



THE LONG *Goodbye*



A **STUDY GUIDE** BY MARGUERITE O'HARA



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Above: Myrle & Ken Hauser, April 2008

Memory is a way of holding on to the things you love, the things you are, the things you never want to lose. – Kevin Arnold

Introduction

Every week 1300 more Australians are diagnosed with dementia and the numbers continue to escalate in line with our ageing population. There are currently 245 000 Australians living with dementia and it's estimated that there will be over 1.13 million by 2050. Raised in the unparalleled optimism and prosperity of the '50s and '60s, the baby boomers are accustomed to controlling their own destiny. As the dementia epidemic looms it is unknown whether science will save them this time.

The Long Goodbye follows the journeys of three families living with dementia as they struggle to maintain the identity and dignity of those they love. Filmed over a three-year period, the documentary celebrates the capacity of the human spirit to search for meaning and hope when the end is known and inescapable.

– Kay Harrison, filmmaker

Synopsis

The three families we meet in this documentary are at different stages of the condition we call dementia and they each offer a different perspective.

Michael, a criminal barrister with four dependant children was diagnosed with early onset Alzheimer's disease at the age of forty-nine. Three years on and still in the early stages of his condition, Michael retains insight and articulately shares his thoughts and feelings from within the disease. Although adamant he will fight on with a positive attitude and a sense of humour, Michael struggles with the loss of his professional identity and the shifting relationship dynamics within the family home. As his condition deteriorates, Michael and his family bravely strive to maintain as normal a family life as possible and to live each day as it comes.

The second strand is from the perspective of Myrle, an elderly carer committed to looking after her husband of 60 years until his dying day. Well into the mid stages of his Vascular dementia, Ken requires constant care and supervision. A fiercely independent woman, Myrle knocks back all offers of help; she sees it as her duty and is determined to carry out the caring responsibility alone. Although Myrle maintains control over all aspects of Ken's care she is unable to control the decline of her beloved. As Ken's condition deteriorates, Myrle is faced with the fact that she is losing the love of her life. The burden of care continues to build and Myrle's health is significantly threatened. Forced to relinquish control over Ken's care Myrle must find a new way to stay with her man.

The final strand is from the perspective of Tom, a 72-year-old carer who is desperately struggling to look after his wife Brenda who is in the latter stages of her Alzheimer's disease. No longer able to care for Brenda at home, Tom very reluctantly opts for dementia specific residential care. Racked with guilt and loneliness, Tom struggles to cope with his new life separated from his wife. As Brenda's memory and speech continue to diminish and she slowly withdraws from the world they shared, Tom refuses to let her go. He finds a new way to remain connected with his soul mate, the woman who loves him yet no longer remembers his name.

– Kay Harrison, Filmmaker



Above: Myrle gardening, Ken in background

Curriculum Relevance

The Long Goodbye would be an excellent film to show to middle, senior and tertiary students across a number of subject areas including Health and Personal Development, Community Services Studies including Studies of Ageing and Family Studies. For students interested in working in Geriatric Services and undertaking certificates in Personal Care and/or Aged Care, this film has much to offer and explore through discussion of some of the issues raised.

For Media and Film Studies students this is a fine example of a sensitively made documentary that shows people at their most vulnerable while retaining a respectful distance and respect for their dignity and need for privacy. While these are stories of individual families, there are some factors common to all people living with, understanding and learning to cope with, the challenges and sense of loss engendered by this illness in all these situations. The film raises the issue of how as a society and as individuals and family members we can best serve and care for an ageing population. What is the most appropriate form of care for both individuals with forms of dementia and for those who love them? How do we know when we can no longer manage the family member at home?

ABOUT THE FILM

The Long Goodbye is a 55-minute documentary by Luminous Films Pty Ltd and Kaye Harrison, produced in association with Screen Australia, Screen NSW and ABC TV.

Director, camera and sound recording: Kaye Harrison

Editor: Karen Johnson

Producer: Gina Twyble

Music: Caitlin Yeo



Above:
Sandy & Brenda

PRE-VIEWING STUDENT ACTIVITY

Growing Older

Will you still need me, will you still feed me when I'm 64. – The Beatles

I want to die before I get old. – The Who

As we age we are more likely to develop illnesses like cancer and heart disease. As the information and data about dementia provided earlier in this guide demonstrates, the likelihood of developing some form of dementia increases as we age. The Key Facts from the Alzheimer's information organisation page state:

- *The baby boomer bulge in the Australian population means that the coming decade will see an acceleration of the impacts of ageing on dementia prevalence.*
- *The first baby boomers turn 65 in 2010 and there will be 75, 000 baby boomers with dementia by 2020*
- *Dementia is the fourth most common cause of death after heart disease, stroke and lung cancer.*

While people are living longer because of developments in medical science and better access to treatment and care, there are social and economic factors that need to be carefully considered in relation to a growing ageing population.

Respond to the following questions designed to encourage your thinking about the realities of ageing and how we care for older people in our society.

- In general terms at what age do you consider people to be 'old'? Is it at retirement age, pension age, when their hair turns white or falls out, or when people can no longer manage to live at home?
- Have you ever, or regularly, visited a relative or friend in a hostel or nursing home?
- What are some of the difficulties young visitors experience when they visit relatives in nursing homes or other care facilities?
- Should immediate family members be responsible for providing primary care for their relatives as they age? In what circumstances might this be difficult or impossible or just 'too hard'?
- Do you think housing elderly people together, whether in a retirement village, hostel or nursing home, is a good model in economic and social terms for caring for people who are no longer able to stay in their own homes unassisted?
- How else can older people be cared for within their own environment?
- Are you aware of how other cultures such as the Chinese, the Americans or the Italians, look after ageing relatives?
- When people retire from their jobs, what kind of activities do they generally take part in?
- Is it important for older people to be able to make contributions to their society and family when they are no longer in paid employment? In what ways can they contribute and feel integrated into the community and family?
- What kind of wisdom are older people often able to offer to younger people?
- With an increasing number of people living and ageing at home, what processes and structures need to be developed to cater for their needs as they age and may develop debilitating illnesses such as Alzheimer's?
- What picture comes into your mind when you hear that someone is suffering from dementia or Alzheimer's?
- In a culture that worships youth and beauty and tends to deny and attempt to turn back the normal physical effects of ageing, how do you feel about the inevitability of your own ageing or in the words of The Who's 'My Generation' song – Do you want to die before you get old?

Background material about dementia

Our brain makes us who we are, it gives us our memories, our ability to think, to understand the world around us and it gives us our sense of self. All this is slowly stripped away for a person living with dementia.

The following Background Notes are sourced from the *Alzheimer's Australia* website:

Key Facts about Dementia (Alzheimer's Australia in reference to the Access Economics Report:



Left: Chris and Michael at graduation

PEOPLE IN THE FILM

1. **Michael** and Jane and their four children

2. Myrle and **Ken** and their adult son and daughter

3. Tom and **Brenda** and their adult daughter

'*Keeping Dementia Front of Mind: Incidence and Prevalence 2009–2050*' released September 2009)

- Dementia is fatal and there is no cure – it is not a normal part of ageing
- There are an estimated 245,000 people with dementia in Australia
- Without a significant medical breakthrough that is expected to increase to 591,000 by 2030 and again to 1.13 million people by 2050
- *Every week there are more than 1,300 new cases of dementia in Australia. That will grow to more than 3600 by 2030 and to 7400 by 2050.
- The baby boomer bulge in the Australian population means that the coming decade will see an acceleration of the impacts of ageing on dementia prevalence.
- The first baby boomers turn sixty-five in 2010 and there will be 75,000 baby boomers with dementia by 2020
- Dementia is the fourth most common cause of death after heart disease, stroke and lung cancer
- Dementia has an impact on every part of the health care system
- Australia faces a shortage of more than 150,000 paid and unpaid carers within a generation. The direct cost of dementia is already estimated at \$5.4 billion per annum
- The cost of replacing all family carers with paid carers is estimated at \$5.5 billion per annum
- By the 2060s, spending on dementia will outstrip that of any other health condition, reaching \$83 billion (in 2006–07 dollars) and representing around eleven per cent of all health and aged care expenditure
- Dementia is already the biggest single cause of disability in older Australians (aged sixty-five years or older)

What is dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a

progressive decline in a person's mental functioning. It is a broad term, which describes a loss of memory, intellect, rationality, social skills and normal emotional reactions.

Who gets dementia?

Dementia can happen to anybody, but it is much more common over the age of sixty-five. People in their fifties, forties and even in their thirties can also have dementia. The incidence rate rises with age. For people eighty-five years and over, one in four have dementia.

Alzheimer's disease is the most common form of dementia, accounting for between fifty and seventy per cent of all dementia cases. It is a physical disease which attacks the brain resulting in impaired memory, thinking and behaviour. As brain cells die, the substance of the brain shrinks. Abnormal material builds up as 'tangles' in the centre of the brain cells and 'plaques' outside the brain cells, disrupting messages within the brain, damaging connections between brain cells. This leads to the eventual death of the brain cells and prevents the recall of information. Memory of recent events is the first to be affected, but as the disease progresses, long term memory is also lost. The disease also affects many of the brain's other functions and consequently, many other aspects of behaviour are disturbed.

Vascular dementia is the second most common cause of dementia. It is the broad term for dementia associated with problems of circulation of blood to the brain. In Vascular dementia, very small blood vessels are blocked, resulting in the death of small areas of brain tissue on the cerebral cortex.

(Further Information about the causes of and approaches to the treatment of dementia appears later in this guide. It would be best to watch the documentary *The Long Goodbye* before reading through this information)

	MICHAEL AND JANE	KEN AND MYRLE	BRENDA AND TOM
Age at which dementia was first diagnosed			
Type of dementia			
Length of time person has lived with their dementia			
Previous occupation			
How person now spends their time			
Family situation			
Use of outside respite, day care or institutional care			
Ages of spouse and other family members			
Involvement of other family members apart from live-in husband or wife			
Main areas in which the individual with dementia shows decline			
Reasons for considering external care and assistance			

STUDENT ACTIVITY

Suggested ways to watch the documentary

This is an emotionally engaging film and while there are some factors common to the progression of their particular form of dementia amongst all the individuals and their families, there are differences in how all these people respond to and manage their situations. Students could make notes about the three families under the following headings to map some of these differences and similarities as they watch the film. **SEE TABLE ABOVE.**

- What do you think is the most difficult aspect of living with the progress of this disease for both the individual and their immediate family members in each case?
- What positives are there for these families in the relationships they already have within their family?
- What kind of intervention and assistance is shown to be available to families caring for relatives with dementia?
- Why might some people be reluctant to use these community support services?
- How does having a sense of humour, (albeit sometimes black) help people cope with this condition?
- How do the individuals with dementia spend their time each day, particularly Michael and Ken whose condition is less severe and advanced than Brenda's? How do any of these activities relate to their previous work lives as a barrister and a police officer?
- Running through this film are recollections and images of the person before they became ill. How important are such things in creating a complete picture of someone's life?
- What kind of insights is Michael able to offer into the nature of his illness?



From top: Michael upset in doctors; Jane & Michael, September 2009; Tom & Sandy upset interview

STUDENT ACTIVITY

Insights

What do people say about living with dementia?

When you have read through the quotes from the film listed on pages 8–10, choose one family and write a report about their situation.

Base your report on both your observations of their daily life as seen in the documentary and what different family members say, using some of the quotes below extracted from the program.

These may be used as part of:

- a) A report recommending the need for a different level or type of care or
- b) A tribute to the people and their lives.

If you choose to prepare a report, conclude with your recommendations about what sort of care or assistance you think would be most helpful in this family's situation at this time. Remember that 'one size does not fit all' when you are advocating changes or/and ways to improve the lives of all family members.

If you choose to prepare a tribute/memory piece, be sure to provide details about the earlier lives of the family and the individuals now living with dementia.



MICHAEL AND HIS FAMILY

'I feel like a moron a lot of times.' – Michael

'Things that happen during the day are sort of like on a floppy disc and they tend to disappear or dissipate over the days.' – Michael

'Alzheimer's sucks, there's no question about that.' – Michael

'He's a fifty-year-old five year old. He is the biggest kid in the house.' – Chris, Michael's 21-year-old son

'I can't imagine that he won't know who we are and who his children are or who his family is. I can't imagine that time.' – Jane, Michael's wife

'... we were given a ten year sentence, life sentence and they know that it's death at the end.' – Jane

'The earlier that it's picked up in younger onset, the better that it is. Because you can make plans ... and you can adapt.' – Jane

'If there is nothing you can do about it – you adjust, adapt, overcome. Simple as that.' – Michael

'As nice as it is to be with my wife ... she doesn't need to see me here every day and asking her something every thirty seconds and driving her crazy. And I don't particularly want to be doing it either.' – Michael

'I like to have something to do and when there's nothing to do, it's very depressing.' – Michael

'I decided to retire because I couldn't remember everything that I was reading.' – Michael

'I'm just sick and tired of being brain dead.' – Michael

'Depression is quite common in dementia.' – Professor Susan Kurrle, geriatrician

'I'm not supposed to be happy about it ... I was very clever. I could walk and talk at the same time.' – Michael

'I'm just trying to sort of get through the day without stuffing everything up. And then you have an argument or a discussion, you know, husband and wife, kids whatever, there's two different versions. So when you are a brain-dead moron you add that to the uncertainty of your recollection in the first place and multiply it by Alzheimer's, I'm fucked.' – Michael

'That burns me. When he kind of fabricates things to try and implicate me in doing something wrong.' – Chris



Above: Jane & Michael d'Arbon, May 2008

'It sort of makes me feel like I'm always going to lose every conversation or lose everything because as they used to say in court, I'm not a reliable witness anymore. And that won't be solved. And I'll be remembering less and being more distressed about that.' – Michael

'There's been an obvious change ... he has inappropriate responses and inappropriate reactions to things that I say.'

– Jane to doctor when Michael is being re-tested

'I don't know what's coming ... I don't feel prepared. Things are going to get hard ... you just have to get through it and rely on each other.'

– Chris

'I don't know what is actually going to happen to me ... but I don't need to work all of that out for something that's in a year or two or five years or ten years ... when we are all in the present.'

– Michael

'Later down the track I will look at nursing homes. I haven't crossed that off at all ... He's saying "you'll need six blokes to get me in there" ... but [by then] he'll probably be at the stage where he won't know what is happening and he may be more comfortable in a nursing home ... It's all if, what, when.'

– Jane

'I might not be able to do it as well today as I did a couple of years ago and I might be even bloody more hopeless in a couple more years. But I think the kids and Jane know that I love them and they love me. Most of the time these days (laughs).'

– Michael

'I can't imagine that he won't know who we are and who his children are or who his family is. I can't imagine that time.'

– Jane, Michael's wife



Above: Myrle & Ken dancing.

'I wake up in the morning and I say, well you're still with me love and I'm still with you ... he's my whole life.'

– Myrle

MYRLE AND KEN

'He cannot understand why I get maggots having to answer the same question time and time and time again.'

– Myrle

'My wedding vows would be the most important thing in my life. Even over my children ... for richer, for poorer, in sickness and in health and you can either accept your responsibility or you can reject it and say "well, I can't handle this, I'll put you in a nursing home" and to me that is not your vows.'

– Myrle

'No person likes to think that they've lost their memory.'

– Ken

'I don't care whether I forget or not because nobody suffers.'

– Ken

'I don't need help ... don't need help at all.'

– Ken

'I have a big concern about her [Mum's] welfare.'

– Peter, Myrle and Ken's son

'Mum's a very independent person ... she thinks that she can do it all herself. And when she's eighty-one she's going to be able to do less than what she's doing now.'

– Jenny, adult daughter

'I wake up in the morning and I say, well you're still with me love and I'm still with you ... he's my whole life.'

– Myrle

'A lot of things have shifted with the responsibility because now I take the controlling role which

I have to, it's not because I want to ... because I know that Ken's not going to be able to make those decisions.'

– Myrle

'God, I can remember when I was in charge. I didn't go for a second in charge.'

– Ken

'It probably hurts him when he says he used to be the boss ... but he's not any more.'

– Jenny

'My dad was six feet two ... very strong in character ... a person to look up to.'

– Peter

'As soon as he goes out the door I think to myself – am I doing the right thing letting him go? And I've got to say to myself – yes I am. I can't take his independence away too early.'

– Myrle

'My family, who are very close, have no idea what goes on here seven days a week. They only know what goes on here what I tell them and that's not very much because what can they do about it? It's my responsibility to look after the man I married.'

– Myrle

'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 ... I know I'm losing him and that really hurts ... if he'd been a bugger of a husband – probably easier to bear.'

– Myrle

'I'm not going to be independent any longer. I'm going to accept the help that's freely given ... my fervent prayer is to stay together. And if I've got to be a little bit humble and accept help then I'll do it.'

– Myrle



Left: Tom & Brenda

TOM AND BRENDA

'What would it be like if you didn't love the person that you were looking after?' – Tom

'You don't really notice it. You just seem to take over. Take up the slack of whatever has been left, you know, whether it's washing and ironing or cooking or cleaning or whatever ... until you're doing it all. – Tom

'... the things he does for Mum you know ... the bathing and putting creams and lotions and potions ... and tucking her into bed ...and putting her bra on ... you know he just does it.' – Sandy, Tom and Brenda's daughter

'We were born on the same day and Mum always used to make us an outfit and go into the city for the day and she'd get compliments – oh, you must be sisters, it can't be your mother.' – Sandy

'She had a beautiful tan and she had this big head of black curly hair. She was a different girl then, full of life, very fiery at times too ... and I thought that's the one. I want to be the one to look after her for as long as I can. Obviously I'm reluctant for her to go into care.' – Tom

'You feel tired all the time ... worn out so I don't think there's anyone to say that it's time. I'll know the time. Maybe it's just sheer exhaustion that makes you go ahead and do something.' – Tom

'It's sort of wearing me down a bit with things that happened with Brenda recently, about getting up during the night ... at one stage she was up the

'One of the things I think she likes is the bodily contact ... I think she misses that.'

– Tom

other night every hour on the hour no matter how many times I put her back to bed. I'm getting more and more concerned about leaving her on her own.' – Tom

'It's time. And he knows. For her to go into full time care. He still can't do it ... For [dad] it's giving his wife away. Giving up on her. He just loves her too much. – Sandy

'I think what we have to help him through is the guilt ... it's hard. He's grieving too ... he looks so lost.' – Sandy

'It's been six weeks since she has been home and it's just empty ... I do have trouble coping with the fact that Brenda's in there ... the only way I can cope is to shut it out to a certain extent because I get very emotional thinking about it.' – Tom

'There's the loss of relationship that you described and yet there is still a relationship.' – Paul Pickering, Pastoral Care co-ordinator

'One of the things I think she likes is the bodily contact ... I think she misses that.' – Tom

'I know I made the right decision ... but I think there will always be that ache inside regardless, that she had to go in there and away from home and away from me.' – Tom

'We still have that unspoken attachment. I can just see it in her face. She's like a living part of me.' – Tom

'He's my man.' – Brenda

STUDENT ACTIVITY

The style, structure and look of this documentary

Here are some observations from Kaye Harrison who directed this documentary, about her experience making the film. Read through them before responding to the questions that follow about the film.

I have personal experience with dementia. My Nana died with the condition when I was in my mid twenties. In her more advanced stages she no longer recognised her children, let alone her grandchildren. I visited her less and less in the nursing home as it was a painful experience. I believed there was no point as she was already 'lost' and didn't know me anyway. Perhaps making The Long Goodbye was a subconscious effort to understand what was going on for my Nana in those latter years?

When I began researching the topic, I came across Christine Bryden's (Boden) book Who Will I Be When I Die? I had only ever associated dementia with the elderly. My misconception was blown away when I discovered Christine was a high achieving forty-six year old when diagnosed with Alzheimer's disease. Her book took me right inside the disease and I was particularly intrigued by her exploration of identity; if our memories make us who we are, then who do we become when we lose our memories?

I wanted to challenge the stereotype commonly associated with the condition so I set out to find an early onset participant. They also needed to be in the early stages as I wanted to capture that intriguing insight from within the disease. When I met Michael, I knew he was the perfect participant for my documentary. He was articulate, funny and completely free of self pity. The fact that he had four children still living at home and was a retired criminal barrister just made his story all the more tragic. He had already lost so much and had so much more to lose in the future.

I developed quite a close relationship with Michael. Even though he wouldn't be able to recall anything we have discussed and shared in the making of this film, he has trusted me enough to share his story. He is the only character in the film with dementia who remembers me and I think that's why our relationship has a different feel about it. Witnessing his deterioration and the impact on his family has been difficult and at times very painful. The second visit to the doctors where it was obvious he had deteriorated significantly was quite traumatic for us all. It is very rare to see Michael upset and he was totally devastated during that visit. The only positive that came out of it was that half an hour later he had forgotten about it all. Poor Jane was left with the lingering sadness.

One thing I have learnt from making this film is that it is possible to protect those with dementia by not reminding them when they have forgotten something. It's surprising how often you tend to raise a subject by saying 'do you remember?' Of course this is the last thing you want to do as no, they probably won't remember and you have just inadvertently reminded them of their deficit. It is also pointless to constantly correct someone who has dementia as once again this rubs it in their face. What is right and what is wrong gradually becomes a lower priority. 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.

Filming with the Myrle & Ken was an absolute delight. Ken is such a cheeky and lovable character and the banter between them continues whether the camera is running or not. Over the three years of filming I developed a very close relationship with Myrle. I think she really enjoyed the visits and found it cathartic. It was an opportunity for her to get some things off her chest without having to burden her family. It would have been easy for me to judge Myrle's devotion and refusal of help as that of a martyr. However Myrle was raised at a different time when there was a greater emphasis on values and duty in a relationship. I learnt to accept that it would be very difficult for an 80 year old woman who is very strong and independent to suddenly change her behaviour, despite its obvious flaws. Myrle's illness was the trigger. It was heart breaking to see her so beaten by the illness and so anxious about Ken's welfare. For the first time in her life she seriously contemplated that she might pass away first. Although it took a fright to change her attitude, I do feel great admiration for Myrle. Very humbly she was able to let go of the reins a little bit and accept some help. I think it was only her love for Ken that gave her the strength to take those first brave steps. I can only hope that when I am her age I have the capacity to show such love and devotion to my man!

Filming with Tom & Brenda was an intensely emotional journey. I was so moved by the tender care that Tom showed his wife and how devastated he was by their eventual separation. I had to carefully judge when I really needed to film certain moments in order to faithfully document the journey but at the same time be very careful to not overdo it and become intrusive. It was a constant balancing act which required a lot of mixed emotions on my part. My natural inclination is to let people be and respect their privacy when they are experiencing such pain; however to withdraw at this point would have seriously undermined our shared objectives for the film. I wouldn't have documented their journey honestly and to the best of my ability.



Above: Myrle and Peter on verandah.

The decision to put a loved one in fulltime residential care could be the toughest decision that a person ever has to make in their life. Tom's story powerfully conveys the guilt and anguish leading up to that decision. I am hopeful that those watching who are quick to judge others who make that same decision will feel greater empathy for carers. I am also hopeful that those who have or are about to make that decision and are experiencing similar guilt will feel some sort of validation and support.

I stopped visiting my Nana in the nursing home as I believed she was already 'lost' and didn't know me anyway. Through the making of this film, I now think that my view was fairly selfish and misguided. I have seen how people living with dementia can be reached, that a connection can be made even if they don't know who you are. Family and friends experience the pain of being forgotten and the tragedy of seeing their loved one become a shadow of their former self. However, I hope people will find some comfort when they witness the ongoing connection between Tom and Brenda. Despite the advanced nature of her dementia she was not 'totally lost'. Love can be given to those living with dementia and in most cases they will be comforted by this. I wish I had known this when my Nana was deteriorating with the condition.

– Kaye Harrison, Filmmaker

- Do you think Kaye Harrison has succeeded in her aim 'that those watching who are quick to judge others who make that same decision [to put a family member into residential care] will feel greater empathy for carers'?
- Has she managed to balance the need for privacy with the need to faithfully document the journey of these families?
- Were there any questions you would have liked to ask of any members of the families?
- Were you conscious of the presence of the filmmaker and the camera at any points in the film?
- What part does the musical soundtrack play in this documentary?
- What do the close-ups of people's faces show the audience? Give some examples from the film where the silent image is as poignant as any dialogue.
- This is a documentary dealing with an important subject that many people would rather not acknowledge or think about. How do the stories of individuals tell this story more eloquently than any amount of statistical information could hope to do?
- Has watching this documentary been an informative experience for you? What have you learnt or been encouraged to think about in relation to ageing and dementia?
- Was there one individual or family whose story particularly moved and engaged you? Explain why this was the case.
- What do you think the title – *The Long Goodbye* – suggests about the effects of dementia on families and individuals?

STUDENT ACTIVITY

Everyone is Different – Being a Carer

Tom Valenta's wife was diagnosed with early Alzheimer's in 2004 aged 54. In his 2007 book, *Remember Me, Mrs V? Caring for my wife: her Alzheimer's and others' stories*, he writes about the progress of his wife's illness and includes the stories of 13 other families. The final chapter of his book offers



Above: Michael & Jane

what he calls ten golden hints for surviving as a carer. He prefaces this list by stating that 'every case is different and every carer must run his or her race in his or her own way'.¹ Here are his ten golden hints.

1. Get organised from day one
 2. Don't accept second-rate medical advice
 3. Acquire survival skills – quickly
 4. Accept genuine offers of help
 5. Know when you need respite
 6. Look after yourself
 7. Don't become isolated
 8. Try to make the system work for you
 9. Have a view of the future without making specific plans
 10. Never lose touch with reality
- Investigate the assistance and financial support available to those caring for a person with a debilitating illness such as Alzheimer's by exploring the Carer's Australia website at <<http://www.carersaustralia.com.au>> and Alzheimer's Australia website at <<http://www.Alzheimer's.org.au>>.
 - What are some of the factors we see in *The Long Goodbye* that would make it hard for carers to focus on some of the above hints?
 - Do you think Tom Valenta's hints could be equally valid as advice for anyone with a carer's role, whether of someone with a form of dementia or with any other illness?

Further Information about dementia (Alzheimer's Australia website)

Causes of Alzheimer's disease

Scientists are rapidly learning more about the chemical changes which damage brain cells in Alzheimer's disease but it is not known why one individual gets Alzheimer's disease late in life and another does not. A variety of suspected causes are being investigated including factors in the environment, biochemical disturbances and immune processes. The cause may vary from person to person and may be due to one factor or a number of factors.

Preventing dementia

Although there is no proven way to prevent dementia, research indicates that a healthy lifestyle and engaging in physical, mental, and social activity may help to reduce the risk of developing dementia. The Access Economics Report: *Keeping Dementia Front of Mind*, includes projections showing that reducing the number of Australians who are physically inactive by twenty per cent would result in six per cent fewer cases of dementia in 2050. Numbers would be reduced a further six per cent by simply maintaining current trends in improvements in management of high blood pressure.

'WHEN I'M 64' – LYRICS OF THE BEATLES' SONG

When I get older, losing my hair,
Many years from now,
Will you still be sending me a valentine
Birthday greetings bottle of wine?
If I'd been out till quarter to three
Would you lock the door,
Will you still need me, will you still feed me,
When I'm sixty-four?
oo oo oo oo oo oo oo ooooo
You'll be older too, (ah ah ah ah ah)
And if you say the word,
I could stay with you.
I could be handy mending a fuse
When your lights have gone.
You can knit a sweater by the fireside
Sunday mornings go for a ride.
Doing the garden, digging the weeds,
Who could ask for more?
Will you still need me, will you still feed me,
When I'm sixty-four?
Every summer we can rent a cottage
In the Isle of Wight, if it's not too dear
We shall scrimp and save
Grandchildren on your knee
Vera, Chuck, and Dave
Send me a postcard, drop me a line,
Stating point of view.
Indicate precisely what you mean to say
Yours sincerely, Wasting Away.
Give me your answer, fill in a form
Mine for evermore
Will you still need me, will you still feed me,
When I'm sixty-four?
Whooh!²

Treatment of Alzheimer's disease

At present there is no cure for Alzheimer's disease. However, one group of drugs called cholinergic drugs appears to be providing some improvement in cognitive functioning for some people with mild to moderate Alzheimer's disease. Drugs can also be prescribed for secondary symptoms such as restlessness or depression or to help the person with dementia sleep better. Available medications can reduce symptoms and improve quality of life in some people, but they do not stop the progress of the disease.

Current research into the treatment of dementia

Researchers are continually searching for new treatments for Alzheimer's disease and other dementias. The potential treatments discussed below are in the early stages of research and are not currently available. However, they are all part of the research effort to find more effective treatments for Alzheimer's disease and ultimately a cure.

Alzheimer's Vaccine and Immunotherapy – Researchers have been attempting to develop a vaccine for Alzheimer's disease for several years. The strategy behind the immunotherapy approach is to use the body's own immune system to destroy amyloid-beta plaques.

Gene therapy – Gene therapy has been promoted as a promising technique for many different conditions. A very small trial of gene therapy for Alzheimer's disease has shown beneficial effects - slowing the progression of the disease by about 50%. Although, the study is very preliminary, it indicates that gene therapy may provide beneficial treatment for Alzheimer's disease in the future.

Non Steroidal Anti-inflammatory Drugs (NSAIDs) – Several studies have shown that non steroidal anti-inflammatory drugs (NSAIDs), which include drugs like aspirin, may be protective against Alzheimer's disease. In a 1997 study, people taking NSAIDs were shown to have half the relative risk of developing Alzheimer's disease of those not taking the drugs. However, other studies have reported no benefit. Additionally, some NSAIDs can have serious side effects. Other trials using NSAIDs for the prevention or treatment of Alzheimer's disease continue, using NSAIDs with a lower risk of side effects. Results are still pending on whether safer NSAIDs will be an effective preventive strategy for Alzheimer's.

Targeting amyloid-beta production – Several treatment strategies for Alzheimer's disease rely on targeting amyloid-beta. One such strategy focuses on trying to understand the role of enzymes which are active in the production of amyloid-beta protein.

Researchers are trying to develop drugs that inhibit these enzymes in order to stop the production of plaque forming amyloid-beta. However, as both beta and gamma secretase have many other roles in the body, it has proven difficult to selectively inhibit their effects on APP and amyloid-beta.

Cholesterol lowering medications – Several studies have indicated that the use of cholesterol lowering drugs, such as statins, is linked to a lower risk of developing Alzheimer's disease. This may indicate an important role of cholesterol in the pathology of Alzheimer's disease. More research is needed to fully examine the effects of cholesterol lowering medications on the development and progression of Alzheimer's disease."

There are many therapies in different stages of development currently being tested in clinical trials around the world. These include new medications, such as Alzhemed (aims to prevent plaque formation by binding amyloid and reduces inflammation at existing plaques), Flurizan (aims to reduce the level of circulating amyloid-beta protein), and Metal Protein Attenuating Complexes (MPACs, aims to reduce the binding of metals to amyloid-beta), as well as other therapeutic interventions such as vitamin trials (including Vitamin E and Selenium) and herbal formulas (including Huperzine A, a natural Chinese herb with anti-cholinesterase effects).

I have drawn a lot of the information about dementia and the making of this documentary from the materials accompanying the film and would like to acknowledge the work of Kaye Harrison, the filmmaker, in providing this very helpful material.

Resources and References

<http://www.alzheimers.org.au>

Alzheimer's Australia is the peak body in Australia for information and assistance about the illness. There are many pamphlets and references available from this site to further explore the topic and investigate the state of current research into Alzheimer's and other forms of dementia.

Alzheimer's Australia address and phone number
Alzheimer's Australia
PO Box 4019
Hawker ACT 2614
+61 (2) 6254 4233

The National Dementia Helpline – 1800 100 500
Christine Bryden, *Dancing with Dementia*, Jessica Kingsley Publishers, 2005.
Christine Bryden (Boden), *Who Will I Be When I Die?*, Harper Collins, 2004.
Bryden was diagnosed in 1995 with early-onset dementia and has written two books about her life with dementia. She also has a website at <http://www.christinebryden.com>.

Tom Valenta, *Remember Me, Mrs V? Caring for my wife: her Alzheimer's and others' stories*, Michelle Anderson Publishing, Melbourne, 2007.

An account of Valenta's story of his wife's early onset Alzheimer's and those of thirteen other carers.

Terry Pratchett, successful author of numerous fantasy novels, was diagnosed with Alzheimer's in 2008 when he was sixty. He has written and spoken a great deal about his illness to encourage people to understand and support research into the illness. Read a speech he gave about his condition at <http://www.freerepublic.com/focus/f-chat/1986843/posts>.

An ABC radio presenter Barry Cook was diagnosed with early onset Alzheimer's aged 49. This is a really inspirational story about how Barry and his wife continue to live their lives and stay positive with the help of Alzheimer's Australia. It also describes how the use of medications can assist with the worst symptoms of the disease. A transcript can be downloaded from the ABC Radio National website for 360 Degrees: <http://www.abc.net.au/rn/360/stories/2010/2765301.htm#transcript>.

Endnotes

- ¹ Tom Valenta, *Remember Me, Mrs V? Caring for my wife: her Alzheimer's and others' stories*, P. 274, Michelle Anderson Publishing, Melbourne, 2007.
- ² <http://www.sing365.com/music/lyric.nsf/When-I'm-Sixty-Four-lyrics-The-Beatles/925C6BF15FAC44F048256BC20013EBF7>



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