



ANTICIPATORY LOSS AND GRIEF IN CAREGIVERS

Anticipatory loss involves a range of intensified emotional and interactional responses over the course of the illness. Anticipatory loss includes the mutual influence of family dynamics with:

- family members' threatened loss of the ill member
- ill member's anticipation of losing his/her family
- ill member's expectation of disability and/or death

Threat of loss encompasses:

- the person
- the relationship with the ill senior
- the intact family unit

Anticipatory grief refers to individual emotions during the terminal phase.

INTERVENTIONS TO DECREASE THE STRESS OF CAREGIVING

Recognizing Signs of Caregiver Burnout:

- Denial about the disease and its effects on the person: 'I know Mom will get better'
- Anger at the affected person: 'If he asks me that question once more, I'll scream'
- Withdrawing socially, losing touch with friends and favorite activities
- Anxiety about facing another day and what the future holds
- Depression, feeling sad and hopeless much of the time
- Exhaustion such that completing daily tasks seems barely possible
- Sleeplessness with middle-of-the night waking or stressful dreams
- Emotional reactions such as often being irritable, crying at minor upsets
- Lack of concentration and finding it difficult to complete complex tasks
- Health problems, including weight gain or loss, chronic headaches or backaches

Ways to Help Prevent Caregiver Burnout:

- Plan early to find ways to support yourself to stay healthy through diet, exercise, vitamins and supplements, yoga, meditation, time for yourself.
- Take time off to pursue some interest or hobby.
- Take advantage of offers for help from family, friends and community agencies.



- A caregiver who does not take care of him/herself is not much good to his/her loved one. Do things that bring you joy and keep you going. You need to balance everything so that you can find the equilibrium that gives you energy for things you'd like to do as well as the things you have to do.
- Be patient with yourself, recognizing that some days are going to be more difficult than others, but maybe tomorrow will be better.
- Try to think of at least one good thing that happened today.
- Have at least one person you can confide in who can give you support and to whom you can provide support as well in a mutual relationship.
- Spirituality can provide support.
- Maintain contact with others in a similar situation through support groups.
- Get information about resources available through the Alzheimer Society; the Canadian Cancer Society or other community resources and take advantage of what is out there.
- Realize there may well be a time that you will be unable to continue to care for your loved one at home and you need not feel guilty about this."
- Try to get enough rest.

Ways Health Care and Social Service Providers can Help Prevent Caregiver Burden:

- Focus on the contribution to caregiver overload and intervene to prevent overload, rather than simply relieving it.
- Develop strategies to prevent overload by training caregivers in technical skills or in obtaining emotional support before they actually need it.
- Create supportive, educational approaches to develop skills, empower caregivers, and reaffirm their existing skills, abilities and knowledge.
- Provide emotional support as an intervention as higher levels of emotional support may decrease depression.
- Evaluate the health and disability of the care recipient and determine the level of care needed.
- Determine the resources available to support the care giving process.
- Encourage caregivers to develop skills to elicit desired emotional support from family and friends.
- Provide caregiver education and assistance.



- Use therapy and concrete problem solving.

It has been suggested that the reason for the reduced quality of the relationship between caregivers and seniors with Alzheimer Disease is the loss of their relationship with the loved one. The period of actual care giving may not be the time for intervention. This may be the period of grieving the relationship loss.

Needs of the Family:

- to adapt to the fact that their loved one is dying
- to mourn for the senior and for the loss of their family as it exists
- to reorganize and restructure family roles and functions and to plan for the future
- to attend to the needs of individual family members, bearing in mind age, health status, maturity, coping skills and the nature of the relationship with the dying person
- to care for those of the group most closely involved with the senior's care
- to gain information about the illness, the treatment options and what they can expect from the care giving system for practical assistance with such things as housekeeping chores, finances, respite, finances, advocacy to plan for the funeral and burial
- to say goodbye to their dying loved one
- to have someone really listen to their concerns and fears, and to acknowledge that these may be difficult to express
- to understand the disease, its possible causes, and options for its treatment
- to learn how to deal with symptoms

Suggestions for Family Members Considering Placement:

- Do as much planning as possible. Waiting lists can be long and when the time comes for a move, you want to choose the best residence or other facility that you can.
- Ask someone in the health system who knows what community facilities are available to steer you in the right direction.
- Get the paperwork and planning out of the way as soon as possible. Visit the facility ahead of time to make the unfamiliar familiar. Ask for a facility tour.
- Be frank when it's time to acknowledge that you cannot provide the care that is needed. Try to focus on the senior and everybody else involved, and talk honestly about it.



- Involve other family members so that all stressful decisions do not fall to you.
- When you come home after placing your loved one, have someone there to talk and share your grief.
- Identify potential financial and legal issues, e.g., dealing with Power of Attorney for finances and personal care; making decisions regarding end-of-life care and when to intervene.

Advantages of Dying at Home:

- A familiar environment can result in increased psychological comfort and reassurance, resulting in an improved quality of life during the terminal stage.
- Family caregivers may be better able to maintain family ties, reduce feelings of guilt and cope better with the eventual bereavement.