



Dementia

Caring approaches to a disease of our time

The Benevolent Society is Australia's first non-profit organisation. Established in 1813, its vision is to connect people across society to support each other. It is driving social innovation in order to create more caring and resilient communities. It provides a range of services focussing on Ageing, Children, Women's Health and Social Leadership.

Our diverse range of services provide quality community and residential care for nearly 1,000 older people a day, many of whom have dementia. Our approach to caring for people with dementia is based on valuing and respecting the individual. The key to quality care is well trained staff who understand the needs of people with dementia and their families.

The Benevolent Society acknowledges the financial support of the Commonwealth Departments of Health and Aged Care and Family and Community Services and the NSW Ageing and Disability Department, for our community and residential services.

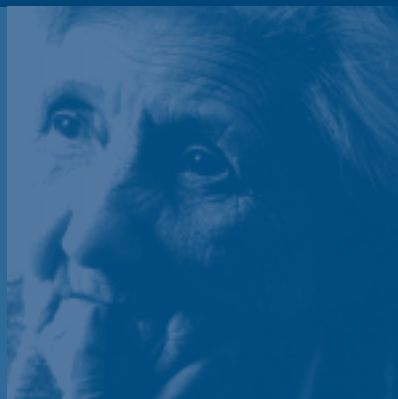
Additional funding and volunteer support are urgently required for our Centre on Ageing services. If you are able to help, please ring 1800 819 633.

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Snapshot

Dementia is a disease of our time. As the number of people living into their eighties and nineties steadily rises, one in four citizens is affected by a dementing illness such as Alzheimer's disease. Nearly everyone in the community is touched by the impact of dementia.

Though the fear of being affected personally is widespread, dementia does not have to mean despair.

The Benevolent Society's services for people with dementia and their families view the on-going dignity of the individual as more important than the disease. With thorough diagnosis, caring support and choices that reflect where possible the individual's own wishes and lifestyle, quality of life can be maintained to a large degree.

The majority of people with dementia live in their own homes, often with the help of caring relatives and access to services that help them stay at home. Others enter hostels, where today approximately 2 in 5 residents have some form of dementia, or nursing homes where the figure is around 3 in 5.

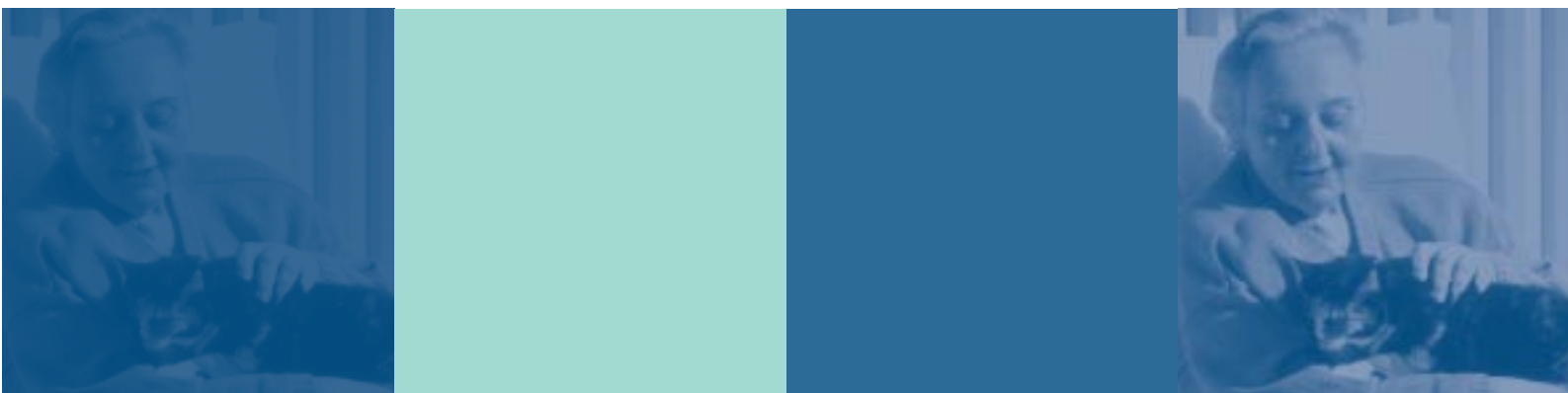
This report, *Dementia – Caring Approaches to a Disease of our Time*:

- 1 explains what dementia is, how many people are affected, its causes and how it is diagnosed (p. 4 – 12).
- 2 describes The Benevolent Society's caring response to dementia, both for people who stay at home (p. 13 – 15) and those who enter residential facilities (p. 19 – 23). Stories illustrate how good care decisions and training for all staff can provide positive responses to a widely feared disease.
- 3 offers support and advice for carers, including useful contacts and publications (p. 16 – 18).
- 4 outlines how The Benevolent Society is engaging the community to support people with dementia and their families. Respect for privacy, individuality and dignity are the keys to The Benevolent Society's approach (p. 24).



Key facts about dementia:

- Dementia is a significant cause of death and disability. Only depression robs more people of years of healthy life.
- Dementia does not affect everyone the same way; its course varies from person to person.
- Although there is no cure for Alzheimer's disease, new medications offer some sufferers the hope of delaying the advanced symptoms.
- Dementia's impact on family and carers can be extreme - respite care is important so they can get a break.
- Damage to short term memory causes acute panic in some dementia sufferers who may behave in ways that others find difficult.
- Staff training is important to minimise problems from difficult behaviour and offer understanding to people with dementia and their families.
- Community awareness is important as increasing numbers of dementia sufferers continue to live in their own homes.
- Caring approaches to this disease of our time are based on valuing and respecting the individual. The keys to quality care are increasing knowledge of dementia, well trained staff who understand the needs of people with dementia and their families, and support for carers.



What is dementia and how extensive is it in Australia?

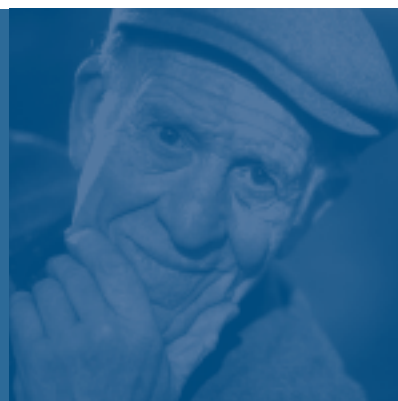
In October 2000 an elderly woman in Adelaide wrapped some items in Christmas paper and boarded a train bound for Sydney. Perhaps Alice C hoped for a happy Christmas with family members; perhaps her Adelaide connections hoped that her Sydney relatives would take responsibility for her. Either way, disappointment lay ahead.

The case of Mrs C, who was found dazed and disoriented at Sydney's Central Railway Station, became the centre of heated criticism in the media. Her family was castigated for neglecting her. The story as it emerged however was far more complex - caring for a relative with dementia can place unprecedented strain on families.

Mrs C's Sydney family protested that they had no idea she would be arriving and were in no position to give her the level of care she required. Her overwhelmed son exclaimed, "Our mother has dementia." Subsequently a non-profit organisation provided Mrs C with accommodation, shielded her from intrusive interviews, and arranged suitable care back in Adelaide.

Alice C's story throws into sharp relief the dread and panic that dementia can provoke for family members. Knowledge, respect for the individual and good decisions about care can overcome many of the challenges dementia presents. The keynote of a caring response is dignity.

Dementia is a major disease of our time. With one in four of our oldest citizens affected, it is a serious and growing health, social and economic issue for Australia. Nearly everyone in the community is touched by the impact of dementia on someone they know. Everyone who lives to be 80 or older - no longer a rare achievement - inevitably sees some of their contemporaries suffer from dementia. The fear of being affected personally is widespread.



Dementia takes a heavy toll on people affected and those around them. The majority of people with dementia (at least 56%) live at home, often cared for by a husband, wife or adult daughter. Responsibility for someone with dementia is also a potential cause of conflict: friends and relatives, all acting from the best motives, often argue about what is best for the person affected.

In personal terms, dementia is disorienting for sufferers, while their carers are at risk of loneliness, exhaustion, depression, low income and stress-related health problems. Carers face years of increasingly demanding effort in caring for the person with dementia. The course of the disease may run anything from three to twenty years, with the average being eight to ten years.

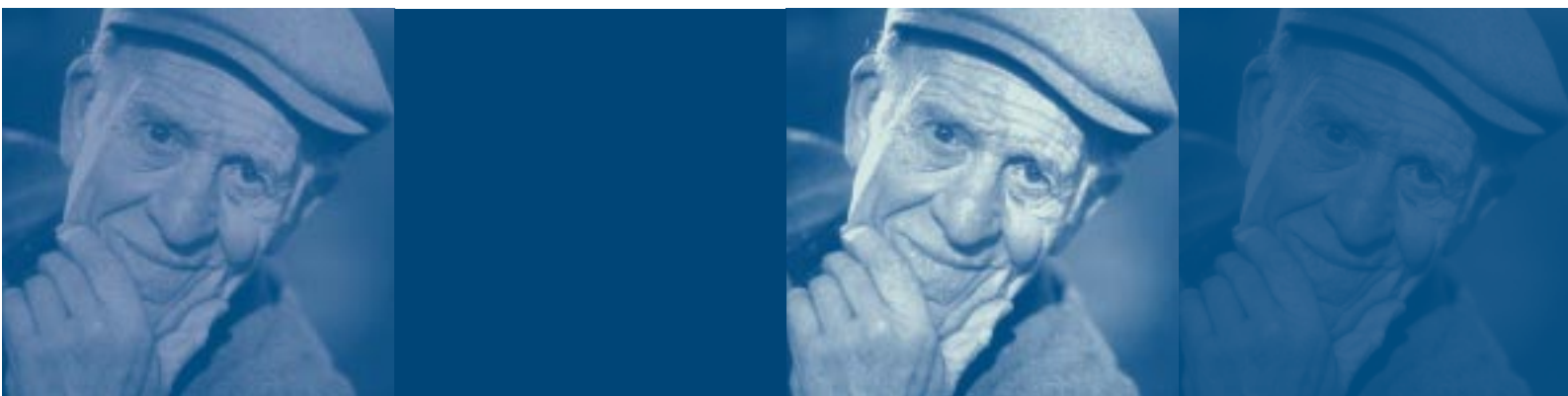
For the community as a whole, quality and choice in aged care are now high on the social and political agenda. Aged care is a very significant item of government expenditure - residential care and community programs cost the Commonwealth alone nearly \$4 billion per year, nearly half of which is spent on people with some form of dementia. For communities, families and individuals, the challenges posed by dementia are acute.

But dementia does not have to mean disaster: the keynote of a caring response is dignity. Appropriate assessment and support can greatly improve quality of life for people with dementia and their families. And perhaps for ourselves, if we live long enough.

Estimates of dementia

Already an estimated 160,000 Australians have been diagnosed as suffering from dementing illnesses. In New South Wales an estimated 55,000 people have moderate to severe dementia, and probably as many again are experiencing symptoms of the early stages.

Dementia is a significant cause of death among older Australians - currently the sixth most frequent cause of death after heart disease, stroke, lung cancer, chronic lung disease and colorectal cancer. It is also a major cause of disability - people affected lose years of healthy life to the condition.



The causes of dementia

Dementia is the general term for a range of medical conditions that interfere with the working of the brain. Symptoms include anxiety, memory loss, personality changes, impaired judgement, loss of initiative and difficulty acquiring new skills.

The most common cause of dementia is **Alzheimer's disease**, a progressive condition which gradually destroys memory, reason, judgement, language and the ability to carry out tasks. Named after Alois Alzheimer, the German physician who described the syndrome nearly a century ago, Alzheimer's disease is characterised by plaques and tangles of amyloid protein, which interfere with the communication between brain cells. The disease is rare among people under 60, but the prevalence increases with age. As yet there is no cure.

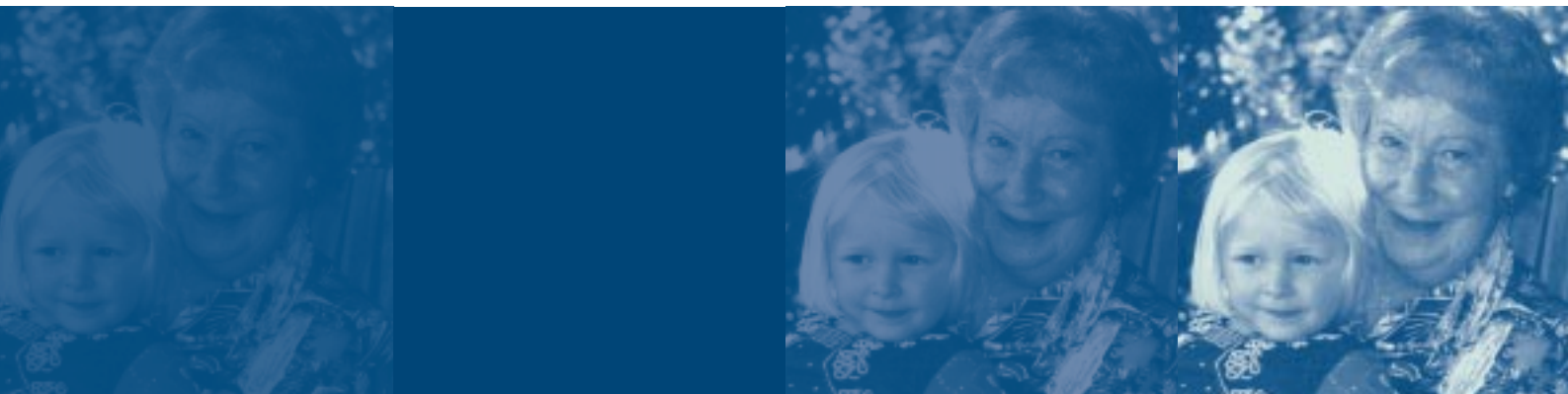
Other conditions which can cause dementia include vascular disease (strokes and hypertension), Parkinson's disease, Huntington's disease, brain tumours, HIV infection and substance abuse. Temporary confusion may occur after a fall, an operation or a major illness.

Some older people have adverse reactions to drugs bought over the counter or prescribed by a doctor. "Polypharmacy" - the interaction of medications for different conditions, often prescribed by more than one doctor - can sometimes impair brain function.

Longer life brings a higher risk of dementia

On average, people are living 20 years longer than their great-great-grandparents did. In Australia today the average life expectancy is 76 for men and 81 for women. In 1900 only 6% of the population was aged 60 and over; the figure is now 16%. By 2016, as many as one fifth of Australians are expected to be over 60. People aged 75 and over make up the age group which is expanding most rapidly.

Year	Life expectancy for men (at birth)	Life expectancy for women (at birth)	% of population over the age of 60
1901	55	59	6
1998	76	81	16



Indigenous Australians have a younger population profile than non-indigenous Australians. Only 1.5% are aged 70 and over (the non-indigenous figure is 8%). Reflecting this shorter life expectancy, indigenous Australians make use of aged care services at younger ages.

Most older people are active and healthy. For them the extra years of life are a great benefit - more time to enjoy fulfilling relationships, work, hobbies, travel and community activities. Unfortunately longer life also brings the risk of significant disability in old age, particularly in the last two or three years of life.

Dementia is not a normal part of ageing - it is caused by disease. However, the major dementing diseases are more prevalent in old age. The risk rises with each year of life from 60 onwards. Prevalence statistics are only approximate, as the early stages of dementia often go undetected, and diagnostic tests vary.

Age	Under 65	65-69 yrs	70 -74 yrs	75-79 yrs	80-84 yrs	85+ yrs
Approx. prevalence of dementia	Less than 1%	1%	3%	6%	11%	24%

Source: Jorm A F, Henderson A S - *The problem of dementia in Australia, 1993*.
 Figures have been rounded to the nearest whole number.

Risk factors for Alzheimer’s disease

As yet, experts cannot pinpoint exactly what makes people vulnerable to dementia. Known risk factors - apart from age - include Down’s syndrome, head injury and (especially when the disease takes hold before the age of 60) family history. To lessen the risk, doctors can only give the usual healthy lifestyle advice - avoid smoking, excessive drinking and obesity; keep active; remain involved in organisations and community activities; maintain friendships and social supports; eat plenty of fruit and vegetables. In some studies, higher education levels show up as a protective factor.



How is dementia diagnosed?

Accurate diagnosis is crucial and health problems should not be dismissed as “just old age”. The picture is often complicated by the fact that dementia can overlap or coexist with physical frailty and illnesses. Careful diagnosis is important to establish whether someone really has dementia, because some of the presenting symptoms (for example, depression) respond well to the right treatment.

General practitioners may refer patients to a psychogeriatrician (a specialist in the mental conditions of older people) or a neurologist, for diagnosis and advice. Assessments are also made by specialist Aged Care Assessment Teams (ACAT). These assessment teams are multi-disciplinary and may include a range of professionals such as doctors, nurses, social workers, psychologists and occupational therapists. The team works with primary carers to make decisions on the most appropriate care.

Symptoms that may indicate dementia

Dementia varies from person to person. The following symptoms generally indicate that an assessment for dementia should be made:

- Difficulty handling complex tasks, such as shopping for the week's food, preparing a two-course meal, navigating simple routes or paying bills.
- Difficulty solving problems that would once have presented little difficulty.
- Increasing difficulty finding the right word or following conversations.
- Uncharacteristic passivity, irritability or suspiciousness; other unusual behaviour or mood swings.

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The following outline gives an idea of how dementia progresses, but it is not an inevitable step-by-step sequence of events.

Early stages

Symptoms are intermittent at first and diagnosis may take some time. Family members and friends are likely to become concerned. The person affected usually manages at home with some help from family or services such as Home and Community Care (HACC). This may be a good time for future planning such as arranging a power of attorney, appointing an enduring guardian and making an advance health directive.

Intermediate stage

The person with dementia, aware of problems with cognitive function, is likely to express frustration. Most manage at home with the right support. Diagnosis leads to a discussion of future options. Carers may wish to use respite care. Hostel care may be a good option if support is not available at home.

Moderate dementia

Most still remain at home despite problems with memory and judgement. Restlessness may lead to "wandering". There may be outbursts of anger, reflecting inner confusion. Residential care may be considered.

Severe dementia

The person may remain at home but the impact on carers can be extreme. There can be loss of mobility, incontinence and communication problems. Many people with advanced dementia enter a nursing home. Individuality and dignity remain crucially important. Well trained staff who understand dementia are the key to quality care.

Confusion can lead to behavioural difficulties

Damage to short term memory deprives people with dementia of the ability to put events into logical sequences. This is very disorienting. Sometimes they experience acute panic, unable to make sense of events and surroundings. In their confusion, some give vent to outbursts of rage or unsocial behaviour.

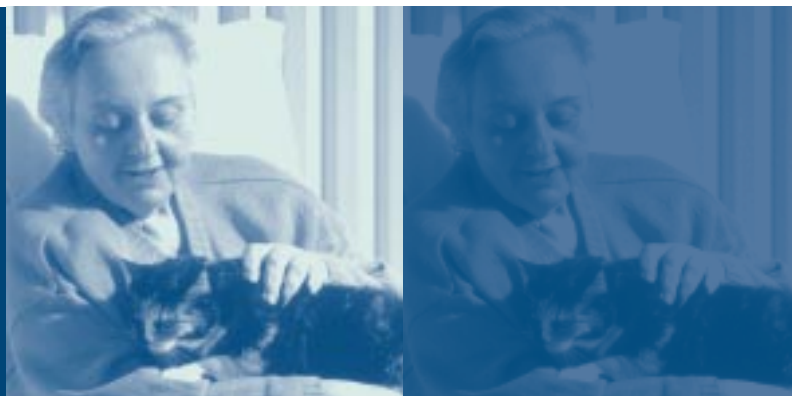


In the last years of her life the English novelist Iris Murdoch suffered from Alzheimer's disease. Her husband John Bayley wrote lovingly of his years as her carer in his book *Iris*. There were many amusing and affectionate moments and the couple remained devoted to one another. However, there were times when even this calmest of men had his patience tested - when Iris had a craze for watering the indoor plants, which all wilted, soggy with over-watering, or when she made an almost non-stop scene on an inter-city bus. On outings she repeated over and over, "When are we going home?"

Things can get much worse. Some people with dementia shout insults or threaten carers with physical force. Demure old ladies have been known to swear like troopers. Simple tasks such as putting on socks can develop into a battle of wills. Other problems include inappropriate sexual behaviour and general agitation. However, it is important to recognise that many people with dementia never engage in difficult behaviour and this stage can pass - as already stated, dementia does not have the same effects on all. The Alzheimer's Association and other advocacy groups such as Carers NSW provide advice and support on how to deal with problems such as abusive behaviour or "wandering", the compulsion to walk long distances alone, often without much sense of direction.

What is the difference between normal forgetfulness and early Alzheimer's?

Occasional lapses in remembering names, or all the items on a list of errands, are not a cause for panic. Ordinary forgetfulness is not usually a sign of dementia, despite the frequent comment, "It must be Alzheimer's." It is easy to distinguish moderate or severe dementia from ordinary forgetfulness, but the early stages are more ambiguous and present greater difficulties for diagnosis. The current wisdom seems to be that self-reports should be taken seriously when people find themselves unable to remember details they used to recall easily **and which are significant to them**. A large part of memory relates to how meaningful the information is to the individual. Someone who takes little interest in films would be unlikely to be able to name Mel Gibson's most recent movies. On the other hand, a film buff who can no longer name favourite movies should not be fobbed off with reassurances about occasional forgetfulness being entirely normal. Anxiety about memory may be well-founded. Persistent forgetfulness or loss of skill with tasks should be discussed with a doctor if it is worrying.



The following table appears on the Alzheimer’s Association’s web-page, www.alznsn.asn.au

Description	Person with dementia	“Normal” older adult
Forgets	Whole experience	Parts of experience
Forgets words or names for things or objects	Progressive	Occasional lapses of memory
Delayed recall of names	Often	Rarely
Follows written or verbal directions	Gradually unable	Usually able
Ability to use notes, reminders, cues from the environment	Gradually unable	Usually able
Follow a story on TV, in a movie or a book	Gradually loses ability	Usually able
Calculations	Gradually loses ability	May be slower than before
Self-care capacity (dressing, bathing, cooking, etc.)	Gradually unable	Usually able

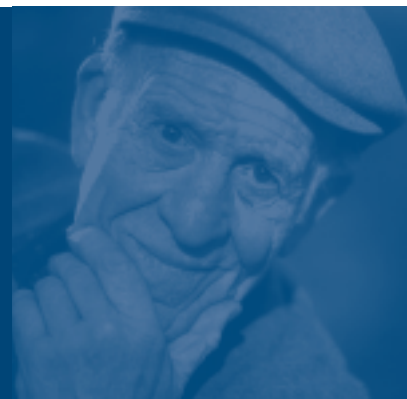
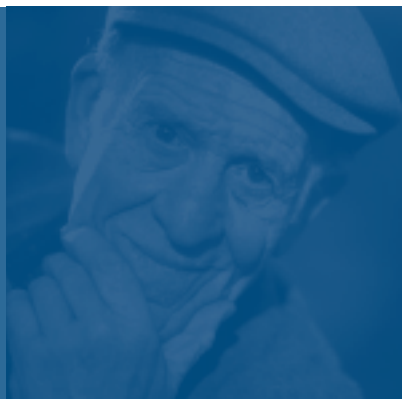
Research suggests that while diseases that involve memory loss cannot be prevented, it is definitely possible to make the most of existing memory and abilities. Positive steps include enjoying one’s curiosity and love of learning; keeping up stimulating pursuits such as reading, crosswords, bridge and chess; using diaries and personal organisers to keep track of information; and remaining confident of being able to meet life as it comes.



A ray of hope - preventive medication

As with any widely feared disease, there are regular announcements of treatments and research results, and people jump at any hope of prevention or cure. Two drugs, Aricept and Exelon, can slow the progression of the disease in some sufferers. Aricept and Exelon are available for prescription by doctors under the Pharmaceutical Benefits Scheme to people with early to moderate Alzheimer's disease. They do not effect a cure - there is as yet no drug which can prevent deterioration in the long term. Reduction in the progression of symptoms may improve quality of life and delay the need for residential care. Pharmaceutical companies are searching for further medications that will inhibit or retard the disease in its early stages, thus extending the years of relatively good health. Many people who experience the early stages of dementia die of some other condition before the disease can run its course. Successful early intervention with preventive medication could increase the chance of avoiding the advanced stage of dementia.

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Help at home for people with dementia

The individual is more important than the disease

Each person affected by dementia is unique. The individual's existing lifestyle is the best guide to what will remain fulfilling, even if some abilities deteriorate over time. Because the individual is more important than the disease, plans for care and lifestyle decisions need to start with his or her preferences, relationships, skills, routines and cultural background. Activities that maintain existing skills and promote self esteem, while providing opportunities for social contacts, are vitally important. Many people with moderate dementia are still able to perform familiar tasks. They value contact with family and friends, respond to jokes and favourite stories, and many enjoy the undemanding affection of their pets. (Some aged care facilities provide specially trained "therapy pets" as an emotional outlet for animal-loving residents.)

The advantages of home care for people with dementia

Most older people put a high value on living independently in their own home. Familiar surroundings are reassuring for people with dementia, who can be upset by changes to routine, new faces or strange places. For this reason, care at home is preferred in the majority of cases, at least until dementia becomes severe. By staying at home, people who may be reluctant to acknowledge that they need help, can maintain their long-established routines despite fluctuations in short-term memory. Other benefits of remaining at home include:

- Flexible home care services support people in ways which help them to maximise control over their lives.
- Challenging behaviours can be reduced by allowing the person with a dementing illness to behave in a way which would be harder to accept in a residential facility.
- Staying at home enables people to maintain their own social and cultural traditions more freely than in other settings. Older people from non-English speaking backgrounds are less likely, on current statistics, to be in residential care than older people born in Australia.



- The cost of providing help to someone in their own home is far less than the cost of maintaining them in a residential facility, until they require constant supervision.

A range of services to help people continue living at home

Support is available from a number of sources to help people with dementia to stay living at home. Because these services are tailored to individual need, they cannot be summed up in neat definitions. Broadly speaking, the main types of services are:

Home and Community Care (HACC) services - services for those who would otherwise be at risk of premature admission to an aged care facility. Services include housework, shopping, personal care, transport to medical appointments, home modification and delivery of meals.

Community Aged Care Packages (CACPs) - a package of support services designed in consultation with an older person, with overall supervision from a local aged care agency. Many CACP clients have moderate dementia.

Community Options - a number of support services co-ordinated by a local agency to meet the individual needs of people with complex care needs including those with dementia.

Individual fee-paying services - individuals or their families pay an agency or individual for the exact service they need, for example, someone to do some cleaning.

For some services, assessment by an Aged Care Assessment Team is necessary to determine eligibility. ACAT assessments can be arranged through a general practitioner or local hospital. The Seniors Information Service or aged care workers at local councils can provide contact details of other services.

How The Benevolent Society is helping older people with dementia to stay living at home

The Benevolent Society has an excellent record of providing older people, including those with dementia, with a range of choices for individual care in the community. Dignity is the keynote of our response. Good training gives Benevolent Society staff a depth of understanding about dementia, with the result that the Society is able to offer services to many people who have been regarded as difficult elsewhere.



The Benevolent Society's community services for older people include:

- Help at Home programs - (Community Aged Care Packages) – in Northern Beaches, North Shore, Canterbury, Marrickville, St. George, Riverwood and Penrith.
- Multicultural Help at Home – Northern Sydney.
- Eastern Suburbs Community Options Program - staff coordinate a range of services for clients with high needs.
- Northern Beaches Food Services.
- Greenwood Cottage Day Centre for Older People.
- Homeshare NSW - an innovative program where an older person offers free accommodation to a younger person in their home in exchange for ten hours help per week around the home.
- Endeavour - a fee-for-service program supporting people at home.

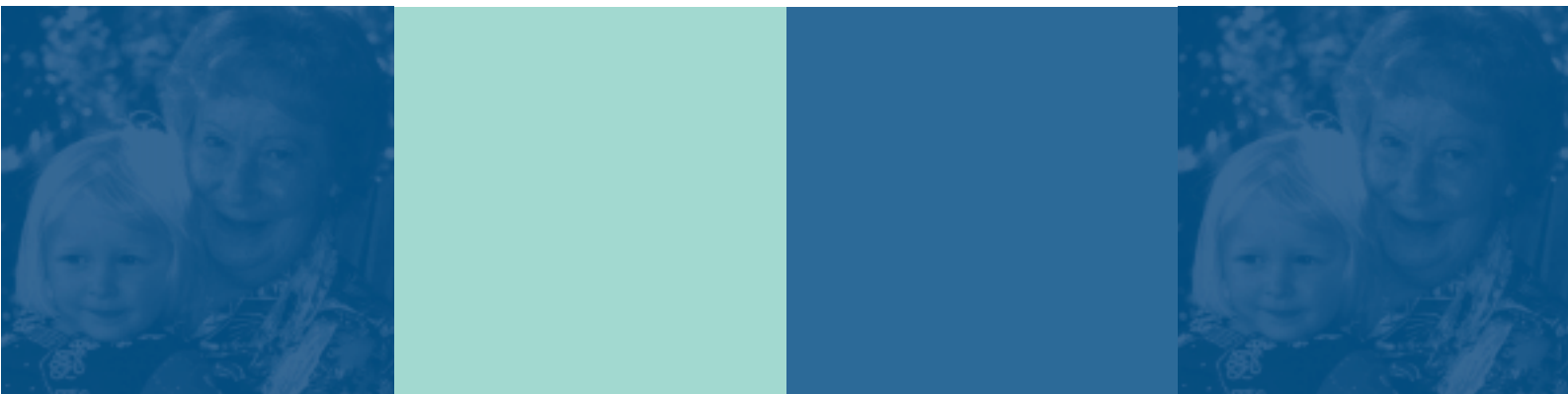
For a list of service contact numbers and other services for older people, see the back page of this publication.

Accepting help at home can be a difficult step for many older people. I said to an old lady, who was clearly unhappy about receiving assistance, "What you would really like is to be independent, so you didn't need us coming in to help you." She looked at me hard and replied, "You never spoke a truer word."

On the other hand, many families of older people with dementia want to place their relative in a residential facility to ease the anxiety and responsibility about how they're managing on their own.

In all of this we need to offer a model of care that helps older people feel they still have dignity and some control over their lives. We take responsibility for ensuring the older person will be safe and comfortable in their home. We can't remove all the risks but we can offer a supportive relationship and strategies to ensure they receive the essential help they need.

From "A Home-based model of dementia care," a paper by Sally O'Leary, The Benevolent Society



Support and advice for carers

Avoiding stress on special occasions

Special occasions like family get-togethers can be a strain for someone with dementia who is used to a settled routine. The Alzheimer's Association operates a free, 365 days a year Dementia Helpline - 1800 639 331 - for families or other people needing advice about dementia. The Helpline receives more than 20 calls a day in NSW alone, and the number goes up at times like Christmas when family stress levels rise and many health professionals are on holidays.

Advice from the Dementia Helpline on how to avoid problems on special occasions includes:

- Encourage the relative to tell stories from the past - perhaps prompted by photos.
- Don't argue the point if the relative says something confused or wrong.
- Give the usual carer a break by taking over the care of the relative with dementia.
- Ask people to congregate in different rooms to prevent a large, noisy gathering which could cause confusion or distress.
- Your relative may like to help prepare the meal, or to be taken for a walk.

Finding the meaning behind the words

A person with moderate dementia may have a reduced vocabulary or may substitute unexpected words and phrases for the desired word. Communication problems can be reduced by listening for the meaning behind the words - the emotional tone, the context, the person's attitudes to particular topics and people. Sometimes this process is referred to as 'listening to the emotional music'. If it is possible to pick up the general sense and continue a conversation, the meaning often becomes clearer as the person provides further clues. Good communication can then be achieved once the code is cracked. Insistent demands for clarification, on the other hand, can lead to acute frustration and may discourage the person with dementia from communicating.



Carers need to take a break

Caring for someone with dementia is hard work. Respite care - giving quality care to people with dementia while their usual carers have a break - is very important so that carers can maintain their own wellbeing. Respite gives carers a break from their exhausting responsibilities while ensuring the person with dementia is well looked after. The right support at the right time can make all the difference in a carer's ability to keep going. Respite services range from day programs for older people to occasional residential care to enable regular carers to have a holiday.

The Commonwealth Department of Health and Aged Care funds Carer Respite Centres throughout Australia. The Benevolent Society runs the South East Sydney Carer Respite Centre which provides advice and support for carers seeking short-term respite care for frail or disabled people. While most respite care services are provided after careful planning, some emergency services are available.

Many carers also like to keep in touch with others in similar situations, through groups supported by organisations such as Carers NSW and the Alzheimer's Association of NSW.

Rada was a sophisticated, well-travelled woman who enjoyed a very full life. She worked in the Women's Army Corps during World War 2, married and brought up two daughters, then lived in Europe for several years before returning to Sydney's eastern suburbs. Her illness had an insidious onset. It was some time before Rada's disorientation when driving and her lack of interest in some of her usual activities were identified as symptoms of early dementia. Rada's devoted husband David cared for her at home because he felt she would do best in her own environment. This proved to be a major undertaking, for her illness lasted six years. For the first year or so, one of their daughters came to stay occasionally to give David a break. Then the family inquired about respite care, and discovered that Rada could attend day care two mornings a week. She was also able to spend a fortnight in a hostel every six months, giving David the regular breaks he needed. In the last stages of her illness Rada received extra support from a community options program. Thanks to these services, a committed local doctor and her excellent family support, Rada was able to end her life peacefully at home.



Useful publications for helping older people with dementia

In *At Home with Dementia*, experienced carers give hints for solving problems and avoiding pitfalls. It gives practical advice on improving the home environment with safety features and suggests simple approaches to household tasks, personal care and finding one's way round. It gives tips on how to discourage wandering and even lists suitable gifts for someone who has dementia. The book is available from the NSW Ageing and Disability Department or can be downloaded from their website, www.add.nsw.gov.au.

Another useful publication is *Taking Charge*, a discussion paper written by The Benevolent Society and the Centre for Education and Research on Ageing, for the NSW Committee on Ageing. It suggests ways of organising matters such as power of attorney and enduring guardianship in advance, so that if someone loses the capacity to make decisions themselves, necessary decisions to do with health, finance, wills and other legal affairs reflect their wishes. It is available from the NSW Committee on Ageing website, www.coa.nsw.gov.au.

There is a fact-sheet, *What if something happens to me*, based on this publication. It is also available at www.coa.nsw.gov.au or by ringing the NSW Committee on Ageing, (02) 9367 6860.

How The Benevolent Society is supporting carers of people with dementia

The Benevolent Society's services for carers of older people, including carers of people with dementia, include:

- South East Sydney Carer Respite Centre – provides advice and can arrange short-term respite.
- Community and In Home Flexible Respite, Southern Sydney – provides respite for carers of people with dementia and challenging behaviour.
- Eastern Suburbs Options Programs – coordinate a range of services for carers who look after people with high support needs.
- Endeavour Home Support – a fee-for-service program supporting people at home.
- Greenwood Cottage Day Centre for Older People.
- Residential respite care – provided in the Society's hostels and dementia specific nursing home, Eric Callaway House.

For a list of service contact numbers and other services for older people, see the back page of this publication.



Residential services for people with dementia

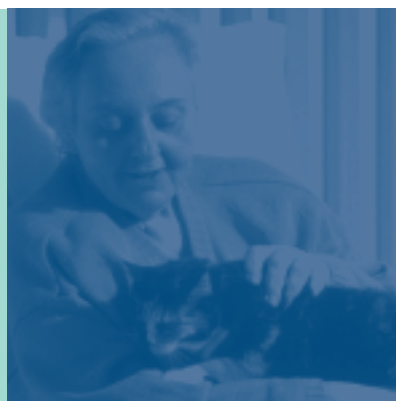
Whilst the majority of people with dementia live at home, many live in residential facilities. The main types available are:

Retirement villages - unit accommodation for older people, usually in the form of self-care units for single people or couples who can take care of themselves. Some villages provide home care services on a fee paying basis. This type of accommodation seldom suits people with dementia. Village residents with dementia may have to move to a hostel or nursing home.

Hostels (low care aged care facilities) - accommodation for frail older people needing personal care. The hostel provides meals, cleaning, laundry facilities and some recreational activities. Most residents have a single bedroom with an ensuite bathroom. Residents may require low or moderate level care, but 24 hour nursing is not provided. Many residents have early to moderate dementia. Hostels encourage residents to maintain their links to the community, through family outings, friendships, visits by their own doctor, and so on. There are also communal activities such as bus trips, craft activities such as pottery, music, aromatherapy, massage, quiz sessions, bingo, exercise classes and walks. Eligibility is assessed by Aged Care Assessment Teams (ACAT). About 38% of Australia's hostel residents have some form of dementia.

Dementia specific hostels - accommodation dedicated to people with dementia who may wander, have difficult behaviour and are still mobile. Meals, cleaning and laundry services are provided, as well as recreational activities and secure grounds for walking. ACAT assessments are required.

Nursing homes (high care aged care facilities) - accommodation and 24-hour care for people needing extensive nursing care. A trained nurse is on duty at all hours. Some nursing homes are dementia-specific, with secure grounds and staff who are trained to care for people with dementia. ACAT assessments are required. About 59% of all nursing home residents have some form of dementia.



Often dementia remains undiagnosed until a crisis occurs. Annette lived alone for many years. She kept her house and garden in good order. None of her family lived nearby but she had a fairly active lifestyle. In her eighties Annette spent more time on her own and began accumulating things in the yard. Her neighbours complained about the jumble of cartons, wire bundles, empty tins and bottles that gradually covered all the outdoor space and spilled on to the nature strip. Annette's daughter, who lived in another city, was called in. At her daughter's request, Annette consulted her local doctor. Later an ACAT team assessed Annette, who had moderate dementia. For a few months she was able to remain at home with some support services, but eventually residential care became necessary.

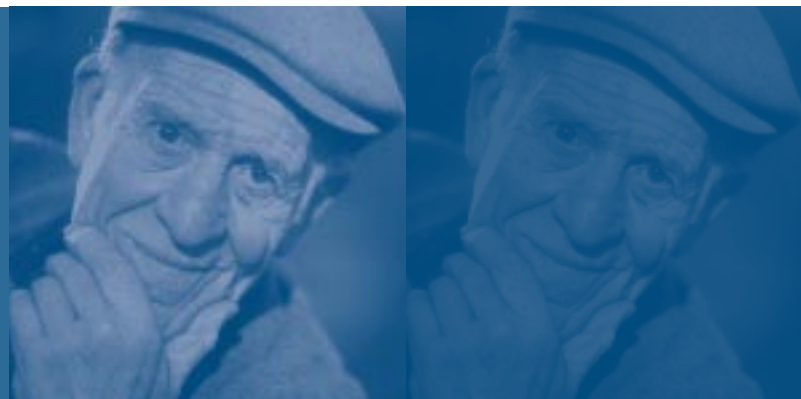
When a nursing home becomes almost inevitable

The care of someone with severe dementia is sometimes beyond the capacity of home carers or hostel staff. Factors that make nursing home care a likely choice include:

- Reduced mobility - needing support from two people in order to walk.
- Incontinence of both urine and faeces.
- Behavioural problems that are not helped by a supportive environment or medication.
- Persistent wandering.

Dementia sufferers and their families can be traumatised by the need to move from one place to another. The person with dementia needs time to adjust to a new setting, which may include a shared room. There is often a period of guilt and anxiety for family members. Staff training is important to ensure that these emotional transitions are understood by everyone on the caring team.

Staff who understand dementia can prevent distressing scenes. A nursing home resident positioned himself at the locked front gate, determined to leave the moment someone opened it. A very junior member of staff, who had been trained to "go with the flow" rather than let a conflict escalate, simply said to him, "We have to go inside to get the keys first." She was able to lead him gently back inside without any fuss.



How The Benevolent Society's residential services support older people with dementia

Kirby Court, a dementia specific hostel

In 1997 The Benevolent Society opened its pioneering dementia hostel, Kirby Court. Located in Harrow Road as part of the Society's Bexley Centre, it looks like a Federation bungalow. The hostel provides residential care for active people with moderate dementia and behavioural difficulties who cannot be cared for in mainstream hostels.

People with dementia can easily become confused and upset. They can feel alienated in long corridors and large institutional surroundings, so Kirby Court is built to the scale of a normal house. Each resident has a single bedroom with an en-suite bathroom. Private bedrooms enable residents to keep their own pictures and other belongings around them.

All staff are trained to understand dementia and deal calmly with behavioural difficulties.

The tranquil atmosphere at Kirby Court offers an ideal environment for people who need support but are still mobile. It provides a homelike setting with living room, breakfast room, television nook and a leafy veranda. Energetic residents can walk with safety in the garden. Initially built for 15 residents, Kirby Court will soon be enlarged to accommodate another ten people. At least one bed is reserved for respite care.

Eric Callaway House, a dementia specific nursing home

Eric Callaway House, The Benevolent Society's dementia specific nursing home at Phillip Bay, has 43 residents and 60 staff. A high proportion of patients have behavioural difficulties. The facility is being renovated to provide a quieter, more calming environment and to improve the range of activities and recreation available to residents.

"We emphasise to relatives that someone with dementia doesn't cease to be an individual," says Sue Owens, Director of Nursing at Eric Callaway House. "It's very important that we respect people's privacy and dignity. We have to be flexible because we can't forecast what course the disease will take with any individual. We need to show love and concern to them and their families."



The home is part of a closeknit support community. Most residents come from the surrounding area, having been referred by the ACAT teams of south east Sydney, the South East Sydney Respite Centre, Benevolent Society hostels or other hostels such as Strickland Cottages, Little Bay.

Most staff see the residents and their relatives as a big extended family. Although some residents die in hospital, most receive palliative care at Eric Callaway House in the final stages of their illness. Eric Callaway House has a tradition of making visitors so welcome that many return as volunteers to help with other residents long after their own relative has died.

When Melina's husband Paolo died after suffering from Alzheimer's disease for a long time, Melina was exhausted. She told staff at Eric Callaway that she would come back to offer voluntary help, but not for a while. She needed time to grieve and renew her energy. A year later Melina was back, full of zest, delighted to see old friends and ready to offer help to others.

The staff all receive training in understanding dementia and challenging behaviour and can respond in ways that avoid or minimise problems. Sue Owens says that her staff are trained to walk away from conflicts when necessary. "It is better for our staff to leave a particular task and go back later when the resident is feeling perfectly agreeable," she explains. "When staff encounter resistance to care, we tell them to inform management and move on to the next thing. It is better for someone to keep a stained shirt on for an hour or so than to have an all-out battle changing it. Staff often feel it's a reflection on them to leave something like that unattended. We have to explain incidents to visitors sometimes too, because that kind of thing can be misinterpreted. Generally though, everyone around here works as a team and when one person runs into difficulties, someone else takes over. When behavioural difficulties occur, we need to talk it over with their families and reach an agreed way of responding. What works for one won't work for another."



There is also good local support from Maroubra Rotary Club and Botany Rotary Club for Eric Callaway House. Some club members have been connected through their parents residing at the home. Other long-serving volunteers provide transport, organise barbecues, arrange activities such as massage and beauty therapy and play music for community events. The Friends of Eric Callaway Committee is helping to raise funds for a new bus. "At Eric Callaway, breakfast isn't much of a problem," Sue Owens says. "Most people are alert enough to feed themselves, but by lunch time many will require help. Dinner is a demanding time, as even more residents need help with feeding. When we mentioned this in a supporters' newsletter, many of our morning visitors rescheduled their visits so they could help us at lunch and dinner time."

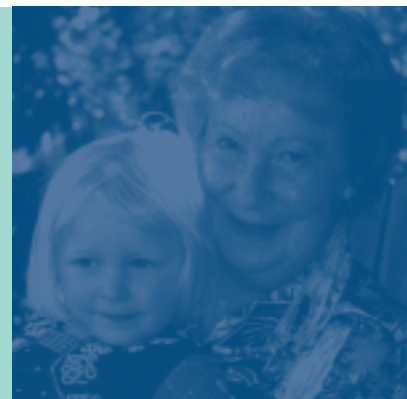
Hostels supporting older people, including those with dementia

All The Benevolent Society's hostels (low care aged care facilities) provide quality residential care to older people, a significant number of whom have dementia. The Society's hostels are Waratah Lodge in Allambie Heights, Margaret Lim U in Bexley, Chapman House in Bondi and Sans Souci Gardens in Sans Souci.

Margery and Victor were teenage sweethearts who married when Victor was 19 and Margery only 18. It was a happy marriage, with a lot of hard work as they raised three children. In his late sixties, Victor retired from his job and spent more time at home and enjoying hobbies such as bowls.

Margery first realised something was wrong when Victor seemed unable to finish do-it-yourself tasks with his usual efficiency. She noticed he kept sweeping the same bit of the yard. She no longer felt safe when he drove the car. Within a year, Alzheimer's disease was diagnosed. Margery cared for Victor at home for three years. She was happy to do so because he had always taken care of her when she was sick.

When Victor's dementia became severe, he became a resident at Eric Callaway House. Margery visited daily. She liked the family atmosphere, the friendliness of the staff and the chance to share experiences with other visitors. As Victor's illness entered its final stages, he became very frail and was confined to bed. Margery continued to visit each day, helping Victor with his meals and reassuring him by her loving presence.



The need for community awareness

Dementia was once very largely a hidden problem. That is no longer the case. As dementia becomes more prevalent, information for the general public is of great importance. Community awareness campaigns featuring bus posters and media segments have had positive results. In the long term, everyone in the service sector, from shop assistants and bus drivers to doctors' receptionists, will be able to respond better if they understand how dementia affects people. "Every one of our staff who comes to a better understanding of dementia and enjoys their interaction with residents is an ambassador for better community awareness about dementia," says Gabrielle Taylor, Senior Manager of The Benevolent Society's residential services.

Community engagement and dementia

An ageing population presents challenges for many individuals and their families, organisations in the health and welfare sector and the community as a whole. The Benevolent Society sees dementia as our collective responsibility and is committed to engaging the wider community in its efforts to support older people with dementia and their carers.

The diversity of services provided by The Benevolent Society's Centre on Ageing is one of its greatest strengths, enabling it to reach across generations and communities. These services enable older people to stay in their own homes, or if they enter residential facilities, to maintain their links to the community. The families of residents become a valued part of the support network for the whole organisation, not just their own relative. Residents are valued as individuals and as far as possible make their own decisions. Staff are encouraged to network with their peers and with students, to share knowledge that will enhance the quality of care. Volunteers make an enormous contribution to the wellbeing of older people. Local service clubs and businesses give valued support to residential facilities. Many people keep up their link with hostels and nursing homes through voluntary visits and other services. Others become donors or pledge bequests to The Benevolent Society.

Caring approaches to this disease of our time are based on valuing and respecting the individual. The keys to quality care are increasing knowledge of dementia, well trained staff who understand the needs of people with dementia and their families, and support for carers.



Contact details for The Benevolent Society's Centre on Ageing Services

Email: coa@bensoc.asn.au

Community Care Northern Sydney

- Help at Home Northern Beaches & North Shore
- Multicultural Help at Home
- Peninsula Domestic Assistance
181 Allambie Road
Allambie Heights 2100
Ph: (02) 9975 3174

Community Care Southern Sydney

- Help at Home St George, Canterbury, Marrickville & Riverwood
- Assistance with Care and Housing for the Aged
405 Bexley Road
Bexley 2207
Ph: (02) 9556 1022

Community and In Home Flexible Respite Southern Sydney

20 Market Street
Rockdale 2216
Ph: (02) 9556 3677

Eastern Suburbs Community Options Programs

24a Ocean Street
Bondi 2026
Ph: (02) 9365 6122

Endeavour Home Support

181 Allambie Road
Allambie Heights 2100
Ph: (02) 9975 3885

Greenwood Cottage Day Centre for Older People

20 Harrow Road
Bexley 2207
Ph: (02) 9556 2915

Homeshare NSW

20 Market Street
Rockdale 2216
Ph: (02) 9599 2273

Northern Beaches Food Services

6 Jacksons Road
Warriewood 2102
Ph: (02) 9970 8399

South East Sydney Carer Respite Centre

20 Market Street
Rockdale 2216
Ph: (02) 9599 0233

The Allambie Centre

- Waratah Lodge (hostel)
- William Charlton Village
181 Allambie Road
Allambie Heights 2100
Ph: (02) 9451 6686

The Bexley Centre

- Margaret Lim U (hostel)
- Kirby Court
(Dementia specific hostel)
- Rockdale Centenary Village
28 Harrow Road
Bexley 2207
Ph: (02) 9567 1219

The Bondi Centre

Chapman House (hostel)
18 - 22 Ocean Street
Bondi 2026
Ph: (02) 9389 3660

Walter Cavill Village
30 Wellington Street
Bondi 2026
Ph: (02) 9365 0035

Eric Callaway House

(Dementia specific nursing home)
23 Adina Avenue
Phillip Bay 2036
Ph: (02) 9661 5222

Mirrabooka Village

1409A Anzac Parade
Little Bay 2036
Ph: (02) 9661 5340

Rotary Court Village

71 Alexander Street
Alexandria 2015
Ph: (02) 9516 1546

Sans Souci Gardens (hostel)

188 Chuter Avenue
Sans Souci 2219
Ph: (02) 9583 1599

Useful information and contacts

NSW Seniors Information Service 13 1244
(TTY Freecall 1800 806 830)

Age Page in the telephone book has many useful contact numbers, including Aged Care Assessment Teams (ACAT).

National Dementia Helpline Freecall 1800 639 331 - a free service operated 365 days a year by Alzheimer's Association and available throughout Australia.

National Carers Resource Centre
Freecall 1800 242 636

The Alzheimer's Association of NSW offers extensive information resources and help notes on its website, www.alznsw.asn.au Ph: 9805 0100

Information about the Carer Payment 132717

Carers NSW can be contacted on 9299 1499

At Home with Dementia, a useful book of advice by M. O'Sullivan, is available on the NSW Ageing & Disability Department's website www.add.nsw.gov.au

Taking Charge, a discussion paper written by The Benevolent Society and the Centre for Education and Research on Ageing for the NSW Committee on Ageing. It suggests ways of organising matters such as power of attorney and enduring guardianship in advance. It is available from the NSW Committee on Ageing Website, www.coa.nsw.gov.au. There is a fact-sheet, *What if something happens to me*, based on this publication. It is also available at www.coa.nsw.gov.au or by ringing the NSW Committee on Ageing, (02) 9367 6860.

Aged care workers at local councils are also a good source of information about community resources.

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