

## A Long Goodbye: Ed and Mary's Journey with Lewy Body Dementia

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*A Long Goodbye:  
Ed and Mary's  
Journey with Lewy  
Body Dementia*

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**Please cite as:**

Baldwin, A., Anderson, S., Inskip, M., Johns, K., Lindsay, D., Mathiesen, B. & Bodak, M. (2021). *A long goodbye: Ed and Mary's journey with Lewy body dementia*. James Cook University. <https://jcu.pressbooks.pub/alonggoodbye/>



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# *Introduction*

Often the lessons to be learned from recipients of care are overshadowed by more formal learning strategies. Ed's story is one of compassion, strength, laughter, loyalty and loss. It chronicles the journey of caring for a loved one diagnosed with dementia with Lewy bodies. Unfortunately, diagnosis of any form of dementia is more frequent in our communities than many of us are aware. Very few people, however, journal their story as their lives, and that of those around them, change. Thus, the richness of learning from recipients of formal care and support is a unique opportunity for all health professionals working in dementia care. Further, the raw, honest insights in Ed's story are a valuable learning tool for any health professional from any discipline, particularly those who are still learning their craft. Sometimes the impact our words and actions have on patients and families is not apparent, and Ed's reflections allow us a glimpse into how the actions and words affect them, both positively and negatively.

Ed's journal has been presented in two ways. One, as a whole journal, presented verbatim that allows the reader to follow the story from start to finish. Secondly, the contents of the journal are presented in context with the key elements for essential knowledge about caring for someone with dementia. To complement the text, video vignettes where Ed talks about his and Mary's experiences, are linked to each theme. There are also further links to external

sites for support groups, government and non-government agencies related to dementia care. Those involved in Ed and Mary's journey, as well as the project team, and other professionals the team encountered along the way, were invited to share their reflections, some of which have been made available as part of this resource.

This ebook built around Ed's journal, chronicles Ed's experiences as a carer following Mary's diagnosis with Lewy body dementia. Students and experienced health professionals are rarely afforded an insight into how their words and actions are interpreted by, and impact, patients, families and friends. Formal and informal carers also seek better understanding of dementia types, causative factors, symptoms, strategies to assist, services available, without necessarily having access to reliable resources. To meet the needs of such a diverse audience, Ed's story is freely available and accessible to any community member who seeks information about dementia care. As a first edition ebook, *A Long Goodbye: Ed and Mary's Journey with Lewy Body Dementia* will undergo ongoing review and updating of content to ensure accuracy, and make sure that the content reflects best practice.

### **WHO IS THIS FOR?**

Ed's story provides information and education resources related to dementia care. Although specifically focusing on Lewy body dementia, the resources have been developed to be transferable to caring for people with any type of dementia. The resources are suitable for use by students in the health professions, educators, formal and informal carers.

### **HOW DOES IT WORK?**

Each section links to Ed's journal, some with video vignettes, provides some background knowledge and includes teaching strategies for educators. The activities and resources for each section are suggestions.



**Module 1** provides an overview of dementia and the burden of disease in the Australian context.

**Module 2** describes the experiences of patients, carers, family and friends.

**Module 3** specifically outlines issues pertaining to carers.

**Module 4** provides links and resources to access services, including emergency services.

**Module 5** gives users the opportunity to read Ed's journal in its entirety, read the reflections of family, friends and carers of people with dementia, and the reflections from the project team.

**Module 6** has a list of recommended readings.

**Module 7** gives users the opportunity to watch all of the video vignettes in one place.

*A long* GOODBYE

## *Acknowledgement of Country*

James Cook University is committed to building strong and mutually beneficial partnerships that work towards closing the employment, health and education gap for Australian Aboriginal and Torres Strait Islander peoples. Our students come from many backgrounds, promoting a rich cultural and experiential diversity on campus. We acknowledge the Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the Australian lands and waters where where our staff and students live, learn and work. We honour the unique cultural and spiritual relationship to the land, waters and seas of First Australian peoples and their continuing and rich contribution to James Cook University and Australian society. We also pay respect to ancestors and Elders past, present and future.



*Kassandra Savage (JCU Alumni), 'Coming Together and Respecting Difference', acrylic on canvas, 2014, 90cm x 90cm.*

# *Acknowledgements*

We would like to thank the family of Ed and Mary for allowing us to share Ed's story in this eBook.

Cover image created using designs by Jane Tarlington. Illustrations by Jane Tarlington (designbyjane@live.com.au).

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In memory of Ed and Mary



# MODULE 1 — DEMENTIA: WHO, WHAT, AND WHY

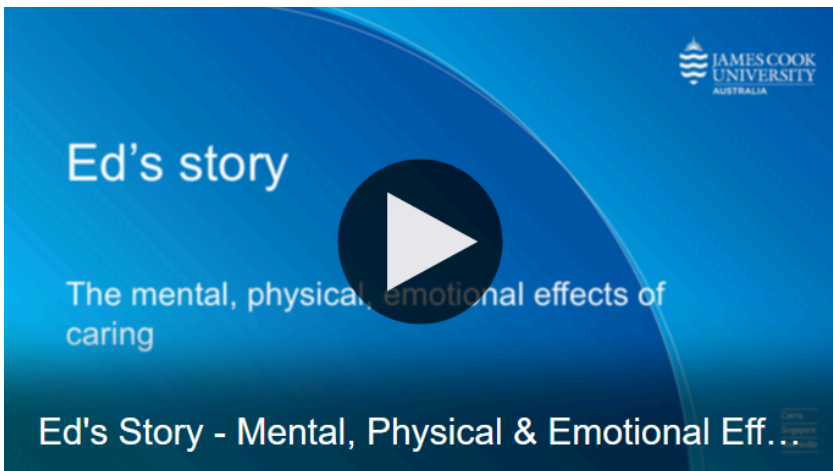
Module 1 discusses dementia in the broad contexts of disease incidence, different types of dementia, pathophysiology, presentation and progression. It includes discussion about the burden of disease, highlighting the prevalence in our communities, the financial and social costs, demonstrating why this topic is a high priority for health departments, health workforces, communities and families. It shows there is more to national and international health provider decision making than budget; the resulting ripple effect on families and communities is far greater than that. It is therefore imperative that, in the spirit of person-centred care, the experiences of patients, families and friends provide the background upon which planning for health service provision and workforce education is based.

The theoretical knowledge gained from this module is enhanced by additional learning opportunities. The content of this module is linked to examples in Ed's narrative, activities and learning strategies to better understand the concepts.



# *Ed's Story: The mental, physical and emotional effects of caring*

[VIDEO]



*Video Acknowledgments:*

*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*



# *Dementia overview*

Michael Inskip PhD, ESSAM AEP

## INTRODUCTION

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Dementia is a degenerative neurological condition that involves the progressive loss of neurons (brain cells) within the brain, which then causes a gradual decline in cognition (thinking) and functional independence (Reisberg, 2006). Currently, it is the most prevalent neurodegenerative condition—estimated to affect over 44 million people worldwide—and is expected to increase to 131 million affected people by 2050 (Prince et al., 2015). In Australia, over 400,000 people live with dementia, with similar increases expected over the next 30 years to 1.1 million affected people by 2050 (Brown et al., 2017). Additionally, while it is important to note that dementia is not a normal part of ageing, its prevalence does increase dramatically with age due to the increased vulnerability of the brain to underlying degeneration and disease burden. The prevalence of dementia by age group increases from approximately 5-10% in the 70-80 years of age bracket, up to 30% in those aged over 100 years of age (Nichols et al., 2019). An increase in population and a general shift towards an ageing population, in conjunction with advances in treatments and typical life expectancy are driving this increase at both a global and national level (Nichols et al., 2019). Consequently, it is estimated that in Australia alone,

the total cost of dementia to the economy is AUD10 billion, rising to over AUD24 billion in the next 30 years (Brown et al., 2017).

## TERMINOLOGY

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The term dementia is often viewed as synonymous with Alzheimer's disease, and incorrectly used interchangeably in public discourse, the media, and even in healthcare. Dementia is in fact an umbrella term for over 100 different underlying diseases and degenerative processes which can cause the pattern of progressive decline in cognition and function that is observed in the clinic (Brown et al., 2017). Disease processes that can cause dementia include Alzheimer's disease, cerebrovascular disease, Lewy body disease, frontotemporal degeneration, and many other rarer causes such as HIV, Huntington's disease, alcoholism and viral infections such as meningitis, to name a few. While it is increasingly understood that multiple disease processes may be contributing to the symptoms of dementia, the true extent of each cannot be determined while the person is living, so the dementia is therefore often named after the disease process likely to be contributing the most (Irwin et al., 2017). The most common dementia types therefore include Alzheimer's disease dementia (contributing to 60-70% of all cases), vascular dementia (10%), Lewy body dementia (5-20%), and frontotemporal dementia (10%)(Brown et al., 2017; McKeith et al., 2017).

## ETIOLOGY & PROGNOSIS

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The risk of developing dementia is a complex and difficult concept to map. However, what is clear is that risk factors are accrued throughout the lifespan starting from before birth right up until the point of diagnosis (Livingston et al., 2020). Additionally, the processes that causes dementia can begin up to decades before there are even any noticeable symptoms (Beason-Held et al., 2013).

While most dementia is considered sporadic, or randomly occurring, there are a handful of genes that make a small contribution to an increased risk of dementia. These include genes such as APOE4, SCNA, and PARK4, to name a few, which do not cause dementia, but likely increase the vulnerability of the individual to other risk factors throughout life, which accumulate and increase the risk of disease (Orme et al., 2018).

In early life, disruption of normal childhood development and less education can predispose an individual to dementia, mostly through decreasing what is known as cognitive reserve (Livingston et al., 2020; Wang et al., 2017). Cognitive reserve refers to level of cognitive ability and structural resilience of the brain above and beyond what is needed for independent function. Effectively, it represents a buffer in brain function whereby it can handle higher levels of damage from underlying disease for longer before reaching a critical threshold whereby the individual experiences symptoms (Fleming et al., 1995; Valenzuela & Sachdev, 2006; Wang et al., 2017). Other well known risk factors for dementia in mid and late life include concussion, hypertension (high blood pressure), alcoholism, obesity, smoking, depression, social isolation, physical inactivity, diabetes, air pollution and other neurological diseases (Ashby-Mitchell et al., 2017; Livingston et al., 2020). Promisingly, it is estimated that between 40-48% of the risk of developing dementia can be modified through readily accessible changes to lifestyle (Ashby-Mitchell et al., 2017; Livingston et al., 2020)

Mild cognitive impairment (MCI) is a stage just prior to dementia known as a prodromal stage (Gauthier et al., 2006). In this stage, individuals are concerned about mild impairments in cognition that are supported by cognitive tests but are yet to experience any significant dysfunction in daily life from this impairment. This stage represents a unique target for treatment as individuals with MCI are indeed more vulnerable to transitioning to dementia at up to six times more likely to than their cognitively-intact counterparts

(Boyle et al., 2006). However, between 16-44% of individuals with MCI may also revert back to 'cognitively normal' within a year of diagnosis, indicating that the processes contributing to the progressive decline may be in some part reversible in the earliest of stages and also partly due to the sensitivity of testing (Gao et al., 2018; Koepsell & Monsell, 2012). In fact, there are many potentially reversible causes of cognitive impairment such as thyroid dysfunction, vitamin B12 deficiency, dehydration, and infection, to name a few, which if treated, often alleviate any cognitive symptoms and should also be monitored throughout dementia (Fleming et al., 1995).

At the time of dementia diagnosis, a tipping point has been reached whereby the burden of the underlying damage to the neurons in the brain causes significant impairments in everyday life which progressively get worse over time. People living with dementia typically have four other comorbidities on average, compared with those living without the disease. Common comorbidities include hypertension (53%), pain conditions (34%), depression (24%), diabetes, stroke and visual impairments (17-18%) (Bunn et al., 2016; Scrutton & Brancati, 2016). Furthermore, people living with dementia have an incidence of falls eight times greater than those who are cognitively intact (Allan et al., 2009), a two times greater risk of sustaining an injury from a fall (Jørgensen et al., 2015), are 15% more likely to be hospitalised due to that fall (Harvey et al., 2016), are 43% more likely to be admitted to hospital for any cause (Shepherd et al., 2019) and almost twice as likely to die during admission (Fogg et al., 2017). Additionally, the prevalence of frailty even in those with mild dementia is already as high as 37%, with Lewy body dementia (LBD) having the highest risk of frailty (Borda et al., 2019).

The life expectancy from diagnosis varies greatly and is influenced both by the type of dementia and a diverse array of risk factors accrued throughout life and during the disease process. Generally,

for the most common types of dementia there is a reported mean life expectancy of around 7-10 years from diagnosis, with an estimated transition to residential aged care for one-fifth of affected persons 2-3 years after diagnosis (Mjørud et al., 2020; Mueller et al. 2017). Established risk factors which predict a more rapid decline include being male, older at diagnosis, and having more functional impairments, comorbidities, Parkinsonism, multiple disease pathologies, high risk medications, malnutrition, frailty and sarcopenia, to name a few (Mueller et al., 2017). Similar to the risks factors for developing dementia, many of these risk factors are potentially modifiable through a combination of lifestyle changes, supportive care and early treatment and can improve and maintain quality of life and independence in dementia for a longer duration. However, our current understanding is that underlying disease process causing dementia continues mostly unaltered by treatments and eventually the person will die from complications in the end stages of disease, as dementia is a terminal diagnosis (Galimberti & Scarpini, 2011). Often this comes about through complications resulting from weakened input from the brain to organs such as the lungs, leading to pneumonia and infection (Degerskär & Englund, 2020).

## DIAGNOSIS

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Diagnosis of dementia is a clinical diagnosis, meaning that it cannot be diagnosed by a single test such as a scan or blood test. Instead, dementia is diagnosed by trained physicians, general practitioners and/or psychologists through thorough examination of the person and gathering a comprehensive history. The common diagnostic feature among all dementias is a progressive loss of cognitive function from previous levels which leads to a functional impairment in daily living (Reisberg, 2006).

Determining cognitive decline often relies on cognitive tests

completed in the clinic, as well as reports from the person or their caregiver (proxy/informant) of their previous level of cognition. Determining the level of functional impairment is also determined through questions asked to both person and informant. The pattern and history of cognitive impairment in conjunction with the presence of other motor (movement), psychiatric (mood) and autonomic (regulation) symptoms can help to further refine the type of dementia. Imaging, blood tests, biopsies, nerve conduction studies and genetic testing may also be performed depending on the circumstances to support diagnosis of a certain type of dementia, as well as rule out other potential reversible causes previously mentioned (Fleming et al., 1995; Reisberg, 2006). The clinical diagnosis is sufficient for the purposes of determining prognosis and initiating appropriate treatment. However, the qualifying terms 'probable' and 'possible' in research and some clinical settings placed in front of the diagnosis reflects the level of certainty the clinician has regarding the underlying disease process that is causing the dementia (McKeith et al., 2017). The pathological cause of the dementia is only able to be confirmed on autopsy (after death) by examining the pathology present within the brain, however the majority of individuals will never undergo this process.

Following diagnosis, the severity of dementia can be classified using a variety of tools and classification systems. Broadly, dementia is categorised into mild, moderate, severe, and end stage (van den Dungen et al., 2012). The stages typically reflect either the level of cognitive dysfunction on testing or the level of functional impairment in daily tasks, or a combination of both. The Clinical Dementia Rating (CDR) scale is a common tool used to classify dementia and is scored on a combination of cognitive and functional impairment in the domains of memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care (Morris, 1997). Diagnosing and staging

dementia can be challenging as the tool used can lack sensitivity (i.e. not pick up subtle changes), and reports of previous levels of cognition and function can often be missing or unreliable (De Lepeleire et al., 2004).

## PATHOPHYSIOLOGY & MORPHOLOGY

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The processes underlying dementia vary greatly, but ultimately at the neuronal level the pathology leads to cellular dysfunction and impaired metabolism, impaired communication between cells (known as synaptic transmission) and then eventually cell death (Cunningham et al., 2015). In some dementias, the abnormal accumulation of certain proteins within the cell body of the neuron, and/or the cells that support the neuron (glia) cause a cascade of dysfunction leading to cell death, wherein other dementias an error in producing a certain protein, viral damage to the cell, or damage to blood vessels supplying the neuron contribute. Not only can many of these processes occur simultaneously, but they can also alter the cellular environment within the brain, increasing local inflammation which in turn impairs cellular function, altering gene expression and the process of neurogenesis (creation of new neurons) (Cunningham et al., 2015).

In the most common type of dementia, Alzheimer's disease dementia, the main pathologies are the proteins amyloid beta and tau, which form plaques (known as amyloid plaques) and tangles (known as neurofibrillary tangles) inside the cells of the neuron and glia, respectively. However, there is also extensive cerebrovascular damage observed in Alzheimer's disease which can be similar to that noted in vascular dementia, whereby blood vessels become stiffer, lesions occur in blood supply at a micro level, and inflammatory markers are elevated within the brain (Santos et al., 2017). In addition, the Lewy body dementias involve clumps of alpha synuclein protein (known as Lewy bodies) inside the cell

that cause dysfunction and death and also often show signs of the Alzheimer's disease pathology and cerebrovascular pathology described above on autopsy (Mueller et al., 2017). Thus, the processes that lead to dementia are increasingly understood to be a complex combination of abnormal protein accumulation, vascular impairment, inflammation, gene regulation and impaired neurogenesis within the brain (Irwin et al., 2017).

To make matters more complicated, the amount of pathology present within the brain of an individual may not always correlate to the cognitive symptoms experienced or the severity of dementia while living (SantaCruz et al., 2011; Valenzuela & Sachdev, 2006). The cognitive reserve and grey matter (neuron cell bodies) volume of the individual may play a significant part in how the disease manifests (Arnold et al., 2013). For instance, there are associations between lower volumes of grey matter, higher levels of cerebrovascular damage and the severity of dementia (Stout et al., 1996). Additionally, certain regions of the brain are particularly vulnerable to insult or damage from underlying disease processes more so than others (Stout et al., 1996; Suzuki et al., 2019). Examples include small areas of the mid brain that contribute to fundamental cognitive processes such as the hippocampus (a hub for memory formation and retrieval) and basal ganglia (motivation, movement), as well as larger areas such as frontal lobe which is involved in decision making, attention and personality (Forrest et al., 2019; Mueller et al., 2017; Suzuki et al., 2019). The general pattern that is observed is atrophy (shrinkage) of these regions ascertained through imaging as well as on autopsy, which corresponds to the cluster of symptoms experienced by the individual.

In addition, a loss of neuronal mass, decreased metabolism and a decrease in the production of key neurotransmitters (chemicals involved in sending signals between neurons) in these regions lead to functional changes in how the neurons connect and



communicate with each other, as well as the blood supply to that area to supports this activity (known as hypoperfusion) (Chabran et al., 2020; Mueller et al., 2017; Schumacher et al., 2019). The ability of the brain to resist or adapt to the pathological damage of dementia is believed to reduce with disease progression as well as with normal ageing (Ebaid & Crewther, 2020; Kumar et al., 2017). Several theories attempt to explain the early adaptations of the brain in dementia, such as recruiting more diffuse networks of neurons to perform tasks, albeit less efficiently (Ebaid & Crewther, 2020). However early in the disease course, at the MCI or early dementia stage, non-pharmacological treatments such as exercise can positively alter the size and functional connectivity of key brain structures indicating that neuroplasticity is possible even amid a backdrop of degenerative disease (Ahlskog et al., 2011; Broadhouse et al., 2020; Herold et al., 2019). The extent to which the brain can resist the disease pathology varies and is still largely unknown. However, treatments can build resilience within these networks and in some cases restore, albeit temporarily, the imbalance of neurotransmitters within these damaged regions. The complex and multifaceted nature of dementia means that treatments are unlikely to work in isolation, and a combination of pharmacological and non-pharmacological treatment strategies are required.

## TREATMENT

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Treatments for disease generally fall into four categories: curative (complete reversal), disease-modifying (change the course of pathology), symptomatic management (treat the symptoms of the disease), and preventative (reduce the risk of disease occurring). Currently, there is no cure for dementia. Furthermore, the majority (99.6%) of medications trialled for the treatment of dementia through targeting the pathology have ultimately failed in human trials (Cummings et al., 2014). This may be due to a combination

of reasons including, but not limited to highly variable cohorts, targeting only one component of a complex disease, as well the possibility that starting treatments when someone has symptoms may be too late to significantly modify the underlying disease process. Up until very recently there have also been no disease-modifying treatments available that alter the progression of the underlying pathology. A recent medication approved for use in the US has been surrounded by controversy and shown relatively weak evidence that it modifies the disease course in individuals with dementia with more trials needed to explore this finding (Thomas et al., 2021). The majority of treatments for dementia are therefore either aimed at lowering the risk of developing dementia, or treating the variety of symptoms that are observed within dementia (Cunningham et al., 2015).

In regards to prevention, recent modelling in Australia suggests that reducing the yearly incidence of dementia by as little as 5% could lead to reductions in the estimated amount of people living with the disease in the next 35 years of up to 24% and save up to \$120.4 billion cost to the economy (Brown et al., 2017). This could be achieved through addressing the modifiable risk factors mentioned previously through changes in lifestyle and managing other chronic diseases effectively. However, for those living with dementia currently, symptomatic treatments are the only type of treatment accessible and can have significant impacts on quality of life and longevity, especially early in the disease course (Cunningham et al., 2015). A feature of the literature in non-pharmacological, and to a lesser extent, pharmacological treatments is that often the results are mixed in terms of effectiveness due to variation in how the treatment is applied and the diversity among people living with dementia in what is a complex disease. All treatments should be discussed with a doctor to develop a strategy appropriate for the unique circumstances of each person living with dementia.

## PHARMACOLOGICAL

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Currently, there are limited symptomatic treatments for dementia. The goal of treatment is to slow down the development of symptoms and preserve memory and function for as long as possible and reduce behavioural disturbances to delay transition into residential aged care. Medications are prescribed only when the potential benefits for the individual are perceived to outweigh the risks by the treating team.

Currently there are two main classes of medications used to improve cognition; acetylcholinesterase inhibitors (AChE) and NMDA receptor agonists (Cunningham et al., 2015). The former includes common medications such as rivastigmine, galantamine and donepezil, which work to slow down the breakdown of the neurotransmitter acetylcholine in the synapse (connection between neurons), which is depleted in dementia. The latter includes the medication memantine which works to antagonise (impair) the function of the NMDA receptor in the synapse and prevent a build-up of another neurotransmitter glutamate, which in excess is believed to contribute to toxicity and the dysfunction of neuron. The effects of these medications are generally positive, however results vary for each individual and by dementia subtype (Cunningham et al., 2015). A review and meta-analysis (combination of data) of available clinical literature indicates that AChE medications provide a modest, clinically significant improvement on common measures of cognition at least over a 12 month period, which translates to around a sustained one point increase on a common measure of cognition, the mini-mental state exam (MMSE) (Knight et al., 2018). For memantine, the treatment effects were smaller and more varied, with some experiencing larger gains and some no benefit at all (Knight et al., 2018). In addition, these effects are studied predominantly within Alzheimer's disease dementia, with the literature on the effects of

these medications on other types of dementia limited, of lower quality and mixed outcome (Cunningham et al., 2015).

In addition to the medications used to treat cognition, commonly medications are prescribed to help manage behavioural symptoms in dementia. Antidepressant medications such as selective serotonin reuptake inhibitors (SSRI's) including citalopram, sertraline, and atypical antidepressants such as mirtazapine are often prescribed within dementia to treat depression (Cunningham et al., 2015). A recent review found high quality evidence of little or no effect of these medications on depression scores in dementia over a few months compared to a placebo group, and moderate quality evidence that there was no long term benefit. However, those who experienced remission from depression (symptoms no longer present) were more likely to have been on medications when this occurred (Dudaset al., 2018). However, the effects between individuals can vary significantly and these medications may be beneficial for individuals after discussion with their physician. Other medications for behavioural disturbances in dementia include atypical antipsychotics or neuroleptics such as risperidone which are used for irritability and aggression, and benzodiazepines such as clonazepam used to relax and calm anxiety (Cunningham et al., 2015).

The use of neuroleptic medications in Alzheimer's disease dementia is associated with an increased risk of faster disease progression and earlier mortality, and its prescription in other forms of dementia such as Lewy body dementia is not recommended due to the high risk of adverse events (Mueller et al., 2017). Medications may also be used for specific types of dementia to treat symptoms or comorbidities associated with that condition. Dopaminergic medications which increase the level of dopamine, a neurotransmitter involved in motivation and movement, may be used in Lewy body dementia due to the presence of Parkinsonism, however is often discontinued due to its exacerbation of

hallucinations and delusions (Mueller et al., 2017). Antiplatelet medications may be used for vascular dementia to reduce the risk of further stroke and damage to the vessels within the brain. Melatonin, a natural occurring substance within the brain which promotes restfulness and sleep, may also be supplemented as a lower risk option to improve disrupted sleep cycles in those with dementia.

Lastly, but perhaps most importantly, an important pharmacological strategy in dementia is the deprescription (removal) of medications which may no longer be beneficial to the person with dementia, particularly if there are side effects which outweigh the benefits. Potentially inappropriate medications (PIMs) are common in adults with dementia, with 66% of those living in the community with dementia estimated to have at least one PIM (Bala et al., 2019), while over 80% of those in residential aged care meet this criteria (Eshetie et al., 2020). Additionally, those with dementia subtypes such as Lewy body dementia are 50% more likely to have PIMs than those with Alzheimer's disease dementia (Ramsey et al., 2018). The presence of PIMs is a risk factor for the development of frailty in those with dementia, as well as an increased risk of falls and mortality (Mueller et al., 2018). The current Australian guidelines recommend that to treat frailty the deprescription of hazardous medications where appropriate must occur in conjunction with robust exercise and dietary fortification (Dent et al., 2017). Specialist aged care physicians, called geriatricians, work with the treating team to minimise or substitute hazardous and ineffective medications where possible to improve outcomes for the person with dementia.

## NON-PHARMACOLOGICAL & SUPPORTIVE CARE

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In the recent decade there has been a renewed focus on non-pharmacological treatments for dementia due to consistently small

to moderate effects on cognition, behaviour and in particular functional independence relating to mobility, transferring and performing everyday activities of living (ADLs). Supportive care involves the use of technology, home modification and medical care to enable the individual to maintain independence for as long as possible and manage complications. Thus, the main goal of non-pharmacological treatments are to improve quality of life for the individual and enable 'ageing in place', which is not only a government policy but a best practice initiative to support the person living with dementia in their home and delay transition to residential aged care where possible. Ageing in place not only reduces the stress of transition for the person with dementia, but enables the existing network of support to remain in place, while being more cost effective for the family and government in the long run (Vreugdenhil, 2014). Additionally, compared to those who transition to residential aged care, outcomes relating to cognition, depression and incontinence are maintained for those ageing in place (Luker et al., 2019). However, the decision to remain in place or move to aged care is highly individual and must be weighed up by the person with dementia, their caregiver and the treating team.

The main, most accessible non-pharmacological treatment for dementia and the comorbid frailty that develops with the disease and accelerates decline in cognition and function independence is exercise. Robust exercise can not only improve cognition throughout the lifespan but can increase the volume of key structures within the brain such as the hippocampus and broader cortex, as well as functioning of neural pathways that are susceptible to the damage in dementia (Ahlskog et al., 2011; Broadhouse et al., 2020; Herold et al., 2019).

In the prodromal stage of dementia mild cognitive impairment (MCI), exercise programs that involve a component of progressive resistance training (PRT), a form of training which targets your strength, have small to moderate effects of cognition and are most

effective at treating frailty (Gates et al., 2013). In those with dementia, it is important to include aerobic training (exercises that raise heart rate), PRT, as well as balance exercise to be most effective in improving and optimising cognition, managing comorbidity, and delaying the onset of frailty (Dent et al., 2017; Northey et al., 2018).

To maximise the effect of exercise, programs need to be ongoing and of a moderate to high intensity (at least enough to make you puff or feel as though you're pushing a weight hard), while session length should be kept to under an hour in duration to avoid fatigue. Additionally, aerobic exercise especially those that are functional such as walking and/or require a cognitive challenge such as dancing, should be performed most days of the week. While PRT and balance should be performed at least 2–3 non-consecutive days per week. As dementia progresses and frailty develops in those who are at risk of becoming bed-bound, the importance of anabolic exercise modalities such as PRT and balance increases and it becomes vital that frequent, shorter bouts of walking or other aerobic exercise are performed throughout the day to avoid prolonged period of sedentary activity (Dent et al., 2017). It is well established that frailty has an effect on cognition in part separate to the underlying disease pathology (Buchman et al., 2014; Wallace et al., 2019). Thus, it is vital that exercise programs includes resistance training to provide the anabolic stimulus required to treat frailty, which is readily amenable to the robust exercise, dietary fortification and deprescribing of hazardous medications (Dent et al., 2017). Exercise should form an integral part of all treatment strategies for dementia and organising a consult with an Accredited Exercise Physiologist (AEP), who specialises in the prescription of effective exercise for chronic conditions is a good strategy to ensure you are getting the optimal benefits from exercise.

Additional non-pharmacological treatments such as cognitive training (CT), cognitive behavioural therapy (CBT), reminiscence

therapy (RT) and music therapy may also be helpful in the treatment of dementia. Cognitive training involving challenging tasks targeting areas of impairment may provide some small improvements in cognition for those with mild to moderate dementia, however the outcomes reported in the literature are mixed (Bahar-Fuchs et al., 2019). A practical application of cognitive training may be to learn a new skill which requires sustained attention and practice. A small base of literature has found a small but significant positive effects on cognition in those with mild dementia who take up a new, stimulating task and practice it weekly (Park et al., 2014). Cognitive behavioural therapy (CBT), which involves improving awareness about conditions and actions, may provide moderate benefits for reducing stress and anxiety in those with mild dementia. However, these benefits may be limited to those in the early disease stages (Tay et al., 2019). Reminiscence therapy, which involves sharing life experiences and memories, has been reported to have small effects on quality of life and cognition but it is unclear if these effects translate into noticeable changes in everyday life (Woods et al., 2018). Likewise, music therapy which involves the use of music to increase engagement in activities and mood, has small but significant effects on quality of life, and depressive symptoms but not on cognition (van der Steen et al., 2018). It is unclear what benefits remain beyond short term (less than a month) use.

For many of these non-pharmacological therapies for behaviour and quality of life, the effects will vary from individual to individual and are hard to capture in the research. Ultimately, if the intervention is enjoyable and can lead to a positive outcome for the person with dementia, albeit for a limited time, then these therapies should be considered.



## CONCLUSION

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Dementia is an umbrella term for a range of diseases that cause progressive cognitive decline and functional impairment. While not a normal part of ageing, the prevalence of dementia does increase with age, and with a general shift to an ageing population and longer lifespan, the number of people living with dementia is expected to rise steadily from 44 million globally to 115 million by 2050. The symptoms of dementia are diverse, extending beyond the stereotypical problems with memory to include psychiatric, autonomic, and even motor symptoms depending on the sub-type of dementia. Additionally, there is a high burden of comorbidities in dementia including the high prevalence of frailty that requires a targeted pharmacological and non-pharmacological treatment strategy individualised to the person. The core aim of treatment is to optimise quality of life and longevity in the disease course, minimise frailty, and delay transition to higher care for as long as possible with a focus on ageing in place.

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# *Lewy body dementia overview*

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## INTRODUCTION

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Lewy body dementia (LBD) is an aggressive and little-known type of dementia that is estimated to represent approximately 10-20% of all diagnosed dementia cases (Mueller et al., 2017). Like all other dementias, LBD involves a progressive decline in cognition leading to a functional impairment in daily activities. However, the defining features of LBD are the presence of a combination of core symptoms of Parkinsonism, fluctuating cognition, visual hallucinations, and sleep disturbance that affect the motor, psychiatric and autonomic system in addition to cognition (McKeith et al., 2017). There are not many known risk factors for the development of LBD, which develops sporadically, apart from older age, being male and some minor contributions from genes that increase the abnormal expression of proteins implicated in the disease process such as amyloid beta (amyloid plaques) and alpha-synuclein (Lewy bodies). However, the risk of adverse events and comorbidities in LBD when compared with Alzheimer's dementia are higher, including the risk of falls, frailty (Ahmed et al., 2008; Borda et al., 2019), polypharmacy, infection, behavioural disturbances, and malnutrition (Aarsland et al., 2001; Hasegawa

et al., 2013; Imamura et al., 2000; Peball et al., 2019; Roque et al., 2013; Soysal et al., 2019).

Research into effective treatments for LBD is relatively scarce and of low quality. For instance, medications approved for use in Alzheimer's disease dementia and Parkinson's disease are often less effective and carry a higher risk of adverse effects, while knowledge around the application of non-pharmacological treatments specific to LBD is lacking (Connors et al., 2018; M. Inskip et al., 2016). Additionally, many individuals with LBD are excluded from clinical trials in dementia and in Parkinson's disease due to the presence of both cognitive and motor symptoms, despite similar clinical presentations (Inskip et al., 2016). However, in recent decades since the publication of the 1996 LBD consensus guidelines and updates in 2005 and 2017, there has been an increased focus on research into the aetiology, diagnosis and treatment of people living with LBD (McKeith et al., 2017).

## TERMINOLOGY

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Lewy body dementia (LBD) is an umbrella term for the two presentations associated with this pathology; namely dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). These two presentations of LBD are distinguished by a clinical cut off known as the 'one year rule'; whereby dementia onset at the same time as Parkinsonism or within one year of symptoms is classified as DLB, and dementia onset greater than one year following a diagnosis of Parkinson's disease is classified as PDD (McKeith et al., 2017).

Both dementias as well as Parkinson's disease are caused by the same underlying disease; Lewy body disease, and all have similar symptoms. However the medical community remains divided on whether these two dementias are in fact two sides of the same coin or distinct entities that warrant different approaches (Postuma et

al., 2016). In practice, the treatment strategy for someone who has had Parkinson's disease for a decade and then develops dementia (PDD) can be substantially different to someone who develops dementia and Parkinsonism concurrently (DLB), even though they might converge in the later stages of the disease.

## ETIOLOGY & PROGNOSIS

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Lewy body dementia typically develops in the seventh decade of life and like all dementia the person may undergo a prodromal stage (mild cognitive impairment [MCI]) where symptoms appear but are not severe enough to impact daily activities. However, given it is substantially more difficult and time-intensive to diagnose LBD in clinical practice than Alzheimer's disease dementia, it is relatively rare for someone to receive a diagnosis of MCI of the LBD subtype. In the case of Parkinson's disease dementia (PDD), Parkinson's disease (PD) may be present for decades prior to a dementia diagnosis and increases the risk of developing dementia by 5-fold (Anang et al., 2014). Indeed, up to one-third of people with PD will converted to PDD over a 4-year period.

There has also been a focus in recent decades on the relationship between the presence of rapid eye movement sleep behaviour disorder (RBD), a sleep disorder involving the acting out of dreams during deep sleep, and the transition to dementia with Lewy bodies (DLB) later in life (McKeith et al., 2017). Both diseases are classified as synucleinopathies due to the involvement of abnormal clumps of alpha synuclein protein involved in the disease process. Those who develop RBD in mid to late life have an increased risk of being diagnosed with LBD. Longitudinal studies following people with RBD for more than a decade report that 90% will convert to a neurodegenerative disease, of which a quarter will be Lewy body dementia (Galbiati et al., 2019).

For people with either a DLB or PDD diagnosis, the average life

expectancy from diagnosis is estimated to be 3–8 years (Mueller et al., 2017). Known factors which accelerate the disease course in LBD include comorbid Alzheimer’s disease pathology, the presence of hallucinations and fluctuating cognition, gait abnormalities, decreased brain volume, and orthostatic hypotension (significant lowering of blood when standing up) (Mueller et al., 2017). The risk of adverse events in LBD is much higher than Alzheimer’s disease dementia as previously outlined and in addition up to 25% of those with LBD are likely to experience at least one episode of delirium, an acute cognitive and psychiatric disturbance that can worsen dementia if left untreated (Mueller et al., 2017). Furthermore, those with LBD enter residential aged care 0.5 to 1.8 years earlier on average than their counterparts with Alzheimer’s disease dementia, and the cost of care is 2-fold higher (Mueller et al., 2017).

## DIAGNOSIS

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Broadly, the classification of either PDD or DLB is defined by the ‘one-year rule’, however there are specific criteria which are used to diagnose each dementia. Testing for dementia will normally involve a thorough history given by the person or their caregiver/informant, cognitive testing, questionnaires relating to daily function, as well as additionally blood tests, imaging and other investigations to rule out potentially reversible causes or other conditions (de Lau et al., 2005).

The diagnosis of Parkinson’s disease dementia (PDD) is based upon the 2007 MDS criteria (Emre et al., 2007), and requires the presence of established Parkinson’s disease. Dementia is diagnosed when it is evident there are significant impairments in more than one cognitive domain that represent a decline from previous levels of cognition, and there exists an impairment in everyday activities as a result of this cognitive deficit (in contrast to the physical impairments of the PD).



The diagnosis of DLB is based upon the 2017 DLB Consortium criteria (McKeith et al., 2017). Consistent with all dementia, the essential criteria is that there must be a significant decline in cognition which leads to a functional impairment in everyday activities. Most often in both DLB and PDD, these cognitive deficits are observed in domains such as executive function (decision making), attention and concentration, and visual perception, with memory not necessarily impaired at diagnosis. In addition to this essential feature, diagnosis of DLB under most circumstances requires at least two core features to be present of the following: (1) Fluctuating cognition, especially in attention and alertness; (2) Recurrent and well-formed visual hallucinations; (3) REM Sleep Behaviour Disorder (RBD), and/or; (4) one or more features of Parkinsonism (i.e. rest tremor, bradykinesia or slowness of movement, or rigidity) (McKeith et al., 2017).

The diagnosis may be further reinforced by supportive features and biomarkers. Imaging can confirm low levels of dopamine in the basal ganglia region of the brain, or sleep studies can confirm the presence of RBD, to name a few. Additionally, a history of falling, anxiety, depression, delusions, orthostatic hypotension, and a sensitivity to antipsychotic medications are all supportive features of, but not crucial to the diagnosis.

## PATHOPHYSIOLOGY

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Lewy body dementia belongs to a group of pathologies called synucleinopathies, which describes a range of diseases caused by cellular dysfunction due to the accumulation of abnormal levels of alpha synuclein protein. A particular type of alpha synuclein protein accumulation called a Lewy body that forms in the cell body causing cellular dysfunction and eventually neuronal death, defines the disease called Lewy body disease. Lewy body disease is the main pathological process that underlies Parkinson's disease

(PD), Parkinson's disease dementia (PDD), and dementia with Lewy bodies (DLB).

Degeneration in key regions of the brain leads to a cluster of cognitive, psychiatric, motor and autonomic symptoms in LBD. Generally, for those who have PDD, Lewy bodies are first predominantly found in the brainstem and basal ganglia in the mid brain which control movement and autonomic processes, producing the symptoms consistent with Parkinson's disease . The spread of Lewy bodies and death of neurons connecting to, or situated within, higher cortical regions involved in cognition is often a sign of disease progression and the onset of dementia. For DLB, Lewy bodies are often diffusely spread throughout the brain which in part explains the close onset of cognitive and motor symptoms, and predicts a more aggressive disease course (McKeith et al., 2017). The advancements in imaging and pathological staging over the last decade has enabled further classification and understanding of disease progression and proposed new biomarkers for tracking cellular damage and inflammation (McKeith et al., 2017; Mueller et al., 2017)

## TREATMENTS

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Treatment for LBD is symptomatic, with no known disease-modifying or curative therapies currently available. The management of people with LBD is difficult due to the diverse and complex disease presentation, thus an individually tailored, multidisciplinary approach involving a combination of pharmacological and non-pharmacological treatment strategies is required.

## PHARMACOLOGICAL TREATMENTS

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Pharmacological treatments used in Alzheimer's disease for

cognition such as acetylcholinesterase inhibitors (AChIs) also show promise in LBD for improving global cognition and activities of daily living, while potentially slowing cognitive deterioration early in the disease course. The use of medications with anticholinergic properties (i.e. those that reduce acetylcholine, a neurotransmitter involved in normal cognitive processes) such as some antipsychotic, bladder incontinence or respiratory function medications may further impair cognition. Additionally, the use of antipsychotic medications to manage psychosis in LBD is generally not recommended unless there is clear benefit, as there is an increased risk of worsening of motor symptoms as well as a higher risk of having an adverse reaction and developing as potentially life-threatening syndrome known as neuroleptic malignancy syndrome (Taylor et al., 2020).

Conversely, dopaminergic medications (i.e. involved in improving dopamine signalling for movement symptoms) commonly used in Parkinson's disease can exacerbate symptoms of psychosis such as hallucinations, agitation and delusions and may have to be titrated, substituted or discontinued by the treating physician depending on the severity of side effects. There is also a high prevalence of polypharmacy (>5 medications prescribed) and adverse effects in LBD with an average of eight medications prescribed five years after diagnosis (Borda et al., 2019). Often, additional medications needed for symptoms of constipation, urinary dysfunction, sleep disturbances, anxiety, and depression may add to overall pharmacological burden. The combination of medications used to treat the diverse spectrum of symptoms in LBD can often cause unwanted side effects and reduce the effectiveness of each, requiring a careful and considered approach by the physician to manage the most debilitating symptoms first and foremost (Taylor et al., 2020). See this [fact sheet](#) for more information.

## NON-PHARMACOLOGICAL TREATMENTS

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There is little known about the effects of non-pharmacological treatments used specifically for LBD. Several reviews of the literature have concluded that more research needs to be done specifically within this cohort (Connors et al., 2018; Inskip et al., 2016). Currently, many of the treatments used within LBD have been effective in similar cohorts such as those with PD or other types of dementia and adapted to this condition.

Very limited evidence in a small number of case studies and pilot trials suggests electroconvulsive therapy (target application of electric pulses to areas of the brain) may improve symptoms of depression, anxiety and hallucinations. Similarly, a few case reports on deep brain stimulation (implanting a device to stimulate a specific region of the brain) document mild improvement in cognition and motor symptoms, however patients still declined with disease progression (Connors et al., 2018).

Exercise has promising effects for both PD and broadly in dementia, and yet is still widely under-evaluated in this cohort. Recently, the first pilot trial of exercise specifically in a Lewy body dementia cohort was conducted in Australia in a small group of nine individuals with varying disease severity (Inskip et al., 2019). Improvements were reported in strength, physical function, functional independence, frailty, mood, and cognition after a short eight week robust exercise intervention involving high intensity progressive resistance training, challenging balance exercises involving cognitive tasks, and training of functional tasks needed for daily living such as standing from a chair and transferring (Inskip, 2020). More details for exercise can be found [here](#). Exercise of this type and intensity is likely the optimal for addressing the movement symptoms and high prevalence of frailty and falls risk noted in those with LBD. Research into exercise for LBD is in its infancy but moving in a promising direction. Larger and

higher quality trials evaluating exercise for longer periods of time are needed to capture the effect of exercise against a backdrop of a rapidly progressing disease with frequent fluctuations in condition.

## CONCLUSIONS

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Lewy body dementia, consisting of PDD and LBD, is a little-known, fast progressing dementia that contributes to 10-20% of all dementia cases and has a higher prevalence of adverse events and conditions such as falls, frailty, depression and earlier entry into residential aged care. A relatively smaller prevalence compared to other dementias, shorter disease course, and a diverse spectrum of impairments affecting cognition, movement, mood and autonomic regulation makes the development and evaluation of treatments in LBD difficult. However, in recent decades LBD has increasingly been the focus of research into the etiology, pathophysiology, diagnosis and effective treatment which has led to comprehensive guidelines and a greater understanding of the condition, as well as a better quality of life for those living with LBD.

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# *The social context of dementia*

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## INTRODUCTION

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The increasing prevalence of dementia around the globe mandates that healthcare workers have a solid understanding of the complexities of dementia care, particularly in a practical context. Contemporary healthcare is person-centred, with the recipients of care and their support network at the centre of care planning and health management. Therefore, lived experiences and personal narratives are rich sources of knowledge that can inform how health professionals approach their work.

Ed's Story is one of those lived experience narratives – it is Ed's journal that describes his world as he cares for Mary, diagnosed with Lewy body dementia. This chronicle brings a sense of reality to discussions about care provision for dementia sufferers and provides valuable insight into the world that carers are thrust into upon diagnosis.

Further, Ed's Story provides a foundation for better understanding the world of a carer and how service provision impacts on the health outcomes for the patient and those around them (Nicholson, 2009). This ebook is designed to provide learning

experiences for health science students that they can draw on as foundation knowledge for practice. Ed and Mary's story is suited to enhancing the understanding of formal and informal carers, educators, policy makers and anyone who has an interest in dementia care. This section presents current evidence to promote discussion about health as a social construct and thereby the social impact of dementia diagnosis.

## DEMENTIA – AND WHY IT IS IMPORTANT NOW

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Dementia is recognised as a global challenge with over 7 million new diagnoses annually worldwide (Svendsboe et al., 2016), and is one of the Australian government's identified health priority areas (Australian Institute of Health and Welfare [AIHW], 2012). This means that considerable resources for disease management, service provision and education have received federal funding to improve the quality-of-life outcomes and thereby the cost of dementia as a burden of disease.

## BACKGROUND

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As dementia typically affects older adults, the concept of caring for dementia sufferers in the community is related to two key features of the current global and Australian population: an ageing population and an increase in the number of diagnosed cases of dementia. An ageing population is reflective of good standards of care across the lifespan. That is, to reach old age is an indicator of how healthy a person has been throughout their life. There are, however, physiological changes that occur as a person ages. These are normal changes of ageing that predispose older adults to chronic illnesses that can challenge their health and wellbeing. For these reasons, older adults comprise a large portion of the consumers of healthcare. Other risk factors of chronic disease for older adults include demography, behaviour, biomedical factors,

genetics, environment, social or comorbidity factors (Bramble, 2014).

In Australia, ageing in the Aboriginal and Torres Strait Islander peoples must be given special consideration, particularly in the context of the 'Closing the Gap' initiative. Currently, the life expectancy of Aboriginal and Torres Strait Islander people is around 17 years less than the non-Indigenous population in Australia and the Closing the Gap initiative aims to reduce the gap in life expectancy. The social determinants of health impact significantly on the quality of life for our Indigenous people and are a key factor for poorer health outcomes and chronic disease rates for this population group. For example, Aboriginal and Torres Strait Islander people have higher rates of diabetes, hypertension, cardiovascular disease, and chronic renal disease than the non-Indigenous population (AIHW, 2015). Dementia incidence for Aboriginal and Torres Strait Islander people is also believed to be higher than the national average (Qin Li et al., 2014), despite suspected low diagnosis and reporting rates. Further, the age of onset of dementia in Aboriginal and Torres Strait Islander people is lower. Figures from the AIHW (2105) reporting on Indigenous people in residential aged care facilities show:

- 51% of Indigenous residents had a diagnosis of dementia (similar to the 52% of non-Indigenous residents)
- 26% of Indigenous residents aged 55 years and under had dementia
- 61% of Indigenous residents aged 75 years and over had dementia (AIHW, 2015, p. 123).

Recognition of the health disparities for Aboriginal and Torres Strait Islander people requires health professionals to consider culture as a measure of ageing. That is, ageing is more than chronological ageing. Rather, ageing is a multidimensional concept.

An holistic approach to the concept of ageing underpins the principles and frameworks for care of older adults. Consideration is given to the influences on how people age such as chronology (years), biology, physiology, biomedicine, psychology, social and cultural values and beliefs, and economic and spiritual influences. For this reason, among others, it is important that all health professionals consider ageing as a multidimensional concept as well as considering individual persons.

This is not, as warned by Duckett (2016), evidence of support for the “apocalyptic argument” (p. 212), the “silver tsunami” or subscribing to the concept of “voodoo demographics” (p. 212). However, it is important to consider the entry of the baby boomers into the realms of older adulthood that began in 2011. Baby boomers are those born between 1946 and 1964 and represent the biggest single increase into older adult numbers ever. As well as the increase in numbers of people requiring access to services due to age related health changes, there are features of the baby boomer cohort that will influence or frame how care is provided. Baby boomers are expected to have higher expectations than previous generations, based on a greater proportion of the cohort having previously higher incomes, higher education levels and higher paying and influential employment prior to retirement (Bramble, 2014). Therefore, recognition of all the factors that influence care provision and health outcomes is imperative to understanding the world view of the older adults and their carers.

Healthcare is one of the largest expenditures for any government, and as the population ages, with the associated increase risks of chronic disease and co-morbidities, it is expected that there is an associated increase in the cost of healthcare provision. For this reason, governments and policy makers around the world have prioritised healthy ageing and aged care service provision, promoting an ageing in place philosophy (Brown & Bond, 2016). The dementia statistics over recent years highlight why dementia

care should be prioritised, whether from a social, health or economic perspective.

Dementia is recognised as a global challenge with over 7 million new diagnoses annually worldwide (Svendsboe et al., 2016), and the increase in numbers of Australians diagnosed with dementia is consistent with the global data. For example, in the Australian context, dementia was the second leading cause of death in 2015. Alongside that, government expenditure linked to dementia care in Australia was approximately \$428 million in 2015-16 (AIHW, 2020). Further, the increasing numbers and the potential economic impact of those numbers means that dementia as an area of health is working its way closer to the top of the Australian government's health priority areas. This means that considerable resources for disease management, service provision and education will be supported by federal funding in order to improve the quality-of-life outcomes and thereby reduce the cost of dementia as a burden of disease.

Burden of disease is a phrase commonly used to describe the impact any particular disease may have on the broader population. From a burden of disease perspective, dementia remains in the top four causes. According to the AIHW (2015; 2020), the disease incidence of dementia is expected to increase threefold in the coming decades to around 900,000 in 2050. These predictions mandate that serious consideration is given now to models of care and strategies for service provision that promote quality of life for our communities.

The following table (Table 1) shows the actual, estimated and predicted number of dementia cases in Australia, across several decades (AIHW, 2016; AIHW, 2020). These numbers are presented cautiously, as it is the philosophical stance of the Ed's Story team that care should be individualised, and we recognise that each one of the numbers referred to below is a member of our community.

Each number (person) is part of an intricate family and social network, so that for each 'one' diagnosed, the ripples of impact extend to many others.

**Table 1**

*Dementia diagnoses by number in Australia*

Year	Number of people diagnosed with dementia
2015	342,800 (actual)
2020	400,000 -459000 (estimated)
2030	>550,000 (predicted)
2050	900,000 (predicted)

*Note.* Source: (AIHW, 2016; AIHW 2020).

Statistically, dementia affects around one in ten people over the age of 65, and three in ten over the age of 85 (AIHW, 2015). These statistics are evidence of the prevalence of dementia diagnoses in our communities, and when they are considered in the context of at least one in ten families/friendship groups affected by a dementia diagnosis, the importance of quality, appropriate and relevant health care is apparent.

While statistics for dementia are grouped together, current research such as that by Svendsboe et al., (2016) shows that there are notable differences into the effects on caregivers between different types of dementia (Nicholson, 2009). For example, these authors found that caregivers for people with Lewy body dementia report different types and manifestations of stress than caregivers for people with Alzheimer's dementia.

## WHERE ARE THEY?

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Currently 50% of residents in residential aged care facilities have dementia and one in three people with severe dementia live in the community. Dementia sufferers living in the community require round the clock care. These figures, combined with the incidence statistics, highlight how dementia impacts on our communities.

Accordingly, the provision of care must recognise the needs of the person, their family, and the community, adding value to the need for healthcare workers in all disciplines to have a solid understanding of dementia care and their role in the healthcare team. The cost of long term service provision, including workforce implications, has resulted in initiatives to promote dementia sufferers staying at home, with appropriate support, for as long as possible. Recently, the Australian government has implemented numerous packages that dementia sufferers can access to remain living at home.

## MODELS OF CARE

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There are numerous models of care implemented around the world that reflect current best practice with the aim of providing the best possible care and optimising quality of life for the person diagnosed with dementia and their family.

### *CAPABILITIES MODEL OF DEMENTIA CARE*

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Models of care vary between organisations and locations. Moyle's Capabilities Model of Dementia Care (CMDC) (Bramble, 2014) is one model of care that frames dementia care provision, particularly in relation to residential aged care provision. These same principles can be applied to dementia care in acute healthcare facilities and community setting. Key to the CMDC are 10 capabilities that are



considered “fundamental opportunities” (Bramble, 2014, p. 39). These 10 capabilities are:

1. Feel valued
2. Experience the best health possible
3. Live independently with compassionate support from important others
4. Enjoy pleasurable experiences through senses, imagination and thought
5. Experience and express emotion in a way that is true to oneself
6. Reflect and decide on things that matter to oneself including plans for the future and end of life
7. Experience connection with others where they can contribute and be contributed to and where there is self-respect, dignity and a sense of shared humanity with individuals and the wider community
8. Live in a way where engaging with nature (plants, animals, sun, moon) is a natural part of life
9. Play in a way that is meaningful and fun
10. Experience a sense of control in how to live their life

(Bramble, 2014, pp. 39-40)

### *COMMUNITY CARE PACKAGES*

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In recent decades, there has been a strategic move to shift long term care for dementia sufferers to the community, away from residential care. Changes to community service provision are ongoing, with funding frameworks evolving to suit consumer demand. Before 2015, eligible recipients of care packages were

entitled to a range of services provided within a rigid framework. In 2015, the way in which funding is provided for community care was amended to give the patient, and their support networks the ability to build a care package that is individualised and tailored to suit their needs. This frames what the government has termed 'consumer directed care'. Consumer directed care places the patient and their carers at the centre of care planning, as is consistent with the person-centred philosophy of contemporary healthcare.

### AUSTRALIAN LEGISLATION

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There are legislated guidelines for the provision of aged care in Australia within which services are provided. The legal parameters are defined by the *Aged Care Act*, the *Aged Care (Transitional Provisions) Act 1997*, the *Aged Care (Accommodation Payment Security) Act 2006*, and the *Aged Care (Accommodation Payment Security) Levy Act 2006*. These Acts are supported by several legislative instruments made under the *Aged Care Act* and the *Transitional Provisions Act*. In addition the *Australian Aged Care Quality Agency Act 2013* sets out the functions of the Australian Aged Care Quality Agency.

The objectives outlined in the *Aged Care Act* are:

- promoting high quality care and accommodation,
- protecting the health and wellbeing of care recipients,
- helping recipients of aged care enjoy the same rights as all other people in Australia,
- ensuring that aged care is accessible and affordable for people who require it,
- planning effectively for the delivery of aged care services,
- ensuring that aged care services and funding are targeted

- towards people and areas with the greatest need,
- encouraging services that are diverse, flexible and responsive to individual needs,
  - providing funding that takes account of the quality, type and level of care,
  - providing respite for families and others who care for older people, and
  - promoting 'ageing in place' – that is, helping older people stay where they want to live, by linking care and support services.

Within the current legislation, the government is committed to: providing financial support in the form of subsidies and grants; overseeing the approval of payments to providers; regulating fees; and ensuring providers fulfil their responsibilities within the Act.

Current and potential recipients of aged care services in Australia can build an individualised Aged Care Package via the '[My Aged Care](#)' website, with further information for [carers](#) available too. The opportunity to build a personalised aged care package is a reasonably new initiative, in response to demand from both consumers and care providers. However, consider for a moment, the age group most likely to require these services. While many older adults work well on electronic media, there is a proportion of this age group who are not familiar with online activities. There are options for those who do not have, or are unfamiliar with, the internet, but these options are not actively encouraged. Thus, there is the potential for the older adults who are not familiar with working online to face barriers, or even exclusion, to accessing services.

Providing care for dementia sufferers in the community is more than the aged care packages outlined above. It relies heavily on informal carers who are family or friends who provide care and

support for loved ones. The role of carers is far more complex than it initially appears. In addition to learning about the disease processes, and navigating a complex health system, there are considerable personal changes they undergo. There are relationship and role changes within the relationship with the person with dementia, with subsequent changes in family dynamics and family relationships.

## THE AUSTRALIAN EXPERIENCE

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It would be remiss, in 2021, to present any discussion about dementia care without referring to the recently concluded Royal Commission into Aged Care Quality and Safety. The scope of this Royal Commission was beyond dementia care, exploring all the current issues in aged care in Australia. However, as a significant number of older people living in the community and residential aged care facilities do have a dementia diagnosis, it is essential that the Commission's findings are considered in this context. The previous section discusses the ways in which aged care in Australia is provided and creates the context in which the Commission conducted its business.

There are many profound insights presented in the Royal Commission into Aged Care Quality and Safety's Final Report (Commonwealth of Australia, 2021), some of which are not surprising to anyone who has lived or worked with older adults in need of care. There are also some criticisms of the extent to which the Commission delved into many of the 'wicked problems' inherent in aged care provision. What is apparent is that this very complex system does have weaknesses and does not meet the needs of some of the people who require it. Regardless of the limitations of the Royal Commission and the changes that may come from it; it is a start. There is a distinct shift in how aged care is viewed and at the very least, the Royal Commission has indicated

that the way forward in the title of the final report, Care, Dignity and Respect, which says:

Over the course of our inquiry, we have identified clear common themes in what the community expects from the aged care system: dignity and respect, control and choice, the importance of relationships and connections to communities, and the desire for a good quality of life and ageing at home (Commonwealth of Australia, 2021, p.78).

In relation to Ed and Mary's Story, section 1.3.5 of the final report volume 1 (Commonwealth of Australia, 2021, pp. 101-104), addresses some of the challenges Ed faced. This section, *Giving thanks and giving back: Support for informal carers and volunteers*, recognises the hidden work of informal carers in the community. It further recognises that support for informal carers is lacking in the current system(s). The Commissioners suggest that a preventative approach to carer support is adopted; in which carers are provided with improved access to services and supports as well as opportunities to gain the skills necessary to fulfil the role. There are three main challenges for carers identified by the Commissioners: formal links between carers and services; assessment processes; and the fragmented system they are required to work within and around.

Having identified the challenges outlined above, the Commissioners propose changes to the current systems that allow for linkages between systems so that informal carers do not need to access multiple sites to access appropriate supports and services. Of note, is that the Commissioners identified that the lives of carers themselves may be impacted and their ability to undertake paid employment is inevitably hindered. The suggestion in this document is that employee entitlements, similar to that of parental leave, be considered and that this is done sooner rather than later, given the growing demand on aged care services and the associated increase in informal carers.

As always, outcomes of the Royal Commission are findings and recommendations, and it is up to national decision makers to accept and implement, or not. Many older adults requiring care, and their families and support networks, report struggling to have a voice and feeling invisible in the system. The Royal Commission has, at the very least, offered the opportunity to be seen and heard in the process of moving aged care into the future.

## CARERS – THE INFORMAL WORKFORCE

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A carer is a family, friend, or community member, usually known to the person, who provides some form of supportive care that enables the person to remain in their own home. Informal carers are not usually paid for their services and in many cases do not have a professional background in healthcare. There are also cultural implications for informal carers. In some cultures, caring for older adults across generations is expected and accepted as a normal family function. In other cultures, it is not as accepted as part of family responsibilities. These factors must be taken into consideration when discussing the role of carers and their experiences, particularly when planning care as part of a healthcare team.

Caregiver strain or burden has been contextualised in several ways, but, according to Leggett et al., (2011), can generally fit in the dimensions of role strain and personal strain, although their research showed a third category of worry about performance. Caregivers report that dealing with behavioural changes and emotional challenges are two of the most stressful factors in caring for someone with dementia, particularly Lewy body dementia (Leggett et al., 2011). These authors also found that being an older caregiver was generally linked to increased role strain while being a younger caregiver was linked to worry about performance. This is interesting because in many cases, the spouse is the primary carer

for someone with Lewy body dementia. Therefore, it is important to be cognisant of the carer's predisposition to feeling the pressures of role strain. Adult child caregivers also report higher levels of carer distress, which is important to consider when reading Ed's Story, as his daughter Maree became Mary's fulltime carer for several years. Although Maree coped quite well, when you read her poem about caring for her mother, the pressures she felt are apparent.

The physical, psychological and emotional pressures faced by informal carers can manifest in different ways. For example, approximately 1 in 3 informal carers reported fatigue related symptoms and 1 in 3 reported feeling worried/depressed as demonstrated in the following tables.

**Table 2**

*The adverse effects of caring*

	<b>Primary carers of people with dementia</b>	<b>All primary carers</b>
Feel weary or lack of energy	34.3	32.9
Frequently feel worried or depressed	33.2	30.1
Diagnosed with stress-related illness	10.3	11.3
Frequently feel angry or resentful	14.7	12.1
Not stated	7.9	10.0
One or more of the above adverse effects	57.2	48.2

*Note.* Source: (AIHW, 2012, p. 131).

Table 2 clearly illustrates that at least half of all primary carers of people with dementia report some adverse effects. In some areas, primary carers of people with dementia report more adverse effects than primary carers in general. It is unstated, but may be reasonable to assume, that the adverse effects described in Table

2 may well be manifestations of role strain or personal strain. Further, the worry reported by carers may include some worry about performance as described by Leggett et al. (2011).

**Table 3**

*Carer's sleep disturbances*

<b>Sleep disturbance due to caring role</b>	<b>Primary carers of people with dementia</b>	<b>All primary carers</b>
Sleep interrupted frequently	34.0	24.2
Sleep interrupted occasionally	32.4	24.4
Sleep not interrupted	26.6	42.0
Other	7.0	9.4

*Note.* Source: (AIHW, 2012, p. 131).

Table 3 shows that carers for people with dementia report greater disturbance to sleep patterns. This information, taken in context, provides insight into the strain of care giving on the carer. Lack of sleep can, in turn, predispose the carer to mental and physical fatigue and even exacerbation of their own health challenges. Lack of sleep can also affect their emotional state and mood which has the potential to translate into anger and frustration with the person for whom they are providing care. While this may not place the recipient of care at increased risk of abuse or neglect, it may well change the dynamics of the relationship between family members and/or friends, fracturing the very important support network for both the person with dementia and their carer.

**Table 4**

*Carer's self-reported satisfaction with the caring role*



<b>Satisfied due to caring role</b>	<b>Primary carers of people with dementia</b>	<b>All primary carers</b>
Feels satisfied	18.7	20.9
Does not feel satisfied	73.4	69.1

*Note.* Source: (AIHW, 2012, p. 131).

The combined data in Tables 2 to 4 highlight the effect of care giving on the carer under the broad umbrella term of dementia. However, as previously stated, the specific symptoms of Lewy body dementia have been identified as most likely to trigger caregiver burden (Nicholson, 2009).

The statistics in the above tables show the impact that informal caring can have on anyone, regardless of age, health status and background (Brown & Bond, 2016). However, consider for a moment that frequently informal carers for older adults with dementia are their spouses. That is, they too are older adults, in many cases with their own health concerns. As previously pointed out, lack of sleep and stress can exacerbate underlying medical conditions. When added to the normal physiological changes of ageing which can alter physical and mental endurance, the possible implications are concerning.

The take home message from this section is that as healthcare professionals and policy makers, we need to remain mindful of whom is shouldering the responsibility for day-to-day care of people with dementia in the community. That is, consider what we are asking and of whom. Informal care provision relies on emotional ties and a sense of obligation and commitment that should not be undervalued. Despite the best of intentions in the long run it may have a profound detrimental effect on the health and wellbeing of more than one older adult, and thereby create another level of complexity to the existing challenges of an ageing population in the community.

## WORKFORCE IMPLICATIONS

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The previous discussion highlighted the impact of informal caring on the caregivers. There are also significant workforce implications associated with decision making about informal caregivers. There are effects on the health workforce and the roles they play as well as the effect on the workforce in general when members of the workforce provide care for a community member or loved one outside their paid duties.

The role of informal caregivers influences decision making and policy development about care provision which in turn decides formal workforce planning for dementia care. For example, if an informal caregiver is providing much of the day-to-day care, the frequency of visits from healthcare professionals, in particular, nurses, is reduced. The carer often attends to the daily tasks of personal hygiene and meals and the nurse attends to wound care and medications. This means that more visits to more people may be allocated to each nurse and the workload is distributed accordingly.

There are predicted health discipline workforce shortfalls over the coming decades that add further urgency and importance to the provision of care in the community for dementia sufferers. The ageing population and the predicted increase in dementia diagnosis combined with the predicted workforce shortfalls and the burgeoning costs of health care mean that alternative ways of providing care, including the use of informal carers must be considered. Notably, the presence of informal carers and the role they play is recognised in current policy and, it appears, that by promoting ageing at home, that role will become even more significant. Therefore, it is also imperative that the role of carers, often older adults with complex comorbidities themselves, is considered and incorporated into health care planning. It is also important that health professionals in all areas, at all levels, include

informal carers as part of holistic health assessment and care planning.

AIHW (2012) estimates that in 2011, there were approximately 200,000 informal carers in the community. These figures consider informal carers to be someone who lives with the person with dementia are most likely to provide >40hours of care per week.

While the strain of caregiving is well documented, particularly in the context of caregiver burden, there is also some evidence about what happens to the caregiver after their caring role is finished. When the person for whom they have been providing care dies or is moved to residential care, what effects stay with the carer and how long term are these effects? Brown and Bond (2016) report that there is very little difference in the effects on the caregiver in relation to the cause of separation. That is, whether the caregiver role finishes due to death or permanent relocation to residential aged care facility, the effects on the caregiver are similar. However, it is also prudent to remember that even in the best of circumstances the carer will have aged since they began their caring role. Thus, in addition to their altered physical capacity brought on by the caring role, the normal physiological changes of ageing may be more apparent. Research conducted by McConaghy and Caltabiano (2005) supported the body of evidence but added new knowledge that depression did not contribute to the carers' perception of wellbeing.

In conclusion, the experiences of our older adults with dementia and the people who care for them are entrenched in current and future dementia care planning at all levels. The complexities presented, briefly, herein are not comprehensive and only touch the surface of the ripple effect of caring for someone with dementia at home or in the community. There is no doubt that dementia changes lives, shifts responsibilities and permanently alters relationships. There is also no doubt that the people with dementia

and those who love them, would have it any other way. They just need the appropriate support and suitably qualified people to guide them on the journey. Ed and Mary's story shows the tension points where systems and people collide; it shows the warmth and the joy; it shows people at their best and their worst. Most of all, it shows the truth, and as Ed and Mary intended, provides some insight for those on their own journey.

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# Journal excerpt and associated resources for learning and teaching

## JOURNAL EXCERPT 1.1

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*Mary was on reception at the hospital when I went for treatment. I liked her immediately and eventually she agreed to go out. We courted, became close and I asked her to marry me. She said, "Speak to my father". I did. He grinned and said, "Ask her mother". We married, honeymooned in the mountains, and settled in the city until I finished my studies. We were very happy and so much in love. We asked ourselves, do good times like this last forever? Later she felt ill and consulted her doctor who told her she had miscarried. I was dismayed – would we ever have a family? Cheerfully she replied, "Of course, we will! Don't worry – everything will be OK". And so it proved to be. We reared four healthy children and enjoyed the journey. As the children matured, she build [sic] a career and travelled within Australia and overseas both professionally and socially. She led an active and rewarding lifestyle. We both looked forward to a satisfying retirement.*

### 1.1 Points to consider

- How does a person's life experiences and history affect their response to diagnosis with chronic or terminal disease?
- How may a diagnosis of chronic or terminal disease affect the relationships the person has with family and loved ones?

### JOURNAL EXCERPT 1.2

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*She drove to the medical centre for a routine visit. Her doctor, noticing she was disoriented, suggested further tests. Eventually, she was diagnosed with Lewy Body Dementia.*

*Our lives were to change dramatically. She was gradually to lose her cherished independence – could no longer drive, required assistance with personal care and other activities at home and in public. Luckily, she retains her cheerful nature, wry sense of humour and full recognition of people and places.*

*Upon becoming a carer, major changes took place in my lifestyle. –I'm not resentful – not much anyway – because I believed I owed much to Mary – a loving wife and devoted mother to our children for over 50 years. I wanted to repay her for her kindness and provide care to help soften the problems arising from her dementia.*

*Dementia has been described as a 'long goodbye'. Tonight we will be close. We'll talk, recall past experiences, sleep and dream. Tomorrow*

*we'll wake together to another beautiful day. We are so fortunate. We know now that good times do last forever.*

### 1.2 Points to consider

- What type of psychosocial effects might a terminal diagnosis have on the patient?
  - their immediate family?
- As an older patient/couple, how might Ed and Mary's experience differ from a younger patient/couple?

### 1.2 Suggested activities

- Use a **jigsaw classroom** to explore:
  - Psychosocial effects of a terminal diagnosis across the lifespan
  - Dementia types
- Introduce concept of 'reminiscence tools'
- Relate theories of grief and loss to the lived experience for



patient and carers. In particular, consider the process of reconciling old expectations with new ones as limited by the diagnosis.

- Consider how your values, religious or cultural beliefs frame your understanding of death and dying, and how this may influence your response in a situation like Ed and Mary's.
- In particular, consider the concept of 'obligation' and what it means to you. How may this be different to someone from a different background/culture/religion/social group to you? How does this change depending upon the role a person has within the family/group?
- How can life history be used positively?
- In what ways can family and friends gather memories with the person diagnosed with dementia?

### JOURNAL EXCERPT 1.3

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**Friday, 7 November 2008**

*Mary having a lot of delusions:*

*Wants to go home.*

*"Lewy's" men (up to three in room) and watching her.*

*Asks at bed-time "Which bed is she going to sleep in tonight?" Pictures still being shifted about (by "Lewy")*

## **7 February 2009**

*Mary 'sat down' on way to shower. Going to use shower chair with wheels in future. Mary, Jess and I went to lake for walk and lunch.*

### **1.3 Points to consider**

- What behavioural management strategies and tools can be employed to support the patient?
- How can trust in service/s be engendered?

### **1.3 Suggested activity**

#### **Debate:**

- Natural therapies
- Pharmacological management vs. behavioural management

## **JOURNAL EXCERPT 1.4**

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## **8 February 2009**

*Using shower chair. Seems successful.*

**10 February 2009**

*Mary has reached 'new' stage in her decline.*

**26 February 2009**

*Mary very tired. Quieter and reflective. Appears to be 'depressed'. Having more difficulty in speaking. Getting hard to understand. Mobility not good.*

**1.4 Points to consider**

- Reflecting on the nurse's attitudes and behaviour in response to change in the person being cared for what is the nurse's role in fostering behavioural, emotional and environmental safety
- How might you approach someone to help with ALs?

**JOURNAL EXCERPT 1.5**

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**Thursday, 12 March 2009**

*Collected (urine) specimen and tested at Doctor's surgery. Positive – put her on antibiotics for 7 days.*

**Monday, 16 March 2009**

*New behaviour: Hallucinations all night and early morning. Up six times. Incoherent most of the time. Aggressive.*

**17 March 2009**

*Mary hallucinating again all night. One episode involved a snake and Mary inflicted a tear on her lower arm. Dressed in a waterproof cover.*

*Mary [sic] hallucinations cover a wide field of imagination. Having great difficulty in swallowing tablets. Taking liquids OK.*

### **1.5 Points to consider**

Medication:

- How is it best administered?
- Is it appropriate for late stage care?

### **1.5 Suggested Activities:**

With changed behaviour, consider:

- Positive behaviour management
  - communication tools
  - safety
- Swallow assessment.

## JOURNAL EXCERPT 1.6:

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### **Tuesday, 28 April 2009**

*Agreed: Anti-biotics cease. Not having any effect and continuation could cause side effects and diarrhoea.*

*Discontinuing feeding by cannula, except potassium. Feed subcutaneously into muscle in mid-body. Continue oxygen but finish feeding in 1 to 2 days.*

*Mary not alert enough to feed by mouth. Monitor, and if Mary becomes more alert, feed by mouth. Move to single room. Unlikely Mary will leave hospital. End will come any time from days to weeks. Mary alert this evening – strong grip; trying to speak, moving arms, etc.*

### **1.6 Suggested Activities**

High-fidelity scenario:

- Simulation of nurse-led therapeutic communication with Ed and family

## JOURNAL EXCERPT 1.7

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### **The Goodbye**

*We put Ma to bed as usual on the night of ... April 2009. Ma walked slowly from the lounge room, down the hallway to her bedroom asking as she did 'where am I going? Where am I sleeping tonight?' We gave*

*our usual reply 'In your bedroom where you always sleep'. Satisfied, Ma snuggled comfortably between the sheets as we hugged and kissed her goodnight. She smiled and said 'thank you' and looking peaceful and contented she dozed off. Little did we know that these were to be the last words we would speak.*

*Next morning I prepared her medication, 'Lewy medication' she called it, and took it to her bedside announcing my presence with a cheery 'Good morning, how did you sleep?' Ma didn't stir; she seemed to be sleeping soundly. I decided to let her sleep until S., the carer, arrived. We were unable to wake Mary and decided to give her a bed-wash and change of pull-up pants. Nurse visited and suggested Mary go to hospital by ambulance. I consulted Dr N. J. who agreed. In hospital Mary had various tests – blood tests, X-rays, urine etc and placed on drip and given oxygen. Further tests tomorrow. We advised family of Mary's situation and then O., K. and M. – visited this evening.*

*A-A planning to come to Canberra from Sunshine Coast. I discussed further treatment with Dr D. E., including what action to take if any possibility of recovery passes. I expressed some surprise to be having this discussion at the time. Dr D. explained that this was routine as it was preferable for the medical team to know the thoughts of the family when commencing normal treatment regime. Dr D. explained that it could be days or even weeks before a decision needs to be made.*

*For the rest of April, Mary remained in Canberra Hospital under treatment but showed no signs of recovery. Many friends visited daily.*

## **JOURNAL EXCERPT 1.8**

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*On Saturday, 2 May 2009 Mary passed away peacefully at 11 am. I was present and A-A., M, O., and K. soon arrived. We stayed 'til 2 pm except M. who stayed longer. K. began funeral arrangements. As an organ donor Mary's eyes were accepted for research purposes.*

### **1.8 Suggested Activities:**

#### **Jigsaw classroom -**

What does the research say:

1. Legislation concerning organ donation and transplant
2. Policies and procedures around organ donation and transplant

#### **Role play:**

Therapeutic communication:

1. Broaching the subject of organ donation
2. Dilemma

#### **Discuss:**

How is the family's need/desire to say goodbye/stay with the patient balanced with the need to move forward with the donation/transplant procedure?

That is, who's in charge of the end-of-life moment?

### **1.8 Points to consider**

- What happens now?
  - carer?
  - family?
  - care workers (paid and unpaid)?
- What kind of support will the family need?
- How would the nurse support a family through organ donation decisions?
- How would the nurse support a family through the organ donation process?

## **1.9 Suggested Activity**

### **Jigsaw classroom:**

- What does the research say about mourning and grief?
- Develop some strategies to use in the clinical setting?



## *Websites of interest*

- [My Aged Care](#)  
An Australian Government resource
- [Organ donation](#)  
The Australian organ donation website
- [Advanced Care Planning Australia](#)  
Funded by the Australian Government and administered by Austin Health
- [Power of attorney](#)  
An Australian Government resource
- [Enduring Power of Attorney](#)  
An Australian Government resource
- [Wills](#)  
An Australian Government resource
- [Adult Guardian \(individual\)](#)  
An Australian Government resource
- [Public Advocacy \(services\)](#)  
An Australian Government resource
- [Centrelink](#)  
Australian Government agency
- [DVA](#)

Department of Veterans Affairs

- [Rare Dementia Support](#)

Rare Dementia Support is a UK-based service provided by the UCL Dementia Research Centre and partners.

- [Lewy Body Resource Centre](#)

The Lewy Body Dementia Resource Center is a US-based charitable non-profit organisation created to provide much needed resources and assistance to those with Lewy body dementia and their care partners.

- [Lewy Body Resources](#)

A series of resources discussing Lewy body disease provided by Dementia Australia

# MODULE 2 — EXPERIENCE: PATIENT, CARER, FAMILY

Module 2 expands on the content presented in Module 1. It humanises the broader understanding of dementia and discusses how a dementia diagnosis affects the patient, their family and friends. Many health professionals do not have opportunities to see their patient outside their workplace. That is, working in an acute healthcare facility may limit a nurse's view of patients and carers and their everyday experiences. Likewise, community workers may not have the opportunity to see the patients' acute healthcare experiences. While communication between health services is core to service provision, and each service interfaces with the others, the opportunity to see the services and the transitions between them from a consumer perspective is rare and valuable.

The theoretical knowledge gained from this module is enhanced by additional learning opportunities. The content of this module is linked to examples in Ed's narrative, activities and learning strategies to better understand the concepts.



# *Ed's Story: A life changing experience [VIDEO]*



*Video Acknowledgments: Video Producer/DoP – Dan Sanguineti, Camera Operator/Assistant – Michael Watson, Video Editors – Peta Lioulios and Dan Sanguineti.*

# Journal excerpt and associated resources for learning and teaching

## JOURNAL EXCERPT 2.1

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*The most important thing for me now is to give caring for her (Mary) top priority*

*Our younger daughter has come to live with us to care for her mother.*

*When she was a child she would tell her mother, "Mummy when you get old I'll look after you". Her kindness is so much appreciated.*

*Upon becoming a carer, major changes took place in my lifestyle. -I'm not resentful - not much anyway - because I believed I owed much to Mary - a loving wife and devoted mother to our children for over 50 years. I wanted to repay her for her kindness and provide care to help soften the problems arising from her dementia.*

*The most important thing for me now is to give caring for her top priority - to be available when needed, to share humorous episodes with her, to help with activities that Mary can no longer handle alone and to cry with her when she is depressed, and in doing so to try to keep myself calm and healthy and most importantly to do all of this in our*

*own home environment until such time when we accept that she would receive better treatment in a residential nursing home than we could possibly provide at home.*

*Initially home care did not seem very onerous. Mary's main symptoms included hallucinations at night involving attacks by snakes. In repelling this imaginary attack [sic], Mary sometimes injured her arms or legs. As a result of a special problem, Mary was prone to falling and to having difficulty in reading and writing.*

### **2.1 Points to consider**

- What is happening here?
- What support services are available to Ed and Maree?

### **2.1 Suggested Activities**

Individual and group activities to identify and explore the concept of roles and responsibilities. Consider the challenges and potential impact caring for the person who once cared for you.

#### **Jigsaw classroom:**

- Students gather the evidence for best practice and present their findings to the group
- Identify the key points from Ed's insights. How could this important information be used to develop action plans for Mary's care that support Ed, Maree and Mary?
- Using an example of a 'typical' home where you live as a guide, consider the support services, alterations and potential challenges to providing care. Mary's symptoms would be managed differently in a hospital/aged care facility. Consider the strategies that may be implemented in a care facility to meet Mary's needs. What advice would you give Ed?

## JOURNAL EXCERPT 2.2

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*Fortunately Mary showed no inclination to wander, nor become angry. Her short-term memory deteriorated yet her long-term memory remains, and she has little problem in recognising people and objects.*

*So in the early years of Mary's dementia, my caring role was not too demanding or stressful. However, as the years passed and Mary's condition slowly deteriorated, it became more demanding, especially at night when it became necessary to get up and assist her to the toilet. This was when I noticed that my broken sleep pattern was taking (a) toll on my body both physically and mentally. I became fatigued easily and was losing interest in participating in social activities which I (had) previously enjoyed.*



*I began to worry, and wondered if my symptoms resulted from my caring role or from some yet undiagnosed more serious health problem. I decided to seek the advice of my GP, and made an appointment.*

*We explored the situation. My doctor appreciated the situation from caring could sometimes result in the carer showing signs of depression. However, he wished to explore all possibilities and suggested a range of blood tests as a first step. I agreed and made another appointment to discuss the results.*

## **2.2 Points to consider**

- What is carer fatigue?
- How would you discuss this with Ed?

## **2.2 Suggested activities**

Divide a page into three columns:

- Column 1 – physical/psychological challenge to be addressed
- Column 2 – for each challenge, identify a strategy

- Column 3 – for each strategy, identify tools and resources required

Ed's insights are a valuable learning tool for healthcare providers. Reflect on the changes you would make to providing care for Mary that considers Ed's needs

### **Jigsaw classroom**

Research and present current best evidence on the concepts of 'activity of living' and 'activity of dying'.

## **JOURNAL EXCERPT 2.3**

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### **Wednesday, 9 January 2008**

*Mary a bit (lot) 'weepy' today. Concerned (still) about spending one night at (respite centre). Says it's hard for carer and me to understand how she feels. She can't speak or feed herself! Explained that the Cottage is different to the Nursing Home where she had respite previously – small and someone would look after her. Said 'they didn't on Tuesday at lunch time and I spilled peas everywhere!' Mary loves to be at home with Maree and myself. She's happy because she loves us and knows we'll care for her. Also there are nice friendly people coming and going all the time.*

### **2.3 Points to consider**

- What does respite provide?
- What should respite/carers provide?
- How do we support the decision-making response?

### **2.3 Suggested Activities**

Discuss (in groups)

1. The activities of daily living – where on the continuum is Mary?
2. How do we balance/can we balance the carer's need for respite and the patient's wish to not be 'in care'?
3. What is your position?
4. How might your personal attitude affect your ability to work with patient? Carer?
5. Develop some strategies.

## JOURNAL EXCERPT 2.4

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*Mary says she knows that she shouldn't interfere with our lives – we have our own lives to lead. I assured her that there is nowhere else I want to be and that she is not affecting anyone's life!*

### 2.4 Points to consider

- Consider Mary's emotional/psychological state
- How might the nurse respond to Mary's declaration?
- How might the nurse/health care team help Mary at this point?

### 2.4 Suggested activities

Reflect on your own attitudes/ideas

- How do you think dying people should be cared for?

## JOURNAL EXCERPT 2.5

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### Monday June 2008

*Mary ok. In past week or two has had delusions during day. Such*

*as house has been altered (changed). Pictures on wall taken and returned. 'Bump' on floor.*

*In this period – showed photos to friends but could not recognise her relations – Grandchildren etc., upset.*

### **2.5 Points to consider**

- What specific assessment/s could or should be done at this time?
- How is the person being cared for and the carer involved in the falls management plan?
- What does it mean to have poor/inconsistent insight?
  - to Mary?
  - to Ed?

### **2.5 Suggested Activities**

Discuss questions the nurse might use to clarify (with Ed) what is happening.

## JOURNAL EXCERPT 2.6

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### **Wednesday, 15 October 2008**

*Still having delusions (seeing things) during day. 'Lewy's' red-headed lady friend woke, ... sits on the divan in the lounge. Also two to three 'men' in the family room. Still sleeping well at night; doesn't 'bounce' out of bed in the morning. Waits for carer to arrive before getting up.*

### **Saturday, 18 October 2008**

*Mary fall [sic] in lounge room. Tears on her upper and lower parts of arm. Greenall (aged care services) nurse attends. Pia dressed upper arm. Keep dry - if wet contact Greenall. Dressing not water-proof. Lower arm - dressed with water-proof 'bandage'.*

*Mary having delusions about being out somewhere (at races - Caulfield Cup) and having to get home before it becomes dark. We have no drivers [sic] licence to drive bus. Quite a dilemma. Can't walk about in somebody's house without an invitation (Mary heard M. walking in our house). Mary finds it hard to realise that we are in our own house all the time.*

### **2.6 Points to consider**

#### **Carers:**

- Type of involvement
- When to be involved
- How much involvement

- Trust-building exercises.

What should the student nurse know?

What principles does Ed need to understand (e.g. touch technique)?

Health management and managing delusions

- How should/could carer respond?

What is the difference between hallucination and delusion?

- Review and characterise 'episodes' over the progress of Mary's Lewy body.

## **2.6 Suggested Activities**

- Develop a wound care strategy
- Develop a falls management strategy
- Demonstrate how you would help carer understand what to do
- Develop a 15-minute presentation using layman language that would help Ed understand what to do.

## JOURNAL EXCERPT 2.7

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### **Monday, 20 October 2008**

*Lewy's red-headed lady friend has been in at various locations in the lounge and family rooms today. Mary's fractured ribs troublesome today.*

### **Saturday and Sunday, 25 and 26 October 2008**

*Mary sleeping most of the day since falling. Also talking a lot to herself – mostly incoherent. Ribs sore a lot of the time. Left arm dressed on Friday. Healing very well. Nurse Neeson lives north side.*

*Mary depressed today (Sunday) – everything going wrong – can't read or write and so on. Jess here for next week caring for Mary. Maree in Sydney at Buddhist retreat.*

### **2.7 Points to consider**

Assessment

- What type?
- When?

When home care/community nurse is not easily accessible, what does the carer need to know?

Assessment and management (medication).

Diversional technique



- Creative outlets.

## 2.7 Suggested Activities

### Role Play:

- Sleep assessment
- Skin assessment.

## JOURNAL EXCERPT 2.8

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### Monday, 28 October 2008

*Mary confused about where she is. Will ask where she was and wanted to go home and take her portrait with her. Difficult to convince her that she is at home. Asked where her bedroom was.*

## 2.8 Points to consider

Fluctuating levels of insight

- How can this be managed?

## 2.8 Suggested activities:

Research, discuss, share with group:

- Palliative care
- When could/should this subject be broached with patient?  
Family?

## JOURNAL EXCERPT 2.9

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### Sunday, 12 December 2008

*Mary finds it difficult to focus on T.V. Asks where is it? Still wants to go home – take me home. Today she said: “take me home, to die”. Mary’s [sic] often talks about dying or wanting to die. Frustrated that she can’t do things.*

**Saturday, 24 January 2009**

*Mary depressed. Just wants to “lie down to die”.*

*Has UTI, very tired and has been quieter than usual the last couple of days.*

**2.9 Points to consider**

What effect does Mary’s depression have on Ed?

Building /supporting resilience:

- What needs to be in place to support the carer?

**2.9 Suggested Activities:**

Develop or adapt physical or psychological assessment.

**JOURNAL EXCERPT 2.10**

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**Tuesday, 29 January 2009**

*Mary slept 8:30 pm to 8:00 am when she took her Exelon then slept again and did not wish to get up for a shower and dressing [sic] at 10:30. Eventually got up and had breakfast and medication at 11:00*

*am. After lunch had sleep. Was 'down' this arvo. Had nothing left and wanting to die. Later told me that I should see that she is "going down".*

**Sunday, 1 February 2009**

*Mary, ... new delusions, dropped me off somewhere and had to pick me up. Also saw a child in the house, ...*

**Tuesday, 3 February 2009**

*New delusion, 'Bride', being married in a tub in the laundry. 'New' man in lounge room; big man; had his door open one day.*

**6 February 2009**

*Mary very tired. Started Movicol daily. Definitely lost ability to clean teeth. Still incoherent most of time.*

**2.10 Points to consider**

The process of physical and mental deterioration:

- Change
- Reminiscing
- Time travel
- Reduction of Anxiety
  - What?
  - How?
- Increased physical load to the carer.

## 2.10 Suggested activities

### Research and group discussion:

- Types of medication for dementia:
  - What?
  - Why?
  - Actions?
  - Compatibility?
- Other dementia-related medication
- What would you be teaching the carer about drug/side effects?
  - Carer information written for the carer.

## JOURNAL EXCERPT 2.11

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### 11 February 2009

*She has become angry with me in the morning believing I am going to 'get rid of her'. Asked me where is the rope that I am going to strangle her with. Has looked at me with fear and anger and haven't [sic] wanted me to touch her.*

*Later on Tuesday she told Kalab that she 'put on an act' this morning and later in the day asked me 'what did I think when she acted as she did this morning. Mary is more confused now. Asks a lot as to 'what is going on' and is obviously more confused. Cries a lot and complains*

*that 'she is useless'. Still says at times that she 'wants to die'. She is much quieter during the day and doesn't speak and enjoy the day as much as she used to. Also with longer hours in bed 7:30 pm to 10 am (14 1/2 hours) she is more restless during the night.*

## **22 February 2009**

*Mary shows sign of anger and frustration at carer (Ellena) for first time this morning. Also insisted that someone had been stealing her clothes. (Still believes that 'Lewy' is moving her portraits, particularly her portrait and that 'Lewy's' men are in the house).*

### **2.11 Points to consider**

- What's happening with Mary?
- Depression in dementia
  - How is it managed?

### **Journal excerpt 2.12:**

#### **Saturday, 14 March 2009**

*Mary have [sic] ... today and seems depressed. Still taking antibiotics for UTI. At one stage was saying the Holy Mary and talking of God. Still seems to be affected by UTI. Adrienne called late afternoon. Has torn skin on leg. Seems very tired.*

#### **Saturday, 25 April 2009**

*Spent day at hospital. Kalab, Aiden, , Hannah, Bella Osmond, Orlando, Betty (Greenall), Becca Redding, Jacintha all visited.*

*Little change in Mary's condition. Appeared once or twice to recognise someone but could not be sure.*

*Unable to talk.*

### **2.12 Points to consider**

- Role of spirituality in care?
- Reflect on own beliefs and attitudes
  - What does the research say?
  - Application to practice
  - Wound care.

### **Journal excerpt 2.13:**

*To be realistic, one must conclude that unless there is some unexpected change for the better, Mary is unlikely to leave hospital.*

*Some decision (or suggestion) will be forthcoming from the medical staff on Tuesday 28th 10 am to 12 pm.*

### **Tuesday, 28 April 2009**

*Phoned those who should or would like to know Mary's condition. Beatrix M, Dannika and Abbie A said to visit in next day or so.*

### **2.13 Points to consider**

What evidence would the HP/team use to inform decision?

### **2.13 Suggested Activities**

**Debate** the pros and cons arguments/solution for 'where to from here?'



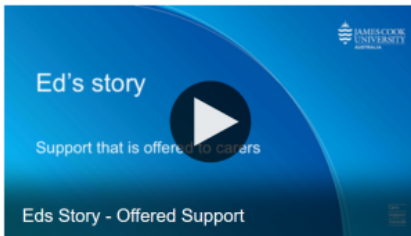
## **MODULE 3 — CARER: WHO, WHAT, WHY**

Module 3 recognises the role of informal carers for dementia patients, who they are, where they are, and what role they play in enhancing wellbeing for patients. It is now well documented that the role change and strain placed on informal carers can impact their own health and wellbeing negatively. The contents of Module 3 give insight into the toll that providing unpaid and often unrecognised care for dementia patients can have. Health professionals need to include informal carers into their care planning and this added insight may facilitate the provision of informed, individualised care.

The theoretical knowledge gained from this module is enhanced by additional learning opportunities. The content of this module is linked to examples in Ed's narrative, activities and learning strategies to better understand the concepts.



# *Ed's Story: Support offered for carers [VIDEO]*



*Video Acknowledgments:  
Video Producer/DoP – Dan Sanguineti,  
Camera Operator/Assistant – Michael  
Watson,  
Video Editors – Peta Lioulios and Dan  
Sanguineti.*

# Journal excerpt and associated resources for learning and teaching

## JOURNAL EXCERPT 3.1

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### **Tuesday, 5 February 2008**

*Mary to Dr Samantha Roberts. Good Report. Seven years since Mary was diagnosed (20 February 2001). "Should be in Guinness Book of Records." Keep same medication and routine. No further appointments. Maree returned.*

### **3.1 Points to consider**

- Polypharmacy
- Seven years since diagnosis
- What does the research say regarding Lewy body progression?

### 3.1 Suggested Activities

- **Discuss** the effects of long-term caring on the:
  - primary carer
  - family
  - friends
  - carers
- Paid
- Unpaid.

### JOURNAL EXCERPT 3.2

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#### **Wednesday, 7 May 2008**

*Mary more confused. More than usual today. Sleep [sic] a lot in chair in lounge this evening. Had difficulty in waking her to take her to her bedroom. At 7: 30 pm she went to bed and went to sleep immediately. She called for a drink at 11:45pm. In very clear English she told me this: "I was coming out of a dance at Mullumbimby when a gentleman said, 'Excuse me, may I speak to you?' I said yes certainly. He said that the band was only playing three dances and that five would be better. I agreed. He said that someone should tell...about it. I did my bit."*

### 3.2 Questions to consider

- What should the nursing student know about the trajectory of dementia/Lewy body?
- What should the carer know about the trajectory of Mary's disease?
- What are some key strategies that could be used when communicating with Mary when she is confused?

### 3.2 Suggested Activities

- Mapping the trajectory
- Review the trajectory\*

\*trajectory should be reviewed on a six-monthly basis (date-dependent)

## JOURNAL EXCERPT 3.3

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*I looked at Mary and said five dances aren't many. Did you go to dances in Mullumbimby? "Yes we used to go sometimes." "Was this before or were you dreaming it now?" "Yes I was dreaming it", and she grinned.*

*"Ok I'll see you in the morning", and as I walked to my room Mary said, "Can I have the next dance?"*

*"It's a bit late", I replied." I think they have finished the fifth dance already." "Yes", she replied and fell asleep.*

### **Saturday, 8 November 2008**

*Evening – Mary began to sing prompted by something viewed on T.V. She sang 'The last rose of summer' and we asked her to repeat it? We recorded her singing on our digital camera with sound.*

*On her way to bed she asked, as she often does, "where am I sleeping tonight?" We gave the usual answer: "In your own comfortable bed as usual." Mary seemed satisfied.*

*Comfortably tucked into bed she unexpectedly asked, "Do I get paid for washing the sheets?" Maree, thinking quickly, jokingly replied "If you do a good job." Mary smiled and soon was asleep.*

### **15 November 2008**

*Mary's mobility seems to be a little worse. Today Mary has seen Lewy busily employed "collecting his gear in the family room and taking them [sic] away". Later she explained that her tormentor was to be called 'Dr Who' in future as she didn't know 'who he was'.*

*Mary is spending more time concentrating on the invisible people who occupy her world and is resting and sleeping a lot more now. This includes sleeping longer in the morning.*

### 3.3 Points to consider

The role of reminiscing

- Tools and techniques
  - Reminiscing through:
    - Music, photographs, food, books, storytelling, sensory stimulation such as aromatherapy
    - Song
    - Dance
- What music, songs, dance?
- Contemplate the benefits of reminiscing
- How might reminiscing keep the carer motivated?

The care approach:

- Care/caring response.

### 3.3 Suggested Activities



- Adapt and/or brainstorm help sheets to develop person-centred care plan
- Use help sheets to help explain to Ed what is happening to Mary
- Develop material for Ed.

### JOURNAL EXCERPT 3.4

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#### **Sunday, 28 December 2008**

*Mary still having delusions during day. Can 'see' people in the house – men, woman. Her frustration about not being able to 'do things and ... alone. Two days ago Mary was alone in the lounge. She got out of her chair and while walking over the lounge fell on the floor. Luckily she landed on the carpet without hitting any furniture as she fell.*

*I was alone (Maree in Toowoomba and Jess away for Christmas Day. I couldn't lift her so made her comfortable on the floor). Luckily, Becca and Raif Redding were to visit, and when they arrived two hours later Raif helped to get Mary to the chair. Lately it usually takes two people to assist Mary to get from one place to another in the house, e.g. Lounge to bed, lounge chair to divan, chair to commode, and lounge to sun room. It is no longer possible for me to manage Mary at home on my own.*

*Mary is sleeping longer during the day. However she sleeps soundly at night – from about 10pm to 6 -7 am next morning. Appetite still good and bowels working well.*

### 3.4 Points to consider

- What can we do to support the carer in situations such as this?
- When change occurs, re-assessment is needed:
  - Important areas include: mobility, physical environment, falls risk, mini mental status examination, general health
  - What strategies can be put in place to address the above?
- Assumptions and understanding:
  - What assumptions might be made regarding Mary's cognitive state?
  - What might Ed's main concerns be at this time?
  - How could we assist him?
- Isolation
- Support systems
- Impact
- Societal/generational expectations of support
- Is it time to discuss the next stage of care?
  - What next?
- What's happening to Mary's skin?

- Integrity
- Plan and action

### **3.4 Suggested Activities**

1. Summarise the autonomic, motor, cognitive and behavioural changes that Mary is experiencing. How are these impacting her activities of daily living?
2. Consider what support services are available in your local community for people with LBD. What if you lived in a rural or remote location?
  - What supports could Ed be linked to:
    - local councils
    - community group and faith-based groups
    - carer groups (bringing people in to talk to the carers).
  - Review of services
  - Understanding equipment use, such as mobility aids, and medications.

## JOURNAL EXCERPT 3.5

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### Thursday, 1 January 2009

*Tonight I realised that Mary does not know for sure who I am. In a quiet talk with her she said that I am not her husband but didn't know who I was.*

*'No, you are not my father, he is dead.' Neither was she sure about Maree. "She is in bed". "Yes", I replied, "but who is she?" "I don't know, she is a bit of a mystery", she said with a grin.*

*Later I pursued the subject, asking: "How many children do you have?" "Four", Mary replied. "Who are they?" "Ava-Leigh, Maree, Kaleb and Orlando", she replied after some hesitation. "There you are, so Maree is your daughter." "So you must be my husband", she volunteered.*

### 3.5 Points to consider

- The loss and grief process
- Remembering
- Acknowledging
- Enabling all family members to express how they are feeling about their loved one as the disease progresses.

### 3.5 Suggested Activities

Reflect on the relationship between Ed, Mary and their children at this stage:

- Think about your own feelings in this situation
- Think about your own response in this situation, the cycle of grief and loss
  - Theorists/theories
  - Identified stages
  - Application to practice.

### JOURNAL EXCERPT 3.6

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*Mary often asks about her portrait, the one painted by Mrs Solesi in Bathurst in the mid 50's. "Where is it?" "Hanging on the wall behind you." "How long has it been there?" "30 years"*

*Mary believes that "Lewy" takes the original away and replaces it with a copy. Similarly, with her other paintings hanging on the lounge room walls.*

*Often when Mary is going from the lounge to her bedroom at night she asks where is she going and why are we going "this way". She will also ask which bed she is sleeping in tonight.*

### 3.6 Points to consider

- Artefacts
  - What are they?
  - What is their importance?
  - How are they used?

### 3.6 Suggested Activities

**Examine/ discuss** the effect on the carer of conversations that are not conversations:

- repetition
- Just managing the situation

That is, the effects on the carer of caring approach/management.

### JOURNAL EXCERPT 3.7

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*She asked about our wedding photo and whether I was her first or*

*second husband and where have I been over the years when she has had "Lewy". I said that I have been here looking after her with others.*

*She asked if we were divorced and whether I had died.*

*Mary continues to have delusions practically on a daily basis. See [sic] Lewy and his friend; sometimes animals. "Saw" children sitting on divan in the lounge this afternoon. Spoke to Mary about the possibility of going into residential respite. Agreed best to look after Mary at home. Matter closed.*

*Mary said that she saw Lewy on T.V. 'Border Patrol' - trying to get her painting through customs. However he was stopped and asked to explain.*

*Mary still asks [sic] "I want to go home."*

*"You are at home; this is our home 42 Wallaby Way, Warenda. It has been our home for a long time."*

*When Mary starts to walk from the lounge to her bedroom she often asks where we are going. "Where am I going to sleep tonight?"*

*"In your own bed where you always sleep."*

### **3.7 Points to consider**

- Carer communication with the person being cared for:
  - Importance

- Anticipating (type and response)
- Understanding of what is happening
- Are social contacts being maintained?
- Is respite available/being used?
- What is the role of the family at this time?
- Priorities: whose come first?
- What type of support is needed and how could/should it be offered?
- Why do you think the 'matter' is 'closed'?
- What are the short and long term effects of the 'matter' being 'closed'?
- Are the carer's emotional/psychological/physical needs being met?
- Time travelling
  - Refer to historical assessment
  - Reiterate the progress of the disease
  - Communication
- Artefacts
  - What might help Mary recognise where she is?



## JOURNAL EXCERPT 3.8

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### **Friday & Saturday, 13/14 February 2009**

*Giving Mary medication she asked "why are you keeping me alive?" "Because I haven't finished digging the hole in the back yard!" I replied. Later in conversation with Ellenna (carer) who said, "My husband wants to be buried, but I want to be cremated". Mary chipped in to say: "I want to be cremated too". "Well", I added, "I'll have to fill in the hole in the backyard!"*

### **27 February 2009**

*Mary losing ability to clean her teeth. I have to assist her or do it myself. Mary having periods of 'depression' – crying for no apparent reason and speaking in a way that is impossible to understand. Mobility is getting worse. Appears she has 'gone down a peg'.*

### **3.8 Points to consider**

End of life considerations – having conversations about death and dying. What if Mary had requested voluntary euthanasia when she was still cognitively intact?

### **3.8 Suggested Activities**

**Discuss:**

- What is end of life care?
- Change (**amplified loss of function**)
- Swallow (review diet).

Task/exercise

- Develop a menu for Mary that takes into account her nutritional needs, is acceptable to her and able to be consumed.

**Journal Excerpt 3.9:**

**Thursday, 12 March 2009**

*Mary not responsive this morning. Just wanting to sleep. Unable to shower, Lana gave her top and tail. Mary took Exelon OK but not able to eat – very sleepy. Not talking or responding in any way. Phone Greenhall who suggested I call an ambulance – maybe a semi-stroke. Spoke to Nadia James. – definitely not an ambulance – they don't understand her Lewy Body situation. Nadia suggested we get a specimen of urine (UTI). Tried but not successful. Nadia will call again at lunch time.*

**Wednesday, 29 April 2009**

*Mary restless this morning. No great recognition. Had visitors Phillipa, Lana, Abbie Armstrong, Lailani, Maree, Kaleb, Odette. Have phoned everyone who may like to know. Tried to feed by mouth – two small lots of yogurt.*

*Continuous flow of morphine. Saline solution but no nourishment. Water swap [sic] in mouth.*

**On Saturday, 2 May 2009**

*Mary passed away peacefully at 11 am. I was present and Ava-Leigh, Maree, Orlando and Kaleb soon arrived. We stayed til 2 pm except Maree. who stayed longer. Kaleb. began funeral arrangements with (Funeral Directors). As an organ donor Mary's eyes were accepted for research purposes.*

**3.9 Points to consider**

- End of life care
  - Start talking
  - Develop a plan
  - Medication.
- An interdisciplinary approach
  - Develop a more concerted team approach
  - Active
  - Visible.

# MODULE 4 — SUPPORT SYSTEMS AND SERVICES

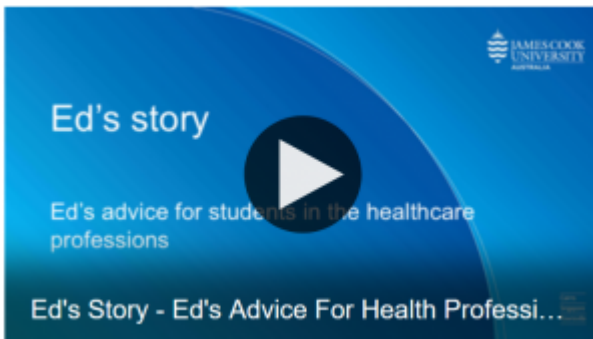
In this module, Ed discusses the support he and Mary received from health professionals and gives advice to students of health sciences, providing insights from the perspective of family and carers.



# *Ed's Story: Advice for students in the health professions [VIDEO]*

## **Ed's advice for students in the health professions**

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*Video Acknowledgments:*

*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*



# *Ed's Story: Discussion on support from health professionals*

[VIDEO]

## Involved health professionals

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*Video Acknowledgments: Video Producer/DoP – Dan Sanguinetti, Camera Operator/Assistant – Michael Watson, Video Editors – Peta Lioulios and Dan Sanguinetti.*

# Journal excerpt and associated resources for learning and teaching

## JOURNAL EXCERPT 4.1

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*Mary's speech is getting more difficult to understand, particularly at morning and night. I'm getting advice and suggestions from a number of quarters in regards to the ventures [sic] of continuing to look after Mary at home vs. putting Mary in a nursing home. E.g. Nadia James suggested Malanni (aged care home)- close. Could easily visit etc. Someone advised from ... , Jess, family (Kaleb & Ava-Leigh). Emphasis seems to be on my needs – health etc. I think Mary is not yet ready for residential care. Her quality of life is best served at home. I must take a more relaxed attitude and put Mary's interests first. Take each day as it comes and the pursuit for what may happen in the future.*

*Leave doing some activities till later. Bridge, dancing, golf – at least on a ... basis. Mary's mobility is slowly deteriorating which could be a problem in the future.*



#### 4.1 Points to consider

- Decision-making for the future
  - Explore/understand own belief systems
  - Family involvement:
    - is it a decision to be left to the primary carer?
- When considering future planning, refer to **tasks of mourning**
  3. 'Adjusting to an environment from which the deceased is missing'
- Communication is critical:
  - What role does the professional have?
  - Need for professionals' honesty
  - What would the professionals say and do to support Ed?

#### 4.1 Suggested Activities

##### Jigsaw classroom

## Research.

- Understanding not letting go
  - What does it mean?
  - What is the long-term impact?
  - Impact on family (what is left of the family? Family dynamics.)
  - Informed decision-making.
- Providing good support
  - Role of the support worker
  - Informed
  - Non-coercive approach
  - Relating it to specific context (Ed)
  - Knowledge of incapacity/capacity of carer (over time/ during the process).

## JOURNAL EXCERPT 4.2

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**21 April 2009**

*Unable to wake Mary this morning. Eyes open a couple of times. Shania and I gave bed wash and change [sic] pull-up pants. Lacie and Rebekah. visited. Suggested ambulance to hospital. I suggested we consult Dr Nadia James's opinion first. Nadia agreed to visit Mary*

*after morning practice. Arrived 3pm. Decided should go to hospital by ambulance at 4pm.*

*Visited 5 – 7 pm. Looking for 'something to treat'. On drip, giving oxygen through mask, urine taken. Further tests tomorrow. Orlando, Kalab and Ava- Leigh told.*

*Had talk to Dr Darcy. Evans. Female nurse, Belinda, and Male nurse, Jack. Discussed continuing life support if all possibility of recovery has passed. (Continuing equivalent to 2-3 days).*

*Explained that Mary and I had discussed this matter. We chose to discontinue support past a reasonable stage.*

#### **4.2 Points to consider**

- When does the act of dying begin?
- Generational approach to health care
  - What information?
  - When/what is appropriate delivery?
  - Who are the stakeholders?
  - Who should information be offered to?
- Advocacy
  - What does the research say?
- Advanced care directives

- Organ donation
- The model for nursing
- At what stage/time is it appropriate to begin discussing palliative care?

### JOURNAL EXCERPT 4.3

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*Surprised to be having this discussion at this early stage. Darcy indicated that this kind of discussion was routine as it was preferable for the medical team to know the thoughts of family members before commencing normal treatment regime.*

#### **Tuesday 10:30 pm**

*Phone call ... Dr Kaur, hospital. Asked about Mary's past medical history and behaviour over recent past. Mentioned that Dr Kilbee was on leave. Dr Shay still at hospital.*

*Mary will be admitted – check tomorrow where she is located and who her Dr is.*

#### **Thursday, 23 April 2009**

*Mary in hospital. Awake but not talking. Maybe she can hear and maybe recognise family. Ellena, Lana phoned, Lailani called.*

*Orlando, Kaleb visited hospital. Spoke to Ava-Leigh. and Maree. Someone (Adrienne?) left flowers. Phillipa came 2 hours – phoned her tonight.*

**Thursday, 23 April 2009**

*Mary 'semiconscious' today. Still nil by mouth. No further draining of lungs – cough not evident. Examined by 'Conner'. (Speech Therapist) no swallowing problem. Decided to continue nil by mouth [sic]. Mikhaela. (nurse) put in new catheter in arm, and re-started drip.*

*Roxanne, Dr. Somme, ... Hospital registrar. Had good talk. Cause of Mary's condition still elusive. Admits to puzzle. Tested, brain, chest, urine, skin – nothing positive. Will continue antibiotics for 2-3 days. Dementia patients sometimes act "differently".*

*Orlando, Aiden, Oodette and Hannah. visited. No positive signs of recognition.*

**Sunday, 26 April 2009**

*Mary improved today. Showed signs of recognition of people around her e.g. Nurse, Beatrix, Hannah and family. Seemed to be trying to talk e.g. 'go home' = I want to go home.*

**Monday, 27 April 2009**

*Mary showed some improvement today. Spoke a few words to nurse. Tried to speak throughout day. Looked more comfortable.*

*Maree and self visited during day. Kalab at night. Beatrix Matthews. called.*

**Tuesday, 28 April 2009**

*Conference between Dr ... Sofit, Roxanne (registrar), Orlando, Maree, Kalab and self.*

### 4.3 Points to consider

- Who and how many are involved in Mary's care
- 'Outside' intervention and sidelining the primary carer
- Communicating care to the family:
  - Who is in charge?
  - Who communicates?
  - Consistent messaging
  - What is the nurse's role?
- Type of support and appropriate support:
  - Culturally
  - Generational
  - Inter-generational.

# MODULE 5 — ED'S JOURNAL

This module presents Ed's Journal, which shows the journey an elderly couple traveled when one became the full-time carer for the other. It is an invaluable insight into the world of carers, their families and those being cared for.



# Ed's Journal

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## A LONG GOODBYE

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BY ED

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### **How they met**

*Mary was on reception at the hospital when I went for treatment. I liked her immediately and eventually she agreed to go out. We courted, became close and I asked her to marry me. She said, "Speak to my father". I did. He grinned and said, "Ask her mother".*

*We married, honeymooned in the mountains, and settled in the city until I finished my studies. We were very happy and so much in love. We asked ourselves, do good times like this last forever?*

*Later she felt ill and consulted her doctor who told her she had miscarried. I was dismayed – would we ever have a family? Cheerfully she replied, "Of course, we will! Don't worry – everything will be OK".*

*And so it proved to be. We reared four healthy children and enjoyed the journey.*

*As the children matured, she build [sic] a career and travelled within Australia and overseas both professionally and socially. She led an active and rewarding lifestyle. We both looked forward to a satisfying retirement.*



*She drove to the medical centre for a routine visit. Her doctor, noticing she was disoriented, suggested further tests. Eventually, she was diagnosed with Lewy Body Dementia.*

*Our lives were to change dramatically. She was gradually to lose her cherished independence – could no longer drive, required assistance with personal care and other activities at home and in public. Luckily, she retains her cheerful nature, wry sense of humour and full recognition of people and places.*

*Our younger daughter has come to live with us to care for her mother.*

*When she was a child she would tell her mother, “Mummy when you get old I’ll look after you”. Her kindness is so much appreciated.*

*Dementia has been described as a ‘long goodbye’. Tonight we will be close. We’ll talk, recall past experiences, sleep and dream. Tomorrow we’ll wake together to another beautiful day. We are so fortunate. We know now that good times do last forever.*

*Upon becoming a carer, major changes took place in my lifestyle. –I’m not resentful – not much anyway – because I believed I owed much to Mary – a loving wife and devoted mother to our children for over 50 years. I wanted to repay her for her kindness and provide care to help soften the problems arising from her dementia.*

*The most important thing for me now is to give caring for her top priority – to be available when needed, to share humorous episodes with her, to help with activities that Mary can no longer handle alone and to cry with her when she is depressed, and in doing so, to try to keep myself calm and healthy and most importantly, to do all of this in our own home environment until such time when we accept that she would receive better treatment in a residential nursing home than we could possibly provide at home.*

*Initially, home care did not seem very onerous. Mary’s main symptoms*

*included hallucinations at night involving attacks by snakes. In repelling this imaginary attack [sic], Mary sometimes injured her arms or legs. As a result of a special problem, Mary was prone to falling and to having difficulty in reading and writing.*

*Fortunately Mary showed no inclination to wander, nor become angry.*

*Her short-term memory deteriorated yet her long-term memory remains, and she has little problem in recognising people and objects.*

*So in the early years of Mary's dementia, my caring role was not too demanding or stressful. However, as the years passed and Mary's condition slowly deteriorated, it became more demanding, especially at night when it became necessary to get up and assist her to the toilet. This was when I noticed that my broken sleep pattern was taking (a) toll on my body, both physically and mentally. I became fatigued easily and was losing interest in participating in social activities which I (had) previously enjoyed.*

*I began to worry, and wondered if my symptoms resulted from my caring role or from some yet undiagnosed more serious health problem. I decided to seek the advice of my GP, and made an appointment.*

*We explored the situation. My doctor appreciated the situation from caring could sometimes result in the carer showing signs of depression. However, he wished to explore all possibilities and suggested a range of blood tests as a first step. I agreed and made another appointment to discuss the results.*

### **A Case of Mistaken Identity by Ed**

*My wife Mary was diagnosed with Lewy Body Dementia in 2000. Hallucinating is a major disturbing symptom of the disease and occurs regularly during the night.*

*As her primary Carer, I had to take precautions to minimise any damage Mary might inflict upon herself during these nightmarish episodes, which often involved her frantically attacking snakes.*

*These precautions included Mary putting gloves on her hands and knee-high stockings on her legs.*

*Once [sic] evening when Mary was ready to retire, I helped her put on the gloves and stockings, tucked her into bed, kissed her 'Goodnight', put the bell on the bedside table, dimmed the light and retired myself.*

*I hoped that when I was called later it would be to help Mary to the toilet, rather than deal with one of her nightmares, which could be frightening.*

*The ring of the bell awoke me at around 2am. Barely awake, with eyes half closed in the dim light, I made my way cautiously to Mary's bedside and assisted her to the toilet. As I waited, I threw back the doona and top sheet to make it easier for Mary upon her return. It was then I noticed the 'poo' on the bottom sheet in the centre of the bed. I was somewhat surprised because Mary is not incontinent...but sometimes accidents happen! Quickly I grabbed an old white towel from the linen cupboard, placed it over the 'poo' and carefully scooped it up. I hurried to the laundry and placed the towel and the contents on the floor. The bottom sheet did not appear to be soiled and I decided not to mention the mishap to Mary. Soon she was comfortably settled into bed and sound asleep.*

*The next morning, I casually mentioned to Mary what had happened. 'That's [sic] can't be right', she protested, 'I never do that kind of thing!' 'Well', I replied, 'I'll show you'. We went to the laundry and I carefully unwrapped the towel to expose its contents. Mary laughed 'That's not poo, that's my short stockings. I took them off under the bed-clothes during the night. See how they roll themselves into a neat bundle'. I joined in the laughter. A case of mistaken identity.*

**Wednesday, 9 January 2008**

*Mary a bit (lot) 'weepy' today. Concerned (still) about spending one night at (respite centre). Says it's hard for carer and me to understand how she feels. She can't speak or feed herself! Explained that the (respite centre) is different to the Nursing Home where she had respite previously – small and someone would look after her. Said 'they didn't on Tuesday at lunch time and I spilled peas everywhere!' Mary loves to be at home with Maree and myself. She's happy because she loves us and knows we'll care for her. Also there are nice friendly people coming and going all the time.*

*Mary says she knows that she shouldn't interfere with our lives – we have our own lives to lead. I assured her that there is nowhere else I want to be and that she is not affecting anyone's life!*

**Tuesday, 5 February 2008**

*Mary to Dr Samantha Roberts. Good Report. Seven years since Mary was diagnosed (20 February 2001). "Should be in Guinness Book of Records." Keep same medication and routine. No further appointments. Maree returned.*

**Wednesday, 7 May 2008**

*Mary more confused. More than usual today. Sleep [sic] a lot in chair in lounge this evening. Had difficulty in waking her to take her to her bedroom. At 7: 30 pm she went to bed and went to sleep immediately. She called for a drink at 11:45pm. In very clear English she told me this: "I was coming out of a dance at Mullumbimby when a gentleman said, 'Excuse me, may I speak to you?' I said yes certainly. He said that the band was only playing three dances and that five would be better. I agreed. He said that someone should tell ... about it. I did my bit."*

*I looked at Mary and said five dances aren't many. Did you go to dances in Mullumbimby? "Yes we used to go sometimes."*

*"Was this before or were you dreaming it now?" "Yes I was dreaming it", and she grinned.*

*"Ok I'll see you in the morning", and as I walked to my room Mary said, "Can I have the next dance?"*

*"It's a bit late", I replied." I think they have finished the fifth dance already." "Yes", she replied and fell asleep.*

### **Monday June 2008**

*Mary ok. In past week or two has had delusions during day. Such as house has been altered (changed). Pictures on wall taken and returned. 'Bump' on floor.*

*In this period – showed photos to friends but could not recognise her relations – Grandchildren etc., upset.*

### **Wednesday, 15 October 2008**

*Still having delusions (seeing things) during day. 'Lewy's' red-headed lady friend woke, sits on the divan in the lounge. Also, two to three 'men' in the family room. Still sleeping well at night; doesn't 'bounce' out of bed in the morning. Waits for carer to arrive before getting up.*

### **Saturday, 18 October 2008**

*Mary fall [sic] in lounge room. Tears on her upper and lower parts [sic] of arm. Greenall (aged care services) nurse attends. Pia dressed upper arm. Keep dry – if wet contact Greenall. Dressing not water-proof. Lower arm – dressed with water-proof 'bandage'.*

*Mary having delusions about being out somewhere (at races – Caulfield*

*Cup) and having to get home before it becomes dark. We have no drivers [sic] licence to drive bus. Quite a dilemma. Can't walk about in somebody's house without an invitation (Mary heard Maree walking in our house). Mary finds it hard to realise that we are in our own house all the time.*

### **Monday, 20 October 2008**

*Lewy's red-headed lady friend has been in at various locations in the lounge and family rooms today. Mary's fractured ribs troublesome today.*

### **Saturday & Sunday, 25 and 26 October 2008**

*Mary sleeping most of the day since falling. Also talking a lot to herself – mostly incoherent. Ribs sore a lot of the time. Left arm dressed on Friday. Healing very well. Nurse Neeson lives north side.*

*Mary depressed today (Sunday) – everything going wrong – can't read or write and so on. Jess here for next week caring for Mary. Maree in Sydney at Buddhist retreat.*

### **Monday, 28 October 2008**

*Mary confused about where she is. Will ask where she was and wanted to go home and take her portrait with her. Difficult to convince her that she is at home. Asked where her bedroom was.*

### **Friday, 7 November 2008**

*Mary having a lot of delusions:*

*Wants to go home.*

*"Lewy's" men (up to three in room) and watching her*

*Asks at bed-time: "Which bed is she going to sleep in tonight?" Pictures still being shifted about (by "Lewy").*

### **Saturday, 8 November 2008**

*Evening – Mary began to sing prompted by something viewed on T.V. She sang 'The last rose of summer' and we asked her to repeat it? We recorded her singing on our digital camera with sound.*

*On her way to bed she asked, as she often does, "where am I sleeping tonight?" We gave the usual answer: "In your own comfortable bed as usual." Mary seemed satisfied.*

*Comfortably tucked into bed she unexpectedly asked, "Do I get paid for washing the sheets?" Maree, thinking quickly, jokingly replied: "If you do a good job." Mary smiled and soon was asleep.*

### **15 November 2008**

*Mary's mobility seems to be a little worse. Today Mary has seen Lewy busily employed "collecting his gear in the family room and taking them [sic] away". Later she explained that her tormentor was to be called 'Dr Who' in future, as she didn't know 'who he was'.*

*Mary is spending more time concentrating on the invisible people who occupy her world and is resting and sleeping a lot more now. This includes sleeping longer in the morning.*

### **Sunday, 12 December 2008**

*Mary finds it difficult to focus on T.V. Asks where is it?*

*Still wants to go home – take me home. Today she said: "take me home, to die". Mary's [sic] often talks about dying or wanting to die. Frustrated that she can't do things.*

**Sunday, 28 December 2008**

*Mary still having delusions during day. Can 'see' people in the house – men, woman. Her frustration about not being able to 'do things and ... alone. Two days ago Mary was alone in the lounge. She got out of her chair and while walking over the lounge fell on the floor. Luckily she landed on the carpet without hitting any furniture as she fell.*

*I was alone (Maree in Toowoomba and Jess away for Christmas Day. I couldn't lift her so made her comfortable on the floor). Luckily, Becca and Raif Redding were to visit, and when they arrived two hours later Raif helped to get Mary to the chair. Lately it usually takes two people to assist Mary to get from one place to another in the house, e.g. Lounge to bed, lounge chair to divan, chair to commode, and lounge to sun room. It is no longer possible for me to manage Mary at home on my own.*

*Mary is sleeping longer during the day. However she sleeps soundly at night – from about 10pm to 6 -7 am next morning. Appetite still good and bowels working well.*

**Thursday, 1 January 2009**

*Tonight I realised that Mary does not know for sure who I am. In a quiet talk with her she said that I am not her husband but didn't know who I was.*

*'No, you are not my father, he is dead.' Neither was she sure about Maree. "She is in bed". "Yes", I replied, "but who is she?" "I don't know, she is a bit of a mystery", she said with a grin.*

*Later I pursued the subject, asking: "How many children do you have?" "Four", Mary replied. "Who are they?" "Ava-Leigh, Maree, Kaleb and Orlando", she replied after some hesitation.*



*"There you are, so Maree is your daughter." "So you must be my husband", she volunteered.*

*Mary often asks about her portrait, the one painted by Mrs Solesi in Bathurst in the mid 50's. "Where is it?" "Hanging on the wall behind you."*

*"How long has it been there?" "30 years"*

*Mary believes that "Lewy" takes the original away and replaces it with a copy. Similarly, with her other paintings hanging on the lounge room walls.*

*Often when Mary is going from the lounge to her bedroom at night she asks where is she going and why are we going "this way". She will also ask which bed she is sleeping in tonight.*

*She asked about our wedding photo and whether I was her first or second husband and where have I been over the years when she has had "Lewy". I said that I have been here looking after her with others.*

*She asked if we were divorced and whether I had died.*

*Mary continues to have delusions practically on a daily basis. See [sic] Lewy and his friend; sometimes animals. "Saw" children sitting on divan in the lounge this afternoon. Spoke to Mary about the possibility of going into residential respite. Agreed best to look after Mary at home. Matter closed.*

### **... January 2009**

*Mary said that she saw Lewy on T.V. 'Border Patrol' – trying to get her painting through customs. However he was stopped and asked to explain.*

*Mary still asks [sic]: "I want to go home."*

*"You are at home; this is our home 42 Wallaby Way, Warendra. It has been our home for a long time."*

*When Mary starts to walk from the lounge to her bedroom she often asks where we are going. "Where am I going to sleep tonight?"*

*"In your own bed where you always sleep."*

### **Saturday, 24 January 2009**

*Mary depressed. Just wants to "lie & own [sic] to die".*

*Has UTI, very tired and has been quieter than usual the last couple of days.*

### **Tuesday, 29 January 2009**

*Mary slept 8:30 pm to 8:00 am when she took her Exelon then slept again and did not wish to get up for a shower and dressing [sic] at 10:30. Eventually got up and had breakfast and medication at 11:00 am. After lunch had sleep. Was 'down' this arvo. Had nothing left and wanting to die. Later told me that I should see that she is "going down".*

### **Sunday, 1 February 2009**

*Mary, ... new delusions, dropped me off somewhere and had to pick me up. Also saw a child in the house ...*

### **Tuesday, 3 February 2009**

*New delusion, 'Bride', being married in a tub in the laundry. 'New' man in lounge room: big man; had his door open one day.*

### **6 February 2009**

*Mary very tired. Started Movicol daily. Definitely lost ability to clean teeth. Still incoherent most of time.*

### **7 February 2009**

*Mary 'sat down' on way to shower. Going to use shower chair with wheels in future. Mary, Jess and I went to lake for walk and lunch.*

### **8 February 2009**

*Using shower chair. Seems successful.*

### **10 February 2009**

*Mary has reached 'new' stage in her decline.*

### **11 February 2009**

*She has become angry with me in the morning believing I am going to 'get rid of her'. Asked me where is the rope that I am going to strangle her with. Has looked at me with fear and anger and haven't [sic] wanted me to touch her.*

*Later on Tuesday she told Kaleb that she 'put on an act' this morning and later in the day asked me 'what did I think when she acted as she did this morning. Mary is more confused now. Asks a lot as to 'what is going on' and is obviously more confused. Cries a lot and complains that 'she is useless'. Still says at times that she 'wants to die'. She is much quieter during the day and doesn't speak and enjoy the day as much as she used to. Also with longer hours in bed 7:30 pm to 10 am (14 1/2 hours) she is more restless during the night.*

### **Friday & Saturday, 13/14 February 2009**

*Giving Mary medication she asked "why are you keeping me alive?" "Because I haven't finished digging the hole in the back yard!" I replied.*

*Later in conversation with Ellena (carer) who said, "My husband wants to be buried, but I want to be cremated". Mary chipped in to say: "I want to be cremated too". "Well", I added, "I'll have to fill in the hole in the backyard!"*

### **Friday, 20 February 2009**

*Mary's speech is getting more difficult to understand, particularly at morning and night. I'm getting advice and suggestions from a number of quarters in regards to the ventures [sic] of continuing to look after Mary at home vs. putting Mary in a nursing home. E.g. Nadia James suggested Malanni – close. Could easily visit etc. Someone advised from ..., Jess, family (Kaleb & Ava-Leigh). Emphasis seems to be on my needs – health, etc. I think Mary is not yet ready for residential care. Her quality of life is best served at home. I must take a more relaxed attitude and put Mary's interests first. Take each day as it comes and the pursuit for what may happen in the future.*

*Leave doing some activities till later. Bridge, dancing, golf – at least on a ... basis. Mary's mobility is slowly deteriorating which could be a problem in the future.*

### **22 February 2009**

*Mary shows sign of anger and frustration at carer (Ellena) for first time this morning. Also insisted that someone had been stealing her clothes. (Still believes that 'Lewy' is moving her portraits, particularly her portrait, and that 'Lewy's' men are in the house).*

### **26 February 2009**

*Mary very tired. Quieter and reflective. Appears to be 'depressed'. Having more difficulty in speaking. Getting hard to understand. Mobility not good.*

**27 February 2009**

*Mary losing ability to clean her teeth. I have to assist her or do it myself. Mary having periods of 'depression' – crying for no apparent reason and speaking in a way that is impossible to understand. Mobility is getting worse. Appears she has 'gone down a peg'.*

**Thursday, 12 March 2009**

*Mary not responsive this morning. Just wanting to sleep. Unable to shower, Lana gave her top and tail. Mary took Exelon OK but not able to eat – very sleepy. Not talking or responding in any way. Phone Greenall who suggested I call an ambulance – maybe a semi-stroke. Spoke to Nadia James – definitely not an ambulance – they don't understand her Lewy Body situation. Nadia suggested we get a specimen of urine (UTI). Tried but not successful. Nadia will call again at lunch time.*

*Collected specimen and tested at Doctor's surgery. Positive – put her on antibiotics for 7 days.*

**Saturday, 14 March 2009**

*Mary have [sic] ... today and seems depressed. Still taking antibiotics for UTI. At one stage was saying the Holy Mary and talking of God. Still seems to be affected by UTI. Adrienne called late afternoon. Has torn skin on leg. Seems very tired.*

**Monday, 16 March 2009**

*New behaviour: Hallucinations all night and early morning. Up six times. Incoherent most of the time. Aggressive.*

**17 March 2009**

*Mary hallucinating again all night. One episode involved a snake and Mary inflicted a tear on her lower arm. Dressed in a waterproof cover.*

*Mary [sic] hallucinations cover a wide field of imagination. Having great difficulty in swallowing tablets. Taking liquids OK.*

### **21 April 2009**

*Unable to wake Mary this morning. Eyes open a couple of times. Shania and I gave bed wash and change [sic] pull-up pants. Lacie and Rebekah visited. Suggested ambulance to hospital. I suggested we consult Dr Nadia James's opinion first. Nadia agreed to visit Mary after morning practice. Arrived 3pm. Decided should go to hospital by ambulance at 4pm.*

*Visited 5 - 7 pm. Looking for 'something to treat'. On drip, giving oxygen through mask, urine taken. Further tests tomorrow. Orlando, Kaleb and Ava-Leigh told.*

*Had talk to Dr Darcy Evans. Female nurse, Belinda, and Male nurse, Jack. Discussed continuing life support if all possibility of recovery has passed (Continuing equivalent to 2-3 days).*

*Explained that Mary and I had discussed this matter. We chose to discontinue support past a reasonable stage.*

*Surprised to be having this discussion at this early stage. Darcy indicated that this kind of discussion was routine as it was preferable for the medical team to know the thoughts of family members before commencing normal treatment regime.*

### **Tuesday 10:30 pm**

*Phone call ... Dr Kaur, hospital. Asked about Mary's past medical history and behaviour over recent past. Mentioned that Dr Kilbee was on leave. Dr Shay still at hospital.*

*Mary will be admitted - check tomorrow where she is located and who her Dr is.*

**Thursday, 23 April 2009**

*Mary in Hospital. Awake but not talking. Maybe she can hear and maybe recognise family. Ellena, Lana phoned, Lailani called.*

*Orlando, Kaleb visited hospital. Spoke to Ava-Leigh and Maree. Someone (Adrienne?) left flowers.*

*Phillipa came 2 hours – phoned her tonight.*

**Thursday, 23 April 2009**

*Mary 'semiconscious' today. Still nil by mouth. No further draining of lungs – cough not evident. Examined by 'Connor'. (Speech Therapist) no swallowing problem. Decided to continue nil by mouth [sic] ... Mikhaela put in new catheter in arm, and re-started drip....*

*Roxanne, Dr Somme, .... Hospital registrar. Had good talk. Cause of Mary's condition still elusive. Admits to puzzle. Tested, brain, chest, urine, skin – nothing positive. Will continue anti-biotics for 2-3 days. Dementia patients sometimes act "differently".*

*Orlando, Aiden, Odette and Hannah visited. No positive signs of recognition.*

**Saturday, 25 April 2009**

*Spent day at hospital. Kaleb, Aiden, Hannah, Bella Osmond, Orlando, Betty (Greenall). Becca Redding, Jacintha all visited.*

*Little change in Mary's condition. Appeared once or twice to recognise someone but could not be sure.*

*Unable to talk.*

*To be realistic, one must conclude that unless there is some unexpected change for the better, Mary is unlikely to leave hospital.*

*Some decision (or suggestion) will be forthcoming from the medical staff on Tuesday 28th 10 am to 12 pm.*

### **Sunday, 26 April 2009**

*Mary improved today. Showed signs of recognition of people around her, e.g. Nurse, Beatrix, Hannah and family. Seemed to be trying to talk, e.g. 'go home' = I want to go home.*

### **Monday, 27 April 2009**

*Mary showed some improvement today. Spoke a few words to nurse. Tried to speak throughout day. Looked more comfortable.*

*Maree and self visited during day. Kaleb at night. Beatrix Matthews called.*

### **Tuesday, 28 April 2009**

*Conference between Dr ... Sofit, Roxanne (registrar), Orlando, Maree, Kaleb and self.*

*Agreed: Anti-biotics cease. Not having any effect and continuation could cause side effects and diarrhoea.*

*Discontinuing feeding by cannula, except potassium. Feed subcutaneously into muscle in mid-body. Continue oxygen but finish feeding in 1 to 2 days.*

*Mary not alert enough to feed by mouth. Monitor, and if Mary becomes more alert, feed by mouth. Move to single room. Unlikely Mary will leave hospital. End will come any time from days to weeks. Mary alert this evening – strong grip; trying to speak, moving arms, etc.*

*Phoned those who should or would like to know Mary's condition. Beatrix M, Dannika and Abbie A said to visit in next day or so.*



**Wednesday, 29 April 2009**

*Mary restless this morning. No great recognition. Had visitors Phillipa, Lana, Abbie Armstrong, Lailani, Maree, Kaleb, Odette. Have phoned everyone who may like to know. Tried to feed by mouth – two small lots of yogurt.*

*Continuous flow of morphine. Saline solution but no nourishment. Water swap [sic] in mouth.*

**On Saturday, 2 May 2009**

*Mary passed away peacefully at 11 am. I was present and Ava-Leigh, Maree, Orlando and Kaleb soon arrived. We stayed til 2 pm except Maree who stayed longer. Kaleb began funeral arrangements with (funeral directors). As an organ donor Mary's eyes were accepted for research purposes.*

**Saturday, ...**

*We put Ma to bed as usual on the night of ... April 2009. Ma walked slowly from the lounge room, down the hallway to her bedroom asking as she did: 'where am I going? Where am I sleeping tonight?' We gave our usual reply: 'In your bedroom where you always sleep'. Satisfied, Ma snuggled comfortably between the sheets as we hugged and kissed her goodnight. She smiled and said 'thank you', and looking peaceful and contented, she dozed off. Little did we know that these were to be the last words we would speak.*

*Next morning I prepared her medication, 'Lewy medication' she called it, and took it to her bedside announcing my presence with a cheery 'Good morning, how did you sleep?' Ma didn't stir; she seemed to be sleeping soundly. I decided to let her sleep until Shania the carer arrived. We were unable to wake Mary and decided to give her a bed-wash and change of pull-up pants. Nurse visited and suggested Mary*

*go to hospital by ambulance. I consulted Dr Nadia James who agreed. In hospital Mary had various tests – blood tests, X-rays, urine, etc., and placed on drip and given oxygen. Further tests tomorrow. We advised family of Mary's situation and then Orlando, Kaleb and Maree – visited this evening.*

*Ava-Leigh planning to come to Canberra from (interstate). I discussed further treatment with Dr Darcy Evans, including what action to take if any possibility of recovery passes. I expressed some surprise to be having this discussion at the time. Darcy explained that this was routine as it was preferable for the medical team to know the thoughts of the family when commencing normal treatment regime. Darcy explained that it could be days or even weeks before a decision needs to be made. For the rest of April, Mary remained in Hospital under treatment but showed no signs of recovery. Many friends visited daily.*

# Reflections

## ED TEACHES THE TEACHERS: REFLECTIONS FROM THE INITIAL PROJECT TEAM

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### **Adele - Academic**

Looking back on the project, I cannot get past the thought of “Wow, what a ride”. Personally, I have not had the experience of dementia affecting my loved ones. I have been a nurse and a midwife for thirty years and although my professional area of expertise is not dementia, Ed’s journal struck a chord.

Maybe it was because I considered myself somewhat of a novice in the area, I learned so much from his insights as a recipient of care. I don’t know if Ed or his family and friends understand how valuable his writings will be to future nurses and health professionals. Nor do I know if any of us fully appreciate how this may affect care provision for other families. I do believe, strongly, that Ed’s Story will resonate with others, just as it has with us, the project team. I feel privileged to have been entrusted with Ed’s Story; proud of the product we have developed; proud of every one on the team who brought their expertise and gave generously and willingly to the project; and excited that we now get to share it with others.

## **Kellie – Learning Advisor**

When first invited to join the collaborative project, I approached Ed's story as purely an academic task with a tangible outcome: develop a learning resource to help nursing students better link the theory of caring with practice. How wrong I was. Ed's and Mary's lived experience became something I deeply cared about; Ed's complete giving of himself and willingness to share with strangers made me want to develop the best possible learning resource and make certain it was made available to the whole community.

Ensuring that every member of the team had insight to who Ed and Mary are was the beginning of the quality approach to the project; this way, we were letting go our individual objectives and giving ourselves over completely to Ed's story. I believe this helped progress the project, and carry the team through when unforeseen changes in the makeup of the team could have derailed the project.

Overall, knowing this was an opportunity to learn from the inside out – learn from the lived experience of a carer for a spouse with dementia, will, I believe, deepen students' insight into the topic and help us better care for the carer.

## **Stephen – Librarian**

Ed's Story resonated strongly with me. When we started this project, my Nan, for five years previous, had a disease that caused the slow deterioration of her body and her ability to control it. For the first two years my mother was the sole carer for Nan but my mother could no longer physically do the things needed to care for her. So the family made the difficult decision to put Nan in a high-care nursing home where my mother still visited Nan 4-5 days a week. The challenges that Ed had to face mirrored what my mother went through caring for Nan. Through this project I came

to understand better what my mother was going through and the need for other family members and health professionals to care not just for the patient but also the carer.

## Reflections from family, friends and carers

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### **Kel – Family**

One of the great challenges of dementia is that long established and long accepted roles and responsibilities within a family are slowly but surely thrown into chaos.

As the debilitating effects of the disease took hold, Mary was unable to carry out domestic duties and fulfill family caring roles that had long been her domain and field of expertise.

The baton fell to Ed—at a relatively late stage in life—to take on roles of chief housekeeper and carer. Roles which were new and inevitably challenging for him. But as is the nature of life, marriage and family, these were roles he fulfilled in unforeseen and difficult circumstances with love.

### **Ann – one of the care workers for Mary**

Lewy Body's Dementia may have replaced Mary's memory with hallucinations and demons, but it could not take away her beautiful personality or her cheeky sense of humour. I first learnt of Mary's sense of humour when I found out that she had nick names for her usual care workers as a way of remembering their names. I was Pommie Ann, then there was Quiche (Lorraine) and Sorry Mary. We were all so appropriately named. The best part of my visits were "morning tea". This was when I got to really know Mary and Ed. For as long as she could Mary would take me to her photo wall and she would tell me who was who and talk about the photos. As the

Lewy Body's worsened, the photo wall helped me so many times to calm Mary, re-focus her and trigger good memories for her. The "morning tea" was also chance for Ed to have someone to talk to, not just about how things were with Mary, but about life outside of his 24hrs a day, 7 days a week, 52 weeks a year caring role. Lewy Body's may have robbed Mary of coherent speech, but laughter and tears over "morning tea" spoke volumes.

### **John - Long time friend**

At age 78 in 200, Ed's Ed's primary home care for Mary's Lewy Body dementia steadily became more demanding with broken sleep patterns, physical and mental heartbreak, fatigue, interest lost in previously enjoyable social activities and inertia bordering on depression.

Over nine years Mary had some dreadful falls in occasional Respite Care: a vindication perhaps of Ed's home care for her in familiar surroundings.

At Mary's funeral following her death on Saturday 2/5/2009, Linda from Canberra' Goodwin Home Care reflected:-

"I [Linda] could always leave the home knowing she [Mary] was in good care with her loving family."

To me it seems that the well being of the primary carer too should become a priority when dealing with age related dementia care provided by one loved one, to one so loved.

### **Gordon**

I first met Ed when I was conducting research on the history of the 2/9<sup>th</sup> Australian Infantry Battalion in which Ed served during World

War Two. At this time I met Ed's wife Mary and was aware that she was not well but did not realise just how ill she was and how sick she was to become.

However, by the time my research concluded Ed and I had become friends and fallen into the habit of having lunch together at one or other of the local clubs or coffee shops. We became very relaxed in each other's company and our conversations shifted from the events of the war to more general conversations about his life, my life and life in general.

As Mary's condition deteriorated I saw her less and less and I must confess remained largely unaware of just how serious her condition had become or the enormous strain Ed and his family were experiencing. Most days she was in her room when I called or if she was up we spoke only briefly before she excused herself and returned to her room. At lunch Ed rarely, if ever, raised the subject of Mary's illness and beyond a polite "How is Mary?" nor did I.

Nevertheless, in spite of my failure to fully appreciate the reality of Ed's situation I like to think that those times when Ed and I went off to have lunch and talk about this, that and nothing at all may have provided him with some valuable respite. Perhaps this time out just talking to a friend who was not part of the family or closely involved with Mary's illness gave Ed the opportunity, for a short time at least, to just be himself without the overwhelming weight of Mary's illness bearing down upon him.

Anyway, I hope it did.

## **Kay**

I now know that living in another country does not lessen the impact of a loved one with dementia. I live in Australia, Dad lives

in New Zealand. He turns 95 in 2016. For the past 10 years he has been “lost” to me in so many ways, and in the last 5 years, our ability to communicate has gradually gone to almost nothing. I think he knows who I am when I telephone but I’m not really sure and although his dementia has been diagnosed as mild, that combined with deafness ... well that’s like a brick wall, harder to scale than it would be to swim the Tasman that lies between us. There are complex reasons why the visits have been few, but I’ve tried to make up for that. Do I feel like a bad daughter for not being there? Yeh, quite often. But I just do the best I can. Hopefully he understands, somehow, on some level and still loves me as his daughter.



# *Love Matters by Maree Jones: A poem*

## **Love Matters by Maree Jones**

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I hear the bell; I wake from my sleep,

I think, "Is it really the bell or the chimes out back,

Or maybe I dreamt it?"

I listen for the rustle of sheets or the sound of her voice.

I drag myself from my warm bed, I see my mum awake in her bed.

Sometimes she will greet me with a smile and a 'hello darling'

Sometimes she will be confused and not aware of much,

Sometimes she will talk but I won't understand what she says

Sometimes she will have a little chuckle to herself.

I help her to the commode,

Sometimes she can move okay; other times she is stiff and immobile.

Sometimes she will say 'I can't move',  
Sometimes I say 'yes, you can, give it a try; I will help you'.  
And sometimes in the morning when she can't move,  
I give her medication.  
It takes about an hour to work, to get her mobile, so she can move  
her frail body by herself.  
Sometimes while we are waiting for this, I sit on her bed.  
Sometimes we talk,  
Sometimes she is scared;  
Scared for the future, the unknown, and what it may bring her;  
How her dementia will progress, the memories of her own  
mother's senility haunting her.  
I tell her not to worry. We will be here.  
Dad and I, we will look after her.  
I try to reassure her, to allay her fears.  
Sometimes I reflect on the past, on how she was when she was  
younger,  
How she lovingly brought up us four children,  
How she helped us bring up our children.  
Giving us all unending amounts of love,  
Unconditional love, warmth, reassurance, encouragement,

Setting an example of how to be a mum: how to love your kids,  
Showing us that love matters more than anything.

I am grateful for this opportunity to be with her, to help her, to  
love her.

I hear that song in my head...

“a time to be born, a time to die,

To everything, there is a season, turn, turn,

A time to reap, a time to sow, a time to dance, a time to mourn”

I know everything has its time.



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Maree Jones, Ed and Mary's daughter, wrote this poem while helping to care for her mother.

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# MODULE 7 — A CONVERSATION WITH ED

The entirety of this resource is centred on Ed and his journal about caring for Mary. This module links to the videos of a conversation with Ed. His frankness and honesty about a very difficult time in his life add to the written content provided. Ed answers the questions that, as health professionals, we cannot ask our patients.

The video vignettes are also linked to other modules and add to the narrative in the written journal in place. In this way, the reader has the opportunity to listen to Ed, seeing and hearing the lived experience that may inform their future practice.

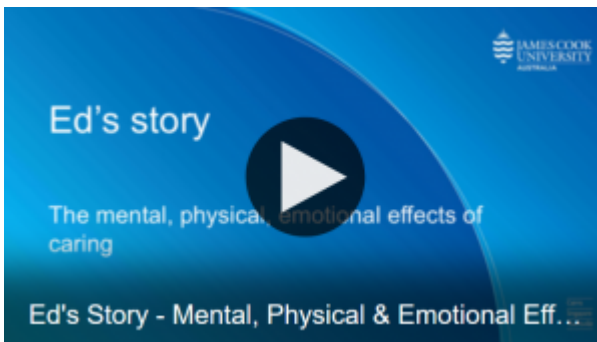




# *Ed's Story: A Conversation with Ed [VIDEOS]*

**Ed's Story: The mental, physical and emotional effects of caring [VIDEO]**

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*Video Acknowledgments:*

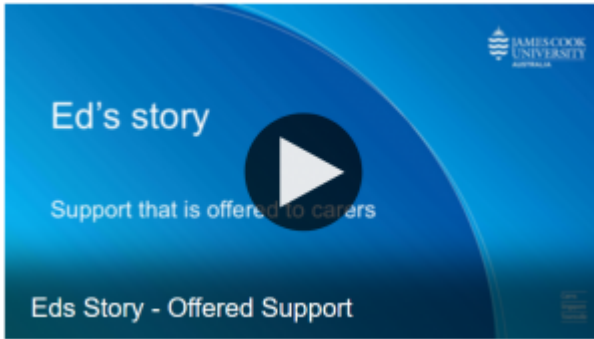
*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*

## Ed's Story: Support offered for carers [VIDEO]

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*Video Acknowledgments:*

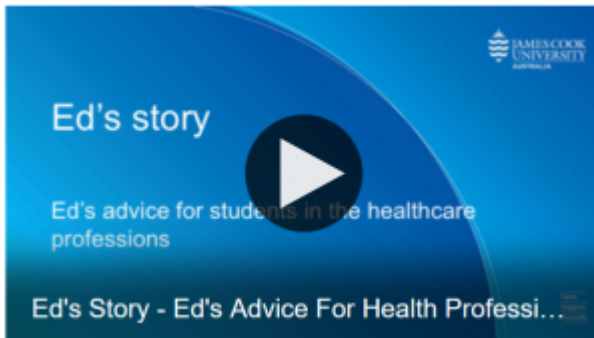
*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*

## Ed's Story: Advice for students in the health professions [VIDEO]

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### *Video Acknowledgments:*

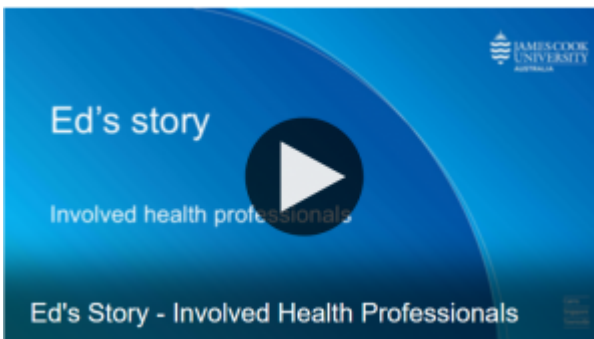
*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*

## Ed's Story: Involved health professionals [VIDEO]

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### *Video Acknowledgments:*

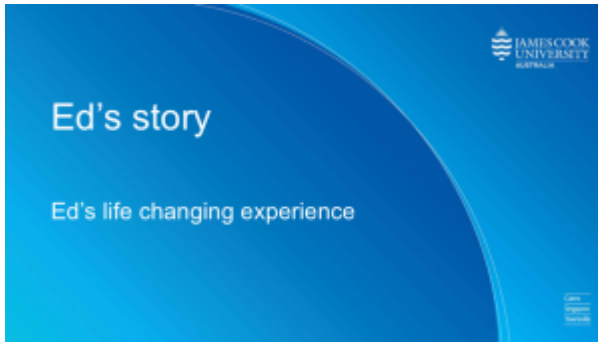
*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*

## Ed's Story: A life changing experience [VIDEO]

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*Video Acknowledgments:*

*Video Producer/DoP – Dan Sanguineti,*

*Camera Operator/Assistant – Michael Watson,*

*Video Editors – Peta Lioulios and Dan Sanguineti.*

# Glossary

## Jigsaw classroom

The Jigsaw technique is designed for cooperative learning in small groups. Students are provided the opportunity to become "experts" in a particular subject, and share that knowledge with their peers. Source: [Institute for Teaching & Learning Innovation](#)

See [appendix](#) for a short guide to the jigsaw classroom.

## Tasks of mourning

Worden's four tasks of mourning:

1. Accept the reality of the loss
2. Experience the pain of grief
3. Adjust to an environment with the deceased missing
4. Find an enduring connection with the deceased while embarking on a new life.

[Source](#): Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (4th ed.). Springer.

# *Appendix: A Short Guide to the Jigsaw Classroom*

Kellie Johns

## THE JIGSAW CLASSROOM

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Through the jigsaw cooperative learning model, one's intellectual, emotional, and practical abilities can be simultaneously developed. Myriad opportunities are provided for students to be active, "think and argue, and act creatively and innovatively in their learning process" (Nopiyanto et al., 2021, p. 27).

Structured small group cooperative jigsaw learning activities effectively increase participation (Drakeford, 2012), independence, discipline and organisational skills (AlKhaibary et al., 2021), enhance student learning motivation and student learning outcomes (Nopiyanto et al., 2021), and improve students' conceptual understanding (Palennari, as cited in AlKhaibary et al., 2012). In addition, as no one else in the group is doing the same thing, each student experiences a higher sense of ownership and accountability to the members of their group (Dabell, 2019). As well, each student in each group becomes the teacher, encouraging cooperation, friendship and knowledge development (Dabell, 2019).

However, challenges accompany this transformative process (AlKhaibary et al., 2021):

- Moving from passive to active learning requires the student to become more independent and autonomous, in so doing may increase anxiety (AlKhaibary et al., 2021).
- The jigsaw method requires students to learn from each other (rather than from the perceived expert) and so learning cannot succeed without students working sympathetically together (Dabell, 2019).
- The expectation of the jigsaw approach is that all group members participate equally; the teacher/organiser will need to monitor and encourage participation (Dabell, 2019).
- For a task to be successful, everyone must take part, exchanging pieces of information and learning from each other (Dabell, 2019).

Jigsaw activity steps, as set out in this resource, are a general guide only and can be adapted as needed for use with students, clients, carers or community participants (adapted from Dabell, 2019):

1. Divide students/ clients/ carers/ participants/into manageable-sized jigsaw groups (five to six-persons).
2. Appoint one student/ client/ carer/ participant/from each group as the group's representative/leader.
3. Divide the topic into five to six segments.
4. Assign each group's student/ client/ carer/ participant to explore/discuss/find information about one segment.

5. Give each student/ client/ carer/ participant/time to share information with their jigsaw group, and /discuss/reach consensus over what the group will convey to other groups.
6. (whole) topic knowledge is shared by having the representative/leader from each jigsaw group join other groups, telling the 'new' group what was found/discussed.
7. Bring the students/ clients/ carers/ participants/back into their original jigsaw groups.
8. Each group's topic knowledge is collated.

During the jigsaw classroom session, the workshop leader:

9. Floats from group-to-group, observing the process.
10. At the end of the session, each group could present (in a format decided on by the group) their work.

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