Carers' responses to shifting identity in dementia in *Iris* and *Away From Her*: cultivating stability or embracing change?

ABSTRACT

An emphasis on supporting and maintaining self-identity in dementia for as long as possible has gone hand in hand with the revitalisation of interventions, services and empowerment for people with dementia. However, recognition of the need for change, adaptation and personal growth is as necessary when living with dementia as at any other time in people's lives. Those who care for people with dementia must constantly navigate this tension between continuity and change within the context of memory loss, knowing when to respond by reinforcing the 'self' they have known over time, and when it may be better to respond by acknowledging the changes that have taken place. The creative arts are avenues for the exploration of the caring relationship under these conditions, conveying the challenges and stimulating audiences to ask themselves how they might choose to respond in a similar situation. This article considers how the scenarios of two noted films, *Iris* (dir. Richard Eyre, 2001 UK) and Away From Her (dir. Sarah Polley, 2006 Can), present the dilemmas of identity and care. In both, a husband cares for a wife experiencing cognitive decline, but responds differently in each to her shifting needs and changes in identity. We argue that the two films reveal complementary and provocative perspectives on this situation, and, though they offer no easy answers, provide insights into the dilemmas and decisions characteristic of caring for someone who has dementia.

INTRODUCTION

Explaining her reasons for writing about her mother's dementia in 1998, Linda Grant commented on 'a silence, a taboo,' which meant that

the meteor of dementia that strikes families and wipes out so much is supposed to be part of the realm of privacy. What you don't talk about. What you keep to yourself.¹ If this was once the case, proliferating representations of the dementia experience have done much to break that silence over the intervening period. The creative arts, notably literature² and cinema³, have played a significant role in exploring what it is like for carers to see a family member go through dementia. This article discusses how two noted films address the relationship between a wife who develops Alzheimer's Disease and a husband who must adjust to the change, raising questions about the continuity of personal identity as memory and recognition fade, and about the role of loved ones in relation to that continuity.

The films in question, *Iris* and *Away From Her* (*AFH*) are only two among a range of cinematic treatments of dementia. Yet we have chosen to concentrate on this pair because to date *Iris* and *AFH* remain the only English-language films to have achieved mainstream commercial success where dementia, and its direct effects on relationships, are the very core of the work's subject matter. While in other works it serves as a narrative device (e.g., *The Notebook*, dir. Nick Cassavete, 2004 US) or is treated as one among other major themes (e.g., *The Iron Lady*, dir. Phyllida Lloyd, 2011 UK), both *Iris* and *AFH* treat the challenges, dilemmas and even joys of living with dementia as their central focus. In depicting the extraordinary but everyday situations facing carers and people with dementia, these films engage viewers with the question of how the carers might suitably respond to the inexorable decline of memory and the slow fading of a couple's shared history together. Both films are adaptations, but their distinctive visual and aural modes of immersion involve and challenge audiences in ways that differ from their original written source material and that merit study, both in conjunction with those texts and in their own right. Doing so makes it possible to

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ⁱ Since this article was first prepared, *Still Alice* (2014 US, dir. Wash Westmoreland / Richard Glatzer) has been released and also falls into this category.

analyse how the cinematic drama enables viewers to explore existential issues that dementia throws into sharp relief. This article specifically considers the ways in which the films' caregivers try to respond to one of the key challenges that dementia poses: at what points to try to preserve continuity in aspects of the self in the person with dementia, and by contrast when to recognise and facilitate shifts in that person's identity and self.

DEMENTIA, IDENTITY AND RESPONDING TO CHANGE

Consisting of a family of conditions, of which Alzheimer's Disease is the best known, dementia's defining feature is progressive, irreversible deterioration in selective areas of brain functioning. Though only one symptom among many over the course of the disease, memory loss is the characteristic that is most notorious, arguably because of the fundamental role that remembering plays in contemporary Western thinking about the constitution of personal identity and the self. In this vein, an influential intellectual tradition, of which seventeenth-century thinker John Locke is the classic exponent, argues that identity is founded on a human being's continuous self-consciousness – that is: memory and awareness of oneself as an uninterrupted, internally consistent sentience. By implication, an individual's very personhood and selfhood are destroyed by dementia and its effects on recall.⁶ However, as social and psychological theory have shown, identity consists of more than just a personal, individualised aspect. Self-identity is in part defined, or at least influenced, by how individuals present to others and how those others, in turn, respond. This is the aspect of self that can be thought of as 'social identity'. 7-8 This approach to the constitution of self-identity, through the interplay between individuals' self-presentation and what those around them reflect back in response, has been influential in dementia studies. Landmark research by Tom Kitwood – who showed how repeated 'de-personalising' interactions with people who have dementia can be at least as disabling as the condition itself⁹ – and Steven Sabat – who

focused closely on the damaging effects that negative symbolic, social and discursive practices have on selfhood and self-worth in dementia¹⁰ – made clear the extent to which other people's validation can affect the individual's sense of self, already under siege from the effects of the condition. Their findings have inspired a prolific stream of literature drawing attention to the many ways in which the self can be undermined in dementia and proposing how it might instead be preserved.¹¹⁻¹²

This approach has produced enormous benefits by raising awareness of the ongoing personhood and potential of people with dementia. However, it is also worth asking – as Sarah Lamb¹³ does with regard to the 'successful aging' movement – whether there can ever be downsides to the emphasis on preservation of self. Lamb identifies the notion of "permanent personhood" contained within 'successful aging' discourse, and questions whether the weight placed on prolonging independence and "declining to decline" discourages people from coming to terms with the shadows of these aspects of life: interdependence, transience and impairment. She asks whether, despite the inspirational benefits of the model, it may set people up for failure by inculcating unrealistic expectations and concealing the meaningfulness that can be found in age-related changes, or 'decline.' The notion of "permanent personhood" can be identified as a driver behind dementia studies such as the ones referred to above. Though any aspiration towards 'permanence' is always attenuated by the well-known relentlessness of decline in dementia, the aim remains to stave off as much change as possible for as long as possible.

Indeed, it is hard to object to this. Most of us deeply fear the dissolution of our identity and are repelled by the idea of becoming someone unrecognisable. Fundamental and commonplace ideas of 'health' that inform biomedicine and society alike rest on saving and

preserving function, so that any changes produced by dementia are liable to be seen as 'deterioration.' And often one of the most difficult aspects of dementia for relatives to cope with is to find oneself suddenly a stranger, as though years of a shared past had been wiped away. Responding to these considerations, the instinct of family is commonly to do whatever they can to maintain the person with dementia as the self that they have known. Yet, as Clive Baldwin points out, change as well as continuity is necessary in the lives of people with dementia, just as for all of us. ¹⁴ Some take an even stronger view, claiming that

decisions affecting a demented person at a given time must speak to the person's point of view as current at that time. Heeding values and wishes that the patient no longer espouses and that cannot be said to represent her present needs and interests can do no good for the patient.¹⁵

Despite the fact that the need for change and development – whether positive or not – is widely accepted in everyday living, in dementia binary notions of 'preservation vs. loss' may all too easily prevail over more nuanced views of 'preservation vs. change', eclipsing alternative perspectives that seek to highlight the value that life retains even when we – in various different ways – "forget memory." ¹⁶⁻¹⁸

While such debates about the continuity of selfhood may seem to be primarily abstract philosophical questions, they actually throw into sharp focus dilemmas that present themselves to carers on a regular basis, as immediate and specific demands to respond in one way or another to the person before them. At what moments is it better to do so by reaffirming the person that they have known for so long, and when might it be better instead to acknowledge and validate transformations in the self, brought about – at least in part – by Alzheimer's? *Iris* and *AFH* each dramatises this choice and its impact on the people involved slightly differently. In *Iris*, Iris' professional and intellectual identity as a writer undergo

profound shifts, to which her husband mostly reacts by struggling doggedly to maintain continuity in the face of the changes wrought by the dementia. In *AFH*, it is the relational aspect of identity that is brought centre-stage, and the husband ultimately responds with considerable flexibility. The contrasts should not be overdrawn; all caring relationships are invariably multidimensional and involve some degree of both change and continuity, so these characterisations are far from absolute. Moreover, some of the dissimilarities stem from the different stages of dementia that Iris and Fiona reach; while Iris' decline is charted to the final stages leading up to her death, Fiona is less starkly affected in the course of the film, leading to different kinds of change and placing different demands upon their respective husbands. Yet comparison between the two is instructive for the empathic insights it affords into the experience of deciding how far to honour an identity that is facing unprecedented challenges, and how far to adjust to the changes taking place. Neither film offers answers, but the questions raised invite audiences to consider how they themselves might deal with similar instances of ambivalence between flux and stability.

THE FILMS

Iris tells of the writer and philosopher Iris Murdoch, ranging through a sequence of biographical episodes from both her earlier life and the much later period when her dementia became manifest. Switching back and forth between these two timelines, one narrative introduces us to Iris' younger self and charts the unfolding of her courtship with John, while the other tracks the growing encroachment of Alzheimer's Disease into their life together. As the younger John gradually overcomes his initial awkwardness, jealousies and insecurity over Iris' bohemian lifestyle, the older John finds it increasingly hard to cope with the strain of caring for Iris.

AFH tells the story of Grant, whose wife Fiona's dementia causes her to enter residential care. Once there, she no longer recognises Grant, but develops a close relationship with another resident, Aubrey, and becomes deeply depressed when he returns home. Grant, desperate to prevent Fiona's rapid physical and mental decline, pleads with Aubrey's wife, Marian, to allow him to return. It is only by starting an affair with Marian that he eventually convinces her to do so. However, at the moment when he brings Aubrey back to see Fiona, she seems to have miraculously recovered, recognising Grant and lovingly validating his ongoing concern for her.

A key difference between the two films is genre. Iris' source material is the memoir by her husband John Bayley. 19 AFH, by contrast, is adapted from a fictional short story, 'The Bear Came Over the Mountain' by the Nobel Prize-winning Canadian author, Alice Munro.²⁰ Although adapted works should perhaps be considered and critiqued on their own merits, it is worth noting that their different origins in life writing and fiction, respectively, influence both how the films were constructed and how they were received by audiences. With regard to the themes the films explore, it may be that dealing in fiction gives Polley (and Munro) ethical freedom to delve into questions of relationships and sexual faithfulness with fewer qualms than Eyre (although he does not shy away from portraying such matters for the younger Iris). Less speculatively, much of *Iris*' audience comes to the film with expectations already formed from some degree of prior knowledge of Iris Murdoch as a public figure, evidence of which is found in some of the sharp criticisms the film received for not sufficiently foregrounding Iris' real accomplishments.²¹ The past life of the fictional character Fiona, by contrast, is in many respects a cipher about which only small, though significant, hints are given; this is one reason why the film has received praise for emphasising the value to be found in living in the present with dementia, rather than comparing with the past¹⁶.

Contending neither with the ethical responsibility of memoirists to the person they are representing and to the historical record²², nor with audience reception of the work shaped by these considerations, *AFH* has more scope than *Iris* to emphasise flexibility of relationships. By contrast, Bayley's memoir was subject to attack on the grounds that some of the decisions he made about what to disclose about Murdoch's life demeaned her dignity²³, and inadvertent misrepresentation is another ever-present risk in writing about the illness experiences of those who can no longer represent themselves.²⁴ Awareness of this perhaps informs the repeated acknowledgement in *Iris* of how difficult it is for even John to be confident of really knowing her fully [e.g., 50:55, 1:08:43].

CHANGING SELVES AND CARER RESPONSES

Both films, alongside much dementia-themed mainstream cinema, have been criticised for the focus on carer experience and the relative marginalisation of the person with dementia. ²⁵²⁸ Certainly, it is noteworthy that the climactic moment in each film centres on the woman with dementia granting a form of absolution to her husband, as Iris tells John that she loves him (implicitly in spite of the times when he has lost his temper with her) and Fiona tells Grant that he is a good man for persisting in trying to make her happy (implicitly despite his affair in the past); hence the plot structures, in remarkably parallel approaches, resolve with the person with dementia offering redemption to the carer. The key point of narrative resolution comes when *the carers* have their struggles to perform their changing roles apparently validated, thereby foregrounding this process as a key plot thread. Furthermore, John's experiences of learning about and trying to understand Iris are the film's main focus, while the younger Iris' own emotional life apart from him is left comparatively unexplored. Even more markedly, *AFH* predominantly adopts Grant's perspective in his quest to know

how to respond to the changes in Fiona; the camera rarely adopts Fiona's perspective [01:25:25]. However, that they spotlight the carer's experience of Alzheimer's Disease need not be seen as a problem inherent to these films themselves; rather, it becomes a problem in the context of how dominant this approach is in cinema overall, and how scarce the voices of people with dementia have been as a result.

In themselves, the perspectives of carers are a fully legitimate subject for cinematic treatment and exploration, with the potential for rich insights into how they may respond to the often intense dilemmas and pressures they face. ²⁹⁻³⁰ *Iris* and *AFH* can be read as the two husbands' explorations of the shifting nature of their relationships as, having been thrust into the caring role, they attempt to navigate the changes they see in their wives. The specific dilemma that is the focus of this article relates to what the clinical literature discusses as "supporting the self,"12 and the role that the carer can and should attempt to play in it. This is not to suggest that there is not rich material for analysis on how the women themselves navigate their changing relationships, or for that matter, on other ways in which John and Grant negotiate the role reversals and shifting power dynamics that they are experiencing; indeed, far more could be discussed than there is scope for in this article, and the critical literature has already tackled some of these issues^{21, 26, 31}. This article's contribution therefore focuses on what messages the films convey about the conscious strategies adopted by the two men in seeking to facilitate the well-being of their wives, either by accepting or rejecting changes in the latter's selfhood. In portraying the effects of their strategies on the two women, the films invite viewers to wonder how things might have gone if different approaches had been tried, potentially stimulating nuanced reflections on change and continuity in dementia.

"Such things you wrote!": Iris and the Dissolution of Writerhood

In *Iris*, John's struggle to know and understand Iris begins long before the onset of dementia. From wondering about the relationships she has with her other friends and lovers, to musing on the "unknown and mysterious world" [50:55] into which she disappears when writing, the younger John is at times equally as perplexed about understanding her as he becomes later, when Alzheimer's Disease has taken hold. The younger Iris herself comments on this, comparing herself to Proteus, the shape-changing Greek sea-god [1:02:00]. Just as Hercules kept hold of Proteus as he took on the forms of lion, fish and snake, so she urges John to keep hold of her no matter what facets of her 'self' and identity come to the fore, an instruction that resonates later as dementia's changes become manifest. Soon after, she reiterates this advice when John complains that he knows so little about her life: "You must accept me as I am[...]Just keep tight hold of me and it'll be alright" [1:07:23]. Cutting back and forth between youth and later life, the film underscores the limits of how well we can get to know another's inner self by strategically juxtaposing this scene with the older John shouting at Iris: "I've never known anything about you at all and now I don't care" [1:08:43], and then with the younger Iris telling him that "You know more about me than anyone on Earth" [1:11:02]. This sequence more than any other emphasises that there is no direct access that enables even a close lover to know, define, and fix in place another individual's identity, as John seems to feel the urge to do; meta-textually, it serves as a reminder of the inescapable ambiguity of both memoir and adaptation.

The dilemmas are further sharpened for John once Iris starts to dement. It is clearly important to him to maintain her identity as a writer. Iris herself is rarely heard commenting on the issue of the changes in her identity. One exception comes when John declares to the doctor that "Words have meant everything to her" [30:57], to which Iris adds that "It frightens me and then sometimes it doesn't frighten me, and that's worse, because that's it winning, isn't it?"

But, with the exception of one early scene [29:29], the film overall does not present Iris herself as profoundly troubled by the loss of her authorial capabilities; instead, it is John who struggles to accept that the talents he has so admired may no longer be accessible. The first time that he loses his temper with her is when she does not register the significance of her newly-published book [33:23]. Rather, she is preoccupied with repeating the phrase "Only the postman," having found herself unable to find the correct word for him when he showed up to deliver it. Her new book, apart from the moment when John first shows it to her, is never really foregrounded in the *mise en scène* and is given scant attention by Iris, signifying the gradual dissolution of her identity as a writer. Because of the excitement that he had anticipated the book's arrival would spark for her, John is not able to adjust to her immediate and greater concern of losing her memory of words. By contrast, his delight is palpable when she later unexpectedly remembers that "I ... wrote" [45:26]. Viewers may wonder who truly benefits from the attempt to maintain her identity as a writer.

When John and Iris visit their friend Janet at her beach-house, John does all he can to ensure that Iris keeps writing: "Just talk to her – say things to her that she can write. She can, you know" [49:03]. Iris, however, sits by herself on the shore, peers at her biro, and pulls the blank pages out of her notebook, weighing them down with pebbles so they do not fly away. Though Janet, with John's encouragement, asks Iris to sign a copy of her book, Iris throws the pen and volume away, apparently unable to work out what is expected or unwilling to attempt it [53:30]. She abruptly snatches away each of the pebbles acting as paperweights and the notebook pages flutter away on the wind. We do not see Iris try to write again in the film; the discarding of the pebbles represents a milestone in the changes in her identity and relationship to her past self³². The camera then cuts to Janet soaping Iris' back in the shower and Iris laughing delightedly. She calls Janet an angel and later finds reassurance in dancing

with her. The *mise en scène* emphasises contrast: in the beach scene, the color theme is a melancholic, distancing greyish-blue, and Iris is shown mostly as physically isolated and with her back to her friends and husband; the shower scene, on the other hand, depicts a warmer yellow theme, and Iris is shown in happy and intimate physical contact with Janet. It is difficult to escape the question here of whether the attempts to maintain her selfhood as a 'writer' are actually beneficial to her, or whether Janet's physical contact and communication with Iris do more for her well-being in the moment. Iris' presentation of embodiment has been interpreted both positively and negatively: as a way of attempting to encourage viewer identification with Iris and move beyond the objectification of dementia²⁸; and as a postfeminist, patriarchal way of "systematically reduc[ing her] to her body". 21 Yet these critics do not acknowledge the importance afforded to embodiment as an integral element of selfhood (both for men and women) in recent dementia theory. 18, 33 By the way in which it highlights the body here, the film invites viewers to ask whether John's tendency to privilege the intellectual aspects of Iris' identity, epitomised in the nostalgic wonderment with which he exclaims "Such things you wrote!" [46:30], may at times, although done with the best of intentions, do more harm than good.

In the book from which the film is adapted, John Bayley wrestles more explicitly with these questions. ¹⁹ Noting that his attempts to read to Iris were "not a success" (p. 45), he speculates about this activity being "a reminder of the loss of identity" (p. 46). Musing that Iris herself had said that she never really understood what it was to feel a sense of identity, he ponders whether this might have made the process of dementia easier for her (p. 47). He too has moments where he finds it difficult to remember that Iris might once have been different (p. 51). Although it may seem an ironic term to use in dementia (literally, 'de-' or 'un-minding'), his experience has taught him that the most successful approach is a form of 'mindfulness.'

"Being in the present moment," rather than responding primarily to the pressures of maintaining continuity in Iris' self, emerges as the most promising way for him to interact with her, while the film depicts the strains that result from doing otherwise. In this Bayley's experience echoes that of other advocates of mindfulness within the medical humanities.³⁴

"Some who accept what comes their way": Accepting Change in Away From Her Unlike Iris, AFH has its origins in fiction and is unconstrained by the boundaries of 'what really happened' within an individual's recollections. As such, it addresses head-on questions of continuity and change in relationships by presenting Grant with a sharp dilemma. While Iris's past lovers are very much in John's mind at several points, Fiona's real and immediate attraction to Aubrey becomes evident before Grant's very eyes. Should he try to keep her as who she was, or should he accept and be guided by her preferences in the present? There are moments when Grant attempts to assert Fiona's previous self (for example, complaining that she is wearing someone else's sweater: "No, it's not pretty, it's tacky. She would never wear something like that!" [59:40]), but, in contrast to John's approach in *Iris*, he soon decides that the best course is to let Fiona change. He doesn't interfere with her activity in the centre, but visits daily to watch her and sometimes to converse. When Aubrey leaves and Fiona despairs, Grant actively tries to bring them back together, judging that the only way to ensure Fiona's well-being is to efface their own married relationship and facilitate her in forging a new one. Ironically, it is only through starting his own relationship with Marian, and thereby from one perspective betraying Fiona, that Grant is able to show his faithfulness. The plot rewards him for his choice, ending with a scene where Fiona loses interest in Aubrey, recovers her health, realises that her clothes had been mixed up, and expresses her gratitude to Grant. The fictionality of AFH, as opposed to Iris, means that the narrative can follow a trajectory that apparently restores equilibrium. Although the ironies and uncertainties of this scene make it

somewhat ambiguous, she nevertheless appears to validate his decision to let her forge new relationships by suddenly restoring value to their old one. As she points out, Grant has not abandoned her; left unsaid is that neither has he forced her to remain someone she no longer was for his own sake.

Despite this moment of narrative resolution, the viewer is left to wonder whether this startling recovery will last and what will now happen between the characters. The structurally parallel climactic scene in *Iris* is quickly followed by Iris' entry to residential care and death, but Polley is content to leave the conclusion of *AFH* open-ended, in defiance of the archetypal representation of progressive decline and death in dementia-related works. ^{16, 35} Shortly before, Marian had commented that:

Sometimes you have to make a decision to be happy. [...] The only thing that separates one kind of person from the other, is that there are some who stay angry about it, and there are some who accept what comes their way. [...] I was pretty damn mad, but right now, looking at what came my way ... I think maybe I could become the other kind of person. [1:31:27]

This kind of flexibility in response to what life holds in store echoes something of the decisions that Grant has made over the course of the film to prioritise Fiona's present happiness over her self-continuity. It also perhaps sheds light on a puzzling moment at the outset of both the short story and the film, as Fiona's habit of leaving labels around the house to help her remember the names of things brings to mind a tale about German military patrol dogs in Czechoslovakia during the War [07:46]. Asked by the Czechs why each dog wore a sign saying *Hund*, the Germans simply replied, "Because that is a *Hund*." One interpretation of this rather ambiguous episode might be that it points to the arbitrariness of names, and by extension, the arbitrariness of labelling or defining people. Signifiers such as these signs or

Fiona's notes do not quite manage to keep definitions stable, just as wisdom for Grant lies in not holding Fiona to a stable identity; as he put it only moments before, it may be that "all the labels [...] are defeating the purpose" [07:13].

CONCLUSION

In both films, carers struggle to know what the right thing to do is, and the viewer is drawn into their dilemmas. As so often happens in questions of care and relationships, there is no single right answer, but by opening up the questions, these works provide a corrective to the too ready assumption that continuity of identity in the person with dementia must always be the primary value for their carers. They remind us that, while life lasts, identity is never settled or firm. Among the elements that reinforce this message is the use made by both directors of motifs drawn from nature that both bookend and recur through the films: in Iris, water; in AFH, snow. In remarkably parallel treatments, at times both the water and the snow threaten serious dangers to Iris [37:05, 01:02:22] and Fiona [14:41] respectively, but at other moments provide the opportunity for enjoyment of swimming or skiing [e.g., Iris 02:17, 36:58; AFH 00:55], resisting any univocal interpretation of their meaning. This very unsettledness allows the films to imbue these natural elements with symbolic resonance with the transitions that the two women find themselves undergoing. Iris explicitly references the transformative associations of water as a fluid, formless and changeable medium through the invocation of Proteus, whose domain it was and whose transformations are identified with those of Iris herself. The river is thus a particularly potent setting in which to highlight visually the transitions between solitude and companionship [e.g., 01:34], pleasure and danger, youth and age [37:04], and life and death [01:23:46]. In AFH, Grant's and Fiona's ski tracks in the snow punctuate the whiteness, but at different times in the film go in parallel [09:30, 01:41:07], separate from each other and form single tracks [01:26, 14:41], or are

covered over by the uniform mantle of further snowfall [42:46, 01:19:55], much as the couple

move through different phases in their relationship and different levels of closeness. These

natural features both mirror the changes in the characters' identities and force them to

confront them.

It is often the case that the most appropriate response in dementia for the person who has it,

the carer, or both, is to work at preserving those aspects of identity and selfhood that have

meant the most to them over time. However, it should be recognised that living with

dementia does not exclude opportunities for change and potentially even growth; identity

maintenance should not come with a commitment to stability that might, under other

circumstances, be seen as stagnation. By communicating this in their different ways – Grant

by what he does, John by what he does not do – these films offer insight into the everyday

decisions, from small to large, that make up the day of both carer and the person with

dementia. They bring these questions with them into the cultural imaginary of dementia,

inducing us to ask ourselves how we would respond in those situations and unsettling easy

assumptions.

Competing Interests: None

Funding: None

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