CARING FOR A FAMILY MEMBER WITH DEMENTIA

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Progressive dementia is one of the most devastating and burdensome illnesses with far-reaching consequences, not only for the afflicted individuals and their families but also for communities and for society as a whole. With an increasing risk of developing dementia with advanced age and a substantial growth of the elderly population in the next 40 years, our society faces a great challenge, and so do families. According to data from the Canadian Study of Health and Aging Working Group (1994), 253,000 persons in Canada suffered from dementia in 1991. For the year 2031, the prevalence for dementia in Canada is expected to triple to 778,000 cases.

Families play a crucial role in the care of persons who suffer from dementia. Many families are determined to keep their spouse or parent at home as long as possible. Family members, many of them elderly themselves, face numerous problems in their role as caregivers, a role for which they are often not well prepared. The stress associated with providing care, can jeopardize the caregivers' quality of life, physical and mental health.

It is difficult at first for family members to recognize that a problem exists when it is a dementia with an insidious beginning such as Alzheimer's disease. Often, spouses or children of these persons assume that their behaviour is intentionally malicious. Families believe in a change of personality when they are quarrelsome and antisocial. At times, these changes appear before weaknesses in the execution of routine tasks and memory lapses become evident. Caregivers start worrying when these events happen more frequently. Once the family consciously perceives that something is wrong, the person has to be convinced to consult a physician. This is often a difficult task to accomplish because of denial and resistance. The physician may recommend a comprehensive evaluation, executed by specialists in the field, as a next step. At this point, there are still many questions that need to be answered. Are the problems reversible? Is there an underlying physical illness? Is the person

depressed? What type of dementia is it? Families require information on prognosis, the expected evolution of the illness, treatment and day-to-day management.

At the time when a probable diagnosis is given, the family members have to support the person who just received a verdict with enormous consequences while dealing with the new reality themselves and having to cope with their own feelings. The consequences will be as enormous and very stressful for the family caregivers and will also affect their relationship with the newly diagnosed patient. Roles within the family system change. Very independent persons are becoming increasingly and in the end totally dependent on their spouse or on their children. The caregiver wants to ensure that the person with dementia is safe, that the person cannot walk out the door and get lost. The caregiver has to decide: Can he/she stay alone at home? In the daily care of the patient the caregiver frequently faces issues such as the following: How can I prevent him/her from getting anxious or aggressive? What do I do when he/she does not want to take a bath?

Where can families find answers to these and many more questions? Across the country as well as in the rural part of the Eastern Townships, the local chapter of the Alzheimer's Society plays an important role. Amongst many other services, this organization provides information and training sessions as well as support groups for families. In the context of group sessions family caregivers meet people who face similar problems. Participants find encouragement when they realize that they are not alone walking this long and often very lonely road as a caregiver for a loved one who suffers from dementia.

A major challenge for caregivers is how to overcome communication barriers because the patient not only shows worsening memory deficits but also becomes easily distracted, develops more and more difficulties in comprehending instructions and in expressing thoughts and feelings through language. How do you respond to your spouse, father or mother when he/she says something that does not make any sense? How do you interpret non-verbal messages when a loved one has stopped talking altogether? Communication problems, rapidly changing moods, often unpredictable and difficult behaviour are challenges caregivers face daily. Common sense responses are not necessarily appropriate to meet the individual's needs. It is evident that families need support and instructions, based on scientific findings and clinical experience. We have to provide them with tools, to overcome these problems.

However, tools and techniques are not sufficient. We have to talk about the philosophy of dementia care as well. Basic principles are to preserve, as much as possible, personhood, the psychological continuity of the individual. We have to show respect and treat the person with dignity. This can be achieved by validating the person's experiences and also maintaining their self-esteem, for example by assisting them to do what they might not be able to do on their own.

Important practical goals are to include the individuals as much as possible in activities they are familiar with and to avoid too much change. In the early stages, they need emotional support to help them accept the illness and to cope with the numerous losses. When the disease progresses, the caregiver has to tune into their feelings and accept their reality even if it contradicts reality as we perceive it. All senses ought to be stimulated, and laughing, singing and dancing could provide body contact and comfort. Some of the psychosocial group approaches can be beneficial in counteracting social isolation and fostering feelings of belonging.

The question arises if these and other services, such as respite care and transportation, are available or accessible to patients and families. In the context of rural communities it may be particularly difficult to have access to services.

In the course of a dementia, families face problems that encompass every aspect of life. Many decisions have to be made and many actions have to be taken. This process is often difficult and painful. Family caregivers have to adapt the living space in order to facilitate daily activities and to assure the safety of the patient. They have to watch the physical and mental health condition of the patient in order to detect physical illnesses and symptoms of depression and anxiety as soon as possible. It is important for families to learn about the drugs prescribed to the patient in order to be aware of their expected effect and potential side effects. In the process, they have to learn how to communicate with the patient in order to be able to meet the patient's needs and increase his/her comfort. They also have to learn how to deal with difficult behaviours in order to reduce conflict and to increase quality of life both for the recipient of care and the caregiver. The patient's daily activities have to be maintained as long as possible to preserve his/her self-esteem and dignity. Sexual relations between the patient and his/her spouse need to be adapted in a way that is beneficial to both partners. Financial issues need to be addressed as soon as possible to incorporate the patient's ideas while he/she is still able to voice an opinion. A will and a mandate have to be written while the patient is still capable

to assure that the patient's wishes are documented and legally valid. Families have to come to terms with and arrive at decisions on levels of care, do-not-resuscitate orders and palliative care for the patient to assure the best possible care at the final stage of life in concordance with the patient's expressed wishes. A decision regarding private or public curatorship for the patient should ideally involve the whole family to assure the appropriate guardianship for the patient's health and estate. If funeral arrangements have not yet been taken care of they ought to be made as early as possible to avoid the stress of having to organize them under pressure.

In most cases, families have to decide on placement in general and on the institution in particular to assure that the care needs of the patient are fully met, but also to prevent caregiver burnout and to give the caregiver a chance to resume his/her own life. The day of admission is frequently described as the worst day in the lives of family caregivers. At this time, families are usually guilt-ridden and extremely vulnerable. They are frightened and ask themselves what will happen to their loved one, but they also ask themselves what will happen to them once they relinquish their often full-time role as caregivers. After the placement of the patient, families have to adapt to their new and different role to allow the patient to get settled and to build a constructive relationship with the professional caregivers. Family conflicts ought to be addressed while the patient is still able to participate in the resolution process in order to make peace and provide closure both for the sake of the patient and the members of the family.

In addition to these numerous tasks that family caregivers address in the patient's best interest, those issues that are more directly related to the caregiver need to be addressed as well. Accepting the illness requires time, psychological strength and coping skills. There are families that uphold their denial and may never accept the illness. Others find it difficult at first, but with time they are able to accept reality. In addition, the new role as caregiver has to be integrated and accepted. Important components are the willingness to learn, to be flexible and to sacrifice personal goals the caregiver may have had for the time being. The principal caregiver may have to cope with members of the family who do not understand or accept the condition of the patient and may even accuse the caregiver of making the wrong decisions, thus adding to the burden instead of alleviating it.

For numerous reasons, accepting help and services is difficult for many dedicated caregivers. Their commitment to their loved one is

so strong that taking care of oneself is secondary. Many caregivers, especially elderly spouses, are socially quite isolated because of their 24-hour-a-day task. Their physical and mental health is in danger. It is paramount that they get a regular reprieve from their arduous task to pursue social and recreational activities. The ability to cope with these numerous and complex tasks is different from person to person. There is abundant literature on what is called "caregiver burden" in dementia care. Numerous studies show elevated levels of depressive symptomatology, even high rates of clinical depression and anxiety among caregivers, linked to dysfunctional patient behaviour (Schulz et al., 1995). Female gender, increasing age and decreasing physical health point to an increased burden. Caregivers who have more social support and interaction with family and friends are less distressed (Vitaliano et al., 1991). The association between physical morbidity and caregiving is more equivocal because of numerous contributing factors that may play a role (Schulz et al., 1995).

When families provide care to dementia sufferers in their home environment, society has to acknowledge that they relieve the health care system of colossal cost. Both clinicians and planners of health and social services have to be aware that for each patient suffering from a dementia there are services required not only for the patient, but also for the family caregivers. If these services are not provided at the time when they are required, the future health care cost may increase drastically because caregivers require treatment, possibly hospitalization, and because the person suffering from a dementia may have to be institutionalized earlier than otherwise needed. The necessity of preventive services to preserve the physical and mental health of family caregivers cannot be stressed enough in the light of their complex and continued commitment.

RESUME

Les familles qui doivent s'occuper d'un parent souffrant de démence irréversible ont à relever un défi énorme, qui exige d'elles un engagement total. Avec le temps, elles en arrivent à prendre en charge tous les aspects de la vie du malade. Non seulement elles doivent s'adapter aux changements qui affectent sa personnalité, son humeur et son comportement, mais elles doivent aussi faire face à une surcharge de travail et à leurs propres sentiments de perte. La société doit tenir compte des besoins complexes de ces familles et fournir les services nécessaires pour assurer la santé physique et mentale des aidants.

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