POSITIVE SOLUTIONS

to the

CHALLENGES OF RESIDENTIAL RESPITE

for people with dementia

by

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CONTENTS

Introduction

The Elements of Successful Respite

1. Assessment
   - Building Rapport
   - Assessment Tools
   - Gathering Information from Various Sources
   - Health Status

2. Preparation
   - Information Provision
   - Respite Forums
   - Pre-admission Facility Visits
   - Practical Assistance
   - Emotional Support and Counselling

3. Selecting the Right Environment
   - Community Respite Houses
   - Dementia Specific Respite Cluster Model
   - Dementia Units within an Aged Care Setting

4. Supporting the Respite Stay
   - Brokerage
   - Volunteers
   - Reminiscence Books
   - Monitoring

5. Supporting the Facility

6. Review and Evaluation - Learning from Experience

Residential Respite Carer Support Worker’s Role & Carer’s Experience

Conclusion
The physical and emotional challenges of caring for someone with dementia can often be formidable. Residential respite, which provides a short break for frail aged people in an aged care facility, is often essential to support carers and enable them to continue in their caring role at home. However, residential respite is often fraught with difficulties because either the family or the facility is insufficiently prepared for the challenges involved. The Residential Respite Network (RRN), which is a subgroup of the Victorian Carer Services Network (VCSN), has been working to address some of the barriers to the provision of successful residential respite for people with dementia. Successful respite occurs when a respite stay is completed, a re-booking is made, and there is positive feedback from all parties involved. This paper seeks to tease out the elements of successful respite based on the experiences of the RRN.

The RRN consists of Commonwealth Carer Respite Centre (CCRC) staff who play a critical role in the field of residential respite development. These CCRC respite coordinators encourage and support aged care facilities to provide respite services, and often operate a respite booking service in partnership with the facilities. They also support and encourage families to access planned respite and promote the development of innovative and flexible respite options. The RNN operates as a subgroup of the VCSN, which is a network of CCRC’s, Commonwealth Carer Resource Centres and State-funded Carer Support Services. The aim of the VCSN is to promote an accessible, responsive and integrated statewide carer support system.

ELEMENTS OF SUCCESSFUL RESPITE

We have identified the following factors to be critical in the provision of successful residential respite for people with dementia and their carers:

- **Assessment** - a thorough and holistic assessment of relevant information relating to the person with dementia and their carer
- **Preparation** - preparing all parties thoroughly for the respite stay
- **Selecting the right environment** - to meet individual needs
- **Monitoring and Support** - Supporting the person with dementia and carer, as well as the aged care facility during the respite stay
- **Review and Evaluation** – feedback from all parties involved

POSITIVE SOLUTIONS TO THE CHALLENGES OF RESIDENTIAL RESPITE FOR PEOPLE WITH DEMENTIA
1. ASSESSMENT – GETTING THE REAL PICTURE

Successful respite starts with a thorough and holistic assessment of all of the factors that may affect the respite stay. These include past experiences, daily routines, behavior factors, general health factors and issues affecting the carer.

The assessment process should assist us to:

- Gain insight into the needs of the person with dementia and the carer.
- Explore the best ways to support the carer and person with dementia to prepare and access respite.
- Select the most appropriate facility at which to access respite.
- Identify and organise additional supports to support the respite stay.
- Anticipate issues that may arise and explore possible strategies.
- Commence a care plan for the person with dementia.

We have found that thorough and holistic assessments require input from a variety of people, the use of a number of assessment tools and good rapport and communication with the carer and person with dementia.

Building Rapport

Gaining the carer’s trust is essential to enable the carer to disclose all the relevant information that is needed including information that carers may consider sensitive or embarrassing. For example, a carer may not feel comfortable raising the fact the person with dementia is incontinent, is disinhibited or is prone to aggressive behaviour. However, if respite is going to be successful, these ‘sensitive’ or ‘embarrassing’ behaviours need to be identified and addressed and the carer enlisted in the development of strategies. Furthermore, issues that may arise during the respite stay are best managed by having a strong rapport between all stake holders.

Assessment Tools

There are a number of assessment and application forms required before respite can be arranged. What works well for people with dementia and their carers is the use of streamlined uniform tools that provide necessary information about the person and which are portable between facilities.

The Commonwealth requires the completion of its Aged Care Client Record (ACCR) which is administered by the Aged Care Assessment Service (ACAS) and is a mandatory requirement in order to access respite at a Commonwealth funded Aged Care Facility. The ACCR assesses the level of care required for the person with and is used throughout Australia. It is a useful tool but it is generally completed within a limited time frame and cannot provide details on the
changing functioning of the person often associated with dementia and their likely response to an unknown environment such as a nursing home.

Aged Care Facilities need specific information on basic care and health needs, routines, and personal information. Most facilities have developed their own individual forms based on admission for permanent care and containing varying degrees of specific information on the carer. Like the ACCR these forms often provide limited information on the psycho-social needs of the person with dementia.

The RRN have found that what works well for families is the customization of facility information forms that can be used across different facilities and include personal profiles/psycho-social information.

The CCRC Barwon Region have been able to arrange for all the facilities in which they book respite to use the same residential respite assessment and application tool. If a carer is re-booking respite at the same or a different facility, the assessment and application tool only needs updating.

The CCRC Eastern Metropolitan Region have designed a ‘Respite Passport’ tool which is used with facilities which insist on using their own assessment and application forms. This tool compliments the facility’s own form by focusing on the person’s personal background and history, current lifestyle and daily routine.

CCRCs also require information on the carer and person with dementia in order to meet their own reporting obligations and to arrange an appropriate respite booking. The CCRCs in Victoria have jointly developed a Carer Profile which is now used throughout the State when making and receiving referrals.

**Gathering Information From Various Sources**

Past experience has shown us that input and cooperation is required from a variety of sources to ensure the respite is successful. It is unlikely that one person holds the key to fully understanding the various care needs of a person with dementia. In addition to the information provided by the person with dementia and the carer, respite coordinators often need to liaise with:

- Extended family members or friends if they take an active role in the care of the person with dementia.
- The GP who is required to complete medication charts and refer to a locum service if he/she is not able visit the facility should a consultation be required during the respite stay.
- ACAS worker to clarify the details of the ACCR assessment.
- The Case Manager, Care Coordinator or Carer Support Worker who may be working with the family. These workers often play a significant part in facilitating the respite stay due to their relationship with the carer and the person with dementia.
Health Status

While assessing for residential respite we are always conscious of the importance of the client’s health status. The presence of underlying health issues such as urinary tract infections, diabetes, dehydration or side-effects of a new drug can have significant impact on the functioning of a person with dementia. Such illnesses need professional diagnoses and treatment prior to the respite stay as untreated the illnesses may exacerbate behaviors of concern.

The CCRC Eastern Metropolitan Region manages a booked respite cluster model with nine beds at Olivet Nursing Home in Ringwood, Victoria. Following a thorough assessment of the person with dementia, a decision is made as to whether blood and urine tests are recommended prior to the respite stay. This is especially the case in situations where the carer is reporting significant changes to the person’s behaviour. Such testing tends to reduce the potential for an underlying illness adversely affecting the respite experience.

2. PREPARING FOR RESPITE

Thorough assessment is the starting point for exploring the best ways to support the carer and person with dementia to prepare for the respite stay. Some carers report being in such a high state of exhaustion that what they value most is practical support such as someone to help with sewing on name tags on the clothing the person with dementia will take to respite. Other carers identify that their biggest worry is dealing with their own feeling of guilt and prefer emotional support and counselling to assist them to prepare for respite.

Information Provision

For respite to be successful, carers and the person with dementia need to be well informed. Respite Coordinators convey the necessary information in a variety of ways and at the most appropriate times to avoid information overload. The necessary information is provided through a combination of letters, telephone contact, home visits, respite forums and information packs and booklets.

To streamline information provided to families, the CCRC Barwon Region has developed two Residential Respite Booklets. The “Carers Residential Respite Information Booklet” is given to potential users and provides information about the steps involved when accessing residential respite, including the emotional impact of respite.

The second booklet is designed to provide specific facility information to carers and respite residents. Although many facilities have their own information packs for permanent residents, this booklet has been condensed to target the specific needs of respite users.
Respite Forums

All Commonwealth Carer Respite Centres in Victoria run residential respite forums to assist carers to prepare for the experience. A Residential Respite Forum Manual has been developed by the RRN and is available on the VCSN website (www.vcsn.infochange.net.au). The aims of the forums include:

- Demystifying residential respite.
- Increasing awareness of the practical processes of accessing respite, for example, the role of the ACAS worker.
- Exploring some of the emotional issues associated with residential respite.
- Encouraging regular respite bookings.

These forums often include a presentation by a carer who is familiar with respite and a Director of Nursing (DON) from a local facility that provides respite.

Some of the reported benefits for carers of people with dementia are that carers:
- Feel more confident about using residential respite.
- Begin to develop trust with the DON and facility staff.
- Feel less isolated and feelings are normalised.
- Begin to identify the issues that need to be resolved for the respite stay to be successful.
- Experience peer support.

Pre-Admission Visits To The Facility

A pre-admission visit to the facility is an essential component of preparing for respite. Carers tell us that admissions can be a highly stressful experience and we are aware that the information provided to the carer during this time is not always retained. Carers often prefer to attend this appointment without the person with dementia to avoid unnecessary stress and anxiety.

The pre-admission appointment is most effective when it includes an individual tour and an appointment with a key staff member such as the DON.

Benefits of pre-admissions visits include:

- The carer becomes more familiar with the location of the facility. Concerns about parking and travel time can be resolved.
- The carer can meet the facility’s staff member who will be their main contact during the respite and a relationship can be established.
- The carer is able to tour the facility and see the respite room. This assists in clarifying which items may or may not need to be brought to respite, for example, the respite room may have a television and therefore one is not required to be brought from home.
• The carer learns about the day to day operations and routines of the facility as well as the services which may be available during respite, such as hairdressing.
• Issues regarding appropriate clothing for respite, laundry facilities and the labelling of clothes can be discussed.
• The staff member can complete the facility’s information and care plan documentation.
• Questions about the suitability of the facility and its ability to meet the person’s care needs can be explored in detail by the carer and the DON.
• All relevant documentation, such as the completed medication chart, can be provided to the facility with time to clarify any issues.

Practical Assistance

The practical support that carers and the person with dementia may require is variable and dependent on their own level of stress, the time they have available to complete the practical tasks and degree of informal supports available. Some of the practical supports CCRC’s Respite Coordinators provide to carers have included:

• Ensuring the GP has filled in the medication chart correctly and in time for the respite admission.
• Assisting the carer with transport to the facility for the pre-admission appointment, admission, discharge or carer visits.
• Providing information on how to get the electrical audit done on electrical appliances being taken to respite.
• Providing a list of suitable clothes and other items to take to respite.
• Purchasing labels and arranging a brokered worker to sew these on where the carer is unable to do this.
• Assisting the carer and person with dementia to develop a reminiscence book to take to respite.

Emotional Support And Counselling

Emotional issues such as feelings of guilt, loss and grief are one of the major reasons for the failure of residential respite. The importance of identifying these issues and providing access to appropriate support cannot be underestimated. CCRC’s have access to Carer Support Workers and Respite Coordinators who provide short-term outreach professional case assistance to deal with emotional barriers to respite such as carer guilt, reluctance by the person with dementia to access respite and negative pre-conceived ideas of aged care facilities. This short-term outreach professional case assistance is often supplemented by formal professional counseling services by services such as the Carers Victoria Counselling Service.
3. SELECTING THE RIGHT ENVIRONMENT

People with dementia especially those with behaviors of concern need the right environment for respite to be successful. Successful respite occurs when clients and facilities are effectively matched, when the facility has a focus on respite as a service in its own right and when there is a genuine commitment to meeting the needs of people with dementia.

The provision of successful respite often incorporates a mix of:

- Good initial information and appropriate targeting.
- Appropriate staffing ratios including one to one support at critical times of the day.
- Well supported staff who are qualified and experienced in working with people with dementia.
- Staff who understand and appreciate the demands of the caring role at home.
- Consistency of staff for the person with dementia.
- Maintenance of individual daily routines.
- Good activities program that taps into the person’s biography and current interests at home.

The following models are examples of best practice in providing residential respite for people with dementia.

Community Respite Houses

Community respite houses are home-like facilities dedicated to respite and often incorporate day or other community based programs. They have been shown to be successful in the following ways:

- They are flexible – for instance hours of admission/discharge and duration of the respite stay can be varied. Carers have a choice of respite types including day programs, evening only, overnight or several nights of respite.
- Individual routines can be managed such as the time of showering, eating, sleeping.
- Activities can be individually tailored.
- Create a homely environment.
- Staffing can be flexible to meet individual needs eg a regular pool of staff is used ensuring consistent staffing, staff with appropriate languages and varied staff ratios to meet needs.

Kilby House

Kilby House, a Community Respite House operated by Benetas, is extremely successful in meeting the respite needs of people with dementia – approximately 80% of the respite bookings are for people with dementia. This success is based
on Benetas’ commitment to making Kilby House a flexible, person centred-respite service.

**Dementia Specific Respite Cluster Model**

The respite cluster model involves providing a cluster of about ten respite beds, within a facility. The theory is that a critical mass of respite beds facilitates the development of:

- A strong and positive ‘respite culture’.
- Systems and processes that promote better respite assess, monitoring and support of the carer, respite resident and the facility.

**Montgomery Aged Care**

Montgomery Aged Care is a 30 bed dementia specific facility situated on the grounds of the Caulfield General Medical Centre and has a cluster of 4 respite beds. Montgomery’s successful respite outcomes can be attributed to:

- The staff’s experience and commitment in meeting the care needs of people with dementia.
- The staff’s commitment to carers and valuing the role carers play in the community.
- The management’s commitment to use additional resources obtained through the model to fund increase staff to support the respite stay.

**Dementia House and Dementia Unit within an Aged Care Setting**

**Carnsworth Nursing Home**

Carnsworth (a Garoopna Uniting Care facility) caters for 147 residents and includes a 30 bed dementia specific wing. Carnsworth has been able to provide successful respite to those people with dementia and challenging behaviours who have had ‘failed’ respite experiences in other facilities - including those with so-called dementia units. Some of the reasons why Carnsworth has succeeded include:

- Careful targeting of people who are appropriate for the facility. The unit provides for people with dementia who are active and able to mobilise unaided, who may exhibit aggressive behaviour or who may wander or abscond.
- The staff are well experienced and supported in working with people with dementia and challenging behaviours.
- The staff and management are sensitive to the needs of the carer.
- Activities programs are appropriate for the needs of the client group.
- The facility is fully secure.
- The facility ‘fosters an environment focused on the needs of residents by the creation of an organisation where residents, families and staff feel valued'
Sefton Lodge
Sefton Lodge, also operated by Garoopna Uniting Care Sefton, is a 13 bed low level dementia specific facility. Sefton Lodge attempts to offer a “one stop shop” or “continuity of care” model of respite, where many of a person’s respite needs can be met within the one aged setting. Sefton Lodge provides:

- Planned activity groups (PAG) for people living at home.
- Planned activity groups for the facility’s permanent residents which often combined with the PAG group for increased socialisation and recreational opportunities.
- A booked residential respite program.
- One unlicensed respite bed for overnight or extended respite.
- Two carer support groups, one specifically for carers of someone with early onset dementia.

Sefton Lodge is ideal for people with dementia as it reduces the stress and disorientation associated with attending different facilities to access different types of respite. This type of respite model reduces the divide between the residential and community care sector.

Eureka Village Hostel
The CCRC Grampians Region in partnership with Eureka Village Hostel run a very successful Dementia Respite Program. The Hostel is a 45 bed low care facility in Ballarat that provides one respite bed. The success of the respite program is due to:

- Focus on rapport building and assessment.
- Focus on supporting staff through training.
- Focus on supporting carers through a designated respite worker at the Hostel.
- The partnership approach with the CCRC as the referral and booking agency.

Further information on the Eureka Village Hostel Dementia Respite Program is available at this conference from the Hostel’s poster presentation ‘Dementia Respite – A New Collaborative Approach’.

There are only a small sample of facilities that provide successful respite for people with dementia and their carers.

4. SUPPORTING THE RESPITE STAY

Brokerage

A key element in providing successful respite is the capacity of CCRCs to provide additional flexible brokered support to respite providers. The assessment
and preparation processes may have indicated a specific need for targeted additional support for the facility to ensure the respite stay is successful. Examples of such support are:

- Assisting a person with dementia during sundowner times when s/he becomes agitated and disruptive to other residents.
- Reducing the stress and anxiety of a person from a CALD background by brokering a worker from the same cultural background to converse with the person.
- Supporting continuity of care by having a known personal care worker assisting with personal care.

**Use of Volunteers**

In some regions, such as the Eastern Metropolitan Region and the Loddon Mallee Region, CCRC trained volunteers are used to support the respite stay.

If the carers and respite residents agree, a volunteer is arranged to make ‘companionship’ visits to the respite resident at the facility during the respite stay. The visits may include a walk in the garden, afternoon tea, reading the paper or a game of cards. Some clients who exhibit extreme behaviours such as physical aggression may not be suitable for these programs.

Benefits of the volunteer program have included:

- A carer reported feeling less guilty about not visiting daily as she knew that her husband would receive visits from the volunteer.
- A man (care recipient) who had been reluctant to use respite agreed to respite re-bookings as he developed a strong friendship with the volunteer and enjoyed their times together.
- A volunteer was able to support a man with dementia who was a retired executive and who insisted that someone take on the role of secretary and take minutes and make calls for him. The staff at the facility were not able to provide him with the one to one attention he was needing so a volunteer was able to meet his needs. This had benefits for both the person with dementia and the facility staff.
- A person whose care needs excluded him from the facility’s’ group activity program was able to engage in one to one activities with the volunteer.
Reminiscence Book

A reminiscence book can play a significant and powerful role during the respite stay. It can:

- stimulate conversation between respite facility staff and the person with dementia.
- Can reassure the person and have a settling effect if the person is feeling bewildered or confused at being in respite.

Decisions about where the reminiscence book will be stored and how it will be used need to be clarified prior to the respite stay.

Monitoring

Monitoring the respite stay is a crucial element in problem solving and preventing unexpected issues from derailing the respite stay.

No matter how much preparation, support and careful selection of an appropriate place for respite, residential respite can be challenging for all concerned. These challenges may be a result of:

- Changes in care needs due to unforeseen medical conditions.
- Confusion and distress caused by the change in environment.
- Carer stress caused by unrecognized feelings of separation, guilt, grief and loss.
- Carer lack of confidence in the ability of the facility to provide appropriate care.
- Unanticipated staffing or other issues within the facility.

Communication and monitoring throughout the respite stay allows the CCRC to identify and address developing issues. Some of the strategies could include:

- Providing one to one support for the carer including referral to a Carer Support Worker or counseling services as appropriate.
- Liaising between the carer and facility when communication issues arise.
- Monitoring the effectiveness of brokered support to assist the facility.
- Supporting the facility to access specialist assistance including Aged Psychiatry Assessment Teams or Dementia helplines.

5. SUPPORTING THE FACILITY

In most facilities, respite is a minor part of the overall service provision. Respite is often seen as difficult, labour intensive and financially unrewarding. Staff may have experienced unsupported respite programs and have developed negative
attitudes to respite itself. As a result, staff may be unaware of or indifferent to the respite resident’s specific needs or the needs of the carer.

It is critical therefore that CCRCs work to highlight the benefits of successful respite programs and encourage a culture that values and supports carers.

CCRCs use a variety of strategies to assist facilities:

- Maintaining regular telephone contact with the DON and visits to the facility.
- Ensuring ACF staff understand that they can refer families back to the CCRC if families are finding it difficult to manage during the respite stay.
- Assisting facilities to develop internal processes for debriefing after stressful situations with families.
- Facilitating staff training/in-service on carer friendly practices.
- Co-ordinate respite bookings and organise relevant paperwork.
- As indicated above, use brokerage funds to provide assistance in meeting the care needs of people with dementia and challenging behaviours.
- Providing opportunities for feedback on individual respite stays.

6. LEARNING FROM OUR EXPERIENCE – GETTING EVERYONE’S FEEDBACK

Learning from experience is crucial in improving respite programs. The RRN is currently developing best practice guidelines in evaluating respite stays. Feedback is not necessarily forthcoming unless it is actively sought so a structured approach to evaluation is important.

Feedback is needed from all stakeholders – carer, person with dementia whenever possible, facility and CCRC. A variety of approaches is needed, for example, carers need to be given the opportunity to have a face to face or telephone interview rather than completing a questionnaire whilst facilities may prefer to complete a checklist.

RESIDENTIAL RESPITE CARER SUPPORT WORKER’S ROLE AND CARERS’ EXPERIENCE

The CCRC Western Metropolitan Region has developed the role of Residential Respite Carer Support Worker (RRCSW) to support carers who have or are likely to have significant difficulties with accessing residential respite. This innovative position was created after a pilot program identified the needs of carers who are: reluctant first-time users or re-users of residential respite, who are caring for someone with complex care needs – including dementia and challenging behaviours, or who are from culturally and linguistically diverse backgrounds. The position encapsulates the key elements of successful respite outlined in this
paper including using flexible brokerage to support both the carers, care recipients and the age care facilities before and during the respite stay. The position also has a service development role in promoting quality residential respite and carer friendly practice within aged care facilities.

The presentation of this paper includes a carer and her adult daughter speaking about their personal experiences of accessing and using residential respite for the carer's husband. They discuss the difficulties they encountered and how, with the support of the RRCSW, were able to overcome the challenges and make respite a successful experience.

**CONCLUSION**

Residential Respite can enable carers to continue their caring role with enhanced quality of life for themselves and the person with dementia. However, the decision to access respite is often a difficult one - there are many barriers: practical and emotional barriers and limited availability of suitable respite.

To increase respite availability and reduce respite barriers for carers of people with dementia, the VCSN/RRN recommend further development of strategies and models based on feedback from all stakeholders. Much of that development does not involve significant increases in financial resourcing and can be easily implemented as it relies on the expansion of current services and using pre-existing infrastructures.

In particular, the VCSN/RRN strongly believe that:

- CCRCs should be supported to further develop their ability to have professional staff working in partnership with key stakeholders to support the respite – before, during and after the respite stay.
- The various dementia respite models described in this paper should be expanded to meet the increasing and diverse respite needs of the community.
- There is no substitute for thorough and holistic assessments which can forestall many potential problems.
- The use of flexible brokerage can aid successful respite.
- Supporting facilities to promote a culture which acknowledges and values the role of carers promotes successful residential respite.