Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Senators,

## Commonwealth Home Support Programme

This submission seeks first to share with you my experience as a carer for my wife who died in 2019 of dementia at the end of a 20-year journey in which we suffered her diminished cognition.

In the year following my wife's death, I wrote and published a series of eleven booklets for fellow carers. I wish to emphasize to you that these works were written not as a sample-of-one experience, but as the collected experiences of over two hundred carers.

I wrote for carers, not only for spouses at home, but staff in residences. I was surprised to receive requests from teaching professors seeking to use my booklets as resources for students studying nursing degrees. I readily consented and made my work royalty-free for all academic and research purposes. This has become the largest distribution channel and extends now to four continents with some booklets translated into four languages. For these research and teaching purposes, these resources are now compiled within one book, a Word copy of which is attached to assist your Committee in identifying matters in need of improvement in the wellbeing of seniors and their carers.

My wife's symptoms commenced about 2000, and I had to resign my job as Council CEO to become sole 24*7 carer on our rural property in Central Victoria. After four years as sole carer, I flew her brother from his home in USA to assist. By 2015, her needs were greater than our combined efforts could support. She became a resident of a regional nursing home and I visited daily. I befriended some other carers, learned their stories and later became a mentor.

Along our journey, we experienced many instances in which care needs and the wellbeing of seniors and their carers were poorly met. The following quotes are examples in my booklets and the attached word file. Please note that these quotes are selected to illustrate to Senators the problems and deficiencies in the present care of seniors, those subjects needing better and more universal care :

QUOTE

I want you to survive this. To do so, you must accept that you are at risk. Take seriously the early signs of fatigue, depression, and caregiver burnout and follow our formula. Your health and your survival are at stake. This series of booklets is designed to cut the following risks and avoid having you become a victim:

Caregiving as a risk factor for mortality:The Caregiver Health Effects Study
Richard Schulz, PhD; Scott R. Beach, PhD, *JAMA.* 1999

> After adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease, participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregiving controls.

If you are a spouse, relative or friend of a person with dementia, your relationship is personal, one-to-one and your focus is the welfare of that one person. The role is intense and consuming. While the person with dementia is living at home, you can be on-call, on duty 24*7. The frequency of your caring duties increases as the disabilities increase of the person with dementia.

If you are a carer, social worker or nurse, your relationship is with a number of patients, one-to-many (or one-of-several-to-many). During your working day, you care for the welfare of all patients in your charge. This is your vocation or your career. It is demanding work for the whole duration of your shift, involving incidents and emergencies which intrude into routine caring duties. The stresses of this work are very significant and must be countered with off-shift relief.
(p.5)

Carers need more **validation** at this time and they typically don't get it from doctors. Doctors deal with patients, not carers. Doctors typically think dementia starts with dx (I have had a doctor specialising in dementia patients say that to me in writing). That is the start of a doctor’s role and the first opportunity (for a doctor) to participate in patient wellbeing.
(p.7)

Caring for a person with dementia is stressful. The same may well be true of other fatal diseases, but it is very significant when your LO does not know who you are. And it is that stress which raises the carer mortality by 63%. This says risks are real and severe and require conscious management and a **superior strategy**. This statistic is probably greater than being a circus performer. On par with going to war (the US 16th Infantry leading the D-Day invasion lost 31%). It’s as risky as playing in the NFL.
(p.7)

Way back in 2012, the (aged care support) assessor asked me "How do

you cope?" I misunderstood the question and started to describe the things I did... "But... HOW do you cope?" I said "We lower our standards" and I think she immediately regretted asking. But it was true. Cleaning happened less often. Some objectives were abandoned. We choose our battles. We lower our standards. We abandon some retirement plans. And we forgive ourselves some of our limitations. These are necessary adjustments for carer survival and the tolerance of the loads that otherwise result in carer burnout.
(p.8)

Your Survival Strategy does not end with the death of your LO. It has to extend at least as far into the grieving period as the **turning point at which renewal starts** (Book 11). Grieving presents risks of depression, isolation and giving up. Some of your dreams of Life After Dementia have to develop into plans and progress before you can feel you have survived.
(p.9)

…behaviours go un-noticed by other family members who see the patient infrequently, for short periods, when on their best behaviour ("show-timing"). Similarly, the patient's doctor, with short consultations, has no opportunity to assess the trends (Ref: Diagnosing Dementia). The carer, as a result, becomes increasingly isolated or alone in this perspective, often concluding the patient has become a complete jerk and is left unvalidated.

The patient most commonly has no insight into their own degraded behaviours (this is anosognosia, wholly involuntary and not to be confused with denial) but can observe the results of the failing relationship, the harsh words, the time sought apart.
(p.9)

To be around for your LO in the future, you must survive every crisis. To do that, you have to take care of yourself, all the time. You are now the only responsible, capable adult in this relationship. It is not selfish to look after yourself. If you are run into the ground, you cannot effectively care for your LO.

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- Use the opportunity (diagnosis) immediately to get your insurances, will, advance care directives and powers of attorney in place. A delay may cause your patient's wishes to be later challenged on the ground that he/she lacked competence.
- Get support. Involve other family and friends in the caring role early in the journey so they learn the behaviours of the person with dementia and the appropriate responses. If you leave it until later,

the gap becomes too daunting. Consider joining an online forum. Consider whether you would benefit from counseling.

- Scan and share with relatives the important documents including advance care directive and powers of attorney (and the location of the originals of very important documents like deeds and wills).
- Learn the techniques for getting reluctant patients to attend to Powers of Attorney/PoAs. Be willing to brief an attorney in advance. Consider seeking the advice of an elder lawyer regarding notifying the patient’s employer. Some have to stop working immediately because serious errors in judgment may put the employer at risk. Notifying the HR department avoids unfair dismissal and can help watch for the patient’s interests.

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"Tips for newbie carers" is a huge topic, very scary for real newbies. When your eyes are glazed by fresh diagnosis (dx), there are so many subjects coming up at once. Each newbie has different issues, concerns and values which are not addressed by the plethora of superficial brochures thrust upon them.

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... confusion, distress, anxiety, refusal, rage, fear/terror, resignation.

These emotions are heightened by a move into residence. And the very persons with dementia whose behaviours at home are so extreme as to necessitate urgent placement are the same persons whose responses to the change of environment are most extreme.

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**Apathy**
*Apathy is the most common neuropsychiatric symptom of dementia, with a bigger impact on function than memory loss -- yet it is under-researched and often forgotten in care.*

The clinical literature talks about this symptom exclusively as “apathy”. But the symptom is most commonly “entropy” where the person with dementia loses not only interest, enthusiasm (apathy) but energy (entropy). They lose the ability to walk far or fast. They would rather sleep than be bothered with activity. As a result of diminishing exercise, they may suffer other health issues, have disturbed sleep, wander without objective.
(p.25)

**Dementia and Driving** At the same time that you are pursuing a diagnosis of dementia, the difficult subject arises : when should a person with dementia stop driving? The same behaviours and symptoms that caused you to search out diagnosis are affecting driving performance.

The ability of a person with dementia to drive is determined not by their skill. The determining factor is their ability to make correct decisions in an emergency. The brain when affected by dementia can 'get around wrinkles' when it has time and when arousal is within the required band. (This is termed 'plasticity', the ability of the brain to find another way.) But the brain with dementia freezes in an emergency and arousal instantly elevates. Denied the time and conditions it needs to perform, the brain with dementia makes no decision or the wrong decision in an emergency.

The person with dementia can typically not perceive the problem. Their inability to recognize their own symptoms (called 'anosognosia') means they struggle to accept why they should not drive. Their response looks like 'denial' but is different, they really cannot see the issue. The subject becomes very challenging for them. It is more than their driving that is at stake. It is more than their independence. Their license is seen as a validation of their ability and identity and its threatened withdrawal is a devastating loss.

Managing this subject is likely to be a great early test of the carer. It will call for great empathy (think Mother Teresa scale). It will be a protracted process calling for patience. The carer has to manage the risk and keep the person with dementia safe. There are consequences for other road users, legal and insurance issues. Emotions run high. All of these demands fall upon a carer at a time they are just learning the skills of the trade.

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As the LO loses some mental faculties and aspects of their personality, the carer loses and grieves aspects of their relationship. “Anticipatory grief” is real, hurtful, and difficult to address. Typically, the carer will not receive validation for their loss of relationship nor their anticipatory grief from friends and family who do not see them daily. Comments such as “You still have your spouse/dad/mom” can cause lasting hurt.

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As a carer for a person who may have dementia, you may not need to be able to diagnose the disease. You do need to know why it is difficult, time-consuming, uncertain, likely to be delayed.  You do need to know how to gain the cooperation of your LO in the diagnostic process, perhaps repeatedly.  It will help greatly if you know how to present to the diagnosing practitioner the symptoms and trends you have experienced. You do need to know what the results mean.

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There are two things I want to kick and scream about the practice of diagnosing FTD.

First, the Diagnostic Criteria Chart accurately reflects the most common current practice. Notice that it requires for a dx of ‘Probable bv FTD’ that all three mandatory conditions A,B and C are met? Notice that C requires imaging results consistent with bvFTD? The problem is that magnetic resonance imaging (MRI) does not portray damage until neurons dissolve in a significant volume and that can be long after symptoms are present. This modern, increasing reliance upon scans is a conservative practice which considerably delays dx.

Second, all practitioners and carers know there is no objective test for FTD until autopsy. The best diagnosis of FTD presently possible is symptomatic. When cognition and behaviours are impaired and the trend shows decline, carers should accept that treatment and care should proceed as if FTD is diagnosed. But if a practitioner states only "behaviours are consistent with a dx of FTD" then carers are unreasonably denied a diagnosis. This practice compounds the problems of families suffering FTD. It denies them proper validation, leaving family disagreements about care unresolved. It denies them grounds to have driving licenses reviewed. It denies them eligibility for some insurance, veteran and welfare support. It does harm to the patient and that is inconsistent with the practitioners' duty.

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MMSE is so commonly used because it is quick.  For the most extreme contrast, a full battery of neuropsychological test instruments selected for a particular case can take days, requires very rare expert resources, requires the cooperation of carer and patient (which cannot be presumed).  Even then, a battery of neuropsych tests produces only results which are compared with a population average.  It needs at least two such batteries to produce a patient trend. Sometimes, a score sufficiently below the expected range will persuade a testing physician that it should be read as “decline”.

The world has many innovative tests.  Several, including ACE-R, are more effective than MMSE when used as a screening test for cognitive dementia. The Addenbrooke's Cognitive Examination – Revised (*ACE-R*) is a brief cognitive dementia screening *test* battery.

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**Problems:**

**1 Conducting psychometric testing first requires SUSPICION of cognitive or behavioural abnormality. By the time suspicion is aroused, damage from the onset of the disease has already caused symptomatic decline in the health of the patient and probably in the family relationships.**

**2 Testing requires COOPERATION. Patients with anosognosia (most) and those with some obsessions (few) are likely to not cooperate. There are caregiver skills which will often gain cooperation, discussed later.**

**3 Testing requires REPEAT(s) to establish a trend of declining patient symptoms, necessary to meet the cognitive diagnostic criteria. You get to do all this fun again !**

“We diagnose Alzheimer’s Disease too late,” Dr. Stephen Rao at Cleveland Clinic’s Lou Ruvo Center for Brain Health. “For most people, the disease is probably going on for ten, 15 years before they’re diagnosed.”
https://www.beingpatient.com/worrie...are-the-questions-you-should-ask-your-doctor/
And "ten, 15 years" from onset to dx is for Alzheimer's Disease!

Alzheimer's Disease is effectively screened using MMSE, but the other dementias including the FTDs are not detected effectively by MMSE. The other dementias are further delayed before dx.

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**PROGRESS?**

This is small progress, but in the right direction, I think:
https://www.mdmag.com/peer-exchange...ommendations-for-diagnosing-alzheimer-disease
Is there a conceptual framework that you use to approach the diagnostic process that you would recommend?
**Bradford C. Dickerson, MD:** “Yes...
Currently, I think we advocate for a 3-step framework that starts by describing the person’s overall cognitive functional status. What we mean by that is, does the person have mild cognitive impairment? Does the person have dementia? Maybe they don’t even have mild cognitive impairment. Maybe they have some subjective cognitive decline that they feel they’re experiencing. And when Dr Shaughnessy tests them, they

perform normally on neuropsychology tests. So in the beginning, we don't always need neuropsychology. What we really need to do is interview the person ***and, ideally, an informant***, and find out what they are lacking in terms of independent functioning. What have they lost? What do they need help with?

"... if you, as the care partner, can leave the person and go on a trip for a weekend or a week, would they function independently in daily life? If the care partner says, "No, I would never do that," you can pretty comfortably say that the person probably has crossed the threshold into dementia. I think that's the starting point, No. 1.

"No. 2 is, what's the particular cognitive behavioral syndrome that the person is experiencing? ... Is the main problem executive function? Is the main problem language? Are there multiple problems? A lot of times we see, I think, this common presentation of a person who has memory loss. They're just not holding on to information, and they also have executive dysfunction. They're not able to reason. They're not able to perform tasks to the level that they used to be able to in order to get the job done to reach goals in a valid way.

"And then the third level is, what's the brain disease that is the cause of the problem?"

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Our Royal Commission knows and reports (2020):
"Australia's population is ageing and there are increasing numbers of older Australians living with dementia."
Quite simply, we die more often from dementia which has no cure than we did in the past because cancer, heart disease, tuberculosis, whooping cough etc were greatly cured in the 20thCentury.
What is hard to measure is whether the age-specific rates of dementia are changing. That is only hard because dementia is not yet accurately diagnosed nor reported.

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**Pledge to 'detect cancer and dementia BEFORE symptoms'**

https://www.express.co.uk/news/uk/1...o-general-election-dementia-cancer-brexit-spt
This is a Great British objective, though funding is scant.

We have heard researchers talk before about a new approach to advance the diagnosis of dementia.
This is the first time I have heard the idea endorsed by a prominent

politician. And it is done in the circumstances of a closely contested election.

Of course dementia is currently diagnosed by analysis of the symptoms, so it currently must await the development and recognition of symptoms and the diagnostic queues, overcome patient non-cooperation etc. The attempt to diagnose dementia before symptoms appear is radical and requires a wholly different mindset examining biomarkers in an exploratory way in people who are not symptomatic.

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…Professor John Bell said: “The Accelerating Detection of Disease programme will ... research ... early diagnosis and help us shift the standard in healthcare forever. We have a vision to live in a world where you ***prevent disease rather than treat it too late***."

I have to say, having watched for about 20 years in a world of little effective treatment for dementia, administered too late, the vision is highly appealing.

This particular program involves a lot of genome sequencing and artificial intelligence. It will mean the analysis of biomarkers in people who are not symptomatic. There are troubling implications and not only for the maintenance of privacy.

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It is a fascinating and favourable development that the avoidance of dementia has reached a political prominence sufficient to become an electoral pledge. That is new and I believe a welcome development, regardless of which political candidate raises the subject. We have long begged for more government attention to those suffering this disease.

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[Harvard neurologist Dr. Rudy Tanzi] said he receives between a dozen and two dozen emails a day from people who took **a direct-to-consumer genetic test** and tested positive for the APOE4 variant. He tells them the gene doesn’t guarantee that they will get the disease and that many other risk factors can protect or increase one’s risk. “There are enough people doing these consumer genetic tests that you know that many more are finding out their APOE status than ever before,” Dr. Tanzi said. “The question is, is it useful? If knowing your e4 status is going to stress you out, well, stress is a risk factor. You have to think about the effect of the stress of knowing. It’s also important to consider the consequences of family members inadvertently learning they may have the e4 gene variant, too~~,~~” he noted.
https://www.wsj.com/articles/should-you-find-out-if-youre-at-risk-of-alzheimers-11563196415

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The major websites for dementia resources have two major omissions.

- Remarkably, the words “terminal” and “fatal” do not appear. The major associations avoid being the sources of this important bad news. If you need to demonstrate to your insurance company or your hospice provider that FTD is fatal, you may need your medical practitioner.
- There is little advice to help family members manage the most difficult symptoms of FTD. The major associations try to not be the cause of frightening new carers. They do not provide tips for communicating with dementia patients even though failing communications may be the major cause of fading family relationships. And they omit advice for managing rages which are common dementia symptoms.

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Before diagnosing dementia, doctors require poor cognition and declining abilities and behaviours. It takes time to observe these changes as trends.

### CASE EXAMPLE 1

Support is required when help and guidance is needed, when cause is in doubt, not when a stranger issues a diagnosis. “I wish I had access to this 10 years ago when, like many here, dementia hadn’t been mentioned and I wondered why our marriage was heading for the rocks. I wish when I was wondering ‘what now?’ I knew which resources to seek and trust and which ones were an insulting waste of time and money. I could do it all so much better now.”

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“My husband is now obsessed with a favourite sex act. He has filled the memory of his phone with porn pictures of it. He talks about it loudly in stores. He wants it every day, sometimes more often. I comply because if I don’t, his mood is negatively impacted, and it leads to episodes of rage. I have not received the support that other victims of the rage stage might receive, in part because I haven’t been open about what’s happening.”

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### CASE EXAMPLE 5

“My energy levels (physical, emotional, psychological, spiritual) while he was still living at home were, well, let's just say I was running on empty for years, and aware of it.

FTD taught me not to try to predict the future at all. I had to live in the moment. One day at a time.

I now realise that much of his violence and hostility toward me was caused by fear, fear that I could not provide him what he needed. He was right, I couldn't! It takes a village, a three-shift team of professionals with a secure facility to take care of someone who is physically able yet has lost his marbles.

He hit me on five or six occasions, a couple of times resulting in broken ribs.

It took a year or so after his placement for me to start emerging from FTD-land. A lot of my energy now goes towards trying to repair the damage that FTD has caused to our family.”

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It is very important that the carer communicates to others (doctors, family members etc.) their justified fears. One effective way to do this is to record (audio or video) the sufferer’s rages as proof of what they are trying to deal with. This may have to be done without the sufferer knowing, which seems initially like an invasion of privacy, but can turn out to be life-saving.

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If, as a carer, you want head-patting, the rosy glow brigade will carefully avoid telling you that dementia is terminal, carefully avoid discussing rage and violence and refer you to hotlines where these issues are treated as if they are exceptions. One outcome is that you and other such carers are isolated with no peer support from the big organisations.

The National Institutes of Health and the National Institute on Aging have produced a booklet "for Patients, Families and Caregivers" on FRONTOTEMPORAL DISORDERS.

The introduction sets our expectations: "NIA leads the federal government effort conducting and supporting research on aging and the health and well-being of older people."

https://order.nia.nih.gov/sites/default/files/2017-07/ADEAR_FTD_508.pdf

I read it through and it contains some useful information and no obvious errors but I was uneasy.

There was something missing. I ran my word search through it:
"terminal"? No hits.
"fatal"? No hits.
"death"? Only in reference to autopsy...

Sure enough, this leading publication from this leading research and support agency was shying away from the truth ! Eventually, on page 25, we find this gem of politically correct evasion:

**"End-of-Life Concerns**

"People with frontotemporal disorders typically live 6 to 8 years with their conditions, sometimes longer, sometimes less. Most people die of problems related to advanced disease."

Eh? Come again? "Concerns"? "Most people die..." ? The NIA has shied away from telling us the truth.

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"It takes a village" to provide 24*7*365 care for a person with dementia. And yet many carers struggle on alone in the earnest belief that they alone care more and try harder and love their relative with dementia ("Loved One" or LO)... and can do better than a three-shift professional, trained, rested operation in purpose-built premises. We often kid ourselves too long, to our detriment, and the detriment of our LO. Their opportunity to bond with carers and other residents is deferred, sometimes too long. Caring for a loved one with dementia takes a village with a mechanic, plumber, electrician, food hygienist, occupational therapist, speech therapist, personal hygienist, emergency nurse, an auditor... or a very handy wife!

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The time for placement arrives when the home caregiving environment is stressed and stretched to cope with a bad day. These signs are unmistakable and are apparent as near-calamities in nutrition, hygiene, health or safety. A caregiving team that barely scrambles to avert a disaster on a bad day may fail next time, when the problem may not be just a little bit worse.

In my experience (of hundreds of cases), the great majority of carers leave the time of placement until later than ideal. In waiting too long (and I include myself) they took unnecessary risks with the wellbeing of the person with dementia and those with whom they interact. Those risks include the real risk of injury to the person with dementia and those innocent bystanders with no knowledge of their condition or the best ways to interact with them. In waiting too long, they also deny the person with dementia the best opportunity to forge meaningful relationships with the staff and other residents.

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## CHOICE OF RESIDENCE FOR PLACEMENT

Families need to carefully deliberate the choice of residence.

The task demands extensive research, expert evaluation and calm selection. But the task comes at a time that families are under maximum duress, are often divided in direction, choice and timing. Too often, placement decisions are delayed until they are driven by a caretaking emergency. The choice of a dementia residence is very far removed from all our pre-dementia retirement plans. We work and plan all our careers for a comfortable retirement. Images of relaxation, travel, hobbies, families and fun fill our heads. And we are blindsided when faced with an alternate reality in choosing a residence for a person with FTD and challenging behaviours. Our selection criteria are rarely well matched to the new needs of the patient. Many of us are seduced by potted palms, architectural features, a grand entrance like a London hotel. We are usually at great risk of making a poor choice initially, until time, errors and adjustments occur.

There are issues to be unpacked here. The first is facility ignorance about the behaviours they are facing in a potential resident with FTD. They often have too little experience. The second is that some conduct appraisals to assess the 'suitability' or 'match' of a prospective client with their community or facility, but the appraisal is brief, not conducted in residence and often fails. The biggest risk falls not on the residential facility conducting the assessment, but on the carer or family that must manage the horrors of a poor assessment.

The commercial vultures circle, knowing families are easy prey. It is the families who are taking the biggest commercial risks and risks of stress and relocation. Contracts are written to commercially favour the supplier, not the client. The problem is not confined to residential placement but applies also to in-home care.

Families need better advice. Even the best advice available is not yet good enough. The scoresheet advice from Alz Assoc is a failure.
http://www.agis.com/Document/2/default.aspx

Families need time and counselling and they are instead in emergency stress.

Families need to not be fraudulently misled. There are websites of facilities making claims which mislead families.

Choosing a residence is a very important subject affecting all but a handful of FTD carers. I feel I was very badly advised at the time of Carole's extreme and urgent need. We survived and succeeded only because I knocked on the door of every facility within two and a half hours' drive and asked questions and made inspections until I learned enough to ask the right questions and make the telling observations.

Then, when I identified the right home for Carole, the system which meters and prioritises access got in the way.

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When I sold the farm in 2016, I burned a wheelbarrow full of brochures, directories, guides and advice about choosing residences. Mostly it was correct, but it was incomplete and not useful.

The best facilities are scarce resources. Demand exceeds supply. The task of the carer is very difficult because the right sort of residential facility for your LO at the time of placement bears no resemblance to anything you imagined in your dreams of your retirement.

The needs of dementia patients upon first placement with very few exceptions must deal with behaviours and disabilities that require specialised staff and purpose-built facilities. In late stage, when a LO can no longer walk or exhibit aggression, the needs change. Then, the care for a dementia patient becomes much closer to those of a person in hospice in an aged care facility.

There are published checklists such as
http://www.agis.com/Document/1/adult-day-care-center-checklist.aspx
I found them all unhelpful as they omitted real priorities and included factors of low significance.

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Try the reception at your local hospital and ask “Who deals with the placement of dementia patients with challenging behaviours?” Try the same question with the help line at the Alzheimer’s Association. Somebody knows what you need to know and they are hard to find.

There are commercial agencies which can be useful. One in USA is “A Place For Mom”. But they can at best give you a good short list and final selection is yours.
One that I used in regional Australia was a service called Direct2Care :
http://dpp.grampiansml.com.au/ongoing-management-and-care/recommended-referrals-post-diagnosis/direct2care/

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Successful placement happens before somebody gets hurt or killed, before family wealth is substantially squandered, before family members are sexually abused or relationships ruined, before carer health is needlessly sacrificed.

I did not reach that success and nor did many other carers I know, while others did.

Here is the problem. If you deserve the medal for successful placement, you don't get a Purple Heart for taking injury. You don't get the satisfaction of thinking "I went right to the wire."

Let me tell you very clearly that Success is far better, and I have seen both up close. To achieve Success, you don't cross one of those lines and nobody gets hurt.

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The time for your husband's placement is often expressed by health workers to be related to his behaviours and condition. That is true for broken ribs and it is not true for FTD. The time for placement of an FTD patient has nothing to do with the patient's age or stage. It is when the carer says : "On the worst day, I cannot cope with the behaviours or cannot keep everybody safe". "Everybody" is not just the spouse and kids, it is other road users, checkout chicks, cops, neighbours, shoppers, anybody he interacts with. Residential placement is necessary when the load of caring becomes too great for the family resources available. It is appropriate when the load ***once*** becomes too great, not when the load is on average too great, or always too great. On your worst day, if you cannot cope, you are at risk of injury to patient, carer or both or to unsuspecting bystanders.

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Benzodiazepines can cause significant behavioral disturbances in dementia patients in addition to **increasing the risk of falls, fractures, and worsening cognition.** [87,88] Benzodiazepines are inappropriate especially if used for behavioral disturbances that are secondary to medical problems. Nonetheless, there is a high prevalence of inappropriate use of benzodiazepines in frail, older adults in nursing homes and in the community. Best practice recommendations for benzodiazepine use in patients with dementia include (1) emergency or short-term (few days) use; (2) use of short half-life agents, preferably metabolized through phase 2 (e.g., lorazepam, oxazepam); and (3) avoidance of other central nervous system depressants. In long-term care facilities, it is recommended to follow the criteria set forth by Beers [89]: **benzodiazepine use is inappropriate (1) if it includes any use of flurazepam, diazepam, or chlordiazepoxide and (2) if the following recommended dosing limits per 24 hours are exceeded:** lorazepam (3 mg), oxazepam (60 mg), alprazolam (2 mg), temazepam (15 mg), triazolam (0.25 mg), and 5 mg for the nonbenzodiazepine hypnotic zolpidem.

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. Palliative medicine and palliative care have as their objective the relief of suffering and the provision of comfort. Hospice has as its objective the quality of life of the whole patient and that includes their relationships with family members when the end of life is inevitable and life must be brought to its close. So palliative care may start earlier than hospice, but hospice is a broader concept encompassing all things and people surrounding the patient.

Hospice is particularly important in dementia cases because it cares for the whole patient and their family. It is a huge departure from the medical practitioner ethos of curing disease in the patient. Hospice is immediately relevant and appropriate for the dementia journey because the needs of the carer have been subordinated always, for years, to the needs of the patient. Hospice is a bigger benefit to a dementia carer because they have been deprived of support by conventional medical practice.

Hospice is part of the health system, costs money, and is under resource stress, so gets surrounded with bureaucracy and rules. Depending where you go and what rules apply, "eligibility" may require a life expectancy not greater than six months or twelve months, may require significant decline over a specific observed period, may require treatment for a comorbidity factor within the last year, and a dozen more measures. They are poor measures, but they are present in a bid to meter out scarce resources.
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4. We must have an Advance Directive (Even if we aren't sick we need to have an Advance Directive.) An Advance Directive tells medical professionals how we want to live our life until we are not living it anymore. Without an Advance Directive the medical professionals will decide how we live and die. https://www.legalnature.com/lp/ahcd/Free-Advanced-healthcare-directive-form?utm_source

5. A terminal illness is a gift of time. Most people don't know when or how their death is coming. When the doctors tell us they are having a hard time fixing us, as difficult as it is, they are giving us a gift, a gift of time. This is the time to do and say what we want said and done.

(p.120)

We can choose to turn our limited future over to medical professionals and go with whatever they decide to do with us if that is what we want. Or, and many people don't know this, we can choose to take the reins, do some research, ask questions and make decisions on how we want our final act of living to unfold. It doesn't have to be all or nothing either. What do we want our last experience to be? We have the power to make it so.

(p.121)

…I set myself a target.  The things I would write to help other carers learn from our journey would be written before 23 April 202 … Nothing should exceed a ten-minute read because that is all the time carers can find.

(p.130)

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**The Money**
One part of my "Picking Up The Pieces" has been **finances**.  It is all progressing, but I have learned a couple of lessons. So I thought I would record the story and the conclusions I reached.

Carole had some retirement savings in a superannuation fund. As PoA, I could have drawn them down and expended them on her care. But I did not.

Australia has a financial arrangement for financing residential care partly through the deposit with the provider of a Refundable Accommodation Deposit. (The provider gets the benefit of interest on the investment.) And the other part of the residential care is funded through a daily fee. Within limits, a carer (exercising Power of Attorney for the LO) can trade off between these two costs, reducing the up-front lump in exchange for higher daily fees.

In our part of rural Victoria, the RAD (set by market forces) was $350k in Jan 2015. In the larger cities, the RAD is typically around $1m for a high care Nursing Home.
There are several major factors influencing the RAD/daily fee tradeoff decision:

- interest rates. When rates are low, as now, it hurts less to pay the RAD and forego the interest on investment.
- prognosis. When time is short, it hurts less to pay a higher daily rate.
- affordability. Carole did not have $350k in retirement savings but I did.

So my decision in Jan 2015 was to pay the max RAD to reduce the daily fee. Good decision. But I paid it from my funds, and later realised that complicated things because the eventual refund goes to the estate of the resident. I took legal advice. 'No worries, there are no death duties, you get it all back from the estate.' True. But I now learn that is not quick or easy. Carole's new NH (2019) has a policy to only refund the RAD upon grant of probate. But for that policy, her estate would not have been sufficient to require probate. And probate costs over $1,000 and takes 9-ish months. (I did it myself because I am a JP and understand the language and process, but I incurred minor delays because of remoteness from the court and difficulties getting certified copies. Throwing $3,000 extra at a probate attorney might have saved say two months.)

The new NH got to care for Carole for three months, but got my money for 12 months. Bad decision. I should have paid minimum RAD in 2019.

But there is one part of the story that survives export to other countries.
My decisions were partly emotional. Carole was losing so much with dementia, I did not want to see her lose her money too. So I preserved it by paying for her care. Not clever. I should have preserved just enough to pay her bequests to her kids.
It would have been very easy to pay for her care using the PoA I held. I could have done that as long as her money lasted, down to a balance to pay the bequests.
So the message is to use LO's money first to pay for care costs. That's what Power of Attorney is for.

(p.135)

UNQUOTE

I should conclude with some consequences of our journey in caring for a senior approaching death.

It was more successful than most. My wife died with no cognition, therefore no fear. I survived despite the heightened mortality statistics for carers.

I lost friends who were carers in similar circumstances who did not survive the journey.

Many old friendships faded because, in the focus and workload of caring, they were not nourished. But new friendships were forged in adversity, from the admiration for the work, dedication and spirit of other carers.

Financially, the experience was disastrous. We had been healthy and wealthy, with big income, large property, no debt, comfortable savings and generous superannuation provisions. Now, the costs of the journey and residential care have left me with no property and obliged to live within only residual savings.

I learned much and recorded the lessons. They have greatly helped other carers and nursing students. I hope they help guide the work of the Committee.

Sincerely,

Glen Davis