer support, drop-in support groups, an Orientation to Practice (i.e., respectfully connecting with Aboriginal groups), police agencies with senior involvement or focus, and specialized ethno-cultural programs

### Tertiary Prevention

Aimed at actively intervening in serious abuse situations; these activities include involving the criminal justice system or treatment systems in addressing specific situations that are by now fairly entrenched. Examples include:

- National: intervention tools disseminated by the National Initiative for the Care of the Elderly, and a national legislative overview that compares/contrasts legislatively-driven interventions
- Provincial/Territorial: various legislative approaches for addressing abuse of older adults
- Local: various justice system adaptations such as dedicated police units, crowns, courts, interdisciplinary response and consultation teams, and specialized housing programs

Recently, additional themes<sup>219</sup> have emerged that emphasize a number of perspectives to support prevention:

- Viewing abuse of older adults as a human rights issue
- Using several lenses: Bias-Free and Diversity Lenses, Gender Lenses, culturally-relevant gender-based analysis
- Understanding cultural safety as a means to providing the most respectful support and assistance
- Recognizing health literacy as an indicator of mortality with a corresponding impact on older adults who may be abused
- Harnessing what is known about seniors and learning to most effectively and actively involve older adults in solving the most critical issues in this field

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<sup>219</sup> BC Association of Community Response Networks. (2010). *SNAPSHOT 2009: Promising Approaches in the Prevention of Abuse and Neglect of Older Adults in Community Settings in Canada*. Ottawa, ON: Public Health Agency of Canada.

## **VOICES OF STAFF AND VOLUNTEERS: A SURVEY**

The need for an array of education, from awareness through to management of crisis situations, is emphasized in the literature, as well as questions for further research. The Alzheimer Society is a unique "community" equipped to pilot potential tools and approaches to support the translation of knowledge into practice. With this in mind, a survey of Alzheimer Society staff and volunteers was conducted as part of this research project to further inform future planning. In development of the survey, two Alzheimer Society focus groups from British Columbia and Manitoba were utilized to review the questions and to pilot test the survey.

The purpose of the national survey was to explore questions (see Appendix) regarding respondents' exposure to abuse in their work and volunteering with persons with dementia and family caregivers, their use of screening questions, their confidence responding to situations that indicated potential abuse, their personal learning needs in this area, their greatest concerns, and suggestions of promising approaches. The survey was distributed electronically (October 2010) via "Survey Monkey" to each provincial Alzheimer Society. A copy was available to fax if electronic completion was not possible. The response included 125 Alzheimer Society staff and 50 volunteers.

The survey provides demographic snapshots of respondent staff and volunteers across Canada; for example:

- 50.4 percent of staff who completed the survey have worked for the Alzheimer Society for one to five years. 18 percent have worked less than one year. Similarly, 54.2 percent of volunteers have worked for one to five years and 12.5 percent for less than one year.
- 47 percent of staff and 46 percent of volunteers have health care backgrounds.
- Approximately 18 percent of both staff and volunteers have an education background.

The following are highlights of the survey responses.

### **Exposure to Abuse Situations**

In response to the question, "Have you ever observed or suspected that abuse was occurring among the families to whom you provide support or education services?", 74.4 percent of staff and 65.9 percent of volunteers answered "Yes, but infrequently." 4.4 percent of staff and 2.2 percent of volunteers answered, "Yes, frequently." 21 percent of staff and 31.7 percent of volunteers answered, "No, I have never seen or suspected abuse."

### **Learning Needs**

There were 121 written responses to the question regarding personal learning needs for the topic of abuse, "What type of learning opportunities and resources would help you increase your knowledge?" The responses were clustered into the following themes of content, methods and resources:

#### ***Content of the Education***

The following content was consistently requested:

- Forms of abuse
- Signs and symptoms of abuse
- Risk factors

- How to establish trusting relationships to enable conversations
- Guidelines for response
- Legal perspectives

### **Methods**

There were suggestions for a number of methods to facilitate opportunities for learning:

- Webinars
- Teleconferences
- Workshops
- E-Learning programs

### **Resources**

Along with the opportunity for online material, requests for printed material included:

- Checklists
- Handbooks
- Fact sheets
- Screening tools

The following responses provide snapshots of staff and volunteer learning needs to better address abuse issues:

- *Anything that increases the comfort level of professionals so that they are able to respond with confidence—when we feel unprepared to respond I think there is a greater tendency to want to ignore the cues. One conference I attended included a role playing scenario and that was a very powerful experience.*
- *Abuse: Response training on abuse, how to respond when abuse happens, how can we bring the person to talk about abuse. What are the regulations in place that can protect elders? Dementia: How can we interact with individuals with dementia, develop tools to involve them (in housing, services, etc.)?*
- *More workshops at the local level to give people more tools to help in their caregiving and feel more confident in handling difficult situations.*
- *Local workshops with health care, RCMP, lawyers, etc., would help with a team approach to the problem.*
- *Practical ways to address issues where people feel supported. I would not want to report incidents of abuse if there was nothing to offer the family in terms of support or solutions that would not be worse than the current situation.*
- *Screening guidelines (how to recognize/identify situations where abuse may be happening). Other community resources that individuals can turn to if they are experiencing abuse, educational sessions for staff members on how to deal with potentially abusive situations (i.e., mechanisms for prevention).*



- *A toolkit for steps to follow when elder abuse situations are identified.*

Two of the 121 respondents indicated that they did not need more training.

### **Increasing Public Awareness**

Increasing public awareness and specific education for caregivers is seen as a priority by staff and volunteers to prevent and/or reduce abuse of persons with dementia. The themes from the responses are represented in the following quotes:

- *Some individuals don't recognize what elder abuse is; they don't understand that borrowing money from mom/dad without consent and not returning it is financial abuse or leaving mom home alone for 8 hours when she is in middle stages of dementia is neglect. Therefore education needs to be provided so more understand what elder abuse stands for!*
- *Increasing knowledge/education and support for family members and other caregivers including paid so it doesn't happen or so people can recognize it and do something about it.*

These responses were consistent with the themes that arose in the two focus groups.

### **Screening Opportunities**

The survey provides information on the current utilization of screening tools and insights for future planning. Formal screening tools are not utilized by the respondents; however, some staff and volunteers use questions and cues of an inquiry nature:

- 23 percent of staff and 37 percent of volunteers utilize questions and cues.
- 77 percent of staff and 63 percent of volunteers indicated that they do not make this inquiry.

Themes of the responses are captured in the following quotes:

- *Staff need tools to assist in what may be considered to be abuse vs. caregiver stress and what to do.*
- *I think that staff members need to be more alert to warning signs of potentially abusive situations. Having a set of questions that they could follow when they suspect abuse would assist them in determining if the situation was volatile or problematic.*

### **Level of Confidence**

The survey inquired: "Through your work at the Alzheimer Society, you may have heard individuals talk about feelings or situations that you have found disturbing (e.g., in support groups, one-on-one support sessions or through a telephone helpline). Whether or not you have ever experienced this type of situation, how confident do you feel in responding?"

- 5.3 percent were unsure or felt uncomfortable
- 13.1 percent were not confident
- 50.9 percent were somewhat confident
- 20.0 percent were confident
- 10.5 percent were very confident

## Response to Crisis Situations

There was a range of responses to the question of how one would respond to a crisis situation, which could reflect different provincial policies and individual understanding and confidence.

## Familiarity with Legislation

The survey asked if respondents were familiar with their provincial guardianship legislation. 50 percent of staff and 57.1 percent of volunteers indicated that they were not familiar with provincial guardianship legislation.

## Greatest Concerns

The responses to the question, "What are your greatest concerns regarding elder abuse and dementia?" were compiled into themes and are represented in the following quotations:

### *Aging Issues*

- *One of my greatest concerns comes out of the Rising Tide report<sup>220</sup>—knowing that the number of people diagnosed with dementia is going to rise dramatically and subsequently so will elder abuse. What will happen if we don't find a cause and a cure?*
- *How complicated it is with long-standing relationships usually involved such as spouse and children.*

### *Vulnerability*

- *These elderly are our most vulnerable.*
- *That people are living in fear and pain and we will not be there to help them.*
- *Lack of an advocate for the elder person and the person with dementia OTHER than the person who is abusing them.*
- *My greatest concerns are the abuses that go unnoticed, the lack of set professional guidelines, obscure legislation, lack of frontline social workers to respond to crises, lack of full-time social workers in First Nations communities where there is a high prevalence of alcohol, drugs and domestic violence. Many seniors live alone, many have illness or infirmities and they cannot get to help right away. Too many temporarily funded support programs rather than fully funded government ones.*

### *Legal Issues*

- *Even when abuse is identified, it may be difficult to prove and the police may not be able to intervene or lay charges.*
- *Society not being properly equipped with knowledge, policy and process in place and something happens and we missed it or didn't know what to do and the associated liability and credibility to the organization.*

### *Caregiver Support*

- *There needs to be more support / respite services provided to families so that they don't burn out.*

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<sup>220</sup> Alzheimer Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canadian Society: Executive Summary*. Toronto, ON: Alzheimer Society of Canada.

- *Not enough caregiver support, especially financially or with time off. Not enough short term respite beds and too much red tape to access those we have available. More help for younger caregivers when their spouse needs long term care placement. Education, Education, Education.*
- *The unknown cases of families struggling without supports. If we could reach this population our prevention tactics would be more effective.*
- *The stress caused by not totally understanding dementia and the right ways to deal with it.*

#### **Societal Values**

- *My greatest concerns are shifting societal values regarding the elderly, not having enough resources to offer individuals and families that would make a real difference in their experience of caregiving. Realizing that sometimes, the evil you know is better than the evil you don't know. The whole system needs to change and be more responsive to and supportive of families and the elderly.*
- *The fact that this issue is not considered important from a social perspective, because it affects seniors.*
- *There is still a stigma attached to dementia and this has to change for the better of all concerned.*

#### **Education and Guidelines**

- *Once we have detected signs of abuse, how do we respond?*

#### **Primary Role for the Alzheimer Society**

53.6 percent of staff and 22.9 percent of volunteers identified education as the primary role for the Alzheimer Society, whereas 57.1 percent of volunteers and 26.2 percent of staff identified public awareness as the primary role.

#### **Supporting the Development of Resources**

38 staff and 15 volunteers expressed interest in assisting with the development of new documents and pilot testing.

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## RECOMMENDATIONS

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### Next Steps

The stigma of dementia and the hidden problems of abuse are significant challenges for families impacted by dementia, health care providers and society. The Alzheimer Society of Canada, in partnership with other agencies and health care associations, is in a unique position to lead the development of evidence-based resources specific to prevention of abuse of older adults affected by dementia and their caregivers. In addition, the staff and volunteers of the 150 chapters of the Alzheimer Society across Canada are well positioned to implement education and training initiatives for persons with dementia and their caregivers.

This report informs the next steps for the Alzheimer Society of Canada, including moving forward on:

- Development of approaches to support learning and identification of system changes to sustain the learning;
- Development of strategies and tools to support prevention and identification of abuse;
- Identification of "promising approaches" and "best practices" for education and support of caregivers.

### Knowledge Mobilization Framework

Initially targeting Alzheimer Society staff and volunteers, the framework will guide the development of "best practice" learning resources and knowledge translation processes for family caregivers. Content topics will include:

- Person-centred philosophy of care
- Legislative obligations/requirements for each province and territory
- Capacity and consent
- Human rights
- Prevention components (education and support)

The framework will include infrastructure and processes to meet the learning needs of Alzheimer Society staff and volunteers and enable them to develop and deliver education and support initiatives including:

- Design of a comprehensive variety of learning resources that meet the needs of adult learners.
- Development of a tool kit, (i.e., a "how to" process for when staff and volunteers suspect abuse).
- Development of specific strategies such as "tips sheets" for caregivers to deal with the challenges of behavioural and psychological symptoms of dementia (BPSD).

The framework can be implemented and evaluated via orientation programs and piloting of screening tools:

- ***Orientation***

A comprehensive orientation on abuse issues for staff and volunteers incorporates research-based content, methods and resources.

- ***Abuse Screening Tools***

The abuse screening and other tools developed by the National Initiative for the Care of the Elderly (NICE) may be helpful in the Alzheimer Society's work, in particular as they identify and pilot/adapt appropriate tools that will support the development of evidence-based practice specific to care of people with dementia.

To summarize, the next steps can be a catalyst for evaluation of promising approaches, including the development of templates for a variety of learning resources and tools for prevention, inquiry, and to support the process when abuse is suspected or observed.

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## APPENDIX

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Dementia and Abuse Questionnaire
<b>Demographics</b>
<b>* What is your association with the Alzheimer Society?</b> <input type="radio"/> Volunteer <input type="radio"/> Staff Member
<b>Demographics</b>
<b>* How many years have you volunteered or worked with the Alzheimer Society?</b> <input type="radio"/> Less than 1 year <input type="radio"/> 1 to 5 years <input type="radio"/> 5 to 10 years <input type="radio"/> Over 10 years
<b>Demographics</b>
<b>* What is your background? (check the most appropriate choice)</b> <input type="radio"/> Business <input type="radio"/> Education <input type="radio"/> Health Care <input type="radio"/> Other  Please feel free to be more specific <input type="text"/>
<b>Demographics</b>
<b>* Are you or have you been a family caregiver?</b> <input type="radio"/> Yes, currently <input type="radio"/> Yes, in the past <input type="radio"/> No
<b>Demographics</b>

## Dementia and Abuse Questionnaire

### \* What is your current and primary role at the Alzheimer Society?

- Administrative  
 Advocacy  
 Caregiver / Family Education/Support  
 Individual Education / Support  
 Governance / Board Member  
 Professional education

## Recognizing Abuse

Abuse is categorized by the World Health Organization (WHO) in the following terms:

- Physical Abuse: the infliction of pain or injury, physical coercion, or physical or drug-induced restraint
- Psychological or Emotional Abuse: the infliction of mental anguish
- Financial or Material Abuse: the illegal or improper exploitation or use of funds or resources of the older person
- Sexual Abuse: non-consensual sexual contact of any kind with the older person
- Neglect: the refusal or failure to fulfill a caregiving obligation

### \* Have you ever observed or suspected that abuse was occurring among the families with whom you provide support or education services through your work with the Alzheimer Society?

- Yes, but infrequently  
 Yes, frequently  
 No, I have never seen or suspected abuse

Comment

## Recognizing Abuse

### \* If yes, what type of abuse and the frequency?

	Frequent	Infrequent
Physical	<input type="radio"/>	<input type="radio"/>
Psychological/Emotional	<input type="radio"/>	<input type="radio"/>
Financial	<input type="radio"/>	<input type="radio"/>
Sexual	<input type="radio"/>	<input type="radio"/>
Neglect	<input type="radio"/>	<input type="radio"/>

## Dementia and Abuse Questionnaire

### Responding

**\* Through your work at the Alzheimer Society, you may have witnessed highly disturbing situations, heard feelings expressed such as those that are shared within a support group or in a one-to-one support session, or through a telephone helpline. Whether or not you have ever experienced this type of situation, how confident do you feel in responding?**

- Unsure or feel uncomfortable
- Not confident
- Somewhat confident
- Confident
- Very confident

### Responding

**\* For example, if you have concerns that a person with dementia is being abused or is living at risk due to neglect, how would you respond?**

**Please select the most appropriate response.**

- Unsure how I would respond.
- As soon as possible, and no later than the next day, contact a supervisor to assist me to take appropriate next steps.
- If my supervisor is not available, call a community helpline for information and advice.
- Report to appropriate external authority.

### Responding

**\* If within a support group a caregiver made the following statement: "I'm going to kill him." (not jokingly) or "I'm going to kill myself," how would you respond?**

**Please select most appropriate response.**

- As soon as possible, and no later than the next day, contact my supervisor to assist me to take appropriate next steps.
- If my supervisor is not available and I want to talk to a health professional, call a community helpline for information and advice.
- Report to appropriate external authority.
- Uncertain how I would respond.

### Responding



## Dementia and Abuse Questionnaire

**\* Although emergency situations are rare, if you have any reason to believe that there is immediate danger and/or a crime is occurring, how would you respond?**

- Call 911.
- Call my supervisor immediately for guidance.
- Uncertain how I would respond.

### Support

**\* The literature confirms that elder abuse is under-recognized. What do you think are promising approaches to IDENTIFY situations of abuse?**

### Support

**\* From your experience, what types of support need to be in place to PREVENT a crisis?**

### Support

**\* From your experience, what types of support need to be available when a CRISIS occurs?**

### Questions (Tools)

**\* Are you currently using a “tool”, that is particular questions or cues that may help provide information regarding elder abuse:**

**For example, do you use cues to help trigger a conversation with a person with dementia such as: "Have you ever felt abused?"; "Is the abuse happening currently?"**

- Yes
- No

## Dementia and Abuse Questionnaire

### Questions (Tools)

**\* If yes, please list other questions/cues that you regularly use.**

### Questions (Tools)

**\* Would you regularly ask a caregiver questions such as: "What strategies do you use to balance your own needs with those of the person you care for?"; "What types of help do you have in place to support you in your caregiving role?"; "Have you ever felt that you were close to losing your temper or control?"**

Yes

No

### Education:Future Development

**\* Legislation and policies are specific to each province and territory. What do you suggest as the primary role for the Alzheimer Society in the area of elder abuse and dementia?**

Public awareness

Education

Advisory

Research

Other

Please specify

## Dementia and Abuse Questionnaire

\* How familiar are you with your provincial/territorial guardianship legislation?

- Familiar
- Unfamiliar

### Education: Future Development

What types of learning opportunities and resources regarding dementia and abuse would help you to increase your knowledge?

Please be as specific as possible.

### Education: Future Development

In your experience, what approaches and resources do you regard as most helpful in PREVENTING abuse?

### Education: Future Development

Are you interested in assisting with development of educational resources and/or policy development on the topic of abuse (e.g., assisting with development of documents, or pilot testing new resources and tools)?

- Yes
- No

Please provide us with your email address.

Note: Dr. Harrigan will be compiling the list of those interested.

### Concerns and Issues

**Dementia and Abuse Questionnaire**

**What are your greatest concerns regarding elder abuse and dementia?**