8 Dementia Care in Alternative Settings

8.1 Project description

Southern Cross Care Western Australia received an allocation of 35 flexible care places to operate an Innovative Pool dementia service for eligible residents of the southern suburbs of Perth. Dementia Care in Alternative Settings (DCAS) was funded to operate for 2 years.

Southern Cross Care Incorporated in Western Australia is a not-for-profit provider of residential and community aged care services. Southern Cross Care WA operates eight dementia-specific units within its residential care facilities that accommodate up to 128 people in addition to two high care psychogeriatric residential units. The organisation also manages retirement village units. For approximately six years, Southern Cross Care WA has delivered community care programs including adult mental health (low level support), HACC services, CACP services, and two HACC-funded dementia-specific day centres. Its services extend to Bunbury and Broome. Southern Cross Care WA provides consultancy services, employing a dementia consultant, clinical nurse consultant, occupational therapy consultant, registered mental health nurse and occupational health and safety consultant to work with clients across the full range of Southern Cross Care WA programs.

A provisional allocation for the project of 25 places was increased to 35 places in June 2003 for a catchment area that covers the Local Government Areas of Cockburn, Fremantle, Canning, South Perth, Victoria Park, Belmont, Gosnells and Armadale. DCAS was established in October 2003 and accepted its first clients in November 2003. A steering committee comprising members of Southern Cross Care WA Incorporated, the Western Australia office of the Department of Health and Ageing, Bentley Aged Care Assessment Team, the Seniors Mental Health Service, and consumer representation provides guidance and monitoring.

Project objectives

DCAS is based on a philosophy that it is possible for people with severe dementia, including those who live alone and those with severe psychological and behavioural symptoms, to live at home provided there is sufficient flexibility to deliver truly client-focused care. The stated objective is to provide additional care options to members of an existing Southern Cross Care client base who were previously being supported on a high number of hours through the CACP service and to expand services to new clients in the community.

Target group

The project targets older people with moderate to severe dementia who wish to remain living in their own homes and who are not actively seeking residential care placement. Clients are those people whose needs cannot be met by provision of a CACP. Participation in

DCAS requires that the client and his/her family are committed to the client receiving care at home.

Care recipients with behavioural disturbances are accepted, provided that 24.5 hours of service per week is adequate to support them safely. Approximately 84% of clients received assistance through government support programs prior to entering DCAS, which is one of the higher rates of previous government-funded service use recorded by Innovative Pool Dementia Pilot projects.

ACAT approval for low or high level residential care is required and assessment processes must demonstrate that a client has moderate to severe dementia and/or behavioural symptoms of dementia.

Service environment

Flexible respite is an area of high unmet need, according to Southern Cross Care. Community respite services tend to offer respite for short periods of time, typically just a few hours, or for longer periods in short bursts of two to three days. Either model may not adequately assist a carer with other high demands time such as employment or other caring responsibilities, or a carer who needs longer periods of respite over a sustained period to help them cope with the demands of dementia care. Residential respite can be hard to access at short notice and is not the preferred respite service for many care recipients and their carers. The DCAS team believes that lack of flexibility in respite care delivery, and more generally, the limited hours of in-home care available through mainstream care packages contribute to people with moderate to severe dementia entering residential care prematurely despite a strong desire for care at home.

There are programs that support individuals who are at an equivalent level of hostel care and need approximately 4–8 hours per week of service delivery, for example, CACP. Programs that provide an equivalent level of nursing home care and provide approximately 12–17 hours are limited in their geographical allocation and number of places,for example, EACH.

DCAS is trialling a service model designed to deliver up to 24.5 hours per week to meet the observed higher needs of the target group.

Care model

DCAS comprehensive care packages provide for service on seven days per week and up to 3.5 hours per day. The Memorandum of Understanding between Southern Cross Care (WA) and the Department of Health and Ageing specifies that each care recipient will be allocated a maximum of a three-person team where possible, comprising a primary, secondary and relief support worker to ensure consistency of care and to minimise confusion for client and family carers. Services are tailored to individual client needs and may include personal care, medication management, meal preparation and assistance with feeding, domestic assistance, escorting for shopping and appointments, social support, respite care, therapy and behaviour management, continence management and carer support services.

The high number of hours and flexible rostering of DCAS to ensure a minimum number of staff delivering services to a client are key innovative features of the project.

Southern Cross Care uses Innovative Pool funding to offer day centre and emergency overnight respite care to complement the in-home respite service. Southern Cross Care contributes two adjoining units in a Southern Cross Care retirement village and uses Innovative Pool funding to run the respite care service. Day respite is available four days per week with two staff in attendance each day. DCAS respite clients normally spend 5 to 7.5 hours at the centre on each day of attendance. Residents in the retirement village assist staff on a volunteer basis and appear to enjoy the opportunity to contribute, while respite care clients benefit from the social atmosphere of the centre. Activities and lunch are included and transport to the centre can be arranged. The service allows DCAS to provide quality dementia-specific day respite services on an efficient basis. The provision of respite care in alternative settings provides for maximum flexibility which has met with high acceptance from care recipients and carers.

The project coordinator suggested a range of conditions which might signal that DCAS may no longer be able to adequately support a client:

- Maximum hours provided are insufficient to meet client needs.
- Client behaviour poses a risk of injury to support staff and behaviour management options have been exhausted.
- Unsafe care situation, for example, client wanders without supervision or other risk associated with severe cognitive decline.
- Deterioration in physical functioning that renders a client unable to manage at home alone.
- Carer breakdown to the point that having a partner at home is no longer sustainable despite extra support from the project.
- Client unable to safely transfer or mobilise with the assistance of one person.
- Nursing care needs exceed dementia care needs.

If a client is discharged to an aged care facility, DCAS support staff are available to visit for a reduced number of hours over a few weeks to assist with the settling-in process.

Staffing

At the time of the AIHW site visit, 17 salaried care workers were delivering in-home and respite centre services under the direction of one full-time coordinator/case manager. The one case manager is responsible for coordinating service delivery to all DCAS clients. The services of two care professionals are brokered for an average of two hours per week. Full-time administrative support was budgeted at a rate of 30 hours per week.

The case manager arranges for other experts to become involved in client assessment and management on a case-by-case basis. The Southern Cross Care dementia consultant and occupational therapist have a high input to the project.

Staff communication is facilitated by monthly meetings of support workers. Communication books are used to relay information to each support worker who comes into a client's home.

Delivering a highly flexible service has had some staffing implications and difficulties have been encountered, for example, finding staff for clients located over a large geographic area, staffing for a mix of substantial blocks of time and short periods both inside and outside normal working hours. In particular, expansion of the project to cover the local government areas of Fremantle and Cockburn was said to have had a major impact on service delivery due to staffing difficulties.

Early progress

The AIHW evaluation team visited the DCAS project team in July 2004. The project reached full occupancy within a short time of establishing. By mid-2004 the waiting list contained 26 names and the coordinator was receiving an average of two enquiries per week, either about the project or the waiting list. Thirty-nine clients had been accepted into the project and eight discharges had taken place in the year since November 2003.

Clients were either previously supported by family without formal services (14), receiving CACP services (21), or receiving HACC, nursing agency or similar services (four). Clients who were on a CACP before DCAS were referred to DCAS because they needed more hours or full-time case management, had become resistant or aggressive to existing support staff and needed dementia-specific care, or family had become unable to manage with CACP-level support. Discharges involved transfer to residential care either because of escalating nursing care needs, carer illness or refusal to accept support at home.

By 30 June 2004, five clients on the waiting list had entered permanent care and another two clients on the waiting list were actively seeking placement.

DCAS recorded information about clients on the waiting list to use as a basis for comparing accommodation outcomes with the evaluation group. It was intended that follow-up would occur at least 6 months after referral to facilitate a valid comparison; however only four of those not placed with the project were located 6 months or more after referral. Most follow-up was completed within just 3 months of referral. The waiting list data show that people who were unable to be placed on the project have similar living arrangement and core activity limitation profiles to the DCAS evaluation client group (see section 8.7).

Successes, challenges and lessons

The day respite centre is considered a major factor in the project's success. Clients have responded well to respite care in a home-like setting where their individual needs and preferences can be catered for. This model of respite is particularly well suited to clients who have an employed primary carer and who can benefit from a social form of care in a homely environment.

Support for carers has placed heavy demands on the project coordinator and support workers. It has been observed that in many cases, carers have managed without an adequate level of support from formal services so that by the time a client is accepted into DCAS, the carer can be experiencing severe strain. It is thought that earlier intervention for these carers may help to avoid some of the difficulties that the project has encountered in introducing higher levels of support.

Recruiting and keeping staff has been another challenge for the project, exacerbated by the project's large catchment area. This makes it difficult to achieve the goal of no more than three different care workers per client, although the goal has been achieved for some clients. The coordinator reported that staff need to be rotated more often for some clients with behavioural symptoms in order to avoid burn-out.

Severe mobility restriction, high risk of falls, and wandering behaviour in the absence of 24-hour supervision from a family member are the major risks for continuing care with DCAS. Southern Cross Care WA has a no lift policy, although the project has supported one client with the assistance of a hoist.

Case studies

DCAS provided three case studies.

Case study 1

'Client was referred to DCAS by the geriatric medicine team of a local health service in November 2003. At the time she had been receiving a Community Aged Care Package (CACP) that provided 7 hours of care a week.

The CACP care staff had been unable to provide the care required. Client was not taking her medications. She was not eating properly, and would not allow the care staff to cook, clean or assist her with personal care. Her food handling caused concern, as she would leave food out in the heat or defrost and then re-freeze food, putting herself at risk of food poisoning. She was not showering, and her clothes were old, dirty and ripped. If staff tried to carry out any personal care, she became very agitated and physically and verbally aggressive. Service times varied greatly which made it very difficult for any routine to be established.

Client was frail, stooped in posture and often wandered the grounds of the retirement complex she lived in. She was paranoid about people stealing her money and possessions, and would often approach the village administration staff about these concerns. Client presented as depressed, a condition that had persisted since the death of her husband several years before.

Client lacked insight into her abilities which made it very difficult for any successful interventions and she constantly complained about all the strangers entering her home and interfering with her possessions.

The CACP care staff found that they were unable to establish a rapport with the client, especially within the time constraints. She had no family support, and only one supportive friend. Client strongly wished to remain in her home, and was thus referred to DCAS.

Initially, the support workers offered companionship. Due to the client's reluctance to accept care, the priority was seen to be building rapport and a sense of trust. The client verbalised concerns at her initial assessment that DCAS was trying to put her in 'a home' and became quite distressed by this. Much reassurance was required to convince her that the priority was to assist her to stay in her home and to provide friendship rather than to take over her life.

Medication prompts and meal prompts were introduced. After about three months the support workers had developed a good relationship with the client, and she would allow them to assist her with personal care, including showering. Soon after that she decided to recommence day centre attendance.

Some other strategies included performing duties when she was not at home so that the client wouldn't become distressed, for example, doing the washing while she was having lunch with her friend. The hours of care were increased so that the support workers could take the client for outings and to the shops, which she loved. Domestic services were provided one day a week, while client was out with friends. The client's package was then increased to the full hours available.

Outcome

With the above care and services, the client coped well at home. She loved the social interaction provided by the visits from support workers. She especially loved a cup of tea, and this provided an important time for the relationship building to take place. Wandering virtually ceased. She was prescribed an antidepressant medication by her doctor and her mood continued to fluctuate, but showed an overall improvement. Her paranoia diminished, and she was no longer complaining to the village staff as often about things going missing. Her physical health improved greatly as she began eating regular, healthy meals.

Unfortunately, the building the client was living in was scheduled for demolition, and she was forced to relocate. Some of her behaviours began to escalate again as she felt under pressure from the village administration to go into residential care. Some of the alternative accommodation offered was inappropriate. An application was made for a public guardian to be appointed to assist in ensuring that the client's interests would be met.

In September 2004 the client moved to dementia-specific hostel accommodation. Some of her problems resurfaced following the move, but she has since settled into her new environment. Hostel staff members expressed surprise that she had been able to live alone at home for so long, given the severity of her dementia. Client is still able to enjoy the companionship of others along with regular outings and activities. An interim period of support was given by her community support workers to assist with her settling in process. However, if she had not been forced to relocate she would have been able to continue to live in her own home for longer with the assistance of her flexible care package.'

Case study 2

'Client was referred to the service by Fremantle Aged Care Assessment Team (ACAT) in August 2004. The client lived with her husband, who was physically frail and unwell. She had been receiving a Community Aged Care Package (CACP) of 7 hours per week. Her husband also received some respite support.

Client was doubly incontinent, and had mobility problems. She was paranoid about what her husband might do, for example, 'run off with someone'. This meant that she wouldn't let him out of her sight. Therefore, there was no break from caring for her husband, and he was becoming extremely worn down.

At the time of referral to the project, the situation was desperate as the client's husband was becoming increasingly stressed and unable to cope well. Although family lived next door they were providing little support due to a previous disagreement. The client's husband admitted that he had previously made a pact with his wife that they would never be separated and had considered ways of departing this world together. Despite having reached this point, the husband was initially reluctant to accept the full 24 hours of care per week that could be made available.

Services commenced within a few days to provide personal care and companionship along with respite for the client and daily assistance for domestic support for her husband. This made a big difference to his ability to cope.

In October, when the husband was diagnosed with a terminal illness, the situation again reached crisis point. He was strongly advised to access residential respite for his wife to give him some time to himself but when respite was arranged for his wife she began threatening that she no longer wished to live and that he had promised this would never happen. A crisis care intervention was arranged, whereby a carer stayed with the couple for 72 hours until the situation settled and the couple felt confident that they could stay at home safely.

Following the crisis intervention, care was provided in the couple's home, seven days a week. This included domestic assistance, personal care, assistance with meal preparation, and spending companionship time with the client to allow her husband a break. After this episode the client's husband was able to be convinced to reconsider her attending day centre care as this would give him full days of respite. The client agreed to start attending a day respite centre. She now attends four days a week, and loves it. She is picked up and dropped off by the centre's bus. She always enjoys her time there, and her husband reports that she sleeps much more soundly at night after the daytime stimulation. This is a great relief to him.

Outcome

Since the care workers have developed a trusting relationship with the client, they are able to support her in her grief on the occasions when she is lucid. The couple's family was encouraged and is now far more supportive. This is a great help. Grief counselling has been arranged for the couple through the Alzheimer's Association and plans are being made for residential care for the client due to her husband's failing health. The client's husband was reassured in knowing that appropriate arrangements are in place.

Currently the client's husband feels much stronger and able to cope with the day-to-day issues and he is no longer reluctant to ask for assistance. Family assists in the evenings to prepare the client for bed as her husband becomes exhausted from minimal effort.'

Case Study 3

'Client was referred to DCAS by the Fremantle Aged Care Assessment Team (ACAT) in February 2004. She was living alone and receiving support through Community Aged Care Packages (CACP) totalling 7 hours of care a week. Over a period of a year or so the client had become very depressed and withdrawn. She had isolated herself from everyone, even family. She did not leave the house and always kept the curtains and windows shut, so that she was sitting in the dark. She would binge eat, which was causing weight and health problems as she is diabetic. The client would wear soiled clothing over and over, did not attend to domestic duties, and was fast becoming reclusive.

DCAS services began slowly, with support workers simply visiting to start with, to build rapport and trust. The client would allow people in and speak with them, but maintained that she didn't need any help. Visits continued three times each day. After about two weeks the client began to allow the support workers to assist her with personal care. She began to wear clean clothes and use continence aids. She also allowed the support workers to prepare her meals and snacks. Medication prompts were given, as client had not been remembering to take her tablets. She accepted these prompts and took her medications as prescribed. The client enjoyed the social aspects of the visits, and the companionship they provided. She began to allow the curtains and the windows to be opened, slowly reconnecting her to the outside world.

After about two months the client began to go out grocery shopping with the support workers. She enjoyed these outings, when prior to this she had not left her house for over a year.

Outcome

Client has a supportive family who are astounded at her improvement. They had been so concerned before commencement of the service, but their attempts to help had been to no avail.

Now the client's GP has reported that her health has significantly improved. She has lost weight, and her diabetes is well managed. She loves going out, not only shopping, but to cafes and a theatre group as well. With prompting she will even attend her doctor's appointments by herself. She has been able to take the initiative to buy flowers for her daughter-in-law and arrange for them to be sent. She has been reading books and writing letters again with prompting. Support workers started accompanying her on walks around the river and now the client has purchased a pedometer, which she uses to make sure she gets enough exercise.

Now that she is taking her medication as prescribed, eating a healthy diet and enjoying a good level of social interaction the client's Mini-Mental State Examination score has improved by eight points, from 16 to 24. Correspondingly, her level of functioning has improved markedly, and she is certainly enjoying a much better quality of life. Her family is very pleased with her progress.'

A profile of DCAS evaluation clients during the reporting period 14 June to 30 November 2004 follows.

8.2 Client profiles

DCAS supplied data for 33 clients, including 10 men and 23 women.

Age and sex

Ages of evaluation clients ranged from 70 years to 94 years (mean 82.6 years). Twelve clients were aged 85 years or over (Table B8.1).

Table B8.1: Dementia Care in Alternative Settings, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
65–74	—	4	4
75–84	6	11	17
85+	4	8	12
Total	**10**	**23**	**33**
		(per cent)	
65–74	—	12.1	12.1
75–84	18.2	33.3	51.5
85+	12.1	24.2	36.4
Total	**30.3**	**69.7**	**100.0**

— Nil.

Language and communication

Seven clients had little or no effective means of communication. The remaining 25 clients in the evaluation could communicate effectively in spoken language. Four national languages were represented in the group (Table B8.2).

Table B8.2: Dementia Care in Alternative Settings, number of clients by language spoken at home and English proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	26	4	—	30
Eastern European [(a)]	2	1	—	3
Total	**28**	**5**	**—**	**33**

(a) Includes Croatian, Estonian and Polish.

— Nil.

Accommodation and living arrangement

Clients were living in private residences or a retirement villages (Table B8.3) and all were in their usual place of residence at time of referral.

Table B8.3: Dementia Care in Alternative Settings, number of clients by usual accommodation setting and living arrangement

	Usual living arrangement			
Accommodation setting	**Alone**	**With family**	**Unknown**	**Total**
Private residence	14	13	1	28
Retirement village—independent living unit	1	4	—	5
Total	**15**	**17**	**1**	**33**

Years at usual place of residence ranged from less than one to 55 years. Four clients had been living in the same home for 30 or more years.

Carer availability

All 33 DCAS clients had a family carer and 14 carers were living with the care recipient (Table B8.4). Carers' ages ranged from 32 to 80 years, averaging 56.7 years (Table B8.5).

Table B8.4: Dementia Care in Alternative Settings, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Carer does not live with client	Not stated	Total
Spouse or partner	7	—	—	7
Son or daughter	6	16	1	23
Son- or daughter-in-law	—	1	—	1
Other relative	1	—	—	1
Friend or neighbour	—	1	—	1
Total clients with a carer	*14*	*18*	*1*	*33*
Total clients				**33**
Per cent of clients with a carer				100

— Nil.

Table B8.5: Dementia Care in Alternative Settings, number of carers by age group and sex

Age (years)	Males	Females	Persons
25–44	2	3	5
45–54	4	6	10
55–64	5	4	9
65–74	1	4	5
75–84	2	2	4
Total	**14**	**19**	**33**

Income and concession status

Government pensions were the primary source of cash income for 32 clients (Table B8.6). Thirty-two clients held a health care concession card and 10 clients received a discounted weekly contribution rate for the DCAS due to financial hardship.

The majority of clients were contributing $5.43 per day towards the cost of services (rates varied from $1.43 to $5.57 per day).

Table B8.6: Dementia Care in Alternative Settings, number of clients by principal source of cash income, health care concession card status and project concession status

	Number of clients	Per cent
Principal source of cash income		
Age pension	25	75.8
DVA pension	7	21.2
Nil income	1	3.0
Total	**33**	**100.0**
Health care concession card holder	32	97.0
Project concession status	10	30.3

Previous use of government community care programs

Five clients were not receiving assistance from government community care programs before entering DCAS (Table B8.7). Twenty-eight clients had been receiving help prior to entering the project, 10 of whom were receiving assistance from multiple sources. Nineteen clients were receiving assistance through the CACP program, eight in conjunction with services funded by other programs. HACC had been providing assistance to six clients, Veterans' Home Care was assisting four clients and eight clients received services through Day Therapy Centres.

Of the 16 carers who had accessed any form of respite care in the 12 months prior to entering the project, 11 had used mainly residential respite and five had used mainly in-home respite. Eight carers reported that, despite having had a need for respite care in the 12 months prior to DCAS, they had not used a respite care service. Nine carers said they had not needed respite care services.

Table B8.7: Dementia Care in Alternative Settings, number of clients by use of government support programs prior to DCAS

Previous use of government support programs	Number of clients	Per cent
Government support program		
Community Aged Care Packages	11	33.3
Home and Community Care	4	12.1
Veterans' Home Care	2	6.1
Day Therapy Centre	1	3.0
Multiple programs (CACP & other)[(a)]	8	24.2
Other multiple programs[(b)]	2	6.1
Total clients with previous government program support	*28*	*84.4*
Clients without previous government program support	5	15.2
Total	**33**	**100.0**
Use of respite care in the 12 months prior to the project		
Respite care used	16	48.4
Respite care not needed	9	27.3
Respite care needed but not used	8	24.2
Total	**33**	**100.0**

(a) Other includes DTC, HACC and VHC.

(b) Other includes VHC with DTC and DTC with NRCP.

One client is reported to have been on a waiting list for residential aged care during the evaluation.

Assessment and referral

ACAT assessments are performed by Bentley Health Service, Armadale Health Service and Fremantle ACATs. During the evaluation period, nine of the 33 clients had been approved by an ACAT for residential low care and 24 clients had approval for high level residential care.

Twenty-four clients were referred to the project by an ACAT (Table B8.8). The other nine clients were referred by Southern Cross Care WA or another agency.

Table B8.8: Dementia Care in Alternative Settings, number of clients by source of referral.

Referral source	Number of clients
Aged Care Assessment Team	24
Southern Cross Care WA	5
Other agency	4
Total	**33**

Some clients on a Southern Cross Care CACP commenced services with DCAS a time after initial needs assessment, hence DCAS recorded service commencement date as distinct from referral or initial needs assessment date. Most clients had completed an ACAT assessment before commencing on a DCAS package (Table B8.9).

Table B8.9: Dementia Care in Alternative Settings, number of clients by days between completion of ACAT assessment and commencement of services

Completion date of ACAT assessment	Number of clients
Before commencement of DCAS services	
0–20 days	3
21–60 days	6
61–90 days	5
91–120 days	3
121–365 days	12
Total	*29*
After commencement of DCAS services	**4**
Total	**33**

A registered nurse managed the care of all clients.

The HACC Needs Identification instrument, Bristol Activities of Daily Living Scale and a 12-item Caregiver Strain Index are routinely used in DCAS for client and carer assessment and review, which facilitated adaptation to the evaluation data collection tools.

Health conditions and health status on entry

The number of health conditions that each client had at the time of entry to the project ranged from one to nine. Twenty-six clients had three or more health conditions. All DCAS clients have dementia recorded as the primary health condition—30 cases of dementia in Alzheimer's disease and three of vascular dementia.

Seventeen clients out of 33 were assessed as being at risk of falls due to impaired gait or balance and seven clients had diagnosed depression (Table B8.10).

Table B8.10: Dementia Care in Alternative Settings, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	17
Hearing impairment	12
Vision impairment	10
Diagnosis of depression	7
Total or partial paralysis	1

Clients were taking between zero and nine different medications. Nineteen clients were taking four or more different medications.

Clients were asked to rate client health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Twenty-four carers gave a proxy report and nine clients were able to self-report.

Eight clients were said to be in excellent or very good health. The remaining ratings were good (13 clients), fair (nine clients) and poor (two clients). Most raters said that the client's health was somewhat worse (23 clients) than one year earlier.

Level of core activity limitation

Most DCAS clients experienced mild to moderate activity limitation in the areas of self care, mobility and communication (Table B8.11). Twelve clients had a severe or profound activity limitation in at least one core activity.

Severe or profound activity limitation was most often found to be related to self-care.

Table B8.11: Dementia Care in Alternative Settings, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	1	9	12	11	**33**
Mobility	6	17	10	—	**33**
Communication	6	18	5	4	**33**

— Nil.

Use of medical and hospital services prior to entry

Of the 33 DCAS clients, 32 had visited a medical practitioner at least once in the 6 months before joining the project. The reported number of visits to a medical practitioner in this period varies from zero to 40 per client. One client reported 40 medical consultations outside hospital and in addition to two unplanned admissions to hospital in the 6 months prior to entering the project. Cumulatively, the 32 clients recorded 169 visits to a medical practitioner outside of a hospital setting over an estimated 5,760 person days.

Eleven clients contributed to a total of 18 hospital admissions in the 6 months before entry. One client had a planned admission only. The remaining 10 clients with one or more hospital admissions recorded unplanned or urgent admissions and most had visited a hospital emergency department. These clients collectively accumulated 124 unplanned hospital bed days over approximately 1,620 person days. Individually, they recorded between three and 28 days in hospital for unplanned admissions.

Conditions recorded as occasioning admissions to hospital for clients in the pre-entry period include:

- injuries to leg/knee/foot
- oedema
- fracture of the femur
- falls
- transient cerebral ischaemic attacks
- influenza and pneumonia
- blackouts, fainting, convulsions.

Three clients had experienced a serious medical emergency during the pre-entry period, all of whom had also suffered a fall with injury. Another five clients suffered a fall with injury, two of whom were rendered immobile and unable to summon assistance for more than 30 minutes. All but one client who had a medical emergency or fall were reported to have presented to an emergency department or had unplanned admissions to hospital.

8.3 Client assessment results

Cognitive function

MMSE scores were recorded for 28 clients when they entered the project (Table B8.12). Non-zero scores range from a minimum of 4 to a maximum of 24 out of a possible 30 points (mean 13.4).

Table B8.12: Dementia Care in Alternative Settings, number of clients by Mini-Mental State Examination score at entry

MMSE score	Number of clients
Zero	2
1–15	15
16–18	5
19–24	6
25–30	—
Missing	5
Total	**33**

— Nil.

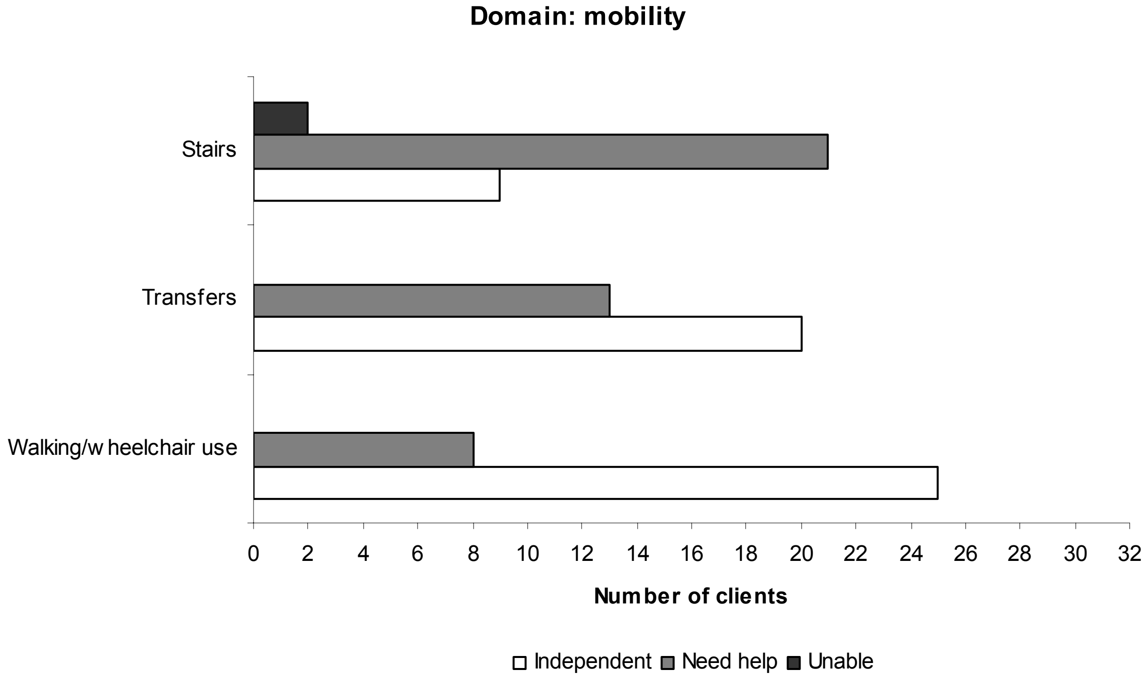
A score of 23 points or lower is usually taken as a positive screen for cognitive impairment, although 24 points is often used when higher sensitivity for screening mild impairment is required.

It is recommended that level of education is taken into account in the interpretation of MMSE scores. Cut-points to account for educational attainment were applied to the DCAS entry MMSE scores (see Uhlmann & Larson 1991), indicating that 27 of the 28 clients who completed the test screened positive for cognitive impairment. One client who recorded a score indicative of no cognitive impairment at time of entry to the project was re-tested at a final assessment and did not register as cognitively impaired at that time either.

On the basis of MMSE results, it is concluded that DCAS was targeting the intended client group.

Activities of daily living

MBI scores reveal that, at entry to the project, at least half of DCAS clients needed assistance in tasks involving self-care and mobility (Figure B8.1). MBI scores at entry ranged from zero to 20 out of a total 20 points. The mean score was 13.0 points.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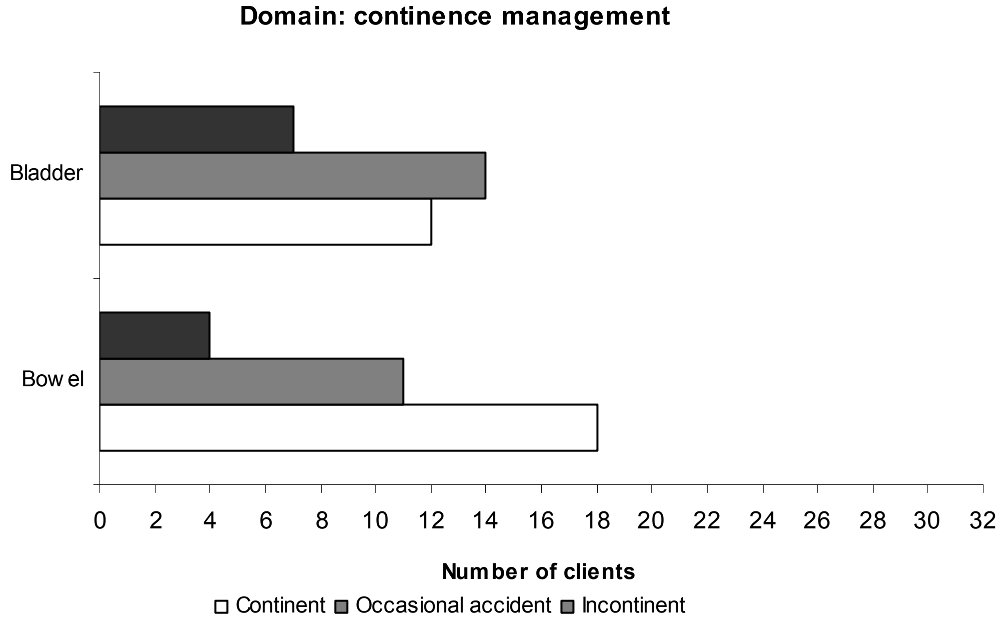
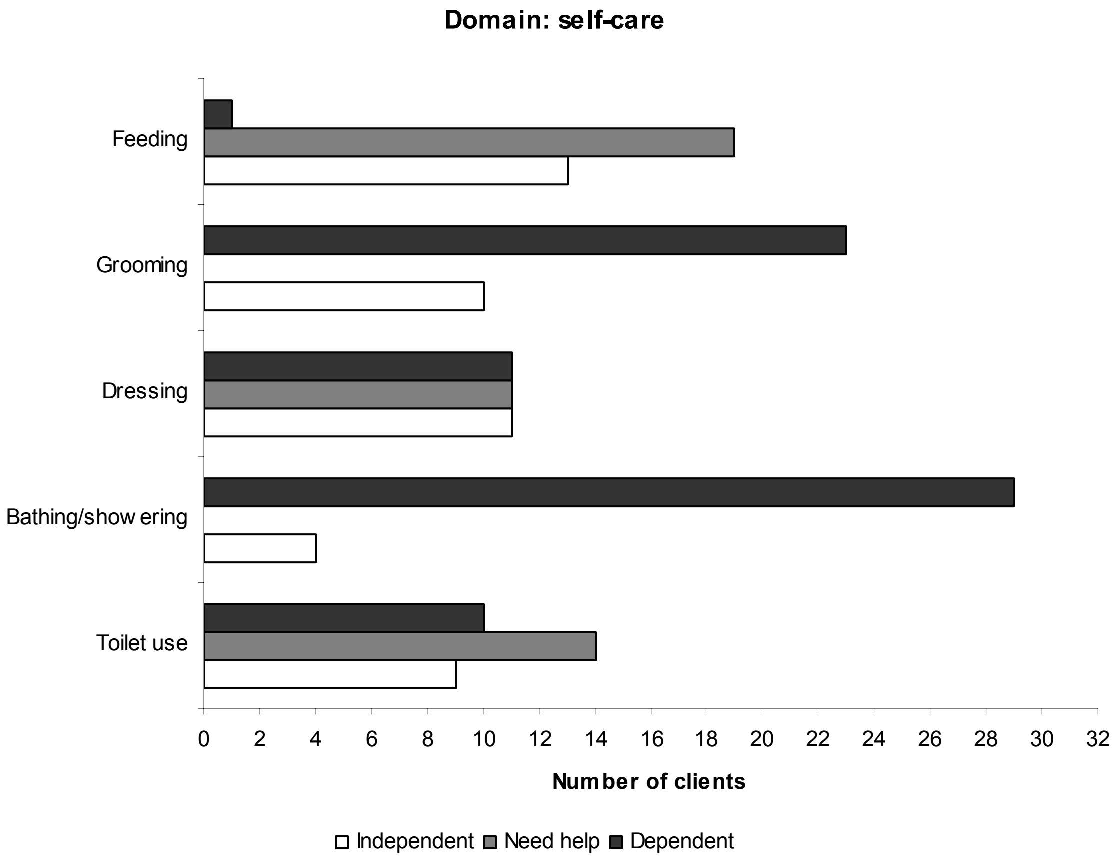

Domain: continence management

Figure B8.1: Dementia Care in Alternative Settings, number of clients by level of ADL function at entry

(continued)



Domain: self-care

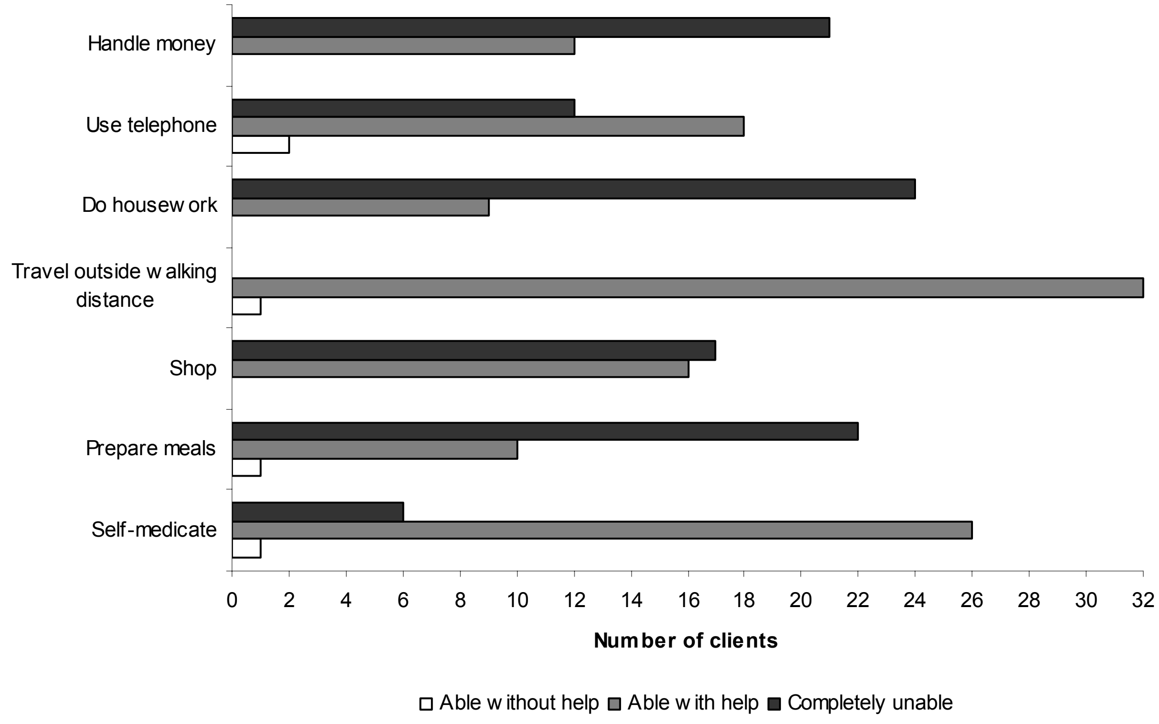
Source: Appendix Table B21.

Figure B8.1 continued: Dementia Care in Alternative Settings, number of clients by level of ADL function at entry

Using a classification scheme for the Barthel Index (Shah et al. 1989), 17 clients exhibited severe dependency in self-care and mobility at time of entry, 13 clients exhibited moderate dependency and two clients showed slight dependency. One client was independent in self-care and mobility at entry to DCAS, however this person needed help in all but one IADL.

Fourteen clients were doubly incontinent. Twenty-nine clients were unable to bathe or shower without assistance. Twenty-four clients needed help to use the toilet and 13 clients needed help with transfers. Most clients also needed help in the areas of dressing, grooming and feeding.

Most DCAS clients were highly dependent in IADL when they entered the project and travelling away from home without assistance was not a possibility for any client (Figure B8.2). On average, DCAS clients were completely dependent in three out of seven IADL at the time of entry. Three clients were totally dependent in six out of seven IADL.



Source: Appendix Table B22.

Figure B8.2: Dementia Care in Alternative Settings, number of clients by level of IADL function at entry

The project recorded two more assessments after baseline. In some cases only one additional assessment was possible. Figure B8.3 shows the MBI scores for clients at baseline, interim and final assessment by accommodation setting at follow-up. Clients in care at follow-up were either in residential high or low care, or in hospital. Clients in the community were either still on Dementia Care in Alternative Settings, in other community care or were not accessing government-funded care services.

There is no discernable overall difference in the pattern of functional change for clients who entered residential care versus clients who remained in the community at time of follow-up. Both groups include individuals who remained functionally stable or gained ADL function and others who lost ADL function over time. A wide range of MBI scores at the baseline and final assessments is seen in both groups.

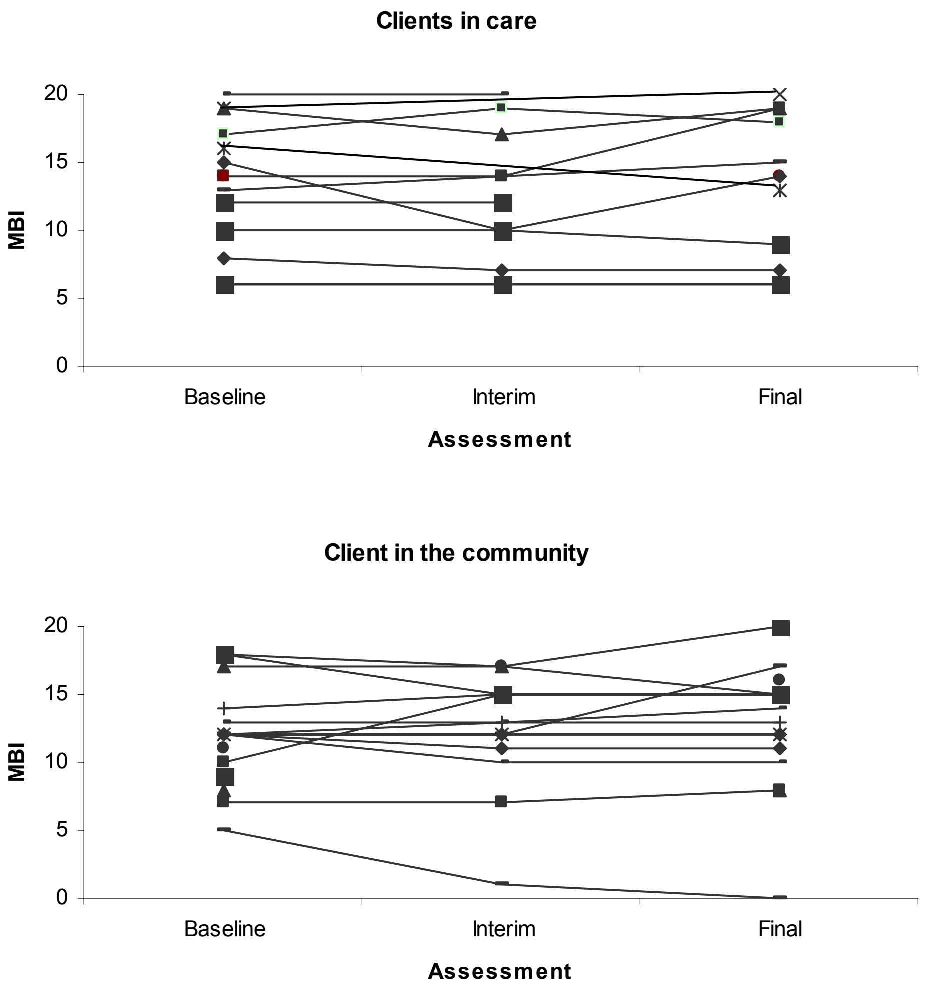


Figure B8.3: Dementia Care in Alternative Settings, baseline, interim and final MBI scores by follow-up accommodation setting (one symbol per client)

Psychological and behavioural symptoms

All clients showed signs of intermittent or extensive memory loss (Figure B8.4). Twenty-seven clients exhibited emotional or psychological symptoms of dementia on an intermittent or extensive basis. Twenty-six clients were reported to be a danger to themselves or others at least occasionally. Thirty-one clients exhibited two or more of psychological and behavioural symptoms on an intermittent or extensive basis and 24 of these clients exhibited two or more symptoms on an extensive basis.[13] Eighteen clients were reported as having other unspecified dementia-related intermittent or extensive behaviours.

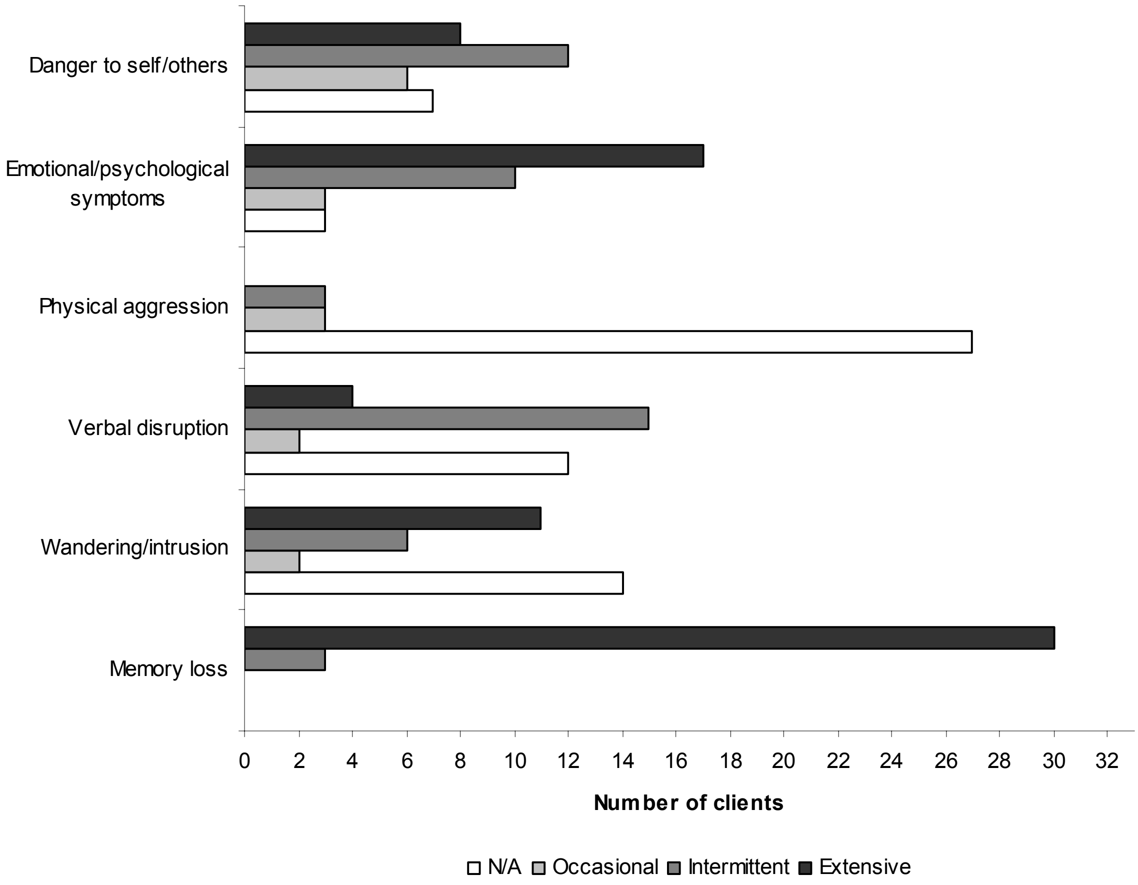


Figure B8.4: Dementia Care in Alternative Settings, number of clients by frequency of psychological and behavioural symptoms at entry

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[13] This includes data from a seventh category called 'Other behaviour'.

8.4 Carer assessment results

Most carers reported that they were in good to excellent health (20 carers). Nine carers reported their health was fair, and four said that they were experiencing poor health.

Southern Cross Care WA uses a 12-item variant of the CSI as part of normal practice in assessment and care provision. Thus, assessments of carer strain had been performed at or around the time of entry to the project in most cases and assessments for the evaluation were readily incorporated into ongoing assessment and review.[14]

The DCAS baseline scores of carer strain ranged from 2 to 12 points, with a mean score of 8.4 (standard deviation 2.5). Twenty-four carers recorded scores above the threshold for carer strain, and five more carers scored one point below the case threshold.

Baseline and final CSI measures were recorded for 27 carers. Twenty-four of these carers registered at or above the threshold for carer strain at baseline; 17 recorded at or above the threshold on the final assessment. The median change score is the median of the paired differences between carers' final scores and baseline scores. This median, calculated across all carers with complete sets of scores, was –3 points (mean –2.9, standard deviation 2.4), indicating an average decrease in carer strain for DCAS carers between the two assessment points. CSI change scores range from –7 to 3 points. Twenty-one of the 27 carers who completed baseline and final assessments registered a reduction in carer strain.

Twenty-one carers also completed the GHQ-28. Nine carers scored 14 points or higher on at least one sub-scale. Five carers recorded scores of 14 points or higher for somatic symptoms; eight carers recorded scores of 14 points or higher for anxiety and insomnia, one of whom scored the maximum 21 points; six carers scored over 14 points for social dysfunction; and one carer scored over 14 points for severe depression. Two carers scored 14 or higher on one sub-scale; four carers scored 14 or higher on two sub-scales; two clients scored 14 or higher on three sub-scales; and one carer scored 14 or higher on all four sub-scales. According to these self-reports of psychological wellbeing, many carers were experiencing considerable disturbance or distress across a range of domains at the start of the evaluation.

Twenty-eight carers completed the GHQ-28 at a final assessment, of whom three scored above the 14-point threshold on at least one sub-scale. The number of carers reporting psychological symptoms associated with recent changes in circumstances was lower at final assessment than at the baseline assessment.

DCAS CSI and GHQ-28 data are included in an overall analysis of carer outcomes for the Innovative Pool Dementia Pilot long-term projects.

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[14] Clients who commenced on the DCAS before the beginning of the evaluation period were assessed using a 12-question abridged version of the Carer Strain Index. A case threshold of 6 has been used for these clients.

8.5 Service profile

Half to three-quarters of evaluation clients received personal assistance, domestic assistance, allied health care, food services, social support, transport and respite care during the evaluation period (Table B8.13). This project was able to deliver up to 24.5 hours of care per client per week, if required. Some clients received two or three visits daily, often to coincide with meal times so that the care assistant could help with meal preparation and provide companionship throughout the day.

High levels of respite care were observed, with a median of 4.6 hours per client per week but ranging up to 36.5 hours per week (including in-home respite and respite provided in the small group respite care unit). Carer support covered services other than respite such as counselling, information, advice and referral.

Specialist dementia care and memory and behaviour therapies are also featured in the DCAS service profile. These services draw on existing dementia care expertise within Southern Cross Care WA.

The project did not supply financial data to enable a breakdown of expenditure by service category.

Table B8.13: Dementia Care in Alternative Settings, summary of services delivered per client per week, June–November 2004

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Personal assistance	Hours	25	1.0	4.0	11.1	4.6	2.7
Domestic assistance	Hours	24	0.1	1.1	3.3	1.1	0.8
Allied health[(a)]	Hours	24	0.0	0.0	1.5	0.2	0.4
Food service other than delivered meals	Hours	24	0.3	4.6	22.7	5.2	4.7
Social support	Hours	19	0.2	2.0	9.7	2.8	2.5
Respite (in-home and day)[(b)]	Hours	13	0.3	4.6	36.5	8.9	10.4
Nursing care	Hours	3	0.1	0.2	0.4	0.2	0.2
Aids and equipment combined	Dollars	6	0.1	3.0	56.9	12.2	22.2
Dementia care, memory and behaviour management	No. contacts	13	0.0	0.1	5.6	0.7	1.6
Assistance—GP consult.	No. contacts	9	0.0	0.1	0.3	0.1	0.1
Assistance—geriatrician consult.	No. contacts	4	0.0	0.1	0.1	0.1	0.0
Nursing/medical other	No. contacts	3	0.1	0.1	0.6	0.3	0.3
Community mental health service	No. contacts	1	0.0	0.0	0.0	0.0	—
Overnight respite	No. days/nights	1	0.1	0.1	0.1	0.1	—
Carer support other than respite	No. events	23	0.0	0.2	0.9	0.3	0.2
Information advice and referral	No. events	19	0.0	0.2	0.5	0.2	0.1
Medication review	No. events	13	0.0	0.0	0.2	0.1	0.0
Personal other	No. events	12	0.2	0.9	13.5	3.3	4.6
Community service other	No. events	1	0.1	0.1	0.1	0.1	—
Delivered meals	No. meals	8	2.3	3.9	12.1	5.4	3.3
Community transport	No. one-way trips	16	0.1	0.7	4.8	1.2	1.3
Dietetics	No. referrals	1	0.0	0.0	0.0	0.0	—

(a) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(b) Assumes one-day respite date is 6 hours.

Note: DCAS did not provide services data for six clients, consequently this table reflects services provided to 27 of the 33 clients in the evaluation.

— Nil.

8.6 Accommodation outcomes

Follow-up of DCAS evaluation clients was completed by 7 June 2005. Table B8.14 shows accommodation setting and government support program status for all clients at follow-up (that is, approximately 11 months from the start of the evaluation period). Just over half of the original group were still with the project. Most discharges were to high level residential care.

Table B8.14: Dementia Care in Alternative Settings, number of clients by follow-up status, June 2005

Follow-up status	Number of clients
At home	
On DCAS	16
Home and Community Care	1
Total living in community	*17*
In care	
Residential aged care—high	12
Residential aged care—low	2
Total in residential aged care	*14*
Deceased	2
Total	**33**

One client who was with DCAS at time of follow-up had actually been discharged from the project in December 2004 to enter high level residential care. This client was subsequently discharged from the aged care facility to return home in January 2005 and recommenced DCAS services.

Twelve of the 24 clients with ACAT approval for high level residential care were still at home (and with DCAS) at follow-up (Table B8.15).

Table B8.15: Dementia Care in Alternative Settings, number of clients by type of ACAT approval at entry and follow-up status

	Follow-up status				
ACAT approval	At home	Residential low care	Residential high care	Deceased	Total
Low care	5	2	2	—	9
High care	12	—	10	2	24
Total	**17**	**2**	**12**	**2**	**33**

— Nil.

8.7 Wait list clients

DCAS supplied information about 33 people who were placed onto a waiting list for the project from December 2003 onwards. Nine of these individuals were eventually placed onto DCAS as places became available, leaving 24 on the waiting list as a potential basis for comparing DCAS client outcomes.

The waiting list group comprises 16 females (67%) and has an average age of 81 years. Twenty-four per cent (24%) of the group was aged over 85 years at the time of referral to DCAS. Thirty-six per cent (35%) were living alone. Fourteen waiting list clients had a co-resident carer and nine had an ex-resident carer (carer availability was not recorded in two cases). Thus, the waiting list group had a similarly high rate of carer availability, albeit with a slightly higher proportion of co-resident carers (56% of wait list clients versus 46% of evaluation clients).

At time of referral, nine of the 24 people in the waiting list group were not receiving assistance from government support programs. Home and Community Care was providing support to more people in the group than any other program (Table B8.16). The wait list group recorded a higher proportion (36%) of clients with no previous government program support compared to the DCAS group (15%).

A comparison was made of the wait list group and DCAS evaluation clients with respect to a selected number of dependency items:

- presence of severe or profound core activity limitation
- level of mobility limitation
- level of self-care limitation
- level of communication limitation
- bladder incontinence and bowel incontinence (Modified Barthel Index item)
- level of dependency in mobility (Modified Barthel Index item)
- need for assistance with meal preparation (OARS IADL item)
- need for assistance with medication administration (OARS IADL item).

Both the wait list and evaluation groups recorded 64% of people with a severe or profound level of core activity limitation. No significant differences were found between the groups in respect of incontinence, level of self-care limitation, or need for assistance with meal preparation and medication use. Proportions of DCAS and wait list groups on selected ADL items, respectively, were: 12% versus 12% bowel incontinent; 21% and 24% bladder incontinent; 36% versus 33% with a severe or profound self-care limitation; 67% versus 68% unable to prepare meals; 18% versus 44% unable to self-medicate. The wait list group recorded a higher rate of independent mobility (100% versus 76% of the DCAS client group) and a lower rate of severe communication limitation (no clients in the wait list group compared to 12% or four clients in the DCAS group); however a higher proportion (44%) of the wait list group experienced at least moderate communication restriction than the DCAS client group (27%, which includes clients severely limited in communication activities). To summarise, the wait list group reported to the evaluation is similar to the DCAS client group in many important respects.

The purpose of collecting minimal baseline data for a wait list group was to compare baseline characteristics of this group with the evaluation clients to facilitate a valid comparison of 6-month accommodation outcomes. Unfortunately, follow-up was not consistent and much of the follow-up of wait list clients was completed well within a 6-month time frame (one-third of the people were not located at follow-up). By the (varying) time of follow-up, all of those located alive were receiving one or more types of government-funded assistance (Table B8.16). The Home and Community Care Program, with or without other sources of assistance, was the most commonly accessed government community care program for people assessed as eligible for DCAS but who could not be placed onto DCAS. There is evidence of multiple program support, that is, use of HACC services together with assistance funded by other programs.

Three of the 16 people who were located had entered residential care.

Table B8.16: Dementia Care in Alternative Settings wait-list clients, government-program support at referral and follow-up: wait-list data recorded for national evaluation, 2004

	At home at follow-up							In care at follow-up						
	No government-funded support	With government-funded support												
		HACC	**HACC+**	**DTC**	**CACP**	**EACH+**	**Total community**	**Low care**	**High care**	**Total residential**	**Deceased**	**Total follow-up**	**Not located**	**Total**
Support program at date of referral														
No support program	—	2	—	1	—	1	*4*	1	1	*2*	—	6	3	**9**
HACC	—	2	—	—	—	—	*2*	—	1	*1*	—	3	—	**3**
HACC plus other	—	1	3	—	—	—	*4*	—	—	—	—	4	—	**4**
Veterans' Home Care	—	—	—	—	—	—	—	—	—	—	—	—	1	**1**
Day Therapy Centre	—	—	—	—	—	—	—	—	—	—	—	—	2	**2**
CACP	—	—	—	—	—	—	—	—	—	—	1	1	—	**1**
State program	—	—	—	—	1		*1*	—	—	—	—	1	1	**2**
Not stated	—	1	—	—	—	—	*1*	—	—	—	—	1	1	**2**
Total	**—**	**6**	**3**	**1**	**1**	**1**	**12**	**1**	**2**	**3**	**1**	**16**	**8**	**24**

— Nil.

9 The Sundowner Club

9.1 Project description

ECH Incorporated[15] received an allocation of 15 flexible care places under the Innovative Pool Dementia Pilot to establish The Sundowner Club, a new model of respite care and socialisation for people with dementia. The Sundowner Club began as a partnership between ECH and Eldercare Incorporated.

Both ECH and Eldercare operate on a not-for-profit basis. ECH is a large provider of residential aged care and retirement village accommodation in South Australia. ECH is an approved provider for the CACP program, operates community Day Therapy Centre services and is a collaborative partner within regional HACC programs. ECH also offers a range of food services to its own clients and those of other aged care providers. In parallel with The Sundowner Club, ECH has participated in the Australian Government Retirement Villages Care Pilot. Eldercare Inc. is a large provider of residential aged care including high and low care facilities and dementia-specific facilities. Retirement living is the other major area of business for Eldercare. In total, Eldercare provides 730 residential aged care beds and 180 retirement units across 10 metropolitan and rural locations. ECH and Eldercare operate secure dementia units within their residential care facilities.

The Sundowner Club was designed for people with dementia who live in the community and experience specific difficulties associated with 'sundowner' behaviours. 'Sundowning' is a term used to refer to behavioural symptoms associated with dementia that tend to manifest more intensely in the late afternoon and early evening, often causing distress to carers and families and risk of harm to the person with dementia.

The Sundowner Club commenced service delivery in April 2004, operating five nights per week based at two locations in metropolitan Adelaide.

Project objectives and target group

The objective of the project is to test the effectiveness of an evening respite and socialisation program for people with dementia-related behavioural symptoms that contribute to carer strain and social isolation for the person with dementia. In particular, the project aims to provide:

- appropriate social activities, encouraging ongoing community participation and maintenance of existing social and ADL skills for people diagnosed with dementia
- monitoring of the person with dementia who lives alone, for example, physical health, changes in capacity for self-care
- supervision of participants for whom late afternoon and early evening can be a period of acute disorientation, wandering and confusion

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[15] Formerly Elderly Citizens Homes of South Australia Incorporated.

- respite for carers of community-living people with dementia who are approved for residential high care placement (Sundowner Club Pilot Proposal, joint application by Elderly Citizens Homes of SA Inc. and Eldercare Inc., November 2002).

ECH and Eldercare expect The Sundowner Club to achieve the following key outcomes:

- respite for carers
- supervision of clients with dementia
- improved quality of life for clients and carers
- extended periods of independent living and thus delayed entry to residential care, especially by supporting carers
- improved management of client behaviours on participating nights
- education for carers and significant others on successful ways of managing behaviours associated with dementia.

The program was initially intended to provide services to existing ECH and Eldercare independent living unit residents with dementia who were at risk of placement into residential care, with a view to extending the service to community clients according to program capacity.

The Innovative Pool entry criteria for clients included a diagnosis of dementia and approval for residential care placement. Initially targeting people who had been approved for high care, Sundowner Club entry criteria were broadened to include low care approvals following negotiations between ECH and the Department of Health and Ageing in mid-2004. In addition, clients were required to need supervision in the early evening and to be physically able to leave their home environment safely.

Service model

The rationale for The Sundowner Club is to address a gap in mainstream service provision for people with dementia who have specific 'after hours' care needs, and those who find it difficult to access or are reluctant to use traditional forms of respite care. People who live alone, for example, may be excluded from respite services by virtue of not having a co-resident carer, adult day care programs are frequently rejected as 'childish' or as providing inappropriate activities by the intended service recipients, and men and younger people with dementia are observed to resist the idea of joining day programs where the 'very old' comprise the majority of participants (Sundowner Club—Pilot Proposal, ECH and Eldercare, November 2002).

Over time, the ECH supportive services coordinators in each of the three metropolitan service regions had become increasingly aware that people in the target group may be placed in residential care as a result of frequent complaints about sundowner behaviour. Yet, it is also apparent that most people in this situation are able to manage at other times of the day with appropriate formal and informal supports. The Sundowner Club was thus conceived as a means to overcome a general lack of formal support services that extend into evening hours.

Services provided include socialisation, meals, supervision of medication and transport. Service recipients are transported to a community facility from their home address and returned home at the end of the evening. An evening meal is served in a congregate setting with access to social activities. Recipients participate in meal preparation and clean-up. Activities are designed with the flexibility to meet the needs of different groups such as men and younger people with dementia. The Sundowner Club caters for up to eight people each evening over five evenings per week. Each participant is able to attend on multiple evenings in a week. The program operates between 3.30 pm and 8.00 pm, Monday to Friday, with two evenings based at a site in Norwood and three at a site at Henley Beach. Maximum capacity lies between 20 and 30 service recipients at any one time.

The Sundowner Club is unique among the Innovative Pool Dementia Pilot long-term care projects in that it is a stand-alone evening meal and socialisation program rather than a comprehensive care package service. Clients are expected to continue in any pre-existing support arrangements, with The Sundowner Club providing supplementary respite and socialisation. The project reports that around 80% of Sundowner Club clients receive assistance from other community care services and continue to do so while taking part in the evening program. Clients who require ongoing case management will access that support through another service since The Sundowner Club does not operate a case management model. These clients usually have a primary case manager, either through a CACP, ECH Support Coordination Service, or a HACC-funded service. Sundowner Club staff liaise with the primary care manager to address changes in the client's needs or status.

Staffing

In mid-2004, The Sundowner Club staff comprised one care manager (0.7 full-time equivalent) and two part-time care workers. In addition, the project receives a high level of support from the ECH senior support coordinator. At the same time ECH was in the process of recruiting a casual additional assistant coordinator to cover leave periods for permanent staff.

Recruitment of staff has proven to be more problematic than anticipated. Few applications were received for the advertised position of project coordinator and enquiring applicants indicated that the working hours were a disincentive. Attracting suitably experienced applicants also proved to be a challenge.

Filling the assistant coordinator positions was less difficult as the working hours are well suited to tertiary students and these positions offer the opportunity for health sciences students to consolidate practical skills.

Successes, challenges and lessons

The Sundowner Club highlights the positive features of a small group model in supporting community-living clients with advanced dementia. The model is an innovative form of respite and socialisation with significant benefits for clients and family carers, described below under 'Case studies—carer feedback'.

ECH reported that a major achievement of The Sundowner Club is the enriched social participation and increased service acceptance among recipients that takes place over time. Examples were cited of clients who had previously been resistant to the idea of formal services coming to accept assistance, initially through the Sundowner Club program and progressing to additional in-home services. It was noted that people with dementia who have led active social lives in the past do not stop enjoying social outings because they have dementia. The positive experience of an 'outing' and social interaction provides reassurance to clients that service providers support their desire to remain at home. Family members have reported to coordinators that The Sundowner Club provides them with valuable support, both in the form of respite and in the easing of care recipient behaviours. One carer said that her husband's aggressive behaviour had lessened significantly since he started attending Sundowner Club evenings to the extent that she felt able and willing to continue caring for him at home and was no longer considering residential placement for the foreseeable future.

It is often observed that a new client is initially apprehensive about attending The Sundowner Club. Many clients exhibit some degree of paranoia and suspicion, particularly in regard to new activities and activities initiated by ECH and Eldercare, which are viewed as manoeuvres to place people in residential care. Sundowner Club coordinators have had to make multiple home visits to build rapport and trust before a number of clients would agree to leave home to attend the program. Clients who agree to trial the program for one night have quickly settled into a pattern of regular attendance and some have requested more frequent attendance. Similarly, clients who initially required substantial assistance to leave their units are frequently now waiting to be picked up by staff (staff ring earlier in the afternoon to prompt clients and some clients are able to get ready independently despite significant levels of confusion).

During the evening sessions staff members have observed changes in clients' ability to interact with one another and with staff. One very confused client was initially unable to speak unless spoken to on a one-to-one basis. This client is now able to engage in appropriate, spontaneous conversation with other clients in response to activities occurring at the time and has developed a friendship with another person who attends on the same evening. Over time, clients begin to confide in staff about problems at home that they are unable to resolve. Information withheld during the assessment process is gradually divulged. Some clients have told staff that their Sundowner Club night(s) are the only occasions on which they eat a meal with other people. The opportunity for supported social interaction is observed to engender a heightened sense of self and has helped to encourage a greater interest in self-care and appearance in many clients.

The project reports that the behavioural symptoms of clients are somewhat different to what was anticipated. Clients generally show signs of self-neglect and/or aggressive behaviour instead of wandering and intrusive behaviour. Undiagnosed depression is suspected to be a factor for some clients. The process of introducing new clients has been modified as the importance of minimising disruption to the dynamics of a relatively cohesive group became evident. Some clients become agitated with changes to their familiar environment. This resulted in slower than anticipated recruitment of clients into the project to allow groups to settle before the introduction of a new client.

Issues encountered during the establishment of The Sundowner Club included recruitment of suitably experienced/qualified staff willing to work regular evening hours; education of referral sources to make appropriate referrals to the program (both within ECH/Eldercare and other service providers, ACAT, GPs, etc.); and waiting time for ACAT assessments (at the time the program commenced some clients waited a number of months after referral to ACAT before being ACAT assessed).

Project coordinators experienced difficulty in deciding whether to commence services for a client while they show a willingness to do so, or to wait for ACAT approval and risk client refusal of the service at a later date. Waiting times for ACAT assessments can be 3–6 months in some areas. Delays have also occurred because ACAT approvals have been given for respite and flexible care, but not residential care, as required. ECH reported that some ACATs appear to have assigned low priority to assessments for clients referred to The Sundowner Club and it is thought that this is because Sundowner Club referrals are competing for ACAT resources with referrals for clients seeking residential placement.

Sometimes clients contribute to assessment delays. Some clients refuse to sign the ACAT approval or refuse ACAT entry to their home. The assessment process undertaken by The Sundowner Club coordinator and/or ECH senior support coordinator is too lengthy to undertake in a single session and normally requires several in-home assessments, which makes the process expensive and resource intensive. Clients are frequently suspicious of the assessment process and gaining cooperation has been difficult in a number of cases. Clients recognise the Mini-Mental State Examination, which is used frequently by medical practitioners, specialists and other service providers and tend to be highly resistant to this type of assessment. They are often unwilling to share information that is perceived to increase the likelihood of residential placement and will thus deny the existence of problems such as incontinence, medication management and ADL difficulties. Often the real situation only emerges when a client feels comfortable with staff on their Sundowner Club evenings. Assessment issues are thought to be a particularly salient consideration when designing programs and working with members of the target group.

From the perspective of the Adelaide ACAT, by the time the ACAT conducts an assessment, ECH has already assessed the client and has mapped out a service plan. There is some feeling that the ACAT assessment is essentially a 'rubber stamp' by that point, however the team has found ECH assessments to be generally accurate and the proposed services appropriate. The ACAT enjoys a smooth working relationship with ECH. Adelaide ACAT has a benchmark of five days to conduct an assessment after receipt of a referral. If a service is immediately available the assessment is given priority status and the client is seen sooner, sometimes on the same day. Were The Sundowner Club service not available, clients without existing services would most likely be placed on a CACP waiting list, which at the time was running at between 6 and 24 months, depending on the provider. Most clients, particularly those with dementia, cannot remain in their homes and wait that long for services, so a move to residential aged care is often inevitable.

The key issues affecting placement for those Sundowner Club clients who subsequently moved into residential aged care appear to be the lack of available high care or dementia-specific case management services, lengthy waiting lists for CACP services, the lack of other community programs able to support clients with dementia and challenging behaviours on an ongoing basis, and the withdrawal of informal carer support (either spouse, family or friends). In most cases, withdrawal of support was by family members (son, daughters, niece and nephew) or a friend, whereas one client moved into residential care following the sudden death of her spouse who was her carer. In all but the latter case, carers had been actively seeking placement prior to the clients commencing with The Sundowner Club and most clients remained living in the community for some months after commencing with the Sundowner Club program.

Case studies—interviews with family carers

While the Sundowner Club program was not intended to replace case management or packaged services, the program has been effective in supporting clients and carers by providing regular respite which is valued by the client and carer. The importance to carers of receiving out of home respite for the person with dementia has been emphasised repeatedly by carers in feedback to Sundowner Club staff throughout the program and during follow-up evaluation in September 2005. Various carers have reported that being able to have regular time at home to themselves has been an important factor in enabling them to provide ongoing care. Likewise they have emphasised the importance of feeling that the person with dementia is enjoying the experience, with several reporting that they feel intensely guilty about receiving respite (and less likely to continue with the service) if they feel that the person with dementia is unhappy or doesn't enjoy attending a respite program.

ECH interviewed family members about their experiences. The stories highlight a strong desire for social participation in people with dementia, which becomes more difficult as the dementia advances, often leading to social isolation for both the person with dementia and their family carer. The impact of The Sundowner Club on people's quality of life and its potential to help sustain caring roles is described in selected interview transcripts below.

A daughter reported to staff that her mother (who has advanced dementia and is no longer able to speak English and only speaks in single words in her first language) came home with a smile on her face for the first time in months after her first visit to The Sundowner Club. Similarly, the daughter has reported to staff that her mother is 'happy all the next day even though she can't remember going to the Club, she is still happy' and that her mother has once been able to tell her daughter 'I had a good time'. One wife also spoke of her difficulty in finding activities which her husband would enjoy at home, stating that he gets bored when he is at home with her and needs his own 'normal' social outlet despite the extent of his dementia.

Two women caring for husbands with advanced dementia who attended The Sundowner Club were interviewed. Both showed signs of high levels of stress which they associated with their role as a carer. One spouse is still able and willing to actively support her husband to remain living at home however the other is actively seeking residential care placement for her husband in the near future due to his verbal and physical aggression towards her and other family members. This client's aggression is also evident to Sundowner Club staff who report sudden threatening movements, for example, sudden, unexpected hand gestures towards staff, threatening facial expressions, including verbalising aggressively through clenched teeth and verbally aggressive statements towards staff and other clients. These behaviours were observed during the period of re-assessment of clients in 2005, including some verbal and threatened physical aggression towards the assessor.

Both carers spoke of the isolating effects of Alzheimer's disease experienced by themselves and their husbands. One described her husband's experience as 'the slow torment of losing his mind' which she felt was particularly difficult for a man who had previously been extremely successful in business and a gifted artist and musician. Both reported that as their husbands' ability to participate in social activities has declined, the number and frequency of their longstanding social contacts has diminished.

One carer described having to restrict the number of people invited to attend luncheons (compared to previously regularly hosting large gatherings for lunch and dinner parties) due to her husband's difficulty coping with large groups and his withdrawal because he is no longer able to follow or participate in conversations to his satisfaction. She reported that a luncheon party of six people is feasible for him because in the smaller group there is usually only one conversation which he can follow and feel that he can contribute whereas once the group expands to eight people there are usually two conversations and her husband is unable to follow or participate in either conversation. They also choose to have luncheons because he is less tired and less likely to struggle socially at that time of the day. She commented about the irony of their peers (many of whom were medical practitioners like her husband) being unable to cope with her husband's diagnosis and the resulting constriction of their social network. Both she and her husband reported their ongoing sense of loss and grief at his diagnosis. His ability to be insightful fluctuates, however he is very aware that his illness is affecting his wife as well as him. He was also able to clearly describe his loneliness and frustration, including his word-finding difficulties which slows his participation in social situations. He commented repeatedly on the importance of The Sundowner Club to him, including a statement that 'I would certainly miss not having some contact with people'. His wife reports that he has previously been referred to other community-based groups, however his participation has been short-lived because he has been frustrated by the activities offered (which he felt were inappropriate and patronising) and by his difficulty coping with larger groups of people. She reported that she felt that the small number of clients attending The Sundowner Club was key to his willingness to continue to attend the group, along with the activities offered, which he enjoyed. She also reported that she felt that while The Sundowner Club offered her some respite, it was of greater importance to him because it enabled him to retain a valued social role with other people, whereas prior to attending he had become increasingly withdrawn.

The other carer reported that 'a carer goes through more hell than the patient' because the carer has to cope with their own sense of grief and cope with their partner's fluctuating insight and loss. She reported that she most missed being able to have a meaningful conversation with her husband and her difficulty coping with her husband's increasing egocentricity, especially during a recent period of illness when she needed support and he was unable to respond to her needs and placed extra demands on her. She talked of the importance of The Sundowner Club to her—'the beauty of it (The Sundowner Club) is that he leaves here and comes back' (door-to-door transport is provided) and 'I get about 5 precious hours to myself—I can watch the news without him constantly interrupting me because he can't follow what is happening on the TV anymore'. She fears that his mobility will deteriorate to the point that he is unable to board the Sundowner bus and that this will mean that he is no longer able to attend the evening. She also talked of the importance of the evening to her husband: '[her husband] gets bored at home with me' and 'he really enjoys the music. He has always loved music and singing, and [the coordinator] is able to bring out the best in him because she can just pick up a tune and play it on the piano while he sings. He gets a great deal of enjoyment from singing, but even that is slipping and her skill is that she can work out what he is singing so he still feels that he is doing well'. This carer feels that her husband's participation in The Sundowner Club has been valuable for him by enabling him to continue to participate in activities which he has previously enjoyed while also providing her with invaluable respite enabling her to pursue her own interests.

Both wives spoke of the importance to them of feeling that they could get out of the house on their own and resume their own interests and lives during the respite offered by The Sundowner Club. One uses the time to have coffee with her daughters, and more recently has joined an adult French language class for her own mental stimulation, whilst the other (older) carer enjoys being able to phone her adult children who live interstate without having constant interruptions from her husband. She reports that her children are a major source of support to her but that she can rarely speak to them freely when her husband is present. She also watches the evening news uninterrupted which she says 'on the surface is a small thing, but it means a lot to me because I am so isolated in the house with [her husband] and I need to know what is going on in the world or I feel even more isolated'.

The interviews with the carers highlighted the following issues and strengths of the small group model utilised by The Sundowner Club, including:

- their experiences of increasing social isolation, loss of meaningful social contacts and infrequent participation in valued community activities due to their responsibilities as a carer
- carers' desires to regain intellectual stimulation (and social activities) to replace the interaction with their partners which their partners are no longer able to sustain

- increasing social isolation for the person with dementia despite the desire on the part of the individual to maintain meaningful social contacts
- the importance of supporting the individual with dementia to retain their own valued social roles
- the difficulty experienced by people with dementia in coping in large group settings where they are overwhelmed by and unable to cope with or participate in multiple conversations or stimuli
- the importance of a small group model in enabling the client to participate and interact to the best of their abilities
- the importance to the client with dementia of being able to participate in a program which offers socially (and developmentally) appropriate activities and interaction
- the frustration experienced by clients with dementia of being expected to participate in programs which they perceive to be demeaning or infantile, resulting in reluctance to attend and/or service refusal
- the importance of staff being able to be respectful, flexible and responsive to individual needs in a group setting, adapting and changing activities to maximise each individual's participation.

9.2 Client profiles

Formal evaluation of the program commenced shortly after The Sundowner Club started operating. At this time the program was still being established, including promotion to other service providers and recruitment of clients. Just prior to commencement of data collection in 2004, eight of the initial group of Sundowner Club clients had entered residential aged care. Three of these clients were assessed and accepted into the project but took up a residential place before attending their first Sundowner Club evening. Another five clients were assessed and accepted into the project and attended one evening before moving to residential care. Evaluation data were not recorded for these clients, leaving 15 members of the early client intake to participate in the evaluation who tended to be a higher functioning group. This early pattern of rapid discharge to residential aged care suggests that the initial target group included people with high care needs who may not have had adequate support in addition to The Sundowner Club to remain at home and/or people who were actively seeking residential placement.

Since The Sundowner Club was a completely new program, client selection criteria were refined as experience with the target group increased. Data collected in 2004 reflect the profile of a program in its formative stages rather than a well-established program. ECH conducted a follow-up evaluation in September 2005 to report on the established service. These results are included where applicable to highlight changes in the profile of Sundowner Club clients that have taken place as the program matured. The main differences between project snapshots of mid-2004 and mid-2005 are that clients in the established program are more likely to come from a culturally and linguistically diverse background, more likely to live in the community with a co-resident carer, and more likely to score poorly on the MMSE or to be unable to be assessed due to language difficulties and/or highly confused state than the early client intake.

Age and sex

The mean age of the evaluation clients during the reporting period was 85.3 years (age ranges from 79 years to 92 years). Eight evaluation clients were aged 85 years or over (Table B9.1).

The 21 clients in September 2005 averaged 83 years of age.

Table B9.1: Sundowner Club, number of clients by age group and sex, 2004

Age (years)	Males	Females	Persons
		(number)	
75–84	2	5	7
85+	3	5	8
Total	**5**	**10**	**15**
		(per cent)	
75–84	13.3	33.3	46.7
85+	20.0	33.3	53.3
Total	**33.3**	**66.7**	**100.0**

Language and communication

During the formal evaluation all 15 clients used spoken language effectively and spoke English at home.

In September 2005, six out of 21 clients were from culturally and linguistically diverse backgrounds including Latvian, Serbian and Italian nationalities. One such client was living alone in an ECH independent living unit (with a non-resident family carer) while the remaining five clients were all living with family carers (either partners or sons/daughters and their respective partners). Generally, the clients from culturally and linguistically diverse backgrounds demonstrated more confused behaviours including frequent wandering, higher levels of agitation and frequently repetitive speech (often in a mixture of English and their first language) when attending The Sundowner Club. Four of these clients required extensive staff assistance for basic personal care tasks including eating and toileting.

Accommodation and living arrangement

All original evaluation clients were living in independent living units within retirement villages managed by ECH or Eldercare at the time of the evaluation (Table B9.2). One client was living in a private residence at the time of referral and subsequently moved into a retirement village. Years at usual accommodation range from 2 to 33. Eight clients had been living in the same home for 10 or more years.

Among the clients who participated in the evaluation in 2004, more were living alone (including those managing without carers) than had originally been anticipated by ECH. Changes in carer availability and carer co-residency profiles that occurred over the 12 months to September 2005 are described below and reflect a decrease over time in the proportion of Sundowner Club clients who live alone.

Table B9.2: Sundowner Club, number of clients by usual accommodation setting, living arrangement and accommodation setting at time of referral to project, 2004

	Usual living arrangement				
Accommodation setting	**Alone**	**With family**	**With others**	**Not stated**	**Total**
Retirement village—independent living	11	4	—	—	15
Total	**11**	**4**	**—**	**—**	**15**

— Nil.

As awareness of The Sundowner Club grew, the project received referrals from a greater number of sources and ECH reported that the majority of clients in the follow-up evaluation had been referred by service providers other than ECH or Eldercare.

Carer availability

The profile of carer availability and carer co-residency changed noticeably between the initial evaluation and follow-up in 2005. Nine of the original 15 evaluation clients (60%) had a carer and only four carers were reported to be living with the Sundowner Club client (Table

B9.3a). In September 2005, 81% of clients had a carer and most carers lived with the Sundowner Club client (Table B9.3b). Thus over the course of the evaluation, The Sundowner Club increasingly functioned as a respite program for co-resident carers as well as socialisation for clients.

Carers' ages in the original group ranged from 41 to 86 years, averaging 68 years, and four carers were aged 75 years or over (Table B9.4).

Table B9.3a: Sundowner Club, number of clients by carer availability, carer relationship to client and co-residency status, 2004

Relationship of carer to client	Carer lives with client	Carer does not live with client	Not stated	Total
Spouse or partner	4	—	—	4
Son or daughter	—	3	—	3
Other relative	—	1	—	1
Not stated	—	—	1	1
Total clients with a carer	*4*	*4*	*1*	*9*
Total clients				**15**
Per cent of clients with a carer				60

— Nil.

Table B9.3b: Sundowner Club, number of clients by carer availability, carer relationship to client and co-residency status, September 2005

Carer availability	Carer lives with client	Carer does not live with client	Total
Has a carer	12	5	17
Does not have a carer	. ..	. .	4
Total clients			**21**
Per cent of clients with a carer			81

. . Not applicable.

Table B9.4: Sundowner Club, number of carers by age group and sex, 2004

Age (years)	Males	Females	Not stated	Persons
25–44	—	1	—	1
45–54	1	1	—	2
55–64	—	—	—	—
65–74	—	—	—	—
75–84	—	3	—	3
85+	1	—	—	1
Not stated	—	1	1	2
Total	**2**	**6**	**1**	**9**

— Nil.

Income and concession status

Evaluation clients relied on the age pension or a DVA pension as their primary source of cash income. All clients held a health care concession card.

All clients make a co-payment of $1.50 per day to attend The Sundowner Club. This amount is recorded as the full co-payment that applies for the project.

Previous and concurrent use of government community care programs

Nine clients were not receiving assistance from government-funded community care before joining The Sundowner Club (Table B9.5). One client was receiving HACC-funded services, another received CACP services and one client was receiving services through another unspecified program. Previous source of assistance is unknown for three clients.

The three carers who had accessed respite care in the 12 months prior to entering the project had used mainly residential respite care. Two carers reported that, despite having had a need for respite care prior to the care recipient entering The Sundowner Club, they had not used a respite care service. Two carers reported that they did not need respite services. Use of respite services is unknown for two carers.

Since The Sundowner Club is not a case management/care package service, some clients continue to receive services funded by other programs while taking part in The Sundowner Club. In the original evaluation group one client was referred to The Sundowner Club from a Retirement Villages Care Pilot project operated by ECH and one client was referred to the ECH Retirement Villages Care Pilot project after commencing in The Sundowner Club. Two clients were receiving delivered meals five times a week through HACC, and one client had a CACP service. One other client began receiving delivered meals through HACC and was referred to Mental Health Services for Older People at the end of the evaluation.

Table B9.5: Sundowner Club, number of clients by previous use of government support programs, 2004

Previous use of government support programs	Number of clients	Per cent
Government support program		
Home and Community Care	1	6.7
Community Aged Care Packages	1	6.7
Other program	1	6.7
Total clients with previous government program support	*3*	*20.0*
Clients without previous government program support	9	60.0
Not stated	3	20.0
Total	**15**	**100.0**
Use of respite care in the 12 months prior to project		
Respite care used	3	37.5
Respite care not needed	2	25.0
Respite care needed but not used	2	25.0
Not stated	2	12.5
Total	**9**	**100.0**

Five clients were on a waiting list for residential aged care.

Assessment and referral

The majority of clients in the 2004 evaluation group were referred to the project by ECH or Eldercare (Table B9.6). By September 2005 The Sundowner Club was receiving referrals from other community service agencies and the majority of clients at that time had in fact been referred from the wider community.

Table B9.6: Sundowner Club, number of clients by source of referral, 2004

Referral source	Number of clients
ECH or Eldercare	9
Other community service agency	3
Aged Care Assessment Team	1
Other person	2
Total	**15**

The Innovative Pool entry criteria for clients include a diagnosis of dementia and approval for residential care placement. Initially, The Sundowner Club targeted people who had been approved for high care but entry criteria were broadened to include low care approvals following negotiations between ECH and the Department of Health and Ageing in mid-2004. In addition, clients were required to need supervision in the early evening and to be physically able to leave their home environment safely.

Five clients had completed an ACAT assessment on the same day or prior to referral to the project. For these clients, the time between completion of an assessment and referral to the project varies up to 255 days (Table B9.7). ACAT assessment was completed after referral to the project for nine clients, up to 191 days after referral.

ACAT assessment end date is not recorded for two clients. The project reported that one of these clients had had an ACAT assessment but the details are uncertain. The other client waited approximately 7 months for an ACAT assessment. The project had accepted this client prior to ACAT approval because of the uncertain waiting time for assessment which could have prevented the client from participation.

Thirteen clients are reported to have had one ACAT assessment in the 12 months prior to entering the project. Number of ACAT assessments is not reported for two clients.

Table B9.7: Sundowner Club, number of clients by days between completion of ACAT assessment and date of referral to project, 2004

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–30 days	2
31–60 days	2
61–90 days	—
91–180 days	—
181–365 days	1
Total	*5*
After referral to project	
Between 6 and 191 days post-referral	9
Not stated	1
Total	**15**

— Nil.

Health conditions and health status on entry

The number of health conditions recorded for The Sundowner Club clients at entry to the project ranges from one to six. Seven of the 15 clients had four or more health conditions. Table B9.8 shows the primary health conditions recorded on the Aged Care Client Records for clients in the initial evaluation group. Fifteen of the 21 clients in the follow-up evaluation had a primary health condition of dementia.

Table B9.8: Sundowner Club, number of clients by primary health condition, 2004

Primary health condition	Number of clients
Dementia in Alzheimer’s disease	7
Heart disease	3
Skin cancer	1
Parkinson’s disease	1
Deafness/hearing loss	1
Hypertension	1
Diseases of the musculoskeletal system	1
Total	**15**

Seven clients in the initial group were assessed as being at risk of falls due to impaired gait or balance and seven had a diagnosis of depression (Table B9.9). Two clients presented with both hearing and vision impairment.

Table B9.9: Sundowner Club, number of clients by selected sensory, mental and physical conditions, 2004

Health condition	Number of clients
Impaired gait or balance—at risk of falls	7
Diagnosis of depression	7
Vision impairment	4
Disorientation/confusion	3
Hearing impairment	2

Eight clients were taking between one and nine different types of medication at the time of reporting. Four of the eight clients were taking four or more different medications.

Clients and carers of clients were asked to rate client health status and change in health status over the past twelve 12 using a five-point Likert scale (Short-Form 36). Seven clients gave a self-report, a carer responded on behalf of five clients, and a care worker responded for one client. Health status is not recorded for two clients. Health status was rated as very good (four), good (four), fair (four) or poor (one).

Change in health status was recorded for 12 clients. Nine clients were reported to be in about the same state of health as 12 months earlier. The health of two clients was rated as somewhat worse than 12 months earlier, and one client was said to be in a much worse state of health than one year earlier.

Level of core activity limitation

Most Sundowner Club clients are recorded as experiencing no difficulty or mild difficulty in the areas of self-care and mobility (Table B9.10). Two clients are recorded as having a severe or profound limitation in at least one core activity. While this is one of the lower rates of severe or profound core activity limitation recorded by Innovative Pool Dementia Pilot projects, the core activity limitation profile of Sundowner Club clients is likely to have changed given the results of cognitive function assessments in September 2005 that reveal a more highly impaired client group. Assessments of physical and ADL function were not performed in September 2005 due to time constraints.

Table B9.10: Sundowner Club, number of clients by level and area of core activity limitation, 2004

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	4	7	3	1	**15**
Mobility	5	6	3	1	**15**
Communication	8	4	2	1	**15**

Use of medical and hospital services prior to entry

Baseline profiles contain information about client use of medical and hospital services in the 6 months prior to entering the project —the 'pre-entry period'. Of the 13 clients for whom these data were recorded, 11 had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner in this period varied from zero to 12 per client. Cumulatively, the 11 clients recorded 55 visits to a medical practitioner outside of a hospital setting over an estimated 1,980 person days.

Three clients used hospital services in the 6 months prior to entering the project, one of whom attended an emergency department but was not admitted to hospital. The other two clients had planned admissions only; reasons for admission were not recorded. The project recorded no unplanned or urgent hospital admissions for clients in the 6 months before entry.

9.3 Client assessment results

Cognitive function

MMSE scores were recorded for all 15 Sundowner Club clients in the original evaluation group. Scores on entry ranged from 3 to 30 points out of a possible total of 30 points (mean 19.9; standard deviation 6.85; median 21). One client scored 3 points and the remaining 12 clients scored between 14 and 30 points.

Cut-points to account for educational attainment were applied to the entry scores (Uhlmann & Larson 1991). The results suggest that nine of the 15 clients had probable cognitive impairment and six clients did not display cognitive impairment on the basis of entry MMSE scores. During program implementation The Sundowner Club targeted a mixed group of older people, including some without MMSE indication of cognitive impairment.

ECH reported that clients who attended The Sundowner Club in its early days differed from the anticipated client profile by scoring higher on the MMSE and showing greater independence in personal care and instrumental activities of daily living (higher ADL and IADL scores). The higher functioning client profile found in the original evaluation is thought to reflect a number of factors including:

- the number of independent living unit clients with mild–moderate cognitive impairments who 'self-neglect', who are perceived to be at risk of placement into residential care due to those behaviours
- the inability to measure behaviours which place community-living clients at risk of residential care placement, for example, inability to initiate activity or passivity, but which do not include aggression, wandering or intrusiveness. The RCS behavioural questionnaire tool chosen for the evaluation reflects behaviours difficult to manage in a residential care setting where residents live in close proximity to others
- the small numbers of clients with dementia who are able to be supported to remain in independent living without extensive case management and services once 'disruptive' behaviours (for example, intrusiveness and wandering) become evident
- the number of clients who present as having cognitive deficits and poor functioning in activities of daily living who may be experiencing depression and who respond positively to opportunities for supportive socialisation provided by The Sundowner Club

- recognition by staff that these clients could benefit from support in the evening
- early confusion amongst referral sources about entry criteria for the program
- acceptance of early referrals into the program to boost client numbers and establish the program quickly, without adequate screening of referrals.

On this advice, the AIHW suggested a reassessment of clients, which was completed in September 2005. Seven of the original 15 evaluation clients were still attending The Sundowner Club. Six clients who were able to be reassessed (one client was in hospital) recorded a median decline of 2.5 points on the MMSE score since entry to the project. The median score at reassessment was 18 points (range 15 to 23 points).

Counting new clients, ECH administered the MMSE to a total of 14 clients for the follow-up evaluation. Seven clients could not be assessed due to hospitalisation, difficulty comprehending or responding in English and/or a highly confused state (ECH described the circumstances in each case). An MMSE score indicative of cognitive impairment was recorded for all reassessed clients (Table B9.11). Eight clients scored 16 points or below, which has been found to be an indicator of the onset of rapid loss of ADL function. Three clients scored under 10 points, indicating severe cognitive impairment and eight clients scored in the range of moderate cognitive impairment.

Table B9.11: Sundowner Club, number of clients by Mini-Mental State Examination score, September 2005

MMSE score	Number of clients
Zero	—
1–15	7
16–18	4
19–24	3
25–30	—
Not assessable	7
Total	**21**

— Nil.

Activities of daily living

At entry to the project, at least half of Sundowner Club clients needed assistance in tasks involving self-care and mobility (Figure B9.1). MBI scores at entry ranged from 10 to 20 out of a possible 20 points. The mean score was 17.2 points with a standard deviation of 2.8 (median 17 points).

A classification scheme for Barthel Index scores (Shah et al. 1989) indicates that four clients were independent in self-care and mobility, three clients showed slight dependency, seven were moderately dependent and one client exhibited severe dependency on entry to the project. Around 50% of clients were fully or partially dependent in two or fewer ADL. Nine of the 15 clients required continence management and four clients were doubly incontinent. Three clients were unable to bathe or shower without assistance and four clients needed assistance to use the toilet. Fourteen clients were able to mobilise independently. Around one in four clients needed help in the areas of dressing, grooming and transfers.

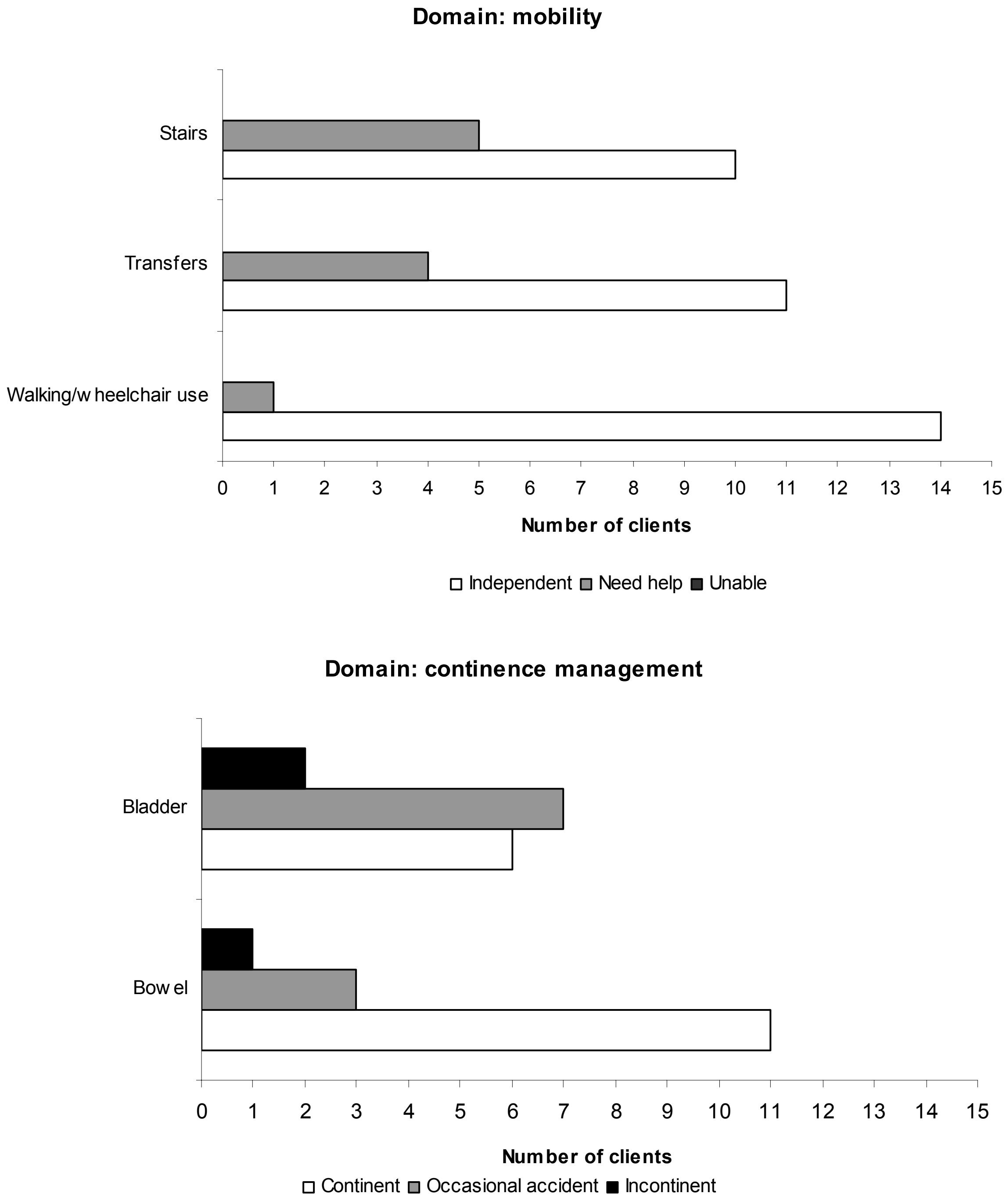
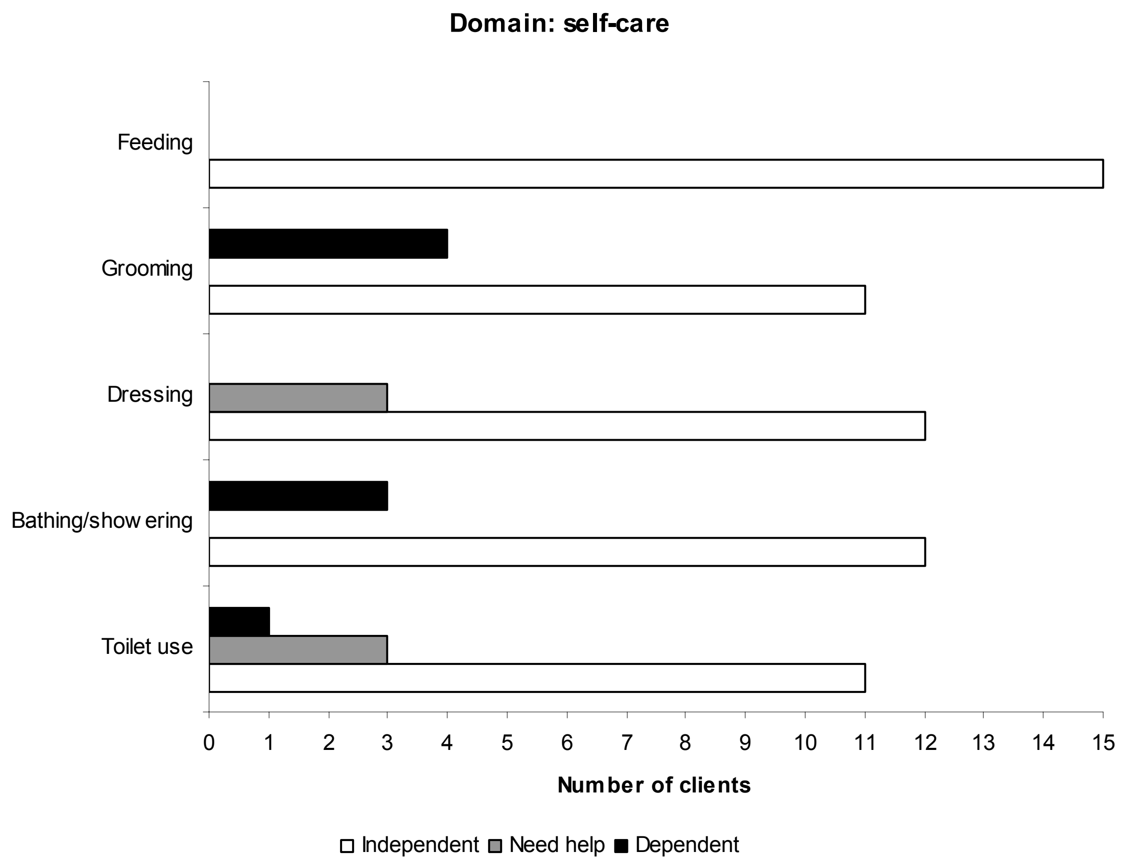


Figure B9.1: The Sundowner Club, number of clients by level of ADL function at entry to project

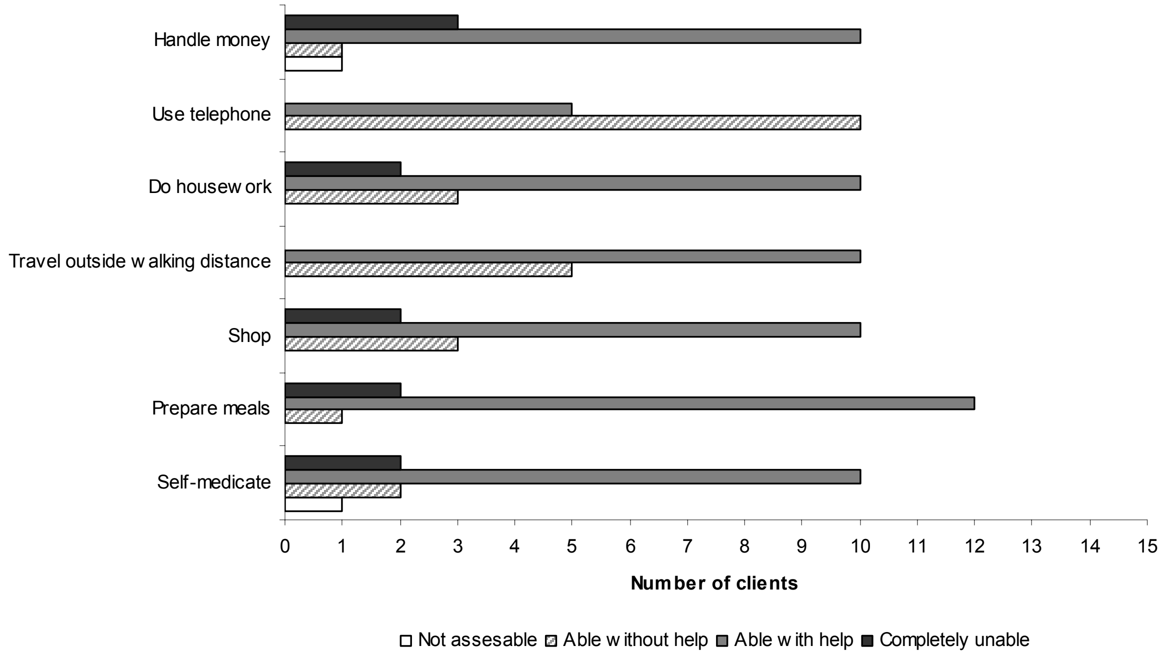
(continued)



Source: Appendix Table B23.

Figure B9.1 continued: The Sundowner Club, number of clients by level of ADL function at entry

IADL data were recorded for evaluation clients in 2004. Apart from telephone use, most clients needed assistance in IADL when they entered the project (Figure B9.2). Clients were totally dependent in between zero and three IADL. Five clients were independent in all seven IADL. No client was unable to travel to places outside of walking distance, reflecting the requirement that clients are able to travel to a central location via minibus with the assistance of staff.



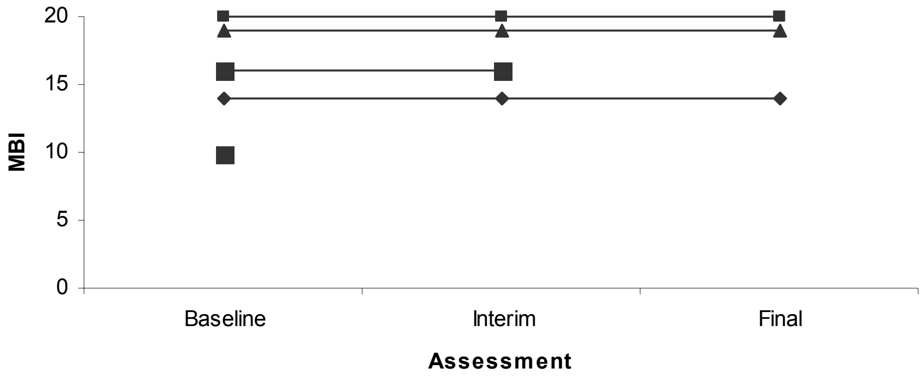
Source: Appendix Table B24.

Figure B9.2: The Sundowner Club, number of clients by level of IADL function at entry

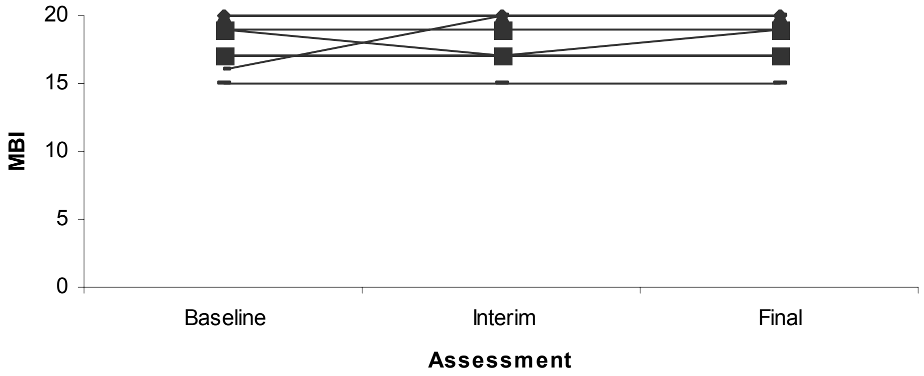
ECH was asked to record the results of three assessments in total. In some cases only one further assessment was taken. Figure B9.3 shows the MBI scores for clients at baseline, interim and final by accommodation setting at follow-up. Clients in care were either in residential high or low care, or in hospital. Clients in the community were either still in The Sundowner Club, in other community care, or were not accessing formal care.

Patterns of ADL functioning over time for Sundowner Club clients are distinctive from those of other Innovative Pool Dementia Pilot client groups in the clustering around and above 15 points on the MBI. The overlap of ADL scores for clients with different follow-up outcomes as seen in other projects is also evident.

These results are thought to reflect the higher functioning profile of the initial evaluation group. ADL assessments of the follow-up evaluation group were not performed due to time constraints. ECH reported that clients in the established program tended to need higher levels of personal assistance and support in IADL compared with the group in 2004. The lower cognitive function profile of The Sundowner Club in 2005 provides further indication that the ADL support needs profile is likely to have changed over time.



Client in care



Clients in the community

Figure B9.3: The Sundowner Club, baseline, interim and final MBI scores by follow-up accommodation setting, 2004 evaluation group (one symbol per client)

Psychological and behavioural symptoms

All of the initial evaluation clients displayed signs of memory loss and most showed emotional or psychological symptoms on an occasional or intermittent basis (Figure B9.4). Few members of the 2004 client group exhibited wandering or intrusive behaviour, verbally disruptive behaviour, or high risk behaviours. Five clients showed two or more behaviours on an intermittent or extensive basis; two of these clients displayed two behaviours on an extensive basis.

In the follow-up evaluation of September 2005, several clients exhibited verbal aggression and one client was physically aggressive towards family members and staff. ECH reported that client behaviours were a major factor in the decisions for some clients to move to residential care.

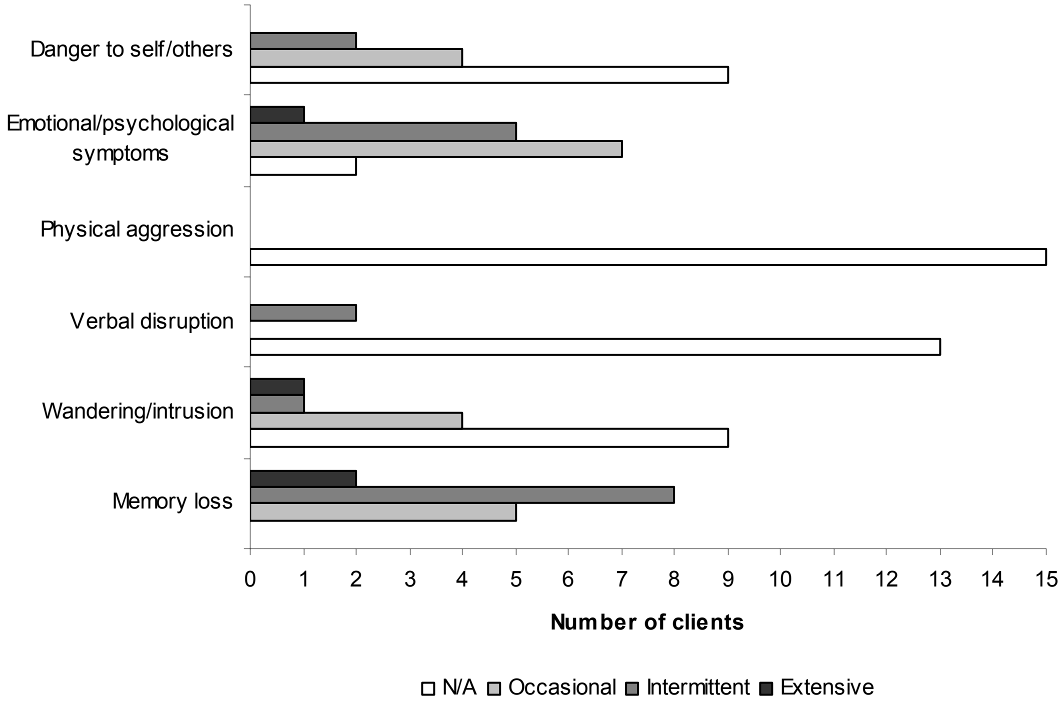


Figure B9.4: The Sundowner Club, number of clients by frequency of psychological and behavioural symptoms at entry

9.4 Carer assessment results

All carers gave a self-report of health status when their care recipient entered the project. Six reported excellent or very good health, and three reported good health.

Eight carers completed the CSI at a first assessment. Three of these carers scored on or just above the threshold for high carer strain.

Carer strain assessments were not repeated in 2005 when the project was servicing a higher number of clients with a co-resident carer.

All carers completed the GHQ-28. The GHQ-28 is designed to measure the appearance of psychological symptoms that are associated with recent changes in circumstances. Scores recorded for the evaluation cover four sub scales: somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. A four-point Likert scale is used to generate a score between zero and 21 points for each sub scale. A sub scale score of between 14 and 21 points would indicate that the respondent reported feeling worse or much worse than usual on a significant proportion of the sub scale items. No carers scored above the case threshold on any of the GHQ-28 sub scales at the first or final assessment.

Analysis of change in CSI and GHQ-28 scores was performed across the projects due to small sample sizes in individual projects.

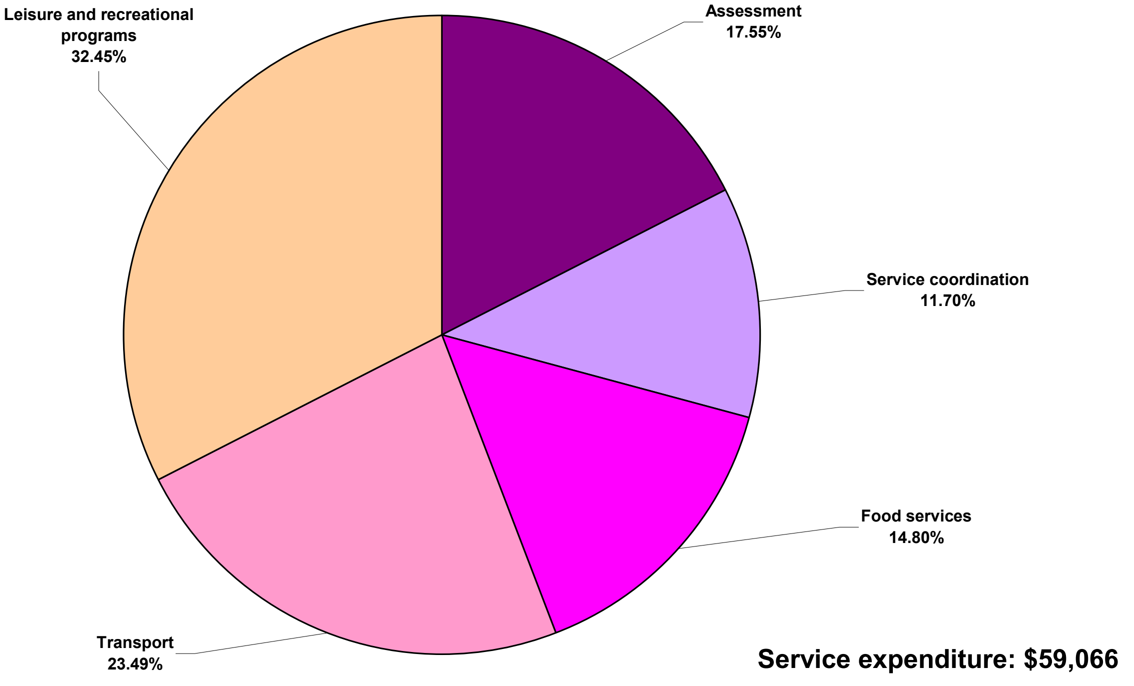
9.5 Service profile

Service provision involves transport, food service and programmed activities (Table B9.12). On average a client would attend The Sundowner Club twice per week.

Table B9.12: Sundowner Club, summary of services delivered per client per week, 2004

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Recreation/leisure programs	No. days/nights	15	1.0	2.8	5.6	2.8	1.5
Community transport	No. one-way trips	15	1.5	2.8	5.6	2.9	1.4
Delivered meals	No. meals	14	1.0	2.4	5.6	2.8	1.5

Activity programs and transport comprised approximately one-third and one-quarter respectively of direct care expenditure between 1 July and 31 December 2004 (Figure B9.5).



Source: Appendix Table B26.

Figure B9.5: The Sundowner Club, expenditure on services, 6 months ending 31 December 2004

9.6 Accommodation outcomes

The Sundowner Club reported accommodation status of 14 evaluation clients in mid-April 2005 and of one client in early June 2005 (Table B9.13). By this time, five clients had entered high level residential care. Three clients were receiving CACP services and one client was receiving support from a Day Therapy Centre while continuing with The Sundowner Club. Accommodation outcomes, however, are not especially relevant in the context of The Sundowner Club as a stand-alone evening meal and activity program and the residential outcomes of people attending the program depend to a large extent on other support arrangements.

Table B9.12: Sundowner Club, client accommodation setting and government program support at follow-up in June 2005 (2004 evaluation group)

Location at follow-up	Number of clients
At home	
Sundowner Club, no other formal support program	6
Sundowner Club plus CACP	3
Sundowner Club plus Day Therapy Centre	1
Total living at home	*10*
In care	
Residential care—high	3
Residential care—low	2
Total	*5*
Total	**15**

ECH provided the following update on original Sundowner Club evaluation clients to highlight the importance of access to care packages and/or care from family for members of the Sundowner Club target group:

> 'On follow up, a number of the original Sundowner Club clients who participated in the evaluation were attending the program, while eight others (including participants and non-participants in the evaluation) have moved into residential aged care or been referred to more suitable programs meeting their needs. Four clients transferred to residential high care, one to a low care secure facility, one to low care and one into residential care with care level unknown. Of those seven original Sundowner Club clients who have moved into residential care, four lived within the eastern metropolitan area of Adelaide, including three living within one local government region where there are currently no high care or high care dementia-specific package services available and the sole CACP service operates a 2-year waiting list. It was felt that all clients could have been supported at home in the community for longer, and in one case the crisis which precipitated admission to residential care might have been avoided if a care package had been available.
>
> Three previous Sundowner clients (who have subsequently left The Sundowner Club program) were living on ECH independent living unit sites in the western suburbs and were able to access package services via the Retirement Villages Care Pilot, including one client who received a high care package before moving into a high care residential placement. Another client was supported at home from March 2004 (when placement was first sought by family) until July 2005 during which time her carer went overseas for 2 months and she was hospitalised and returned to her independent living unit with ongoing Sundowner Club and Retirement Villages Care Pilot low level supports. She was finally placed into low care when her son (carer and guardian) obtained a permanent bed. By contrast, one client whose wife (carer) was actively seeking placement due to his aggressive behaviours prior to his Sundowner Club attendance (which was initiated as a 'stop gap' to tide her over until placement could be found for him) was able to be discharged and referred to a community group for less disabled clients and remains living at home in the community with his wife after his behaviour improved and his aggression

> stopped. It was felt that his 'dementia' might have been an undiagnosed depression which improved when he was supported to resume social contact outside the home (he had been unable to get out of their home due to his poor mobility and medical conditions).'

Accommodation outcomes for clients are in part a reflection that The Sundowner Club has accepted clients who, or whose families, are actively seeking a residential placement. The project has demonstrated that some decisions can be reversed when appropriate formal supports for family carers are put in place. The Sundowner Club model of respite and socialisation has met with high acceptance from clients and carers and represents a truly novel approach to service provision for the target group. The project experience highlights that an adequate supply of care packages needs to operate alongside innovative respite services if members of the target group are to be supported in the community for longer periods.