

# Carers – who's going to care

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## INTRODUCTION

In June 2004, Carers Australia published *Who's going to care – informal care and the ageing population*<sup>1</sup>, a report prepared by the National Centre for Social and Economic Modelling (NATSEM) at the University of Canberra, with the support of The Myer Foundation and the Brotherhood of St Laurence. This report highlighted caring in the future by projecting the demand for and supply of care over the next 30 years. The findings of the report were startling, with wide implications for people who will need care, those who will be called on to provide the care and the community broadly.

This paper is a summary of Carers Australia's discussion paper that responds to the NATSEM report. It explains the background to the report and its findings and discusses the implications of those findings from the perspective of carers and the unpaid care they provide to family and friends. The full NATSEM report<sup>1</sup> and the discussion paper can be obtained from Carers Australia at [www.carersaustralia.com.au](http://www.carersaustralia.com.au).<sup>13</sup>

## BACKGROUND AND RATIONALE FOR THE NATSEM REPORT

Over the past few years the ageing population has become a major public policy issue and is likely to continue to be so for many years as Australia's demographic pattern changes and the full implications are felt.

As the "baby boomer" generation ages, and the impact of lower fertility rates and mortality rates are felt, the population share of people aged 65 years and over is expected to double from about 13 per cent of the population to about 27 per cent over the next 50 years. The share of people aged 80 years and over is expected to more than treble, from about 3 per cent of the total population in 2003 to about 11 per cent in 2051.

This obviously poses a strategic challenge to governments and the community in sustaining economic growth to living standards and managing public spending to provide the services that people expect.

In the corollary debate about care for the ageing population, Carers Australia was concerned that the integral role of carers and informal care was being overlooked and largely ignored in the public debate on the ageing population.

In terms of population numbers, the Australian Institute of Health and Welfare<sup>2</sup> estimate that in 1998 over 711 000 people aged over 65 years were living at home with unpaid carers providing support, either with or without support from formal services, compared to only 127 900 people living in residential aged care and 8800 receiving Community Aged Care Packages. (Support from carers ranged from occasional assistance to 24 hour care.).

In economic terms, in 2003, the Australian Institute of Health and Welfare<sup>1</sup> estimated there were 2.5 million carers in Australia, whose unpaid caregiving is valued at least \$19.3 billion per year. In stark contrast, the Federal Government spent \$4.3 billion on aged care in 2002–03 as

well as the Home and Community Care Program, funded jointly by the state and federal governments, which cost \$1.2 billion.

As the population ages and the number of people requiring care increases, it is obvious that unpaid care by family and friends cannot be ignored as the main source and less expensive form of care. While there are substantial costs to the community and the individual in giving unpaid care, the alternative is high cost hospital and residential care or less expensive formal community care services which enable people to live in their own homes. The least socially desirable option is to leave people to manage on their own with no-one caring. Therefore, with the support of The Myer Foundation and the Brotherhood of St Laurence, Carers Australia commissioned NATSEM to investigate the demand and supply of informal care and how 'market forces' would respond to the needs of the ageing population.

## THE FINDINGS OF THE NATSEM RESEARCH

The findings of the NATSEM report provide a startling and challenging insight into what we can expect if its projections eventuate. The rapid increase in the number of aged people with disabilities and illness, will far exceed the number of primary carers available to give the care needed.

Based on current rates of disability and need for assistance, the number of people over 65 needing care is projected to increase by 160 per cent, from 539 000 people in 2001 to 1 390 000 in 2031. (These people had a profound or severe disability which served as a proxy for the need for care). People aged over 85 years are projected to account for 25 per cent of all profoundly or severely disabled persons, up from 14 per cent.

Over the same period, the number of people likely to be informal carers of older people will increase by 57 per cent from 198 000 to 312 000. The bulk of these will be co-resident carers, aged over 65 years and predominantly women.

The results of the modelling projected the biggest increase in carers would be co-resident, rather than non-resident who would decline from 37 per cent of all carers in 2001 to 31 per cent in 2031.

Carers themselves will be ageing – between 2001 and 2031 carers aged less than 65 years will grow by 19 per cent while those aged 65 years and over will grow by 110 per cent. Consequently, older carers will comprise 56 per cent of all carers, up from 42 per cent in 2001.

NATSEM project that the gender composition will vary only slightly and is expected to remain predominantly women.

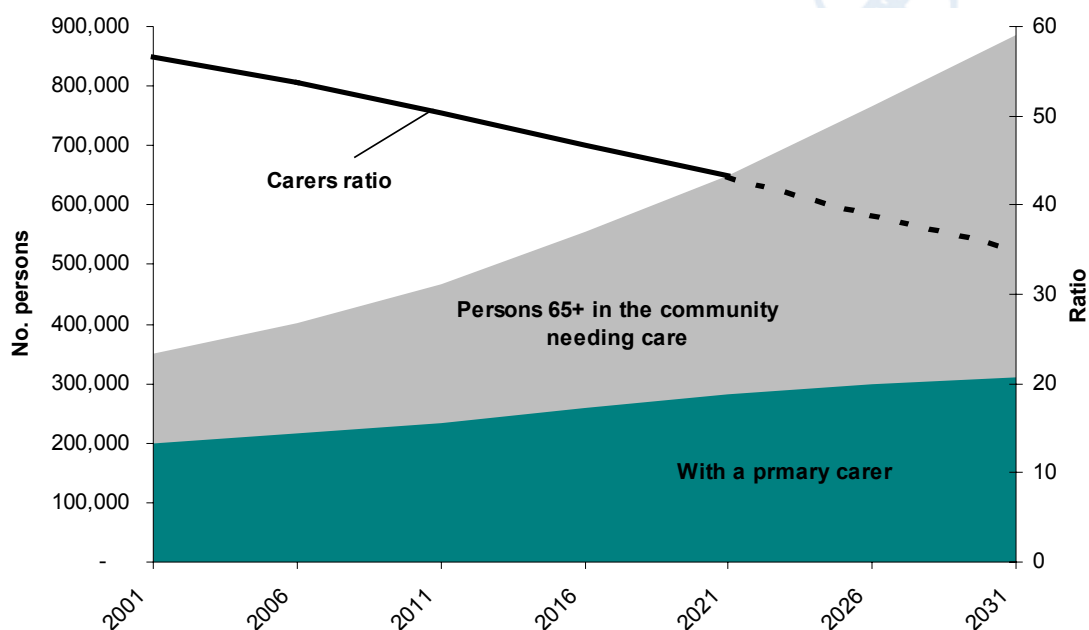
The critical issue is the intersection between demand for care and supply of care. The projections in the NATSEM modelling indicate that the ratio of carers to people aged over 65 needing care and living in the community drop will dramatically over the next 30 years. The rate is currently 57 primary carers for 100 people in private dwellings aged 65 years and over needing care. By 2031 it is projected that this ratio will have fallen to 35 carers for every 100 people, which is shown in Table 1 and Graph 1.

**Table 1 Projected caring circumstances of persons aged 65 and over with a profound or severe disability, Australia 2001–2031**

	2001	2006	2011	2016	2021	2026	2031
	%	%	%	%	%	%	%
All dwellings							
In non-private dwellings	35	36	36	36	36	36	37
In private dwellings	65	64	64	64	64	64	63
Private dwellings							
In community with a primary carer	57	54	50	47	43	39	35
In community without a primary carer	43	46	50	53	57	61	65

NATSEM simulated projections, Carers Australia, 2004, p. 31

**Graph 1 Projected caring circumstances of persons aged 65 and over with a profound or severe disability, Australia 2001–2031 – NATSEM projected simulations**



While these figures are projections, rather than forecasts, and any number of unforeseen factors could intervene to vary the outcome, the modelling has been based on sound assumptions. The assumptions behind this are that, firstly, the rate of disability will not change.

Expert opinion on whether disability rates are changing varies and whether longer life means longer periods with an age related disability, and the level of restriction that disability imposes, or whether disabilities are postponed to the end of life is unresolved. Therefore in the initial modelling and figures quoted here, the rate of disability is held constant at 2001 levels.

It was assumed that the utilisation rate of formal care by persons over 65 would remain constant across the 30 year period, based on the 1998 ABS Disability, Ageing and Carers Survey.<sup>3</sup> The supply of formal care is largely regulated by government planning and public funding, coupled with peoples' preference for living at home. There is no apparent evidence to suggest these factors will vary greatly and nothing that is quantifiable for plausible modelling.

The study concentrates only on primary carers as the persons needing care had a severe or profound core activity restriction and needed assistance with specified activities on a daily

basis. This leaves open the impact and influence “other carers” and potential carers might have in projecting future supply of carers.

## **THE IMPLICATIONS AND POSSIBILITIES**

It is well accepted that the majority of people prefer to live independently in their own homes as they age, rather than in health and residential aged care facilities. The type and intensity of care needed is likely to rise as the level of disability, illness or frailty increases. The ABS 1998 Disability, Ageing and Carers survey<sup>3</sup> indicated that, for people aged 65 and over with a profound or severe disability living in the community, 33.8 per cent were receiving only informal care from family members and friends, 61 per cent received informal and formal assistance and only 3.5 per cent received formal assistance only.

The role of the carer is important as aged people living alone are more likely to move to residential care and it is more likely to be low level residential care than high level care. This is believed to reflect psychosocial factors as well as physical care needs for people living alone<sup>2</sup>.

The findings of the NATSEM report, along with the ageing population policy debate so far, prompts many questions about care and carers and raises further issues.

### **What will the care system look like in the future, and is ‘ageing in place’ the preferred model of care for the future?**

The first priority, as per the Government’s “National Strategy for an Ageing Australia”<sup>4</sup> is to encourage people to have a healthy lifestyle to avoid or delay the need for care. Beyond that people will expect to have a choice in high quality services, preferring services to be delivered to their home with strong co-ordination of care.

The Hogan Report<sup>5</sup> observes that not only will the ageing of the population increase demand for services, but demand for specialised aged care services in the area of dementia will increase. Aged care services tend to be utilised most in the last two years of life, regardless of how old the person is so healthier ageing may delay the need for care and care may be intermittent intensive support for complicated conditions.

Hogan also comments on the important role of carers and the declining “caretaker ratio”. He notes that Australians prefer to remain in their own homes with the support of formal services, and, interestingly, “that older people’s preferences appear to be moving toward the use of formal rather than informal care in their home”.

The growing demand for care and preference for home care is already reflected in the shifting formal care planning ratios.

### **Can we assume that the current unmet demand for formal care services will continue and will public funding grow to meet demand?**

There is strong evidence to suggest that current levels of formal service are not meeting demand. While the level of real funding has increased, so too has the demand indicated by waiting lists and minimal levels of service available. Hence funding is spread across more people and the level of real funding per client has been reduced<sup>6</sup>.

The Intergenerational Report<sup>4</sup> estimates that over the next forty years to 2041, spending on aged care will more than double to 1.45 per cent of GDP. Community care spending is

estimated to increase by a similar proportion to 0.32 per cent of GDP. What is not clear in these long term projections is if the contribution of unpaid care has been factored in and if the estimates allow for the declining ratio of carers to people needing care and the support carers need to fulfil their role in caring for our ageing population.

It is also not clear just how much the increasing income and wealth of older people will influence the demand for services and how much individuals will be willing to pay for services.

## **What motivates carers and how can people be encouraged to fulfil a caring role, with so many other pressures in everyday life?**

In modern life many factors will impinge on caring, such as the changing expectations of women with high levels of education and skill and long term connection to the workforce or fractured family structures where people needing care do not live together.

Quantitative modelling by NATSEM<sup>1</sup> and AIHW<sup>7</sup>, suggests that single factors in isolation such as women's workforce participation or changes to household composition may not have a large impact. Despite this, as various factors compound it is likely to mean that a person's capacity and willingness to care becomes a more a complex issue.

Analysis of ABS survey data<sup>8</sup> indicates that caring is not simply a matter of emotional obligation, no-one else being available or an immediate family relationship, which means further inquiry is needed into who are potential carers, what are the motivating factors and to what capacity care is offered.

## **The risks of caring and why carers need support in their caring role**

Over the past decade there have been many studies on the impact on caring, particularly in relation to the health and well-being of the primary carer. It is undisputed that long term caring can cause extra stress on the carer, and a decline in physical health and emotional well-being.<sup>7,9,10,11</sup> These costs and benefits flow through the community, making it a public issue.

For example, with the ageing of the population and the prevalence of such conditions as dementia expected to increase, the economic cost to the community and to carers is and will be an increasingly substantial component of GDP. Access Economics and Alzheimers Australia<sup>12</sup> estimate dementia already costs \$6.6 billion per year, including \$1.7 billion in carer costs (replacement care), \$324 million in Centrelink carer payments and \$592 million of tax forgone each year for people with dementia, their families and carers. Access Economics estimate dementia costs may exceed three per cent of GDP by mid century, from nearly one per cent today.

## **Carers themselves will be ageing and have their own care needs**

The NATSEM<sup>1</sup> study found that the largest growth in the numbers of informal carers is projected to occur amongst older persons. Between 2001 and 2031, carers aged less than 65 years will grow by 22 000 (19 per cent) while those aged 65 years and over will grow by 91 000 (110 per cent). By 2031 older carers (aged 65 years and over) are likely to comprise 56 per cent of all carers.

As ageing carers they will be vulnerable to normal risks of age related illness and disability, which may be compounded by their caring responsibilities. What extra support will be needed

for such carers will need to be a major consideration in determining directions and priorities within community care.

In addition to health and welfare considerations, in line with general demographic trends and population profiles, more carers are likely to be from culturally and linguistically diverse backgrounds. Therefore accommodating this diversity will need to be factored into policy making and service delivery so that all groups of carers are catered for according to their particular needs.

## **How will the growing number of people without a primary carer manage and receive care if and when needed?**

Using data from the 1998 ABS Survey<sup>3</sup>, NATSEM calculated that of the population aged 65 years and over living in private dwellings and needing care 43 per cent were without a primary carer. By 2031 the percentage of older persons in private dwellings needing care but without a primary carer is projected to grow to about 65 per cent.

These figures point to the number of people already living in the community with a profound or severe disability and without a primary carer and how they are managing their situation.

The care that is needed may be provided by a single person caring for more than one person; from several people at less individual intensity; from formal services; or from a variety of sources. A potential source of care may be people outside of the immediate family, but this cannot be assumed as motivation is complex.

Formal community care is a very important option for people both with and without primary carers. AIHW<sup>7</sup> has examined the relationship between usage of services and carers status for the Community Aged Care Package program. It found that clients without a primary carer used social support, domestic assistance, food services, transport, home maintenance and rehabilitation support more than those with carers. The biggest difference was in social support, where 75 per cent of clients were without a carer.

## **THE SUSTAINABILITY OF INFORMAL HOME CARE**

So what is needed to make care in the home sustainable for the carer and the person needing support? The following points highlight some of the areas that need to be addressed in caring for carers and the ageing population.

- Perceptions of caring – caring is in the private household sphere and unpaid and, therefore, carers and caring work are often perceived as a free resource, under-valued and under-estimated. Official recognition by governments is important in changing this perception in the community with carer specific policies and support measures.
- Community care support – demand for all community care services has risen dramatically in recent years as primary and aged care systems have been de-institutionalised, with funding and services not keeping pace with this demand. The care provided by family and friends, supplemented with formal services, is integral to sustaining the care situation and enabling people to live at home for as long as possible.
- Community care support for carers – carer well-being is negatively affected by the extent that caring impacts on other roles and activities, as well as the demands of the caring role. Services aimed specifically at carers integrated into the formal community care system have proven valuable providing carers with information, social networking, respite,

counselling and advocacy. Building public awareness and uptake of these services, tailoring them to a diversity of clients and having them available when needed remains a challenge.

- Carers in the paid workforce – a substantial proportion of carers will continue to be of workforce age with competing workplace and family commitments. Employers who recognise and value their employees who have caring responsibilities will have a staff policy to accommodate the needs of carers and be willing to negotiate with those employees so that both parties benefit.
- Financial planning for carers and their ability to meet their day-to-day needs is very difficult for many carers. Caring is a big factor in an individual's income earning capacity, ability to save and accumulate assets. The extra expenses involved in caring also have a large impact on incomes and capacity to save. The Carers Allowance is not sufficient to cover the costs and the Carer Payment is only a very basic income support.

## CONCLUSION

As the NATSEM study highlights we can expect over the coming thirty years to experience a declining ratio of carers to the number of older people needing care. Because of our preference for care at home and our heavy reliance on informal care by family and friends as the major component of our community care system, policy makers need to be planning ahead over the longer term to manage the situation and avoid a crisis in caregiving.

This is a real challenge as developing and implementing public policy for the long term is a difficult process. As mentioned at the beginning of this paper, governments in Australia and around the world are concerned about the implications of ageing populations and policies are evolving to deal with it, for example superannuation and workforce participation.

While there is considerable uncertainty surrounding such debate and long term planning, the demographic trends leading to a greater proportion of people in our community being aged and needing care is well accepted. The intensity of care and the type of care needed is uncertain and may be influenced by a range of factors such as:

- the type of disability and the restrictions in activities it causes;
- research and technological developments that may prevent or ameliorate the effect of disability;
- the capacity of people to pay for care with increasing wealth and income, the response from the private sector market, and the public resources that governments are prepared to allocate to care;
- the availability of people able and willing to give informal care to their family and friends.

It cannot be assumed in policy making that informal care from family and friends will be available for people needing care. Where people are willing and able to provide the care needed, they need supplementary support and services to sustain the care situation because of the substantial commitment and costs that caregiving carries. To ensure that aged people suffering from frailty, disability and illness receive the care and assistance they need, the major role of informal care and carers needs to be foremost in the care policy agenda and more than residential aged care.

If the supply of care is to meet demand adequately, there has to at least be public debate on such issues as:

- To what extent should formal community care supplement informal care and how people without primary carers manage
- How do we accurately estimate unmet need and establish appropriate levels of service, which are then reflected in benchmarks, planning ratios and resourcing
- To what extent should public funding be used to provide formal care and will the private sector respond to demand.

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## PRESENTER

**Julie Austin** has been the policy adviser for Carers Australia for the past two years. Her role is to undertake research, develop appropriate policies and advocate in the interests of Australia's 2.5 million carers. Prior to joining Carers Australia and the community sector, Julie worked on issues of public policy concerning rural Australia and agriculture for the National Farmers Federation and as a political adviser to the Parliamentary Secretary for Agriculture, Fisheries and Forestry. Julie lives in Canberra and is married with two children.

