



24 January 2007

The Hon Senator Santo Santoro
Minister for Ageing
Parliament House
CANBERRA ACT 2600

Dear Minister,

REVIEW OF SUBSIDIES AND SERVICES

I am pleased to be able to send you the submission we have made to the *Review of Subsidies and Services in Australian Government Funded Community Aged Care Programs*.

Alzheimer's Australia regards community care as the corner stone of aged care. This is because as the least cost sector good community care services promote efficiency in other parts of the health care system and because community services are the element of aged care which enables older people to stay for longer in their homes.

In preparing this submission we have had a significant input from the Alzheimer's National Consumers Committee and from the state level consumer committees of Alzheimer's Australia state and territory member organisations. I hope that the submission is helpful to you in carrying forward this important review.

Best wishes for the New Year.

Yours sincerely

Glenn Rees
National Executive Director



**SUBMISSION TO THE
REVIEW OF SUBSIDIES AND SERVICES IN
AUSTRALIAN GOVERNMENT FUNDED COMMUNITY
CARE PROGRAMS**

SUBMISSION TO THE REVIEW OF SUBSIDIES AND SERVICES IN AUSTRALIAN GOVERNMENT FUNDED COMMUNITY CARE PROGRAMS

EXECUTIVE SUMMARY

This submission represents the views of Alzheimer's Australia on the future of community care in Australia. The submission has been informed by the views of the National Consumer Council for Alzheimer's Australia.

Community care in the home is the preferred option for the majority of people with dementia needing care. Community care services such as CACPs, EACH, Dementia EACH and HACC need to be significantly expanded to meet this demand.

Continuity of care is a crucial feature of care for people with dementia, who require consistency and reliability in care provision as their condition deteriorates. To improve continuity of care it is proposed an extra level of Commonwealth funded packages be created to cover the existing gap between CACPs and EACH.

Four special needs groups require extra resources to help meet specific needs. These are younger people with early onset dementia, people with culturally and linguistically diverse backgrounds, Indigenous people, and people living in rural and remote areas.

Respite care, community transport and day care are the service types that need special attention. They are key components of a care system which seeks to help people with dementia and their carers.

Subsidy levels need to receive the same increase afforded to residential care under the Conditional Adjustment Payment, and indexation needs to be fixed at a level which reflects cost increases in the sector. There is no case for increasing consumer fees.

Current work seeking to reduce inconsistencies between HACC and Commonwealth funded packages should be completed as a matter of urgency.

The main challenges facing the community care system of the future are the availability of a skilled workforce, and the need to provide for the increasing prevalence of dementia. Australia's community care system could be made ready to meet these challenges if the reforms set out in this submission were to be adopted.

RECOMMENDATIONS

- 1 The target provision ratio for Australian Government funded community care places should be increased from 20 places per thousand people aged 70+ years to 30 places per thousand people aged 70+ years.
- 2 Continuity of care is critical for people with dementia and their families and carers and requires key workers who can be a constant point of support and who can provide access to diversified community services that have the opportunity to be familiar with the circumstances of the person with dementia and their families and carers.
- 3 Additional resources are required to assist providers deliver care to people with younger onset dementia, Indigenous people, people of culturally and linguistically diverse backgrounds, particularly those who do not speak English at home, and people living in rural and remote areas. More resources are also needed to enable providers to train staff to cater for these groups.
- 4 The National Respite for Carers Program should be expanded, particularly in regard to dementia respite and overnight and short term “cottage” respite, and in regard to brokerage funds, and eligibility rules should be made more flexible. Consideration should be given to funding more dedicated residential respite places with financial incentives to increase the availability of both low care and high care residential respite for people with dementia.
- 5 Additional funding should be provided by the Australian Government to increase the availability and co-ordination of community transport for people with dementia.
- 6 An intermediate level of care packages should be established and subsidised at approximately the mid point of subsidies for CACPs and EACH.
- 7 Subsidy levels for CACPs and EACH should be increased by the amount of the Conditional Adjustment Payment, and by any increase in COPO indexation that flows to residential care.
- 8 The interface issues between HACC and EACH/CACPs cause confusion for consumers and should be addressed. Growth in HACC funding should be maintained and the work of “The Way Forward” should be expedited, particularly in regard to providing help for consumers to be aware of the whole range of community care services available to them and ensuring that HACC services remain a flexible option for consumers. CACPs and EACH should be seen as specialised programs, not replacing the more comprehensive and flexible HACC program.
- 9 The current user fees regime for CACPs and EACH should remain; user fees for community care should not be increased, but efforts should be made to eliminate inconsistencies between HACC user fees and CACP and EACH user fees, having regard for the need for an upper limit on user fees for people receiving care from several programs.

- 10 The Australian Government should immediately develop an aged care workforce strategy to address the urgent workforce issues threatening the viability of community care. The Government should also be more active in safeguarding clients receiving community care.
- 11 CACP and EACH providers should be required to provide details of the level of service (including the number of hours of care a week) a care recipient should expect, and to give details of the complaints service: consideration should be given to promoting a degree of competition among community care providers.
- 12 The Government should consider expanding the choices for aged care service consumers by moving towards a single set of aged care subsidies which would be paid to people regardless of their accommodation. There should also be consideration of new approaches to community care that empower to consumer to make service choices.
- 13 The Australian Government should develop and fund an Australia wide network of comprehensive dementia specific community services to manage the impending large increase in the prevalence of dementia. These services should supplement generic services and cover early intervention, counselling and guidance, personal care, day care and respite care.
- 14 The Transition Care Program should be expanded, subject to the results of the evaluation; hospital discharge planning to ensure continuity of care with community services should be a mandatory feature of hospital care for older people.

Alzheimer's Australia
24th January 2007

SUBMISSION TO THE REVIEW OF SUBSIDIES AND SERVICES IN AUSTRALIAN GOVERNMENT FUNDED COMMUNITY CARE PROGRAMS

INTRODUCTION – THE IMPORTANCE OF COMMUNITY CARE

From a consumer perspective, community care is the cornerstone of the care system. Community services provide the choice for an older or younger person with dementia to stay at home longer, and it is clear that that is the wish of the majority of those cared for. Well designed community care services build on the capacities of people to remain independent. Institutional care reduces independence.

For people with dementia especially, the importance of continuing to live in familiar surroundings for as long as possible cannot be stressed enough. The move from home to residential care is often a traumatic time for people with dementia, and can lead to a deterioration in emotional well being and increased behavioural and psychological symptoms of dementia when the person is no longer able to follow familiar routines in familiar surroundings.

The balance of care services between community and residential care is critical. Over the last twenty years the Australian Government has been able to reduce the target provision ratios for residential care from 100 places per thousand people aged 70+ years, to 88 places per thousand people aged 70+ years. This has been largely due to an expansion of community care services which have provided people with alternatives to premature institutional care.

RESPONSES TO QUESTIONS POSED BY THE REVIEW

1 SERVICE MIX

What range and diversity of community care services are required for frail older Australians with complex care needs and their carers?

Level of provision

What is needed most is a significant increase in the level of community care being provided. Despite recent increases in target ratios, the overall balance in Government expenditure between residential and community care has not changed significantly over the last twenty years.

The majority of people with dementia prefer care in the home where possible and this is being reflected in falling occupancy rates, particularly in low care residential facilities. Nonetheless, it should be remembered that for some, low care does provide security and social interaction and an alternative to what may be social isolation in the community.

Government policy should give priority to increasing the resources in the care system for community care and responding to the increasing demand for these services from users. Day Centre attendance is particularly important for the person with dementia and their carer where the person wants to remain at home. Day care needs to be stimulating and appropriate to the social characteristics of the person.

An increase in the provision ratio for CACPs and EACH (including Dementia EACH) is strongly recommended. It is recommended that the ratio increase from 20 places per thousand people aged 70+ years to 30 places per thousand people aged 70+ years, with the 30 per thousand being achieved within three years. This would result in some 21,500 extra community care places by June 2010.

RECOMMENDATION 1 The target provision ratio for Australian Government funded community care places should be increased from 20 places per thousand people aged 70+ years to 30 places per thousand people aged 70+ years.

Continuity of care

Continuity of care is of crucial importance for people with dementia and their families and carers. The reforms proposed under “The Way Forward” could help this process. Providing a single point of contact through access points under *The Way Forward* is supported but **ONLY IF** it is accompanied by the availability of key workers who can provide on going advice and support to those navigating the care system and needing access to services. Further, there are significant advantages in diversified community services able to provide the range of services.

Dementia is a progressive condition and good care is dependent on knowledge of the person with dementia and their families and carers. While it may appeal to a sense of bureaucratic neatness to have HACC services provided for people with basic care needs, and CACPs and EACH provided for people with more complex needs, this does not promote continuity of care and having to change service providers can be disruptive and confusing for consumers as their needs increase.

Evidence from dementia care workers indicates that HACC is more and more providing care for people with complex care needs, and to restrict HACC to people with basic care needs would be very damaging to clients with dementia.

One of the key issues in dementia care in the community is to equip Day Centres with staff resources to enable care recipients to continue to attend as their condition deteriorates, while at the same time enabling them to remain in the same familiar location on a daily basis. This provides a structured, familiar and stimulating environment for the person as well as continuing respite for the carer.

RECOMMENDATION 2 Continuity of care is critical for people with dementia and their families and carers. It requires key workers who can be a constant point of support, who can provide access to diversified community services, and who have the opportunity to be familiar with the circumstances of the person with dementia and their families and carers.

Special needs groups

There are four particular needs.

Firstly, there are the needs of people with younger onset dementia. Access Economics estimates there are around 20,000 people in Australia under the age of 75 with dementia. Access to services for this group is poor. Services need to be tailored to the needs and interests of younger people with dementia.

Secondly, there is the need for culturally appropriate services that respond to the needs of people from CALD backgrounds. Alzheimer's Australia recently published research that indicates that around 12% of people with dementia do not speak English at home. Government needs to recognise the extra resources required to provide appropriate care for this group. This may involve interpreter services, information about services for people who do not speak English.

In some instances it may be helpful to "cluster" people with similar cultural and language backgrounds so that one provider can provide appropriate care in an efficient manner. "Cluster" services should be able to admit people from a wide geographical area, not just the region where they operate.

Thirdly, evidence is accumulating that the prevalence of dementia among Indigenous people at younger ages is relatively high. Different models are required to help care for Indigenous people who for various reasons are unable to access generic services.

Fourthly, the needs of service providers in rural and remote communities require special consideration. Because of fewer numbers of clients, and the extra costs of service provision related to travel time and expenses, unit costs for services delivered in rural and remote areas will usually be higher than for urban areas. Innovative

models of service delivery are therefore required to ensure that clients living in rural and remote areas are not unfairly disadvantaged.

RECOMMENDATION 3 Additional resources are required to assist providers deliver care to people with younger onset dementia, Indigenous people, people of culturally and linguistically diverse backgrounds, particularly those who do not speak English at home, and people living in rural and remote areas. More resources are also needed to enable providers to train staff to cater for these groups.

Respite care

The National Respite for Carers Program has proven to be a useful means of funding a range of innovative respite care programs and services tailored to suit people's needs. However, coverage remains uneven particularly in respect of cottage respite. Eligibility rules for some of the component programs are also somewhat rigid in terms of defining who is a carer and who can access help under these programs.

People with dementia have particular difficulty accessing community respite. As the demand generally for respite is so high, providers tend to take "easier" people who do not exhibit the behaviour commonly shown by people with dementia. Dementia respite is difficult, and there needs to be a special financial incentive for respite care providers to accept people with dementia. The best way to provide this incentive is to expand the dementia respite component of NRCP, funded at a higher level than general respite, but with entry restricted to people with dementia.

People with dementia also find it difficult to access emergency respite in instances where the carer becomes ill or has an accident.

Younger people with dementia also have difficulties accessing respite care appropriate to their age.

The brokerage component of NRCP is considered an excellent initiative, especially for the categories of special needs groups mentioned above. This too should be expanded, with consideration being given to allowing family members to be brokers (subject to certain restrictions on how the money can be spent).

Residential respite continues to be underutilised, compared to the bed days available and particularly compared to the planning ratio of three places per 1000 people aged 70+ years. It is apparent that enabling respite places to be used as permanent places tends to restrict the availability of respite, and consideration should be given to funding some dedicated respite places, recognising that these places would have much lower occupancy levels than permanent places. In the meantime, the practice of “cashing out” the unused residential respite hours into NRCP should be continued.

RECOMMENDATION 4 The National Respite for Carers Program should be expanded, particularly in regard to dementia respite and overnight and short term “cottage” respite, and in regard to brokerage funds, and eligibility rules should be made more flexible. Consideration should be given to funding more dedicated residential respite places with financial incentives to increase the availability of both low care and high care residential respite for people with dementia.

Community transport

One service type that is particularly important for people with dementia is community transport. Because people with dementia usually do not have physical disabilities, their carers are sometimes not eligible for disability taxi vouchers or for disability parking permits. Taking people with dementia to hospital and medical appointments, or even just for shopping excursions, becomes very difficult for a carer, and practically impossible for people with dementia who live on their own.

Community transport is a very cheap service for governments as it is operated largely by volunteers. A relatively small injection of funds by the Commonwealth, especially earmarked for community transport for people with dementia, and particularly for co-ordination of transport services to maximise the use of available resources, would be a cost effective way of dealing with this issue.

RECOMMENDATION 5 Additional funding should be provided by the Australian Government to increase the availability and co-ordination of community transport for people with dementia.

2 FUNDING ARRANGEMENTS

How could funding arrangements be improved?

Range of packages

The current gap in subsidy levels between CACPs and EACH is far too great to enable a care package provider to offer appropriate continuity of care. A provider cannot manage a person with increasingly complex care needs on a CACP subsidy, even allowing for averaging across low and high need clients. The eligibility for EACH is often far too strict to enable people to move seamlessly from a CACP to an EACH package.

It is recommended that an intermediate level of care package be established, with a subsidy level of around \$70 per day. These packages could be provided from normal growth in the program, particularly if Recommendation 1 (to increase the provision ratio) is adopted.

The ratio of CACPs to EACH to Dementia EACH should reflect the numbers of people with different levels of need. It is proposed that a ratio of 3 CACPs to 2 EACH to 1 Dementia EACH would be a good approximation to the need.

RECOMMENDATION 6 An intermediate level of care packages should be established and subsidised at approximately the mid point of subsidies for CACPs and EACH.

Subsidy levels

Subsidy levels for CACPs, EACH and Dementia EACH were originally set to be the equivalent of the relevant residential care RCS level subsidy. However, residential care over recent years has received the benefit of the Conditional Adjustment Payment as recognition of increased costs in the sector. This was not paid to

community care providers. This parity should be restored. Similarly if there is to be any increase in the COPO indexation for residential care, this should also flow on to community care.

RECOMMENDATION 7 Subsidy levels for CACPs and EACH should be increased by the amount of the Conditional Adjustment Payment, and by any increase in COPO indexation that flows to residential care.

Linkages with HACC

The current inconsistencies between CACPs and EACH on the one hand and HACC on the other are very confusing for consumers. The work of “The Way Forward” should be expedited, particularly in terms of providing a single point of contact where a person needing help can be guided through the whole range of care options in all community care programs.

People with dementia are particularly in need of some guidance through the system at the early stages, and in need of case management as the disease progresses.

Continued growth in HACC funding is essential for programs involving early intervention and prevention where the person’s needs have not reached the stage of them requiring a CACP.

HACC is also crucial for people with more complex needs. If given the choice, the majority of people with moderate or high needs would prefer HACC funded services to CACPs or EACH. Generally speaking, HACC offers a higher level of services at lower cost to the consumer than CACPs or EACH. Departmental data estimates that some 25,000 HACC clients are receiving services at the packaged care level. While it is recognised that HACC policy is largely determined by the States and Territories, it is nevertheless important that CACPs and EACH are made as consistent as possible with the much more comprehensive HACC program.

Transition from HACC to CACPs needs to be made easier, as well as transition from CACP or EACH back to HACC. The emphasis in “The Way Forward” should be very much on making the system easier for consumers to access.

RECOMMENDATION 8 The interface issues between HACC and EACH/CACPs cause confusion for consumers and should be addressed. Growth in HACC funding should be maintained and the work of “The Way Forward” should be expedited, particularly in regard to providing help for consumers to be aware of the whole range of community care services available to them and ensuring that HACC services remain a flexible option for consumers. CACPs and EACH should be seen as specialised programs, not replacing the more comprehensive and flexible HACC program.

3 USER CONTRIBUTIONS

What user contributions are most appropriate?

The current user fees system for CACPs and EACH (including Dementia EACH) is considered appropriate. This system allows for means testing of fees, with all user fees retained by the provider, without reductions in subsidy. This enables money to be collected from those who can afford to pay, with those funds being able to be reallocated to other care recipients. Means testing is carried out on income only. Asset testing the family home, which occurs in residential care, is not appropriate as the person needs to stay living in their own home.

Some people purchase from the same provider extra hours of service over and above the hours provided by the subsidised package. This practice is supported, but consumers need to be clearly aware of the number of hours they are entitled to from the subsidised package. Providers need to inform care recipients and their families (perhaps through printed information sheets) exactly what the user fees are and what services they can expect for those fees.

Any further increase in user fees is strongly opposed. It is important for there to be a financial incentive for people to stay living at home. Setting user fees at the same level as residential care would remove this incentive

The disparity between HACC user fees and CACP or EACH user fees is a source of confusion for many consumers. The attempts of “The Way Forward” process to sort out these inconsistencies are strongly supported. In particular there needs to be an

upper limit of user fees for people who receive both CACPs (or EACH) and HACC services.

RECOMMENDATION 9 The current user fees regime for CACPs and EACH should remain; user fees for community care should not be increased, but efforts should be made to eliminate inconsistencies between HACC user fees and CACP and EACH user fees, having regard for the need for an upper limit on user fees for people receiving care from several programs.

4 OPERATING ISSUES

How can the Australian Government improve the effectiveness and sustainability of the community aged care programs?

Workforce issues

The biggest threat to the viability of community care programs is the increasing shortage of a skilled, trained workforce. CACP and EACH providers are finding it progressively more difficult to employ trained care providers. This is proving to be particularly the case in high income areas, where low paid workers such as domestic assistants cannot afford to live in these areas.

Alzheimer's Australia supports the Aged and Community Services Association (ACSA) in its call for the Australian Government to address this issue. Specifically it is recommended that the Government develop a national aged care training strategy, provide funding for competitive remuneration packages commensurate with the responsibilities of care workers, and fund an industry based recruitment campaign.

Dementia care has its own specific workforce issues, as dementia care is often seen as a less desirable form of employment than physical care. Diversional therapy is a particular need area. Given the increasing prevalence of dementia as more people enter the older age groups, it is crucial that funding is provided for community care providers to ensure that their workers are adequately trained in dementia care.

Furthermore, the Commonwealth Government should be much more active in ensuring that community care staff are appropriately trained, and observe strict codes of behaviour when visiting a person in their home.

The Australian Government has taken a welcome and active approach to ensuring that elderly people are properly protected in residential care. Similarly there is a need for a more active approach in ensuring that community care staff are appropriately trained, subject to appropriate checks and observe strict codes of behaviour when visiting a person in their home.

RECOMMENDATION 10 The Australian Government should immediately develop an aged care workforce strategy to address the urgent workforce issues threatening the viability of community care. The Government should also be more active in safeguarding clients receiving community care.

Quality and accountability

Quality of care is just as much an issue for community care as it is for residential care. However, given the completely different setting in which care is delivered, different approaches should be tried.

In community care, the care recipient or their carer is the customer, and should have similar rights to customers generally. However, because the distribution of CACPs and EACH is generally on the basis of one provider per area, the customer in community care has little alternative if they are unhappy with the quality of care.

In this situation it is important for the funder (the Australian Government) to provide and publicise an avenue for complaints about the quality of care. Such an avenue currently exists but is not often used. CACP and EACH providers should be required to provide each care recipient with the details of the complaints service. This would also involve the care provider giving the care recipient a clear statement of what level of care can be expected. Since the majority of complaints currently made are about quantity of care rather than quality, such a statement should include an indication of the number of hours of care per week the person can be expected to receive.

A further way to enhance quality would be to provide competition between CACP and EACH providers by allocating them overlapping areas. This would afford care recipients some degree of choice, which would tend to make providers more diligent in ensuring quality.

The current HACC audit system could be expanded to encompass all community based services. This would be in line with the spirit of “The Way Forward”.

An extension of the role of the Aged Care Accreditation Agency to cover community care is not supported. The focus on structural issues, both in terms of the physical premises and in terms of organisational management, is not appropriate for community care, where a much more consumer focused approach is required.

RECOMMENDATION 11 CACP and EACH providers should be required to provide details of the level of service (including the number of hours of care a week) a care recipient should expect, and to give details of the complaints service: consideration should be given to promoting a degree of competition among community care providers.

5 FUTURE REQUIREMENTS

How do you expect service requirements to change into the future?

Choice of care

People in the future are likely to be demanding more choice in how they receive their care. The preference is clearly to stay living in one’s own home, or in purpose built aged housing, for as long as possible. It is imperative that people approved for residential care have the choice of receiving that care somewhere other than a residential aged care facility.

It is therefore considered appropriate for the government to move to a system where aged care service subsidies relate to the level of care being provided, rather than the location of that care. This would inevitably lead to a merger of residential aged care subsidies and CACP and EACH subsidies. Such a move would also make the

residential aged care sector much more open to consumer preference for the type of accommodation they want to live in to receive care.

Within community services new approaches should be developed that enable the person with dementia or their family and carers to have a stronger voice in decisions about the services to be provided, for example, through budget holding.

RECOMMENDATION 12 The Government should consider expanding the choices for aged care service consumers by moving towards a single set of aged care subsidies which would be paid to people regardless of their accommodation. There should also be consideration of new approaches to community care that empower to consumer to make service choices.

Dementia care

The greatest challenge for aged care services over the next 30 years will be the large increase in the prevalence of dementia. This will inevitably occur with the increasing numbers of people moving into the 70+, 80+ and 90+ age ranges. Unlike disorders such as stroke and heart disease, there is as yet no evidence of declining incidence of dementia in the population.

As well as increasing numbers of older people with dementia, there continues to be a small but significant number of younger people with dementia. Access Economics has estimated there are just under 20,000 people under 75 in Australia with dementia. The needs of this group will differ in significant ways from the needs of older people with dementia, particularly in regard to day care and social stimulation. While growth in community care places is rightly tied to growth in the aged population, the needs of younger people with dementia must be considered.

The implication of this inevitable increase in dementia prevalence is the need to develop an Australia wide network of dementia care services which can help people with dementia and their families from the early stages when the disease is first detected through to the more severe stages of the disease.

Although generic community care services can provide basic services such as domestic assistance, delivered meals, home maintenance and home modification,

there are a range of services which need to be dementia specific. These include early intervention programs, programs of support and counselling for people and their families, “Living with Memory Loss” programs, dementia specific respite care, dementia specific day care, case management, personal care services, and assistance with financial, legal and guardianship issues.

The expansion of current dementia care programs to provide a comprehensive nationwide network of support services is one of the most urgent priorities for community aged care into the future.

RECOMMENDATION 13 The Australian Government should develop and fund an Australia wide network of comprehensive dementia specific community services to manage the impending large increase in the prevalence of dementia. These services should supplement generic services and cover early intervention, counselling and guidance, personal care, day care, respite care and special care for younger people with dementia.

Transition care

The transition from hospital to community has always presented difficulties in a Federal system. Concern has been expressed about some older people not receiving sufficient rehabilitation in hospital following an acute episode. Also, there is concern that some people stay too long in hospital waiting a place in an appropriate aged care service. The Transition Care Program appears to be a constructive way to approach this problem and, subject to the evaluation of the current places, consideration should be given to expanding this program.

Discharge planning should be a mandatory feature of hospital stays for older people. The Australian Government should exercise its powers under the Australian Healthcare Agreements to ensure that the discharge of older people into the community is appropriately planned to ensure continuity of care. Inappropriate early discharges without proper arrangements being made for continuity of care through community services often leads to unnecessary residential care admission or a readmission to hospital.

RECOMMENDATION 14 The Transition Care Program should be expanded, subject to the results of the evaluation; hospital discharge planning to ensure continuity of care with community services should be a mandatory feature of hospital care for older people.