Grief, multiple loss and dementia

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Abstract: Alzheimer's disease and the other dementias bring with them multiple losses for the person with dementia, their spouse and family, and professional caregivers. The person with dementia will experience the major losses of memory, role and autonomy, and ultimately of identity and selfhood. Their spouse and other family members may lose the person they knew and loved, as well as their hopes and expectations for the future, and even their home, social networks and other important sources of identity and support. Their bereavement may start long before the person dies. Professional caregivers too may experience loss when a long-term relationship with a client and their family is brought to a sudden end by the death. This article reviews these losses and how bereavement counsellors and supporters can help.

Keywords: Alzheimer's disease, dementia, grief, bereavement, loss, caregiver

Grief is the constant, yet hidden, companion of Alzheimer's disease and other, related dementias. Grief can arise when someone in the early stages of the disease fearfully acknowledges the symptoms and anticipates the losses that the disease entails. Family members will certainly experience grief as they watch the slow deterioration of the memory and even the being of the person whom they love. That grief will increase as family members see, from that decline, a stranger emerge – a stranger who needs constant, unceasing care.

That grief will be experienced even after the death – complicated by all the feelings that arose in the course of caregiving, such as the caregiver's own losses and discomfort, guilt about institutionalisation, and perhaps even troubling feelings of relief and freedom at the death. Professional caregivers who, in moments of intimate care, discovered in the person with a dementia a glimpse of a former self and developed a caring connection may share that grief. Or they may grieve the patient that they came to know – a very different person to the one mourned by the family and intimate network of relatives and friends.

This paper explores the grief inherent in the losses associated with dementia. It begins by examining loss as experienced by the person with dementia and the losses experienced by the patient's intimate network. It goes on to consider the grief experienced by professional caregivers, who often play a large role in the person's end-of-life.

The person with dementia

Someone with dementia may, in the early stages of the disease, experience grief over the diagnosis and the losses associated with the symptoms. In Alzheimer's disease, and in many dementias, these losses can be profound. First, there is the loss of the past as the memory deteriorates and they can no longer recall experiences or relationships. A poignant expression of this loss are these words of one person with Alzheimer's disease who – struggling to recount an incident from childhood – cried: 'I used to remember.'

The deterioration of memory also affects relationships in the present. Memory links people to each other, allowing a person to recall the relationships and histories that bind them to another. The person with dementia may no longer remember who the people are around them and, because they cannot recall it, are unable to describe the relationship. One woman with Alzheimer's disease had a long, close relationship with her daughter-in-law. Yet, as the disease progressed, she could only describe her as 'the woman who married my son' – a term that caused a great deal of grief to the younger woman as it seemed to invalidate their long, positive relationship.

As memory lapses, other important losses follow. The person may no longer be able to function effectively. Work and other cherished roles may have to be relinquished. There may be a gradual loss of independence.

In the early stages of dementia the person may be able

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to access their feelings in relation to loss. As the disease progresses, they are likely to lose the cognitive ability to experience loss and grief. The sense of specific loss and deterioration may be replaced by a generalised feeling of 'wrong-being' – a vague sense that something is wrong. This generalised feeling may instead be manifested in behaviours that indicate inner pain, such as agitation or anxiety. Even though cognition declines, feelings and states of emotional stress remain (Rando, 1993).

Eventually the person is likely to experience 'psychological death', or the loss of individual consciousness. They cease to be aware of self. 'Not only does he not know who he is – he does not know *that* he is' (Kalish, 1966, p247). People around them, of course, can only infer this state from their outward behaviours.

There are still other probable losses. In addition to the dementia, the person may become physically ill or disabled, be admitted to hospital or to a care home, or die. Unfortunately, there is little research that considers how someone with dementia copes with loss (see, for example, Grief & Myran, 2006; Lewis & Trzinski, 2006). Rando (1993) emphasises that loss of cognition should not be seen also to mean loss of ability to experience emotions. A person with dementia will still feel grief, but may show it through changes in behaviour, for example, such as agitation or restlessness, rather than through crying or verbal expression.

However, people with dementia may lose the ability cognitively to register their loss. They may, as mentioned earlier, have a vague sense that something is not right, or that some significant individual, perhaps someone they cannot even name, is missing. People with dementia often confuse the present loss with earlier losses. For example, Herrmann and Grek (1988) documented two cases where bereaved spouses with dementia believed that a parent rather than their husband or wife had died. Others may retain a constant delusion that the person is still alive (Vennen *et al*, 2000). In other cases, memory loss may simply mean that they do not know that a loss has occurred, no matter how often they are told.

Someone with dementia may be unable to retain the information that someone significant in their life has died. They may ask repeatedly where they are and what has happened to them. They may even mourn the loss, only to forget the death, repeat the question and so be forced to re-experience the sadness of their bereavement. Caregivers may find this frustrating, or even a source of grief themselves. They should be reassured that this kind of response is normal in dementia; it is not an indication that they have not explained the situation properly, or an apparent lack of human feeling on the part of the person with dementia. One useful technique may be to show them a photo or recall with them a memory each time the person with dementia questions the loss or expresses a sense of grief. With other people, however, removing reminders may be helpful. As there is limited evidence to guide practice, very often it is necessary to experiment and observe what works best for the individual.

There are no hard and fast rules, and every individual will be different. Are there times, events, or cues that seem to spark questions or expressions of grief? Does it seem more helpful to validate their distress or deflect the issue? Trial and observation will guide caregivers to the strategies that seem to cause the least agitation, distress or anxiety to that individual.

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Lewis and Trzinski (2006) suggest a technique that they call 'spaced retrieval', which they found helped people with moderate dementia to retain new information. In spaced retrieval, the individual is asked to recall a new piece of information again and again, with progressively longer intervals between each recall. This approach may allow the person with dementia to begin to process the loss rather than simply re-experience it afresh as a new piece of information.

Naturally, the expression of grief of people with Alzheimer's or other dementias will be affected by a range of factors, including the stage of disease, loss of awareness of the significance of the relationship, loss of ability to recognise the loss, and loss of ability to communicate their sense of loss. Whether and however it is communicated, it is important to be sensitive to that loss. It has even been hypothesised that significant losses, as well as the inherent changes that occur as a secondary effect of loss, may exacerbate the symptoms of dementia (Rando, 1993; Kastenbaum, 1969). It is also important not to assume that the person will grieve their loss and not to judge them if they do not.

Caregivers should always be sensitive to and respond to the behavioural cues, emotional expressions and reactions of the person with dementia. If there is no perception of loss, caregivers should not feel they have continually to remind the person that a significant loss has occurred.

Two considerations are essential when offering support to someone with dementia – validation and control. When someone has dementia, there is a tendency for others to discount or deny their emotional expressions of loss with glib reassurances that everything is fine. Often this is done to protect them, even though the person with dementia is aware and fearful of the manifestations of the disease. This is unhelpful. People in the early stage of dementia have very clear awareness of the symptoms of their decline. Even those whose illness has progressed to the next stage may have a vague sense of the loss of capabilities. It is important to validate and support their feelings through empathetic listening, expressions of support, reassuring remembrance that reaffirms relationships and, when appropriate, physical touch. Expressive approaches work particularly well with people with dementia. Lewis and Trzinski (2006), for example, have found that play therapy using stuffed toy animals can be helpful in stimulating memories and comforting bereavement.

It is also important to respect the autonomy of the person with dementia as far as possible. As they feel their abilities slip away, they may become determined to maintain as much control of their environment as possible. In the early stages of the disease, they may express anticipatory bereavement (Gerber, 1976); they may need to prepare practically and financially for their eventual loss of capacity – to contact business associates, or create or review advance directives. This too should be supported. However, not every everyone will choose to confront their feelings of fear or grief, or to plan for the future. That, too, is a way of coping.

Family and friends

The family and others in the person's intimate social network will experience grief as well following diagnosis and as the disease progresses. That grief may intensify as the person's symptoms increase (Ponder & Pomeroy, 1996; Ott & Kelber, 2007). Family and friends may experience a deep sense of psychosocial loss of the person's persona; their identity may become so changed that family and friends experience this as the death of the person that was (Doka & Aber, 2002). This is a profound loss, and there are few social mechanisms that allow this kind of mourning while the person is still alive (McEvoy, 2007).

In other cases, family members may refuse to accept the loss and may deny the effects of the disease and try to retain the person that once was. This can especially be problematic if they assume the person with dementia can control his or her behaviours. In such cases it is important to confront their denial and explain clearly to them the nature of dementia and its effects.

This sense of psychosocial loss can be profound. As the dementia progresses, the person's ability to monitor and regulate their behaviour diminishes. They may behave in bizarre and unusual (for them) ways, such as using bad language or manifesting uninhibited and inappropriate behaviours. They may relive earlier traumas – some Holocaust survivors, as their Alzheimer's disease progressed, have hoarded food and experienced troubling flashbacks or heightened anxiety (McCann, 2003). They may lose the ability to self-censor what they say, and express racist or other socially unacceptable views. These behaviours can humiliate, embarrass and isolate caregivers and exacerbate feelings of ambivalence and discomfort, which can subsequently complicate grief. Spouses may become 'crypto-widows' – married in name but not in fact. They may grieve the losses associated with that – losses of emotional and sexual intimacy and companionship (Doka & Aber, 2002; Teri & Reifler, 1986).

The very experience of caregiving may complicate grief. Caregivers may experience secondary losses such as the loss of social and recreational roles, work roles and relationships with others. The unrelenting demands of caregiving may diminish their coping abilities and lead to a tailing-off of social support over time (Bodnar & Kiecolt-Glaser, 1994).

> For some caregivers the death of the person with dementia will be a 'liberating loss'. Others may grieve the loss of the caregiving role

The death of the person with dementia will change the focus of the caregiver's grief. For some it will be a 'liberating loss' (see Jones & Martinson, 1992; Elison & McGonigle, 2003), characterised by feelings of relief that caregiving responsibilities and the suffering of both the person and their family have ended. Others may grieve the loss of the caregiving role. They may now feel a lack of focus and meaninglessness in their life. For some, these feelings may be accompanied by guilt and sadness. They may remember times when they could have shown more patience or empathy. Their grief may be manifested not just emotionally but in their thinking, behaviour and spiritual beliefs. It also may be expressed in physical ill health. Indeed, caregivers frequently experience physical health problems at significant points of transition – when, for example, the person with dementia is admitted to a care home, or dies (Grant *et al*, 2002).

Surviving family members may experience disenfranchised grief (Doka, 1989). Disenfranchised grief refers to losses that are not recognised by others; in effect, the bereaved person is seen as having no 'right' to feel grief and to mourn because their loss is not openly acknowledged or socially sanctioned and publicly shared. Others simply do not understand why this loss is mourned and this may fail to validate and support the caregiver's grief (Doka, 1989, 2002).

Grief over the death of a person with dementia can be disenfranchised for a number of reasons. Often the person with Alzheimer's disease or other form of dementia is seen as old, confused, a burden; their death may be seen as a release for both the caregiver and the person who has died. Sometimes those who are bereaved are expected to have already done their grieving over the course of the illness, and the death itself is seen as unimportant. The usual statements of sympathy and support may be tinged with ambivalence: 'It must be a blessing;' 'It must be a great relief.' There may be little understanding of the impact of the loss and the depth of the bereaved spouse and family's grief, and a presumption of how the bereaved may feel.

Supporting family members

A number of strategies may assist family members as they cope with their loss, both prior to and following the death of the person with dementia (Doka & Aber, 2002).

Provide information about the dementia

It is important to assess how much family members know about the dementia and its course and effects. Often, people know little about the condition, or have mistaken beliefs. One way to gauge this is to ask them what they think causes dementia. This can often be a useful indicator of false hopes or unrealistic beliefs (eg. that the person can control their behaviour, or will get better).

Exploring the beliefs of family members gives counsellors the opportunity to provide relevant information. Information about associations, self-help groups and print and other media – particularly books by people who have experienced similar losses – can all be useful. This approach not only ensures the family has realistic and accurate information about the nature and course of the condition; it also enhances their sense of coping and control. Giving them information can give them a sense of agency – there is something on which they can act – and enables them to anticipate and plan for future contingencies.

Help families deal with emotional issues related to the loss

Often family members feel unable to acknowledge and express their emotions. When the person with dementia is still alive, perhaps still living in the family home, there may be no space or opportunity to express emotions. Family members may feel inhibited from expressing negative emotions, or even face social sanction from friends and relatives who consider it disloyal or unfeeling. Caregivers in particular may feel angry with and resent the person with dementia or others who they feel are unsympathetic or unsupportive. They may feel guilty about their ambivalence in caregiving or their feelings of relief and emancipation at the death. In addition to providing reassurance that such feelings are normal, counsellors can suggest techniques such as journal writing, ritual, or talking to an empty chair, which can help people resolve their tangled emotions.

Help families recognise and respond to changes in their lives

Dementia is likely to lead to major changes in the daily lives of spouses, caregivers and family members. They may feel a loss of companionship. They may have to give up previously enjoyed activities and take on new responsibilities. They may lose contact with friends or relatives. They may experience loss of dreams and expectations, and they may have unmet psychological, social, sexual and financial needs.

After the death, they may experience another set of changes – the loss of a meaningful role as caregiver, for example, or they may have to move house. These changes can occur so quickly that they may not realise just how profoundly their own lives have been affected or have the time to develop effective coping strategies.

Counsellors can help in a number of ways. First, they may want to review with the bereaved person the ways in which their lives have changed. Often the simple question 'In what ways has your life changed since … ?' can release a flood of responses. Counsellors can explore with the person responses and strategies for dealing with these secondary losses, and can help them decide which are the most important and if any aspects of loss can be regained (even if only in a modified way).

Second, they could discuss the family members' support systems: the extent and nature of the support system (which may provide opportunities for discussing respite and resumption of activities that have had to be abandoned), the use of that support system (which may allow further discussion of coping styles and problem-solving abilities), and 'surprises' in the support system (eg. people who have turned out to be there for them, as well as people who have been experienced as unsupportive). This last issue is particularly significant as it may provide further opportunity for the counsellor to discuss emotional responses such as anger and resentment and help people develop their problem-solving skills and coping strategies.

When they revisit the situation, the bereaved person may recognise that they did not communicate clearly their needs or feelings to people in their support system, or that they used people in inappropriate ways.

A woman was very angry that her daughter seemed unable to listen to her complaints about the demands placed on her by her spouse's dementia. On reflection, the woman realised that her daughter's strengths had always been in active doing rather than passive listening. Once the woman realised this, she was able to change her expectations and found that her daughter was, in fact, extremely supportive, as long the requests were for help with active tasks, such as giving lifts in the car or doing chores.

Counsellors can also help families locate additional sources of support, such as self-help groups, day care and respite care and, if necessary, nursing and residential care. This approach can have additional value because it leads to a reduction in stress on family members and provides them with something they can do that may diminish guilt and restore a sense of control. Support groups for caregivers have been particularly successful, and groups for people newly diagnosed with Alzheimer's disease (Wasow & Coons, 1987; Simank & Strickland, 1986; Yale, 1989).

These groups can decrease feelings of isolation, facilitate grief and provide opportunities for the exchange of information and resources. But counsellors must do more than simply help clients identify needs and sources of support. In some cases, counsellors may need to explore resistance and ambivalence toward such support. As Quayhagen and Quayhagen (1988) note, some caregivers may experience considerable guilt about handing over the care of the person with dementia to others; accepting help from care agencies can also mean they are forced to confront the reality of the situation and are unable to take refuge in denial.

A counsellor can explore role issues, dilemmas and ambiguities with families. One of the most significant problems of dementia, especially for spouses, is that it creates considerable role strain and generates additional burdens for the caregiving partner. For example, the spouse may be legally married but effectively be widowed because the companionship and sexual intimacy that were once part of the relationship no longer exist. Often in these situations it is helpful for the person to explore the tensions, ambiguities, burdens and difficulties that accompany crypto-widowhood. It can also be helpful to explore a range of options: even if an option is precluded for moral or practical reasons, just considering it can restore a sense of control and remind the person that there are still choices open to them.

A woman whose husband had been admitted to residential care with Alzheimer's disease became involved in a relationship with another man, but she decided she would not divorce her spouse or cohabit with her new partner. Just exploring these options gave her the sense that she did have some control over events and that the decisions she made now were not necessarily final.

Counsellors may wish to discuss how family members generally cope with change and how they are coping with it now. They can help the person assess which of their strategies are effective, and reaffirm and reinforce these skills, and which are not. This is turn provides an opportunity to explore alternative, better coping strategies. They may also want to explore how family members deal with stress and, if necessary, teach stress-reduction techniques. They can explore the caregiving role. Family members are often very willing to take on caregiving responsibilities, but they may make decisions that do not adequately take into account their own or the other's role. For example, a spouse may decide to leave their job to take care of their partner with Alzheimer's disease, but this may have unintended negative implications: it can remove him or her from an important source of social support; it may deprive them of necessary respite from caregiving; it may lead to financial problems. There may be other ways to resolve the problem.

Counsellors may have an important role in helping family members periodically review their caregiving plans and roles and think about alternatives. Finally, counsellors can help family members by legitimising their own needs and helping them recognise and balance these needs with those of the person with dementia.

Help families plan for the future

The nature of dementia often encourages an attitude of 'one day at a time'. In many ways such a perspective is functional. With irreversible syndromes, the future can seem dismal. Nevertheless, it is important to plan for the future. Planning for the future gives a sense of control and permits people to practice problem-solving skills, anticipate future problems and explore ways of dealing with them now, rather than waiting until they are forced to act. In these sessions it is important for counsellors to reaffirm confidence in the person's abilities, coping skills and hopes and allow them to explore the effects of change on their own sense of self, how they see other people, and their beliefs.

Dementias such as Alzheimer's disease can profoundly change a person's view of themselves or others, as well as affect fundamental beliefs about faith and meaning. People may be worried that they too will get dementia. They may question their feelings and beliefs about other family members – they may, for example, experience a profound sense of disappointment in the reactions or support of others.

Tasks such as putting together videos or photo albums can help reconnect a person with memories of how the person with dementia used to be

They may even feel differently about the person with dementia – if, for example, they witness unexpected behaviours or attitudes. For example, in one case a woman was clearly discomforted by her mother's racist reactions towards black and minority ethnic people. Before the dementia, her mother had been a strong supporter of the civil rights movement and had never expressed such views. Family members will need space and encouragement to talk about these feelings. Asking questions such as 'How does this affect your beliefs about yourself and your family or your beliefs about the world?' can offer an opening. Setting them homework tasks in which they seek out information or talk about the problem with others, including members of their own faith community, can facilitate this process. Tasks such as putting together videos or photo albums can help reconnect a person with memories of how the person with dementia used to be.

Grief in the professional caregiver

Professional caregivers may also experience grief. As many dementias progress over a long period of time, it is not unusual for nursing home aides, home helps and home healthcare assistants to develop long-standing links with family members and the person with dementia. This creates an unusual paradox. Professional caregivers will get to know and become attached to the person with dementia; the family's attachment is to the person before they became ill with dementia. Thus the family is mourning the very person that the professional caregiver knows and to whom they feel an attachment. This can create conflict and distress should the family opt to halt or refuse life-extending treatments to the person with dementia. In such situations, the professional caregiver's views and feelings may be unsought and unwelcome.

There may be other losses. When the person with dementia dies, the professional caregiver faces not only the end of their relationship with the individual but often with the family members as well. They may also be losing a job and income and, for those very reasons, may need to take another position, and develop another relationship, almost immediately. The grief of professional caregivers needs to be acknowledged and supported by the agencies that employ them. Tangible ways to support staff include empathetic debriefings following the death of a longstanding client, encouragement to families to acknowledge their loss, and policies that encourage and enable staff to attend rituals, such as allowing them to attend the funeral in work time.

Conclusion

Grief is a constant companion to Alzheimer's disease and related dementias. It is ever-present for the person with dementia, and accompanies their family members and friends throughout the illness and after death.

It does not, however, have to be the only companion. If family and friends, counsellors and supportive others travel together, the journey through grief may still be long, but it will be less lonely and not quite as frightening. ■

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