The ‘How to’ Guide:

So, you want to provide flexible respite services?

Flexible Respite Options Project

Alzheimer's Australia Vic
Living with dementia

Funded by Aged Care Branch, Department of Human Services

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Part 1: Introduction

PURPOSE OF THE 'HOW TO' GUIDE

The purpose of this Guide is to provide a resource for community-based organisations wanting to establish innovative and flexible respite services.

BACKGROUND

The Guide is based on the recent experiences of a consortium of service providers which joined forces in a project to develop a number of flexible respite services for clients with dementia, and their family carers. The idea for the project stemmed from the desire to provide a respite service which would meet the identified, and very specific, needs for flexible respite for people with dementia.

The consortium comprised representation from:

- Yanada House – a dementia specific day program auspiced by the City of Darebin,
- the Commonwealth Carer Respite Centres/Carerlinks North and Carerlinks West,
- Alzheimer's Australia Victoria,
- Darebin Community Health,
- Moreland Community Health,
- the Cities of Darebin and Moonee Valley, and
- the Department of Human Services.

A carer representative also sat on the Advisory Group.

The project was undertaken with the backing and support of the Victorian Department of Human Services (DHS) and Darebin City Council.

Together, the project partners recognised that the partnerships which were established provided:

- the opportunity to combine resources, maximise service sector capacity and further the benefit to mutual target groups,
- the opportunity for learning and challenging the more traditional models of care,
- a redefinition of what is possible within the existing service sector,
- a breadth of expertise, knowledge of the service sector, resources and community contacts,
- the opportunity to trial and experiment, and
- a prompt for the development of strategic engagements.

This Guide has been prepared and developed by Juliet Frizzell and Debra Barrow of Effective Change Pty Ltd, a Melbourne based consultancy, in conjunction with the Project Advisory Group.

WHO IS THIS GUIDE FOR?

The assumption underlying the design of this Guide is that the development of a flexible service response is occurring in the context of an existing service and attendant infrastructure, for example, a HACC Planned Activity Group (PAG) or respite service.

That is, we anticipate the Guide is being used by service providers already experienced in service sector development and that the new program will build on an existing skill base and infrastructure with associated economies of scale.

For example, in our project, the models developed required only that assessment tools and policies be modified, not developed from scratch. The pilot projects built on, and took advantage of the existing knowledge and experience base of staff already skilled in working with clients with dementia.

Acknowledgements

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- the agencies who generously shared their experiences in providing flexible respite services.

We would also like to sincerely thank the family carers and group participants involved. They engaged in the project enthusiastically and shared their stories with great honesty.

Part 2: What is Flexible Respite and Why is it Important?

WHAT IS FLEXIBLE RESPITE?

Flexible respite is any innovative model of care which provides valuable 'time out' for family carers[1] while ensuring participants are cared for in a safe environment and have the experience of appropriately tailored, meaningful and quality activities.

Flexible respite services take many varied forms, for example:

- Outing or community based respite, i.e. holidays away; small group activities in the community, for example, golfing, fishing,
- Interest groups, i.e. pilates, men's shed activities,
- 1:1 and/or in-home respite, ie. one staff member with one client or small groups of people meeting in a paid carer's home,
- Community-based cottage and overnight respite, i.e. cottage based overnight respite accommodating 2-4 people,
- Weekend respite etc.

WHY IS IT IMPORTANT?

The value of respite can be defined by the benefits it provides both family carers and the respite participants.

Respite allows **family carers** to:

- Pursue their own interests,
- Re-engage and relax with family and friends,
- Feel more able to continue in their caring role with the support of the regular respite – *"it will give me the space and strength I need to keep going"*,
- Feel better prepared to handle daily stresses knowing there would be a break in the routine,
- Feel comforted knowing they have the support of program staff to draw on, should that be required, and
- Feel confident that the care recipient is engaged in meaningful activities with people outside their usual social sphere.

It was the experience of our project that being in receipt of respite also provided opportunity for family carers to experience for themselves, the benefit of a service they might otherwise have resisted. For example, one family carer stated that she had not accepted respite services previously as it had *"taken a while to agree to the need".*

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[1] A preferred term for 'carer', *Dementia Terminology Framework Position Paper 4*, Alzheimer's Australia, December 2004.

The positive experience of respite also encouraged a transition towards the acceptance of additional support services. For example, having been involved with the program, one family carer was willing to trial planned residential respite.

The value of respite for **participants** was reported through our project as the opportunity to:

- Establish positive, engaging interaction outside their home environment,
- Establish patterns of behaviour appropriate within a group situation, and
- Engage in meaningful, interesting activity in a safe environment.

One gentleman expressed his enjoyment of the Men's Group and was also able to acknowledge that his *"wife was very happy too".*

During our project family carers also reported that their partners returned home appearing to be happy, calm and settled – a benefit for both partners.

The overall value of providing flexible, innovative models of respite is the opportunity to:

- Engage a target group who might not 'fit' into the traditional respite service, for example, those people with younger onset dementia or those who are fit and well and dislike being 'contained',
- Engage family carers who might otherwise be reluctant to accept assistance, and
- Provide activities which are driven in part, by client choice.

Part 3: What Issues Need to be Considered?

The following are areas we recommend be considered and explored, prior to embarking on the path to develop a flexible respite service.

Target group

- What is the target group you are hoping to include and why?
- What are their needs?
- Does your agency/advisory group have the knowledge and skill base to provide services to this group?
- Does this target group already access community services?

Potential pool of clients and referral base

- Where and how will you find these clients?
- Who will refer them?
- Do you have existing links with the potential referral group/s?
- How will you approach this referral base?

Lead time for planning, establishment, marketing and promotion

- How much time do you have to plan this model of care?
- Who do you need to introduce the model to?
- How will you do this?
- Do other agencies know of your organisation/programs?
- How will you promote the model and program to potential referral agencies, family carers, clients and other community agencies?
- What internal structures/procedures are you able to build on?

Partnership development

- Would it be beneficial to have a partner(s) in this program?
- Do you need the support / strengths of other agencies to develop this model effectively?
- Do you have existing links with these agencies?
- Do they recognise the benefits of working in collaboration?
- Do they also work with the target group?
- Are they also interested in developing services for this target group?
- Will you also involve consumer representatives in the development of your program?

Capacity to build on existing service(s) within the service sector

- Do you and/or your partner agencies have the necessary support of the local and/or related service agencies?
- Is there capacity within the service sector to absorb this new service?
- Are there the referral numbers to sustain the new service?

Funding/resources

- Do you and/or your partner agencies have the personnel, funding, knowledge and skill base required to develop this new service and to maintain it?
- Will you be able to provide a cost effective service?

Part 4: So, You Still Want To Do This? *- The 'How To' Steps*

The points below present a suggested Guide as to the issues which need consideration, the questions to be asked and the level of investigation required prior to embarking on the development of a respite service.

These following steps will also be expanded on in Part 5 of the Guide:

Step 1. Research the needs, gaps and opportunities

Step 2. Develop strategic partnerships

Step 3. Choose a model of care

Step 4. Logistics and planning

Step 5. Set up

Step 6. Implement the service

Step 7. Monitor and improve the model

Step 8. Evaluate the model

Step 9. Grow and expand the service

Part 5: The 'How To' Steps filled in!

Step 1. Research the needs, gaps and opportunities

At this stage it is important to research both the opportunities and potential barriers to establishing a flexible respite service.

The following steps are recommended:

Identify and Research:

i) The target group:

- What are the specific needs of this group and/or their family carers?
- Are their needs currently being met elsewhere?
- Who is missing out on appropriate respite services now? Why?
- Is there a potential referral base?

ii) The service system:

- What are the services currently operating in the local area and region?
- Would a new respite service complement or unnecessarily duplicate these?
- Who are the potential referral agencies?

iii) The costs of setting up a service:

- What are the costs of developing a new service?
- Estimate the costs associated with:
  - Staffing /coordinating the program,
  - Client assessment,
  - Providing transport, meals, outings,
  - Facilities such as rent, phone, gas, electricity,
  - Infrastructure ie. reporting, reception, quality activities.
- Are there savings which can be made by linking with existing infrastructure?
- What are the relative benefits associated with improving on an existing service or developing a new model of care?

Identify the Gaps:

- What are the gaps in the service system with regards this target group?
- What is the potential for your agency to fill that need?

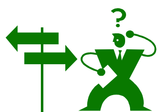
Identify the Opportunities for:

- Service development in the region,
- Building on existing referral pathways,
- Generating new relationships with related agencies,
- Funding - are grants available for the start up / ongoing costs? Do others recognise a service gap and would they be willing to support the development of an appropriate service?

Plan your approach (or How To):

Think about how you will:

- Approach, and talk with clients and family carers about this new service,
- Discuss the service with referral agencies such as ACAS, case managers and other HACC funded agencies,
- Consult with other providers of respite and networks ie. CCRC, Respite Networks;
- Analyse your client data,
- Review demographic information,
- Undertake a literature review.



Make the Decision

Having armed yourself with the information and data now is the time to make the decision to proceed, and to establish a plan as to how to do that, in conjunction with the key players both within and outside your agency.

Our Project:

At this stage in our project we conducted a:
Literature Search which looked at:
i) The principles of good practice respite including:

- the provision of a continuum of options,
- the integration of options ie. PAG and overnight respite within the same facility,
- a variety of care options required to meet the community needs, and
- a well resourced transition function to support clients and family carers, and provide the opportunity and access to the respite system and other care options.

ii) The characteristics of good practice respite such as:

- responsive, quality respite,
- emotional support from and caring partnerships between respite staff and family carers,
- a sufficient number of adequately trained staff to meet participant numbers.

iii) The enablers for the development of a functional respite service including:

- organisational philosophy and approach i.e. person centred care,
- transitional support for the participant and their family carers,
- competent staff with the knowledge of and the ability to effectively manage the behavioural symptoms of dementia, and
- flexible funding options.

Models Review which investigated good practice models for respite care such as:

- facility based residential respite,
- in home respite,
- centre based respite,
- community based respite etc.

Following are some of the examples of good practice we found:

Shell Harbour City Council (NSW):

- Twilight Tours which meet the needs of people with sundowning behaviour,
- Day Trippers program which allows active participants the opportunity to visit and explore places of interest,
- Short holiday respite as an introduction to residential care.

Kilby Cottage (Northern Metro Region):

- Planned overnight respite, with two beds available seven nights per week, linked to a Planned Activity Group.

Banksia Centre (Brotherhood of St. Laurence):

- Overnight respite for four clients with high level care needs. This model allows either for the participants to stay in the home of a respite worker, or for the worker to stay with the participants in one of their homes.

Step 2. Develop strategic partnerships

Building a relationship with strategic partners is essential and can provide you with:

- A broad range of skills and resources,
- A broad support base,
- A broad referral base, and
- Sustainability and options into the future.

In order to do this successfully we recommend you:

Identify the key stakeholders in relation to the project you are planning:

Determine:

- The existing relationships you can foster and build on,
- How and with whom you will establish new, strategic relationships,
- Where your support base will come from eg. local council, DHS or related organisations, for example, Commonwealth Carer Respite Centres and the Department of Health and Ageing.

Establish a rationale for your plans:

As you develop your plans you may be required to 'sell' your idea to those agencies you wish to work with and/or your own Board of Management. In order to do this you effectively will need:

- An established rationale and framework for the project,
- A Memorandum of Understanding (MoU) to Guide interactions with partner agencies, and
- A 'business plan' to present to potential funding bodies.

Establish Roles and Responsibilities:

Determine, in partnership, the roles and responsibilities each agency/partner will commit to in relation to:

- Establishing the service,
- Promoting and marketing the service,
- Funding/requesting funding for the service;
- Setting up and running the service, and
- Monitoring and reporting on the service.

Establish the guidelines and vehicles for Communication:

Agree, with the partner agencies, the guidelines and the communication process which will operate:

- Between partner agencies, and
- With the funding body.

Identify the resources required:

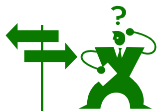
In partnership, identify the:

- physical resources required to 'house' this project and the participants,
- staffing resources required ie. coordinator, fulltime/part-time staff, and
- transport options required.

Identify the funding options available:

Establish with your partners whether:

- existing funding will stretch to this new respite service,
- there are appropriate grants available to apply for.



Make the Decision

Having now established the parameters within which you can operate, you have to make yet another decision!

- Do we proceed? ***or***
- Do we wait for additional resources?

Our Project:

At this stage in our project we:

Established links with stakeholders:
- local government,
- a dementia specific day centre,
- Commonwealth Carer Respite Centres,
- Alzheimer's Australia Victoria, and
- family carers.

Established a rationale for proceeding:

We identified:

- the gaps in the service sector and the appropriate target group,
- the resources required,
- the benefits of a combined knowledge of the service sector,
- the benefits of the broad range of expertise and skill available to the partnership,
- the funding opportunities available to each member.

Established communication protocols between the partners of the project:

We established:

- an Advisory Group to the project, and
- the roles and responsibilities of member agencies.

refer Appendix 1 – Terms of Reference

Step 3. Choose a model of care

Having completed your research into the gaps and opportunities in your region, and knowing the capacity of your agency, now is the time to work towards choosing a model of care.

That is, how and to whom is the care to be provided?

The steps to be undertaken here are to:

1. Identify the *catchment* within which you will operate. For example, is your service going to be available:

- within a local government area,
- within a region, or
- across the state.

It is worthwhile considering at this point if your identified catchment will be large enough to support a robust, sustainable referral base. This is especially relevant if the respite service you are offering is a little 'out of the ordinary' or takes a form which is novel to both referral agencies and family carers, for example, a Sundowners Group (see **Our Project** pp. 18).

2. Identify and specify the *characteristics of the target group* you wish to engage, for example:

- age range,
- gender,
- cultural background,
- disability type, and
- care requirements.

3. Identify the appropriate *respite service* for this cohort. For example:

- centre based respite,
- community activity based respite,
- in-home respite etc. or
- residential respite care.

4. Identify the *principles of care* which will guide your model of service delivery, for example:

- client centred /individual approach, ie. develop a strategy with staff that is based on the modeling of client management,
- reflect a problem solving approach in dealings with clients,
- identify and respond to the triggers of behaviours of concern,
- ensure resources go in to making the family carers and client feel secure in the environment,
- acknowledge that a comprehensive assessment can hold the key to understanding the family carer's capacity, the interaction between client and their family carers and acknowledging with them, the stress of change.

Our Project:

The parameters within which our project was implemented were:

The Catchment: City of Darebin.

The Target Groups:

The focus of the groups was primarily:

- to provide respite services for active men and women who otherwise would not 'fit' the traditional PAG,
- to provide respite services for active men and women who present with changed behaviours and/or high care needs,
- to provide respite services for family carers who are not currently accessing respite /HACC services,
- to provide access to information and support, and
- to facilitate a smooth transition into PAGs and/or the acceptance of other community, respite and home based services such as HACC as needed.

The groups we targeted were:

1. Physically active men with early stage dementia from either an English or Italian speaking background.

2. Individuals presenting with 'sundowning' behaviour, that is, people who become restless, disoriented, agitated and/or impulsive late in the afternoon or early evening.

3. Physically active people with early stage dementia wanting to continue to access and participate in community based activities and interests.

The Models:

1. A Men's 'Out and About' Group. The activities:

- were based in the community, for example, the Museum, a men's shed,
- reflected the interests of the participants,
- encouraged active participation, that is the participants were involved in the planning of outings.

2. A Sundowner's Group. The activities:

- were centre-based, one afternoon /evening per week 2.30 – 8.00pm,
- involved quiet activities such as meal preparation, gentle exercise, hand massage, relaxation,
- reflected the intention of creating a calm environment which would facilitate participants settling into a calm evening and full nights sleep on their return home.

3. A Community Interest Group. The activities:

- were physical and based at community venues such as community houses,
- involved gentle exercise, walking groups, pilates etc. and a social coffee/snack in a cafe afterwards,
- reflect the participants' desire and capacity to continue their involvement in everyday community activities with some support.

Step 4. Logistics and planning

At this point the planning becomes detailed and focused on the day to day logistics of launching your service.

The following are examples of areas requiring decisions:

1. Resources

- Does the facility have an industrial kitchen?
- Is the facility wheelchair accessible?
- Is the facility safe for clients who may wander?
- Does the program have/need access to appropriate transport?
- If your service is in the community, will you need new aids/equipment?
- Will existing building infrastructure be utilised?

2. Staffing

Consider the following questions:

- Are you able to use current staff or will you be recruiting new staff to the service?
- Will staff work fulltime, part-time or casually?
- What level of EFT will be required to staff the program adequately and cover leave?
- What staff to participant ratio will be required?
- What range of experience, skill level and seniority will staff have? That is, will the program employ a dedicated Manager/Coordinator? How many years experience in the field will be considered adequate?
- Will the program require staff to have special driving licenses? Will staff be required to multi skill? ie. will a care worker be required to cook as well as provide care?
- What qualifications will be required of staff?

3. Costings

You will need to have budgeted for the program and understand whether some /all of the new program costs can be absorbed by a current program.

Consideration of client fees is also important at this stage.

The following are examples of areas to be costed:

- **Staffing:**
  - EFT,
  - level of staff qualification,
  - staff to client ratio.

- **Promotional activity/materials:**
  - staff allocation to networking with partner agencies,
  - staff time required to speak with potential referring bodies,
  - staff time required to promote the program to local government , Aged Care Assessment Teams, CACPs and Linkages programs,
  - development of promotional materials,
  - printing costs.

- **Client assessment and monitoring:**
  - staff time to modify existing assessment tools,
  - staff allocation to meet with clients and their family carers,
  - time required to assess a client over one to two visits,
  - time required to write up an assessment and develop a care plan,
  - time required to write client notes following each program session,
  - feedback to referring agency/other program involved in client care.

- **Family carer liaison:**
  - liaison is required with family carers at the time of assessment and throughout the program to ensure family are kept informed and are aware of any changes in client behaviour/health.

- **Client transport:**
  - need to engage a dedicated driver.

- **Meals:**
  - meeting the specific dietary requirements of clients,
  - the costs of centre-based and /or external (restaurant) meals.

- **Program planning:**
  - regular feedback /case discussion as to client progress,
  - weekly planning sessions and transport coordination.

- **Facility costs:**
  - rental, phone, electricity, gas.

- **Activity costs**:
  - entrance to the Museum.

4. Client Activities

Client activities will need to be planned in advance with alternate options factored in, in the case of bad weather, varying client / staff numbers.

Our Project:

The following are examples of how the above points were managed by our project:

Resources:

- an existing facility for a dementia specific day program was used for any centre-based activity, and
- as a drop off and collection point for clients.

Staffing:

- the Coordinator of the day program was seconded part-time (0.1 EFT) to provide overall management of the program, promote the project, recruit clients and staff, assess clients and liaise with family carers and project partners,
- the project was otherwise staffed by 2 care workers from the day program x 0.2 EFT each.

Costings:

- the project facilities were paid for via a pro-rata arrangement,
- promotional activities and materials were funded from the project grant.

Examples of the activities undertaken are as follows:

- *the Men's Group* visited the Point Cook RAAF Museum, National Gallery, Immigration Museum and the Darebin Community Health Men's Shed,
- *the Community Interest Group* attends pilates classes, gentle exercise groups and goes out for coffee socially.

Step 5. Set up

You've completed the planning and negotiation phases of establishing your program – congratulations! Now comes the fun part – the set up phase.

The activities to be completed prior to the implementation of the program are as follows:

1. Marketing/promotion

Having thought previously about who to approach in order to promote the program, and the materials required to support the marketing strategy, now is the time to 'meet and greet'.

i) Prepare the written/presentation materials required to present the program as a new initiative, including points as to:

- ***what*** the program is about,
- ***how*** this program differentiates itself from other, like programs,
- ***why*** agencies should refer to the program,
- ***how*** the referral process will operate, and
- ***how*** the clients and their family carers will benefit from the program's interventions.

ii) Identify those agencies with whom to promote the program:

- potential referral sources ie. GPs, related day programs, local government aged care services, CACPs and Linkages case managers,
- regional agencies ie. Aged Care Assessment Services (ACAS), Commonwealth Respite Centres,
- statewide peak bodies ie. Alzheimer's Australia Vic.

iii) Make appointments to meet with the managers and/or teams of these agencies.

iv) Identify additional marketing opportunities:

- relevant websites,
- promotion through special interest groups eg. Regional Respite Networks, PAG Coordinators meetings, and
- local newspapers.

v) Repeat above.

A word of advice: allow a decent period (approximately 3-6 months) of time to establish and implement your marketing strategy prior to actually looking for referrals and a full case load. Experience shows that the service sector can be slow to respond to a new program even though the word may be that such a service is needed.

Note too that marketing may need to be a repetitive and/or cyclic activity that is undertaken on a regular basis until your program becomes well established, the referral process is integrated into practice and outcomes are known within the sector.

2. Recruitment of Participants

You have identified the target group for the program, now is the time to go out and meet them.

i) As above, actively market the program, targeting those agencies with the appropriate client base and/or waiting list to begin a flow of referrals,

ii) Meet with the clients and their family carers to introduce the premise of the program – this is especially important if:

- the program is offering a novel model of care, and/or
- the diagnosis of disability is recent, and/or
- the family are not currently in receipt of support services and are reluctant to access these.

iii) Assess the clients;

iv) Introduce the client and family carers to the program.

3. Assessment Tool and Care Plan

It may be that the template for the assessment tool and care plan can be adapted from other tools currently in use in your agency, eg. HACC Assessment Tool.

If not, now is the time to develop these.

Have you decided WHO is to conduct the assessments?

Experience will show too, that occasionally, one meeting with a client does not allow for a representative assessment – especially if behavioural /cognitive deficits are present. Building trust with family carers and clients may also require that innovative strategies be employed e.g. Why not invite them to lunch at the facility? Have them sit in on the activities of a similar group?

Our Project:

***Assessment Form* –** was adapted from the assessment tool currently used by the day centre.

The following areas for assessment were included:

- communication,
- social skills,
- psychological /behaviour,
- level of independence in activity,
- orientation,
- mobility,
- continence,
- level of independence in personal care.

***Care Plan* –** was adapted from that used by the day centre.

The following areas were monitored on a weekly basis:

- activities – domestic/physical/social,
- eating/diet,
- communication /social engagement/orientation,
- behaviour,
- mobility,
- continence,
- personal care.

refer Appendices 2 and 3

4. Recruitment of Staff

By this stage you will have decided whether to second staff from within your agency or whether you will recruit new staff.

Either way, you will need to have developed a clearly defined:

- position description including:
  - roles and responsibilities,
  - minimum levels of qualification and experience with the target group, and
  - lines of reporting;
- program outline and operational Guidelines,
- skills development/training program.

5. Skills development/training

Your staff recruitment strategy will have determined on the minimum levels of qualification and experience required to fulfil positions.

However, for ongoing professional development the agency will need to be able to offer either in-house training, or externally provided training at an appropriate standard.

It may be that staff with the new program can be involved in the professional development activities already established within the agency.

6. Policies and Procedures

Now is also the time to begin to either:

- adapt existing policies and procedures, or
- develop new policies and procedures for the operations of the program,
- review and conduct a risk assessment for all tasks – be prepared!

7. Purchase Equipment

Will staff require mobile phones?
Will the agency need to upgrade/purchase wheelchairs/toilet seats/frames etc?
Do you have sufficient cutlery, crockery and cooking equipment i.e. barbeque?
Do you have a portable first aid kit?

Now is the time to go shopping!

Step 6. Implement the service

You're ready, everything is set, all systems are set to go!

Best of luck!

Step 7. Monitor and improve the model

You will need to have regular processes in place for regular monitoring and review of practice. These processes will inform improvements to the program and ensure that a continual feedback loop of review and improvement is in place.

It may be that you implement review processes at a number of levels:

- **Internal:**
  - weekly staff meetings to review client progress, and
  - program practice.

- **External:**
  - monitor referral numbers and sources,
  - seek feedback from referring agencies while on the marketing trail and/or bi/annually.

Our Project:

Weekly staff meetings – were implemented to review client progress and refine program practice.

A weekly diary – was maintained.
This included notes regarding:
- client progress,
- activities ,
- venues visited, and
- outcomes ie. successes and/or failures.

This diary also served to inform ongoing revision of program practice.

Monitoring of our Men's Group prompted rethinking, and changes in our service delivery:
- the length of activities was modified once we had a better sense of the capacity of the group,
- the types of activities were planned to meet the group's interests,
- even having lunch out as a regular activity was modified to better suit the participants' needs to have some settled time before returning home.

Fortnightly meetings of the Project Advisory Group – contributed advice, provided external monitoring and brought a 'big picture' view to the project.

Step 8. Evaluate the model

In addition to monitoring the program, it is beneficial to build in an evaluation process.

Together, the monitoring and evaluation will serve to inform programmatic change and improvement while also providing measurable outcomes for funding bodies and other key stakeholders.

Our Project:

Independent Observation of Group Function:

Consultants met with clients as they were involved in the day's activity.

The clients were observed as they interacted with each other and staff and were also asked questions which factored in cognitive and language capacity, and were designed to elicit responses regarding:

- their level of enjoyment of the program overall, and
- the aspects of the program which were particularly appreciated, eg. the outings, the company, the meals.

Family Carer Survey via Structured Interview:

Family Carers received regular phone calls to help us evaluate the impact of the program.

All carers were asked the same questions, which had been designed to elicit responses regarding:

- the type and level of support services accepted at the beginning of program, and how their views might have altered as to the benefits of support services as they moved through the program,
- their need for respite and how their views might have altered as they experienced the process,
- the benefits they and their partner experienced as a result of their involvement with the program,
- their level of satisfaction with the program,
- their level of satisfaction with the communication from the program regarding their partner's progress,
- their thoughts on how participating in the respite program might affect their caring role and their ability to continue in that role.

Refer Appendix 4

Step 9. Grow and expand the service

Now that you are armed with the positive information gained through monitoring and evaluation, it is time to consider with your partnership agencies, the benefits and potential for expansion of the program.

Expansion may take the form of being able to offer the program:

- to a broader target group,
- across local government boundaries,
- throughout the week to provide the opportunity for participants:
  - to attend more frequently, and
  - experience the potential benefit of carry over.

Expansion may also provide the opportunity to be able to offer additional services such as:

- family carer support groups,
- a broader range of respite services.

Part 6: Resources

RELEVANT WEBSITES

The following are a sample of relevant websites to search when clarifying your thinking and researching your options:

The Benevolent Society
www.bensoc.asn.au/ageing

The Hammond Care Group
www.hammond.com.au/resources

Interchange Respite Care (NSW) Inc
www.interchangensw.com.au

Alzheimer's Australia
www.alzheimers.org.au

Victorian Government Health Information
www.health.vic.gov.au/agedcare

You can access the 'How to Guide' itself from the following websites:

Darebin City Council
www.darebin.vic.gov.au

Effective Change
www.effectivechange.com.au

RELEVANT INFORMATION SOURCES

The following are examples of information sources available to you:

Alzheimer's Australia Vic
Phone: 03 9815 7800
HELPLINE: 1800 639 331

Commonwealth Carer Respite Centres
Phone: 1800 059 059

Eastern Metro	Phone:	03 9852 7455
Northern Metro	Phone:	03 9495 2500
Southern Metro	Phone:	03 9276 6400
Western Metro	Phone:	03 9396 1077

Commonwealth Carelink Centre
Phone: 1800 052 222

HACC Policy and Procedure Manual

National Carers Respite Program

Reducing Behaviours Of Concern – A Hands on Guide, Commonwealth Government Department of Health and Ageing, March 2003.

The *Community Respite House Operational Manual*, Commonwealth Government, 2003.

Yanada House
Coordinator Phone: 03 9486 7520

Flexible Respite Options Project

Advisory Group

Terms of Reference

1. Background

The Flexible Respite Options project is a six month project commencing on July 1st 2004. The project objectives are:

- To improve respite options for carers of older people exhibiting symptoms of dementia and/or behaviours of concern, who don't fit into traditional Planned Activity Groups (PAGs) or in-home respite options,
- To develop and trial innovative, creative and flexible respite options,
- To develop and trial better use of existing services using a dementia specific service as a base,
- To develop, document and evaluate two or three models of care which may be applicable across program boundaries, and
- To build on existing regional knowledge regarding workable respite models and existing respite gaps.

A project worker/consultant will undertake a six month action research project to trial, document and evaluate two or three models of flexible respite care for older people exhibiting symptoms of dementia and/or behaviours of concern, whose needs are not met by traditional Planned Activity Groups (PAGs) or in-home respite options. It is expected that these models would be applicable across agencies and in other settings. In trialing the options, the project worker will utilize the knowledge and expertise of staff at Yanada House, the Advisory Group members and the physical resource provided by the purpose-built facility at 92 Dennis Street and Yanada House.

The project will also document ways in which the knowledge and expertise within specialist centers such as Yanada can be made available to carers and clients across local government boundaries.

The project will also identify facilities, including Yanada, with the potential to provide a flexible overnight respite service. An initial evaluation of identified facilities will be undertaken followed by a costing of the necessary structural changes required to adapt potential facilities. Recommendations setting out the most cost effective way to increase the availability of flexible overnight respite for this target group will documented.

1.1 Stage One
Time frame: July – August 2004

During Stage 1:
- an Advisory Group will be established. The Terms of Reference (ToR) for the group will clarify the role of the group members in relation to providing strategic advice and hands-on support for the project,
- a consultant will be appointed to evaluate the project, and
- a range of pilot projects to be trialed will be identified, in consultation with carers and the Advisory Group. Potential participants for enrolment in the project will also be identified at this stage.

1.2 Stage Two
Time frame: October 2004 – January 2005

During Stage 2:
- two or three models of flexible respite will be trialed over a period of 12 weeks, and
- a feasibility study on overnight respite options in the City of Darebin will be undertaken.

1.3 Stage Three
Time frame: January – February 2005

During Stage 3 a written report will be produced including, but not limited to:
- the flexible respite options trialled and evaluated,
- the templates which were developed,
- the implementation of the new options within existing funding parameters,
- identification of facilities with potential to offer flexible overnight respite, and
- recommendations for further service development.

2. Advisory Group

The Advisory Group will ensure the project retains a regional community development focus and will provide guidance to the project.

3. Roles

The roles of the Advisory Group will be to:

- Guide the project in meeting its values, goals and objectives,
- Communicate and share information with the organization represented by the members,
- Assess and respond to project evaluation and reporting requirements,
- Advocate for clients and carers,
- Support and encourage carer's participation, and
- Identify strategies to establish partnerships, attract resources and explore the potential for long term sustainability of the project.

4. Membership

The membership will include representatives from the City of Darebin, Darebin Community Health, CarerLinks North and Carer Links West, Moreland Community Health Service, Alzheimer's Australia Victoria, the City of Moonee Valley and the Department of Human Services. It is also expected that at least one carer will join the Advisory Group.

Note:

a) Others may be called upon to join the group and assist in completing tasks or to attend meetings in an ex-officio capacity.
b) Members are encouraged to regularly attend meetings to ensure consistency.
c) Members may resign by informing the group in writing and/or verbally at a meeting.

Membership details:

City of Darebin	Mike Webb Manager Aged and Disability Services, Fran Harper Coordinator Extended Care Unit, Milena Pinamonti Yanada House Coordinator and Project Manager.
DHS	Sara Lacey
CarerLinks North	Alexandra Lara
CarerLinks West	Katrina Tzikas
Alz. Association Vic	Suzie Nimmo
Darebin Com. Health	Mary Cigognini
Moreland Com. Health	Ann Clendinnen
City of Moonee Valley	Guy Walters
Carer Representative	Jenny Burns

5. Meetings

- Meetings to be held monthly.
- Notice of meetings including Agenda and minutes of the previous meeting to be provided at least 5 days prior to each meeting.
- The Group will operate on a consensual basis. Where there are issues to be resolved, the group will canvass options and seek to obtain an agreed position. Where issues remain unresolved and a solution cannot be reached and the matter is viewed as significant to the successful operation of the Group, the Group can appoint an independent mediator to assist in resolving the issue or assist the parties/ group to reach consensus.
- Meetings will commence and finish on time.

6. Office Bearers and Administration

a. Meetings will be chaired by the Group's nominee.
b. the project manager will coordinate minutes and agendas for each meeting in consultation with members.
c. the program manager shall provide meeting facilities, catering and administrative support as required.

****

YANADA HOUSE **CITY OF DAREBIN** **"CONFIDENTIAL"**
CLIENT INFORMATION AND ASSESSMENT RECORD

CLIENT INFORMATION

Client's Name ....

Prefer to be called: .... SKK Number: ....

Address: ....

Postcode: .... Phone: ....

Date of Birth: .... /.......... /................ Age: ....

Country of birth: .... Language spoken at home: ....

Interpreter required: Yes ¬ No ¬ Functional English: Yes ¬ No ¬

Marital Status: M S W D Sep DeF

Household composition:...

CARER INFORMATION

Name: .... Gender M / F

Address: ....

Postcode: ……................ Telephone: ....

Date of Birth: ……………………………………… Birth place: ....

Living arrangements: ....

Language: …………………………………….. ABTSI: …….. Yes/No

Referral Source: ....

Pension/Benefit:...

Carer Status: Resident carer / Non resident care

REFERRAL SOURCE

Date of referral: .... / .... / .... Date of ADASS assessment: .... / .... / ....

Name: .... Assessment by: ....

Contact No: .... Day Centre commencement: .... / .... / ....

Organisation *(if applicable)*: ....

Priority of admission to Day Centre 1 2 3

....

CLIENT CONTACTS

Primary Carer *(Next of kin)*

Name: .... Relationship to client: ....

Address: ....

Phone: (Home) …………...……… (Work) ……..……..……… (Mobile) ……………………..…

Second Contact Person

Name: .... Relationship to client: ....

Address: ....

Phone: (Home) …………...……… (Work) ……..……..……… (Mobile) ……………………..…

Formal Guardian *(If applicable)*

Name: .... Relationship to client: ....

Address: ....

Phone: (Home) …………...……… (Work) ……..……..……… (Mobile) ……………………..…

Doctor

Name: ....Phone: ....

Address: ....

Key Safe: .... **Location**: ....

Source of Income

Pension: Aged Pension: Yes ¬ .... No ¬
DVA Yes ¬ Gold Card ¬ White Card ¬ No ¬

Other Income Type: ....

Concessions/Entitlements

Pensioners Concession Card: Yes ¬ No ¬
Ambulance cover: Yes ¬ No ¬
Taxi concession card: Yes ¬ No ¬
Carers pension: Yes ¬ (specify type)... No ¬

Referral required for any of the above: ....

....

DEMENTIA SCREEN

Formal diagnosis: Yes ☐ No ☐ Date diagnosed: ....

Diagnosis by: .... Contact Number: ....

Onset: Sudden ¬ Gradual ¬ Type: ....

Length of disease: .... years

Aged Care Assessment: Yes ¬ No ¬ Date: ....

Contact Person/Case Manager: ....

Client Symptoms

Memory (long and short term) ....

Orientation (time/place/person) ....

Changes in habits (toileting, eating, dressing, bathing) ....

Nutritional Screening Tool: Yes ¬ (see Attached form) No ¬

Interventions by family: ....

Changes in performance of everyday tasks eg: household maintenance, handling money, find way about/interpret surroundings:

....

Interventions by family:

....

Changes in personality (relinquishing interests, apathy, diminished initiative, impairment of regard for others, emotional control):

....

Interventions by family:

....

Changes in Behaviour (reversed day/night cycle, restlessness, agitation).

....

Interventions by family:

....

Safety and security issues: (Include details of follow up action in event of loss of keys or lock out of house)

....

Safety Assessment Scale: Yes ¬ (see attachments) No ¬

....

Client insight/understanding of diagnosis:

....

Family understanding of diagnosis:

....

Coping capacities:

....

RELEVANT HEALTH INFORMATION

Client/carer perceived difficulties and/or health problems (eg: hearing, allergies, incontinence)

Client: ....

Carer: ....

Medication Management:

Self management ¬ Supervision and Prompting ¬

	Drug	Dose	Times Taken
1.	....	....	....
2.	....	....	....
3.	....	....	....

Please circle either an A, B, C or N/A for the following where:

A represents "Independent"
B represents "With assistance" and
C represents "Dependent"
N/A represents "Not applicable"

Shopping/Banking	A	B	C	N/A
Preparing Meals	A	B	C	N/A
House Work	A	B	C	N/A
Home maintenance	A	B	C	N/A
Use of telephone	A	B	C	N/A
Transport	A	B	C	N/A

Comments:
....

Transport Used: Car ± * Taxi ± Public transport ± #
Other/Comment: ....
* Drives (consider Vic Roads Assessment)
# Goes Out alone (consider bracelet / safe return home)

Tasks of Self Care
Is assistance required with the following:

Bathe/Shower	Yes ¬	No ¬	
Dress/Undress	Yes ¬	No ¬	
Eat a meal	Yes ¬	No ¬	
Grooming	Yes ¬	No ¬	
Get in/out of bed	Yes ¬	No ¬	
Use the toilet	Yes ¬	No ¬	
Walking	Yes ¬	No ¬	
Footcare	Yes ¬	No ¬	Podiatry ref Yes ¬ No ¬

Equipment Used to Maintain Independence

Wheelchair - Electric ¬
- Manual ¬

Standing Frame ¬
Hoist ¬
Walking stick/crutches ¬ (specify) ....
Walker

Oxygen Equipment ¬
Commode ¬
Modified Chair ¬
Other ¬

SOCIAL SITUATION

Current Support Networks

Informal Support eg; Carer, friend, social club, church group	Formal Services currently received.

Life History

Family Genogram *(Childhood years)*

Record Names

Mother		Father
Eldest		Youngest

Family Genogram *(Married life)* Record Names

Client			Spouse
Children Eldest			Youngest
Grandchildren			

Place of birth, childhood, family, schooling, occupation, major life events, strengths and achievements.

……

RECREATIONAL INTERESTS

(eg: hobbies and interests)

Past: …………………………………………………………………………………………………

Present: ………………………………………………………………………………………………

Other points of interest: ……………………………………………………………………………

Care Management Goals

Carer: …………………………………………………………………………………………………

Client: …………………………………………………………………………………………………

ACTIONS ARISING FROM ASSESSMENT

Agreed action/service response of assessing service.

……

Agreed referral or action.

……

Referring service notified action taken Yes ¬ No ¬

Appendix 2.

Assessment Summary *(include care needs, whilst at the Day Centre, eg. acceptance of Day Care routines, mobility, continence, nutritional, sensory losses, physical and emotional status)*

....

....

Completed by: .... Date: ..../........./.........

Check List

Provided with information and contact numbers for Yanada House ☐
Info about privacy provided ☐
Service agreement and consent form signed ☐
Informed about rights and responsibilities ☐
Informed of Grievances Process ☐
Information about Carer Support Groups ☐
Provided with information Emergency After-Hours Services ☐

Referral Options:

ACAS	Yes ☐	(please get written Consent)	No ☐
Carer Links North	Yes ☐	(please get written Consent)	No ☐
Alz. Aus Vic (AAV)	Yes ☐	(please get written Consent)	No ☐
Other Day Centre	Yes ☐	(please get written Consent)	No ☐
Migrant Resource Centre	Yes ☐	(please get written Consent)	No ☐
Home Care	Yes ☐		No ☐
In Home Respite	Yes ☐		No ☐
Personal Care	Yes ☐		No ☐
Home Maintenance	Yes ☐		No ☐
Meals on Wheels	Yes ☐		No ☐
Interested in Education	Yes ☐		No ☐

Others

....

CITY OF DAREBIN

YANADA HOUSE DEMENTIA CARE UNIT
INDIVIDUAL CARE PLAN

CLIENT NAME:________________________**CARER:**_____________________**DATE:**

FIRST REVIEW BY:_________**FOLLOW-UP REVIEW DATES (see Progress Notes):**________

____

____**GOAL:**_____________________

____

IDENTIFIED CLIENT CARE NEEDS AND STRATEGIES

ACTIVITIES /
Past & Current Interests:
....
....Participates in
Physical Activities:
....
.... **Social Activities:**
....
....

EATING SKILLS/DIET:
Diabetic:-(Please Circle) **No** **Yes**............**Insulin Dependent** **Diet Controlled**
Likes...
....**Dislikes**..
....
......**Support required** Yes No
....**Nutritional Screening**
Yes (See Attached Form) No
....

COMMUNICATION :
....
....

BEHAVIOUR/PSYCHOLOGICAL:
....
....
Behaviours of Concern: YES (use ReBoC Chart) No
....
……………………………...Interventions:
....

....
ORIENTATION (Time/Place/Person): .... Interventions: ....
SOCIAL SKILLS: ....Interventions: ....
MOBILITY/TRANSFER: ....Interventions: ....
CONTINENCE: .... Interventions: ………………………….. ....
PERSONAL CARE: ....

I understand and agree that the above care strategies reflect the level of support my relative requires and will receive at Day Centre.

______________ ______________________ ____

(Date) (Carer/Client) (Day Centre Representative)

Flexible Respite Options Project

Introduction:

Effective Change has been engaged by the City of Darebin to conduct a project to explore the options for innovative, creative and flexible respite for people with dementia living in the municipality. The project will include the running of two pilot programs:

- a Men's Group for active and/or younger men with dementia, who do not fit easily into the usual day centre type program and
- a Sundowners' Group for those people who become disoriented/ agitated in the early evenings.

The pilots will run for 12 weeks each and we are consulting with the clients and family carers involved to evaluate the success / outcomes of the programs.

The clients (people with dementia) will be interviewed once, halfway through the 12 week pilot, while they are attending the group.

The family carers will be interviewed three times during the project

- at the beginning of the pilot program (Survey #1)
- mid way through the pilot program (Survey #2)
- at the completion of the 12 weeks (Survey #3)

The feedback you provide will inform the refinement and evaluation of the project.

Family Carers Survey #1

[telephone interview at the beginning of the pilot program]

1. Does your family member currently utilise any respite service or a 'service that lets you take a break'? e.g. Yanada House Day Program; in home respite provided by council; residential respite.

   Yes ☐ **No** ☐

2. If you do, what type do you use and how frequently?

   ____

   Weekly ☐ **Fortnightly** ☐ **Monthly** ☐ **Quarterly** ☐

3. If you don't use respite care currently, what is the reason for this?

   ____

4. Do you currently use any other services e.g. Homecare, home maintenance, or attend senior citizens or other group activities e.g. RSL?

5. Do you feel that you and/or your family member need respite "a break"?

6. Why have you (and your family member) decided to accept this service?

7. How do you feel about your family member going to a respite program at Yanada? (nervous, happy, relieved). Why?

8. What do you (as a family carer) hope to get out of your family member attending the respite program?

9. What do you hope your family member gets out of the respite program?

10. How do think participating in the respite program will affect your caring role and your ability to manage in your caring role?

Family Carers Survey #2

[Telephone interview at the mid point of the pilot program]

1. How do you feel about your family member going to a respite program at Yanada? (nervous, happy, relieved). Why?

2. How satisfied are you with the way your family member is cared for at respite?

3. Is the program meeting the needs of your family member? Please explain.

4. How has the pilot program affected you and your caring role? What has changed?

5. Has the respite program enabled you to "have a break"?

6. Does the day and time of the program suit your needs?

7. In your view what is working well? Why?

8. In your opinion what improvements could be made? Why?

Family Carers Survey #3

[telephone interview at the end of the pilot program]

1. How do you feel about your family member going to a respite program at Yanada? (nervous, happy, relieved). Why?

2. How satisfied are you with the way your family member is cared for at respite?

3. Do you feel that you and/or your family member need respite "a break"?

4. Is the program meeting the needs of your family member? Please explain.

5. How has the pilot program affected you and your caring role? What has changed?

6. Has the respite program enabled you to "have a break"?

7. In your view what is working well? Why?

8. In your opinion what improvements could be made? Why?

9. Were your expectations of the program met?

10. If you had not accessed respite before this, are you more inclined to take advantage of respite now? Would you consider using other services?

Questions for Clients

To be administered during the program

Client Profile (source program records)

- name
- gender
- age
- ethnicity: CALD, language, ATSI.
- caring situation
- referral source
- service usage
- case manager (where relevant)

Client Questions

1. Do you enjoy being here?

2. What do you enjoy most:

    - going out?
    - the meals?
    - the activities? (need a list of possible activities)
    - the people?

3. What other activities would you like to do?

4. Would you like to keep coming here?

Case Studies

Men's Group – Out and About

Mr AB:

- initially:
  - attended Men's Group,
  - initially VERY reluctant to leave security of home and wife,
  - demanding and insecure,
  - verbose and 'jargon' type expressive language,
  - isolated.

- outcome:
  - social skills came to the fore within the group,
  - eager to attend on Fridays,
  - confident and happy within group,
  - connected.

Mr CD:

- initially:
  - verbally aggressive towards partner and carers,
  - restless and easily agitated,
  - reluctant to attend and stay.

- outcome:
  - happy to attend and stay with group,
  - singing at home and getting himself ready for the Friday group without prompting from carer.

Sundowners' Group

Mr. EF

- initially:
  - very restless in the afternoon,
  - had a tendency to wander,and
  - not sleep through the night.

- outcome:
  - returning home settled and calm,
  - happy to watch TV quietly,
  - sleeping peacefully at night with less restlessness evident the following day.

Community Interest Group

Ms. GH:
- ❖ lives alone,
- ❖ daughter supportive but busy with own family,
- ❖ subsequently, doesn't get out much.

Began attending weekly exercise group with one paid carer and three other ladies. They go out for coffee and a snack after their class.

Ms. GH reported:
- ❖ enjoying the company – "its great to have a laugh",
- ❖ enjoying the exercise,
- ❖ feeling connected to others ,
- ❖ having something to look forward to through the week.