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Release of “Caregivers and Dementia” Study

Caregivers and Dementia presents the results of a study carried out on behalf of the Alzheimer Society of Ottawa and Renfrew County in collaboration with the Champlain Dementia Network. The study gave rise to a wide range of recommendations for improving respite options for caregivers of persons with dementia.

Recognizing caregiver needs

The concerns raised in this cluster of issues focus upon the fact that caregiver needs are linked to – but are significantly different from – those of care receivers. The first area of need relates to the recognition of caregivers and their engagement in the planning process for care receivers. The second group of concerns involves the information and training required to effectively carry out the caregiving role. The third set of issues speaks to the fact that caregivers themselves may experience a range of stresses and associated mental health problems. Their unique needs should be addressed.

Policy

- Formalize the recognition of caregivers’ significant role through a National Caregiver Strategy similar to those already in place in the United Kingdom, Sweden, Australia and New Zealand.

Program

- Increase broad-based delivery of education programs and individualized training for both family and professional care-

givers around the physical needs of care receivers

- Enhance access to support and interventions for family caregivers through such means as support groups, and telephone and online support.
- Recognize and address the changing roles that place demands on caregivers including the stress and impact on their physical and mental health.
- Develop and implement a Caregiver Burden Index to monitor caregiver relief.

Improve the quantity and quality of services

The concerns raised in this cluster of issues focus upon the fact that caregivers experience two major types of problems around the delivery of supports and services for Alzheimer’s disease and related dementia. The first has to do with the quantity of available services, including the number of hours for in-home support and the waiting time for services like day programs and long-term care. The second group of issues in this cluster is rooted in the quality of service provision – i.e., the flexibility of current arrangements, their appropriateness relative to the needs of care receivers and caregivers, and the quality of staff training. A unique set of challenges is raised about the gaps in service in rural areas and the problems arising from travel distances and associated costs.

Policy

- Extend the maximum number of hours available for in-home services and change

the formula for assigning hours to include – as part of the eligibility assessment – caregiver and care receiver needs, disease progression, change in roles and caregiver coping.

- Introduce greater flexibility in the provision of supports at home, including the availability of individualized funding and self-directed care to enhance responsiveness to the needs of caregivers and care receivers, and programs like the successful Veterans Independence Program (VIP).
- Introduce greater flexibility in the eligibility criteria to ensure service availability for those with dementia under the age of 65.

Program

- Ensure that professionals and service providers receive improved and ongoing training for addressing the continually changing needs of persons with dementia. Training should be culturally sensitive and linguistically appropriate.
- Ensure caregivers be involved in the development, implementation and evaluation of the services provided to them.
- Encourage home care providers to carry out basic animation with care receivers, where feasible, rather than only friendly visiting.
- Analyze and address gaps in the under-utilization of services.

Reduce the costs and financial pressures associated with caregiving

The concerns raised in this cluster focus upon the fact that caregivers typically experience financial stresses that arise from two sources. The first involves the additional expenses associated directly with the condition and includes fees for

home care services, transportation costs for medical appointments, drug dispensing fees, technical aids and equipment, and home modification. The second set of financial pressures derives from insecurity related to employment circumstances for caregivers who are active in the paid labour market. Many must reduce their hours of employment or leave jobs altogether in order to carry out their caregiving responsibilities. Those without leave, insurance coverage or pension protection risk their economic security.

Policy

- Renew the Home Adaptations for Seniors' Independence program when the funding commitment expires in 2009.
- Expand the leave provisions in federal and provincial labour codes
- Extend the compassionate care leave provisions under the Employment Insurance Act to allow special leave for care for persons with progressively degenerative conditions, such as dementia.
- Extend the drop-out provisions of the Canada Pension Plan to cover caregiving for persons with moderate- and late-stage dementia.
- Consolidate the application for government funded subsidies into one centralized access point.

Program

- Research the allowances and other supports for caregivers available elsewhere in the world, such as the National Strategy for Carers in the UK.

For the full "Caregivers and Dementia" report and accompanying Appendices, visit:

www.caledoninst.org
