

The Dementia
'Journey' Legacy of
Trauma and what
to do about it

National Seniors
submission to the
Royal Commission

9 May 2019

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Preamble

Australia is working to achieve best international standards for dealing with dementia. The Commonwealth government added dementia to Australia’s health priority areas in 2012 and, subsequently, the Commonwealth, State and Territory governments developed *The National Framework for Action on Dementia 2015-2019*. Ministerial Dementia Forums were convened to identify strategies to improve dementia care. In 2016, the Department of Social Services analysed existing dementia programs leading to the development of Dementia Training Australia and a redesign of the National Dementia Support Program.

Dementia Australia is a not-for-profit advocacy organisation with excellent services and information and hosts the \$200 million National Institute for Dementia Research. The NHMRC has funded the Cognitive Decline Cooperative Research Centre bringing researchers into contact with providers and consumers to undertake and translate applied research. Projects such as the Dementia Care in Hospitals Project, initiated in Ballarat, are undergoing national trials and many high-quality care Australian providers, like Hammondcare, are consistently world leaders in practice, design and research.

Clearly there has been substantial commitment by government, providers and the community to improving the care of those living with dementia. Many people have been enabled to live a quality of life that would not have been possible without the care initiatives and knowledge translation resulting from the policy focus on dementia and the advocacy of all parties involved.

However, there is a vicious circle of poor care and cumulating carer and consumer trauma occurring which must be disrupted. If it isn’t shifted to a positive process, negative attitudes to aged care and dementia will be continually reinforced by traumatic experiences which flow in to support existing community negativity as pictured below:

The Vicious Cycle of Poor Care and Trauma



1. QUALITY CARE IS NOT REACHING EVERYONE

Dementia is the dominant diagnosis for admission to residential care, but an estimated 70% of people with dementia live in the community. For most families, the dementia care journey stretches back over many years within private home residences prior to the person with dementia entering residential care. Responses from our research and cases presented to the Commission indicate that issues of chronic under-resourcing, care cost, inadequate dementia-specific training and lack of care-worker empathy are common experiences across the home and residential care settings.

In 2018 National Seniors collected consumer experiences of people with dementia. One case clearly articulated system failings and areas that need improvement for people on their dementia journey with their carers.

1.1 One dementia journey

This interview was recorded early in 2018 with an Australian born woman, in her 70s, married with 3 children, one with autism living at home, well-educated with senior work experience, living in a well-off, metropolitan area with extensive aged care services available.

When my husband was diagnosed with Alzheimer's I decided that I was going to care for him at home 'to the end'.

Her journey began with years of caring for her husband at home and, after a considerable time searching, some respite care:

I said I needed respite with a view towards permanency but it's difficult to find respite. The facility though was the best I'd found after 3 respites then this permanent one.

This then led to a painful struggle to access the appropriate level of home care required for her husband. He had been assessed as needing the highest level of care (level 4) but only level 2 was available. The home care received was initially adequate but progressively inadequate because of the disruption of receiving only low-level care along the way and its impact on family:

Home care workers were good in the main and, yes, we had a good relationship. In the end he had one main carer but before we had two who alternated to come in the night but getting the mix is difficult. Despite this, my best option was still to attempt to keep him at home. It was frustrating that in the end there wasn't enough care available. How much does it cost for more care at home compared to residential care?

After a significant delay, he finally received the level 4 care but by that time he was rapidly declining, so home care was no longer viable. With reluctance she had him admitted to residential care. Her struggle to ensure appropriate residential care was complicated by her husband's cancer, in addition to dementia, and by the impact his inadequately supported home care had on the mental health of her adult 49-year-old autistic son living at home:

My husband was assessed for a Home Care Package in 2014 as Level 4 but given Level 2. This was a crime against humanity! Haven't we got legislation saying that everyone needs to be attended to at a certain level and everyone who needs care should get it, right money, at right level for everybody that needs it. He went into respite October-

November 2015, full-time care in December, Level 2, then August 2016 Level 4-12 months and went into rapid decline.

During this period my son, aged 49, had a mental breakdown. We went through years of hell because husband was on level 2 but needed level 4"

As a carer at home she felt 'second class' and then she found that the residential care did not respect the 'personhood' of her husband with dementia:

As a carer at home you're taking crumbs. You're subhuman in your lifestyle. You think at least you're getting some care but there's not enough qualified care. Then going into residential care, you feel you're already a second-class citizen in not paying a deposit and getting poorer standard of room. And feeding them dinner at 4:30pm! It's criminal – lock the monkeys up before they become a nuisance! Unqualified and inadequate care! There's a whole lot of inequity for aged care in training, everything. We miss out on empathy. Age care workers and disability care workers should be psych tested, understand, be sympathetic.

The high cost of residential care for her husband impacted on her now and also for future care options:

It cost \$189 per day in residential care for my husband and not many people that have that amount of money. This leaves the partner still living on subsistence level and trying to fund the person in aged care. I get so annoyed that the funds aren't going where they needed. My father and grandfather went to war but if I have money in my account that's assessed for his care as well. So, my money won't be there to fund my care when I need it!

The lack of training and medication management were a major source of frustration with care standards:

He's on a drug for agitation. What had they done - a chemical lobotomy? But now they're giving him less of the drug and at night not during the day. Why don't they know these things from the start? They would they have kept him on the dementia drugs for 3 months. He couldn't even scratch his nose. They complain when he gets up at 3am but they put him to bed at 6pm. Dementia should be classified as palliative, death row once you've got Alzheimer's! They're dying in their rooms.

Medical care was also 'light touch' at best and limited by a lack of communication with the client and their carer/advocate:

He was under 5 specialists, but I was managing his health. I had to write everything down. They said you've done our work for us. His cancer needed a needle every three months and they hadn't kept a record of when it's done. I've got to go back and make sure that is taken care of. I keep the schedule of when he has the blood tests, when he needs the needle. There was a serious lack of care co-ordination. It's all about money and not about the client.

The geriatrician asked how we get past the business of not enough staff at night in residential care. You have to sleep on a time clock or you're drugged. So she said: 'Stop it with advocacy!'. I don't know where to start, I've done it all my life with my son.

My husband has cancer and can't wear shoes, it's the pain. He gives things away. clothing, missal, rosary beads and a wedding ring recently. It was in his pocket! Why did

he take it off? He can't explain if he's in pain. Headache etc you can never tell you, he's at the mercy of the facility and you don't know what they're been given. If the aged person can't tell them what's wrong what chance have they got?

There's a major need for education about dementia to deal with this:

It's education as well – I think society can be educated e.g. wheelchair access for the disabled, all came in. We now have an understanding but not a comprehension of mental health. Saying the word doesn't give you understanding of challenges on everyday basis. This needs legislation and education and put the blueprint in place and make sure everyone is accredited to the right level to be employed.

Standards for training were also evidently not being met:

Before type of training we need legislation not for minimal standard but acceptable standard. Some have no training whatsoever – all geared to money – people without training. They're desperate to get a job, sole parents, living off the smell of an oil rag. It's the Australian psyche, we don't want these low paying jobs, so we have migrant workers with a gap in cultural understanding. We need to pay more.

Staffing ratios, shifts and resources are key issues:

How many beds, quality of care, how to get funding! They're all hell bent on fighting for the dollar they so desperately need. Rationing 3 staff for 33 people all needing personal care, hygienic nappies, shaving, changed beds. There's no time to talk to them so they're isolated. It's all about the government playing games. 3 RNs for 130 each shift, each section will have one RN, 6 AINs and a Level 5 would help. My husband needs a team to look after him, not one person.

In the end she expressed serious dissatisfaction with the residential care provided and carried the legacy from the poor and inadequate care. For consumers and carers there is cumulating trauma which then feeds into persistent negative views about residential care in the community:

He yells and screams when I leave, he hangs onto me. It takes 3 of their staff to hold him down and restrain him when I leave. You leave the place as a complete mess. Mental and aged care are very aligned, having gone through both.

There's no need to reinvent the wheel, throwing the baby out with the bathwater. You just need continuity, work out where it's working and where it's not, and you need confidence because of all the bad press.

I have a voice, many don't. I've done my grieving already.

1.2 Carers' negative experiences at home

Responses to our most recent National Seniors Social Survey and subsequent follow-up interviews suggested that most people with dementia want to be cared for in the familiarity and comfort of their home, and many of their family members want to be able to facilitate that for them. As the disease progresses, care support provided by a home care package can delay or prevent admission into residential care:

The paperwork involved in setting up a Home Care Package plan for my husband was very involved and at times confusing - However worth persevering when the help required is finally put into place. He has Alzheimer's and without the support

provided to us in our home he would by now probably be in full time Residential Aged Care.

However, as is poignantly clear from the case study, accessing appropriate care for people living with dementia at home is challenging and, in worst case scenarios, very distressing, particularly when the support provided is not sensitive to the specific needs of a person with dementia:

With my mother who has dementia, the carers would arrive at all different times and we would get complaints that Mum was aggressive - mainly because we would mark on her calendar the days and times that the carers were coming when they arrived at a different time, Mum would be agitated. It was obvious they had no training in dealing with dementia sufferers.

Also, inadequate training may undermine the support provided and adversely affect the wellbeing of both the person with dementia and their carer by causing additional distress:

(1) Few community staff were trained to manage a client with dementia. Many were either condescending or officious with my mother and their service was rejected on many occasions. The most frustrating negative was the lack of continuity of visiting staff despite repeated appeals made to Managing Staff. Mum's inability to establish a relationship with just a few care staff made her repeated refusal to accept so many different visiting staff extremely problematic. It made my job even more stressful, as I had to deal with her agitation and distress after each episode.

(2) There were not enough workers. They kept having to change the people calling on my older sister who was suffering dementia and this upset her and also made her more aggressive and resistant to having care and help that I was trying to arrange for her.

Just as good home care can avoid the move to residential care, poor care can hasten the process and the carer is left with the perception of contributing to the distress of the person they have been caring for, or dealing with their own distress:

(2 cont.) It finally meant that I had to go to the civil tribunal to obtain an order to put her into an aged care dementia home or a jail as she told me. I found this whole procedure of taking away her freedom and independence for her safety and the safety of others very stressful.

(3) My family struggled for 15 years caring for our dear parents. Mum had Alzheimer's disease, Dad was blind, frail and deaf. They were wonderful, clever, compassionate human beings. The indignities which occurred over these years were sins of omission mainly. Lack of adequate, comprehensive care while at home, resulting in dad having a complete breakdown. I almost joined him. Why are the hours of home care so hard to get and so minimal? This meant premature residential care admission for them both, the HARDEST decision I have ever made. At least they were together.

The systems supporting dementia care provision at home are complex and are the source of considerable carer stress and difficulty:

(1) Stress of navigating My Aged Care, dealing with parent's dementia and organising a calm environment for all the family to assist/support.

(2) The most difficult part of the experience of finding and accessing appropriate care for a mother with dementia was around getting adequate financial advice. Even the process of booking to receive advice through Centrelink was very difficult.

Once home support is approved, the wait for care at an appropriate level extends over months or even years leaving dementia carers powerless to manage the increasing dependency of the person with dementia and no idea of when the promised help will eventuate:

(1) With regards to my mother's ACAT Assessment, it has taken ten months for the assessment findings to be acted upon. This is totally unacceptable and not in accordance with the aim of keeping the elderly at home and out of aged care facilities.

(2) My mother had the assessment. The upgrade from Level 2 to Level 4 with dementia took too long... (over a year) to attain.

1.3 The legacy of caring experiences

Many carers provide dementia care at home for their family member or spouse with dedication and commitment for as long as possible, but as one carer acknowledged, the relentless demands of caring are traumatic:

The most traumatic time of my life involved providing 24/7 support for a spouse with both medical and cognitive (dementia) difficulties. No, I did not have adequate skills but lacking any respite 24/7 was more problematic than the skills lack... skills could be gained but not the "time out".

Although external carers provide support, the management and co-ordination of such care is an additional demand for family members who may be struggling:

It was devastating to meet many at a seminar provided at the Hospital who looked after spouses with Alzheimer's or physically/mentally disabled children and learn that the carers were on heavy antidepressants, were drinking alcohol to excess, etc. This is not healthy. Even with Social Carers, it not only adds to the responsibilities one has, it requires patience, coordination and management.

Ongoing and potentially unlimited care costs are also stressful:

I am writing this survey as if my dear wife who has advanced Alzheimer's, is doing it. As her full 24 hr Carer I do everything in and outside the home. CDC [Consumer Directed Care] so far as we are concerned is a financial disaster. The only way we can keep up with the rising costs is to increase the Additional Daily Fee, which is "open ended so far as the Client is concerned". The Government Subsidy increases do not keep up with the rising costs from [the Provider]. Thank goodness, we have prepaid our funerals.!!

Another carer acknowledged the toll that long-term dementia care had on their physical and mental health, particularly when juggling the demands of work and family with no support leaving her with a legacy of poor health:

I was the main carer for my parents and it was very stressful trying to keep all the balls in the air to look after them and also bring up 2 children as a sole parent working full time. I accessed lots of help for my parents, but there was nothing to

support me. When my father died, I was still the main carer for my mother and as her Alzheimer's gathered strength, my mental and physical health declined accordingly. There was still support for Mum, but nothing for me. Mum (95) is now in residential care and receiving amazing care. Meanwhile the very many years I was stressed and tired have very much affected my health. If only there was support for long term carers, I am sure I would be in a better health situation.

Getting appropriate respite care when the person with dementia has additional complex needs is particularly difficult:

Because my husband, who had dementia, dyspraxia and lost his sight he would not settle in respite and I could not get a break from his care in the last two years. Respite for very high care people with behaviour problems is a serious issue which is not provided for.

Respite care, although sometimes tarnished with the poor reputation of residential care was welcomed by one respondent who highlighted the benefits of day respite and that she could be assured that "he will come home at the end of the day":

I was concerned about placing my husband in Day Respite given responses from my own community and media (TV, newspaper and web). In fact, my husband enjoys the social activity and does things like singing, gardening and cooking- he doesn't do with me. He talks about it as his 'work' where there are different 'rules' of interaction than with myself and his family. Not only does it give me time to catch up with bills, shopping and some me time but it provides him with challenges whilst being assured that he will come home at the end of the day.

1.4 Legacy of residential care – the carer's perspective

For many dementia carers, the decision to move their spouse or family member into residential aged care is difficult and made more distressing by the poor reputation of institutional aged care:

I cared for my elderly parents at home for many years. Mother had Alzheimer's and incontinence, Father was legally blind and had recurrent bowel cancer and suffered significant injuries after a serious car accident. I was completely overwhelmed and struggling with my own health issues but wanted to enable my parents stay at home as long as possible because we were all very concerned about the poor quality of nursing home care.

The picture painted of residential dementia care is a grim one:

My experience has been through my mother's residential care for 2 1/2 years which was the worst experience of her life as well as my own. A slow, torturous process which eventually robs people of their dignity and any shred of independence they once experienced. Staff have no clue how to manage the many different levels of dementia, so it is a generic approach which leaves residents demoralized, isolated and trapped in a system that doesn't offer any hope.

One aged care worker highlighted the lack of staff capacity in the residential care setting to provide quality dementia care:

.... these difficult care needs have to be managed by residential staff with a ratio of limited care staff and one nurse for 60 residents. Families cannot assume their family

member will get one-on-one care. Very often it is routine care. That is why family visits and support needs to be ongoing because care staff are pushed to manage the basic care needs. Week days you have diversional therapists and volunteers who try to include residents in activities, but some residents are past wanting to do activities. Many of these horror stories on TV are dementia residents who are very difficult to care for when they resist care. If families cannot manage them, why do they think carers who have multiple residents to care for will not have problems?

The environment for dementia residents is not always enriching:

My mother was in Aged Care for a number of years until her death. We could no longer support her enough for her to stay at home. It was devastating when her dementia developed to the extent that she needed to be in a secure unit, as the unit where she was to "age in place" was very bleak and spartan.

The shift from home care to residential care typically occurs in the later stages of the disease when care at home has become unmanageable. Most dementia patients will struggle with adjusting to an unfamiliar environment, new routines and the absence of their carer. The process is undoubtedly frightening for the person with dementia and deeply distressing to all those involved in their care.

For spouses and family members, the shift to residential care means entrusting the vulnerability of those they love to care workers and care professionals. Care givers felt disempowered to make complaints about the care being received due to the perception that the quality or even provision of care was jeopardised.

(1) had complaints about my aunt's care but felt if I spoke up it would be detrimental to her in my absence. She had dementia and the administration staff played on that.

(2) When I complained about my mother's care (she had dementia and was in a locked ward) I was told that I had to find a new residential care facility. She had walked out of a locked ward (followed visitors out) and was found at a bus stop a few streets away and the home did nothing, so I complained.

(3) Alzheimer nursing home for my wife for last 6 years. I made suggestions about safety matters and it was suggested that I take my wife to another nursing home. I had 31 years in senior management..... and am a safety expert so my suggestions were not trivial.

The need for recognition and empowerment of carers to be heard on behalf of the person with dementia was expressed by one carer as:

Having the ability to be recognized as speaking for an aged parent or relative who cannot advocate for their own needs is very important.

2. WHAT TO DO: A TRAINING RESPONSE THAT IS URGENTLY NEEDED ¹

¹ Dr Anne Jones provided expert input into this section

The need for training has already been put to the Commissioners by National Seniors CEO Prof John McCallum at the first hearing of the Commission, when giving evidence of consumers care experiences often with inadequate care and staff training with a lack understanding and empathy for people with dementia. Training remains the key option for fundamental improvements in care as recommended in Australia's Aged Care Workforce Strategy 'A Matter of Care'. It is a key to breaking the cycle of traumatic experiences of care feeding into a negative community dynamic around residential care and dementia. This then makes work in aged care less attractive and diminishes the high-quality work of good providers.

2.1 Good data on qualifications is needed

It is of concern that good data on the actual qualifications held in by the aged care workforce is not available. In the broader picture, the *Accentuating the Positive* report noted that declining enrolments in the national VET qualifications did not match the increasing numbers of workers entering the sector. The workforce grew by over 58,000 workers in eight years whilst the numbers in relevant VET training declined dramatically, by 39.4 per cent from 2014 to 2016. It is obvious from the serious failures in care due to training that more detailed data is required for more precise workforce planning.

2.2 Compulsory Training: Mandating the Certificate III in Individual Support (Ageing)

There is an urgent need to mandate a minimum level of education for all personal care workers who provide day to day support for the older Australians who need it. Qualifications such as these are used to ensure minimum quality standards in many industries including children's services and the registered trades in Australia. In a volatile and complex employment environment these qualifications also give individual workers a portable credential providing evidence of their capability to work in the sector. However, history shows that many employers will not invest in formal education and training unless compelled to do so.

Following the Workforce Strategy recommendation, the new Industry Reference Committee (IRC), working through Skills IQ, has promptly responded to the recommendations for repackaging and redesigning Training Package units to better train aged support workers, namely by making the following units compulsory:

- Facilitate the empowerment of older people
- Provide support to people living with dementia
- Meet personal support needs.

However, this only applies to those who enrol in the Certificate. It follows that the Certificate III in Individual Support (Ageing) should be a mandatory qualification held by all aged services personal care workers. Unless this is mandated, and this is oversights, the three compulsory specialist aged services units will not have the expected impacts on care.

Further, all workers engaged in face-to-face services provision to aged clients should acquire the Aged or Home and Community (Ageing) Skills Set – this would include those undertaking household tasks such as cleaning. In short, all care assistants should be required to have the

Certificate III in Individual Care (Ageing). Further all team leaders and others in frontline management roles undertake the Certificate IV in Ageing Support.

2.3 Improving quality of training

Implementation of high-quality compulsory training for existing and new personal care workers is fundamental to lifting the quality of aged support. It would require scaled up availability of highly capable and appropriately experienced teaching staff. There is also a need to invest in innovative on and off the job learning to meet the needs of the large number of adults entering the aged services industry after working in other sectors. They need a careful balance of recognition of prior learning and appropriately delivered formal education.

There must be no exemptions to ensure that all engaged in face-to-face service provision for older clients achieve the competencies specified in the compulsory units. There is a special case for including education in understanding dementia which we've identified as one of the most significant gaps in aged services training. The compulsory units could become part of an induction into aged services work for all levels of employee including administrative and medical staff.

Consideration needs to be given to the best mix of on-the-job and off-the-job learning for current and prospective members of the aged care workforce at all levels. Some training may be more knowledge based (e.g. understanding dementia or the complexities of government funding packages) and may be best acquired in an off-the-job setting. Hands on skills development is best delivered in authentic learning environments, with access to actual or high-quality, simulated home care locations. The training needs to be dynamic and situated. It is important to involve good providers who can implement high quality experiential learning to ensure that workers are well-equipped to deal with the complexities of care work in client homes.

Given that provider organisations are doing significant on the job training, an apprenticeship model should be considered as an option for supporting mandated training in the aged care workforce for those without equivalent qualifications. Such a program could include blocks of off-the-job learning to complement well designed on-the-job skills acquisition. This provides access to a workforce which is motivated but unskilled who can be put into skills escalation programs.

An expansion of the range of units available as skill sets could produce a series of micro-credentials to undertake as stand-alone training (for older career changers with relevant skills) or to accumulate towards a certificate or diploma qualification for those who desire or require that credential. This approach might be supported by those employers in the aged and disability services industries who say that they can't afford to pay for workers to undertake a Certificate III and want something shorter. Dementia training and the other compulsory units would fit well into this model. On-the-job skills training would reduce training costs for employers.

2.4 Improved qualifications of trainers

The qualifications of the trainers need to be reviewed if we want to improve the skills of workers. The national VET quality system requires them to hold the qualification that they are delivering plus a Certificate IV in Training and Assessment and relevant industry experience. This is a minimalist approach and larger providers, like TAFEs, often employ staff

with higher level qualifications in addition to the mandated ones). For a care industry requiring significant cultural change, it is important that the training staff are highly capable with more than minimal understanding of the industry and their educational role in it.

2.5 Content of Training: Focus on care versus support

There is a misalignment between the health culture of the aged services workforce and elderly clients' needs. The workforce is usually referred to as the aged *care* workforce and its members tend to regard themselves as *health* workers. However, the VET certificate III is now the Certificate III in Individual Support (Ageing). *Accentuating the Positive* identified that provision of household services was the most required and under-delivered service for aged support recipients. Services such as cleaning and food preparation are not included in the Cert III. In a recent negotiation (March 2019) with a large aged services provider funded by DVA we were told that the provider's workers were not cleaners even though the approved DVA package for the aged recipient concerned specified only cleaning tasks. Either, household tasks need to be included in aged support training or providers need to employ teams with a diversity of skills.

2.6 Cultural and intercultural capabilities

There are significant gaps in the cultural and intercultural capabilities of many workers in aged service support roles. The current formal qualification does not address these. For example, the Certificate III in Individual Support was designed as a suite of specialisations (disability, aged and community and home) to create a flexible individual support workforce whose members could work across specialisations. While the concept of a flexible workforce with cross-sectoral skills is appealing, it is important to think about how to address changes in the context in which support is provided for workers who transition from one caring sector to another. The behaviour and expectations of elderly people may differ significantly from those of younger individuals needing support for disability. There needs to be clearer assessment of the cultural and contextual training workers need to transition from one individual support context to another, and appropriate action.

Workforce training also needs to address intergenerational expectations and perceptions across many different groups in the Australian aged community such as Indigenous Australians, people identifying as LGBTI and those from different ethnic backgrounds. For example, many elderly people in residential care choose a care provider associated with their own religion or ethnic background as a preference for an environment. Preparedness to respond to such a range of intercultural needs requires a higher level of skill and, perhaps, remuneration.

The evidence from consumers and future foresight indicates a clear need to review the fitness of the current VET qualifications to prepare aged services workers for the client-directed care world. It is important now to know how well the qualifications prepare workers to:

- Be capable of supporting ageing as a positive rather than a negative experience
- Support enablement
- Be active in identifying and advocating domestic and personal problem-solving options

- Be adaptable and able to respond flexibly to new client requirements
- Advise clients on complex policy and funding changes
- Work respectfully and emphatically with a range of clients including Indigenous Australians, LGBTI and various migrant groups and
- Be capable of working with clients with disabilities and conditions such as dementia.

2.7 The Skills Escalator Model

The Skills Escalator Model has been piloted in the UK as a way of upskilling workers from similar backgrounds to many of those employed in Australian aged service provision. In the Skills Escalator approach staff are encouraged through a strategy of lifelong learning to constantly renew and extend their skills and knowledge, enabling them to move up the escalator. Meanwhile, efficiencies and skill mix benefits are generated by delegating roles, work and responsibilities up and down the escalator. This is a future vision for aged care and related services where there is a matrix of skills and roles which people can move within flexibly with formal and on the job training. This will require detailed mapping of skills and cross links across occupations not exclusively the care service industries but also closely related work like hospitality and sales.

The Skills Escalator attracts a wider range of workers by offering a variety of step-on and step-off points. Traditional entry points such as certificated staff continue but they are complemented by other entry routes such as trainee and cadet schemes and role conversion, attracting people in other careers who are seeking new challenges and drawing people back into the labour market. This offers the dual benefit of growing the workforce whilst also tackling problems of unemployment and social exclusion. An active example of this from the UK is bringing immigrant women into birthing support roles and skilling them to take on care assistant and assistant nursing roles and, then, to higher level qualifications. Some type of skills escalator is needed to provide a growing workforce for an emerging and growing industry.

3. ATTEND TO THE MISSING LINK: CARERS AT HOME

The glaring gap in the care strategy including training provision is in the services provided for informal carers who provide for the needs of family and friends in their homes. The National Seniors Social Survey 2018 with follow-up interviews found that most people with dementia want to be cared for in the familiarity and comfort of their home, and many of their family members want to be able to provide that for them. Whilst the majority felt they have the skills to provide the care, they may not have the skills to provide it efficiently and safely. In our large survey some 40 per cent feel that the provision of care is affecting their health. This must be addressed by opening existing courses to informal carers and by promoting high quality online training. Both Dementia Australia and Carers Australia do excellent work in this area, but it is under resourced and under promoted.

Carers' personal characteristics and training requirements to enable quality care at home are similar across residential or home care settings but minimally supported with access to training, for example:

- Understanding of the dementia journey and needs and strategies along the way
- Theoretical and practical knowledge of the lived experience of cognitive decline and its effects on everyday function and capacity
- Understanding the need for enablement of the person with dementia across all stages of the disease
- Help with preparing a safe and effective care plan, and
- Respecting relationships that the person with dementia has with significant others and that care always must be client centred

Training should be promoted and readily accessible and low cost for informal carers. Given the public contribution made by them the cost-benefit would justify free access to training. Alternatively, online training programs such as the University of Tasmania Massive Open Online Course (MOOC) 'Understanding Dementia' provide a useful resource for caregivers.

Finally, there is much discussion of perverse disincentives to self-funding retirement rather than managing finances to get the age pension. There is little discussion of the perversity of disincentives to care for people at home. As revealed in these consumer reports they would include:

1. Taking on significant health and financial burdens to provide care at home versus depending on publicly funded care
2. Being penalised for delaying application for high-level home care by long waiting periods with those who applied at earlier need stages and the subsequent distressing lack of support when it is most needed
3. Family based care often requires complex family-based decision making and interactions that potentially increase the risk for family conflict and stress
4. Due to means and asset tests, financial reserves are depleted for later care needs of partners providing and managing home care
5. Home care enables later entry into residential care that has potentially more transition complications.

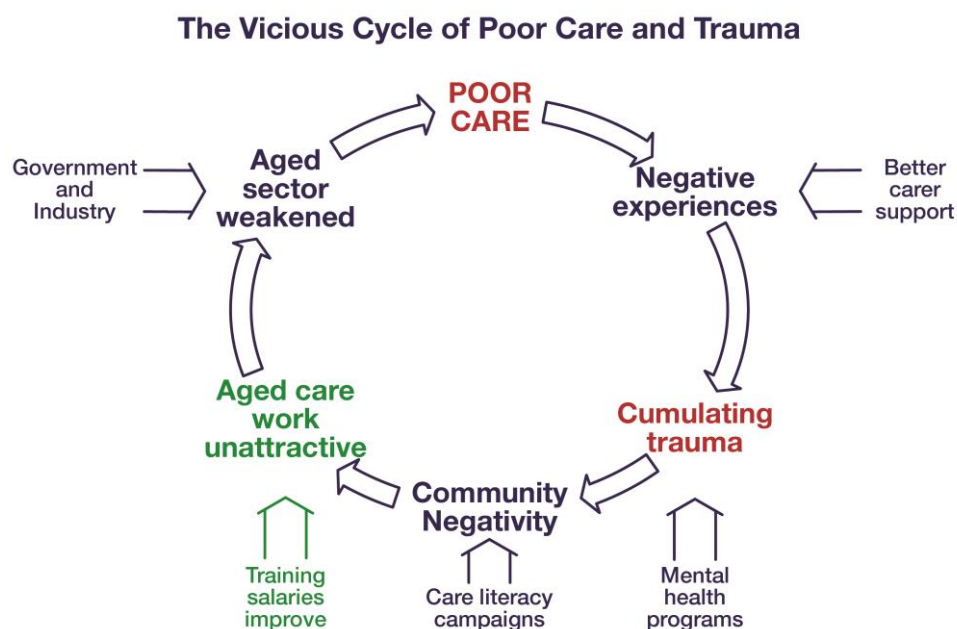
There need to be more incentives and support to maintaining lower cost care at home rather than higher cost care supported by public funds. It is economic irrationality to force people into hospitals and residential care by not providing lower cost home care. The Home Care package gap is the most outstanding case in point which was described by the CEO of National Seniors in the first day of the Royal Commission as "the running sore in aged care".

CONCLUSION: MINIMISING CUMULATIVE TRAUMA AND IMPROVING CARE

The causes of poor and abusive dementia care are complex but have their roots in negative stereotypes and community attitudes, under-resourced care facilities and inadequate training of aged care workers. People are confined to their own homes or care environment, have their rights to choose removed, face a lack of effort to empower them as consumers, lack protective safeguards as vulnerable adults, and are not enabled to maximise their lives with dementia.

This leads to cumulative trauma when the care is poor. Having done so much at home carers have a belief that at least the same standard or better will be achieved in residential care.

Sometimes there is a decline in function on admission, so this may be unrealistic, but when things go badly wrong, and their partner or parent is seriously affected, there's a legacy of trauma through that family.



Given the existing negativity about nursing homes and dementia this trauma reinforces community negativity and stigma. This cannot be reversed without stopping the trauma experienced by families receiving bad care. It will get worse without action because we know that pressures on residential care will continue as the baby boomer bulge moves into older ages and more people live longer. This has been known in demographics since the early 1980s and we are now looking at the consequences of inactivity in some key service areas.

Dementia is much feared but there is 'a light on the hill'. Diseases like cancer and heart disease were once regarded with fear like the way dementia is today. Dementia is different, but we are learning ways to live actively with dementia. We have a long way to go with dementia research with a cure or modifying therapy not expected for at least 10 years. Hence proper quality care has the 'now' priority before cure. And it is also a source of optimism that aged care is an emerging industry that with the right developments, particularly around workforce and training priorities, can enrich the lives of those with dementia and their families.

Professor John McCallum

CEO National Seniors Australia

National Seniors Australia

ABN 89 050 523 003

Level 18, 215 Adelaide Street
Brisbane QLD 4000

GPO Box 1450
Brisbane QLD 4001

general@nationalseniors.com.au



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