FLEXIBLE RESPITE SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CARERS

INFORMATION FOR SERVICE PROVIDERS

UNDERSTAND ALZHEIMER’S EDUCEATE AUSTRALIA FIGHTDEMENTIA.ORG.AU
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The information in this booklet is designed to assist aged care and disability respite providers to deliver flexible services that meet the needs of people with dementia and their carers. It provides:

- Information about providing respite for people with dementia and their carers
- An overview of the components of flexible respite services
- A checklist to assess the flexibility of respite services
- Examples of good practice in the provision of flexible respite for people with dementia and carers
- Recommended further reading and links to further information on respite

As both the aged care and disability sectors move to consumer-directed and individualised funding models, it is increasingly important that providers of respite ensure that their services are flexible to meet the needs of diverse clients. Services must be responsive to the goals, needs and wants of people with dementia, their carers and families.

PURPOSE

1. Phillipson, L., Cridland, E. and Cappetta, K. (2016) Understanding the factors that contribute to ‘flexibility’ in the provision of respite for carers of people with dementia. A literature review, prepared for Alzheimer’s Australia for the ‘Making Flexible Respite a Practical Reality’ project funded by the Department of Social Services.
Respite care is a form of support for people living with dementia and their carers. It ensures the needs of people with dementia are supported, while giving carers the opportunity to attend to everyday activities, work, go on holidays or simply have a break from the demands of their caring role.

**WHAT IS RESPITE?**

Respite used to be seen as a service primarily for the benefit of carers. This understanding is changing and respite is increasingly being recognised as being important for people with dementia as well.

Respite is beneficial for both people with dementia and carers because it:

- Supports the social participation of people with dementia and their ability to pursue activities of interest
- Gives carers time to look after themselves and their own work, health and social needs
- Helps keep carers well and improve the quality of care they provide
- Sustains carers so they can continue their caring role and the person with dementia can stay living in their own home

**WHY IS RESPITE IMPORTANT?**
WHAT TYPES OF RESPITE SERVICES ARE PROVIDED?

Respite can take place in a home, at a day centre, in the community, in an overnight respite cottage or at a residential aged care facility, with respite provided over varying lengths of time in each option.

Government-subsidised respite services can assist people with dementia and carers. Services include:

**Planned Respite**

- **In-home respite:** This type of respite usually involves a care worker coming to the person’s home so that carers can go out for a few hours. Or, they may take the person with dementia out of the house for a few hours.

- **Centre-based day respite:** This type of respite usually takes place at a day centre. It offers personalised, structured activities or group activities.

- **Overnight or weekend respite:** Overnight care may be provided in a variety of settings including a respite house (‘cottage-style’ respite) or the home of a host family.

- **Community access respite:** Community access respite provides social activities to people with dementia, either individually or as part of a group setting. This could include Men’s Sheds or buddy programs.

- **Flexible respite:** Comprises a mixed model where needs can be met by one of the above respite services or a combination of activities in the home, community and centre-based options. The emphasis is that the activity mix, length and location are chosen by the person with dementia and their carer.

- **Consumer Directed Respite Care:** There are a limited number of Consumer Directed Respite Care (CDRC) packages available through Commonwealth Respite and Carelink Centres (CRCCs). CDRC packages allow the consumer to have a greater say and more control over the design and delivery of respite services provided. This means consumers make choices about the types of respite services accessed, how and when they are provided, and who will deliver them.

- **Respite access in Home Care Packages:** People with dementia who have higher care needs can access support through Government subsidised Home Care Packages (HCP). All HCPs are delivered on a consumer-directed care (CDC) basis. To receive respite access in Home Care Packages, consumers need an assessment and approval from an Aged Care Assessment Team (ACAT). This is organised through My Aged Care. This means that consumers have choice and control about what services they access as part of their package, according to their goals and needs. Respite services may be provided as part of a package if chosen by the consumer.

- **Respite in a residential aged care facility:** People who need help every day can arrange to stay in an aged care facility, either on a planned or emergency basis. To receive residential respite care in an aged care facility, consumers need an assessment and approval from an Aged Care Assessment Team (ACAT). This is organised through My Aged Care.

**Respite access for people under the age of 65**

National Disability Insurance Scheme (NDIS): People with dementia under the age of 65 may be eligible to access the NDIS and the ‘Support for Sustaining Informal Supports’ provided for through it. However, it is important to note it is not referred to as respite. It includes respite-like support such as replacement support, group-based facilities or in-home support. The NDIS guidelines are very clear that the person with dementia is the central focus of the plan and supports are aligned with their aspirations and goals. Therefore, the respite-like services must meet this criterion and then the amount included in a plan will be based on the level of support required.

**Emergency Respite**

Emergency respite for people with dementia under and over the age of 65 can be accessed through Commonwealth Respite and Carelink Centres.
FLEXIBLE RESPITE SERVICES: THE NEED FOR CHANGE

Respite is an important opportunity for social engagement for the person with dementia and plays a critical role in providing a break for carers as well. Often respite is essential to ensuring that family members can continue caring for the person with dementia at home.

Over half of co-resident primary carers of people with dementia have indicated they need more support, and the greatest single unmet area of demand is for respite. However, their experiences of respite services are often reported as being unsatisfactory.

“There are a lot of people who won’t attend respite groups because they don’t like the activities offered – this makes it hard for carers to encourage them to go.”

“The activities offered by the Respite Service do not have a purpose. They are just entertaining/fill in the day. From my perspective they seem more like a minding service.”

With the movement towards consumer directed services, respite services need to be improved to meet the underlying demand for more and better respite services.

WHAT DOES ‘FLEXIBLE RESPITE’ MEAN?

The components of flexible respite service provision for people with dementia and their carers include:

- **When**: the time, frequency and duration of the respite service
- **Where**: the setting where respite services are available
- **What**: the range of activities that are considered as providing ‘respite’
- **Who**: including considerations of the person with dementia, the carer and the personnel who may support the delivery of flexible services
- **How**: including the policies and programs that may support the uptake and delivery of flexible services

1. Alzheimer’s Australia (2009) Respite Care for People Living with Dementia “It’s more than just a short break.”
2. Alzheimer’s Australia (2009) Respite Care for People Living with Dementia “It’s more than just a short break.”
3. Phillipson, L., Cridland, E. and Cappetta, K. (2016) Understanding the factors that contribute to ‘flexibility’ in the provision of respite for carers of people with dementia: A literature review, prepared for Alzheimer’s Australia for the ‘Making Flexible Respite a Practical Reality’ project funded by the Department of Social Services
KEY FEATURES OF FLEXIBLE RESPITE SERVICES DESCRIBED BY CONSUMERS

Research\(^4\) with people with dementia and their carers suggests that the following features of services are valued with regards to flexibility and quality.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Features</th>
<th>Details</th>
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| How       | Policy and program guidelines that support flexibility | - Personalisation of services through:  
- assessment  
- coordination and planning  
- consumer direction  
- provision of transport  
- program evaluation |
| When      | Time, Frequency, Duration, Planned and emergency | - Time of day, including overnight  
- Days of the week, including weekends  
- Frequency of access (from occasionally to regularly)  
- Duration of respite (from a few hours, to a few days, to a few weeks)  
- Planned |
| Where     | Setting of respite | - Centre based  
- In home  
- Residential care  
- Cottages and host family  
- Settings that provide day and overnight respite  
- Dementia-friendly environments |
| What      | Choice of activities, Appropriate activities for client’s interests and capacity | - Opportunities for people with dementia to share experiences and knowledge  
- Meaningful activities and engagement with the community  
- Opportunities for carers to participate in activities that maintain social networks |
| Who       | Staffing | - Consistent staff, matched with consumers to facilitate rapport and relationships  
- Dementia-specific training, knowledge and experience  
- Responsive to client needs  
- Personal traits including compassion and understanding |

4. Adapted from Phillipson et.al. (2016)
The top 8 factors that contribute to respite services being flexible as rated by respite providers consulted for this project are shown below, ranked in order of perceived importance.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Factor</th>
<th>Details</th>
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<tbody>
<tr>
<td>1</td>
<td>Staff continuity</td>
<td>Carer/recipient can build and retain relationship with a chosen, trusted staff member</td>
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<tr>
<td>2</td>
<td>Where</td>
<td>Choice of setting meets the needs of person with dementia and carer</td>
</tr>
<tr>
<td>3</td>
<td>Timing</td>
<td>Flexible options in terms of ordinary working hours, after hours or on weekends</td>
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<tr>
<td>4</td>
<td>Activities</td>
<td>Appropriate to recipient, e.g. Younger Onset Dementia, CALD, gender, high needs, tailored experiences, and mixed or graduated, i.e. with some natural &amp; peer supports moving up to full paid 1:1 support</td>
</tr>
<tr>
<td>5</td>
<td>Network</td>
<td>Consistent willingness to work with other services to network a flexible package of respite</td>
</tr>
<tr>
<td>6</td>
<td>Attitude</td>
<td>Consistent staff willingness to go the extra mile, and test the limits of guidelines and policies to deliver respite that meets needs</td>
</tr>
<tr>
<td>7</td>
<td>Costs</td>
<td>Low fees charged to the carer/care recipient</td>
</tr>
<tr>
<td>8</td>
<td>Funding</td>
<td>Carer/care recipient have control over mix and timing of supports</td>
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FLEXIBLE RESPITE CHECKLIST

This checklist can assist you to assess the flexibility of your respite service (or local network of services) and identify areas where improvements can be made to ensure respite meets the needs of people with dementia and carers.

WHEN

- The service operates at times that suit a range of carers, including working carers (extended hours of service)
- Allowances are made to help people with dementia settle in to the respite service (e.g. shorter periods of respite, before building up to full days)
- Transport assistance is provided to and from respite

WHERE

- Centre-based respite services are delivered in environments that are dementia-friendly and inclusive
- Community-based respite activities encourage community participation and social inclusion of people with dementia
- Mobile respite is provided to meet the needs of people with dementia and carers living in rural and remote areas

WHAT

- Assessments comprehensively take into account the needs of both carers and people with dementia
- Life histories of clients with dementia are developed to assist in providing activities appropriate to their interests and expressed needs and wants
- Activities are tailored, adapted and personalised to meet the needs of individual clients
- The culture of the service enables dignity of risk for people with dementia and facilitates their participation in activities

WHO

- Staff and volunteer recruitment practices emphasise personal traits and attitudes such as empathy, patience and compassion
- Staff are well supported, turnover is low and there is consistency for clients
- Staff skills and experiences are matched to the clients they support
- Staff ratios are responsive and flexible in order to meet the needs of the individual
- Service managers/coordinators encourage flexibility and innovation to enable staff to deliver person-centred services

HOW

- Service manager/coordinators network and collaborate with other local service providers
- The service is culturally appropriate and meets the needs of a diverse range of clients (through staffing or relationships with ethno-specific services)
- The views of clients (people with dementia and carers) are included in service review, planning and evaluation
- Organisational policies and practices encourage and support flexibility in service provision
DELIVERING FLEXIBLE RESPITE SERVICES:
EXAMPLES OF GOOD PRACTICE FROM AROUND AUSTRALIA

HOLDSWORTH COMMUNITY CENTRE

Holdsworth Community Centre is based in Woollahra and services clients living in the Eastern suburbs of Sydney. Its services are funded through a variety of sources including CHSP funding, HCP recipients, grants from Randwick and Waverly Councils, and funding from Woollahra Council.

People living with dementia attend a variety of programs of their choice including specialist dementia community outings (including lunch), discussion groups, one to one community participation, a volunteer visiting service, community choirs, Gaden Community Café, exercise programs and yoga, movie matinees and music appreciation.

With a variety of funding streams and a workforce trained in working with older people, people living with dementia and people with disabilities, Holdsworth provides a range of flexible options that clients can choose from. Holdsworth also refers people to other providers for specialist services.

Holdsworth’s purpose is to support people over the age of 65 and their carers to make the most of their lives in changing circumstances by offering social connections and engaging experiences. Holdsworth ensures all people using the services have choices about what they do and where they go. These choices feed into new programs and the development of existing programs. The guiding principle of the service is ‘to make it happen’.

BAPTISTCARE SOCIAL CLUB

The BaptistCare Social Club operates in Red Hill, ACT and provides centre-based respite and outings. The service is not dementia-specific but they have a number of clients who have early to mid-stage dementia. The centre is open from 8am – 6pm each weekday and so is able to meet the needs of working carers. Each day 12-14 clients attend the centre, most of them aged in their 70s and 80s.

Activities are tailored to suit the likes and dislikes of clients. The service has a monthly activities program which is put together by staff with the input of clients. Each Tuesday there is an outing and lunch at the local club, and once a month clients attend the club entertainment. On Thursday afternoons, clients can go out for a scenic drive. Centre-based activities include craft afternoons, Men’s Shed activities, and a once-a-month visit from staff of the local hardware store.

The Social Club staff are trained in dementia support, are very dedicated and develop an excellent rapport with clients and carers. Fees are set at $30 for a full day (including meals) and $15 for a half day. However, the service coordinator is able to offer reduced fees to clients who are experiencing financial hardship.
ALZHEIMER’S AUSTRALIA NSW MOBILE RESPITE SERVICE

Alzheimer’s Australia NSW Mobile Respite Team (MRT) service covers the Bega Valley. It operates on an innovative model that has evolved to provide support, respite, links to community services and a transition to residential aged care for a person with dementia where appropriate. The service includes two support workers employed three days a week working as a team. One staff member works with the carer to provide education and support and the other simultaneously works with the person with dementia.

Through the home visits, respite is provided to the carer as one of the two workers spends time with the person with dementia. In addition, the MRT provides information about other local respite available and helps to apply for financial assistance for respite. Different respite options are discussed separately by one worker with both the carer and person with dementia and then together as a group. They explain the importance of respite for self-care and the relationship. In many cases, there is reluctance for carers to seek respite, both as a result of lack of knowledge about what is available to them, and feelings of guilt and abandonment of the person with dementia. MRT workers ease the guilt of the carers and support both the carer and person with dementia in accessing respite, which in many cases provides a buffer for the relationship crisis many of the clients find themselves in when they access MRT.

More information about the MRT service is available at: https://nsw.fightdementia.org.au/nsw/research

WINGECARRIBEAN ADULT DAY CENTRES

Wingecarribee Adult Day Centres provide centre-based respite services in Bowral and Moss Vale in the NSW Southern Highlands, and also an outreach service to Hill Top. Operating in a rural location means the service has to have good networks with other local service providers to ensure that the needs of clients are met.

The centre operates six days a week, Monday to Saturday. There are four dementia-specific groups and six other social groups that include clients with dementia. The service is funded by CHSP and clients pay $10 per day to attend.

The service used to provide more outings, but now provides more centre-based activities based on feedback from their clients, who regard the visit to the centre as an outing. Community transport is hired to pick up and drop off clients who are unable to get to the centre.

Activities that the clients enjoy include bingo, craft, music, exercise and relaxation sessions, and meal times – morning tea is donated by local bakeries and lunch is a two course meal. The service reviews the activities provided once per month and conducts yearly surveys to ensure they are meeting the needs of their clients.

All staff have a minimum Certificate III in Aged Care. In the general groups, the staff to resident ratio is 1:6, while for the dementia specific groups it is 1:4. The service has a very low staff turnover which means that there is consistency of staff for clients and good relationships with clients have developed.
MACLEAY HASTINGS MOBILE RESPITE SERVICE

Macleay Hastings Mobile Respite Service is operated by the NSW Mid-North Coast Local Health District and is funded by CHSP. The service uses a brokerage model to provide in-home respite to people with dementia and their carers in the Macleay and Hastings local government areas. About half of their clients pay a voluntary contribution of $20 a month for a weekly service. Due to the low or no cost, clients who experience financial hardship are able to maintain the service for a considerable length of time.

The service is currently operating at capacity with 29 clients receiving services. The brokerage model uses local nursing services, primarily staff who are assistants in nursing with dementia training and experience. The same staff see the same clients each week. Clients generally receive three hours of respite per week.

After an initial assessment, the service is reviewed every three months for the first year to ensure that it is meeting the needs of clients. The average client is aged in their 80s; however, the service does have some clients with younger onset dementia.

Although it is considered ‘in-home’ respite, in practice the service is able to give carers and people with dementia choice in how and where the respite is delivered. For example, they can provide out-of-home respite which involves taking people with dementia into community settings. They can also transport people with dementia to centre-based respite services which enables the carer to have more respite time at home due to not having to travel long distances to access respite.

GLEN OSMOND HOUSE

Glen Osmond House is a day and overnight respite cottage operated by Uniting in the Inner West of Sydney. The service provides respite for carers of people over the age of 65 years, caters for clients with low and high care needs, and operates 24 hours, seven days a week.

Clients decide when they want to come. The service can accommodate up to 14 clients during the day and day-stay clients can stay at the cottage for up to 10 hours. The cottage takes seven clients overnight and they can potentially stay from as short as an overnight visit up to a few weeks. Preference is given to those who book in for a one-two week period.

A registered nurse is present on weekdays from 9am to 5pm and there are two workers rostered on during the day, and one overnight. The service has a low staff turnover and high staff satisfaction. Staff pride themselves on providing individualised support that encourages client choice.
HASTING DISTRICT RESPITE CARE SERVICES

Hasting District Respite Care (HDRC) Services provides centre-based and community participation respite services. The service operates centres in Port Macquarie, Wauchope and Laurieton. The service operates on weekdays, and once per month there is a Saturday respite session. Twenty clients attend the centre per session, with five staff in attendance. The staff strongly believe in being responsive and flexible to meet the needs of clients with dementia and their carers.

HDRC Services use the Montessori approach in supporting people with dementia. The Montessori approach emphasises the importance of keeping the person living with dementia as independent as possible, for as long as possible. Independence is kept through different activities: sensory, social, cognitive, and activities of daily living. All HDRC Services staff and volunteers are trained in developing Montessori environments for clients and tailoring activities and roles to support the individual strengths and abilities of clients.


YASS VALLEY HOME LIVING SUPPORT SERVICE

Yass Valley Home Living Support Service is auspiced by Yass Valley Council and provides in-home, community participation and day centre respite services in the Yass Valley local government area. The service uses consistent staff who work on a casual basis to provide respite to clients with dementia and their carers.

One to one respite is provided in the home or the community. Activities are based on the individual needs of clients and include coffee dates, trips to art galleries and the movies, baking, gardening, shopping and exercise. These meaningful activities mean that both the client and respite worker enjoy the experience and feel connected. The service provides respite at times that suit the person with dementia and carer. This increased flexibility is vital to successful outcomes as in the past they found that providing respite within restricted guidelines was not helpful or valuable to people with dementia and their families.

The service also operates a Friday day club which is centre-based respite to encourage socialisation for people with dementia. Respite is generally provided from 9am to 5pm on weekdays but the service has the flexibility to provide weekend respite if required, for example if the carer has an event to attend, at an additional cost.
KINCARE NRCP 24 HOUR LIVE-IN RESPITE

KinCare receives CHSP funding to provide a 24 hour live-in dementia-specific respite service in the client’s own home. The service operates in the Northern Sydney, Western Sydney and Central West regions of NSW and is able to provide both planned and emergency respite.

A key benefit of the service is that the person with dementia is able to stay in their familiar environment and is still able to access other services that are part of their normal everyday routine. The service also provides consistency of staff for regular clients which fosters positive relationships. It also reduces the stress for the carers leaving the person with dementia at home for respite because they know and trust the worker.

Every client is given an allocation of up to 28 respite days for the financial year. Respite is booked in blocks of 24 hours or longer. KinCare works with each client to understand how they wish to use their respite, timings, planned events and emergencies.

Clients may wish to book an introductory visit with a new worker for a smaller block of time before planning a trip. This ensures the client, carer and informal supports have an opportunity to meet and get to know the worker.

Clients are encouraged to meet two-three different staff to ensure flexibility and responsiveness to their respite needs. This choice is guided by client and carer needs and preferences. All home care workers have Cert III qualifications and dementia experience and are hand-picked for their flexibility, initiative and problem solving skills.

Clients planning longer respite bookings, such as two-four weeks for international trips, are encouraged to trial a two day booking first so KinCare can anticipate and respond to any concerns.

Clients identify their usual routines, including day centre participation, service providers delivering existing supports (e.g. Level four package continues), informal supports, and visits from family and friends. KinCare helps clients to maintain these routines.
THE OLD VICARAGE RESPITE HOUSE – ALZHEIMER’S
AUSTRALIA TASMANIA

The Old Vicarage Respite House is located approximately seven kms from the CBD of Hobart. One of the enduring strengths of the service is its commitment to flexibility and person centred responses which meet the needs of clients, carers and families. This strong ethos enables people living with dementia to remain connected to and included in their communities. The underlying philosophy of respect, understanding and collaboration with clients as individuals allows people living with dementia to make decisions, express choices and have a say in activities and the routines of the Vicarage household. There are 11 staff with minimal turnover. This provides consistency and a wealth of practice knowledge.

There are six rooms in the Old Vicarage and an additional emergency bed. The Vicarage offers flexible respite and actively welcomes partners or family members for respite along with clients. There are twin-share and double rooms that facilitate this option being provided.

During the day, clients in overnight respite join with the day club, which operates six days a week. Regular activities are offered including gardening and creative arts. Carers staying overnight can use this time to go shopping, visit relatives or just relax in the respite house and grounds.

The Vicarage operates Monday through Friday nights and additional nights are available through negotiation with the Respite Manager. It is open for day respite from 7.30am to 4.30pm. Transport can be arranged. Clients are either dropped off at the Vicarage or collected by bus.

All clients have a support plan developed by the staff of AAT and the Vicarage to meet their needs. The Vicarage offers individualised activities which will be further enhanced with the implementation of the Hierarchic Dementia Scale Revised. This focuses on a client’s abilities rather than disabilities.
The importance of integrating a care philosophy and the physical environment

Hawthorn House is mainly funded through HACC and CHSP (previously NRCP), and to a lesser extent NDSP and YOD Key Worker Program funding. This funding enables us to provide a broad range of programs that meet the needs of people with dementia and their carers in the Great Southern region. These services include Day Centre Respite, Overnight Respite, In Home Respite, Social Support groups, Younger Onset Dementia program, a program which focuses on storytelling within our Indigenous Communities, Carer Support Groups, Education and Early Intervention Programs.

Since 2001, Hawthorn House has worked on an innovative model of support to provide effective services in the community that allow people to stay living in their own homes. Using the principles of Eden Alternative, the service has created a home like environment where people who are living with dementia can spend time and feel comfortable. A place where their individual needs are met, but they also have the opportunity to support others, interact with people of all ages (playgroup), look after a favourite animal, and participate in what they choose. As this model has grown, it has incorporated far more than just the people with dementia at its core. A full life involves families and friends, so the carers, families and friends of clients have all become part of daily life at Hawthorn House. Fundamental to the Eden Principles is the empowerment of staff and importance of relationships within the community. Creating this workplace home has resulted in an exceptionally low staff turnover, minimal sickness, and a large number of volunteers.

More information about the Eden Alternative is available at: https://wa.fightdementia.org.au/wa/support-and-services/services-and-programs-we-provide/the-eden-principles

A new dementia specific centre on nine acres opened in 2014. The building demonstrates best practice environment standards which are underpinned by the Eden principles. The plan was further developed following discussions with people living with dementia and their families, staff, volunteers, community members and stakeholders. An Australian theme of a simple rectangular building surrounded by verandas that suits the bush land setting has been built. The designer incorporated ease of access and specific detail that is suited to people living with dementia, including ramped access, wide doorways and hallways, large windows, clearly designated rooms, a safe and friendly kitchen and areas for pottering with favourite activities. The building has been designed to be energy efficient and environmentally friendly. Hawthorn House won the Master Builders Association Award under the category of Building Excellence in November 2014.

Hawthorn House has a beautiful and engaging external environment too. The front of the house has bushland, while the back of the house faces farmland with all sorts of wildlife and farming animals including cows and kangaroos. It has a beautiful outlook with wonderful gardens, chook yard (Chookingham Palace), orchard, raised vegetable gardens, Sadie the dog, and with a large and productive Men's Shed. This means all who visit contribute to the running of the house and can be engaged in a range of activities that appeal to the individual. People with dementia can cook the lunch, plant the vegetables, walk the dog, or have a sleep. During the day at Hawthorn House, volunteers outnumber the staff two to one as it is such a pleasant place to spend time, easing the work of staff, and relieving the constricts of a tight budget. Activities are centred on the house, Men's Shed, craft groups, art group, cooking afternoons, and yarning group with the Aboriginal Noongar Community.
ENGAGING IN MEANINGFUL ACTIVITY

Tom had no insight into his dementia so an invitation to be a volunteer at Hawthorn House was extended to him as a way of connecting him with a social network and activities he enjoys. He makes a great contribution, feels valued, empowered, and part of the community. He makes wonderful wooden toys in the shed, and has a great partnership with their craft group which paints the toys and provides the finishing touches.

Tom now feels part of the community. He works alongside staff and volunteers and contributes in a meaningful way. He has high self-esteem and chooses to come to the shed when he feels good during the week. The flexible approach to service access and delivery means Tom can use the services when he wants and needs to. Tom now accesses overnight respite from another funding source.

INCREASING INDEPENDENCE

Mavis accesses a HACC funded Day Centre and services in the community when required. With a flexible approach in place, she can change services when she or her partner need to. Mavis also accesses overnight respite when required. Mavis has stated ‘If I wasn’t coming to Hawthorn House I would be very bored at home. When I first came I was socially isolated and not able to talk to people. Since attending Hawthorn House my life has changed. I feel so much more confident. I can help other Ladies in the Club. I am able to help in the kitchen when I can. I feel comfortable in helping the staff and volunteers. There is always something going on it is never a boring place to be. I have made so many friends. I feel so good about myself.’

Coming to Hawthorn House has changed Mavis’ life. She no longer uses a walker, her medications have changed, her anxiety has decreased and she is more calm and relaxed. Mavis feels more self-confident and her feeling of self-worth has improved. The flexibility of services has enabled Mavis to stay at home and become more independent.

APPROPRIATE SERVICES TO MEET NEEDS

Bill accesses Hawthorn House services, including Cottage Respite. When he attends Hawthorn House Bill is very settled as he feels part of the community here. He participates in daily activities when he stays such as feeding the chooks, exercising Sadie (the dog), watering the garden and working in the Men’s shed. He helps the overnight staff with meal preparation and dishes in the kitchen. With a high staff ratio Hawthorn House is able to personalise activities and engage people with dementia in their interests.
**YOUNGER ONSET DEMENTIA**

Adam was originally a bit reluctant to have any type of respite but because he was happily attending activities with the YOD Social Group and knew others from the group who attended day and night respite at the Vicarage he was willing to give it a try. Adam’s partner Kelly was starting University and it was important for Adam to have company and support while she was not with him. Through consultation with Adam and Kelly, Vicarage staff were able to develop the following plans and put them in place to benefit both Adam and Kelly.

When Kelly started university, Adam was attending Brainstormers, a Cognitive Stimulation group, in the middle of the day on Wednesdays. Because Kelly had university on that day she could no longer transport Adam to Brainstormers. Flexible respite meant that Adam could come to the Vicarage in the morning, be brought to Brainstormers and then be picked up by Vicarage staff and brought back to the Vicarage when the session was finished.

When Kelly had to go to Melbourne to attend to family business, the Vicarage was able to offer Adam three nights’ accommodation while Kelly had to be away.

Whenever Kelly met with other carers for coffee and support, Adam was able to drop in and spend time at the Vicarage for a few hours.

Adam loved to cook but although he could not cook unsupervised due to safety reasons, he was encouraged to contribute to cooking meals at the Vicarage.

Adam has discovered his inner artist and is very committed to his art and now has his own table and space to keep his art supplies and do his art work.

**FRONTOTEMPORAL DEMENTIA (FTD) EXAMPLE:**

Anne is a regular user of respite services at the Vicarage. She has FTD with aphasia and the staff have worked out how to best meet Anne’s needs with careful listening and support.

Anne attends the Vicarage from Monday through Thursday and this has allowed her partner, David, to attend university. David has stated that the flexible respite that they receive has enabled him to concentrate on his studies. The time he then spends with Anne at home is quality time they both enjoy.

Anne was happy to stay at the Vicarage for a week while David did his university exams. This allowed him to concentrate fully on the exams. David and Anne paid for this additional respite.

David and Anne have a package of support, however, it is so rigidly designed that David hasn’t been able to spend it on the things that really matter to Anne’s quality of life. David has commented that there is an enormous difference in the flexibility offered through the Vicarage and the inability of his package providers to meet his and Anne’s needs.

Spending time with Anne at the Vicarage, it is obvious that Anne is comfortable with both staff and clients. She gets to do all the things she enjoys: socialising, gardening, listening to music and being part of a group.
HOLISTIC SUPPORT

George cares for his wife Joan who has Alzheimer’s disease. Until contact with the MRT, George had not had any respite from his caring role. MRT assisted Bill in filling out Centrelink paperwork to receive financial carers allowance entitlements and for financial assistance for respite, informed him of respite services available in the region, and arranged for Joan to be transported to regular once-a-week respite. He said he wouldn’t have done this on his own and that this respite “relieves” him for the day and enables him to continue to play social bowls.

MONTESSORI IN ACTION

A client with high support needs attends the Hastings District Respite Centre five days a week to provide as much respite as possible for their carer. The client is increasingly requiring one to one support from staff. HDRC Services organised for staff who work well with this particular client to be rostered on with them, and have used the Montessori approach to dementia to find purposeful roles for the client. They have also provided support to the carer to implement the Montessori principles at home. This has helped improve the experience of respite for the client and helped sustain the carer at home.
RECOMMENDED FURTHER READING

If you are interested in knowing more about the policy and social context around the delivery of flexible respite services for people living with dementia, the following papers and resources may be useful:

• Bruen, W. and Howe, A. (2009) Respite Care for People Living with Dementia. “It’s more than just a short break” Discussion Paper 17, Alzheimer’s Australia


• Phillipson, L., Cridland, E. and Cappetta, K. (2016) Understanding the factors that contribute to ‘flexibility’ in the provision of respite for carers of people with dementia: A literature review, prepared for Alzheimer’s Australia for the ‘Making Flexible Respite a Practical Reality’ project funded by the Department of Social Services

• Shanley, C. (2001) Promoting Flexible Respite for People Living with Dementia. An information and resource package, Department of Ageing, Disability and Home Care


ACRONYMS

ACAT - Aged Care Assessment Team
CALD – Culturally and Linguistically Diverse
CDC - Consumer Directed Care
CDRC - Consumer Directed Respite Care
CHSP – Commonwealth Home Support Program
CRCC – Commonwealth Respite and Carelink Centre
FTD – Fronto Temporal Dementia
HACC – Home and Community Care (WA only)
HCP – Home Care Package
HDRC – Hastings District Respite Centre
MRT – Mobile Respite Team
NDIS - National Disability Insurance Scheme
NDSP – National Dementia Services Program
NRCP – National Respite for Carers Program
SALO – Service Access Liaison Officers
YOD – Younger Onset Dementia
Visit the Alzheimer’s Australia website for comprehensive information about dementia, care information, education, training and other services offered by member organisations.

Or for information and advice contact the National Dementia Helpline on

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative.