

health

Supporting people in care relationships

A resource for care providers

Supporting people in care relationships

A resource for service providers

Acknowledgements

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1 What can this booklet do for you?

This booklet summarises innovative ideas to spark further development of new supports for carers in the community. It includes a sample of models of service delivery to generate interest in innovation.

You may want to read or dip into this booklet to:

- improve your knowledge about models of respite and support for carers of older people
- find out how your service might be more innovative, flexible and person-centred
- link to other providers' experience and organisations
- get ideas for future service planning
- get ideas for good practice – a 'go to' place of things that work
- help new staff think about flexibility in service provision and spark their creativity
- find out about the effectiveness of different programs with different groups of people
- get ideas about problem solving and relevant hints and tips
- spark ideas about using funding flexibly; for example, through the Home and Community Care (HACC) Program, Support for Carers Program and Support for Carers of People with Dementia Program.

This booklet is designed for management and staff working in services supporting carers and may assist in applying HACC Active Service Model (ASM) and Well for Life principles. It will also be of interest to staff in peak bodies, students, and workers less directly involved than those 'at the coalface' of supporting care relationships.

This booklet includes a selection of services as examples of innovation in service delivery. It refers to extra resources, including website addresses. The internet sources may enrich your reading and give you other ideas to support people in care relationships. Further sources of information are listed at the end of the booklet. An alphabetical list of programs mentioned in this booklet is also provided at section 9.

2 Needs and how to meet them

There is much evidence that demonstrates being a carer is not good for your health.¹ In fact, carers, many of whom are older people, have poorer physical and mental health than the rest of the population.² Research consistently shows that carers have lower life satisfaction and greater stress than non-carers. Carers have been found to have high rates of anxiety and depression. However, carers contribute enormously to the economic and social welfare of the community, which is why government programs try to support them as much as possible.

Caring is not a static role; in many cases a care recipient's needs grow over time, which places increasing pressure on the carer. Planned and regular respite, with education about things such as coping strategies and supports, can reduce the negative impact of caring. Carers can also benefit from general health promotion programs that aim to keep people healthy.

When carers seek services to help them, research³ has shown that they are often looking for:

- consideration of the carer as an important part of the care recipient's support team
- consideration of the carer as a person in their own right with needs and aspirations in and beyond the care situation
- provision of good quality information to the carer and care recipient
- easy access to services
- good quality service provision
- services flexible and responsive to carer and care recipient needs
- choice about type of service, preferred staff and timing and location of service.

Carers in Victoria are supported by all levels of government and non-government advocacy groups. The Victorian Government funds carer support initiatives including Carers Victoria, the Support for Carers Program in every metropolitan and rural region, and other services such as the Home and Community Care (HACC) program.

Carers Victoria is a statewide peak body representing and providing support to carers in the community <www.carersvictoria.com.au>. See section 8 of this booklet for more contact details.

Examples of other programs⁴ that support carers are:

- Carer Allowance and Carer Payment paid to eligible carers by Centrelink <www.centrelink.gov.au>
- Carers Australia, a national peak body for carers <www.carersaustralia.com.au>
- Commonwealth Respite and Carelink Centres <www.commcarelink.health.gov.au>

This booklet has examples of services that support carers. It explores innovative ways that government and voluntary and private agencies support carers. It is not a comprehensive list of services, or organisations, however, it describes types of services in Victoria and elsewhere. You may be inspired to try activities described here in your own service.

¹ Schulz, R., & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108(9), 23-27

² Dow, B., et al. (2004). *What carers value: review of carer literature and practice*. Victorian Department of Human Services, Victoria.

³ Dow, B., et al. (2004). *What carers value: review of carer literature and practice*. Victorian Department of Human Services, Victoria.

⁴ For more information see www.health.gov.au

The booklet includes programs that:

- attempt an innovative non-traditional approach to fill a gap or need in services in the community
- report on-the-ground success, as described by the steering committee or demonstrated in an evaluation
- are ongoing post-pilot phase
- have been funded under the flexible respite, transition and diverse needs and Well for Life pilot funding from the Victorian Government Department of Health
- have good documentation and training materials.

3 Focusing on wellbeing

Introduction

When carers can explore emotional challenges and better manage stress, loss and grief, they have more energy for their own physical health. As physical, emotional and psychological health are linked, improving one area can have positive effects on others.

Well for Life programs: physical activity, nutrition and emotional wellbeing

The Victorian Government Department of Health ('the department') Well for Life program aims to improve health and wellbeing of older people in supporting care relationships through nutrition, physical activity and emotional wellbeing. For carers, the aim is to boost carer health and wellbeing and their capacity to provide good quality care.⁵

Key idea

Services where carers enjoy physical exercise in the company of other carers have win-win outcomes; there are physical, psychological and social benefits.

⁵ Further information about the Victorian Government Department of Health Well for Life projects supporting care relationships can be found at www.health.vic.gov.au/agedcare

Well for Life projects

Victorian Government Department of Health, in partnership with service providers

Well for Life projects, targeting health and wellbeing of carers and the people they care for, have been provided with one-off funding by the department. Well for Life projects include increasing physical activity, improving nutrition and enhancing emotional wellbeing using a range of different activities. Some projects address emotional wellbeing, including grief and loss, group therapy or anxiety management. Others include information sessions on topics such as financial and legal issues.

Sustainability

Activities from Well for Life projects should continue by being embedded in regular programs. Several programs continue to operate. For example, the highly successful 'Well 4 Life - Northcote cares for carers' program, run by the City of Darebin, allows up to 15 carers to undertake regular weekly physical activities at a local YMCA Aquatic and Recreation Centre and offers respite on site. Another Well for Life program that has continued is the Healthy and Wise support and educational program for carers in the Hume region. The Healthy and Wise program is a partnership of Family Care in Shepparton and Seymour, Uniting Care Goulburn North East in Wangaratta and Upper Murray Family Care in Wodonga. For more detail see page 6.

Warrnambool City Council has obtained funding from the Municipal Association of Victoria (MAV) and Council on the Ageing (COTA) for a two-year Positive Ageing Project. They have built on their Well for Life program and encourage carers to go to various groups, including financial literacy programs and using technology workshops. They use this approach for carers who are more comfortable in a broad community group.

Key benefits

Evidence indicates that Well for Life type programs for carers result in improved health and wellbeing for participants. The most thorough study is the formal evaluation of the Villa Maria Healthy Carers Physical Activity Program, conducted by the National Ageing Research Institute in Melbourne. One hundred and sixteen carers were offered yoga, strength training or tai chi for a six-month period. Respite options were offered to care recipients while carers attended sessions. The study found the program was beneficial for carers' balance, endurance, strength and emotional wellbeing. Most carers reported both enjoying the program and self-perceived benefits, including the opportunity to look after their needs and take a complete break from their care role.

Further information

Aged Care Branch
Victorian Government Department of Health
50 Lonsdale Street
Melbourne Vic 3000
Phone: 1300 650 172
www.health.vic.gov.au/agedcare/maintaining/wellforlife.htm

Healthy and Wise Carers Program – the pilot

Family Care in Shepparton and Seymour, Uniting Care Goulburn North East in Wangaratta and Upper Murray Family Care in Wodonga, Victoria

Purpose

To:

- improve the physical and mental wellbeing of carers of older people through healthy ageing education
- establish specific health and wellbeing goals for each participant
- develop links to ongoing interest or activity groups or respite programs.

How and what

Recruitment was through media articles, fliers and newspaper advertisements, service providers and local community networks, and by approaching known carers. The program consisted of eight three-hour sessions conducted weekly at each site using the same approach. Each session included a talk by a local expert, such as a nutritionist or physiotherapist, and was co-facilitated, usually by a carer support worker. Topics included:

- Deciding to be healthy and wise: introduction
- How to be health wise: physical health and fitness
- Nothing is more certain than change: mental health, managing stress and change
- Mind and body: maintenance of memory and active mind
- The social whirl: importance of social connectedness
- Getting things: legal and financial information
- The meaning of life: grief, loss and bereavement
- The getting of wisdom: final session drawing themes together.

Who

- The 57 participants in four programs were aged 55 years and older and cared for an older person or a person with a disability.
- Most participants (80 per cent) did not need additional respite; in-house respite was arranged on request.
- Most had been a carer for at least five years; 18 per cent used respite weekly, 22 per cent one to two times per month, 55 per cent occasionally, and 5 per cent never.
- Twenty-six per cent attended all sessions, 44 per cent attended six or seven sessions, 19 per cent attended four or five sessions and 11 per cent attended two or three sessions.
- Fifteen per cent had never used support services.

Key benefits

- For ongoing peer support and interaction, all groups formed their own local support groups.
- Carers liked the emphasis on emotional and psychological needs in addition to physical support.
- The gift of a pedometer was especially popular!
- After the program, more than 80 per cent of participants made plans to maintain healthy eating, adequate physical activity and social networks.
- Facilitators working as carer support staff reported personal benefits for carers and staff in using a primary or preventative approach in times of non-crisis.

Carers' comments

'It was wonderful to meet other carers and to hear their stories and know we can ask for help.'

'I don't usually feel comfortable in groups but really enjoyed this one. Thanks for putting on such a valuable program.'

Challenges

- Recruitment of carers who do not see themselves as carers.
- Despite plans, pre-course face-to-face meetings with carers did not always occur; this may have reduced attendances.
- Some people had difficulty attending each week; later programs show spreading sessions over a 12-week period helps maximise attendance.
- Appropriately qualified specialist co-facilitators can be hard to find in rural areas
- Carers' diverse needs; for example, the physical capabilities of 80-year-olds tended to differ considerably from those in their 60s.
- Finding ways to assist carers in more remote rural areas to attend.

Further information

Family Care
Carer Support Services
PO Box 1069
Shepparton Vic 3630
Phone: 03 5823 7000
www.familycare.net.au

Complementary therapies

Some therapies are called complementary or diversional. These include:

- art therapy
- aromatherapy
- horticultural therapy
- laughter therapy
- massage therapy
- music therapy
- pet therapy.

These approaches are being trialled with carers to enhance their wellbeing or provide new skills in their carer role. Growing evidence suggests such approaches can help reduce carer stress levels and behaviours of unmet need of people with cognitive decline.

The Commonwealth Respite and Carelink Centre - CarerLinks North encourages alternative therapy groups, including art and music therapy for carers. External providers organise and run these groups in a brokerage arrangement. Group facilitators are experienced and familiar with carer issues. Finding Your Voice is a music therapy group for female carers.

Finding Your Voice

Commonwealth Respite and Carelink Centre – CarerLinks North, Victoria

Purpose

It was identified at CarerLinks North that the role of carer tends to be provided by women. The impacts on women often include isolation, loss of sense of self, and feelings of resentment, guilt and anger. To address these impacts, a program for women has been developed entitled Finding Your Voice. The aim is to provide a reflective space and experience for female carers to reconnect with their needs and emotional coping mechanisms. This complements other programs of education and information. Following a successful pilot, the program is now offered twice a year.

How and what

The two group facilitators have between them many years experience in facilitating as well as qualifications in counselling, art therapy, music therapy and family therapy. They draw on grief and loss, trauma and systems theories and use psychodrama, relaxation and movement to music. Six three-hour sessions include relaxation, breathing and grounding exercises, opportunities for peer support, art therapy including making felted scarves, creating mandalas and co-writing and creating songs. The songs are about the demands, complexities and highlights of carer experiences. Sessions are relaxed and informal, with discussions about:

- self-care
- grief and loss
- changed lifestyle
- anger, guilt and frustration
- confusion
- isolation
- peer support.

Who

The program includes a maximum of 12 female carers registered at CarerLinks North.

Key benefits

Carers rank the program as very helpful or extremely helpful in undertaking their care role.

Carers' comments

'Before attending group, (I) was always thinking of mother's needs; now (I'm) trying to balance this out and take more time for myself and my husband!'

'I go home more happy, and even though nothing has changed at home, I think back to the group and realise everyone is in the same boat. At least for those few hours I feel like a different person.'

'I do the breathing exercises at home now; they help. Also, I have never spoken to anyone else before about my personal life, except for in this group.'

Challenges

Carer feedback suggests a six-week period is insufficient time for the program: *'The group continuing would make it better; can't do this anywhere else, and I feel very lonely.'*

'...definitely a lot longer, as six weeks is not enough.'

Further information

Commonwealth Respite and Carelink Centre - CarerLinks North
4 Bruce Street
Preston Vic 3072
Phone: 03 9495 2500/1800 059 059
www.merrichs.org.au

The inaugural Finding Your Voice Group, May 2008

Extract from 'The Darker Side of Caring'

Sung to the tune of 'Wooden Heart', with apologies and thanks to Elvis Presley

Can't you see, I'm tired and cranky
Please don't wake me through the night
I'm tired of the fight...
And I don't have the energy for you!

Chorus:

There's no time left in the day for me
And I'm torn between love and fatigue!
All I want is to rest,
And to give you all the best,
But now I need a rest!
I just need someone there for ME!

Key idea

Carers gain from music in many forms – singing, listening, creating.

Creative Ways to Care – strategies for carers of people living with dementia

The Commonwealth Respite and Carelink Centre - Southern Metropolitan Region was funded to develop and run the Creative Ways to Care workshop. The workshop was for carers of people with dementia to experience and learn diversional therapy techniques for behaviours of unmet need.

A positive response to the Creative Ways to Care workshop has led to a new, short program of six sessions, including reminiscence therapy, aromatherapy, music and art therapy. Emphasis is on approaches to care, education about dementia and behaviours of unmet need, and improving quality of life. The Commonwealth Carelink and Respite Centre - Southern Metropolitan Region program has a web page that includes a training package for service providers and three online videos with information about respite services and carers interviewed about their experiences, see www.carersouth.org.au.

Creative Ways to Care strategies for carers of people living with dementia

Commonwealth Respite and Carelink Centre - Southern Metropolitan Region



Purpose

For people with dementia, the accessible world shrinks as memory and functional abilities decline. Changes in personality and behaviour are common. Family members and friends may find it increasingly difficult to know how to respond and relate to a person with dementia. Carers advised to redirect the behaviour into meaningful activity often lack the knowledge, energy or resources to do this.

How and what

Creative Ways to Care is an education and training program for family carers. Carers build knowledge, skills, resources and confidence to live positively with dementia.

The program promotes a person-centred, problem-solving approach for:

- purpose; to prevent or respond to behaviours of unmet need or assist with a task
- pleasure; to increase enjoyment and quality of life for both the carer and the person for whom they care.

Developed with services and diversional therapists expert in their field, Creative Ways to Care sessions include:

- dementia behaviour and activities
- reminiscence
- stimulating and soothing the senses
- music
- creative arts
- review session.

The program focuses on learning by doing activities. Carers practise techniques and ideas in a training environment. Competence and familiarity with strategies build confidence and increase the likelihood that carers will use the strategies.

Carers receive resources to help them apply their learning at home. Each session has handouts on key issues, tips for using the strategy, step-by-step instructions, frequently asked questions and other tools.

Carers are encouraged to build a strategies diary and record the success of individual strategies they have tried; this helps them use a problem-solving approach to dementia care. Carers build a grab-bag of resources about how to use strategies in ways meaningful to the individual. Carers add to their grab-bag each week. By the end of the program they have many ideas and resources tailored to the person for whom they are caring, that they can grab when needed, and quickly and easily use.

The program can be run by health professionals who support family carers of people with dementia. Training resources are available free of charge through the Commonwealth Respite and Carelink Centre - Southern Metropolitan Region, and include a facilitator's guide, training manual and DVD.

Key benefits

Creative Ways to Care:

- may prevent or reduce behaviours of unmet need, and stress for carers and people with dementia
- helps carers and others connect, engage and have fun with the person with dementia through sharing meaningful experiences
- may increase physical, cognitive and sensory stimulation of people with dementia
- builds on strengths and enhances self-esteem of people with dementia and their carers
- improves quality of life of carers and people with dementia
- has learnings that can be sustained over time; method and approach taught can continue as dementia progresses
- could be modified for paid care workers.

Challenges

These include supporting carers to attend over six sessions; respite costs can be high.

Further information

Commonwealth Respite and Carelink Centre - Southern Metropolitan Region

Site offices are located at Caulfield, Dandenong, Frankston and Sandringham

Phone: 1800 052 222

www.carersouth.org.au

Key idea

Carers are interested in information about specific skills relevant to their own care experience.

Carer retreats

Carer retreats give carers an opportunity to meet other carers, usually in a holiday-like location. Programs range from separate experiences and accommodation for carers and care recipients, to a mixture of shared and non-shared experiences, to joint attendance with the carer and care recipient. Benefits for carers can include improved mood and wellbeing, reduced isolation, opportunities to interact with other carers and to focus on their needs. Carer retreats are a less formal and often more cost-effective approach to extended respite for carers than traditional respite, such as respite beds in residential aged care facilities. They may also help engage reluctant carers and care recipients to enjoy benefits of planned respite.

Many peak bodies and service providers offer carer retreats. As part of the supports offered by Commonwealth Respite and Carelink Centres, retreats may be a consideration. Carers should enquire with the local centre about the availability of retreats. For example, the One Night Stay program is coordinated by Barwon South West Flexible Respite Service, Alzheimer's Australia Vic (AAV) and St Laurence Community Services, originally developed as part of a Victorian Government Department of Human Services-funded flexible respite pilot project. This program has a 24-hour overnight break for carers and care recipients and includes education about respite options and an informal dinner where carers meet with other carers in a similar situation. One Night Stay can introduce carers and care recipients to respite.

Another example is the Getaway Program coordinated by the Carers Victoria, Respite Connections Program in the western regions of Melbourne.

Getaways

Carers Victoria Respite Connections and Care with Quality

Purpose

To:

- give a two-night, three-day break to carers and care recipients with dementia
- encourage respite use to support care relationships
- offer a respite experience for carers reluctant to use traditional forms of respite; for example, programs for culturally and linguistically diverse groups
- bring a small group of people from similar backgrounds together, with opportunities to bond and develop friendships while learning about respite support options.

How and what

- The Getaway Program is funded by Carers Victoria Respite Connections with a small contribution per participant.
- Getaways are offered within a short driving distance from Melbourne; for example, Daylesford or Philip Island.
- The funded direct care agency, Care with Quality, does home assessments on participant support needs and ability to participate.
- Care with Quality provides two respite workers and arranges accommodation, transport and getaway experiences; for example, visits to local attractions.
- The Looking After Yourself carer-specific education workshop is delivered by Carers Victoria and explores carer reluctance to have breaks and take care of their health and wellbeing.

Who

Carers Victoria Respite Connections Carer Support Workers identify and refer six carers to each Getaway Program. These carers:

- care for a person 65 years and older with dementia
- live in the western metropolitan area of Melbourne
- may be reluctant to separate from the person for whom they care
- have needs not met by traditional forms of respite
- need a short break.

Outcomes and evaluation

Evaluation forms are posted to carers after the Getaway Program. Carers Victoria Respite Connections receives completed evaluations and liaises with Care with Quality about feedback.

Carers' comments

'We all share something in common; it's a stressful life to look after a loved one.'

'Being able to be with other couples who are experiencing the same problems was useful.'

'I am more confident in what I am doing and how I am achieving things'.

'I feel like I have had a holiday.'

Challenges

- Carers may be reluctant to use Getaways during cold weather
- Due to the high demands of a carer's role and responsibilities, carers sometimes cancel on the day or the day before the retreat.

Culturally specific groups need:

- access to interpreters for initial home assessment
- access to appropriately qualified bilingual staff for coordinating groups and education sessions, and interpreting the educational workshop
- bilingual flyers, information handouts and evaluation forms.

Further information

Carers Victoria Respite Connections
Level 1, 37 Albert Street
Footscray Vic 3011
Phone: 03 9396 9550
www.carersvictoria.org.au

Key idea

Getting away from the usual care setting can be of great benefit. Socialising with other carers can provide extra feelings of support.

Support programs for carers and care recipients together

Several service providers and peak bodies have programs for both carers and care recipients in a shared experience. Some respite and carers' programs offer shared experience as part of the overall service. For example, community respite houses (see section 6) or day centres, such as Yanada House, may have joint education sessions. Some events invite both carer and care recipient and some retreats have opportunities for joint and separate experiences.

Alzheimer's Australia Vic (AAV) sessions for carers and care recipients together enable people to engage with others. This may be particularly important when a care recipient can still participate in a group and may have limited time or capacity to engage in a meaningful way with their partner or family carer. AAV is funded to provide two major programs for both carers and care recipients: Living with Memory Loss groups and Memory Lane Cafés. The 14-hour Living with Memory Loss program has group-based information and support on issues and emotions surrounding diagnosis. Memory Lane Cafés have provided an opportunity for people who have attended Living with Memory Loss groups to continue to meet, share experiences and receive information and support on an ongoing basis; an evaluation of Memory Lane Cafés has led to others now being able to attend the cafés.

A number of organisations have adopted an informal café approach with non-threatening, supportive opportunities for carers and care recipients to get together.

Key idea

When it is hard to separate carer and care recipient, activities together can still provide a break for them from isolation.

The café setting

Purpose

Café settings are an informal environment for carers and care recipients to meet and get peer support from other carers and care recipients. Service providers offer education or information in a non-threatening way on relevant community services for carers and care recipients.

How and what

Whistle Stop Café is an informal community café coordinated by Eastern Access Community Health and funded by the Australian Government Department of Health and Ageing. The café is held at the Yarra Sport and Recreational Centre. Run by volunteers, the café is for older isolated people, people with memory loss, and people with other health concerns. Café activities include: exercise, board games, chatting with old and new friends, weekly visits by Yarra Junction Primary School students, and socialising with those using the sport and recreational facilities. The café operates mornings, Monday to Friday.

Alzheimer's Australia Vic (AAV) cafés encourage carers and care recipients to develop social relationships and get counselling and education. There are eight cafés at each of three venues each year. They run for about two hours and include an afternoon tea. New café style support services are being trialled by the Victorian Government Department of Health, Aged Care Branch.

Key benefits

Cafés offer:

- links to community resources and support services
- a social venue for people with dementia, older people who are socially isolated, older people with other health concerns and their carers, where behavioural symptoms of dementia or other unusual personality features are accepted and tolerated
- information and education about health concerns, dementia and related issues, with an entertainer or speaker of interest
- sometimes informal advice and consultation with counselling staff.

Further information

Eastern Access Community Health

46 Warrandyte Road

Ringwood Vic 3134

Phone: 03 9871 1800

www.each.com.au

Alzheimer's Australia Vic

98-104 Riversdale Road

Hawthorn Vic 3122

Phone: 1800 100 500

www.alzheimers.org.au

Victorian Government Department of Health

Phone: 1300 650 172

www.health.vic.gov.au/agedcare

Conferences and consumer participation opportunities

Organisations, including government departments, Carers Australia, Australian Council on the Ageing (COTA), Alzheimer's Australia, and specific research centres, such as the Dementia Collaborative Research Centres, promote engagement of carers and people they care for in forums, conferences, advisory and focus groups. For example, people with dementia and their carers have participated in presentations at the National Dementia Research Forum 2008, Alzheimer's Biennial National Conference 2008, the 2009 Participate in Health Conference, and the 2010 International Federation on Ageing (IFA) Conference.

Such opportunities can help carers and care recipients learn more about a disease or illness as well as developments in research and service provision. They may enable direct input and participation in future planning and decision-making about health and community services and research directions. Participating may be an important and meaningful way for carers and care recipients to be involved with the broader community and improve future care service provision, while having a shared experience.

Key idea

Some people in care relationships can be empowered through appearances at public meetings.

4 Supporting different communities

Introduction

A challenge in forming a successful interest group is attracting participants. Often carers, at least in the early stages of their role, do not see themselves as carers. Some carers may be less likely to participate as they may feel they are a lot younger or physically stronger than others. Some may have language or cultural differences. Male care recipients or carers can be harder to engage than females in health and community care initiatives, partly because of the perceived feminine nature of initiatives (for example therapy) and because some men are reluctant to try new experiences outside their home or usual routine. In some cases it may be more appropriate for carers to attend 'non-carer' groups meeting their specific needs, such as groups designed for men, culturally and linguistically diverse people, or Aboriginal people.

Aboriginal people

Mainstream organisations' respite services may not be culturally appropriate or have the flexibility to meet Aboriginal⁶ communities' respite needs. The concept of respite may have a different meaning for Aboriginal communities; for example, mainstream models of home respite may not suit the needs of Aboriginal people from a cultural perspective. Aboriginal people refer to 'family' rather than 'carers'; there may be a number of family members who have the care role. Respite for Aboriginal families may mean the whole family has respite together.

In 2008, the Department of Human Services, in consultation with the Home and Community Care (HACC) Aboriginal sector, developed the Strengthening Home and Community Care in Aboriginal Communities strategy.⁷ A common respite approach for the Aboriginal community is that the family and care recipient go on a holiday together. Aboriginal families generally are less likely to want to be separated from the person requiring care.

The strategy objectives are to strengthen the capacity of Aboriginal Community Controlled Organisations (ACCOs) to deliver HACC services most important to their communities, and work with mainstream organisations to improve access to the range of services for their communities.

The strategy aims to:

- improve use of a wide range of services for HACC-eligible Aboriginal people
- strengthen HACC service responses from mainstream organisations to Aboriginal communities
- support sustainable HACC service delivery by Aboriginal organisations to Aboriginal communities.

Respite services for Aboriginal communities

Some ACCOs have funding for respite services for Aboriginal communities, for example the Indigenous Respite Program (IRP), Rumbalara Aboriginal Co-operative Ltd.

⁶ In this document 'Aboriginal' refers to people who identify as Aboriginal or Torres Strait Islander, or as both Aboriginal and Torres Strait Islander.

⁷ www.health.vic.gov.au/hacc

Indigenous Respite Program (IRP)

Rumbalara Aboriginal Co-operative Ltd

Purpose

Rumbalara Aboriginal Co-operative Ltd has culturally safe, flexible respite services for Aboriginal carers and care recipients to support healthy ageing, enhance their quality of life and enable them to live at home for as long as possible. Culturally appropriate strategies support individual spiritual, financial, social, emotional, environmental, medical and physical independence and safety. For those with complex health care needs, such as diabetes, renal disease and cardiac disease, the Indigenous Respite Program (IRP) organises services and supports for carers and care recipients, enabling people to live at home for as long as possible. The ability to remain at home and in their familiar Aboriginal community is a priority for Aboriginal people.

How and what

IRP is an Aboriginal-specific approach to direct and indirect respite services to meet the needs of carers and care recipients in a friendly and informal way. The program respects cultural relationships and beliefs, and connection to land, community and family, and with family members interstate, in isolated rural areas and in family kinship networks.

Direct respite care services include residential aged care, overnight community respite houses, centre-based care, community outings, and daytime and overnight respite care at home. Indirect respite care includes home care, personal care, and drop-in or tuck-in services. Flexible options include allied health assessments, transport assistance (for example, for respite with other family members and overnight accommodation), meals provision, systems for medication management, property and garden maintenance, and other flexible services supporting a break from care routines, such as providing art and craft supplies.

Who

The IRP in the Hume and Loddon Mallee areas is for carers of older people, over 50 years old, who have limited finances and live in rural and remote areas. The carer or care recipient must be of Aboriginal background. Aboriginal people often opt to go without services rather than try mainstream options; they may feel ashamed and uncomfortable because ways of accessing mainstream services are often seen as intrusive and culturally disrespectful.

Key benefits

IRP is sensitive to the needs of Aboriginal people including those with dementia and/or behaviours of unmet need. IRP has safe and familiar environments and routines, maintaining or resuming past activities and interests, acknowledging the cultural and spiritual importance of funerals, and respecting individual cultural backgrounds and life experiences.

Carers and people being cared for can maintain relationships with family members interstate, in isolated areas and in institutional care, and homelessness has been avoided.

Further information

Rumbalara Aboriginal Cooperative Ltd
PO Box 614
Mooroopna Vic 3629
Phone: 03 5825 2111
www.raclimited.com.au

Other providers have trialled improving and developing programs for people from Aboriginal backgrounds. Bendigo Health, with their local carer support services, trialled a carer respite program in Echuca. This pilot project involved community consultation by an experienced carer support worker from the Aboriginal community. The pilot identified key issues for the local population, such as inclusive services with group-based experiences for the range of people involved in care. Different viewpoints in the community were incorporated, a program of care implemented, and an annual holiday respite program organised for carers. The holiday respite program is now run by the local Aboriginal co-operative. Bendigo Health has used learnings to inform initiative development for other local communities.

Aboriginal and CALD respite initiatives

Phone 03 5454 7719

www.bendigohealth.org.au

People of culturally and linguistically diverse backgrounds

It has been difficult to attract and retain carers of culturally and linguistically diverse (CALD) backgrounds in respite and carer support programs. Carers may have difficulty getting information about services if no help with translation is available (Neidzweiki & Pierce, 2003). There may be issues of cultural perception about care recipient frailty or illness, such as a different understanding of dementia and acceptability of services outside the family or cultural group. Referrals from some cultural groups such as those from Asian or Eastern European backgrounds are low. Alzheimer's Australia Vic (AAV) has outlined differences in perception of dementia across ethnic groups to help services bridge cultural gaps in understanding dementia.⁸

Service providers aim to raise understanding and awareness of dementia, including seeking help and information on services. The South East Dementia Action Group of five service providers in the south eastern region of Melbourne has coordinated Tastes to Remember multicultural feasts. These feasts are attended by mixed groups from local Vietnamese, Greek, Filipino, Hungarian, Cambodian, Spanish, Polish, Chinese, Russian, Tamil, Indian, Afghan, Arabic, Turkish, Bosnian, Italian and Dutch communities. Given the success of these occasions other regional groups across Victoria have adopted this model.

Approaches to service delivery have been trialled to more successfully attract and meet the needs of CALD groups. For instance, Bendigo Health identified several post-war immigrant groups in their catchment. The largest of these is of Italian background. They speak little English and have few links to the respite system.

As part of an innovative Victorian Government Department of Health pilot respite project, a bilingual member of staff was used to recruit Italian carers and Italian-speaking care recipients for a group program in Swan Hill. These groups have expanded and are ongoing as part of the Home and Community Care (HACC) program.

Yanada House in Northcote, run by Darebin City Council, is another example of a successful multicultural service. Several staff at the day centre are bilingual, giving the centre capacity to have culturally appropriate services for people of Greek and Italian backgrounds. Planned activity groups, respite programs, retreats and information sessions are coordinated from the centre. A particularly successful program is the Men's Out and About group. This group is similar to the MATES program, highlighted later, and involves eight men of Greek or Italian origin going to gym, swimming or sharing meals.

Another successful program is the Chinese and Afghan Lifelong Movers Program, outlined here.

⁸ Alzheimer's Australia, 2008; see www.alzheimers.org.au/content.cfm?infopageid=5338

Chinese and Afghan Lifelong Movers Program

Southern Health – Bunurong Community Care, Action on Disability within Ethnic Communities (ADEC), Endeavour Hills YMCA, and Alzheimer’s Australia Vic.

Purpose

To:

- have culturally specific respite for Chinese and Afghan care recipients
- focus on improving physical, social and emotional wellbeing
- help carers find out about and use other respite services.

How and what

- Eleven care recipients of Afghan background and 12 of Chinese background were identified with the help of Action on Disability within Ethnic Communities (ADEC) support workers and the multicultural officer from Alzheimer’s Australia Vic (AAV).
- Participants were picked up from their homes by taxi and driven to the Endeavour Hills YMCA gym.
- Care recipients had a one-hour group program with a personal trainer.
- There were 120 exercise sessions for: 40 Chinese, 40 male Afghan and 40 female Afghan people.
- After the session, participants enjoyed light, healthy refreshments and socialising.
- Carers attended ADEC carer support groups, with information sessions coordinated by AAV on carer support. These included a session on age-related memory change, dementia, communication with a person with dementia, life experiences for people with dementia, nutrition and appropriate eating, and strategies to manage behaviours of unmet need.

Key benefits

- All 14 carers felt the person they were caring for had improved health after participating in the exercise program.
- Eleven of 14 carers felt the program gave them 'time out' and a better understanding of dementia.

Carers' comments

'My mum is happy and refreshed.'

'He doesn't feel as tired any longer.'

Challenges

- Carers from an Afghan background may confuse symptoms of depression with dementia; providing an all-inclusive aged program not restricted to people with a formal diagnosis of dementia meant a larger number of care recipients from the target group could participate.
- Gender-specific exercise programs increased participation of Afghan people.

Further information

Southern Health – Bunurong Community Care
4th floor, 229 Thomas Street
Dandenong Vic 3175
Phone: 03 8792 2207
www.southernhealth.org.au

Key idea

Being with people of similar background can help prevent feelings of isolation.

Housebound and geographically isolated people

Some carers find it difficult to get to traditional support services outside their home. Some live in isolated areas with limited transport options or have poor mobility. Some carers become reluctant to leave home once their care recipient needs more support. Carers and the people they care for can be embarrassed or less well-tolerated in public places when help with continence is needed or different behaviours are exhibited.

Traditional telephone-based counselling and support services include the Carers Victoria Counselling and Advisory Service and the Alzheimer's Australia Vic (AAV) Telesupport and Telephone Outreach Program. Internet technology can support isolated and housebound carers without them leaving home. The internet has an advantage over older technology such as telephone contact as it is available 24 hours a day, can support group interactions and allows social anonymity. Internet-based support groups for older carers are relatively rare, with exceptions such as the Dementia Care Australia website <www.dementiacareaustralia.com>. Many people older than 55 years are unfamiliar with internet use. People in regional and remote areas continue to use home computers and the internet at a lower rate than people in major cities (Australian Bureau of Statistics, 2004).

Studies in the United States and Europe have investigated training older people to use computer systems for support. These have included customised computer systems in people's homes. Computer systems have been set up for older people with arthritis and visual impairment, using technology more familiar to older people such as a television screen instead of a monitor, and a remote control instead of a mouse. Findings show benefits for carers, including new ways to communicate. In Australia, the National Ageing Research Institute (NARI) has studied use of internet technology that does not need special equipment to link older carers (NARI, 2006). An overview of the study follows.

Key idea

The internet can help isolated carers. It can provide specific help for depression and anxiety. Carers can benefit from websites such as <www.moodgym.anu.edu.au>.

Rural Carers Online: a feasibility study

National Ageing Research Institute, with help of Infoxchange, Carers Choice and Beyondblue

Purpose

To investigate:

- if information technology can reduce depressive symptoms and social isolation for older carers in a rural area
- if information technology can help older, rural carers link to other carers, carer support services and primary and specialist health services
- whether a larger more robust study is feasible.

How and what

- Carers from the Pyrenees area, about 150km north-west of Melbourne, were recruited via local newspaper advertisements and information handouts to known carers using Carers Choice home care.
- Promotional material asked for carers aged 65 years and over who did not have a computer and were interested in being involved in a study about using computers.
- Baseline assessment was in the carer's home, including assessment of social isolation, extent of carer burden and confidence in computer use.
- Carers received a recycled personal desktop computer with a new 56k modem, including an internet connection with six months of unlimited time and download.
- Two groups of seven carers had weekly three-hour computer training sessions over four weeks. The computer training at beginner level focused on basic computer skills, including sending emails and internet use.
- About four months after the baseline assessment, measures were repeated by researchers in the carer's home.
- All 14 carers were invited to give feedback at a focus group discussion.

Key benefits

- All intended to continue using their computers after the study.
- Depressive symptoms among carers were reduced.
- A larger more robust study was found to be feasible.

Using the Internet and email:

- helped intergeneration connection, including support from younger family members in learning about emails and internet
- provided a cost-effective way of communicating with family members living interstate or internationally, compared with long-distance telephone calls
- assisted with community building and bringing friends closer together
- boosted the confidence of carers about using a computer and learning new skills generally
- gave carers confidence they would still be able to stay in touch if they became less mobile in the future.

Carers' comments

'I always thought that I'd like to know about computers but the idea terrified me...Using a computer is terrific. If I want to know something I can look it up and I also use it to email the grandchildren.'

'I had a computer but I wasn't coping very well with it....I was frightened of touching things in case I wiped all of the data... I think it's going to be a great help to me because I've got a lot of interests, outside interests and it'll help me keep in touch with a lot of people.'

'I think that with where I am now it's more of a prevention thing as to what may happen later on. Because tomorrow is another day and there is a degree of unknown as our life will change.'

Challenges

- Too much use of the computer by some family members may reduce social interaction and outings.
- Some carers reported they did not have much time to use the computer.

Further information

National Ageing Research Institute
34-54 Poplar Road
Parkville Vic 3054
Phone: 03 8387 2305
Website: www.nari.unimelb.edu.au

Women

Women are generally easier to recruit into traditional carer support services than men, being more willing to seek social support from peers and mentors. Female carers tend to respond to support services in a different way than male carers. Many service providers are aware of different gender preferences and responses to support programs. For instance, Commonwealth Respite and Carelink Centre - CarerLinks North coordinates and organises separate support programs for male and female carers. They have a music and art therapy group for women, Finding your Voice (outlined in section 3), and traditional education and information sessions for their male carer support group.

Some groups of women are reluctant to use health and community services. Barwon Health Carer Respite and Carelink Services seeks to address the reluctance of women with early dementia to attend respite services. This group is least likely to attend traditional respite, including their one-night stay program, as they are often still managing at home to some extent, even though their partner and carer may be desperate for respite. Two morning groups are held for women who have attended Alzheimer's Australia Vic Memory Lane Cafés. A local service provider, Best of Care, has care and support workers. The groups appear to be highly successful and male carers have opportunities to meet while their partners attend the groups.

Men

Men can be difficult to engage in health and community services. Older men face issues with significant change, including health, retirement, isolation, disability and separation as older carers and care recipients.

Different approaches are used to try to engage men, such as community-run men's sheds. Located in shed or workshop-type spaces in community settings, sheds offer opportunities for regular hands-on experiences by groups mainly, and deliberately, comprised of men. They offer friendship and a sense of belonging through informal life experiences with other men. Men's sheds achieve positive health, happiness and wellbeing outcomes for participants and their carers, families and communities. Nevertheless, there are challenges in meeting initial costs, regulations and complexities of establishing a safe working environment, and getting funding for coordination and supervision of participants (Golding, Brown, Foley, Harvey & Gleeson, 2007).

Initiatives include the Reluctant Male Respite Users Group in Heathcote, coordinated by the carer support services at Bendigo Health, and the Base Camp program coordinated by Villa Maria. These successful programs with proven sustainability aim to engage men reluctant to use respite. In the Heathcote group, a local Neighbourhood House was used, well-resourced in equipment and space; ten men involved in the program determined their own activities and other men became involved as volunteers. Female family carers enjoyed the respite and friendships resulting from the group. Flexible respite approaches continue from the partnerships developed in the program, see <www.bendigohealth.org.au>.

Another highly successful and sustainable initiative focusing on outings rather than a shed location is MATES: Men's Adventures to Exciting Sites, for socially isolated, rurally based men. See the following overview.

MATES: Men's adventures to exciting sites – the pilot

Latrobe Community Health Service

Purpose

To:

- provide an outing-based program for male care recipients, often with dementia and other conditions
- attract isolated and rurally based men not usually interested in participating in life outside home and regular routines
- include men who need help with socialising and getting to events
- encourage men to identify where they would go and what they would do.

How and what

- Care recipients were identified by two community health services and a regional hospital.
- Carers were contacted by the Commonwealth Carer Respite Centre and were given information about respite options.
- Monthly outings over a six-month period were chosen by the men, including fishing trips, visits to a model railway and maritime museum.
- A total of 19 care recipients and 19 carers were involved in the project.

Key benefits

- Carers, all female partners, received a break and were introduced to activities and services in a positive non-threatening way.
- Care recipients regularly attended outings where previously they had been reluctant to leave home.
- Care recipients made friendships in the group.

Sustainability

New programs have been developed in other areas of the region.

Further information

MATES Gippsland Southern Health Service

Phone: 03 5654 2791

MATES

Bass Coast Regional Health

Phone: 03 5671 3343

Men on the Move

Bass Coast Community Health Services

Ph: 03 5678 5388

Carers in paid employment

Family carers of older people may find it difficult to use traditional support services while holding down a paid job. Government departments and service providers are beginning to recognise this. For instance, Baptistcare in the eastern and bayside regions of Melbourne has a program, Flexible Respite for Employed Carers, see <www.baptcare.org.au>

Respite is offered seven days a week between 6am and 8pm at two locations, enabling a carer to get day care for the care recipient while the carer goes to work. Baptistcare offers personal home care and opportunities for carers and care recipients to be involved in centre-and community-based activities.

Best of Care in Geelong, Bellarine and the Surfcoast offers a Career Angels program, see <www.bestofcarebarwon.com.au>.

This service has before and after hours day centre respite, in-home care at irregular times when there is no other respite (for example nights and weekends), and scheduled outings around working hours.

Carers Victoria has released a DVD, 'Supporting Working Carers', explaining services in the community for working carers, see <www.carersvic.org.au>.

Key idea

A focussed activity away from caring can be a break in itself for carers.

5 Encouraging service use

Introduction

For various reasons, some people do not access services that could support them. For example, they may be socially isolated or reluctant to use services.

Social networks are important for the wellbeing of individuals and families, creating and maintaining social cohesion and a sense of community. Social networks promote feelings of wellbeing. They give people a sense of predictability, stability and norms for behaviour and encourage feelings of self-worth and belonging.

Carers may benefit from encouragement and help to develop support networks from people who understand the challenges carers face. Some carers may become isolated because families and friends are reluctant to accept or deal with illness or difficulties the care recipient is experiencing. Others may find it difficult to attend social events due to embarrassment or concern about actions of the care recipient. If a carer becomes socially isolated they may feel a lack of support and greater sense of carer burden. The quality of care they provide may decline. Many group programs help develop new peer relationships and support networks for carers and care recipients; for example, informal café groups.

Careful planning is needed as carers may be unable to participate in a program without respite services. Some carers are reluctant to use respite. Organising respite can be emotionally challenging, and carers' feelings about organising respite, such as their fears or anxieties, may not be acknowledged or addressed. Carers may be reluctant to use services for other reasons, including cultural appropriateness and whether services fit in with their hours of employment.

Some carers cancel scheduled respite at the last minute because they have worries about using respite that they have been unable to discuss.

This section outlines ways of encouraging service use, through supporting isolated people and reluctant service users.

Education and training

Carers Victoria has a free counselling and advisory service and workshops for carers to address worries about using respite services. For example, the Respite Without Tears course helps carers explore respite, from informal breaks to formal residential options. It discusses stepping up to levels of respite to reduce the anxiety of leaving the person they care for in someone else's care, whether for an hour or a couple of weeks.

Alzheimer's Australia Vic (AAV) has free education programs for carers. Programs include information on navigating the service system and respite services. Limited respite can be provided for carers attending long programs. Carers of people with dementia are encouraged to use their regular respite service for consistency.

Education workshops and programs can increase uptake in respite services, as carers understand better the impact on them of not seeking respite. Carers can also receive peer acceptance to use respite, particularly important for some carers from culturally diverse backgrounds.

Carer-oriented groups can be:

- about carer physical and mental wellbeing using traditional and alternative approaches
- camps and conferences
- combined groups for carers and care recipients
- new approaches to interest groups, which may be attractive to people who do not see themselves as carers.

Carers Victoria has workshops on how to establish and maintain successful carer support groups, and follow-up support.⁹

Some care recipients live alone, without a full-time family carer. They may be supported by one or more adult children who visit on a part-time basis. Alternatively their closest family member, for example, their partner, may also have an illness or disability, and the couple may act as carers for each other. In these cases people may need help to maintain their social and care relationships and support their independence for as long as possible.

Case manager-led individualised approaches

Some older people avoid mainstream experiences due to stigma about their illness, and the difficulty others have understanding and accepting some behaviours. In individualised approaches, a case manager assists people, especially older people with dementia, psychiatric illness or longstanding homelessness, to build social networks. Case managers are health professionals who design a goal-focused program for individuals. The case manager:

- builds trust
- does a psychosocial assessment
- reviews a person's interests
- introduces appropriate local activity options to the person
- provides ongoing support for a person to attend an activity
- withdraws support when the person feels comfortable participating in an activity.

Program examples include the Community Care Socialisation program coordinated by the Brotherhood of St Laurence (Hillier, 2007; www.bsl.org.au) and the Southern Psychogeriatric Activity Service (SPAS) by Central Bayside Community Health Service. SPAS has received the Gold Australia and New Zealand Mental Health Service Achievement Award in the psychogeriatric category.

⁹ See also the National Carer Counselling Program services – www.carersaustralia.com.au

Southern Psychogeriatric Activity Service (SPAS)

Central Bayside Community Health Service

Purpose

To:

- support the unmet needs of older people with psychiatric illness or cognitive impairment to maintain psychosocial networks in the community
- improve emotional wellbeing
- protect against development of a psychiatric disorder or relapse in older people.

How and what

- SPAS has four case managers with allied health qualifications such as occupational therapy, social work or psychiatric nursing. Three are in southern and bayside metropolitan areas and one is for people in supported residential services, rooming houses and private hotels.
- Each case manager works with a person and undertakes comprehensive psychosocial assessments over about three visits for less complex issues through to six or more for complex psychiatric issues.
- Assessment focuses on a person's interests and the SPAS staff member suggests local activity options and supports the person to attend an activity until they feel comfortable and independent.
- SPAS works closely with family carers.
- SPAS provides support, education and consultation to local activity services.
- SPAS links aged care, aged people's mental health and local activity services.

Who

- People are referred to SPAS by aged care assessment teams, mental health services and other acute health, specialist clinics and rehabilitation centres for older people.
- All people referred to SPAS are 60 years or older, with over 50 per cent older than 70 years.
- About 60 per cent of people have a psychiatric illness such as depression, schizophrenia, alcohol abuse or personality disorder, and 24 per cent have an organic diagnosis such as dementia.

Key benefits

- In a nine-month demonstration project about 45 per cent of people were involved in an ongoing activity.
- Much qualitative evidence, including case studies, shows ongoing benefits and improvements in emotional wellbeing and mental health for people involved in community experiences.

Challenges

- Despite intensive assessment and encouragement some people do not use mainstream community activities.
- Some people suitable for the program are currently ineligible. For example, people under 65 years who have early onset dementia may benefit from SPAS.
- The SPAS model may be considered resource-intensive; qualified allied health staff are needed for flexible, comprehensive psychosocial assessments.

Further information

Central Bayside Community Health Service
335 Nepean Hwy
Parkdale Vic 3195
Phone: 03 8587 0200
www.cbchs.org.au

Key idea

Some people need extra encouragement to use community supports and stay connected in their community.

How volunteers can help

Many local councils have befriending or social support services for older people to reduce loneliness and improve emotional wellbeing. These services can involve encouraging people to participate in council-led activities and providing a volunteer as a friend. Befriending services can increase the overall confidence and wellbeing of an older person, improve social networks, offer advocacy and support for families and help people stay at home.

Social rehabilitation programs are mainly staffed by volunteers with coordination by a qualified case manager, and use a time-limited, task-oriented model of service. Social rehabilitation programs are being piloted in Australia by the Silver Chain service in Western Australia, see <www.silverchain.org.au>.

Activities range from helping with shopping and attendance at social venues to more specialist tasks such as computing, cooking and gardening. Outcomes for people include greater confidence and opportunities for social contact, reduced mental health problems such as depression and anxiety, opportunities to take up old interests or relationships or find new ones, and ways to regain personal confidence and social identity.

Homeshare, run by Wesley Mission in Melbourne, supports older people to live independent lives within their homes and communities. The program matches older people and Victorians with a disability with younger people. Victorians who need help with household tasks are matched with younger people looking for accommodation in a friendly home environment. The program particularly suits isolated older people interested in sharing their home with a mature, responsible and friendly young person. The program helps break down cultural and generational barriers, with many successful matches involving mature, young international students. Homeshare coordinators draw up and negotiate agreements detailing the arrangements for living together, including specific tasks, and sharing or managing living costs. The coordinators also provide ongoing support during a person's stay.

Key idea

Volunteer programs can increase resources and involve more community members in supporting people in care relationships, and people living alone.

Other ideas out of the box

Coupons for carers

This trial by The Brotherhood of St Laurence Banksia Services for Seniors aimed to encourage people to use respite. Coupons for Carers was an innovative 13-week trial funded by the Victorian Government Department of Human Services. It encouraged carers of family members with dementia to use a coupon system for purchasing 156 hours of their choice of respite. Booklets of coupons were presented to families, with each coupon representing one hour of care. The ability to use one-hour units of service, rather than the normal six-hour block, increased program flexibility and capacity.

Respite services that could be 'mixed and matched' included:

- centre-based day experiences and socialisation 6 hours
- centre-based evening into overnight respite 18 hours
- centre-based weekend respite 24-48 hours
- centre-based early morning or evening respite flexible hours
- in home overnight respite (including weekends) 10 hours
- in home evening respite (including weekends) flexible hours
- in home weekday respite flexible hours
- host home weekday respite 6 hours

In addition, for four coupons people in care relationships could go on bus trips for organised, supported social outings such as shopping, picnics, exhibitions, or a boat trip to Queenscliff.

Key benefits

- Coupons were a fun, easy-to-use way of introducing new carers to respite options.
- Flexibility of coupons allowed carers to save up for times of high need, and mix and match cash and coupons to extend the service.
- Group outings helped families establish supportive networks with others in similar stages of caring.
- Carers felt empowered to choose respite options that best met their needs; they were less stressed as they could use respite when it was needed.
- Waiting lists for services were reduced.
- Staff became more receptive to change and to developing more flexible respite options.

6 Using different settings for respite

Introduction

Programs have respite in different settings, catering for the flexibility needed by carers. A change of scene can be a break from the stress and strain of full-time caring. Not all carers respond to using planned activity groups, residential respite or other more traditional settings for respite. This section has more examples of respite programs in different settings.

Community respite houses

Some facilities offer flexible options for carers and care recipients via community respite houses (The Nucleus Group, 2002). Often such houses are purpose-designed, domestic-style houses, with large lounge areas, kitchens and well-established secure gardens. The houses have activities for people and options for short-stay day or overnight respite, planned or unplanned (Uniting Care Goulburn North East, 2004). People who go to such houses tend to have physical and cognitive impairments and often dementia. Carers can use services in community respite houses flexibly, choosing hours that suit their needs, and counselling and information about support services. In some cases carers can stay overnight in a residential facility to assist a care recipient to transition to a new environment. Experiences for care recipients may include lunch, regular weekly bus outings, music, movies and social chat, games, and exercise classes. Services such as hairdressing, podiatry, medical or nursing support and pastoral care may be available. Often, education sessions and carer support groups are run that may benefit both care recipient and carer.

Examples include:

- Ballarat Health Services (Eyers House)
- Benetas (Kilby and Hurlingham Houses)
- Brotherhood of St Laurence Banksia Services for Seniors (Banksia)
- Latrobe Community Health Service (Mayfair House)
- St Laurence Community Services (St Laurence House)
- Uniting Care Goulburn North East (Cornish Vale and Neil Stewart Houses)
- Villa Maria Society (Carinya).

The respite model is a community-driven initiative financed from an organisation's funds, such as existing HACC and brokerage funding. Services share similar models of philosophy of care, operation and service delivery.

Mayfair House

Mayfair House in Traralgon has a flexible respite program for carers and care recipients. Beds are nearly always full, with a maximum of three people staying overnight. The house is fully furnished with cooking facilities and starter packs of kitchen and bathroom basics, and has a supermarket in walking distance. The house is a valuable service for carers from rural and isolated communities throughout Gippsland, with good access to medical facilities and other services. Staying at Mayfair House gives carers an opportunity to improve their health and wellbeing, allowing them to be more understanding, patient and able to continue with their care role. Only low care respite is offered.

For further information about Mayfair House contact Latrobe Community Health Service on 1800 059 059 or 1800 242 696.

Key idea

Using available community settings for respite groups can add value to service options and provide a change of scene for carers.

St Laurence House

St Laurence House is a large Edwardian home in central Geelong. It has a flexible mix of respite services in a community respite house. Opened in 1988 to meet identified needs of carers of people with dementia in the Barwon area, St Laurence House remains an industry leader. It operates seven days and nights a week delivering integrated dementia-specific respite programs that evolve to meet changing needs of carers and care recipients.

New programs for carers include:

- A relaxed informal group where couples enjoy an evening meal at St Laurence House on Tuesdays. The respite team leader offers support and advice to new and existing families. This program introduces new families to St Laurence House.
- A monthly Carers Group on the second Monday of each month. Carers gather at a local venue, White Eagle House, where they have afternoon tea and are joined by professionals from Alzheimer's Australia Vic (AAV) and Commonwealth Respite and Carelink Centre. Carers report this monthly gathering is beneficial to their care role as they can speak to others in similar care roles and get professional help if needed.
- A one-night stay program in partnership with AAV and Commonwealth Respite and Carelink Centre. Couples who have completed the Living with Memory Loss program are invited to participate in the program. The person with dementia stays with staff at St Laurence House. The carer stays at the Mercure or Sheraton Hotel where massage and aromatherapy are available to them. The person with dementia is taken out for dinner for the evening with a day-long program the next day; often a day trip to Port Campbell and the 12 Apostles.
- Younger Onset Dementia Group, each Monday at St Laurence Lodge in Ocean Grove, is a practical hands-on group. The group of ten men build projects such as the raised garden beds, model rail sets and woodwork at the Ocean Grove property. This group is highly successful and positive for the men who are able-bodied and physically fit to undertake such projects.

St Laurence has two other properties where families can experience a break in a relaxed holiday atmosphere at St Laurence Lodge, Ocean Grove and St Laurence Caloola House, Portarlington.

A new service, St Laurence's Rural Retreat, creates a unique respite and learning environment for both carers and people with an existing, new or early diagnosis of dementia. This innovative model of care enables carers of people with dementia to enjoy relief from the usual care role. They are also able to gain an understanding of therapeutic models of care without the separation of overnight respite, a barrier identified by carers to using respite. The service helps carers gain skills in implementing a care plan developed with St Laurence's dementia-specific program coordinator, and links into other community-based services like Barwon Carer Respite Centre and AAV. Carers develop an awareness of strategies for the wellbeing of the person with dementia and the carer.

Further information

St Laurence Community Services Inc.
347 Shannon Ave
Newtown Vic 3322
Phone: 03 5229 9943
www.stlaurence.org.au

Individualised in-home approaches

Hope Healthcare in New South Wales has innovative in-home respite services, such as in this case study.

Combining respite with music therapy¹⁰

Sarah, who has dementia and is cared for by her partner Bill, was referred to Flexible Carers Respite Solutions (FCRS) because she had become depressed and anxious. Bill was stressed and could not get her to shower or eat regularly. After assessment, FCRS provided respite carers to help motivate Sarah. The behaviour management specialist provided education and support to Bill. At first, Bill did not want to have the music therapist at the house, stating 'there was no point'. Sarah entered a nursing home for respite care where she met the music therapist. Sarah talked about music often, playing the keyboard a little. On her return home Sarah asked if the music therapy could continue. From a recognised repertoire, Sarah plays the melody on an electric keyboard, with the therapist accompanying on guitar. The music brings back memories of her life.

After the respite and music therapy had started, Sarah agreed to shower and eat when the therapist came. Bill noticed the results straight away. Sarah looks forward to every music therapy session, getting up early and waiting for the therapist to arrive. Music therapy is having a profound effect on Sarah and Bill's lives, vastly improving their relationship.

Further information

Hope Healthcare
Palister House
97-150 River Road
Greenwich NSW 2605
Phone: 02 9903 8366
www.hopehealthcare.com.au

¹⁰ Reproduced with permission from Hope Healthcare

Host home respite

Host family respite programs, like that of the Churches of Christ Homes and Community Services Inc. in Western Australia, are an alternative to formal respite care services.¹¹ Host family carers provide up to 66 hours of planned and emergency respite on each occasion, allowing the regular carer to get up to three good nights' sleep - a key benefit. Hosts must have a Senior First Aid Certificate, police clearance, undergo a medical examination, and have completed a four-day Effective Dementia Care course (Alzheimer's Australia WA). Ongoing training and telephone support are provided. Ideally the care recipient is placed with the same host family carer each time for rapport and continuity of care. The program is promoted through informal small groups and families, health professionals, radio presentations, brochures, vouchers, fridge magnets and posters, including in adult day care centres and community care organisations.

For successful placements, care recipients and host family lifestyles need to be matched on factors like socioeconomic group, ethnic origin, location (rural/urban/city), occupation (current/previous), number and age of children, pets, and life experiences. When there is poor matching, placements are likely to fail.

Advantages of this type of respite include:

- timely and flexible response
- emergency and planned placement options
- individual care
- increased socialisation for the care recipient
- lack of stigma compared with other options: for example, residential respite.

Southern Peninsula Community Care Inc. has six host homes, five on the Southern Peninsula and one in the Westernport Bay area. Some homes are for women, some for men, and one is mixed. Funding was obtained from various sources including a partnership with Banksia Services – Brotherhood of St Laurence, National Respite for Carers Program, Commonwealth Respite and Carelink Centre, in addition to self-funding. The host home program is an innovative model of care providing respite to carers. Flexible care takes place in the home of a qualified host home worker, who has a minimum of Certificate III in Aged Care and First Aid Level II. Host home workers undergo a police check and home inspections for safety, hygiene and general suitability.

Each home has its own unique quality. The home environment includes morning tea, a hot home-cooked lunch, arts, crafts, quizzes and entertainment. On special occasions, the host home carer may take the group, typically four to five participants, out for lunch or morning tea. Carers drop the person requiring care at the host home around 9.45am and pick them up around 3pm. A stimulating activity and social program is developed for each person.

¹¹ Boldy, D., Davey, M., Crouchley, K., & Lilly, E. (2005). Host family respite: description and assessment of a program. *Australasian Journal on Ageing*. 24(2). 94-97

House of Pamper — host home

The House of Pamper was opened in Rosebud in 2005. The host home worker is assisted by a volunteer. The host home has ramps and grab rails and is wheelchair accessible. The five women who attend chat round the kitchen table during the morning, eat morning tea and then lunch. After lunch they get their nails polished, hair set in rollers and hands massaged. When you visit this home you hear the women's laughter from the time you walk in until you leave.

The host home program is a unique small group environment. Day centre programs cater for 25 people or more and some care recipients are more comfortable in a smaller, more intimate setting like a host home. Care recipients can bond more easily and make stronger, lasting friendships in smaller settings.

Further information

Southern Peninsula Community Care Inc.

169 Eastbourne Road

Rosebud Vic 3939

Phone: 03 5986 5255

www.spccare.org.au

Day respite in residential facilities

Another innovative model of care is day respite in aged care facilities. It makes sense to use the infrastructure and facilities of aged care homes, without necessarily having an overnight stay. The advantages include new people joining in activities with permanent residents and allaying fear of the unknown about the aged care facility. There may be facilities already providing day respite in various locations or willing to set up a service. Local carer respite centres know of aged care facilities that provide day respite. For more information call 1800 052 222.

A new day respite option for carers of older people is currently being trialled in 30 aged care facilities across Australia: six of these in Victoria, as the following table shows. This initiative seeks to expand options for carers, in addition to available respite days. Each site has flexible day care, and is collecting data for research on this model of respite.

Aged care facilities in Victoria trialling day respite

Area	Organisation	Project name	Location
Barwon South Western	Lyndoch Warrnambool Inc.	Homestead Day Stay Respite	Homestead Hopkins Road Warrnambool 3280
Eastern Metropolitan	Manningham Centre Association Inc.	Day Guest Respite Service	Cassia House 371 Manningham Road Doncaster 3108
Hume	Southern Cross Care (Vic)	Ave Maria All Day Respite Program	Ave Maria Village 25 Graham Street Shepparton 3630
North and West Metropolitan	Inner East Health Service	Inner East Community Health Service Day Respite – the Caring Café	Sir Eric Pearce House 273 Church Street Richmond 3121
Southern Metropolitan	Jewish Care (Vic) Inc.	Stepping Out	Montefiore Homes Community Residence 619 St Kilda Road Melbourne 3004
Southern Metropolitan	Southern Cross Care (Vic)	Lynbrook Respite Care	Lynbrook Respite Centre 500 Evans Road Lynbrook 3975

Caring Café

Caring Café, operated by Inner East Community Health Service, shares facilities with the Sir Eric Pearce Aged Care Facility and Yarra Health Services in Richmond. The program has flexible day care in a supportive and safe environment for people living in the community with a carer.

Program features include:

- meals
- flexible drop-off and pick-up times if needed
- experienced staff
- appropriate social and leisure interests
- support services for carers, such as counselling.

Caring Café relieves pressure on working carers by providing access to services such as medical and allied health, speech therapy, podiatry, occupational therapy, aromatherapy, hairdressing, dental care, pharmacy, and pastoral care, usually only during working hours. Weekly bus outings, music, movies and social chat, exercise classes, guest speakers and coffee and tea are part of the service.

The Caring Café operates five days a week, with flexible hours to suit carers. Late or early care occurs using aged care facility amenities and staff, with people in care able to join other respite groups for outings or social chat in the Caring Café.

Further information

Inner East Community Health Service

Phone: 1300 650 750

www.iechs.com.au

7 Summing up

This booklet has outlined models and ideas to help support carers. Some ideas may help your service to be innovative, flexible and person-centred.

You are welcome to contact providers and service organisations mentioned here for more information.

From literature and evaluations, we have good evidence about what types of activities and services support people in care relationships:

- We know respite care helps carers feel better and more able to cope, as do counselling and education, particularly for carers of people with dementia.
- Some education interventions can work better when carers and care recipients attend together.
- Support groups are helpful in improving morale and wellbeing and relieving feelings of isolation, loneliness and stress.
- Groups tailored to carers' needs are most successful.
- Support groups via telephone, internet or video-conferencing may help support people in remote or rural areas.

Service providers need to be creative in supporting people in care relationships using principles based on evidence. Caring is not a static job; things are always changing. Service providers need to be alert to new ways of supporting people in care relationships as carers' roles and capacities, and those of the people they care for, change.

8 Resources list

Aged care services

www.health.gov.au/internet/main/publishing.nsf/Content/ageing-whatnew.htm-copy2

Alzheimer's Australia Vic

www.alzheimers.org.au

Carers Victoria - supporting family carers in Victoria

www.carersvictoria.org.au

Carer/respite research information

www.carersaustralia.com.au

Centrelink

www.centrelink.gov.au/internet/internet.nsf/individuals/carer_index.htm

Commonwealth Respite and Carelink Centres

www.commcarelink.health.gov.au

For carers and families

www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/for+carers+and+family

Effective Caring: a synthesis of the international evidence on carer needs and interventions –

Volume 1 www.health.gov.au

Resources in other languages

www.carersaustralia.com.au

Transition Care Program, Program Guidelines – 2005, Quality assurance in transition care

www.health.gov.au/internet/main/publishing.nsf/Content/ageing-transition-guidelines.htm~ageing-transition-guidelines08.htm

Victorian Government Department of Health: Aged Care Branch

www.health.vic.gov.au/agedcare

Working with Aboriginal carers and their communities

www.carersaustralia.com.au

9 Programs and services

The following table lists the programs and services referred to in this booklet in alphabetical order. Please note this is not a comprehensive list of programs and services.

Program/service	Organisation	Contact	Page
Aboriginal and culturally and linguistically diverse respite initiatives	Bendigo Health	Ph: 03 5454 7719 www.bendigohealth.org.au	22
Base Camp	Villa Maria	Ph: 1300 650 615 www.villamaria.com.au	27
Café style support services	Victorian Government Department of Health	Ph: 1300 650 172 www.health.vic.gov.au/agedcare	18
Career Angels	Best of Care	Ph: 03 5272 3133 www.bestofcarebarwon.com.au	29
Caring Café: day respite in residential facility	Inner East Community Health Service	Ph: 1300 650 750 www.iechs.com.au/seph.php	42
Chinese and Afghan Lifelong Movers Program	Southern Health – Bunurong Community Care	Ph: 03 8792 2207 www.southernhealth.org.au	23
Community Care Socialisation Program	Brotherhood of St Laurence	Ph: 03 9483 1183 www.bsl.org.au	31
Counselling and Advisory Service	Carers Victoria	Ph: 03 9396 9550 www.carersvictoria.org.au	24
Coupons for Carers	Brotherhood of St Laurence, Banksia Services for Seniors	Ph: 03 9483 1183 www.bsl.org.au	34
Creative Ways to Care	Commonwealth Respite and Carelink Centre -Southern Metropolitan Region	Ph: 1800 052 222 www.carersouth.org.au	12
Dementia Care Australia	Dementia Care Australia	Ph: 03 9727 2744 www.dementiacareaustralia.com	24
Education for carers	Alzheimer's Australia Vic	Ph: 1800 100 500 www.alzheimers.org.au	30
Education for carers	Carers Victoria	Ph: 03 9396 9550 www.carersvictoria.org.au	30
Finding Your Voice	Commonwealth Respite and Carelink Centre CarerLinks North	Ph: 03 9495 2500 www.merrichs.org.au	9
Flexible Respite for Employed Carers	Baptcare	Ph: 03 9831 7222 www.baptcare.org.au	29
Getaways	Carers Victoria Respite Connections	Ph: 03 9396 9550 www.carersvic.org.au	15
Healthy and Wise Carers Program – the pilot	Family Care	Ph: 03 5823 7000 www.familycare.net.au	6
Host Family Respite	Churches of Christ, Southwest Hub National Respite for Carers Program Project	Ph: 08 6222 9000 www.ministryblue.com	39

Program/service	Organisation	Contact	Page
House of Pamper - host home	Southern Peninsula Community Care Inc	Ph: 03 5986 5255 www.spccare.org.au	40
In-home respite	Hope Healthcare	Ph: 02 9903 8366 www.hopehealthcare.com.au	38
Indigenous Respite Program (IRP)	Rumbalara Aboriginal Co-operative Ltd	Ph: 03 5825 2111 www.raclimited.com.au	21
Italian respite service	Bendigo Health	Ph: 03 5454 7719 www.bendigohealth.org.au	22
Kilby and Hurlingham Houses	Benetas	Ph: 1300 236 382 www.benetas.com.au	35
Living With Memory Loss	Alzheimer's Australia Vic	Ph: 1800 100 500 www.alzheimers.org.au	17
MATES: Men's Adventures to Exciting Sites	MATES, Gippsland Southern Health Service	Ph: 03 5671 3343	28
	MATES, Bass Coast Regional Health	Ph: 03 5678 5388	
	Men on the Move, Bass Coast Community Health Services	Ph: 03 5654 2791	
Mayfair House	Latrobe Community Health Service	Ph: 1800 059 059 or 1800 242 696 www.lchs.com.au	36
Memory Lane Cafés	Alzheimer's Australia Vic	Ph: 1800 100 500 www.alzheimers.org.au	17
Men's Out and About Group	Yanada House Darebin City Council	Ph: 03 9481 9570 www.darebin.vic.gov.au/	22
One Night Stay	Barwon Health Carer Respite and Carelink Services	Ph: 1800 052 222 www.barwonhealth.org.au	14
	Alzheimer's Australia Vic	Ph: 1800 100 500 www.alzheimers.org.au	
	St Laurence Community Services Inc	Ph: 03 5229 9943 www.stlaurence.org.au	
Reluctant Male Respite Users Group	Bendigo Health	Ph: 03 5454 7719 www.bendigohealth.org.au	27
Respite Without Tears	Carers Victoria	Ph: 03 9396 9550 www.carersvictoria.org.au	30
Rural Carers Online	NARI	Ph: 03 8387 2305 www.nari.unimelb.edu.au	25
Social Rehabilitation	Silver Chain Services, Western Australia	Ph: 08 9242 0242 www.silverchain.org.au	33
Southern Psychogeriatric Activity Service (SPAS)	Central Bayside Community Health Service	Ph: 03 8587 0200 www.cbchs.org.au	32
St Laurence House	St Laurence Community Services Inc	Ph: 03 5229 9943 www.stlaurence.org.au	37
Supporting Working Carers DVD	Carers Victoria	Ph: 03 9396 9550 www.carersvic.org.au	29

Program/service	Organisation	Contact	Page
Tastes to Remember	South East Dementia Action Group	Ph: 1800 100 500 www.alzheimers.org.au	22
Telephone Outreach Program	Alzheimer's Australia Vic	Ph: 1800 100 500 www.alzheimers.org.au	24
Telesupport	Alzheimer's Australia Vic	Ph: 1800 100 500 www.alzheimers.org.au	24
Well for Life	Victorian Government Department of Health, Aged Care Branch	Ph: 1300 650 172 www.health.vic.gov.au/agedcare	5
Well 4 Life – Northcote Cares for Carers	Yanada House and Northcote Aquatic & Recreation Centre	Ph: 03 9481 9570 www.darebin.vic.gov.au/	5
Wesley Homeshare	Wesley Mission Melbourne	Ph: 03 9666 1231 www.wesley.org.au	33
Whistle Stop Café	Eastern Access Community Health	Ph: 03 9871 1800 www.each.com.au	18
Women's Group: women with dementia	Barwon Respite Services	Ph: 03 5260 3501 www.respitebarwon.org.au/	27