Submission to Productivity Commission Inquiry

Caring for Older Australians

From Georgina Pinkas

Background

I welcome the Commission's Inquiry into Aged Care. I have cared for three people who lived into their 90's and between them had home care packages, lived in three residential aged care homes at the high and low care levels and transferred between the ACT and NSW at various times in their aged care. I make this submission in response to my great sadness over the inadequate care they experienced at the end of their lives. My submission is personal and based on my experiences over the last five years with responsibility for their care. I also make this submission in response to the, at times, poor care I witnessed happening to others in the aged care sector and my great concern for aged care workers. I also acknowledge the very special care provided by some of those workers.

For privacy reasons I will refer to the people I cared for as A who was a person who had a leg amputation at 89, B who had dementia then got cancer and then broke a hip at 91 and C who at 94 was mentally alert and sociable, but disabled through severe coronary artery blockages. All three are now deceased but their suffering remains clear in my mind so I am compelled to make this submission with a view to hopefully helping to improve care services.

Advocate

(1) Information

All aged people need an advocate to navigate with them through the very complex and confusing array of services from different providers and different levels of Government. While I was a public servant and used to funding and administrative systems, I found it very difficult to build a comprehensive picture of what was available and what could be expected to be provided and by whom. This was made more difficult in that initially the people I cared for lived in two towns in NSW and I lived in the ACT. Local Government Services were varied and complex to unravel in the context of home care programs funded by the Commonwealth. I spent much time finding what programs the person with dementia could access while receiving a home care program. These difficulties were experienced despite being a member of Alzheimer's Australia. I could not find a one stop shop for information. When the social worker from the local hospital in Sydney did an ACAT referral she did not advise of the range of service providers but rather referred B and C to one provider. We had no choice and due to the inability to find other providers we had to stay with that one. The matter was made more complex by the individual local government arrangements which one couldn't access if receiving other programs, but still wasted time following referrals from well meaning but uninformed practitioners. The similarity in names of various programs also made comprehension of the available services more difficult.

B with dementia was given an EACH package but at no stage were we told we could access services up to 20 hours per week, nor were we shown a menu of services. It seemed to me at the time that there was little transparency in the provisions of the home care services and providers. We just had to take what was offered verbally, rather than select from a specified menu of services.

Recommendation

A one stop reference point to cover all aged care services across different levels of government with case manager advisors appointed to assist clients' access the relevant services. Better still perhaps is to have aged care managed by one level of government.

Provide an aged care book similar to one I found in Centrelink, which I was advised was not generally available. This easily readable book covered all fields including pensions, bonds, assets, residential care, home care etc. The booklet must be capeble of having pages updated. This must be provided in addition to information on a website as many older Australians are not familiar with the Web.

2. A Personal Advocate

As well as information gathering and analysis, older people may well need a personal advocate to probe, question, assess and discuss care options and interpret availability of care programs and discuss options with clients. A personal advocate is also needed to ensure continuity of care especially when transferring to and from hospital. Serious health issues can be caused by a lack of information in areas such as transfer or not of medicine, scripts, medical information from GPs and Specialists between them and the treating hospital. This was a particular concern for C with a severe cardiac condition. We found that he had not had his angina medication (warfrin) for almost a week after he was sent home from hospital. The patient could not recognize this as brands of medication were changed in hospital and the patient was sent home with a Webster pack but no advice what was for what with unknown medication terminology and unfamiliar looking pills all jumbled together in a Webster pack.

When B went into hospital for hip fracture, there was no assistance for a person with dementia. No continuity of care and if I hadn't been there the patient would not have eaten or undertaken more than the basic rehabilitation. The physiotherapy regime in the retirement home did not even know of the physiotherapist's notes until I pointed them out having seen them written in the care notes.

A,B and C were lucky in that they had a caring family to advocate for them but even then I would have very much valued a one stop shop point of reference - a care coordinator. When B, with no notice was discharged from hospital and had to go because the ambulance was there, there was no medical discharge report that went with her as to her needs back in the residence nor was there any medicine or scripts. Notes and scripts came about 5 hours later in a taxi with no hope of procuring the medication until the next day. Meanwhile I had to debate with the ACF about what preventative measures were taken to prevent another fracture.

Recommendation

It is important to assign an advocate for each aged person requiring care assistance. Sometimes this role can be undertaken by a family member or friend, however, there should be a means of primary carers accessing an advocate for people who do not have this type of support.

As an information point of reference, an assistant advocate should be made available to support those who can provide that service from within family or friends.

Flow charts and information sheets for accessing services on discharge and what to look for when discharged should be provided eg “When you leave hospital you should have the following: medical transfer report ; medical scripts and interpretation sheet; temporary supply of medication; follow rehabilitation services etc. Notice to people not to leave without the above should be given on discharge. A report should be transferred to hospital with patient including medication

Cross Border Issues

Client A lived in NSW but had his leg amputated and his rehabilitation in the ACT. He had to apply for a wheel chair from a NSW program where there was a very long wait. No arrangements were made while in rehabilitation in the ACT, as there was no allied health practitioner in his home town to fit the chair when it arrived. We were not advised of any of this until discharge. We could have asked for the chair to be ordered at the beginning of rehab and made arrangements to bring A back to the ACT for chair fitting. Hopefully a client advocate would have been able to alert us to this problem and think outside the square. Also these services should be Commonwealth based rather than state based. Not everyone fits neatly within State borders.

Access to Aged Care Facilities

1. How to find a facility and how to access one.

   I had to phone many contacts before I got an understanding of the Aged Care facilities (ACFs) in the areas A, B and C lived in. Booklets should provide a matrix of facilities in a region with the services they provide. A comparative rating system should also be provided to the public with rating assessments made by the Department, medical practitioners, residents and relations. Separate ratings should be given for standard of facilities and standard of care

   It would be helpful if waiting list and bed availability was listed on a website and updated regularly. If this can be done on “Wotif” then it appears possible to do this for residential aged care.

2. **Financial arrangements**

   B was assessed as requiring low care dementia accommodation and C required high care. A major factor in the care of B was that a bond of $350,000 had to be paid. Knowing that a similar Bond would also have to be found for C when B and C transferred later to an ACF nearer to their family and the total bond to be paid for 2 people would be $700,000, I sought financial advice. Luckily I did because the financial advisor told me that if we paid part of the bond as a periodic payment then B's house could be rented and the income not treated as income by Centrelink. This small piece of advice was very significant in enabling B to receive a significant aged pension. We paid $340,000 and paid $10,000 as a periodic payment. Many people I spoke to in and out of Government service were unaware of this provision. I fail to see the logic of it but appreciated the provision. It would be fairer and more sensible to allow this provision to be broadened to all aged care residents who paid bonds and leased out their homes. The periodic payment requirement seems to be not relevant to the issue.

Recommendation:

That income from renting an aged person's home is not counted as income for Centrelink's assessment of income.

Payment of Bond reduction money

The legislation and normal practice is for the retention amount of the Bond to be taken out of the bond for a maximum of 5 years. However, with pressure to accept whatever was offered in trying to find accommodation for 2 people, one with low care dementia needs and one with high care needs, we were at the mercy of the aged care home and accepted an arrangement where we paid the retention amount each month so that the bond figure owed on departure remain the same. Long term this would have become a financial problem and this practice should be made illegal. Too often desperate people accept whatever the residential provider decides, due to the need to access a care bed.

While the legislation specifies when the Bond is paid back that there is an interest rate that applies from the time of death until the bond is paid to the estate. I have received a letter telling me the amount of bond to be paid following probate but no mention of interest.

ACF's should be required to provide, as a schedule to the contract, the relevant parts of the Act at the time of contract with advice to check updates.

Similarly, there needs to be legislation regarding refunds of licence money for independent living units. A person paid a deposit to move into an independent living unit which was still under construction. While waiting to move in the person had a medical event and needed to move into low care rather than independent living. The ACF had no low care vacancy so the person went into another ACF which required a bond. Despite needing the refund for the bond in the new ACF, the person was unable to get the initial deposit on the ILU back for 6 months due to the reticence of the ILU provider. Contracts for such care need to be regulated better.

Care while in RCF

1 .Facilities

The Commonwealth is to be commended over its actions to ensure facilities are upgraded and modernised. There should, however, be standards for new facilities such as solar access to living areas in dementia wards, size of lounge and dining areas to be set per number of residents, craft and activity areas set aside for dementia patients.

2 .Carers

The reducing number of carers and the increasing number of people needing aged care is by far the biggest factor in poor care and a portent of future disasters in the provision of ACF care. Pay conditions for all care workers are totally unacceptable. Registered nurses should get similar pay to RNs in hospitals as should EN's. Personal carers must be paid a wage commensurate with the demands of their jobs. Currently people can earn as much, or more, working in much less demanding jobs in supermarkets and other areas. Our aged should be amongst out most treasured people and deserve the best of care in their last years. Australia is a wealthy country and there is no excuse for not funding the carers of our parents and grandparents adequately. With current rates of pay only the dedicated or the desperate are applying to work in ACFs. Wages should be tied to wages for equivalent workers in the health care system.

An important issue is to have staff client ratios legislated. Too often there were insufficient staff on duty in the ACF. Standards should be set and legislated for the ratio of carers to clients with special standards for dementia and high care areas. If staff ratios can be legislated for child care, why not elderly care? Our elderly are no less deserving than our children and their care is often more critical and complex.

Supervision ratios should also be legislated. In B's dementia care unit a team leader specific for dementia was during staff shortages required to supervise the dementia wing and a low care wing. This arrangement became permanent with resulting deterioration of care in the unsupervised dementia unit. At another ACF there was a permanent supervisor for the dementia area with several deputies to relieve. The care there was excellent due to the team leaders understanding the specific requirements of each client. In the second facility teams leaders were swapped around the whole facility at random with people not knowing the special needs of dementia clients. The carers were also upset at this arrangement and I found very good staff crying with frustration and exhaustion.

There should be a registration system for aged care workers with a register of carers who have abused clients to ensure protection of residents.

Workers are paid so little it is difficult to attract staff and even more difficult to keep them. It has become necessary at times to employ people with poor English skills and at times limited relevant cultural understanding to handle care of our elderly. Better training and supervision and pay will all help address this problem.

I have been amazed at the dedication of carers who have, in my view, appalling working conditions and pay. Many of them do it out of a sense of love and need of the clients but that is exploitation of the carers. Others do it because of their lack of skills they have little choice. What we need "going forward" is well trained, skilled, supervised and appropriately rewarded carers. WITHOUT appropriate pay levels we will not be able to attract people to work in this industry. It is hard demanding, soul wrenching work and requires caring well rewarded, contented workers.

3 Funding for extra care

Client B had sufficient funds to purchase extra carers services to help her in her daily living. There was no way I could achieve this within the ACF administrative processes. So I employed a private carer to assist me look after B. This cost $50 an hour to a private care agency. At times the private carer helped serve meals etc to the other residents as there were insufficient staff on duty. The private carer's duties were to feed and socialise with B. There was very little social stimulus therapy given in the dementia area once people's behaviour prohibited general outings with other residents. Dementia specific activities on a daily basic should be mandated.

Nutrition

Client B was in an ACF for over a year. At no time did I see a dietician to discuss her difficult eating patterns. Food provided at evening meal was totally inappropriate for older people - pizza, party pie, powdered soup, fried rice. Those who were slow in eating were often tempted with bread and jam to fill them up. As one client said to me when I asked what she thought of the food, "Bloomin'horrible". I had to agree.

Personal Care

Nail care was ignored, despite client B being on a high care package in the later days of living in the ACF. Many requests were made for B to see the podiatrist and these were mostly not followed up. B's dentures were not cleaned and it was only when in hospital it was discovered her bottom denture had been missing for some time. No record of this in any report. Sometimes a Doctor had to be requested at my insistence from time to time. Symptoms of the cancer were not followed up until I insisted.

All these issues point to the need for more skilled staff with adequate remuneration and supervision as outlined above.

Psycho Geriatric care

Reference in other submissions raises the issue of care for people with psychological issues. It was very distressing to see the Zombie like status of people in the dementia area who had "settled". While B was suffering from severe anxiety with dementia, I knew there was over medication and had a very difficult time in getting proper assessment of medication needs in relation to anxiety and other disorders. Better access to diagnosis and medication monitoring should be provided for Dementia sufferers.

Funding issues and Other Matters

Greater transparency needs to be given to reporting financial management in ACF's. It needs to be public information on what the ratio of funding direct to paying carers as opposed to management and other overheads.

Provision should be made for those who can afford it to purchase extra care hours from the RCF. Another possibility is to investigate the possibility of some form of aged care insurance on a similar basis to private health insurance.

The division of high care low care in ageing in place facilities is becoming blurred. From a consumer's perspective the distinction in payment regimes is confusing. Why do people in high care pay no accommodation bond in some facilities and yet they same person is required to do so in others? Why do people in High care pay the accommodation fee on a regular basis? I received a letter from the ACF that B had been reclassified from low care to high care by the manager of the ACF. I was not asked to participate or advised of this assessment beforehand. In my view the only difference in the care provided was that B, who could walk and move unassisted, was now showered and dressed. While then assessed as high care, B's bond was still retained. I think this unilateral approach to reclassification is fraught.

Flexible models of accommodation

Consideration should be given to enable couples to stay together either in the same or in adjoining rooms as many older people do not share a room at home. If one person has a need for high care and the other does not, then they still should be accommodated together. Similarly with dementia residents. If it is not too stressful for the person without dementia, then they should be encouraged to live with the person with dementia.

In the ACF in NSW, C was placed in high care due to his coronary limitations – he could not walk more than 20 metres, however, he had full mental functions. He was stressed because he could not socialise with the other high care residents due to their incapacities. There was no attempt made to take him to mix with low care residents. It may be preferable for people to be placed in accordance with their mental ability to socialise rather than their physical abilities.

Would supported community houses for aged people similar to houses for people with disabilities be a good model to consider? Models for aged care provision in a range of developed countries should be considered.

Laundry

Performance in washing clothes for residents in ACFs can be appalling. I did B and C's washing having had many clothes ruined, washed and dried by someone with no laundry skills at all. Such carelessness can be overcome with training and performance monitoring rather than the total acceptance by the ACF management. While this may sound unimportant, respect for belongings of people in ACFs is a part of retaining some dignity.

To go to hospital or not?

C had severe chest pains. When finally a carer came in response to his buzzer, C told me he was given medicine and not sent to hospital. When I asked the supervisor next morning why I hadn't been contacted and why C hadn't been sent to hospital and what medicine had been given, I was told that as a Christian organisation, their philosophy was that people went there to die not to go to hospital and unless the Doctor gave orders to that effect then their practice was not to send people in high care to hospital. They had given him Mylanta. At no time was this matter of going to hospital discussed with C or myself before then and we assumed he would be safer in an ACF and help called for when needed.

At another ACF B had misdiagnosed symptoms. I finally persuaded the GP to do some tests. B and I had to wait 6 hours in Emergency before were reached a doctor in Emergency and then at least 4 hours more until we got a bed as the only way B could be admitted although arrangements were made with her doctor to undertake the tests when admitted. Sitting for 6 hours in emergency waiting with a person who had severe dementia and severe anxiety was most stressful for the person and myself. There has to be a better way to admit patients like this.

Finally the Department's complaints' system needs overhauling. I first lodged a complaint nearly 3 months ago. While I appreciate the effort undertaken, there have been numerous calls to me and as of 2 weeks ago no contact yet with the ACF. This time lapse is not acceptable as residents need quick action in investigating complaints.

Summary

While I have covered a wide range of issues with personal illustrations, I thought these personal experiences would assist in understanding that it is not all about funding models and economics. The care of our parents and grandparents is something that our society can afford. With people living longer and women in the workforce, the old models of the parents being cared for by the family often is not possible. As people live longer, their children are themselves older than in previous times as they have to take the stresses of caring for them. There is little emotional support for people learning to become their parents' parent. No books are available to do that. Stresses on the caring families can at times be very detrimental to the health of the carers, particularly if aged person has dementia. It is particularly stressful if the carer is working or has to give up work to care.

An immediate reform which the Commission can address is the need to set staff resident ratios in ACFs as currently happens in childcare. This will assist in ensuring that funding is directed to staffing and provide consumers with the backing to enquire why there is not sufficient staff to provide the required care.

The most important issue to be addressed in aged care in Australia is ensuring there is an aged care workforce. We need carers who are skilled, safe, caring and appropriately supervised and rewarded. We must pay competitive rates. If we continue to underpay, undervalue and not support our aged carers, we will not be able to provide the care that our older citizens need and deserve.