

# FILM REVIEW

## Intimate relationships and dementia – an extended commentary on *Away from Her*

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### Introduction: Dementia, identity and relationships

We tend to think of our lives progressing in a linear fashion, from start to finish, infancy to old age, birth to death. Within a lifetime, there is the progressive accumulation of experience, understanding, knowledge, memory, and relationships, all shaping our identities, our understanding of who we are, our place in the world, and giving meaning to our lives. Dementia interrupts that linear progress.<sup>i</sup> When memories are lost, or when the capacity to form new memories disappears, an important link to the contents of our own identity can be lost too (Addis & Tippett, 2004; Jetten et al., 2010). Close relationships may be disrupted by dementia (Blieszner & Shifflett, 1990; Hellström et al., 2007)<sup>ii</sup>— persons with dementia may forget their loved ones, losing access to decades of shared experience. While death severs a relationship, leaving a survivor to continue on alone, dementia is different. A relationship may be severed, but both persons continue.<sup>iii</sup> Perhaps the “survivor,” the caregiver or loved one of the demented person, continues on their life trajectory, following the same path, but without the company of the other (see Beeson, 2003; Pearlin et al., 1990). But their former partner, parent, friend now diverges, traveling with dementia, taking a different path for the remainder of his or her life.

The literature on caregivers of persons with dementia is filled with research on the burdens and psychological stresses that the disease places on caregivers<sup>iv</sup> (Gonzalez-Salvador et al., 1999; Volicer, 2007). The vast literature on dementia includes much discussion of the loss of identity and personhood suffered by the demented individual (Degrazia, 1999; Dworkin, 1986; Hughes, 2001; Lindemann, 2009; Naue & Kroll, 2009), but—with a few notable exceptions (e.g. Graham & Bassett, 2006)—little on how dementia alters those identity-constituting interpersonal

relationships such that the loved ones of the person with dementia experience a loss or change of identity as well (Baldwin, 2009:31).<sup>v</sup> They are the collateral damage of dementia.

As Françoise Baylis explains: “Persons are interdependent beings and so it is that a person’s identity – including her traits, desires, beliefs, values, emotions, intentions, memories, actions and experiences – is informed by her personal relationships, these relationships being characterized by varying degrees and kinds of intimacy and dependence” (Baylis, 2010; see Lindemann, 2007:353-354). Much of what makes us “who we are” belongs “not to self reflection but to the mutual recognition between two people” (Oppenheimer, 2006:199-200; see Taylor et al., 1994). For both parties in a dyad, recognition, the lack of it or the perceived lack of it, has profound effects on the way behaviour is viewed and controlled (Graham & Bassett, 2006:337). And as Janice Graham and Raewyn Basset further add:

While many studies focus on maintaining a past self, some researchers examine the construction of a flexible, changing self in the present. Further, the self in the present may be co-constructed in relation to a shared past between carer and cared-for (Forbat, 2005). Where interactions with others are based on a past self, in the present the person still reflects on past roles (Cohen-Mansfield et al., 2000). (Graham & Bassett, 2006:337)

The film *Away from Her* addresses this poignant and neglected aspect of dementing illnesses like Alzheimer’s disease, exploring the ways in which we are anchored by love and relationships, and how the unmooring that accompanies dementia—for example, the loss of shared memory (Bateman, 2007:23)—affects not just those whose memories are lost, but also those whose memories remain intact or, at the very least, much more secure and stable.<sup>vi</sup> As persons partially constituted by their relationships with their forgetful loved ones, those who (can) remember become lost too, as they navigate with now varying degrees of loneliness (Graham & Bassett, 2006), the path along which they once walked with another.

## Prevalence, symptoms, sequelae and the needs of persons with dementia

A 2006 Canadian census has observed that those aged 55-64 are the fastest-growing age group in the country (an increase of 28.1% from 2001), followed next by those over 80 years old (Statistics Canada, 2007). The “baby boomers”, those born between 1946-1965, are turning 60 and reportedly entering the age of greatest risk for dementia (Forbes & Neufeld, 2008). The Canadian Studies on Health and Aging reported in 1994 that 252,600 (8%) of all Canadians aged 65 years and over, and 35% aged 85 and older, suffer from dementia. The same study estimated that if these prevalence rates remain constant, by 2021 the number of Canadians with dementia will rise to 592,000 (CSHA, 1994). At the time of this study, about half of those Canadians living with dementia were cared for within institutional settings and half lived in the community (CSHA, 1994; Graham & Bassett, 2006; Mcdowell et al., 1994). And of those living in the community, almost two-thirds had never been formally diagnosed (Sternberg et al., 2000). The reality is that many persons with dementia are left to cope with their illness (and all the risks attached to it) either on their own, or within the context of their family or set of close relations (Mcdowell et al., 1994; Sternberg et al., 2000).

The behavioural and psychological symptoms of dementia include hallucinations and delusions, depression, sleeplessness, anxiety, physical aggression, wandering, restlessness, pacing, screaming, crying, repetitive questioning, agitation, and other symptoms and behaviours which “are responsible for increased caregiver burden and decreased quality of life for caregivers and patients” (Finkel, 2003:800). Additionally, the social isolation and sense of loss experienced by persons with dementia result in a vicious cycle: people with dementia have the same cluster of psychological needs as everyone else — comfort, attachment, inclusion, occupation, and identity — yet the “dialectical interplay between neurological impairment and social psychology” results in a dwindling of their opportunities for meeting those needs (Kitwood, 1997:83; see Baldwin, 2009). As Tom Kitwood further explains:

The needs are more obvious in people with dementia, who are far more vulnerable and usually less able to take the initiatives that would lead to their needs being met. The pattern of need will vary according to personality and life history, and often the intensity of manifest need increases with the advance of cognitive impairment. (Kitwood, 1997:81).

The result is that just as those psychological needs increase, they become increasingly poorly met, both because of the neurological impairments of the demented person, and because of those needs going unrecognized and sometimes even neglected (see Graham & Bassett, 2006).

Studies show that mental health comorbidities, including mood and anxiety disorders, are more common with Alzheimer’s disease and other forms of dementia than matched controls without the disease (mood disorders: 19.5% vs. 5.3% and anxiety disorders: 16.3% vs. 4.0%) (Nabalamba & Patten, 2010). It is estimated that depression afflicts up to 60% of patients with dementia, although some studies show rates as high as 85% (Finkel, 2003:807; Volicer, 2001:387). Depression has significant negative effects on patients and caregivers:<sup>vii</sup> it can decrease the ability to engage in meaningful

activities; increase dependence in activities of daily living; and lead to several peripheral symptoms, such as agitation, repetitive vocalization, apathy, insomnia, food refusal, anger, irritability, and resistance to care (Volicer, 2001:387).

## The benefits of close, personal relationships

Depression in the elderly (including individuals in the community and residential care) is strongly linked with factors indicating increased dependency marked by decline in functional and cognitive capacity (Anstey et al., 2007). In a study by Thomas and colleagues on the reasons given by informal caregivers for institutionalizing dementia patients previously living at home, it was noted that: i) “the most frequent caregiver complaint at the time of institutionalisation was incontinence, followed by withdrawal”; and ii) “[t]he caregiver’s main problem resulting in institutionalisation was dependence, with behavioural disorders in second place” (Thomas et al., 2004:127; cf. Vernooij-Dassen et al., 1997). Another study by Kales and colleagues has shown that patients with coexisting dementia and depression are high utilisers of inpatient and nursing home care. For patients with coexisting dementia and depression, “nursing home placement correlated significantly with baseline severity of functional impairment and mood measures, but not with other factors, including dementia stage and medical burden”(Kales et al., 2005:441).

Research shows that persons living in residential care facilities, including persons with dementia, benefit from forming companionship relationships with their new neighbours (Kitwood, 1997:82-83; Kutner et al., 2000:201). Friendships and close personal relationships, including those that develop into romances and sexual relationships, can help ease the transition into a strange new environment for dementia patients, who can become easily disoriented in an unfamiliar place. As Kitwood writes, “people with dementia are continually finding themselves in situations that they experience as ‘strange’<sup>viii</sup>, and that this powerfully activates the attachment need” (Kitwood, 1997:82). Bonding and attachment create a kind of safety net when the world is full of uncertainty, and “there is every reason to suppose that the need for attachment remains when a person has dementia; indeed it may be as strong as in early childhood” (Kitwood, 1997:82; cf. Miesen, 2006).

Institutionalization or transition into a residential care facility can result in the loss of important and secure attachments for persons with dementia — cutting them off from friends, loved ones and spouses — undermining the sense of security for persons already vulnerable, insecure, and anxious. The effect can be devastating (see Kitwood, 1997:82; Kovach, 1998). Agitation and behavioural and psychological symptoms of dementia decrease in dementia residents who are involved in ongoing friendship relationships (Kutner et al., 2000:200). Increased frequency of agitated behaviour is observed when friendship interactions end, suggesting a “protective” effect of friendship for people with dementia (Kutner et al., 2000:201). When friendship relationships break up or change significantly, “dementia residents — like the general population — may be at increased risk of feelings of emotional distress” (Kutner et al., 2000:202). A scenario that is familiar to the staff of residential care facilities for people with

dementia is that personal relationships improve quality of life for the residents,<sup>ix</sup> while residents who are socially isolated fare worse.<sup>x</sup> “Without the reassurance that attachments provide it is difficult for any person, of whatever age, to function well,” Kitwood notes (1997:82).

The anecdotal stories abound of relationships that bring renewed happiness into the lives of residents in dementia care facilities: Supreme Court Justice Sandra Day O’Connor was reportedly thrilled when her husband found companionship with another woman after moving into a care facility:

[Justice] O’Connor spoke about the demands of caring for someone with Alzheimer’s, including unexpected, sometimes bittersweet, developments as her husband began to lose his ability to recognize his family. He formed romantic attachments with other patients at an assisted-care center in Arizona, and this transformed him, the former justice said, from someone who had been depressed and introverted into a much happier person.

She told the *New York Times*: “He was in a cottage, and there was a woman who kind of attached herself to him. It was nice for him to have someone there who was sometimes holding his hand and to keep him company. And then he was moved to a different cottage, because his condition deteriorated. And in the new cottage, there’s another woman who has been very sweet to him. And I’m totally glad.”

Ehrenfeld et al. describe several romantic and sexual relationships among institutionalized persons with dementia:

A married man and an infirm widow formed a romantic attachment that included love and caring, which was accepted with joy and understanding by the man’s wife. Each time she came to visit she made sure to bring a tasty treat for the elderly woman who cared for her husband.” (Ehrenfeld et al., 1999:148)

Z, a woman aged 80, showed special concern for D, a 76-year-old man who was not her husband or a relative. She assisted him with dressing and eating, and even checked if he was in bed. The two sat together at meals, conversed, and played cards and dominoes. When D’s wife came to visit, Z quickly left the room, returning only after the wife had left.” (Ehrenfeld et al., 1999:146)

The nature of relationships varies, from nurturing relationships and friendships, to romantic and sexual relationships which are “a reality in long term care” (Lichtenberg, 1997:6). Such associations (especially the latter) are not always accepted, however. Objections to relationships can come from families, spouses, staff, and even other residents of dementia care facilities, particularly when residents develop sexual relationships (Ehrenfeld et al., 1999:148; Lichtenberg, 1997). Ehrenfeld et al. report that “many professionals working in psychogeriatric wards report experiencing difficulties, distress and confusion regarding sexual display between institutionalized patients. Similar uneasiness is also expressed by family members and residents of psychogeriatric institutions” (Ehrenfeld et al., 1999:144). Most frequently, families object when female residents are sexually active, and demand that they be protected<sup>xi</sup> (Ehrenfeld et al., 1999:148; see Nay, 1992). Melinda Henneberger tells of a thwarted romance between two

persons with dementia living in an assisted living facility:

Bob’s family was horrified at the idea that his relationship with Dorothy might have become sexual. At his age, they wouldn’t have thought it possible. But when Bob’s son walked in and saw his 95-year-old father in bed with his 82-year-old girlfriend last December, incredulity turned into full-blown panic... Because both Bob and Dorothy suffer from dementia, the son assumed that his father didn’t fully understand what was going on... Bob’s son became determined to keep the two apart and asked the facility’s staff to ensure that they were never left alone together. After that, Dorothy stopped eating. She lost 21 pounds, was treated for depression, and was hospitalized for dehydration. When Bob was finally moved out of the facility in January, she sat in the window for weeks waiting for him. She doesn’t do that anymore, though: “Her Alzheimer’s is protecting her at this point,” says her doctor, who thinks the loss might have killed her if its memory hadn’t faded so mercifully fast. (Henneberger, 2008)

### Away from Her – from diagnosis to placement with residential care

*Away from Her*, which is based on Alice Munro’s short story “The Bear Came Over the Mountain” (1999), addresses the subject of love, not from the perspective of a person with dementia, but rather from the perspective of the one left behind. Among the most poignant aspects of the story is what happens when the character of Fiona Anderson (Julie Christie), who has Alzheimer’s disease, forgets her husband Grant (Gordon Pinsent) and forms a close relationship with another male companion.

Early in the film, Fiona receives a diagnosis of her condition. She accepts the news with calmness and peace. In a way, she already knew, as she told her friends, that she was “beginning to disappear.” Fiona’s reaction is consistent with the responses of some patients receiving a diagnosis of Alzheimer’s disease, who experience “a sense of relief and validation from knowing their diagnosis” (Aminzadeh et al., 2007:285). Such patients are aware, as Fiona was, that there had been changes to their memory and functioning, and a diagnosis provides them with an explanation, and an opportunity for intervention (Aminzadeh et al., 2007:285). Grant, on the other hand, denies the diagnosis,<sup>xii</sup> and clings to the thin thread of hope that his wife of forty-four years will not get worse. “I’m not all gone...” Fiona tells Grant, “...just going.” Grant experiences Fiona’s going, her disappearing, as a leaving, a going away from him. When Fiona’s “going” gets worse, and she becomes lost and disoriented, she decides to enter a dementia care facility called Meadowlake. Grant has trouble letting go<sup>xiii</sup> (cf. Paun, 2003). It’s just a “rest cure,” he tells her, “experimental” and not “permanent.”<sup>xiv</sup>

The facility’s policies state that new residents cannot receive any visitors or phone calls until thirty days after they are admitted,<sup>xv</sup> a rule designed to (purportedly) promote successful integration, reduce confusion, and ease the transition to the new environment, Grant is told by Meadowlake’s supervisor, Madeleine Montpellier (Wendy Crewson). As such, the rationale for this policy runs contrary to research concerning emotional attachment and dealing



with the effects of loss (Browne & Shlosberg, 2006; Cheston & Bender, 1999; Ingebretsen & Solem, 2004; MacDonald, 2001; Miesen, 1992). De Vries and McChrystal found that insecure attachment behaviour (e.g. rocking and howling) was observed for people with dementia—in this case, as caused by Creutzfeldt Jakob disease—when members from the study group were placed in unfamiliar surroundings with strangers and on departure of family members. “Grieving behavior in individuals, young or old, confronted with the (threatened) loss of an emotional link with people who are important to them, was fundamental to the experiences of these people...” (de Vries & McChrystal, 2010:287).

Notwithstanding the practical challenges involved, research indicates, and most care institutions and programs now recognize, the therapeutic benefits and ethical importance (Hughes & Baldwin, 2006; Martin & Younger, 2000) of:

- i. involving residents and/or their representatives—if not partnering with, informal carers/relatives—in the assessment, planning, provision and evaluation of any plan of care (Kapp, 1996; Ministry of Health and Long-Term Care, 2006: A1.1-5; Pritchard, 1999; Woods et al., 2008b; Woods et al., 2008a);<sup>xvi</sup>
- ii. maintaining continuity of care as much as possible (Carpentier et al., 2008; Forbes & Neufeld, 2008; cf. Kovach, 1998; Ontario Ministry of Health and Long-Term Care, 2006; Vernooij-Dassen et al., 1997); and
- iii. designing environments that establish and maintain links to the familiar for persons with dementia (Cohen & Weisman, 1991; Miesen, 2004).

Several studies have examined the association between selected outcomes and the character of the relationship between caregiver and care recipient with dementia. Norton observes that:

Closer perceived relationships are associated with better adjustment to nursing home placement in persons with dementia (Whitlatch et al., 2001) [and] improved psychological well-being and problem-solving abilities (Burgener & Twigg, 2002). Conversely, avoidance by caregivers or insecure attachment styles in their [close relations] have been associated with more behavioral problems in the latter (Perren et al., 2007).” (Norton et al., 2009:561)

What is more, the evidence also points towards the importance of *continued* attachments for general well-being in later life (Magai & Passman, 1997). For adult populations, the primary attachment figure is most commonly a partner or friend (Hazan & Shaver, 1987). Returning to the movie, then, it would appear that Meadowlake’s policy prohibiting Grant—the primary caregiver and close partner of Fiona—from either telephoning or visiting his wife for thirty days upon initial placement, is unreasonable, not to mention disrespectful. In fact, to make this sort of consent to “treatment”—in a very loose sense of the term, for there is no evidence in the movie that it is medically indicated—as a condition of admission, especially given the fact that most persons upon admission to a long-term care facility are quite vulnerable with few options (Kapp, 1996; Ontario Human Rights Commission, 2010), makes this a matter of injustice. Following such a policy could hardly be seen as motivated by serving Fiona’s best interests as

the patient.<sup>xvii</sup> In fact, the policy flies in the face of evidence which points towards more successful provision of care by harnessing the protective function of attachment bonds, and it is noteworthy that this is especially true for serving persons in later life with dementia (Browne & Shlosberg, 2006; Cheston & Bender, 1999; Jones & Miesen, 2006).<sup>xviii</sup> As such, Grant is more inclined to believe Fiona’s main nurse Kristy (Kristen Thomson) who confides to him that rule is probably designed to make life easier for the facility staff.

### ***Away from Her* – relational identity, resistance and adaptation**

Grant eagerly awaits his first visit with Fiona, but when he returns to Meadowlake after the prolonged separation, he finds her sitting and playing cards with another man, Aubrey (Michael Murphy), who is chronically mute and wheelchair-bound. Fiona approaches Grant, but in the course of their conversation, it becomes evident that she does not recognize her husband, and thinks he is a new resident at the facility. This pattern persists in subsequent visits — Fiona believes Grant to be an especially persistent suitor, but she is politely uninterested, having clearly and firmly bonded with Aubrey, who needs her with childlike dependence and intensity. Grant comes to accept his wife’s need for this new companion — after all, Aubrey is someone she can nurture and care for (Cicero & Detweiler, 2009),<sup>xix</sup> someone present for her in the ongoing immediacy of profound forgetfulness. “He doesn’t confuse me,” Fiona explains.<sup>xx</sup> Even so, Grant persists with visiting Fiona, in spite of being (for the most part) ignored by her. He may not provide day-to-day regular care for her directly anymore, but this has not stopped him from caring very deeply about her (cf. Graham & Bassett, 2006).

David Cockburn aptly notes that: “my conception of the present is, when I care for another, strongly conditioned by my understanding of the past” (Cockburn, 1997:69). The giving and receiving of care that happens between partners where one suffers from dementia, usually takes place in the context of a relationship (not uncommonly a longstanding one) that precedes the onset of the Alzheimer’s disease—a relationship that continues to evolve with the progress of the illness (Ablitt et al., 2009; Davies & Gregory, 2007:485; Forbat, 2005; Graham & Bassett, 2006). Just as aspects of the prior relationship impact how couples negotiate the dynamics and the roles assumed in the exchange of care (Davies & Gregory, 2007; Steadman et al., 2007; Williamson & Schulz, 1990), so also the process of living with dementia impacts on the relationship, “often causing change or loss which is difficult to accept or adjust to (Blieszner & Shifflett, 1990; Hellström et al., 2007)” (Ablitt et al., 2009:498).

As the story of Grant and Fiona’s life together is revealed in his memories, it becomes evident that theirs was a complicated relationship — one in which he, in the past, had been unfaithful. That difficult past — and all the emotional baggage — may be lost to Fiona, something that has drifted away along with her memory of her husband. And so part of what makes Aubrey an ideal companion is that there is no past there to forget, no baggage, no confusion — not for Fiona or Aubrey. They exist solely in the present, and have only a very short past and not much in the way of plans or hopes for the future. Comparatively, Grant, with his

memory intact, exists in a state of compounded loss: he misses his wife now, he grieves Fiona's loss of her past (in a way that she does not grieve for it), he mourns the future they will not have together, and he suffers yet another loss when he loses his wife to another man. Understandably, this pains and confuses Grant as he both resists the changes to the relationship while still trying to make sense of the situation and its implications for his own—personal, social, and moral—expectations for relating to Fiona. At one point Grant speculates in conversation with Kristy whether Fiona may be acting a part through her illness and the cultivation of her new attachment to Aubrey as a way to punish him for his past infidelity to her (cf. Askham, 1995). Grant is hereby struggling to cope with and understand how roles are changing for both him and Fiona (cf. Baldwin, 2009; Lebovitz, 1979; Quinn et al., 2010), and how the past trajectory of his relating to her will or will not continue (cf. Baldwin, 2009:32). His experience of this seems a demonstration of Margaret Urban Walker's claim in "Picking Up Pieces – Lives, Stories, and Integrity" that: "It is not only for moral purposes but also for purposes of intelligibility over time that we read and reread actions and other events backward and forward, weaving them into lives that are anything more than one damned thing after another" (1997:67).

A consistent association between loneliness and the experience of depression has been well documented (Beeson, 2003:137). When Aubrey is removed from the facility by his own wife Marian (Olympia Dukakis), it is Fiona who falls apart, exhibiting the symptomology, including depression, frequently observed among care residents—and, among the elderly more generally (Brodaty & Anstey, 1994; Fielden, 1992:294-295; Godfrey, 2005)—when cut off from close relationships (see Erber, 1994; Kutner et al., 2000). She suffers, suddenly, just as Grant had. Fiona's nurse warns Grant that she is in physical and mental decline, her vulnerability and despair allowing the Alzheimer's to advance more rapidly. Indeed, depression in Alzheimer's patients can aggravate dysfunction, compound memory impairment, "make the affected individual do worse than would be expected from the dementia alone—causing clinical conditions referred to as 'excess disability' states" (Strock, 1994).<sup>xxi</sup>

Although *Away from Her* is primarily about the losses experienced by the spouse left to cope with a loved one's dementia, the movie accurately and touchingly depicts the emotional needs of persons with dementia as well. Whereas popular culture depictions of love in old age and cognitive decline are frequently comedic and dismissive (an expression of cultural discomfort with the subject, and a turning away from it through neglect or mockery) (Zernike, 2007), the film is open to the psychological complexity and emotional importance of Fiona's relationship with Aubrey, and the way that he, in his state of mute dependence, helps anchor and secure her amidst the unfamiliarity that her illness brings. As these events unfold for Grant to observe, he at first desperately seeks to hold onto Fiona as his wife, even becoming insistent in one scene that she remember (and by implication better observe) obligations to him as her husband. In this same scene he also makes a point to her that she is wearing someone else's sweater, not her own. His meaning to her is unmistakable: the person she once was would have never worn such a "tacky piece of clothing", and Grant is adamant she return to and remain that person. However, in time he too comes to see that she now has changed, and he accepts her as a somewhat different person with a new set of needs.

Grant is in a position to help Fiona, to demonstrate his love for his wife by facilitating the companionship she needs now. In this unexpected love triangle, the movie reflects on the meaning of love, and especially the richness, complexity and poignancy of what might be called "old love," to contrast with the intensity and, if you will, hysteria of young love as it is depicted in popular culture (Zernike, 2007; see Cicero & Detweiler, 2009). The kind of self-sacrificial caring Grant shows for Fiona is a kind of holding of her in her identity (cf. Radden & Fordyce, 2006:81) when she can no longer do it herself, a kind of holding that Hilde Lindemann calls "part of the work of preserving, maintaining, and nurturing people" (Lindemann, 2009:422). This holding of a person in her identity is "particularly needed by people with progressive dementias" (Lindemann, 2009:416; see Ablitt et al., 2009; Baldwin, 2009; Surr, 2006). In holding up his end of the marital contract (see McGill, 2008:101), Grant helps to hold Fiona in her identity. That is, just as being Fiona's husband is identity-constituting for Grant, being Grant's wife is identity-constituting for Fiona. If, as Lindemann says, identity is a representation of the self, "a tissue of stories, constructed not only first-person but also [of] many third-person perspectives, depicting the more important acts, experiences, relationships, and commitments that characterize a person and so allows that person and those around [her] to make sense of who [she] is" (Lindemann, 2009:417), then Grant, in ways he gradually comes to understand, must be a kind of identity-keeper for Fiona by dint of his memory-keeping powers (cf. Radden & Fordyce, 2006:82-83). Fiona has it right when she says, early in the film, that she is "beginning to disappear," for she is losing her grip on something essential to her self and identity. Since only Grant can maintain certain relational aspects of Fiona's identity (cf. Lindemann, 2007), he can, essentially, hold it in trust for her, by acknowledging that Fiona is still his beloved wife.

When Grant returned to Meadowlake after the thirty-day separation, he never found the Fiona he once knew. What if Grant had refused to let go of Fiona—which he managed to do—and instead of adapting himself, just abandoned her? After all, much of her apparent behaviour seemed to communicate a preference for him to stay away from her with all the confusion his presence brought to her. Grant chose to step aside, rather than step away, to adapt to Fiona, and for Fiona. Taking this unselfish approach in the face of all that seemed so confusing, Grant recovers something both he and Fiona had lost to dementia (cf. Graham & Bassett, 2006; Quinn et al., 2010; Radden & Fordyce, 2006).

## End Notes:

- i. Hilde Lindemann explains: "Serious injury or illness can, and frequently does, play havoc with one's identity. To be critically ill for more than a few days is to lose control over one's physical and mental processes. It puts a stop to one's professional and social activities and interferes with one's memories, hopes, plans for the future and ongoing projects. It usually involves hospitalization, which means that one is uprooted from one's customary surroundings; denied access to cherished people, pets and objects; and thrust into a milieu governed by insider understandings to which one is not privy. All of this contributes to a disintegration of one's sense of self. Eric Cassell (1982) conceptualizes this disintegration as *suffering*;

to suffer is to feel oneself being undone. Suffering persists, writes Cassell, until the threat to the identity has passed or until the integrity of the identity can be re-established in some manner” (Lindemann, 2007:355-356).

- ii. See generally Ablitt et al. (2009) for a review of the influence of relationships factors in living with dementia.
- iii. “Existing research suggests that dementia can result in changes to marital intimacy and marital satisfaction (Baikie, 2002), joint negotiation and adjustment in acknowledging losses, as well as recognizing resilience and coping strategies (Robinson et al., 2005). More to the point, limited research in this area highlights the need to better understand how couples make sense of and adjust to a diagnosis of dementia and the impact that has on their marriage relationship. In addition, it is important to understand how the marriage relationship influences how dementia enters into the lives of couples, and its place within their marriage biographies” (Davies & Gregory, 2007:484-485).
- iv. At the same time, the emphasis on caregiver burden can be, and historically has been, overdrawn. Quinn notes that: “[w]hilst traditionally caregiving for a person with dementia has been viewed as a negative experience, more recent research indicates that caregiving can have positive outcomes such as feelings of gain or gratification (Kramer, 1997)” (Quinn et al., 2009:143). Nolan further explains that: “More than a decade ago Kahana and Young (1990) argued that one of the most significant challenges for the future of caregiving research was to move beyond the then-dominant unidirectional and asymmetrical models of care (for example, that promoted the belief that the needs of the cared-for person for support inevitably produced a sense of burden in the caregiver) towards relational and dynamic approaches which reflected the potentially negative and positive outcomes of care for both caregiver and care-receiver. They argued that there was a need to be more ambitious and to ‘glimpse beyond dyadic perspectives’(Kahana & Young, 1990) to include not only the wider family system but also the roles and relationship forged between dyads, families and the formal caring system” (Nolan et al., 2002:203).
- v. “‘Loss of self’ is a risk for spouses and children who provide care to partners/family members” (Beeson, 2003:137). Beeson further notes that: “AD [Alzheimer’s Disease] caregiving spouses experiencing ‘couple identity’ in a previously intimate marital relationship often find the transformed relationship with their AD spouse contributory to a loss of identity” (Skaff & Pearlin, 1992)” (Beeson, 2003:137). See also M. Rosenkoetter (1996) on fundamental changes to life patterns of couples when one of them enters an extended care facility.
- vi. Oppenheimer explains well the pain that accompanies the loss of recognition, saying: “When dementia brings loss of language, coordination, and memory, as with a fragmented image, the knowledge preserved in the relationship can allow the gaps to be partly filled in. It is part of loving, to know another so well that their turns of phrase, their responses, their humour can be predicted. It is part of the joy of being loved, to be so predicted. So it jars the relationship badly when you find the person you love (perhaps your wife or your mother) acting in an unfamiliar and unpredictable way and when for their part they see in your response the sudden revelation that you no longer understand them. The poignancy of such moments is all the greater precisely because it is the families and friends of people with dementia who are the most important safekeepers of their identities, insofar as they hold their histories, understand what was important to them in their former lives, and remember their preferences and habits of thought” (Oppenheimer, 2006:199-200).
- vii. Harrison and colleagues have even suggested that care for elderly persons involve “[r]ecognition of the importance of depression and investigation of the possibility that its appropriate management may improve quality of life and sometimes prevent institutionalization”(Harrison et al., 1990:102). Ablitt and colleagues’ review of the literature demonstrated that: “lower current relationship quality relates to increased depression in carers and people with dementia, and to increased strain in the carers. It also relates to reduced perceived self-efficacy in carers and reduced functional ability in people with dementia” (Ablitt et al., 2009:501).
- viii. “In research with dementia patients in different stages of the process, a strong correlation was found between phenomenon of parent fixation, the level of cognitive functioning and attachment behavior. This was explained by postulating that remaining aware of one’s cognitive dysfunctioning in dementia is like going into a ‘strange situation’ in which the person experiences feeling unsafe for long periods of time, powerless and with no structures to hold on to. Therefore the demented elderly have to cope with the same feelings that arise in situations which resemble separation, homelessness or displacement. The ‘awareness context’ brings the sufferer in a chronic trauma. To understand a dementia patient’s behavior correctly one needs to consider his AC [awareness-context]” (Miesen, 2004:68).
- ix. In a study by Bullard-Poe and colleagues it is reported that intimacy is directly related to life satisfaction (Bullard-Poe et al., 1994).
- x. Beeson reports that: “Research has found that the loss of companionship, loss of the reciprocal exchange of affection between spouses, and the loss of a confidant, especially in the marital dyad, can affect the quality of life for both the caregiver and the care recipient, as well as the continuity and quality of care for the AD [Alzheimer’s disease] spouse (Hays et al., 1998; Kramer & Lambert, 1999; Siriopoulos et al., 1999; Yates et al., 1999)” (Beeson, 2003:136).
- xi. See Lichtenberg for a competency tool that can be implemented to protect the patient from exploitation. Lichtenberg also discusses how family involvement, in negotiating these risks “is a necessary and sometimes difficult process” (Lichtenberg, 1997:7).
- xii. See Connell et al. (2004) for a discussion of family and caregiver attitudes to diagnosis of dementia in loved ones. See Pratt et al. for a discussion of “the psychosocial model of experience of receiving a diagnosis of dementia, where social



aspects such as interaction with professionals, services and carer relationships were shown to directly interact with the individual psychological experience of people with dementia and therefore impact on the overall experience of receiving a dementia diagnosis” (Pratt et al., 2006:56). See also Pratt & Wilkinson (2003).

- xiii. “Paun (2003) found a relentless commitment to provide dementia care at home in spite of difficult past relationships, which she attributed to the meaning attached to the marital bond” (Paun, 2003 cited in Davies & Gregroy, 2007:484). See Gaugler et al. (2001) on relinquishing in-home dementia care and the difficulties faced by family caregivers in transitioning their dependents to nursing homes.
- xiv. Grant and Fiona appear to have a close relationship. According to Ablitt and colleagues, lower pre-morbid relationship quality “has been shown to relate to depression, burden and emotional reactivity in carers. Although higher relationship quality appears to be a protective factor, there is some evidence that high levels of past closeness can increase distress in carers” (Ablitt et al., 2009:502).
- xv. The policy serves as a plot device, but to the best of our knowledge, it is very unlikely that such a policy would ever have been in effect for the time featured in the film. Though the type of institution and therefore jurisdiction of the Meadowlake care facility is not made clear in the film, the policy featured could be interpreted as in violation of the Residents’ Bill of Rights which on our reading would appear to guarantee a right to visitation as upheld in the Government of Ontario *Charitable Institutions Act* (Government of Ontario, 2009a), the *Homes for the Aged and Rest Homes Act* (governing municipal institutions) (Government of Ontario, 2009b), the *Nursing Homes Act* (governing for profit institutions) (Government of Ontario, 2009c), as well as Bill 21, *Retirement Homes Act* (2010) currently in its third reading (Government of Ontario, 2010). See also *Tab 09 standards: Residential Care* (Ministry of Health and Long-Term Care, 2006) which contains: i) direction for mechanisms to be in place to promote and support residents’ rights, autonomy, and decision-making at A1; ii) a reiteration of Residents’ rights at A1.11; and iii) long-term care home admission agreement requirements at A2.
- xvi. See J.W. Crane Memorial Library (2009) for a listing of “Current perspectives in the literature on family involvement in long term care”.
- xvii. See Community Legal Education Ontario (2008) for a discussion of the bill of rights for people who live in Ontario long-term care homes. See T. Daniel Frith’s (2007) article on “Nursing home visitation rights” for a discussion of relevant legislation in the United States.
- xviii. See Peak & Cheston (Peak & Cheston, 2002) as well as Woods & Ashley (Woods & Ashley, 1995) for a discussion of the clinical use of simulated presence therapy which mimics the presence of close attachments (to persons or objects) in order to reduce agitation and create calm for people with dementia.
- xix. Cf. Browne & Schlossberg who note that: “The recent advent of ‘doll therapy’ in dementia care is also somewhat based on the principles of attachment theory. Dolls are being introduced into a number of inpatient and residential care settings in attempts to improve communication between staff and residents and meet residents’ needs for attachment and a sense of purpose (Bryant & Foster, 2002; Moore, 2001). It has been observed that dolls can play a number of roles for the person with dementia, with the doll being referred to as a baby, husband, wife or teacher (Moore, 2001). Some residents have reported that dolls are ‘a great comfort’ to them (Moore, 2001) and observations suggest that dolls may rekindle positive emotions of the parental-child bond (Bryant & Foster, 2002). A growing body of case study material is offering support for the use of dolls in dementia care, particularly for clients who are exhibiting problem or challenging behaviours (see Bryant & Foster, 2002)” (Browne & Shlosberg, 2006:140).
- xx. Oppenheimer notes that: “In general, professional carers (whether the staff of nursing homes or home carers visiting intermittently) will take a person entering their care ‘as they are’: the relationship between them is built mainly on the present behavior, communication, and emotional responses, with little regard to their past identities. Over time, relatives who hold the history of the patient may try to educate the carers about them. . . . Sometimes there are advantages in this difference in perspective. The person entering the nursing home can leave their dysfunctional relationship behind, can lose the unpleasant identity they carried, and can make a fresh start with people who have no presuppositions about their character or moral qualities, but will relate to them simply as a person needing care” (Oppenheimer, 2006:201-202).
- xxi. Ablitt et al. also note that: “The findings of Burgener and Twigg (2002) suggest that lower emotional well-being in the person with dementia and poorer relationship quality may lead to further loss of functional ability, and exacerbate the presentation of the dementia itself” (Ablitt et al., 2009:506).

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