

July 2010

## Background

Dementia is a brain disorder causing progressive change and decline in a person's cognitive function that affects the ability to think, speak, reason, remember and move. Memory, language, rational thinking, social skills, behaviour, emotion and personality can all be affected.

The directions paper *Pathways to the Future, 2006 and Beyond - Dementia Framework for Victoria*, and the accompanying *Implementation Plan 2006-08*, identify the implementation strategy of support services for people with dementia and their unpaid carers, especially flexible innovative services that are responsive to the diverse needs of people in care relationships. For the complete dementia framework documentation, visit <http://www.health.vic.gov.au/agedcare/policy/dementia.htm>

The Department of Health Aged Care Branch funds a number of programs to support the families and carers of older people including people with dementia. They include the Support for Carers program which:

- provides respite and support options to carers of frail older people,
- develops support and respite networks,
- assists with linking carers and care recipients into other community supports.

Support for Carers Program services respond to short term needs and provide varied assistance with longer term needs and planning.

From 2008-09, the Support for Carers of People with Dementia Program has been expanded to include the families and carers of younger people with dementia, that is, people with dementia developed before the age of 65. Dementia is rare in younger people who are more likely to have a rarer form of dementia than Alzheimer's disease, or a genetically-based cause of dementia. Dementia in younger people can be Alzheimer's disease, fronto-temporal dementia, Parkinson's disease and related syndromes, alcohol related dementia, vascular dementia, Huntington's disease and other rare familial disorders. Alzheimer's Australia Issues Paper, 2007 demonstrates that people with dementia under 65 are a small sector of the dementia-specific or general care service client base.

### What carers value

The 1999 report *Targeting in the Home and Community Care Program* indicated that the highest levels of unmet need for carers were for home maintenance and day respite. Carers identified the need for more:

- longer stay and regular weekend out-of-home respite, particularly in facilities close to where they live,
- responsive forms of day centre respite,
- in-home respite particularly on weekends and overnight,
- in-home respite especially for those with high care needs or cognitive behavioural needs.

Increased opportunities to access flexible support facilitates families and carers continuing their carer role in the longer term, and the person with dementia being able to stay longer at home. Carers can have greater capacity to undertake other family or carer responsibilities. In addition, increased access to flexible support delays intensive use of a range of health, aged care, and other services by people with dementia.

The *Evaluation of the Support for Carers Report* (2001) indicates that carers value:

- ongoing support, especially around caring for a person with dementia.

*What Carers Value, Review of Carer Literature and Practice* (2004), identifies that carers value respite services that are:

- flexible; adaptive; responsive to need; person centred; available after hours, on weekends and overnight, for example evening activity groups between 5.00 – 8.00 pm so that carers can have a break around meal time; and can provide regular planned breaks from caring.

Innovative supports and opportunities identified by carers include:

- physical activity groups; men's carer support groups; information technology to communicate among carers and with providers; flexible carer retreats; carers continuing to meet after an initial event such as a physical activity group or retreat; the care recipient being involved in or cared for during the activity.

Recent anecdotal evidence suggests that carers may seek support activities that: are recreational, stimulating, social, informal, participatory, physically active, and or creative; are integrated into or separate from existing community activities; foster socialisation and connections with community; and provide meaningful occupation.

The policy *Recognising and supporting care relationships for older Victorians*, and *A Victorian charter supporting people in care relationships* (available at <http://www.health.vic.gov.au/agedcare/policy/carers.htm>)

clarify that people in care relationships are to be:

- recognised, respected and supported by governments and organisations, and
- engaged in care planning, management and service delivery where appropriate.

## **Carers of younger people with dementia**

People in care relationships involving younger people with dementia often: are wage earners; are actively raising a family; have dependents; and have significant financial commitments. In familial onset dementia, a carer may be caring for more than one person with dementia, for example a partner and offspring with younger onset dementia.

Many families and carers of younger people with dementia report not fitting into current services, particularly in rural and remote areas, and generally experiencing lack of recognition in the community that younger people can have dementia. Families and carers of younger people with dementia have identified difficulties in finding appropriate support for their stage in life cycle and activity preferences, and for issues like:

- emotional and social support for children
- being able to continue the same level earning capacity
- financial support to continue raising a family or other family commitments
- capacity to engage in social contact and activity
- physical health and often behaviours of a younger person with dementia
- decisions around genetic testing of children.

Issues younger people with dementia and their families and carers may face can be similar or different to those others face, including:

- difficulty and/or delays in getting an accurate diagnosis
- personal issues related to sense of loss
- difficulty in maintaining relationships with those around them

- family responsibilities including still actively raising a family
- currently working or being only recently retired, or not being able to access superannuation or disability entitlements
- having significant financial commitments based on previous earnings
- needing to revise expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, independence, responsibility for others and driving
- future plans affected at an earlier stage in life
- difficulty in accessing appropriate services, particularly as younger people with dementia are often physically strong and healthy
- early entry to residential care after diagnosis; currently within the first year of diagnosis, 25 per cent of younger people with dementia will be in residential care.

## **Aim**

The aim of brokerage funding is to purchase flexible support services to meet the individual and variable needs of families and carers of people with dementia:

- where there is a gap in the current service system, or
- where it is required and appropriate to top-up carer support services outside generic service systems, or
- in a crisis situation which cannot be met by other services.

## **Service description**

Brokerage funding for flexible support for carers is provided to ten providers, and is allocated in Carer Respite Centres usually by Dementia Care Support Workers (see Attachment 1).

In allocating funding, staff consult with the carer and care recipient to assess needs. There is a cap per annum of \$2,000 per carer of a person with dementia. Where a carer is caring for a younger person with dementia, the cap is \$2,000 per annum per person with dementia being cared for. Flexible support is provided on an as-needs basis with individually tailored, creative and varied packages addressing specific needs.

Flexible support for carers of people with dementia may include:

- Support such as the provision of equipment, family support and counselling, financial counselling, legal services, one-off transport support, and facilitating access to 'time out' leisure activities and interests. To maximise use of brokerage funding, purchased items of equipment no longer required but which may be of use to others are to be returned to the program.
- A range of options for flexible respite care including for carers in the workforce, from in-home to residential and overnight/ weekend respite in purpose built facilities. Purpose built facilities for overnight/ weekend respite need to meet both Regulation 5.15 of the Building Regulations 1994, and Department of Human Services Fire Risk Management Guidelines.

Examples of support services provided through brokerage funding are:

- Providing aids or equipment to assist maintaining the care relationship, for example where hiring or purchasing equipment assists a care recipient to participate in respite options.
- Reasonable costs for small home maintenance items and house modifications.
- Reasonable costs for transport support especially in rural areas for carers to assist carers to have a break, for example a taxi fare for a carer to travel, petrol voucher, one-off transport to and from an engagement or appointment.

- Reasonable costs for heavy linen services.
- Access to outside activities and interests, including recreation and community camps and ‘time out’ away from home, for example an outing for carers three or four times a year to a cinema, weekends away including respite for the person with dementia, where people in care relationships can be together for part of the time, and also have time away from each other.
- Reducing isolation by facilitating carers coming together, and the development of and opportunity for supportive networks with others sharing similar experiences, for example carers of culturally and linguistically diverse backgrounds or carers of younger people with dementia being able to spend ‘time out’ together.
- Family support and counselling, for example: support to manage role redefinition, help identify options and make choices; social and emotional support for carers including for burnout and fatigue, and dealing with feelings of shock, denial, grief and depression; social and emotional support for children of younger people with dementia.
- Financial counselling, legal services, and planning, for example: assistance in financial, budget and income-earning planning, and legal advice including wills and powers of attorney.
- Club membership or support for podiatry, physiotherapy or massage for health and well being through the care role.
- Arranging food shopping.
- Flexible respite in-home/out-of-home, daytime/overnight/weekend, day centre/residential, for example:
  - extended weekend respite from Friday midday to Monday midday
  - one hour per week of in-home respite over an extended period
  - one hour minimum per week of in-home respite short term
  - emergency respite.
- Flexible respite to assist carers to continue working, for example varied start and finish times of day programs.

## **Responsibilities of Dementia Care Support Workers**

Dementia Care Support Workers, in being accountable for expending brokerage funding, need to:

- Assess the carer’s needs in consultation with the carer and the person with dementia. Identifying the needs of Aboriginal carers and carers of culturally and linguistically diverse backgrounds (CALD) requires cultural sensitivity and appreciation of cultural differences.
- Confirm that the carer’s needs cannot be met by existing services and support such as: the Support and Links program [Alzheimer’s Australia Vic (AAV)], Victorian Aids and Equipment Program (AEP), Multi-Purpose Taxi Program, Linkages, Home and Community Care (HACC) services, Continence Aids Assistance Scheme (CAAS), clinical services like the Cognitive Dementia and Memory Services (CDAMS), and the Continence, Pain Management, and Falls and Mobility Clinics, Centrelink options, Commonwealth Health Care Card, Department of Veterans Affairs options, regional initiatives such as the Regional Disability Support Initiatives (RDSI) etc.
- Be able to justify and feel confident about the allocation of the funding in terms of equity of access of carers in the region to the funding.

The use of the brokerage funding can be maximised by Dementia Care Support Workers strengthening links with other providers, such as: the Cognitive Dementia and Memory Services (CDAMS), Aged Care Assessment Service (ACAS), Alzheimer’s Australia Vic (AAV), Aged Persons Mental Health Community Teams (APMH Community Teams), Dementia Behaviour Management Advisory Service (DBMAS), Home and Community Care (HACC), and Disability Services for younger people with dementia.

## **Promotion of the program**

Anecdotal evidence from carers suggests that in some areas, knowledge of the Support for Carers of People with Dementia Program is limited. The ten providers of this program need to promote it to those carers of people with dementia most in need of individualised support.

### **Target group**

Families and carers of people with dementia, including younger people with dementia.

### **Key service requirements**

Flexible support is:

- aimed at filling gaps in the service system, or topping up carer support services outside generic service systems
- provided on an as-needs basis including in crisis situations
- responsive to the needs and preferences of people with dementia and their families and carers
- determined by assessing what the care recipient and carer need in consultation with them
- tailored to meet needs, including those of carers in Aboriginal communities, and of culturally and linguistically diverse backgrounds.
- guided by equity of access to support by carers
- negotiated with other service providers if possible and appropriate.

### **Expected outcomes**

Expected outcomes of the service are:

- Flexible support for the families and carers of people with dementia, tailored to fill service gaps, top-up existing services, and meet individual needs.
- Families and carers of people with dementia being able to continue their carer role in the longer term, and the person with dementia being able to stay longer at home.
- Improved quality of life for the families and carers of people with dementia.

### **Service agreement and SAMS**

Funds are generally transferred to Department of Health Regions on the basis of the 70+ population per region to be provided mainly to the Carer Respite Centres through service agreements. However funds targeting the families and carers of younger people with dementia (from 2008/09) are transferred to regions on the basis of the 30+ population per region. Funds are expended against activity 13155 – Dementia Services in the Aged Care Service Plan.

Note that Dementia Care Support Workers are funded under activities in the Support for Carers Program (SCP), rather than activity 13155 – Dementia Services in the Aged Care Service Plan.

### **Performance measures**

Regions are to add a fourth performance measure to the activity 13155 – Dementia Services, to read 'Occasions of service of flexible respite/support'

## **Targets**

For the first three performance measures in activity 13155 - Dementia Services, regions need to enter '01'.

The target for the fourth performance measure "Occasions of service of flexible respite/ support" is determined by each region in consultation with the community service organisation, and guided by the minimum target per region (minimum annual targets based on: allocation of funds per region, and maximum cap of \$2,000 per carer per annum; where a carer is caring for a younger person with dementia, the cap is \$2,000 per person with dementia per annum). Note that carers of any age caring for a person with dementia can access the service.

## **Funding (excluding CPI)**

Recurrent funding is generally allocated based on the 70+ population per region per annum, and funding targeting the families and carers of younger people with dementia is allocated based on the 30+ population per region. Initial funding became available in 2002/03 on a pro-rata basis from February 2003 to Dementia Care Support Workers in the nine Carer Respite Centres. Since that time, the number of agencies being funded to deliver this service has grown to ten (Attachment 2), and additional funding has become available, so that total funding of the program is as follows:

- \$270,000 in 2002-03 prorata from February 2003
- \$250,000 in 2003-04, prorata from September 2003
- \$250,000 in 2004-05
- \$100,000 in 2005-06, prorata from May 2006
- \$250,000 in 2006-07, from September 2006
- \$300,000 in 2007-08, from September 2007
- \$150,000 in 2008-09, from September 2008 to meet the needs of families and carers of younger people with dementia.

Thus full year recurrent funding for the program totals \$1,570,000 per year from 2008-09.

There is a cap of \$2,000 per carer per annum. Where a carer is caring for a younger person with dementia, the cap is \$2,000 per year per person with dementia being cared for.

## **Reporting and data**

It is useful for service development purposes to have an understanding of how the brokerage funding is being spent on carers, to support the care relationship. A proforma is attached for completion and delivery to the:

- Department of Health regional office, and
- Aged Care Branch, Department of Health

at the end of each financial year (Attachment 3). Please note the proforma asks for a minimum two case studies to demonstrate the use and value of the program to people in care relationships.

## Attachment 1

### Role of Dementia Care Support Workers\*

'Key service requirements include:

- Liaise with Regional Carer Resource Worker and other relevant organisations to ensure timely and efficient responses to identified support needs for carers of older people including those of the prematurely aged \*\*
- Respond to short term support needs for carers and assist carers with planning longer term management strategies
- Collaborate with carers and support services to provide ongoing support and follow up carers with the generic support system
- Investigate the range of service options available to carers and individual support plans which may include purchase of service(s)
- Coordinate, manage and deliver a service to enable the funding of capped, short term, support and respite to facilitate feedback for enhanced collaboration in service provision
- Negotiate carer access to appropriate services
- Support other service system staff to implement and maintain an individual care plan
- Contribute to regional planning and service development relevant to the provision of carer support.

Outcomes of the positions include:

- Increased knowledge and use of services and resources by carers/ consumers
- Carers/ consumers have increased access to respite and other support services
- Carers are able to continue in their role and the quality of life for the consumer, the carer and other dependants of the family is at least maintained, or improved
- The broader service system has an increased knowledge of the needs of carers/ consumers
- A more coordinated support service system for carers/ consumers, where service gaps have been identified and action taken towards addressing service gaps.'

\* There are nine positions of Aged Care and Dementia Care Support Workers, one in each region except for North and West Region where there are two. This role statement is from page 39 *Evaluation of the Support for Carers Report*.

\*\* Identifying the needs of Aboriginal carers and carers of culturally and linguistically diverse backgrounds (CALD) requires cultural sensitivity and appreciation of cultural differences.

## **Attachment 2**

### **Agencies funded to deliver the Support for Carers of People with Dementia Program**

- Ballarat Health Services - Carers Choice
- Barwon Health - Barwon South West Carer Respite & Carelink Services
- Bayside Health – Carer Respite Centre
- Bendigo Health Care Group – Carer Support Services
- Carers Association Victoria – Carer Links West
- Latrobe Community Health Service Inc – Carer Services
- Merri Community Health Services Ltd
- Goulburn Valley Family Care Inc
- Upper Murray Family Care Inc
- Villa Maria Society



## **Section C: Carer consultation and impacts**

Describe your process for consulting with carers of people with dementia in developing individualised support services/ packages to meet their unique needs.

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What difference do you think this program has made to the lives of carers of people with dementia?

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## **Section D: Case studies**

Please provide one or two deidentified case studies and narrative demonstrating what this program achieves for carers of people with dementia, and the people they care for.

### **Case study 1**

## Case study 2

Please return by the end of July to:

1. Your departmental regional contact
2. Service Development Unit, Aged Care Branch

**Mail:**

Diane Calleja  
Aged Care Service Development  
Department of Health  
12<sup>th</sup> Floor, 50 Lonsdale Street  
MELBOURNE 3000

**Fax:**

Diane Calleja  
(03) 9096 9163.

**Email:**

[di.calleja@health.vic.gov.au](mailto:di.calleja@health.vic.gov.au)

**Telephone:**

(03) 9096 7727.

**Thank you**