

## Caregiver Support

### Integrated Knowledge and Practice Tips

#### Caregivers are an important part of our healthcare system

As the elderly population grows, more and more people will have health conditions that prevent them from looking after themselves. Caregivers provide vital assistance to the frail elderly living in the community. Past estimates suggest that almost 50% of elderly community-dwelling individuals are being assisted by family or friends who act as informal caregivers. This figure soars when examining the statistics for people suffering from dementia. Approximately one half of those diagnosed with dementia live in the community and 94% of these patients are cared for by family or friends. When examining this data a little more closely, it is found that 37% of these caregivers are spouses, making them the largest demographic amongst informal caregivers (Canadian Study of Health and Aging Working Group, 1994). This in itself is significant, as it means that a good proportion of caregivers may be elderly and have frailty issues of their own.

Caregivers are often the final link in keeping frail community-dwelling individuals living in their own homes. A caregiver's sense of well-being is well correlated with the need for a frail individual to move into a care institution, and numerous studies have demonstrated that higher levels of perceived burden in the caregiver is linked to earlier cessation of care in the community (reviewed by Dunkin and Anderson-Hanley, 1998). Importantly, it was found in a Canadian sample population that over three quarters of caregivers did not utilize formal support services, about half were dissatisfied with the attention they received from the health system, and over a third reported feelings of stress, depression, guilt, and isolation (Brotman and Yaffe, 1994). Caregivers do important work, and they in turn need the support of their healthcare team.

Recent reports lend very agreeable evidence to the benefits of caregiver support. An intervention, consisting of a small number of counseling sessions, participation in community groups, and the availability of ad-hoc telephone assistance, was provided to Alzheimer caregivers. The result was reduced depression and stress, improved social support, and a delay in nursing home placement of the patient that was predicted to be over one and a half years (Mittelman et al, 2006; 2007).

### When the caregiver becomes in need of care themselves

The chronic stressors involved in caring for another individual add up over time, and have a toll on the well-being of the caregiver. In surveys, caregivers rate their overall health to be worse than the general population. This perception is mirrored by scientific evidence, as caregivers have been shown to have decreased immune system function, cardiovascular problems, and increased physical symptoms over time compared to demographically similar controls. Mental health issues also arise, as caregivers have higher levels of clinical depression, anxiety, social isolation, and psychotropic drug use compared to the general population. It has also been suggested that high levels of burden is correlated with increased mortality in caregivers (Schulz and Beach, 1999).

#### Factors that predict higher levels of burden

- female caregivers compared with male
- closer kinship ties, evidence that spouses have higher burden than adult children
- increased age of caregiver
- low income causing financial stress
- high perceived stress
- low life satisfaction, self-esteem, or self-mastery
- low levels of social or community support
- behavioural problems in care recipient with dementia
- poor prior relationship with care recipient
- co-habiting with care recipient

The effects of burden on the caregiver can soon become a slippery slope, affecting both caregiver and patient.

Burdened caregivers can begin to resort to emotional coping strategies, such as criticism, anger, and hostility, and may become over-involved with the patient, losing the ability to balance their own needs with those of the patient. These caregivers report greater burden, more

stress, greater levels of suppressed anger, higher degrees of depression, and less social support. These behaviours can also start to have a negative impact on the care recipient. Indeed, studies have measured an increase in behavioural problems in dementia patients when their caregivers exhibit these temperaments (Vitaliano et al, 1993). This increased cognitive and functional impairment, in turn, causes more difficulties in caregiving, leading to even greater potential feelings of burden.

### Practice Tip #1 – Screen for caregiver burden

The healthcare team should screen caregivers regularly for signs of burden. This will help to identify individuals who may require more intervention by either your team or who may need to be referred to their own health provider. It is helpful to ask screening questions that cover major aspects contributing to burden: the patient's status, the caregiver's own health and coping strategies, the level of support from family or friends, and the use of available community resources (Parks and Novielli, 2000; Cohen et al, 2001).

#### Suggested screening questions for caregiver burden

1. Has being a caregiver caused you a lot of stress lately?
2. Have you been feeling down or blue, or have you been getting angry more easily?
3. What have you been doing to cope with these feelings?
4. Has your loved one been having more difficulties, such as behavioural problems?
5. Do you see your family and friends as often as you'd like?
6. Do you have help from others, like family, friends, or neighbours, when needed?
7. Do you have outside help, from community agencies or support groups?

There may be particular times over the course of a patient's illness when the caregiver might require more support. Examples might include (Cohen et al, 2001):

- when a diagnosis, such as dementia, is first made
- when the patient's health deteriorates to a point where they can no longer be left alone
- when institutionalization needs to be considered
- when the patient enters the end stages of their illness

It is important to maintain regular dialogue with caregivers and to screen for burden as necessary so that appropriate education and support may be provided to them during times of particular need. Outcome measures such as the Zarit Burden Interview (Zarit et al, 1980) or the Kingston Caregiver Stress Scale (Hopkins and Kilik, 2007) are helpful tools to track changes in caregiver burden levels.

### Practice Tip #2 – Recognize signs of elder abuse

While there is little evidence to implicate caregiver burden as a direct cause of elder abuse, cases may arise where suspicion of elder abuse is warranted. As vulnerable seniors can be at risk of serious harm, it is important to recognize warning signs that hint of elder abuse.

The actions that cause elder abuse may be intentional or the result of passive behaviour such as unintended negligence. In truth, elder abuse is rarely deliberate. More often, it emerges out of frustration when caregivers don't know what to do and aren't aware of resources available to

#### Potential warning signs of elder abuse

- evidence of poor nutrition, hydration, grooming, or hygiene
- presence of bruises, abrasions, or burns on the patient
- signs of overmedication or sedation
- medical needs are left unattended
- sudden changes in financial arrangements
- sudden hypervigilance by caregiver
- atypical personality or behaviour changes
- unexplained withdrawal or social isolation
- evidence of verbal abuse or intimidation

help them. It follows then, that a preventative strategy is to screen frequently for caregiver burden and to provide meaningful assistance to the caregiver when needed. However, in cases where elder abuse is suspected to have happened, consider the following actions:

1. In an emergency or in a case where there is potential for imminent harm – call “911”
2. In cases where harm is not imminent, attempt to reach out to the suspected victim.

Ask them questions like: Are you having trouble at home?

Has anyone at home made you afraid or hurt you?

Has anyone taken your things without your permission?

Do you know where you can get help?

Offer support and provide this patient with the number to the Victim Support Line so that they may get information to access needed help (1-888-579-2888)

3. If the supposed victim does not have the capacity to understand their situation, contact the Office of the Public Guardian and Trustee, who will conduct an investigation. (1-800-366-0335)
4. If the suspected victim resides in a long-term care home, mandatory reporting is required in Ontario by calling the Ministry of Long Term Care (1-866-434-0144)

### Steps to help mediate caregiver burden

Education is an important component to successful caregiving, as very few people are truly prepared to take on a role which, in some cases, arises very suddenly. Caregivers should be aware of the patient's illness(es), its implications, home management strategies, and advanced planning. Caregivers should also be encouraged to develop coping strategies that foster problem-solving and information-seeking when difficulties arise. Caregivers who are successful at doing this report lower levels of burden (Forde and Pearlman, 1999; reviewed in Etters et al, 2008). Furthermore, dementia patients were found to exhibit fewer behavioural problems when their caregivers adopted well-informed problem-solving, and supportive strategies to care (De Vugt et al, 2004).

Caregivers benefit from all the support they can get. Factors mediating caregiving burden that have been well studied include the level of help from family and friends, the quality of prior relationships with family, and the caregiver's own ability to cope with the caregiving role. Indeed, caregivers who have larger social networks and greater satisfaction with their social support consistently report less burden, less depression, greater life satisfaction, and fewer health problems (reviewed in Dunkin and Anderson-Hanley, 1998). Caregivers should be encouraged to maintain strong networks with their family and friends, and should also be well informed about outside agencies and respite services that can provide help

Caregivers also require psychological support. This can be as simple as taking time to acknowledge and validate the important work they do, or can involve individual counseling, family therapy, or group support sessions. When caregivers do report being depressed, individual therapy (eg. referral to a psychiatrist) has been shown to be more helpful than group treatment (reviewed by Knight et al, 1993).

#### Caregivers speak about the kind of help they would prefer

1. Telephone support from a professional (44.9% of respondents)
2. Telephone support from a fellow caregiver (41.0%)
3. A newsletter (40.5%)
4. Volunteer support (24.2%)
5. Support via computer (14.8%)
6. Support via group interventions (10.4%)

Results from the Canadian Study of Health and Aging (Colantonio et al, 2001)

### Practice Tip #3 – Educate the caregiver

#### Education about the disease(s)

- caregivers should be well informed about the medical problems of the patient, what to expect, and how to deal with problems that might arise
- modifications to daily routines or to the home environment that may become necessary
- disease specific information should be provided to help the caregiver cope with changes (eg. communicating with dementia patients, managing behavioural difficulties) – provide contact information to the relevant disease societies or foundations

#### Education about available help

- caregivers should be aware of the programs in the community that are available to help them, and be encouraged to use them when appropriate
- programs and services might include:
  - Community Care Access Centres
  - adult day programs or community centre programs
  - specialized geriatric assessment services or special care units at local hospitals
  - respite care facilities, rehabilitation services
  - community outreach health teams
  - specialized disease societies or foundations
  - homemaker services to help with chores, housecleaning, or home repairs
  - companionship services, transportation services
  - volunteer or church services
  - home delivered meal services
  - home health aid services, in-home respite care
  - medical equipment supply services
  - housing assistance
  - financial/legal assistance
  - telephone hotlines and support services
- Seniors INFOline can provide assistance in locating many of these services in Ontario
  - toll-free: 1-888-910-1999
  - TTY toll-free: 1-800-387-5559

### Practice Tip #4 – Support the caregiver’s well-being

#### Encourage the caregiver to look after their own health

- caregivers should get adequate nutrition, sleep, and exercise
- caregivers need to keep their own medical appointments
- caregivers should protect adequate time for their own leisure activities

#### Encourage the caregiver to maintain strong social support networks

- it is important for caregivers to keep in touch with family and friends on a regular basis
- caregivers can join community support groups to expand their network and knowledge

#### Encourage the caregiver to seek help when needed and accept help when offered

- caregivers should share the responsibility of caregiving with other family members – even relatives living far away can provide financial assistance to help out
- caregivers should not feel guilty accepting help from friends and neighbours when offered
- assist caregivers in finding volunteer services or agencies that can provide assistance
- where appropriate, caregivers should utilize respite stay programs on a regular basis to give themselves a break, not just when a crisis occurs

#### Maintain strong communication with the caregiver

- acknowledge the important role played by the caregiver
- be available to talk with caregivers, via regularly scheduled appointments and ad-hoc telephone conversations if possible
- evaluate the coping strategies of caregivers and provide education and counseling as appropriate to encourage problem-solving and information seeking
- encourage caregivers to express their feelings and to discuss difficulties they are having
- be able to discuss legal and financial issues, or to refer caregivers to appropriate agencies

#### Offer intervention before the caregiver becomes overwhelmed

- screen for caregiver burden (see Practice Tip #1) and offer or refer appropriate help, such as individual psychotherapy, counseling, family therapy, or group support sessions

#### Optimize the care recipient’s treatment plan

- part of providing optimal care to the patient involves considering the ability of the caregiver to look after the patient at home (eg. assess and treat dementia patients to optimize behavioural problems)

### The interprofessional team

Caregivers can be thought of as our “hidden patients.” Indeed, a caregiver’s needs can be as varied as a patient’s, and there is great potential for them to become active patients if their needs are not addressed. The interprofessional team is ideally suited to assessing and providing for the caregiver, whilst addressing the patient’s needs simultaneously. When a frail patient’s health status changes, the caregiver must be provided with education on how to manage these changes at home. This may include training on safe mobility needs, medication management, dietary considerations, use of assistive aids, home modifications, and legal and financial issues. Helping the caregiver rally support, from relatives and friends as well as from available community services, can allow them to continue providing for a patient’s growing needs even when their own faculties might become overwhelmed. Caregivers do important work as a part of the healthcare team, and need to be looked after. The triad formed between the patient, the caregiver, and the healthcare team is a necessary symbiosis in keeping frail elderly individuals safe at home.

