

CHAMPLAIN DEMENTIA NETWORK

CASE STUDY CONTINUUM December 1, 2006

Purpose:

At the September 9th, 2005 meeting of the CDN it was discussed that a Case Study Continuum be developed of the person with dementia and their family member from the point of diagnosis through a 10 - 12 year period. This continuum would identify the stress points in the continuum of care and the corresponding supports and services in the system that need to be in place in order to support both the person with dementia and their caregiver and promote their quality of life. An evaluation of available supports and services within the 3 areas (Eastern Counties, Ottawa, Renfrew County) of the Champlain area will be conducted and the results will be shared with physicians, service providers* and planning groups within the Champlain LHIN as well as more broadly through Dementia Networks in Ontario (Alzheimer Knowledge Exchange) in order to inform, plan and direct appropriate actions.

*Service providers are defined as non-specialized, general service providers

Framework:

The following components have been included in the framework:

- Core component: contains assessment criteria as well as transition points for each of the stages of dementia: MCI, Mild, Moderate, Severe, End-of-Life
- Physician Issues: provides an overview of family physician and specialty physicians services for each stage of dementia
- An “ideal case” followed through the stages of dementia provides a descriptive case study which identifies the key issues, or what needs to happen, as well as the actions that need to be taken.
- How the “case study” would change if the person lived alone
- Report Card: Report cards have been developed for MCI/Mild; Moderate, Severe, End-of-Life stages. Each area within the Champlain Dementia Network: Renfrew County, Ottawa, Eastern Counties, will assess their own ability to provide the actions that are need to be taken for each stage of dementia.
- Appendix: Key definitions and websites are provided for information purposes

Members of Working Group:

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CASE STUDY CONTINUUM CORE COMPONENT

						(Person at home)	
	Memory loss	MMSE	Functional loss*	Behaviour issues*	Interval of need*	Informal services	Formal services
MCI	+	25-30	IADL 0 -1/2 + pADL 0	0	1 – 14 days	0 - +	0
MILD	+ - ++	18 - 24	IADL + - ++ pADL 0	0 - +1	12 – 36 hours	+ - ++	(+/- RH)
MODERATE	+ - ++	10 - 17	IADL ++ - +++ pADL +	+ - +++	4 – 12 hours	+ - +++ (+/- RH)	0 - ++ (+/- LTC)
SEVERE	+++ - +++++	5 - 9	IADL +++ - +++++ pADL ++ - +++	+ - +++++	0 - 4 hours	+ - +++++ (+/- RH)	+ - +++ (+/- LTC)
PALLIATIVE/ END-OF-LIFE	++++	0 –4	IADL ++++ pADL ++++	0 - +	0 – 2 hours	++++	+++ - +++++ (+/- LTC)

pADL: personal activities of daily living

RH: residential home

IADL: instrumental activities of daily living

LTC: long term care

Interval of need: how long a person can be without supervision/assistance

***Caregiver stress** increases as ADL support needs increase, the interval of need shortens and behavioural issues increase.

(+ memory loss/functional is small; ++ memory/functional loss is more noticeable; +++ memory/functional loss requires more assistance; +++++ memory/functional loss is significant)

TRANSITION POINTS

MCI – MILD: moves from no to only mild difficulty; high level IADL to definite loss of some IADL

MILD – MODERATE: develops loss of at least 1 pADL; emerging behavioural issues

MODERATE – SEVERE: loss of most IADL, many pADL; increasing behavioural issues; still “interactional abilities” with others; increasing safety issues

SEVERE – PALLIATIVE/END –OF-LIFE: loss of interactional abilities with others and all pADLs; bedridden

IADL (SHAFT)

S shopping

H housework

A accounting

F food preparation

T transportation

(laundry, medications, telephone)

pADL (DEATH)

D dressing

E eating

A ambulation

T toilet/transfers

H hygiene

Champlain Dementia Network Case Study Continuum Working Group

An “Ideal” Case Followed Through the Stages of Dementia

Time After First Symptom	Ideal Case	Key Issues	Action needed
	Mrs. G.C. is a 76 year old married woman with Grade 12 education, she had a mother who developed Alzheimer’s Disease onset age 84, and a medical history including hypertension, hyperlipidemia and osteoporosis. Her medications are Hydrochlorothiazide, Adalat XL, Lipitor, Calcium, Vitamin D, and Fosamax.		
0 months	In the last six months her husband noted that she did seem to be a little bit forgetful having some problems with names, “not quite as sharp” as one year previously, having a little more difficulty planning the bigger family social events and being a little less interested in leisure activities. She was still driving, shopping, cooking, independent in all her IADL’s although she occasionally needed a reminder to take her medication.	Public Awareness Risk factors <ul style="list-style-type: none"> • Warning signs • Early recognition 	A Framework in place for a Public Awareness campaign
6 months	While at the local Pharmacy her husband noticed that the Pharmacist was offering a 2 minute Dementia Screening Test so he and Mrs. G.C. did the test. He was fine but his wife had difficulties in animal naming (9 in one minute) and clock drawing. He realized that this was a significant issue which needed medical attention.	Screening opportunities and caregiver realization that a problem exists.	Screening Program on early recognition: <ul style="list-style-type: none"> • CDN Physicians Education Committee • Multidisciplinary continuing education such as pharmacists, nurses etc.
7 months	Her husband was now worried that this was more than normal ageing and did in fact arrange an appointment with the family physician. The family physician tested first with the MMSE on which her score was 25/30. Laboratory testing was negative. Essentially the conceptualization was that Mrs. G.C. was not as “sharp with her memory” as she was 6 months previously but no other areas of cognitive function or functional abilities were affected.	Family Physician education for appropriate assessment of cognitive impairment.	Dementia Education for Family Physicians Enhanced diagnostic and treatment services to achieve realistic wait times in urban and rural areas Electronic patient record begun

	<p>The Family Physician explained the concepts of mild cognitive impairment (MCI) and gave advice about being physically, mentally and socially active. He explained that it could progress to more problems with memory and said that he would see her in one year or earlier if there was greater concern about memory or function. The patient's hypertension and hyperlipidemia were well controlled and enteric coated aspirin was started at 81 mg daily</p>	<p>Family Physician awareness of MCI vs dementia.</p> <p>Treatment of vascular risk factors</p>	<p>Dementia Education for Family Physicians</p> <p>Access to medical services and monitoring and assessment</p> <p>Referral to senior's centre for social activities</p>
1 year, 7 months	<p><u>One year later</u> there didn't seem to be any progression of symptoms or functional loss. Her MMSE was now 24/30.</p> <p>The husband and the patient were referred to the First Link Program of the Alzheimer's Society for ongoing education and support.</p>	<p>Appropriate follow-up re MCI and possible progression to dementia.</p> <p>Need for education and support</p>	<p>Monitoring and assessment by Family Physician</p> <p>First Link Program: Alzheimer Society</p>
2 years, 7 months	<p><u>Two years later</u> the husband was more concerned because she got lost once while out driving the car back from her sister's home 30 miles away and because he noticed that she was having more trouble with cooking more complicated meals, being more forgetful about medications and occasionally having angry outbursts. He was a little bit worried about leaving her alone for a weekend to go to his big curling bonspiels in the winter. Her MMSE was 20/30. A CT scan was done which showed periventricular white matter changes and two old lacunar infarcts. The family physician made the diagnosis of mild mixed Alzheimer's and vascular dementia and she was started on anti-dementia drug therapy (cholinesterase inhibitor). Alternatively, the family physician referred patient to specialized diagnostic services.</p> <p>Her physician did further evaluation which showed poor visual spatial function (clock drawing) and poor performance of Trails A and Trails B. Based on her overall assessment he advised her that she needed to stop</p>	<p>Appropriate diagnostic assessment and a trial of a cholinesterase inhibitor for all patients.</p> <p>Diagnosis of dementia mandates appropriate driving assessment with appropriate reporting to Ministry of</p>	<p>Dementia education for family physicians</p> <p>Access to anti-dementia drug therapy available</p> <p>Enhanced specialized diagnostic and treatment services to achieve realistic wait times in urban and rural areas</p> <p>Family physicians are aware of appropriate driving assessment And of on-road specific driving assessment services</p>

	driving.	Transportation	
2 years, 10 months	<u>Three months</u> later she was seen and she had improved. She was more active, more attune to social situations and conversation and more like her old self. Her MMSE had improved to 22. At this stage she only needed a little bit of cueing for finances and shopping. She was referred to a Day Centre at a Senior's Centre for increased stimulation and socialization and to provide her husband with some respite.	Day Program stimulation and respite.	Appropriate Day Program Respite available for caregivers of persons with mild to moderate dementia with realistic wait times in urban and rural areas
3 years, 7 months	9 Months later she was about the same, a little more forgetful. The husband had hired a maid to do some of the simple cleaning services through the local community for profit support agency and he also needed to become more involved in cooking simple meals, shopping and finances. Her MMSE was now 20.	Community support service agency	Referral to community support agency for assistance with IADL's
4 years, 9 months	<u>One year later</u> she was more forgetful, was unable to cook on the stove but still could use the microwave and do simple cold meals. She needed help with laundry and help with shopping. She was independent in her personal ADL's and only occasionally needed some cueing with respect to clothes selection. She did need help with respect to bathing and the CCAC became involved. Respite was tried for the husband's attendance to his curling bonspiel and other leisure activities but she became too upset with residential care respite. Her MMSE was 16. She was more emotionally labile, apathetic and became very anxious if left alone. She was also having episodic bouts of agitation and occasionally aggressive behavior.	Continuing education/support from the Alzheimer's Society. Referral to CCAC Respite. Referral to Psychogeriatric Community Services.	Range of programs and services providing education and support for caregiver Appropriate quantity of community supports available Appropriate mix of community supports Guest House respite for caregivers of persons with mild to moderate dementia Specialized outreach/outpatient assessment services: geriatric medicine, geriatric psychiatry
	Memantine (Ebixa) was started and there was some improvement in terms of cognition, (MMSE 18), ADLs, agitation and anxiety.	In moderate dementia, add on Memantine therapy to Cholinesterase Inhibitor therapy.	Continuing physician education on treatment and management of patients with dementia
5 years, 9 months	<u>One year later</u> her case was considered to be significantly more complex	CCAC Dementia Specific Case	Appropriate quantity of

months	<p>and her care is now being managed by a Dementia Specific Case Manager from CCAC. Her MMSE was 15. Her husband was doing all the instrumental activities of daily living. CCAC was providing more services in terms of bathing and personal care. She was occasionally incontinent. Her gait was unsteady and her fall risk was increased such that she needed to use a walker. She needed help with bathing, hygiene and toileting and there was considerable caregiver stress in that she could only be left alone for approximately an hour.</p> <p>A day program through CCAC (Alzheimer's Day Away) helped with respect to daytime respite and there was an increase in paid services by the husband to lessen caregiver stress.</p>	<p>Management.</p> <p>Contingency planning and crisis prevention and management in place</p> <p>Alzheimer Specific Day Program and increased formal and informal service provision.</p>	<p>community supports available Appropriate mix of community supports</p> <p>Specialized geriatric psychiatry outreach in community for on-going management and crisis intervention</p> <p>Appropriate Day Programming for moderate dementia with realistic wait times in urban and rural areas</p>
6 years, 9 months	<p><u>One year later</u> she had a small stroke leaving her with some weakness on the right side. Her incontinence was worse. She developed a tendency towards wandering about the house and once wandered outside and it was decided that she and her husband would re-locate to residential care. This move was very positive for the husband.</p>	<p>Appropriate relocation to residential care.</p> <p>Continued case management with timely referral to LTC</p>	<p>Incentive based placement coordination system in place</p> <p>Education and support for placement process (Partnership in Transitional Care Program)</p>
7 years, 9 months	<p><u>One year later</u> her communication skills were markedly affected. Her mobility was decreased. She began having increasing hallucinations and angry outbursts and it was necessary to transfer her to the local Nursing Home.</p>	<p>Appropriate relocation to LTC</p>	<p>Specialized geriatric psychiatry outreach in community and LTC for on-going management and crisis intervention</p>
8 years, 9 months	<p><u>One year later</u> after receiving appropriate end of life care she was found deceased on morning nursing rounds.</p>	<p>High quality, end-of-life palliative care available</p>	<p>Palliative care available for persons with dementia and support for family members</p>

An “Ideal” Case Followed Through The Stages of Dementia: How Would the Case Study Change If the Person with Dementia Lived Alone?

1. If the person with dementia has children or very close friends living in the area:

- Generally persons with mild dementia can have IADL assistance by children or close friends and remain in the home with dosettes and reminders for medications plus, if appropriate, formal health services provided or paid for as long as there are not significant safety issues (driving, cooking, nutrition, wandering etc.) or significant psychobehavioural problems (refusal to accept help, hallucinations, delusions, wandering). In mild dementia the interval of need is typically 12 to 36 hours and can be managed by children or very close friends.
- As someone progresses to moderate dementia with the development of personal ADL difficulties (bathing, hygiene, toileting, dressing etc.) the interval of need shortens to 4 to 12 hours and there are increased caregiver demands that generally close friends cannot manage and even children find greater difficulties with provision of services particularly personal ADL assistance. As long as formal services can be provided or purchased, persons with moderate dementia may be able to stay in the home for some period if there are no significant safety or behavioural concerns, but generally planning should begin for residential home or long-term care relocation. As the interval of need shortens below 8 hours and moves towards 4 hours that the person with dementia can be left alone, generally even devoted sons and daughters cannot manage and relocation is necessary.
- As someone progresses from mild to moderate dementia there is an increased need for formal services, caregiver education and problem solving, use of respite services, use of Day Programs, and increased attention to caregiver burden and stress.
- Generally patients with severe dementia will require long term care and can no longer remain at home unless there is an option to relocate to a son's or daughter's home but even then long term care placement will likely soon be required.

2. If the person with dementia has no children or very close friends living in the area:

- In this instance, even persons with only mild dementia and an interval of need of 12-36 hours with no availability of informal services will require increasing formal services. If cooking and nutrition can be managed and there are no safety or behaviour concerns the person can remain at home with increasing formal services. As the person with dementia transitions to the moderate stage of dementia with emerging loss of personal ADL's, such as bathing and hygiene, formal services provided to the person become increasingly stretched and unless there is the availability of paid services, it is likely that transfer to a Residential Care Home or Long Term Care Institution will be necessary.

Champlain Dementia Network

Report Card: MCI/MILD Stage

a = working well; b = under-utilized; c = long waiting lists; d = in some areas

Action	Not in Place	In Place		a	b	c	d	Comments
A Framework is developed for a public awareness campaign: risk factors; warning signs; early recognition								
Screening Program on early recognition is developed								
Enhanced diagnostic and treatment services to achieve realistic wait times in urban and rural areas is in place.								
Electronic patient record begun								
Dementia Education for Family Physicians								
Dementia education framework in place for all service provider staff								
First Link Program: Alzheimer Society								
Monitoring and assessment by Family Physician								
Referral to senior's centre for social activities								
Enhanced specialized diagnostic and treatment services to achieve realistic wait times in urban and rural areas								
Education for Family Physicians for appropriate driving assessment and of on-road assessment services								
Appropriate Day Program Respite available for caregivers of persons with mild to moderate dementia with realistic wait times in urban and rural areas								
Referral to community support agency for assistance with IADL's								
Guest House respite for caregivers of persons with mild to moderate dementia								
Education regarding appropriate re-location to residential care								
Transportation is available for both the person with dementia and for the family caregiver								

1. Mild Cognitive Impairment (MCI):

Memory-wise, the person is not as "sharp" as they were one year previously but there is no effect on other cognitive functions and no impairment of instrumental activities of daily living (IADL: e.g. finances, shopping, cooking, etc.). There may be some mild behavioural complaints (e.g. anxiety, loss of initiative, irritability etc.) The approach is to monitor for change every 6 to 12 months as there is an approximately 10% risk per year of progression to Dementia.

2. Mild Dementia (45% at the time of diagnosis):

Fulfills the criteria of Dementia (change in memory and at least one other cognitive function (e.g. language, visual spatial, judgement, executive function) associated with an impact on IADL's and possibly early psychobehavioural problems but these changes are mild. The interval of need is generally 12 hours to 3 days and there is some need for informal help and minimal formal services. If the person is living at home alone without any informal help there may need to be consideration for residential care if there are significant functional or safety issues

Champlain Dementia Network

Report Card: MODERATE Stage

a = working well; b = under-utilized; c = long waiting lists; d = in some areas

Action	Not in place	In place		a	b	c	d	Comments
CCAC specific case manager assigned								
Continuing education/support from the Alzheimer's Society								
Respite available : in-home, day program and Guest House respite for mild to moderate dementia								
Specialized outreach/outpatient assessment services: geriatric medicine, geriatric psychiatry								
Referral to Psychogeriatric Community Services								
Range of programs and services re: education and support available for caregiver (Alzheimer Society)								
Appropriate quantity of community supports available								
Appropriate mix of community supports available								
Education for person with dementia and family caregiver regarding appropriate re-location to residential care								
Contingency planning and crisis prevention and management in place								
Appropriate Day Programs for moderate dementia with realistic wait times in urban and rural areas								
Incentive based placement coordination system in place								
Education and support for person and family caregiver replacement process (Partnership in Transitional Care Program)								
Transportation is available for both the person with dementia and for the family caregiver								

Moderate (45% at the time of diagnosis):

The major change is that at least one personal activity of daily living (PADL) is affected (e.g. dressing, toileting, bathing, hygiene, ambulation etc.). Behavioural problems may be more significant including delusions, hallucinations and aggressive behaviour. The interval of need is typically 4 to 12 hours and there is a need for both significant informal and/or formal services for support and there may be a consideration of need to relocate to a supervised setting (Retirement Home or Long Term Care).

Champlain Dementia Network

Report Card: SEVERE Stage

a = working well; b = under-utilized; c = long waiting lists; d = in some areas

Action	Not in place	In place		a	b	c	d	Comments
Appropriate relocation to LTC								
Specialized geriatric psychiatry outreach in community and LTC for on-going management and crisis intervention								
Transportation is available for the family caregiver								
Education and support is available for family member								
Staff in LTC receive a coordinated menu of learning opportunities about needs of resident with dementia								
Physicians within LTC receive dementia education								
Appropriate quantity and mix of community supports available for those still living at home								

Severe (10% at the time of diagnosis):

There is now significant impairment in PADL, IADL's are completely lost, memory loss is severe, behavioural problems may become more severe, and generally the person is in a supervised setting (Retirement Home/Long Term Care) or living with a devoted spouse. The interval of need is now 0-4 hours and respite care, formal services, and support of the caregiver is critical if the person with dementia is still at home.

Champlain Dementia Network

Report Card: END-OF-LIFE Stage

a = working well; b = under-utilized; c = long waiting lists; d = in some areas

Action	Not in place	In place		a	b	c	d	Comments
Enhanced service provision for palliative care stage of dementia available in the community								
For family caregiver in the community, appropriate quantity and mix of community supports available								
For family caregiver in the community, respite is available and encouraged								
Enhanced end-of-life care available for persons living in LTC Homes								
Education and support available for the family members								
Transportation is available for the family caregiver								

Palliative/End of Life:

The person is now completely dependent in PADL, generally bed bound, needing feeding and generally in a Long Term Care setting with life expectancy less than 3 months – 6 months. The need is for compassionate terminal care.

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Appendix

Community Care Access Centre (CCAC): coordinates professional health and treatment programs for adults and children in need of assistance in their homes. Services include nursing, physiotherapy, occupational therapy, speech therapy, and other related disciplines. They also provide personal support services to the frail elderly and those who are disabled. The CCAC manages the application process and waitlists for government supported long term care homes and day programs. www.ottawa.ccac.ont.ca; www.renfrewcounty.ont.ca; www.easterncounties.ont.ca

Community Support Services: The Ottawa Community Support Coalition (OCSC) consists of 19 organizations mandated to provide home-based community support services to seniors and adults with physical disabilities. These agencies provide a wide range of community support services designed to meet the needs of individuals living in their community. The range of services offered by these agencies includes Meals on Wheels, Diners Club, Transportation, Friendly Home Visiting, Caregiver Support, Foot Care and Homemaking. www.communitysupportottawa.ca; Eastern Counties: 1-800-267-1741; Renfrew County: www.renfrewcountyhealth.ca

Day Away Program (DAP): programs that provide stimulation and socialization to seniors in the community and to relieve family caregivers. There are specific Alzheimer and related dementias' Day Programs available.

Diagnosis/Treatment/Assessment Services: multidisciplinary assessment services for the diagnosis of Alzheimer's Disease and related dementias as well as management and treatment of associated issues such as functional dependency, safety, caregiver stress, education needs, community services and future planning.

First Link Program: links individuals newly diagnosed with dementia and their families to a community of learning, services and support which is continued throughout the progression of the disease. Eastern Counties: 613-932-4914; Renfrew County: 613-732-1159; Ottawa: 613-523-4004

Guest House Respite: a 12 bedroom bungalow located on the campus of the Perley and Rideau Veterans Health Centre. It has been planned and designed to create a safe, homelike and supportive environment for individuals in the early to mid-stage of dementia. Guests can stay 24 hours a day, with emergency, overnight, and flexible accommodation available. Initial assessment is required through the CCAC. Ottawa: 613-745-5525 www.alzheimerott.org

Instrumental Activities of Daily Living (IADL): activities related to independent living and include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, transportation, and using a telephone.

Personal Activities of Daily Living (pADL): routine activities that people tend to do everyday. There are six basic pADL's: eating, bathing, dressing, toileting, and transferring (walking). An individual's ability to perform pADL's determines the type of care that the individual needs.

Respite: infrequent and temporary substitute care which can provide relief for caring for someone at home. Respite also will provide socialization and activities for the person with dementia. Types of respite include: in-home, Day Programs, in-facility.

Seniors' Centres: provide opportunities for seniors to socialize with other seniors and to participate in many activities and programs such as arts and crafts, games, exercises, fitness, travel, choir, history, languages, discussion groups, guest speakers, lunches, and many other interests.

Specialized outreach/assessment services: an inter-disciplinary approach to case management which includes assessment, counseling, referrals to other agencies, educational resources, psychotherapy for persons with Alzheimer Disease and related dementias. Geriatric Psychiatry Community Services: Eastern Counties (GPCSO): 613-932-9940; Renfrew County: 613-735-6500; Ottawa: 613-562-9777. Royal Ottawa Hospital: 613-722-6521 Ex. 6507