

## Care for the Caregivers

### AIDS PALLIATIVE CARE WORK-ENVIRONMENT STRESSES

*“There is a need for greater teamwork and communication between caregivers.”  
– one voice –*

Care for the caregiver is an essential element of any Palliative Care initiative. While care of the person with HIV/AIDS can be extremely rewarding, at times professional and volunteer caregivers may also find the work to be quite stressful. This section identifies sources of distress, manifestations of stress and burn out in HIV/AIDS caregivers and discusses helpful coping strategies. The message underlying all strategies and information contained herein is the recognition that approaches to caring for the caregiver must be flexible and responsive to the needs of specific individual caregivers.

Research indicates there are stressors that are unique to AIDS care.<sup>1,2</sup> These work-environment stressors have often been found to be more stressful than hands-on work.

#### HIV/AIDS REALITIES:

Caregivers providing support can be stressed by the realities of HIV/AIDS, including:

- multiple deaths
- youthful age of the people for whom they are caring
- sexual orientation
- complex care needs
- dementia
- multiple losses
- conflict over what constitutes Palliative Care (tension between active treatment and comfort care)
- roller-coaster nature of the disease

#### WORK ENVIRONMENT STRESSORS

- scarce resources
- communication problems with administration/board
- unrealistic expectations of/for organization
- team communication problems
- difficulty with resource allocation

#### INDIVIDUAL/FAMILY VARIABLES

- difficulty with person’s lifestyle
- caregivers with HIV/AIDS
- risk-taking behaviour of person/family
- personality/coping problems of person/family
- communication problems between person/family

#### ROLE STRESSORS

- role conflict
- role strain
- inadequate preparation for role
- lack of control in work environment
- active vs. Palliative Care role

#### ILLNESS-RELATED VARIABLES

- fear of contagion
- manifestations of disease: body image, dementia
- mode of contracting disease
- financial costs of disease
- impact of disease on particular communities
- multiple family members
- issues with confidentiality
- difficulty with symptom management

## PERSONAL VARIABLES

*"We lost much of our youth to fighting this epidemic. We woke up one day and found we were middle-aged and had never been young"*<sup>3</sup>

(Saynor, 1994).

### MANIFESTATIONS OF STRESS

- *avoidance of clients/families*
- *grief overload*
- *anxiety and fear*
- *job/home interaction*
- *punitive behaviour*
- *feelings of hopelessness/impotence*
- *feelings of guilt with iatrogenic illness*
- *staff conflict*
- *health problems*

### SYMPTOMS OF BURN OUT<sup>5</sup>

- *emotional exhaustion*
- *depersonalization*
- *reduced personal accomplishment*

## AGE ISSUES

In the early days of the HIV/AIDS movement, it was noted that HIV/AIDS was receiving different attention within the health care system because both persons living with HIV/AIDS and their caregivers were young. While the population of HIV/AIDS caregivers may be aging, their work has forced them to deal with issues of death and dying at an early age. Long-term implications of this have yet to be fully understood.

## SEXUAL ORIENTATION

- one's own sexual preference may affect response to a person living with HIV/AIDS:
  - heterosexual caregivers may be homophobic and want to avoid persons who are gay
  - gay and lesbian caregivers may feel they are constantly exposed to HIV/AIDS in both their personal and professional lives, and suffer from "grief overload"
- caregivers who have "come out" may have difficulty if gay persons living with HIV/AIDS choose not to do the same. Such caregivers may need to reflect on how much of what is identified as the person's "unfinished business" is actually the caregiver's "unfinished business"<sup>4</sup>

## HIV STATUS

- caregivers who are HIV+ may foresee their own future, and worry that there will be no one left to care for them

## PERSONALITY AND COPING STYLE

- working with the dying has been found to shape one's attitude towards death and dying. Those who cope adequately with death tend to live in the present, rather than the past or future. They score higher on inner-directedness, self-actualizing value, existentiality, spontaneity, self-regard, self-acceptance, acceptance of aggression and capacity for intimate contact<sup>6</sup>
- the *hardy personality* is a personality characteristic proven effective in combating work stress in oncology settings, and could be of help in HIV/AIDS settings. This personality type is characterized by:
  - sense of commitment (as opposed to alienation) reflecting the hardy person's curiosity about, and sense of, meaningfulness of life
  - control (as opposed to powerlessness) reflecting belief that one has power to influence the course of events
  - challenge (as opposed to threat) epitomizing expectation that it is normal for life to change and for development to be stimulated<sup>7</sup>

## SOCIAL SUPPORT

- "participating in a network of caring and reciprocal relationships with others, and creating a sense of belonging and a reason for living that transcends one's individual self"<sup>8</sup> or social support, has been found to be one of the most important coping mechanisms. High levels of mental ill health in hospice nurses were found to be predicted by lack of social support

## COPING WITH CAREGIVER STRESS

*Stress derives from interaction between one's personal life and one's occupational life, and may be manifest in physical, psychological or behavioural symptoms. Coping mechanisms need to involve both work environment and individual action*

### STRESSFUL LIFE

- events may serve as a source of strength as well as being a stressor. Previous stressful life events can give one strength to bring to the workplace. However, unresolved previous losses or present stressors, such as illness or impending death of someone close, can leave one vulnerable and lacking emotional energy necessary to cope in the workplace

Given that stress evolves from both personal and professional spheres, coping mechanisms must involve both aspects of one's life. Mechanisms for coping with professional stress have been identified by many authors and include the following:

### ORGANIZATIONAL COPING

- assume roles across continuum of care
- avoid work overload
- regular discussion groups to deal with staff stress issues
- clear awareness of role of person in decision-making about active vs. palliative treatment
- ongoing education about disease, treatment, caregiver risk
- provision of safe environment for the person and his/her caregivers
- involvement of team in decisions about changes in work environment due to economic realities of society
- provision of appropriate time away from direct caregiving role

### DEALING WITH MULTIPLE LOSS

- recognize that one can learn as much about self by focusing on joys as by examining sorrows. Search for and explore past memories of joy and connection
- meaning in life is derived three ways:
  - creating a work or doing a deed
  - experiencing something or encountering someone
  - when we can no longer act, being aware of the attitude we take toward unavoidable suffering, through the courage and grace we assume when all else is lost<sup>9</sup>
- multiple losses from AIDS means that if one were to allow oneself to feel the pain of each grief, one would never get beyond acute grief
- psychological flooding of emotion may incapacitate rather than heal. To defend against this flooding, some people may become emotionally numb, leading to symptoms similar to Post Traumatic Stress Disorder
- encourage those in denial-numbing phase to re-experience their feelings by retelling traumatic events
- those in intrusive-repetitive phase (often characterized by overwhelming emotion) need leadership and external structure. Encourage stress reduction and suppression of painful emotions<sup>9</sup>

### PERSONAL COPING

- avoid excessive involvement which may preclude objective counselling, advice and medical care

*Caregivers need to have permission to say no and to limit their activities in order to sustain their own health and well-being*

- recognize anger directed at caregiver should not be taken personally, but may be part of the person's own coping strategy or the effect of the disease (see *Psycho-Social Issues*)
- do not allow AIDS care to dominate one's life
- personal insight into need for overwork/overinvolvement
- awareness that immersion in caregiving, both in personal and professional roles, may lead to emotional exhaustion and burn out
- maintaining a positive attitude in the face of random suffering promotes coping by enhancing self-esteem and sense of power
- caregivers have self-selected, so that many "stressors" aren't stressful

#### **LIFE STYLE MANAGEMENT**

- participate in outside activities
- engage in physical activities and diversions
- organize non job-related social interaction, i.e. take time off
- attend to personal nutrition and adequate sleep
- use meditation and relaxation techniques
- be aware of what helps you sustain your own well-being

#### **INDIVIDUAL SUPPORT**

- using the above information, individuals involved in Palliative Care need to develop flexible, responsive strategies for meeting their personal needs
- caregivers should look to their own work and personal environments to find those to whom they can relate, creating a personal support network

#### **ORGANIZATIONAL SUPPORT**

- planned, professional interventions for caregiver support (see Organizational Coping above) should be a regular, arranged part of the activities of any Palliative Care setting
- often these interventions are pushed aside due to lack of time or other resources, but they are fundamental to the maintenance of a healthy, caring environment

### **CARE OF THE INFORMAL CAREGIVER**

*"It was very distressing to be in the situation of having to make decisions, rather than simply being a mother."  
– one voice –*

Those closest to the person living with HIV/AIDS often play a large part in providing care. As a result, they are at risk physically and emotionally. There is a strong tendency to be self sacrificing, to do anything possible to help the person living with HIV/AIDS.

Informal caregivers should be:

- taught proper techniques to prevent injuries to themselves and others
- encouraged to seek emotional support through talking to a friend or counsellor
- supported in seeking respite care to allow for physical and emotional rest away from the person living with HIV/AIDS.

This will allow the caregiver to regain energy and enhance the relationship with the person living with HIV/AIDS

- informed of (and encouraged to consider) their need for bereavement care following the death of their loved one

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