A SUBMISSION TO A SENATE COMMITTEE

REVIEW OF CARE AND MANAGEMENT OF YOUNGER AND OLDER AUSTRALIANS LIVING WITH DEMENTIA AND BEHAVIOURAL AND PSYCHIATRIC SYMPTOMS OF DEMENTIA (BPSD)

INTRODUCTION

This submission starts with three stories.

During a recent visit to an aged care facility I overhead a woman pleading with her mother as follows: “Mother, you mustn’t draw attention to yourself by complaining. Just keep a low profile, keep your head down, and make sure you fit in”.

My own mother has been frequently heard to say, in a similar facility “They’re all nuts in here.” My late father complained that attending the weekly happy hour was hopeless because there was no-one with whom he could have a conversation.

In talking to a pastoral worker, before I presided at a monthly Communion service in an aged care facility, she commented that you could run the best service possible, but what the residents craved for was Holy Communion.

THE JOURNEY WITH DEMENTIA

Impact on families

It is well documented that management of dementia is enhanced by early diagnosis. But a common experience is that many of those with dementia will cover up the symptoms of the disease, and indeed, will become quite adept at masking those symptoms.

But coming to terms with parents having dementia is also disguised by their partners, children and other family members, who do not wish to face up to the perceived stigma of managing parents with dementia.

Coping with dementia, places even well-adjusted families under considerable stress. For aging couples coping with any challenge can no longer be taken in one’s stride.

It is families not equipped to deal with dementia and those who face the condition alone who deserve much support. The more elderly persons can remain at home, in familiar surrounds, the better their quality of life and the lesser the burden on over-strained care facilities.

Respite

There can be no doubt that adequate access to respite provides carers with a much needed break, although the effort involved in maintaining a visiting regime by family and friends should not be underestimated. A common purpose in using respite can be the beginning of a socialization process to accustom individuals to the notion of permanent residential care. However, this can lead to resistance to utilizing respite on the part of the person needing care and penalizes both them and their carers.

Government interventions

My experience with some government appointed officials has been most favourable. The Office of the Public Advocate goes about a difficult task efficiently, with compassion, and with respect for the rights and feelings of those affected with dementia and their families and supporters. The Office of the Public Advocate exercises great skill in identifying the wishes of persons affected with dementia, and in protecting their rights.

The Public Trustee performs a valuable and essential role in exercising stewardship over finances. One problem here is that staff turnover in the Public Trustee's Office is high, which means that individuals find themselves dealing with a succession of officers, none of whom has time to become familiar with the needs of their clients.

Assessment of dementia/Alzheimers

Some assessment processes need to be reviewed. The connection between asking a client for quite specific historical and quantitative information, and determining cognitive functions, is questionable. Persons with dementia can be quite capable of knowing their own intentions in certain matters, but existing testing does not seem competent to assess these capabilities, although perfectly defensible in the light of its own standards and norms.

Powers of Attorney/Estate management

One of the least satisfactory aspects of managing the affairs of persons with dementia is in the financial and legal domains. The abuses that can occur arising from misuse of Powers of Attorney are well documented, for example in the report of the Victorian Law Reform Committee. But State Parliaments are slow to enact legislation that assures the competence and accountability of those exercising Powers of Attorney. Nor are there adequate penalties in place for those misusing their powers.

In the same domain are issues around testamentary capacity and the role of Executors.

The situation with Medical Powers of Attorney seems even more confusing. On some medical matters, residential institutions seem to deal with the relative or carer who visits most regularly, and to not consult with, or keep adequately informed, the holder of the Medical Power of Attorney.

Private Care facilities

Many of the items mentioned here may be regarded as trivial, and properly matters for internal management. But their occurrence is frequent and adds to the stress of individuals and carers.

It is quite evident that those entrusted with management responsibilities in care facilities are not fully aware of what is happening at the level of most basic interaction between resident and staff member.

Residents are greatly concerned at tardy or no responses to requests for toilet attention. Soiling oneself is very distressing for residents and family members and all too common. The response of staff to complaints is that they are busy elsewhere, or in one recent instance I am aware of, that the entitlement of staff to meal-breaks took precedence.

Some of the issues of concern can arise from cultural differences between staff and residents. This is especially so where members of staff have predominantly been born overseas. Apart from language difficulties leading to misunderstandings, it is quite clear that staff originating from other countries observe different standards of hygiene.

One staff member once told my wife that although they endeavoured to maintain high standards of care, it is impossible to notice the personal attention matters that a family member would. Do a study into losses of false teeth, irregular cleaning of teeth, irregular cleaning of rooms, frequent losses of clothing or being given clothing belonging to others, and you may better understand the context. Commonly, family members find themselves purchasing items for parents over and over again, because possessions disappear, sometimes at the hands of other residents. Much anecdotal evidence suggests jewellery and valuables are not safe during residence or at death.

Although policies are in place to deter staff from accepting gifts from residents, friendships are formed between staff and residents, and well-to-do residents often desire to be generous towards carers.

Residents who are hard of hearing have particular issues. It is often not appreciated by staff that their communications are not being understood. Or they may take a smile and a nod as indicating assent, whereas the intention of the resident is simply not to give offence and/or to provide the response they believe is required.

Where a resident sustains an accident, has a fall, or some other mishap, I have found the practice in notifying family members varies considerably. In some instances, where a condition continually repeats itself and the solution is well known, some staff will not act without authorization from a medical practitioner. The time delays involved mean that a relatively straightforward situation deteriorates into something far worse.

Some para-medical staff may also not observe correct protocols eg a resident recently was given an eye test without permission or approval being sought.

Securing adequate medical attention can be an issue for example, specialist dental attention and pacemaker checks require a resident to attend professional premises in person. For infirm residents who are over 90 years of age, this is a virtually impossible ordeal to which to submit them.

For someone with advanced Alzheimers, being placed in foreign surroundings can spark terror driven reactions. For relatives to witness a loved one in a hospital setting become absolutely fearful, and then have to drive her back to her place of residence while in a terrified state, is no easy task.

No doubt some residents whose behaviour becomes difficult are subject to sedation, whereas those whose behaviour becomes too difficult to manage are transferred to more specialist facilities.

But people with dementia and Alzheimers do wander, and I have observed what a terrifying experience it can be for elderly people if a complete stranger turns up in their bedroom in the early hours of the morning.

In one instance of which I am aware, an elderly former colleague took on the burden of feeding a lifelong friend who had Alzheimers, attending every day for three years until his friend passed away. This does raise issues about steps taken to feed those no longer able to feed themselves. It may mean that in some places, residents are slowly starving.

Other instances include seating arrangements when residents have meals. Dynamics between elderly persons can change quite quickly due to real or imagined slights. But what does happen is that friendships turn sour, and all of a sudden a former friend becomes aggressively nasty, and the individual being verbally harangued does not have the capacity to deal with this.

While on the subject of meals, my mother-in-law, who had Alzheimers, found herself at one stage taking meals at a narrow table immediately facing a blank wall. No explanation as to why this was necessary was ever provided.

While we are aware that infections can spread rapidly amongst elderly people living closely together, and while the provider response of declaring a shut down is quite defensible, there has to be some means of allowing some form of interaction between the resident and family members during a shutdown. For people with dementia/Alzheimers to be isolated from family for three weeks or more, which I have seen, creates a very difficult situation, which is quite unsatisfactory.

I have noticed that attention to a spiritual dimension of residential care varies considerable across private providers. Some, but not all, provide regular religious services, reasonably representative of denominational interests. Given that residents of aged care facilities are in the final stages of their lives, you might imagine that spiritual issues, and just dealing with the inevitable onset of death might receive more attention than it does.

There is certainly a different atmosphere in those places that provide some person whose role for at least some of the time, is pastoral care. People in these roles can provide and facilitate valuable links with external faith communities.

TREATMENT OF BONDS

I understand the amount payable by way of a bond may vary, and that 10% of accommodation places must be reserved for those in need. However, it seems inequitable to me that care institutions can deduct money from bonds for five years. For the resident, the value of their asset is eroded by inflation, permitted deductions, and their incapacity to earn modest income from their asset. This situation needs to be revised.

ADVOCACY

Being unable to fend for themselves, dementia/Alzheimers sufferers are among the least advantaged members of the community. They also have difficulty in making their feelings about their treatment known, or even are not in a position to do so. Yes, there are regular meetings of family members and residents and there are customer satisfaction surveys, all of which are very laudable. But they fail to get at the root causes of resident disquiet. All too often, the management of residential institutions react defensively to criticism, or provide bland assurances while doing very little to address problems.

Some interest groups become so obsessed with their own expertise, that they become vested interests in preserving "the industry" and their role within it. But they do not get to the heart of issues.

WHAT WOULD I LIKE TO SEE HAPPEN?

1. Enactment of legislation improving the operation of Powers of Attorney, with less reliance on unskilled family members acting in this capacity. Better selection of more competent people to act in this capacity with greater accountability and appropriate penalties for wilful criminal behaviour.
2. Better protection for ensuring that testamentary intentions reflect the wishes of the individual making a will.
3. Improved resourcing for government trustee officers.
4. Improved methods of controlling potential spread of infections other than by using shut downs as a blunt instrument.
5. Better protection for resident private possessions and less loss of items, including items of value. Perhaps inventories of valuable items, such as jewellery should be part of admission processes.
6. Greater use of helping facilities to maintain individuals at home eg cleaning and cooking. A culture of "independence" and "not causing any fuss" works against this.
7. Revision of fitness for purpose of tests used for assessing mental capacity.
8. Consideration of making treatment of bonds more equitable and arresting erosion of the value of such assets.
9. Introduction of earlier diagnosis of dementia/Alzheimers, even by means of compulsory testing or encouragement of individuals over the age of 60 to participate in bi-ennial testing.
10. Increased respite entitlements.
11. Improved management and supervisory capacity for staff holding positions of responsibility in care facilities.
12. Improved hygiene practices on the part of PCA's.
13. Better communication with relatives about medical interventions for residents.
14. Extension of spiritually driven pastoral care eg through chaplaincy arrangements similar to those in schools.
15. Review of advocacy mechanisms so that those with these conditions will be heard.

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