

# The beauty of what remains



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Over a three-year period experienced director and cinematographer, Kaye Harrison observed the highs and lows of three Australian families touched by dementia.

In the opening frames of *The Long Goodbye*, the crisp, controlled voice of Michael D'arbon breaks through the fog of a fading white screen.

The articulate, former criminal barrister and father of four speaks candidly from inside the blurry haze that is his experience of early onset Alzheimer's disease.

Diagnosed at 49 and in the early stages of his condition, Michael retains the insight to contemplate what lies ahead but at the same time lacks the power to control or stop it.

Adopting the legal jargon that once framed his arguments in court, Michael dryly proclaims the irony of his current situation; the aspiring judge has now become "an unreliable witness".

Faced with losing his wit, the very thing that defined his professional career and identity, Michael expresses his frustration with his shrinking world.

"Everything's a bit of a blurry quagmire and that won't be solved. I'll be remembering less and I'll be more distressed about the fact that everything seems to be quoted back to me as being inaccurate or wrong. There's no cheer squad for someone with a bad memory."

*The Long Goodbye* tracks the divergent experiences of three families as they live and manage dementia. Michael, the youngest subject, is a husband and father to four children living at home. Throughout the film, they celebrate significant family milestones and learn to negotiate the household's changing dynamics.

Change also confronts Ken and Myrle Hauser, who have been married for 60 years. Well into the mid stages of his vascular dementia, Ken, a former policeman, requires constant care and supervision.

Myrle stubbornly guards Ken's disease from everyone, including her family, and from offers of outside help because she sees his care as her burden to carry.

By exerting control over every aspect of Ken's care, she believes she can fight the disease but in doing so,

she inadvertently loses a part of Ken; his independence.

The third story in the film is Brenda and Tom. Unable to cope with Brenda's advanced Alzheimer's disease, Tom, her husband and full-time carer, reluctantly makes the decision to place her in a dementia-specific care facility. In her final years, having lost the ability to communicate with her husband, Brenda and Tom's relationship takes the form of a tactile and emotional connection.

For director Kaye Harrison, the documentary is a highly personal one. Harrison lost her grandmother to dementia in her mid-20s and describes the film as a subconscious effort to understand what was happening to her grandmother in her final stages.

While inspired, in part, by her personal history, Harrison says she also thrives on the challenge of making confronting issues accessible to a mainstream audience.

"I tend to be drawn to topics which society turns away from – subject matters which are surrounded by fear and misunderstanding in the community. I feel that dementia falls into this category and is a prime candidate for exploration," she tells *INsite*.

A common thread in the lives of the families she studied was the battle to let go of the person they once knew and loved, in order to accept the person that was evolving.

Myrle's deep commitment to her husband and fear of losing him manifested as a denial of the need for change and tightening the grip of control.

"I know that I'm losing a precious part of my life and at times when I think about it, I go away and I have a little cry. It does hurt because of the wonderful man he was. If he had been a bugger of a husband, probably easier to bear, but he's been such a good person and I can feel him even now slipping away and I'm trying to hang onto him."

While loss and grief are a significant part of the experience of

dementia, Harrison felt uplifted by the "beauty of what remains".

"Love can be given to those living with dementia and in most cases they will be comforted by this," she says.

While their cognitive faculties may be in decline, the physical, emotional and spiritual connection with the person continues.

"It was the core value of the person and how they related to their loved ones that survived and perhaps strengthened. All three families hung onto those things about their loved ones which were central to their understanding of that person and how they related in their family. Michael as a father in a normal family unit, Ken as the love of Myrle's life who she would care for until the end, and Brenda stayed intimately linked to her life partner, Tom, when they would lie together for hours. Although so much was lost by all families over the three years of filming, I was struck by the beauty of what they held onto and what remained," says Harrison.

Through the film, producer Gina Twyble says she wanted to challenge the perception that a person with dementia is somehow 'lost'.

"We wanted to show that even with dementia, each person has a unique and meaningful past and present life. They are still involved in relationships with their spouses, children, wider family and friends.

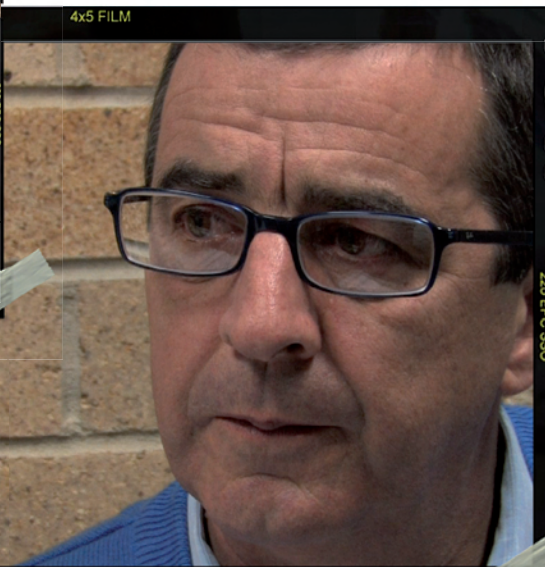
"For the person with dementia and their loved ones, there may be confusion, depression, anguish and all kinds of negative feelings. But there may also be times of joy, humour, respect, connection, calmness and deep love. People do change and relationships shift and alter. But while the past and the future become less relevant, the present moment remains a very strong bond between loved ones," says Twyble.

The power of the present moment is embraced in the playful contact between Michael and his son, in a celebratory dance between Ken and Myrle and in Tom and Brenda's tender smile of recognition.

During one of Tom's many visits







to see Brenda in full-time care, a member of the staff asks Brenda to identify her husband. When Brenda turns to look at Tom, she fails to remember his name but confidently and defiantly declares, 'he's my man'.

As the camera lingers on their intertwined bodies as they lie together peacefully in her room, the audience feels their powerful and continuing connection.

When preserving the dignity of those living with dementia, what is right and what is wrong becomes a lower priority, says Harrison.

"I think it shows true love and compassion on the part of a carer, family or friend to subvert one's own ego, to let their loved one be right, to let them save face and to gently steer them away from painful insights."

Twyble says the three-year shoot enabled the team to capture the complexity and nuance of their living stories.

"It was important to show each family's story as a journey, as something that evolved and changed over time. Filming over three years really allowed the film to attain a depth and intimacy that could not have been achieved without such a long shoot. It was an amazing thing for all three families to remain involved in the film and put so much into it, even at their lowest points," says Twyble.

For Harrison, their willingness to open up and share their intimate stories created a significant burden of responsibility. A significant challenge was to achieve an honest representation of their experiences without compromising their privacy.

"As the stories unfolded and I became closer to the families I was often confronted by a battle between how I felt about them as friends – people I cared about – and my commitment to the film and my integrity as a filmmaker," she says. "Often it was during the more intimate and painful moments when the sadness and grief was closest to the surface. My natural inclination was to want to turn off the camera, give them a hug or leave them in peace. However, I constantly reminded myself that I would be doing a disservice to their stories and to the reason they committed to the project in the first place. They wanted me to show their stories, warts and all."

In her role as director and cinematographer, Harrison successfully balanced the roles of both observer and participant in the lives of her subjects. She was not only making a film about her subjects but for them, says Twyble.

"Kaye's concern was always that each person's story be told with integrity and honesty but without exploiting anyone's vulnerability. The closeness Kaye felt for the participating families made them

the most important audience for the film. It was so important that each felt that the unique essence of their individual story had been properly captured."

In many ways, the documentary became a cathartic process for the families involved and was intimately linked to their self-reflection and understanding of their emotional journey. The film gave them the permission to truly express how they felt, says Twyble.

"For the participants it was a very empowering and validating experience to see their lives and experiences on screen. It was particularly powerful in that it was a shared experience between all the families who had taken part. After the first screening there was a strong feeling of connection and mutual understanding in the room. For us, it was great to know that the participants felt affirmed by the film. They had placed so much trust in Kaye; it was great to know that they believed their trust had been honoured."

In the final days of editing, Brenda sadly lost her battle with dementia. At her funeral, Harrison was struck by the constant reference to the documentary and the role it had played in Tom's life. It became a tangible record of his shared life with Brenda and offered a meaningful contribution to raising public awareness of the disease.

*The Long Goodbye* was produced by Luminous Films in association with Screen Australia, Screen NSW and ABC TV. The documentary will be broadcast on ABC1 in early 2011.

Go to [www.thelonggoodbye.com.au](http://www.thelonggoodbye.com.au)

