

**THE DEMENTIA NETWORK OF OTTAWA**

**POSITION PAPER**

**ON**

**DEMENTIA EDUCATION**

**January 2005**

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## PURPOSE

Providing care and support to someone with dementia can frequently be difficult and challenging. The progressive deficits in memory, language, attention, insight, abstraction, judgement, perception, visual-spatial relationships, and motor organization require all persons who work with persons with dementia to draw on specialized knowledge and skills.

In basic level health, social service, and allied health educational programs, both at the Community College and University levels, the amount of education that is specific to dementia is sparse, and in most cases, non-existent. However, students in these programs, upon graduation, often find themselves working with persons who have dementia. Furthermore, it is noted through anecdotal evidence and limited research that employees currently providing care to this vulnerable population may not have had the benefit of specialized education.

Within the past five years there has been development of post-graduate education programs and courses which address learning needs specific to this population. However, there is no developed framework that provides a coordinated menu of learning which is competency-based and measured against performance evaluations. In order to improve the quality of care provided to those with dementia, there needs to be integration between learning and practice.

As evidenced by recent developments within the federal and provincial governments, there is a growing awareness that all stakeholders must work together in order to improve the health and quality of life of those living with dementia. In October 2004, the National Advisory Council on Aging developed a report on Alzheimer Disease and related dementias and made a number of recommendations including improved training and education. The Ontario Ministry of Health and Long-Term Care is planning to introduce new legislation in 2005 which will focus on five major areas including residents' quality of life and care standards. In order to maintain standards and ensure accountability, education of staff is critical.

The purpose of this Position Paper is to provide an impetus for change. The only acceptable standard of care for persons with dementia is one that provides competent, knowledgeable staff to care for them. Policy makers, professional associations and educational institutions need to come together and cross barriers in order to develop creative solutions to promote change within the existing education and health care framework. **Standards for education must be proposed and competency in performance must be advocated for and supported.**

## BACKGROUND: STATISTICS AND RELEVANCE

Dementia is a syndrome that includes loss of memory, judgement and reasoning, and changes in mood and behaviour. These symptoms affect a person's ability to function at work, in social relationships, or in day-to-day activities.

Alzheimer Disease, the most common form of dementia, is a progressive, degenerative disease of the brain. It affects the person's ability to understand, think, and remember. The ability to make decisions will be compromised. Simple tasks that have been performed for years will become more difficult or will be forgotten. As the disease progresses, there will be a gradual physical decline. These changes will impact on the person's ability to perform day-to-day tasks

independently, such as eating, bathing and getting dressed. Eventually, the person will require 24 hour care until death comes, usually from pneumonia or other infections.

The prevalence of dementia is expected to rise as the general population ages over the next decade. While Alzheimer Disease generally affects those over the age of 65 years, people in their 40s and 50s can also be affected.

- 364,000 Canadians over 65 have Alzheimer Disease or a related dementia <sup>1</sup>
  - 247,520 women
  - 116,480 men
- 1 in 13 Canadians over 65 has Alzheimer Disease or a related dementia
- 1 in 3 Canadians over 85 has Alzheimer Disease or a related dementia
- By 2031, over 750,000 Canadians will have Alzheimer Disease or a related dementia
- Half of those with dementia live in the community and half live in institutions; however, this balance varies from region to region across Canada
- It is estimated that by 2011, there will be 111,600 new cases of dementia <sup>2</sup>
- Over 52 per cent of Canadians know someone with Alzheimer Disease <sup>3</sup>
- Almost 25 per cent of Canadians have someone with Alzheimer Disease in their family
- Alzheimer Disease is the most common form of dementia; it accounts for 64% of all dementias.

With this increase in prevalence, public awareness has grown. Earlier diagnosis has provided an opportunity for persons with dementia and their families to obtain education about the disease and to plan ahead for the time when they are no longer able to manage care requirements. Education programs are available through the Alzheimer Society and other agencies to assist the individual and their caregivers to acquire this information.

Graduates of health, social service, and allied health programs within community colleges and universities receive very little, if any, education related to dementia in their undergraduate program of studies. This means that upon graduation, students entering the workforce in acute-care, community care or long-term care, have not been provided with the necessary knowledge and skills to prepare them to work with the clients who have dementia.

Fifty per cent of the people with dementia live in institutions, such as nursing homes, homes for the aged or retirement homes.<sup>4</sup> Those people in institutions have a greater severity of dementia. In most long-term care facilities and retirement homes, Personal Support Workers/Health Care Aides compose the largest group of health care providers. Within their certificate program, they have received very few hours on the theory of dementia, and yet they are expected to be able to care for frail, elderly residents with a multitude of health problems including dementia. In 1996, 100% of staff from long-term care facilities, residential homes and home care agencies surveyed by Algonquin College in Ottawa, indicated a need for more formal training in dementia care.

Since that time, dementia-specific programs and courses have been developed for delivery on a continuing education basis. These are needs based, addressing the concerns of specific disciplines such as nursing in a leadership role and health care workers in a front-line position. However, there are no standards for base level of training for students pursuing an education within health, social service and allied health programs. In addition, there is no developed framework that provides a coordinated menu of learning which is competency-based and measured against performance evaluations. Assessment of learning and the transference of learning to practice are essential and can best be evaluated when learning outcomes have been

expressed as competencies to be achieved (knowledge and skills), which are then performed in the clinical setting. However, a mechanized approach, which merely deals with acquiring competencies, does not go nearly far enough. The training of staff, if well designed, will set up a process of experiential learning, involving a cycle of action, reflection and consolidation of better practice.<sup>5</sup>

The solution, then, does not lie in creating more programs and courses that are dementia-specific, but rather lies in developing standards and a framework which will provide all disciplines with the knowledge and skills required to provide quality care to persons with dementia.

## **BARRIERS IN ACCESSING DEMENTIA EDUCATION WITHIN THE WORKPLACE**

There are many barriers that exist which prevent access to continuing education programs and courses in the workplace.

- *Financial compensation:* Education budgets within health care are small, and often there is not enough money available to provide education for staff, or replacement costs so that staff can attend education sessions.
- *Delivery methods:* Train the trainer method of delivery is difficult to provide as senior staff have increasing workloads and responsibilities. Costs of providing online learning and teleconferencing to rural areas may be prohibitive. There is a growing need to address dementia education from a multi-cultural perspective.
- *Lack of recognition:* Health care employees who are committed to increasing their knowledge will attend courses on their own time, even though there is no recognition by employers that dementia education is needed.
- *Turn-over of staff:* Due to Community Care Access Centre regulations, there has been a sharp reduction of staff within community home support agencies. New hires are difficult to find, and often, those that are hired, may not have the desired qualifications. Within long-term care facilities, high turn-over of staff who have received on-site continuing education courses, results in continual re-training requiring increased human and financial resources.
- *Preference for hiring:* Dementia care is not recognized as a specialty area, and therefore staff hired to work with patients or residents who have dementia can be persons who have received little theoretical preparation to do so.
- *Unionization:* Unionized environments within the health care sector will direct who can be hired in a particular area. Educational preparation to do so is seemingly not a factor.
- *Philosophy of care:* Within the acute-care sector, Geriatrics is being recognized as a specialty, and Geriatric Emergency Management is a program that encourages the identification of seniors at risk in the Emergency Department. Other programs that deliver care to seniors in acute-care may not be inclusive of the specialized knowledge and skills. There remains the concept of care delivery as “disease-based” rather than recognition of the holistic needs of the population being served.
- *Lack of orientation:* Orientation programs that are directed towards specialty units addressing the needs of the older population will contain knowledge and skills related to dementia; however, other orientation programs may not.

## DEMENTIA EDUCATION FRAMEWORK

In order to provide competent, knowledgeable care to someone with dementia, the following needs to be implemented:

- Standards for minimum base level education in dementia within under-graduate programs
- Requirements for dementia-specific qualifications to work in the health care sector
- Orientation Programs for all new employees which includes a component on dementia (basic general information) and a Specific Orientation for those working in environments with persons who have dementia
- Continuing education programs and courses which are competency-based and can be linked to clinical practice
- Performance appraisals which recognize competencies to be achieved, and encourage the pursuit of continued learning in dementia
- Mentorship in the workplace to assist new hires in caring for those with dementia
- Financial compensation or, alternatively, time off to attend learning opportunities
- Requirements for managers to participate in ongoing learning in dementia in order to maintain their leadership roles
- Current dementia resources are made available and promoted.

## GUIDING PRINCIPLES

The proposed framework is built on a set of three Guiding Principles for Dementia Education as developed by the Dementia Network of Ottawa Education Task Force:

- all persons with dementia will be cared for by staff who have specialized knowledge and skills
- all health care workers should have access to current and on-going resources
- management should promote and recognize, both in principle and practice, specialized knowledge and skills among the health care workers providing dementia care.

### 1. Specialized knowledge and skill

**All persons with dementia will be cared for by staff who have specialized knowledge and skills.**

- a) The curriculum of all health-related programs should ensure that students receive specialized knowledge and skills necessary to provide dementia care.
- b) Specialized knowledge and skills necessary to provide care for persons with Alzheimer Disease or related dementias should be part of all orientation programs to new employees in the health care system, including administrative personnel.

Definition of Specialized Knowledge:

- Knowledge of dementia as a cerebral disease with impact on the family (varying degrees of knowledge according to the health care personnel background)
- Knowledge of patients' and family members' experience of dementia
- Knowledge of communication and care strategies for persons with dementia
- Knowledge of the behavioural expression of dementia
- Knowledge of current treatments available (varying degrees of knowledge according to the health care personnel background)
- Knowledge of principles guiding intervention towards persons with dementia.

Definition of Skills:

Skills are the abilities needed to:

- Preserve and promote patients' self-esteem
- Relieve patients' and care partners' emotional distress
- Sustain functional autonomy at an optimal level
- Promote patients' integration to their environment
- Maximize communication.

The necessary skills are the following:

- Efficient communication techniques, astute observation
- Support in activities of daily living pertaining to nutrition and feeding, hygiene, dressing and undressing, elimination and mobility
- Behavioural and mood management strategies utilizing different frameworks, such as functional analysis and/or problem-solving.
- Establishment of individualized routine which promotes person-centered care.

## **2. Access to current and ongoing dementia resources**

**All health care workers should have access to current and ongoing dementia resources.**

a) Basic dementia education:

- Unregulated health care worker programs
- Diploma in health-related disciplines
- Undergraduate/generic programs for all health care professionals including nursing, occupational therapy, physiotherapy, social work, pharmacy, gerontology, recreational therapy, nutrition, dietary sciences, pastoral care, speech pathology, psychology and neuropsychology.

b) Self-directed learning:

- literature, books, journals, audiovisual, E-learning and on-line library resources.

c) Continuing dementia education:

- Dementia Studies/Working with Dementia Clients – offered at Community Colleges
- PIECES and UFIRST
- Workshops/seminars
- On-site educational sessions
- Informal education from supervisors or clinical educators

- Formal education opportunities.

d) Professional resources:

- Access to dementia resource staff – dementia experts
- Mentorship
- Knowledgeable supervisors and managers.

**3. Support and value-added to having knowledgeable dementia care providers in the health care system.**

**Management should promote and recognize, both in principle and practice, specialized knowledge and skills among the health care workers providing dementia care.**

Support and value to continued learning by managers can be enhanced in the following ways:

- *Financial compensation* or alternatively *time off* to attend learning opportunities are provided (e.g. reimbursement of cost of educational session or course, replacement of staff for formal on-site learning)
- *Current resources* are made available and promoted
- Staff are given opportunities to *identify their learning needs* and to participate in activities which meet these needs
- *Performance reviews* acknowledge and reward continuing education, including on-line learning
- *Informal feedback* provided by management regarding satisfaction with dementia care
- *Hiring practices* favour persons with dementia knowledge and skills
- *Managers participate* in ongoing learning to maintain their leadership positions

## **THE PROPOSED FRAMEWORK**

The proposed framework is a collaborative model where educators, supervisors and administrators in facilities/agencies will work together to develop and implement the components of the framework: specific workshops, a pool of interview questions for new hires, components for general orientation, components for specific orientations, guidelines for mentorship.

The elements of the framework are the following:

1. Coordinator/Program Support

- To coordinate the process
- To establish contacts with educators, supervisors, administrators in all agencies/facilities
- To provide the identified contact person in each agency/facility with appropriate resources
- To prepare and update course material (orientation and workshops) and prepare a bank of interview questions for new hires. Development will be done in collaboration with a curriculum development committee
- To coordinate workshops

## 2. Workshop for Educators, Supervisors, Administrators

- Orientation workshop offered in English and French
- Given by experts
- Content to include:

Overview:

a. Delirium/Dementia/Depression	1.5 hour
b. Caregiver burnout	.5 hour
Best Practice Guidelines <sup>6</sup> - screening for Delirium, Dementia, Depression	1.0 hour
- care strategies for Delirium, Dementia, Depression	
Capacity Issues – Health Care Consent Act	1.0 hour
Behavioural Issues related to dementia	1.0 hour
a. Aggression	
b. Wandering	
c. Sleep Disturbances	
Pharmacological Management	1.0 hour
Interviewing Process for new hires	.5 hour

## 3. Hiring Process

A pool of questions that have been provided related to:

- Assessing the desire to work with persons who have dementia
- Acquired dementia knowledge
- Work experience with clients who have dementia, volunteer work with seniors,
- Ability to apply knowledge and skill in particular/hypothetical situations

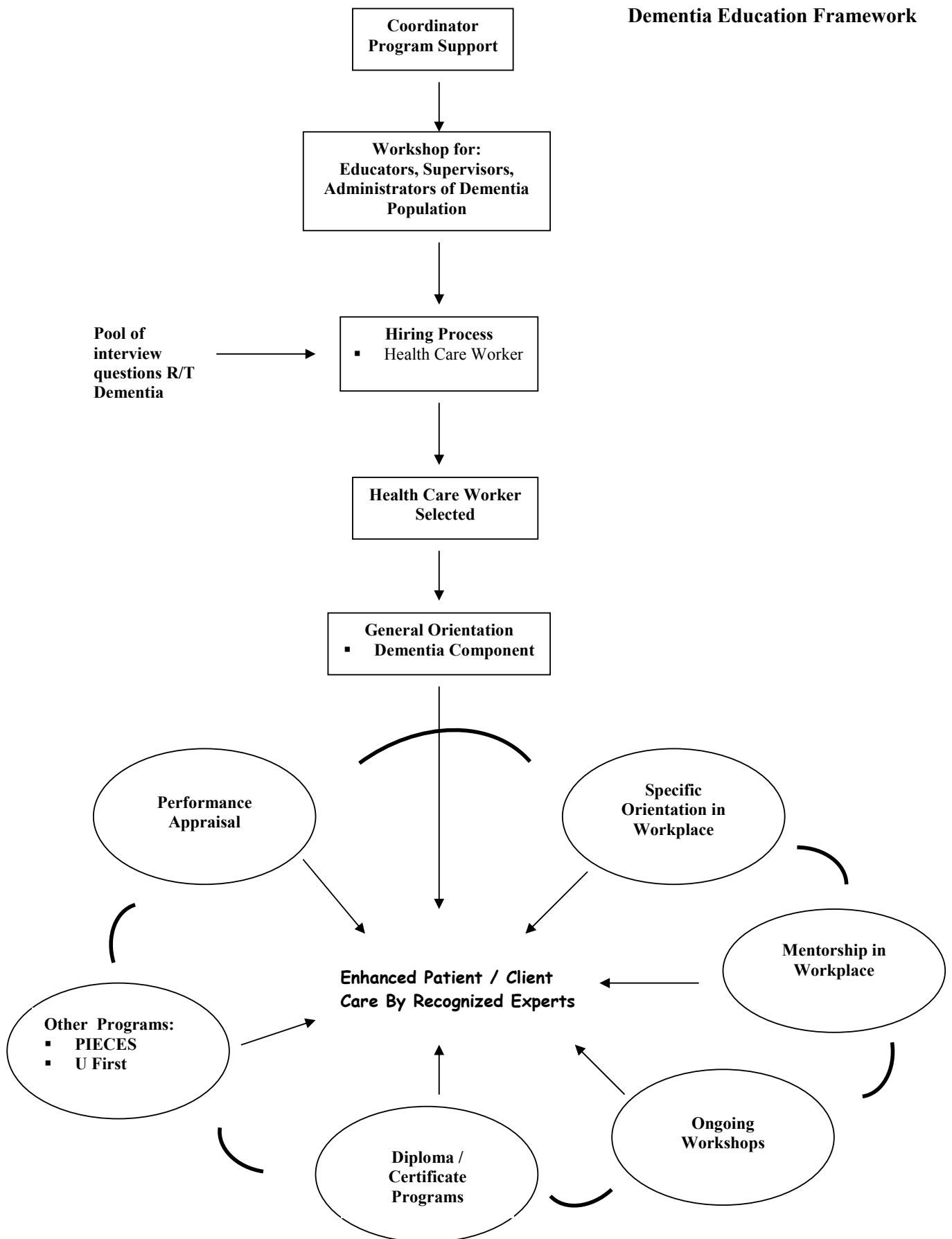
## 4. Health Care Worker Orientation

- General orientation including a component on dementia (basic general information)
- Specific Orientation for those working in environments with persons who have dementia; education tailored to the need of the milieu; competency-based education

## 5. Enhanced Patient/Client Care

- Performance appraisals linked to competencies
- Continuing education encouraged through the use of existing courses and workshops that are competency-based and delivered by experts
- Various workshops provided throughout the year on topics related to dementia specific to the workplace
- Mentorship for new hires in place

# Dementia Education Framework



## CONCLUSION

This Position Paper has been developed to provide an impetus for a dialogue with appropriate stakeholders. It is our hope that we can begin to remove the barriers which impede the access of all health care workers, both regulated professionals and non-regulated workers, to receive the knowledge and skill sets required to provide better care to persons with dementia.

In 1992, the Alzheimer Society of Canada developed *Guidelines for Care* in response to the need for national direction to ensure that people with Alzheimer Disease, whether in the community, hospital, or long-term care, receive the special type of care that reflects the unique nature of this disease. The Guidelines were made available to all relevant health care agencies and institutions.<sup>7</sup>

Much has been accomplished since 1992, especially in the Province of Ontario, to improve awareness of the need for dementia education, and also to develop dementia-specific courses and programs. There is still much more to be done. Together we can work to improve quality of life of those with dementia by providing support and recognition to the many health care workers who care for them.<sup>8</sup>

## REFERENCES

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- <sup>4</sup> Canadian Study of Health and Aging Working Group: Patterns of caring for people with dementia in Canada. (1994). *Can J Aging*, 13, 4, 470-487.
- <sup>5</sup> Kolb, David A. (1976). *The Learning Style Inventory*. Boston: McBer and Company.
- <sup>6</sup> [www.rnao.org/bestpractices](http://www.rnao.org/bestpractices) <<http://rnao.org/bestpractices>
- <sup>7</sup> Guidelines for Care: Alzheimer Society of Canada, (Revised 1999). ISBN: 0-9695 301-3-7.
- <sup>8</sup> Henderson, JoAnne. (2003) "Learning the Ropes in Dementia Care." *Canadian Nursing Home*, 14, 1, Feb/March

## **APPENDICES**

- 1. INVENTORY OF KNOWN DEMENTIA EDUCATION IN BASIC UNDERGRADUATE PROGRAMS IN OTTAWA**
- 2. BACKGROUND TO THE FORMATION OF THE TASK FORCE**
- 3. DNO EDUCATION TASK FORCE MEMBERSHIP**

**APPENDIX 1**

**Dementia Network  
Education Task Force**

**Report**

**Dementia Education in Basic Programs**

February 2004

Programs	Schools	Theory (Hours)			Clinical (FP/hours)
<b>NURSING STUDIES</b>					
BScN ( A collaborative program between U.of O, A.C. and L.C.)					
		<b>U. of O.</b>	<b>A.C.</b>	<b>L.C.</b>	
Year 1		4.5 hrs	-	-	may encounter patients but not always  (Professional Program: 3.0 hrs. + 6.0 hrs theory hours)
Year 2		2.0 Health Assess. -	4 hours + reading + case study	-	
Year 3		-	-	-	
Year 4		4.5 hrs	-	-	
<b>Diploma Nursing (L.C.)</b>					
Year 1			-		-
Year 2			-		-
Year 3			6 hours		60-90 hours @ St. Vincent
<b>Practical Nursing (A.C.)</b>					
Year 1			3 hours		50 hours in LTC
Year 2			3 hours		-
<b>Practical Nursing (L.C.)</b>					
Year 1			3 hours + reading + case study		60-90 hours in LTC
Year 2			-		-
<b>Personal Support Worker</b>					
Algonquin College			13 hours		100 hours LTC
La Cité collégiale			6 hours		150 hours LTC
<b>Refresher Programs (A.C.)</b>					
Registered Nurse			3 hours		70 hours chronic
Non RN Upgrading			3 hours		70 hours chronic
R.P.N. Refresher			3 hours		70 hours chronic care

<b>Programs</b>	<b>Schools</b>	<b>Theory (Hours)</b>	<b>Clinical (FP/hours)</b>
<u>Post R.N. Programs</u> U.of O.			
		9 hours	some clinical when available
<b>COMMUNITY STUDIES</b>			
<u>Developmental Service Worker (A.C.)</u>			
Year 1		–	Some contact with seniors but not assigned specific number of hours
Year 2		6 - 9 hours	
<u>Social Service Worker (A.C.)</u>			
Year 1		6 - 8 hours	If senior placement selected, 210 hours with elderly - may have contact
Year 2		2 - 4 hours	315 hours if senior placement is selected
<u>Social Service Worker (L.C.)</u>			
Year 1		? Some	1-2 students could get placed with seniors
Year 2			
<u>Social Service Worker Intensive (A.C.)</u>			
Year 1		2 hours	400 hours placement if selected with seniors
<u>Police Training (L.C.)</u>			
Police Training		some in Psych. course and in Comm. course	nothing scheduled but could happen
<b>ALLIED HEALTH</b>			
<u>Pharmacology</u> ..... (L.C.)		1 hour	–
<u>Dental Hygiene</u> .....(A.C.)		30 minutes	3 hours
<u>Dental Hygiene</u> ..... (L.C.)		6 hours	–
<u>Respiratory Technology</u> .....(A.C.)		3 hours	–
<u>Massage Therapy</u> .....(A.C.) Year 3		2-3 hours	21 hours in LTC
<u>Physiotherapy Asst</u> ..... (L.C.)		2 hours	pt. assignment in clinical

<b>Programs</b>	<b>Schools</b>	<b>Theory (Hours)</b>	<b>Clinical (FP/hours)</b>
<u>Psychology</u> .....	(U. of O.)	None	-
<u>Ward Clerk</u> .....	(L.C.)	2-3 hours	
<b>CONTINUING EDUCATION</b>			
<u>Palliative Care Training</u> C.E.....	(A.C. / L.C.)		
Level I		6-8 hours	-
Level II		6-8 hours	-
<u>Gerontology</u> .....	(L.C. / A.C.)	Integrated in the Program # of hours - unsure	
<b>CARLETON UNIVERSITY</b>			
<u>Social Work Program</u> Bachelors Level		- (N/A)	depends on student's choice for placement
<b>ST. PAUL UNIVERSITY</b>			
<u>Human Sciences</u> Aging Pastoral Counselling		few hours --	- --

## APPENDIX 2

### BACKGROUND TO THE FORMATION OF THE EDUCATION TASK FORCE

The Dementia Network of Ottawa was officially launched in February 1999. The mandate of the Network is to develop a more coordinated and efficient system for service delivery, education and research related to dementia. Specifically within education, the initial goals of the Network were to develop more coordinated educational and information services in the area of dementia for clients, caregivers, referring physicians, and agencies.

In 2000, the Education Sub-Committee began to develop an inventory of education available to families, physicians, health care professionals, and non-regulated health care workers. It became apparent that basic education in dementia provided within undergraduate programs was sparse to non-existent. Furthermore, while there were continuing education programs and courses available, there was no framework in place that assisted employers to determine the knowledge and skill levels achieved against the dementia care requirements in the clinical setting.

In November 2002, a Dementia Care Forum, sponsored by the Ministry of Health and Long Term Care through the Ontario Alzheimer Strategy, was held in Ottawa. About 60 invited participants, a cross-section of physicians, dementia service providers in long-term care and community settings, as well as family carers, attended. Three workshops provided the focus for the discussions at the Forum: Education and Training for Health Care Workers; Community Services; Coordinated Specialized Diagnosis and Support. Regarding Education and Training for Health Care Workers, three recommendations were made. The first recommendation was the following:

**To develop a framework for dementia education that addresses the training needs of all health care workers working with clients with dementia from early to advanced stages.**

Strategies:

- Develop guiding principles which will underpin the educational framework
- Identify the population to receive dementia training
- Ensure inventory of all available educational activities is complete
- Utilize the First Link Pilot Project Program as a model for developing the educational framework
- Submit recommendations for the educational framework to the Dementia Network of Ottawa for approval.

In February 2003, a Task Force, appointed by the Education Committee of the Dementia Network of Ottawa, and including representatives from all health care sectors, educational institutions and family members, began to work on the above strategies. Three areas of work were completed: Development of Guiding Principles for Dementia Education (see Appendix 1); an Inventory of Known Dementia Education in Basic, Undergraduate Programs in Ottawa (see Appendix 2); a Dementia Education Framework from the point of hiring a new employee to becoming a seasoned employee.

In November 2003, the recommendations of the Task Force were submitted to the Dementia Network of Ottawa for approval.

These recommendations were:

- A Position Paper be developed, sensitizing policy makers, professional associations, and educational institutions on the importance of dementia education

After the Position Paper has been widely circulated, a Forum be held inviting policy makers, professional organizations, and educational institutions to come together to discuss the issues and determine appropriate steps.

## APPENDIX 3

### DEMENTIA NETWORK OF OTTAWA EDUCATION TASK FORCE MEMBERSHIP

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