

Loss-Specific Support Groups: A Case in Point for a Dementia-Specific Bereavement Support Group

Submitted by Christine Longo on Apr 4, 2011

The degenerative nature of Alzheimer's disease and related dementias and the probable changes in both personality and physicality over time in the person with the disease mean that the caregiver experiences abnormal amounts of stress and overwhelming emotions, one being grief, which is often unacknowledged and hidden. The focus of the research and the interventions for the caregiver has been on those actively caregiving and almost nonexistent on the application of interventions to help caregivers cope after the physical death of the person with dementia. This article presents the results of a 'pilot' grief support group held at the Alzheimer Society Peel.

According to the Alzheimer Society of Canada, "Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, and changes in mood, behaviour and communication abilities" (Alzheimer Society Canada, 2009). Since dementia is considered a chronic condition, people with the disease will likely need care for a number of years after their diagnosis, averaging anywhere between 8 and 10 years. Because of these irreversible changes in combination with the long period of caring, caregivers will experience years of grief, often unacknowledged by society and hidden from themselves and others, due to the alterations in their loved one's personality and mental functioning. Furthermore, until the mid to late stages, the disease itself remains hidden from view and the person "appears normal" to the greater society. Caregivers experience frustration, anger, and are guilt ridden by the emotions of caring for a loved one who has dementia, but these emotions are heightened when they cannot express them or they feel unsupported by others. These are some of the unique differences between dementia caregivers and caregivers of loved ones with a physical disease. When death finally physically takes place, these caregivers will have suffered and will continue to suffer a range of emotions much different from those of the caregiver of a person who has died from a physical illness.

The Alzheimer Society Peel, through their mission to alleviate the personal and social consequences of Alzheimer's disease and related dementias, has developed a support group for caregivers after the physical loss of their loved one with dementia in order to help the caregiver to cope with both the pre-and post-death losses experienced during this lengthy illness. Historically the Alzheimer Society Peel has provided support groups for the caregiver and the person with the disease, but there was a gap in services when the caregiver no longer actively provided care.

As in all illnesses, there is a unique experience when dealing with the loss of a loved one from that particular disease that can be understood only by others who have experienced the same journey. Specific to dementia, caregivers live through: the symptoms of the illness, the pre-death losses, role changes, the longer disease cycle, relationship changes, and the lack of ability of the person with the disease to make choices in their own health care and subsequent death and to say goodbye. Furthermore, the stigma of the disease and the unaccommodating social environment are seen in all situations. As the individual with dementia moves from independence to total dependence on the caregiver, the caregiver becomes too overwhelmed with tasks to recognize the need to grieve these losses. These are some of the obstacles that these caregivers face both during active caregiving and post death. The caregiver may be totally unaware that the feelings they are experiencing are grief and be unable to resolve or accept these losses. Due to the ambiguity of the disease and the physical presence of the person, unconcealed grief cannot

occur for the caregiver until the person with dementia physically dies. In addition to the overwhelming physical tasks of caregiving, the caregiver also loses him/herself to the role over the years.

The pilot support group occurred in the spring of 2010 and consisted of 8 consecutive weeks of support, which combined both educational topics on both grief and dementia and time for open discussion. Outreach counsellors who had extensive disease knowledge as well as education in grief facilitation, and a Bereavement specialist from a local hospice facilitated these groups. Some of the topics covered were: Grief: What is it and how do we do it?; Anger and Guilt: a tangled ball of emotions; Where do we go from here? Caregivers in the group all commented that the group was so helpful in that they had all experienced the same dementia journey and had an insight into what they were each going through in terms of emotions as well as fears and physical symptoms. "The information you learn at this group can save you a lot of pain by explaining more about the grief journey." (Mabel, personal communication) Each member felt accepted and that they had the opportunity to voice their grief. It was in the "telling" that they felt that they were healing.

The results of the pilot grief support group were so successful that the Alzheimer Society Peel has continued with providing this type of support group as part of their regular programs. A new session has recently begun. Currently there are no other Alzheimer Societies known that provide this type of support to their members or any other known agency that offers this type of loss specific support group. Support groups are valuable only if the individual is acknowledged, heard, and feel that others understand their experiences. This can happen only for the newly bereaved in a grief-specific support group, as the experiences of dementia are so complex and harrowing.

For further information please contact Christine Longo, Outreach Counsellor, Alzheimer Society Peel 905-278-3667