Community Care Coalition

Most older people and younger people with disabilities prefer to live at home.

For two decades governments have encouraged living at home instead of moving to residential care. Provision of informal care by families and formal community care is an essential and effective way to help people to live in their own homes. Increased government funding, particularly over the last 4 years, has resulted in many programs supporting this goal.

However the community care system in Australia is not meeting all the needs of Australians who currently require it. There are inadequate levels of service provision; it is fragmented, services are often difficult to access and they are unevenly distributed across the country. The attached Fact Sheets outline key issues facing community care in Australia.

It is estimated that by 2006, 1,327,100 Australians will have a severe or profound disability. Australia's population is ageing in both actual numbers (with those aged 65 and over increasing from 2.4 million to 4.2 million over the 20 years to 2021) and proportionally with this age group moving from being 12% to 18% of Australia's total population.

***This rapid growth in numbers of people needing community care will place increased pressure on both unpaid carers and the formal service system which currently cannot deliver enough community based care to meet existing demand.***

**April 2004**

# 1. Why Community Care matters.

*Without the provision of community care services many people would have to leave their own homes to live in residential aged or disability accommodation. This is not what most older people and younger people with disabilities want to do.*

**Mrs Bongiorno**

Is 83-years old, born in Sicily, and came to Australia with her parents as a small child. Her husband died some years ago and she now lives with her unmarried daughter (Theresa). She suffered a major stroke in May 2003 and spent 3 months in hospital before returning home. The stroke severely affected her speech and balance. She also has swallowing difficulties and now relies on tube feeding.

In December, she became ill with pneumonia and was readmitted to hospital. She was assessed as requiring high-level residential care. However, Theresa was very keen to care for her at home. The nursing and physiotherapy staff trained Theresa how to care for her mother and, in mid-January, 2004, Mrs Bongiorno came home. Her local doctor visits regularly as does Mrs Bongiorno's married son. Mrs Bongiorno spends most of the day in bed. She is unable to control her bladder and has limited speech.

Home nurses come for half an hour 3 days each week to help with showering and skin care, and home respite care is provided every Tuesday morning so Theresa can go shopping or visit friends. Mrs Bongiorno is on the waiting list for a community care package which would offer funds to buy in additional services, but Theresa knows that it may be months before a "place comes up".

Theresa is happy to have her Mum at home and is clearly doing what she wants to do for her mother. "She was a good mother to us," Theresa says.

**Ben Dobson and his family**

Nine-year-old Ben Dobson was born with haemophilia, a genetic disease where blood fails to clot. It is a serious illness, and one that can be painful. Ben and his mother, Leonie, have had to cope with the numerous health challenges that are part and parcel of the condition. Every day they contend with a strict regime of constant medication including frequent injections. Regular visits to hospital were normal in Ben's young life.

A major provider of home nursing and healthcare services has worked with Ben's doctor and his family to help him live as normal a life as possible. They have assisted Ben's mother with his care since 1996. Recently Ben's doctor made some changes to Ben's treatment. Administering Ben's new medication meant Ben would need injections. But with Mrs Dobson having an overwhelming fear of needles, nursing care was needed to help with the medication. "I just couldn't cope with injecting Ben myself," said Mrs Dobosn. "Andrea, Ben's nurse, had to come three times a week to do it for me."

However, Andrea has also been educating Mrs Dobson on how to give the injections herself. "I don't enjoy poking Ben with needles," said Mrs Dobson, "It's really been a challenge, but I'm slowly getting used to it." Working together with Andrea, Ben and his family are becoming more independent each day in managing Ben's care. The family's life and routine is much less dependent on visits from Andrea, or disrupted by the once frequent trips to hospital.

“The district nursing service has changed our lives,” says a happy and grateful Mrs Dobson. “Andrea’s visits and help with the needles have meant that Ben does not have to attend hospital for treatment and can live a very normal life, even playing footy.”

**These two case studies demonstrate how many families do want to care for their loved ones but also, how they need support to do this. There is no doubt Mrs Borgiorno would be in residential care without Theresa's unpaid care and the assistance of home nurses and other services. And young Ben has only been able to continue to live a fairly normal life with the help of the complex nursing care given to him and his mother by home nursing staff. Both these stories highlight the capacity of community care services to support people to remain living independently at home and participating in their local community. This is community care at its best – unfortunately this is not the case for all current clients and carers as well as those who need support but are unable to access it.**

**Key Facts:**

- In 1998 an estimated 2,385,100 people aged less than 65 years had some form of disability. Of these 655,000 people or 4% of the population aged under 65 needed ongoing assistance with activities of daily living.
- The 1998 Survey of Disability, Ageing and Carers found of those people 65 and over, needing help with everyday activities*, 83% received help from family and friends, and 59% received help from formal services.
- In Australia in 2001 it is estimated there were 534,500 people aged 65 and over with a profound or severe core activity restriction and a further 241,000 with a moderate restriction i.e. 775,500 older people were needing help/or had difficulty with a core activity task.

## 2. Current Community Care services cannot meet existing demand

*While there are good community care services available to support people, they are often limited by not having enough funding or by rules about what they can and can't provide. Most services cannot meet the needs of all existing clients let alone new people who require support.*

**Mr and Mrs Harris**

Mr and Mrs Harris have lived in an inner city area for 50 years. Peter is 86 and has dementia and poor balance. In July last year he became 'confused' and unable to walk. He was assessed at a major hospital and was found to be suffering from a severe bladder infection. After a week in hospital he was up and about and able to walk safely with his walking stick.

However, the Aged Care Assessment Team assessed him as being suitable for high-level care in a nursing home. Mrs Harris however, was keen to "try him out" at home as she did not want "to put him in a nursing home." Arrangements were made for the local service to send a personal carer twice a week to give Peter a shower and a shave. "He also goes to the day centre every Wednesday and he had two weeks of respite in a local nursing home during December so I could have a rest and visit my daughter in Sydney."

"He was much better when he came home from respite at the nursing home. He doesn't try to run away from here – he knows this is where he belongs. He can help me a bit with the dishes and in the garden and he likes to play with his dog and take him for a short walk. The day centre has referred us to another service because Peter is 'too high care' so we are waiting for a package of care services which includes a case manager. "But I have no regrets. Peter and I have been married for 59 years and we have been together in this house since 1954. I want us to stay together for as long as I can manage."

**This case study highlights both how much community care is valued by Mr and Mrs Harris and that it is an alternative to residential care. But it also demonstrates clearly that Mrs Harris, as the primary "Carer" needs much more support from formal services. For example, most Australians would agree that having a shower and shave only twice a week is not enough. And yet this is all Mr Harris can get until another "package of care services" becomes available. Community care service providers are stretched to the limit and rarely have the funds or staffing capacity to immediately provide the range and levels of care they assess are required.**

**Some key facts:**

- 2.5 million Australians are providing care for family members or friends with a disability, mental illness, chronic condition or who are frail aged. This represents one in every five households.
- Nearly 20% (450,900) of all people providing assistance are primary carers, that is, they provide the main source of unpaid informal support.
- Most primary carers (54%) said that they provided care either because alternative care is unavailable or too costly, or because they consider they have no choice.
- The 1998 Survey of Disablity, Ageing and Carers reported that 40% of people of all ages with a major disability who live independently and need assistance, felt their needs were only partly being met.
- More than 162 000 Australians have a diagnosis of dementia, with perhaps as many again in the early stages of dementia.
- Australians over the age of 85 have a one in four chance of developing the disease.
- The Home and Community Care program (HACC) is the major program providing care at home with the combined Federal and States expenditure last year totalling approximately $1 billion.
- The average amount of domestic assistance received by 198,746 HACC clients last year was just 38 minutes per week.
- The 46,919 HACC clients aged 65 and over receiving personal care assistance average 50 minutes per week.
- Those 11,630 clients aged less than 65 receive on average 2.4 hours per week.
- At least 60,000 older Australians with very high care needs were formally assessed by Aged Care Assessment Teams in 2001-2002 as needing more community care than they were getting.

# 3. Need for a simpler Community Care system

*Community Care is funded and administered by Commonwealth & State Governments. Each level of Government has created a range of community programs to assist those who require it. While this funding and commitment is vital the result is a complex care system, which is difficult and confusing for people to access and is administratively inefficient for Governments and service providers.*

**Mr Brown**

Mr Brown, 74 and a widower, is a DVA (Department of Veterans Affairs) gold cardholder, with a medical history of insulin dependent diabetes and osteoarthritis. He lives alone in a small unit, and

has several children but they all live interstate. He recently contacted a local service to enquire about home care. The Home Care staff referred him to Veterans Home Care (VHC), as he is eligible for services under this Commonwealth government funded program.

VHC undertakes a telephone assessment and offer 1 hour of home care per fortnight (the usual amount offered to clients who live in units). They also advise Mr Brown to go back to the HACC (Home and Community Care) Program at his local service provider as he is likely to receive higher service levels! HACC staff assess Mr Brown at home and finally two weeks later, the services are implemented.

He is very happy to receive 1.5 hours weekly of home care including domestic, laundry and shopping assistance. The service also refers Mr Brown to the Department of Veterans Affairs Rehabilitation Appliance Program where an Occupational Therapist recommends the installation of grab-rails and step modifications for his bathroom and a physiotherapist recommends a walking aid. The HACC service is responsible for installing the bathroom modifications.

Six months later, Mr Brown breaks his leg after a fall in the garden, and is admitted to a public hospital. On discharge from the hospital some weeks later, Mr Brown receives "Post Acute Care" (funded by the State Government) which provides both home care and personal care. Even though the care provided is the same as his service provides he has to receive it from a different organisation because of the program and funding arrangements. This means that instead of knowing the staff well and seeing familiar faces at this very difficult time he has a totally new organisation and staff. After Mr Brown has received the maximum 4 weeks of post-acute care, he returns to the local service for home care.

Three months later, feedback from the care workers about Mr Brown's deteriorating health, prompts a review of his care plan resulting in further increases in home and personal care. These increased service needs, including ongoing monitoring and case management, trigger a referral for a Community Aged Care Package (CACP). There are 17 different agencies providing CACPs in the region.

The referral process requires Mr Brown being accessed by the local Aged Care Assessment Team (ACAT) and then his assessment recommendation is multi-listed with the different CACPs provider agencies. Then he is subjected to further assessment by the individual agencies who potentially might provide the CACP. Some months later he is accepted for a CACP. However, the agency providing the CACP uses a different private sector home care provider so for a third time Mr Brown has yet another change of service provider and care staff, at a time when he is most vulnerable.

**Mr Brown's experience of having numerous assessments and changes of service providers is not unusual. It is both distressing to clients at times when they are very vulnerable and it is wasteful of professional staff time and resources. Many people (whatever their age) with chronic health problems such as Mr Brown's, require access to good health care (both GPs and from time to time, hospital care). Mr Brown's story highlights the lack of integration between these service systems.**

**As a result of different government funding and the restrictions for individual programs, he has had three different home care providers. This is inefficient, costly and most of all, very upsetting for people using the services.**

**Key Facts:**

- Currently there are 17 separate Commonwealth funded programs providing community based care services.
- In addition each state funds many more separate programs all requiring separate reporting and administrative arrangements. For example in Victoria, there are another 22 separate programs operating covering specialist aged health care, disability services and community health services resulting in a total of 42 separate programs (three of these are jointly funded with the Commonwealth).
- In 2002-03, 26.3% of all HACC clients were self referred, family/friends referred a further 16.1%, Public
  hospitals 14.2%, and GPs 12.7 %.
- The lowest number of referrals (0.1%) came from Commonwealth Carelink Centres.

# References


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# About the Community Care Coalition

The Community Care Coalition has been established by Aged & Community Services Australia (ACSA) as part of a national Community Care Awareness Program. The overall project has been funded by The Myer Foundation as part of its 2020 – A Vision for Aged Care in Australia initiative.

Members of the CCC are:

- ACSA
- ACOSS
- ACROD
- ANHECA
- Alzheimer's Australia
- Anglicare Australia
- Australian Association of Gerontology
- Australian Council for Community Nursing Services
- Australian Local Government Association
- Australian Meals on Wheels Association
- Australian Medical Association
- Australian Nursing Federation
- Australian Society for Geriatric Medicine
- Baptist Community Services
- Carers Australia
- Catholic Health Australia
- Catholic Welfare Australia

- Federation of Ethnic Communities' Council of Australia
- Mental Health Council of Australia
- Uniting Care Australia
- Volunteering Australia

Invitations to a number of other peak bodies may lead to more being involved in some way, with the project.

**Contact us:**
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