



Discussion Paper 5

October 2012

**THE MOST  
DIFFICULT  
DECISION:**

**DEMENTIA AND  
THE MOVE INTO  
RESIDENTIAL AGED  
CARE**

**TALKING ABOUT ALZHEIMER'S  
ACROSS AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

# ACKNOWLEDGEMENTS

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If you are a residential aged care provider in Australia and you would like to evaluate your service/s against the data obtained in this research, please contact the General Manager – Policy, Research and Information at the phone number below.

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# CONTENTS

Acknowledgements	2
Acronyms used in this paper	4
Executive Summary	5
Background	8
Purpose	9
Current literature	10
Methodology	11
Results	12
Discussion	14
Service Implications	28
Policy Implications	30
Conclusion	31
Recommendations	32
Endnotes	34

## Figures and Tables

Fig.1: Diagnosed dementia and mental illness in Australian RACFs	9
Fig.2: Expectations of staff	22
Fig.3: The dementia care triangle	23
Table 1: Snapshot of survey respondents	12
Table 2: Key themes for carer experience during the admission of a person to a RACF	18

## **ACRONYMS USED IN THIS PAPER**

ADLs	Activities of Daily Living
AlzNSW	Alzheimer's Australia NSW
BCS	Baptist Community Services - NSW & ACT
BPSD	Behavioural and Psychological Symptoms of Dementia
CALD	Culturally and Linguistically Diverse
HACC	Home and Community Care
HREC	Human Research Ethics Committee
RAC	Residential Aged Care
RACF	Residential Aged Care Facility
UCA	UnitingCare Ageing NSW.ACT

# EXECUTIVE SUMMARY

**Adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyond<sup>i</sup>.**

While policy direction<sup>ii</sup> and the wishes of the person with dementia and their carer can dictate that people with dementia may stay living at home for as long as possible, the impacts of the symptoms and behaviours of dementia mean that ultimately a large number of people with dementia will move into residential aged care (RAC).

Currently there are 280,000 people living with dementia in Australia. Amongst the Australians living in RAC, more than half (52%) have a diagnosis of dementia. Moreover 87% of that number is residing in high care accommodation<sup>iii</sup>.

For the family and carer, the experience of placing a person with dementia into RAC can often be characterised by stress, emotional upheaval, and feelings of relief, loss, grief and guilt. For the person with dementia, moving into RAC can also be disorienting, disempowering and emotional. In addition, the progression of dementia is also occurring, which can exacerbate the problem.

This research identified a high proportion (nearly 50%) of people with dementia who transition directly to RAC from hospital. For these people and their carers, the challenges they encounter are magnified by the speed of the move and the lack of choice and decision-making they encounter. It is anticipated this percentage will grow with increasing numbers of people remaining at home, due to the improved capacity of community-based care, until a crisis results in hospital admission. Both levels of Government can make policy and practice changes to improve the experience of this pathway.

Dealing with the emotional stress of transitioning the person with dementia into care was the most significant difficulty for the carer. Practical strategies which can alleviate this emotional stress include: access to a community based key worker following diagnosis of dementia and a designated contact following entry to the residential aged care facility (RACF), access to dementia specific counselling, participation in carer support groups, standardised forms which are accepted by all agencies, implementing person-centred approaches in the RACF with a strong emphasis on high quality communication at all levels, as well as staff validating the knowledge of the carer and involving them and the person with dementia in their care planning, decision making and service delivery.

A pro-active approach to minimise the negative outcomes associated with moving into residential care should include:

- improved quality and timeliness of information about moving to a RACF
- psychosocial support to negate the impact of emotional stress
- the adoption of a staged approach to 'sharing the care' through easier access to carer respite in a RACF

In addition, carers felt that other aspects which would improve the experience of moving and settling in to a new environment include:

- staff skilled in delivery of quality dementia care
- a higher staff to resident ratio
- provision of meaningful, inclusive activities which interest the person with dementia
- a warm and welcoming environment that is characterised as 'home like'

- strong leadership and management skills to promote quality dementia care before, during and after the placement of the person with dementia into residential care.

This discussion paper incorporates the results of a consumer driven research project and examines the experience of the person with dementia and their carer regarding the placement of a person with dementia into RAC. It presents implications for service and policy development and recommends the following:

### **Australian Government:**

1. Funds a network of key workers to support the carer and person with dementia, which would include the period of moving into residential care.
2. Increases funding to the National Dementia Helpline to provide counselling to people experiencing the emotional impact of moving into residential care.
3. Develops standardised application and information forms which are accepted by all agencies.
4. Develops alternative models of housing which improve the experience of settling in to a new environment, particularly for people with younger onset dementia, Aboriginal people, Culturally and Linguistically Diverse (CALD) communities, and those with mental health conditions.
5. Develops the Aged Care Gateway to ensure:
  - it supports access to information for consumers to make choices about alternative housing options, including Aboriginal and CALD communities
  - it directs and refers people to the National Dementia Helpline
  - the My Aged Care website and associated call centre provides information about RACFs with dementia

specific services and up to date information on vacancies

6. Instructs the Aged Care Standards and Accreditation Agency to monitor dementia design with performance reported on the My Aged Care website.
7. Focus its Living Longer Living Better workforce initiatives on leadership and management in aged care to promote quality dementia care.
8. Consults with people with dementia and carers when developing the trial of consumer directed care in RAC.
9. Amends its policy on respite in RACFs to expand its potential use to include a staged approach to 'sharing the care'.
10. Funds further research that examines the subjective experience of people with dementia about this significant transition period in their lives.

### **NSW Government:**

11. Amends its policy on discharge planning from hospital for a person with dementia to provide two days' notice as a minimum to the person with dementia, their family and to RACF staff to provide better quality of support in the transition into residential care.
12. Instructs Local Health Districts to develop service pathways for the person with dementia and their carer to plan for a future that may include residential care.

### **Service Providers:**

13. Providers of residential aged care:
  - Develop guidelines for good communication standards that acknowledge the value of all stakeholders and enhance relationship-centred care during and after the transition into residential care.

- Acknowledge the emotional impact of the transition into a RACF on the carer and the person with dementia by using a person-centred approach to care.
- Provide education about dementia to carers of residents with dementia as well as all staff working in high care and low care facilities.
- Instigate consumer groups within each facility to hear the voice of the carers and/or support carers to join dementia carer support groups in the community.
- Enable staff to work within a person-centred approach that involves the person with dementia and their carer in their care planning, decision making and service delivery.
- Develop innovative accommodation models to address the needs identified in this research.

14. Dementia service providers develop and promote education for carers about the transition into residential care, before placement occurs.

### What carers told us.....

*I was no longer able to care for my husband – over time I became physically, mentally and emotionally exhausted (wife)*

*I don't think it could have been improved; the social worker made my job very easy and the staff in the home also helped make the move less stressful (carer)*

*It was becoming unsafe for my mother to live on her own despite all the external assistance and help my partner and I were providing her (adult child)*

*Difficult discussing with my sister as she has been in denial that mum has dementia (adult child)*

*As far as I know there was no counselling or even discussions with mum about her future life in an aged care facility and it is a big change from living independently (adult child)*

*It went well, with a period of respite transition into full time care. It was well managed given that my mother resisted the move (adult child)*

*You are not in the right frame of mind to deal with all the paperwork and the practical side of things (wife)*

*Every day I see new residents absolutely lost and bewildered at the huge changes taking place (carer)*

*Taking my mother away from her own home 'and her cats' was the most traumatic and saddest event I have ever had to cope with in my entire life (adult child)*

*The staff gradually developed an intimate knowledge of the person I care for and understood his needs and interests. He clearly trusted, and developed attachments to the staff (carer)*

*The constant lack of staff available for care and activities is a real issue...this puts undue stress on both workers and residents alike (carer)*

*Mum felt safe, welcomed and well cared for. I feel very lucky! The move from home to this facility has been a truly 'happy ending' story. The angst at the outset has been greatly outweighed by the health and well-being enjoyed at the present time (daughter)*

*It was up to me to cope emotionally and after 63 years of marriage this has not been easy (wife)*

## BACKGROUND

**Currently 280,000 Australians are diagnosed with dementia. Without a cure, and the increasing number of ageing Australians, this figure is expected to increase to nearly one million by 2050<sup>iv</sup>. The proportion of people with dementia living in residential aged care is estimated at 34%<sup>v</sup>.**

While policy direction<sup>vi</sup> and the wishes of the person with dementia and their carer can dictate that people with dementia may stay living at home for as long as possible, the impacts of the symptoms and behaviours of dementia mean that ultimately a large number of people with dementia will move into permanent residential aged care facilities (RACFs).

In June 2011, there were 185,482 RAC beds operational across Australia. Of these, 63,923 were in N.S.W.

In Australia more than half (52%) of RACF residents have a diagnosis of dementia<sup>v</sup>. Moreover 87% of that number is residing in high care accommodation<sup>vii</sup>.

Moving into residential care is a time of upheaval for the person with dementia, their carer and family for a number of reasons. Different circumstances and expectations will determine positive or negative perceptions of the move.

The time of transition from home or hospital to residential care can be a stressful time for people with dementia and their carers and families. The carer has often reached a point of physical and emotional exhaustion and is unable to continue the caring role without support. A variety of stressors, such as incontinence and other behaviours of dementia, alongside reduced caregiver resources and greater feelings of burden are all associated with placement.

By the time a person with dementia moves into residential care the person is often in

the mid to late stage of dementia and not able to understand the reason they are moving. They can feel disoriented and lost, having moved from their home, sometimes living with only one other person, to a RACF where they are one of many, often sharing a bedroom and a bathroom.

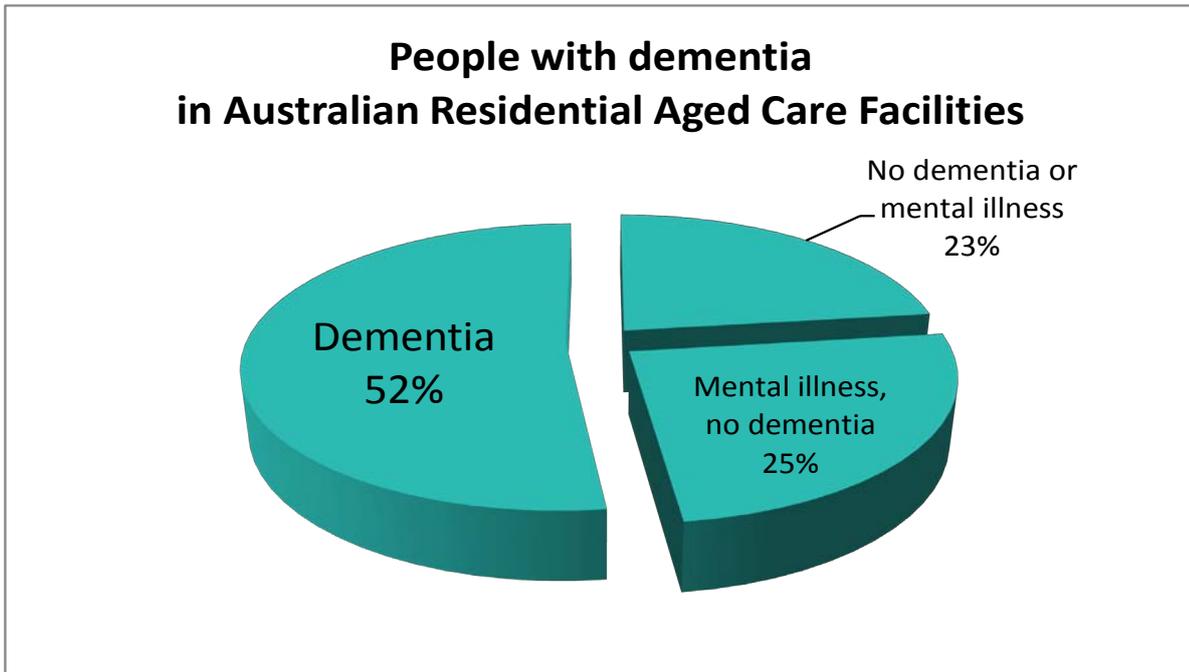
The transition into residential care for a person with dementia is often rushed and may follow a period of time in hospital. The move is often unplanned and the time for decision making may be short and ill informed. This can have a detrimental effect on the person with dementia as well as the carer.

For some carers, placing the person they care for in residential care can be a time of great relief. The carer can feel a sense of assurance that the person with dementia is now safe and in 'good hands' but, the feeling of relief is often outweighed by feelings of guilt or grief and loss. The sense of grief and loss, particularly experienced by spousal carers, is reported to be greater than that following the death of the person with dementia<sup>ix</sup>.

The person with dementia has the right to be included in decisions about the choice of their final 'home' if they have the cognitive capacity to participate, and carers have the right to practical and emotional support via informal and formal means.

Consequently, this transition period needs to be recognised as an important time to ensure the needs of the person with dementia, the carer and the RACF staff are met in a timely and appropriate manner.

Carers and people with dementia deserve an holistic approach to the delivery of support which ensures they have adequate time for preparation, if the need arises, to transfer a person with dementia from either home or hospital, to residential care.



**Figure 1. Diagnosed dementia and mental illness in Australian RACFs**

Source: AIHW (2011)<sup>viii</sup>

## PURPOSE

The purpose of this discussion paper is to examine carer perspectives of the experience of moving a person with dementia into residential care and identify the features of good practice in the care and management of people with dementia and their carers during the transition into residential care.

This paper also examines current literature on issues such as the motivation to move a person with dementia into permanent residential care; the difficulties encountered during the transition period; and the support received during this time.

Ultimately this discussion paper aims to enhance the provision of quality dementia care in RACFs during the important time of transition for the person with dementia and their carer and ultimately, long after placement takes place.

## CURRENT LITERATURE

The literature reviewed acknowledges the emotional toll the period of transition from home, or hospital, to residential care places on the person with dementia and their carer.

Issues that precipitate the decision to move the person with dementia into care are dealt with extensively<sup>x,xii,xiii</sup>. All acknowledge the emotional impact decision-making can have on the carer and family as well as the person with dementia who can be disoriented in unfamiliar surroundings and take time to settle into their new 'home'.

The literature tells us emotional strain is often felt by the carer leading up to placement of the person with dementia into residential care and during the settling-in period that follows. Relinquishing the primary caring role is difficult for some carers, especially spousal carers who have lived with the person with dementia for many years and treat the 'care' of the person with dementia as part of their marital promise. Consequently their experience contrasts in many ways to carers whose relationships with the person with dementia are different.

A number of issues for carers during this important time are highlighted in the literature. These include: when to make the decision to relinquish care; the need for information about the process of moving to a RACF; how to engage with and communicate the decision to the person with dementia; the emotional tension that can exist within families, and; relationships with the RACF staff.

A range of supports, both during and after the placement of the person, is imperative for the carer as well as the person with dementia. The literature tells us the continued support of families after the move enables the person with dementia to settle into their new environment<sup>xiv</sup>.

For carers, social networks such as support groups<sup>xv</sup> and family and friends are important<sup>xvi</sup>, alongside RACF staff who are understanding of the carers needs and circumstances.

There was a significant lack of evidence in the literature that specifically considered the experience of the person with dementia, and meeting their unique needs, during the time of transition into residential care. Much of the literature ignored the capacity, verbal or otherwise, of the person with dementia to communicate their experience, and also, the potential to evaluate the effect of the move into permanent residential care on them.

Furthermore, Crawford et al (2005) state that current literature, on the topic of moving into residential care, often fails to recognise the other more subtle types of 'transitions' that are also occurring. These transitions include the gradual loss of cognition, memory, communication and functional activities. The progression of dementia and its effect on the experience of the person with dementia, their carer and RACF staff is highly significant amidst the practicalities of the move<sup>xvii</sup>.

Grey literature online and in hard copy was also reviewed and included documents to assist carers who need to move a person with dementia into residential care. Overall these were practical, easy-to-read documents which often included checklists to assist the carer in the decision-making process.

## METHODOLOGY

Alzheimer's Australia NSW (AlzNSW) partnered with Baptist Community Services – NSW & ACT (BCS) and UnitingCare Ageing NSW.ACT (UCA) to conduct this project. The research was approved by the BCS Human Research Ethics Committee (HREC).

During the first phase of the project a literature review was conducted. This review included national and international literature on the experience of moving into residential aged care for people with dementia and their carers, government policy documents and grey literature such as information and promotional material to assist people in the process of moving into a RACF.

Focus groups were conducted in metropolitan and regional locations throughout NSW: Inner West Sydney (Campsie), Dubbo, Tweed Heads and Newcastle. Participants were recruited through advertisements distributed by community service providers, Dementia Advisory Services, and Home and Community Care (HACC) Development Officers, and through notices in AlzNSW newsletters, website and social media. Focus groups were conducted with two types of carers - those who had moved a relative with dementia into residential aged care and those who were caring for a person with dementia at home. Separate focus group sessions were held with these groups in each location.

Carers from Aboriginal communities were consulted at the Dubbo focus groups and a focus group was conducted with Chinese background carers in Campsie with the assistance of an interpreter.

After reviewing the literature and analysing the data from the focus groups, a survey was developed for carers who had recently moved a relative with dementia into a BCS or UCA RACF in NSW. This survey was sent to all carers (person responsible) whose relative had moved into a RACF

within the 12 month period May 2011 to May 2012. Respondents were able to complete the survey in paper or online format.

The quantitative data collected was statistically analysed using Survey Monkey analysis functions. Frequencies and cross-tabulations were conducted. Qualitative data was analysed thematically.

At the conclusion of data collection and analysis, a roundtable discussion was held with representatives from BCS, UCA and AlzNSW to workshop the findings, discuss service and policy implications and proffer suggestions for future policy and practice reforms.



## RESULTS

These results are based on survey data collected from carers who had moved a person with dementia into a RACF.

From a sample size of 832 (205 BCS + 627 UCA) carers of people with dementia we received a 30% response rate with 251 respondents (62 BCS + 189 UCA).

The following table provides a demographic snapshot of the combined BCS and UCA cohort who completed the survey:

**Table 1. Snapshot of survey respondents**

Variable	Valid Percent
<b>Relationship of the carer to the person with dementia</b>	
Spouse/partner	27.2
Adult child	60.8
Friend	2.4
Other – included: other family member, godchild	9.6
<b>Gender of carer</b>	
Male	25.2
Female	74.8
<b>Place of residence for the carer</b>	
Metropolitan Sydney*	43.9
Outside Metropolitan Sydney	56.1
<b>Type of accommodation in which the person with dementia lives</b>	
Low care	19.9
High care	31.3
Low care dementia specific	16.3
High care dementia specific	32.5

\*Metropolitan Sydney includes the following Local Planning Areas: South East Sydney, Inner West, South West Sydney, Nepean, Western Sydney and Northern Sydney.

## Key findings about the carer of the person with dementia

- Dealing with the emotional stress of transitioning the person with dementia into care was the most significant difficulty for the carer
- Many carers felt 'rushed' in the decision making process
- Behaviours of dementia were a key instigator to transition the person with dementia into residential care
- Many carers were emotionally and physically stressed and advised by their doctor or family to 'share the care'
- Emotional impact was felt most profoundly by spousal carers
- 'Family' provided the most (68%) practical and emotional support to carers during the time of transition
- Only 5.2% of the participants reported they received no support
- 97% of respondents were allowed to visit the person with dementia during the settling-in period
- 65% of carers were not invited to join a resident and family committee or given information about a carer support group

## Key findings about the person with dementia

- Nearly 50% of people with dementia were transferred to a RACF directly from hospital
- The person with dementia can experience emotional strain during a move to residential care and often cannot understand the reason for the move
- The person with dementia needs to be cared for using a person-centred and relationship-centred approach that includes

the triad of carer, residential care staff and person with dementia

- Providing meaningful activities can assist the person with dementia to feel included during the settling-in period and beyond

## Key findings about the staff of the residential aged care facility

- 96% of carers expected the staff to have a caring attitude and this expectation was met by 90% of respondents
- Carers would like the staff-to-resident ratio to be higher, but acknowledge the current constraints on the aged care workforce
- Carers believe staff are under-resourced and time poor
- Carers would like more regular opportunities to discuss the health and wellbeing of the person with dementia with staff
- Carers believe that many staff do not exhibit evidence of dementia care training
- More than 95% of all respondents expected staff to have a person-centred approach, to have specific training in dementia care, to value the carer's knowledge of the person with dementia and to include the carer in decisions about the person with dementia.

## DISCUSSION

This chapter provides a discussion of the findings from all data in this research project alongside current literature. It highlights quality dementia care as well as areas of concern to be addressed by service and policy development.

### Reasons for moving a person with dementia into residential care

The reasons for placing a person with dementia into residential care reported in this research were varied but replicated those described in earlier studies<sup>xviii, xix</sup>. Reasons included: the need for the person with dementia and others to be safe; the effects of some behaviours of dementia; a need to relieve the feeling of being 'trapped' for some carers, and; a need for carers to allow others to take on some of the caring role due to physical and emotional exhaustion.

*I was no longer able to care for my husband – over time I became physically, mentally and emotionally exhausted (wife)*

When asked why the person with dementia moved into a RACF over 40% of respondents in this research stated the person they care for was moved directly from hospital to residential care. The move was often preceded by a fall or behaviours of dementia that could not be managed by the carer. A doctor or social worker often advised the carer to place the person with dementia into a RACF directly from hospital. In this situation some carers found dealing with the rush and pace of the change very difficult from an emotional and practical perspective.

*The decision that she had to be transferred from the hospital to the aged care facility was hasty and left me little time to fully pursue options available (daughter)*

*Had to rely on the hospital social workers*

*to let me know when a facility had a vacancy, then it was a rush to see them before someone else took the spot (carer)*

Others found that moving directly from a hospital made the transition into residential care easier as support was available, the decision to move into a RACF was taken out of their hands and, at times, the person with dementia was more agreeable and understanding about the move.

*The moving in went very well as Dad came directly from the hospital (adult child)*

*He hated it. Blamed me until I explained that the doctors at (hospital) made the decision not me...now he's glad to see me which is a real bonus (wife)*

Gaugler et al (2000) report that carers' experiences of feeling 'trapped' in the carer role can provide the impetus to place the person into care. This often pertains to adult children carers who can have multiple responsibilities and competing demands on their time such as family and work commitments. Others report they had 'exhausted all options' to assist them including family support and could not go on<sup>xx</sup>.

*It was becoming unsafe for my mother to live on her own despite all the external assistance and help my partner and I were providing her (adult child)*

*My aunt could not live alone because of the behaviour of moderate dementia and she refused to live with my husband and I (niece)*

Some respondents (38%) reported that it became necessary to 'share the care' so that the person with dementia received better support and assistance.

*The spouse of the person I care for died suddenly and the dementia behaviours became difficult to manage (carer)*

## Support received before the placement

Very often the carer of the person with dementia is left to organise moving the person into residential care alone. However, support from family, health professionals and other informal networks can provide both practical and emotional assistance.

'Family' was the highest response (68%) when carers were asked about their sources of support during the placement of the person with dementia in a RACF.

*My family made lots of phone calls and 'teed' up respite care close to where I live whilst he was in hospital. My family also arranged for the ACAT team to visit my husband in hospital and assessed him as high care (wife)*

Alternatively, others found support from other family members was not forthcoming:

*Difficult discussing with my sister as she has been in denial that mum has dementia (adult child)*

*My mother's de facto partner was hindering the process as it affected his income and accommodation in their pensioner unit (adult child)*

During the moving-in period the carer is often working alone with practical tasks such as form filling and inspection of facilities and, as a consequence, their emotional needs are not always met. Health professionals and other service providers can provide invaluable support by recognising the pressures carers experience and work to minimise them wherever possible.

*I don't think it could have been improved; the social worker made my job very easy and the staff in the home also helped make the move less stressful (carer)*

Carers who did not receive such support suggested the need for a counsellor or key worker who could enable a more streamlined process of preparation and admission to a RACF and, at the same time, help to relieve the anxiety and emotional stress that can exist.

*There needs to be a private space where you can have the undivided attention of a counsellor to help you with the emotional and the practical things. Nobody gives you their focussed time (wife)*

Other research<sup>xxi</sup> suggests that psychosocial support can simply come through informal support networks that acknowledge the carer's role and help them with complex decision-making. Shanley et al<sup>xxii</sup> suggest 'just having an empathic person to talk to' is a worthwhile form of support.

## Respite

This research and others<sup>xxiii</sup> indicate that when the person with dementia had previously stayed in the RACF for carer respite they often felt more at ease after the move. A carer still caring for her husband at home reported that he would be happy to move to the RACF he had stayed in for respite as 'they had made a fuss of him'. Others described the benefits of respite before the actual move to a RACF.

*It went well, with a period of respite transition into full time care. It was well managed given that my mother resisted the move (adult child)*

*I put my Dad into respite care for a month about three months before he moved there. He was happy during respite so it was logical to send him back to the same facility (adult child)*

Policy makers and service providers should be aware of the increasing demand for residential respite care that will develop alongside the increasing number of people

with dementia being cared for at home. As a consequence of greater numbers making use of respite care, the experience of 'transition' into residential aged care could well begin at this point, particularly when residential respite ultimately leads to placement in a RACF.

## Information and paperwork

Research tells us that the way the actual process of transition is organised has a significant impact on how carers and people with dementia experience the move<sup>xxiv</sup>.

Many of the respondents in this research described the process of accessing information and finding their way through the maze of paperwork as difficult and overwhelming.

The complexity of information and forms from government agencies and RAC providers, as well as difficulties in financial matters, make the moving in period challenging.

*Dealing with Centrelink, vet affairs and the nursing home was going around in circles – please talk to each other!! (carer)*

*Information is out there but so much information that it's overwhelming (carer)*

*You are not in the right frame of mind to deal with all the paperwork and the practical side of things (wife)*

Information and checklists are available on a number of websites to assist carers with practical decision making about moving a person with dementia into residential care. However, carers do not always know these resources exist. Awareness of these tools needs to be increased to ensure online checklists are accessible and hard copy kits and pamphlets are distributed widely.

Financial advice can be sought from government and private agencies and this

should also be more widely advertised either by the RAC provider or health services assisting the carer and the person with dementia.

Standardised forms across all Australian Government funded aged care services could reduce the stress for carers as they seek to locate a suitable RACF.

## Finding a RACF

Carers who had planned ahead and began looking at RACFs early reported they had greater levels of control over their choice of accommodation. However, for others locating a RACF that provided dementia specific accommodation was often difficult, particularly for those outside metropolitan Sydney. Some carers also reported their choice of facility was limited due to the need to make a hasty decision. One carer suggested:

*A central point to find out where vacancies exist would help. Constant form filling is exhausting and often to no avail during your search. There are different forms to be completed for each facility as you endeavour to find the right place and whether perhaps they may have a vacancy in the future (carer)*

The Australian Government's Living Longer Living Better aged care reform package has proposed the My Aged Care website and associated call centre within the Aged Care Gateway. This reform should lead to consumers being able to access up-to-date information about RACFs.

## Experiences of the move

Moving a person with dementia into residential care is an enormous undertaking on the part of the carer. Sometimes the decision is made with foresight and after much deliberation about appropriate accommodation and care for the person with dementia.



The transition into residential care can be a smooth process with few difficulties and a short period of adjustment for both.

*It is never easy to move someone into a home but every effort was made to make the transition as painless as possible (friend)*

*I was very impressed by the way the move was done with the help of a lot of people (carer)*

However, more often the choice is made at a time of crisis which leads quickly to the placement of the person with dementia in a RACF with little time to make adequate preparations for practical matters and emotional needs.

For some, the move can be fraught with problems followed by long periods of

dissatisfaction and concern for the welfare of the person with dementia.

*I was so emotional. I had to go (wife)*

*Bewildering and belittling because his initial assessment, in my belief, was not adequate (carer)*

*My mother was completely unaware of what was happening. She was very distressed and in a lot of pain (carer)*

To provide support to the newly-arrived person with dementia and their carer, a proper welcome and orientation program should be provided by each RACF.

*I think it helps if a bit of fuss is made of the 'new' person. It makes them feel special (carer)*

**Table 2: Key themes for carer experience during the admission of a person to a RACF**

Source: Davies and Nolan (2004)<sup>xxvi</sup>

<p><b>No pressure</b></p> <p>Being encouraged to take time to make decisions, to be yourself, to say what you want to happen</p>		<p><b>Feeling under pressure</b></p> <p>Feeling the need to make decisions quickly, to confirm, to conceal your own needs</p>
<p><b>Working together</b></p> <p>Being able to work with health and social care staff and with family to ensure best care for the person with dementia</p>		<p><b>Working apart</b></p> <p>Barriers exist to working together with health and social care staff or with family members</p>
<p><b>Feeling supported</b></p> <p>Feeling that others are aware of the consequences of the move for you and your relative and are willing to listen to you, feeling that others are there for you</p>		<p><b>Feeling unsupported</b></p> <p>Feeling that your own experiences and/or those of your relative are of little consequence to others</p>
<p><b>Being in the know</b></p> <p>Having access to all the relevant information to play a full and active role in the life and care of the person with dementia</p>		<p><b>Working in the dark</b></p> <p>Lacking the relevant information to continue to play a full and active role in the life and care of the person with dementia</p>
<p><b>Being in control</b></p> <p>Being able to maintain ownership of decisions about your future and the future of the person with dementia</p>		<p><b>Losing control</b></p> <p>Feeling that decisions have been taken out of your hands, that you can no longer influence events</p>

A handbook/guide, stored in the resident's room, would provide assistance and a resident 'buddy' could be partnered with the person and their carer to help them navigate the daily machinations of the RACF and its environs. Furthermore an admission support worker could work effectively, either with the person with dementia and their carer or via a liaison worker, to ensure positive outcomes during the time of transition.

### Good Practice

The most positive experiences of moving a person with dementia into residential care were reported by those carers who had time to make informed decisions and were supported by informal and formal support networks.

Nolan et al. (1996) present four attributes that predict a positive experience when moving into residential care:

1. Anticipation – the extent to which prior thought and discussion had been given to placement
2. Participation – the extent to which the person with dementia and their carer had participated in the decision making process
3. Information – the quality of information and advice given to the person with dementia and their carer
4. Exploration – exploration of alternatives in the types of care, range of care-homes and of emotional responses to the prospect of placement for the person with dementia and their carer<sup>xxv</sup>.

Furthermore, the key themes of carers' experiences during the transition of the person into residential care, (Table 2) serve as a guide to good practice for RACF staff and health professionals supporting the carer.

### Including the person with dementia in the decision-making process

In this research 41% of respondents indicated that discussing the decision to move into permanent residential care with the person with dementia was a significant difficulty in the period leading up to the move.

*The person I care for keeps changing her mind and in denial about needing extra care (carer)*

But some reported the person with dementia was agreeable to making the move and the carers acknowledged that this not only helped them but also enabled a better settling-in period for the person with dementia.

*Mum settled in quickly, made friends and is very happy. This has made it a lot easier for me and I now do not worry as much about Mum's future (daughter)*

It is acknowledged that often a person is transferred to permanent residential care during the later stages of dementia and may not have sufficient capacity and insight to participate in decision-making. However, attempts to include the person with dementia, where possible, can often be successful and will enhance the person's sense of autonomy and inclusion.

*As far as I know there was no counselling or even discussions with mum about her future life in an aged care facility and it is a big change from living independently (adult child)*

Recent research<sup>xxvii</sup> suggests new diagnoses of depression amongst people with dementia post-transition to residential care could be caused by pre-admission factors and the subsequent move. Often hurried decision making, loss of autonomy and exclusion of the person with dementia can have a detrimental effect on their mental health.



There is no substitute for time spent with the person with dementia, exploring with them the reason for moving, including emphasising their family wishes, but also enhancing their choice and involvement by arranging pre-move visits<sup>xxviii</sup>.

### Settling in

The settling-in period, following the moving-in period, is a time of gradual adjustment for the person with dementia and their family and carer.

The settling-in period has received less attention than the period of moving-in amongst the literature. Yet, the settling-in period has a profound effect on how the placement is perceived by the person with dementia and their carer, and how they react and adapt to the change.

As reported, many admissions occur at a point of crisis for the person with dementia and their carer. Under these circumstances staff at the RACF are often denied the opportunity to get to know the person with

dementia and their family before placement and so must begin the relationship amidst conditions that are not ideal.

For the person with dementia, the settling-in period can be confusing and disorienting. A person with dementia may not always be able to communicate their feelings verbally but they still have emotional responses such as grief, frustration and loneliness.

*I am sure my husband felt lost by the sudden change of surroundings and lifestyle....it was never explained to him why he was there except for my explanation that he needed more help than I could give him (wife)*

*I feel there was inadequate care and time provided to integrate a new resident into the nursing home environment. Every day I see new residents absolutely lost and bewildered at the huge changes taking place. I believe a dedicated trained person should be employed specifically for this role (carer)*

And yet others reported:

*My mother settled very quickly – something that I am most grateful for. I'm sure the excellent staff made my mothers transition as stress-free as possible (adult child)*

*The person I care for was handled with understanding, gentleness, humour and compassion (carer)*

*For my dad it was a difficult time, being Italian origin the family look after the old people. He still hasn't settled (but) the staff are wonderful, very kind and professional (adult child)*

For the carer, the placement of a person with dementia shifts, rather than eliminates, the caregiving experience. Carers often do not give up their role but remain actively caring in different ways. They may be relieved of the continuous, daily care of the person with dementia but, assisting with activities of daily living (ADLs) for the person, and interacting with the staff to enable shared decision-making to meet the needs of the person with dementia, replace their previous activities.

## Emotional impact

Dealing with the emotional stress surrounding the decision to place a person with dementia into residential care was the most significant difficulty reported in this research. This was followed by 'discussing the move with the person they care for' and 'finding a suitable residential care facility'.

*Emotionally it has been very draining and sad. The facility has been very accommodating and displays a fondness and caring attitude towards my mother (adult child)*

*I would have loved some support as it was the hardest thing I have had to do in my life (daughter)*

*For me, taking my mother away from her*

*own home 'and her cats' was the most traumatic and saddest event I have ever had to cope with in my entire life. I don't think anyone could have helped in this situation. The staff were so sympathetic and this put my mind at rest (adult child)*

Feelings of guilt were described by carers, particularly adult children, who questioned whether more could have been done to prevent admission. These feelings were heightened when the person with dementia continuously asked to go home. Even feelings of relief were often countered by feeling guilty to be relieved of the duties of care.

## Significant impact on spousal carers

For the carer, moving the person with dementia into residential care is identified<sup>xxix</sup> as one of the five grief and loss events for a carer:

1. At the time of diagnosis
2. As the known personality of the person with dementia begins to change
3. When the person with dementia moves to a RACF
4. During the time of palliative care and death
5. As the carer's self-identity changes with their caring role

It is a time of significant grief and loss involving issues of intimacy and companionship, especially for spousal carers. This is compounded by the ambiguity experienced by the carer as their primary care role becomes one of 'shared care'.

*It was up to me to cope emotionally and after 63 years of marriage this has not been easy (wife)*

Research<sup>xxx</sup> tells us that spouses often

carry on in the caring role until they become exhausted, with the decision to place the person with dementia being made by health professionals or family members. Adult children can sustain or even improve their relationships with one or both parents following care placement, whereas spousal relationships often deteriorate due to the perceived 'loss' of a life partner and loneliness. These feelings of loss and loneliness can be minimised if RACF staff and health professionals recognise the impact of the transition into care on the spousal partner and include them in decisions about the care, health and well-being of the person with dementia.

## Staff

*An effective collaboration between families and staff that exists throughout the nursing home stay will likely improve the quality of life for elderly residents (with) dementia<sup>xxxii</sup>.*

While moving someone with dementia into residential care can be physically and emotionally stressful for many, the quest to find satisfaction and pleasure during this time must also be recognised. RACF

staff play a key role in enabling this by supporting the carer and fostering the continuation of their relationship with the person with dementia, thus "enhancing the quality of life of family members and the person with dementia – the aim of all good-quality dementia care"<sup>xxxii</sup>.

Many participants in the research gave high praise to the staff caring for their person with dementia.

*I had no idea the staff would be so caring and patient as they are (carer)*

*The staff have been wonderful... I cannot praise them enough (carer)*

*The staff at (X) are EXCEPTIONAL! I can't thank them enough (carer)*

As shown in Figure 2, more than 95% of all respondents expected staff to have a person-centred approach, to have specific training in dementia care, to value the carer's knowledge of the person with dementia, and to include the carer in decisions about the person with dementia. However, these expectations were not always met. The expectation that staff would 'have a caring attitude' was met for most respondents. However the expectation that staff would 'have training

**Figure 2. Expectations of staff**

Source: AlzNSW Moving into residential aged care - Survey 2012



in dementia care' was met for the least number of respondents.

### Relationship-centred care

*The staff were wonderful and gradually developed an intimate knowledge of the person I care for and understood his needs and interests. He clearly trusted, and developed attachments to, the staff (carer).*

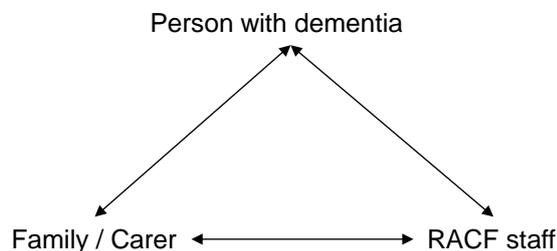
Relationship-centred care describes the interaction between the carer, the person with dementia and the RACF staff. The seminal work of Tom Kitwood (1997)<sup>xxxiii</sup> acknowledged the 'personhood' of a person with dementia in 'person centred-care' and recognised the need to consider their individual lives, their likes and dislikes, their modes of expression and communication and importantly their relationships with other people, especially those who care for them.

By using a relationship-centred approach, the value of carers, whether family or paid care workers, and the social environment are recognised as a network of interactions and relationships which can have a major influence on the person with dementia<sup>xxxiv</sup>.

For a person living in a RACF there are two important sets of relationships: the relationship with the family and carer; and the relationship with various staff members of the RACF. The relationship with the family and carer is an important part of the lived history of the person with dementia and the relationship with staff is important in supporting the needs of the person with dementia. Underpinning these relationships is the relationship between the family/ carer and the RACF staff, as illustrated in Figure 3. Woods et al (2008) tell us that "the strength of this relationship (or the tension within it) can have an effect on the relationships of both parties with the person with dementia"<sup>xxxv</sup>. They use the 'dementia care triangle' to illustrate this point (Figure 3).

**Figure 3. The dementia care triangle**

Source: Woods et al (2008)<sup>xxxvi</sup>



### Communication

Good communication in a RACF includes: a welcoming atmosphere in the home; a commitment from management and staff to engage with, and work alongside, families and; structures that enable communication and information sharing.

Clear communication between parties is important to avoid misunderstandings and misconceptions. Good practice would dictate this begin at the pre-admission stage when staff can help alleviate the concerns of the carer and the person with dementia and also provide an opportunity to exhibit the philosophy and operation of the RACF.

One carer suggested an information pack could be given to new arrivals about how to communicate with staff about particular issues - when and to whom. She also suggested photos of staff and a description of their role could be hung in a prominent place to provide information and a sense of familiarity.

If time is taken to establish good communication between staff and family members from the outset, the relationship between the family and the person with dementia can also be enhanced, especially if the person is reluctant to move into a RACF. Staff can also assist by responding to the emotional needs of the carer by encouraging them to spend time with the person that is 'meaningful' and enjoyable for both. By using a strengths-based

approach, the carer's efforts, knowledge and continued participation in decision-making for the person with dementia is validated.

In this research there were a significant number of reports of staff not being available for information about the person with dementia. Carers often attributed this to the lack of staff time and personnel.

Carers wanted communication with staff to include:

- regular updates about the health and wellbeing of the person with dementia – not just concerns but also reports of positive developments
- sharing personal information about the person to enable a person and relationship-centred approach
- opportunities to participate in decision-making regarding the care of the person with dementia

Carers also reported that staff schedules and timetables often meant that they did not see the same staff member on a regular basis or that information about the person with dementia was not always passed from one staff member to another.

*The staff are polite and helpful when I raise issues but they rotate, so I am talking to different people (carer)*

*An initial care plan was not made in sufficient detail for the large number of shift and relief nurses. Confusion and mistakes could be avoided if clearer instructions were available (especially medication) (carer)*

Communication systems need to facilitate effective sharing of information amongst the staff to maximise the quality of relationships between carers and staff.

## Peer support

Peer support can provide worthwhile mutual aid for those experiencing, or who have experienced, similar circumstances<sup>xxxvii, xxxviii</sup>. Providing a support group within the RACF, and introducing carers and family members to the group prior to admission can provide non-judgmental information, education and problem solving during a potentially trying time<sup>xxxix</sup>. Alternatively, referring a carer to a local carer support group in the area has the potential to provide support through mutual aid.

*I attend a carers group once a month. This is excellent the facilitators are very skilled. However the need is greater than the services provided. A carers' group within a nursing home should be provided on a regular basis (carer).*

Despite the benefit of these groups, 64% of respondents in this research reported that they had not been 'provided information about carer support groups' and 66.4% of respondents had not been 'invited to join a resident and family committee'.

## CALD language barriers

Chinese background carers who participated in the focus group highlighted the need for more CALD specific RACFs, or at least an increase in the number of staff who can speak the first language of residents from CALD backgrounds. RACFs that offered dementia specific care alongside staff members who spoke their language and understood cultural traditions were popular with this group, but also very difficult to access due to demand in the areas where specific CALD groups reside, such as the Chinese population in Campsie where the focus group was conducted.

Chinese background participants reiterated the need for good communication and reported when staff do not use the same language as the resident, person-centred care can be hindered.

A survey participant in this research reported her mother's contentment was due to staff members who spoke her language and said:

*If my Mum could talk English she would thank them very much. So I will say it for her THANK YOU (adult child)*

## Staff skilled in dementia care

Specific training in dementia care was an expectation expressed by the carers who participated in this research but this expectation was not always met. Shanley et al report<sup>xi</sup> when a good level of dementia care expertise is displayed by staff toward the person with dementia a good foundation of trust is established between the carer and the staff.

*I expected the facility to be more knowledgeable about my mum's dementia; they have rung me in the evening to settle her (adult child)*

*I think the staff are learning on the job (carer)*

The needs of a person with dementia are unique to the condition, and knowledge of dementia is essential to provide quality care for this cohort. Some people with dementia exhibit behavioural and psychological symptoms of dementia (BPSD) and yet, evidence in this research indicates that many staff members do not have specific training to manage these behaviours.

## Staff-to-resident ratio

The low staff-to-resident ratio that exists in many RACFs was a significant point of concern for participants in this research.

*The constant lack of staff available for care and activities is a real issue...this puts undue stress on both workers and residents alike (carer)*

*More staff needed to care for patients. Two staff for twenty is not enough (carer)*

*The staff is excellent although additional staff is needed on the weekends and at night (carer)*

Currently the aged care workforce in Australia is constrained by funding issues, attracting and retaining staff, increasingly heavy workloads and limited registered nursing staff with dementia specific training. Low staff-to-resident ratios constrain the capacity of RACFs to provide optimum person-centred care for the person with dementia, time to effectively include carers in the 'care team' and can lead to over use of medication to minimise behaviours of dementia.

Policy makers need to recognise this grave concern and work with service providers to increase staff numbers and their qualifications, thus enhancing the care of people with dementia and the effectiveness of the aged care workforce.

## Activities and outings

*Dementia does not mean frail necessarily (carer)*

There is increasing evidence<sup>xli</sup> that engaging in meaningful activities is related to quality outcomes for people with dementia living in RACFs. Meaningful activities are those that enable the person with dementia to use their skills and ability. Meaningful activities can increase communication and interaction between the person with dementia and others in the RACF and they focus on the capacity of the person with dementia, rather than the incapacity. Moreover, if the family and/or carer of the resident are included in the activity, the settling-in period can be easier for both.

Results from this research indicated that: 'the provision of a range of activities and the engagement of the person with dementia in activities which interest them' was an expectation that was met in varying degrees across the RACFs.

*The only area of concern for me is my*

*husband is left in his room – more effort could be made to involve him in the activities... but this could be because of staff shortages (wife)*

*The team were incredible as far as making my husband feel included in activities and being part of the overall environment at the facility (wife)*

*Mum needs someone to knock on her door and personally invite her to outings/ events. She's a shy person, but once involved becomes quite interested in the activity (adult child)*

Carers expressed a desire for physical activities for the person with dementia to provide stimulation and enable them to maintain their mobility rather than leaving them in their rooms. Some carers reported the person with dementia might not seem interested in the activities initially but if activities were more appropriate, then interest might be encouraged.

Also, due to the higher proportion of women in many of the facilities one respondent stated:

*There's not enough for the men to do (carer)*

Other participants stated the person with dementia is often excluded from activities due to their behaviours of dementia:

*A dementia resident needs specific activities to stimulate and distract them, my parent seems to be excluded because of her behavioural difficulties, and spends hours on end in her room by herself. She is unable to operate the TV, or CD player herself so is totally reliant on staff. Mostly they don't bother or don't have the time as the staff/resident ratio is so low. My parent happily goes to activities if I take her but I didn't expect that I would have to be at the care facility EVERY day to ensure this happened (daughter)*

Eating and the social experience of dining with others is an activity in itself and can aid the wellbeing of a person with dementia. During the time of transition the person with dementia should, if possible, be encouraged to eat with other residents. This will assist them adjust to their new environment and also enable a feeling of inclusion from the start.

## Facility environment

While the staff at a RACF can play a significant role in ensuring a smooth transition into residential care for the person with dementia and their carer, the physical environment is also important.

Amongst the options that were given to participants in the research regarding the features of the RACF, 'cleanliness', 'a secure environment' and 'a warm and welcoming environment' were features where expectations were most commonly met.

*Mum felt safe, welcomed and well cared for. I feel very lucky! The move from home to this facility has been a truly 'happy ending' story. The angst at the outset has been greatly outweighed by the health and well-being enjoyed at the present time (daughter)*

A large number of respondents expressed the view that the more 'home-like' the RACF, the quicker the person with dementia felt 'at home'. Many carers reported angst at having to respond when the person with dementia asked to go 'home'. While this often abates with short term memory loss, a 'home-like' environment engenders a person-centred approach that can reduce the yearning for 'home'.

Evidence of this approach was found in some RACFs who encourage residents to bring photos and other small objects from home to bring familiarity to their surroundings. These personal items also provide valuable tools to staff to inform



them of the person's life history and can be used effectively with reminiscence work.

Providing a 'homely' environment also ensures relatives and visitors feel welcome, comfortable and relaxed, which in turn encourages them to visit often and participate in activities alongside the person with dementia, and so, relieve the anxiety that can exist for the person in the settling-in period.

Most respondents in this research who expected a single room and/or ensuite were happy with the outcome and for those who did not have their own room, some still found the capacity to make it their 'own'.

On the other hand some carers reported the lack of homeliness was detrimental to the transition phase for the person they care for:

*If she were able to have her own room it would be better for her I think as she is not used to sharing with others, we would also be able to bring in some of her personal bits and pieces for her to*

*have around her (adult child)*

*Mum loves to walk and there is NO room to walk anywhere in the facility. The outside area is tiny. She feels trapped (adult child)*

*They need to be integrated straight away....common lounge areas where residents are encouraged to meet, calming music and outings (carer)*

One carer suggested the need for a quiet space or family room where the carer could be alone with the person with dementia or alternatively where they could meet with care staff without interruption. These sorts of settings facilitate a sense of calm, an opportunity to escape the busy-ness of the day-to-day activities in a RACF which can be confronting for someone with dementia.

### **Alternative housing options**

The special needs of people with dementia from Aboriginal communities, CALD communities, people with younger onset dementia, mental health issues and those



with severe BPSD cannot always be met within typical RACF settings and the period of transition can be more difficult for these groups. Cluster housing within a RACF is an alternative configuration of residents which may provide the means to give a specific focus to these groups whose special needs can otherwise be overlooked.

In addition, co-located retirement and residential care housing options provide an alternative for those carers, particularly spousal carers, who want to remain in close proximity to the person with dementia. As mentioned these carers and people with dementia often grieve the separation from their partner and the challenges of settling in can be exacerbated through distance and inflexible accommodation. Examples of these could include vertical villages such as the proposed Apartments for Life model, or the horizontal village developments operated by a large number of aged care providers.

Alternative housing options can address some of the special needs of people

with dementia and their carers during the transition from their home or hospital to a RACF. Appropriate built environments and housing will have a positive impact on their quality of life and the delivery of culturally appropriate and good person-centred care.

## **SERVICE IMPLICATIONS**

Support services need to provide emotional as well as practical support for people with dementia and their carers during the planning and transition period. Evidence proves that the more support a carer has, such as carer support groups, health professionals and the RACF staff during this time, the easier the transition is to execute.

Information about RACFs needs to be accessible, current and easy to understand. Dementia service and primary health care providers should introduce carers to information early so that they have the opportunity to locate the most appropriate RACF to address their particular needs.

If a move into residential care is inevitable for a person with dementia, the situation needs to be judiciously addressed by the carer, the GP and other health professionals to enable the carer to make plans and, importantly, to allow the person with dementia to be part of the decision-making process about their future care. Furthermore carers and people with dementia should be directed to advance planning documents, as early as possible, by service providers and health professionals to ensure RACF staff are aware of the person's wishes if and when they lose capacity.

To support the carer and the person with dementia, a key worker or liaison person working within a case management framework, could provide information and advice before placement as well as during the settling-in period to act as advocate for the person and their carer and so enhance good relationship-centred care.

Davies and Nolan (2003) note that an acute hospital ward is an inappropriate setting for making long-term care arrangements<sup>xliii</sup>. Consequently, community based services need to be flexible enough to allow adequate preparation time to review residential care options and alleviate the sense of 'crisis' that often comes with severe behaviours of dementia and transfers from hospital.

Furthermore, RACF staff need sufficient time to prepare for the placement of a person with dementia into care. Once documents have been received by the RACF it would be beneficial for a staff member to visit the person and their carer before discharge to give all parties the opportunity to get to know each other and provide a sense of familiarity when the person with dementia arrives at the RACF.

Good communication between the carer and family of the person with dementia and the RACF is essential and should exist before, during and after the placement of

the person. Regular care conferences and updates should be standard practice. A relationship-centred approach to include the carer and the person with dementia as key informants promotes good practice. It also provides an opportunity for RACF staff to offer support and empathy which acknowledges the significant emotional impact on carers and people with dementia during the time of transition. This is a proactive approach which can result in a reduction in some behaviours of dementia, as well as anxiety for the carer.

Staff need to be aware of what may have preceded the placement of a person into residential care. Often carers are emotionally and physically exhausted; have taken on the role of carer as part of their identity; have seen the diminution of their social life and felt the effects of the symptoms of dementia as expressed by the person with dementia. RACF staff, as well as community service providers, must recognise that while the person with dementia and the carer are experiencing all that comes with the transition into residential care, they are, at the same time, experiencing the transitional progression of dementia.

Recruiting staff that are happy, engaged and able to develop dementia care competencies is integral to engendering trust within a relationship-centred care approach and provides a sound basis for good dementia care practices.

To that end dementia-specific training is essential for all staff caring for someone with dementia. A mentoring model of support would be a beneficial initiative to enhance the knowledge of all staff in the RACF and provide leadership opportunities for those skilled in dementia care.

Good leadership within RACFs is integral to the implementation of good dementia care practices by all staff. Research<sup>xliiii</sup> tells us that RACF management plays a pivotal role in enabling good outcomes for both

staff and residents and that strengthening leadership and management skills should be a priority.

Publicly available information about RACFs will provide carers with the capacity to identify appropriate facilities to suit the particular needs of the person they care for and their family.

## **POLICY IMPLICATIONS**

While the Living Longer Living Better aged care reform package<sup>xliv</sup> promises more support for those who wish to stay at home it also outlines the need to provide quality residential aged care as part of a streamlined care continuum beginning with consumer directed care received in the community. The reform recognises the need for greater transparency around the quality of service provision in aged care. It acknowledges the distinct needs of people with dementia and the need for better dementia care training for staff, alongside a commitment to address current workforce issues for aged care workers.

Many people with dementia will ultimately need residential care for the reasons outlined in this report. Community service providers, medical and allied health workers have a role to encourage the exploration of long-term care options early in the progression of dementia. Moreover the importance of the integral role, and capacity, for RACFs to provide quality care should also be recognised and reconsidered<sup>xlv</sup>.

The role of respite care needs to be redefined to include its use not simply to relieve the carer of their caring duties for a limited length of time but also to provide a staged approach to 'sharing the care' so that the time of transition can be smooth and with less angst than commonly experienced by both the carer and the person with dementia.

Better cohesion across the aged care industry is required with a stronger focus on leadership and management development in dementia specific care. Better leadership will increase the capacity for staff to implement their knowledge and skills during the time a person with dementia moves and settles into residential care.

To ensure quality person-centred care is delivered during the time of transition and in the long term, staff-to-resident ratios need to be regulated so that adequate qualified staff are available to provide timely and appropriate dementia care for the person with dementia and a sense of inclusion for the carer and family.

A greater policy focus on the collaborative role of hospital staff and RACF staff is required to ensure a person with dementia being discharged from hospital who requires residential care is given a smooth transfer into a RACF. Emotional and practical support for both the person and their family and carer are of increased importance for hospital-to-RACF transfers.

In consideration of the people with dementia and their carers who have additional needs that often go unmet such as Aboriginal people; people from CALD backgrounds; people with younger onset dementia; people with severe BPSD or mental health issues; and people who have been in long-term intimate relationships, accommodation alternatives need to be addressed. Policy makers need to promote the development of alternative living arrangements to meet the needs of these people either as cluster housing on site, shared living arrangements or separate specific facilities.

Finally, policy makers need to be aware that the push for continued home care as 'best' can have the adverse effect of increasing the stress and guilt experienced by carers. Carers and people with dementia need to be assured that the care provided in a RACF can be 'best' care too.



## CONCLUSION

Moving into residential care should be a smooth process that enables collaboration between families, carers, health professionals and staff of the RACF. The voice of the carer and the person with dementia, where possible, should be heard and the emotional strain of placement, often experienced by both, acknowledged.

Some RACFs provide a seamless, quality transition into residential care with good outcomes for the person with dementia and their family and carer. The features of these facilities have been reported and their expertise should be acknowledged in any dialogue that aims to enhance the health and wellbeing of all people living with dementia and their carers.

Quality dementia care and collaborative engagement in RACFs however, should not start and end with the transition stage. Moreover an emphasis on easing the difficulties during placement in a RACF should not preclude the most important

objective: to improve and enhance the quality of dementia care in RACFs. If a RACF is to be the last 'home' for many, engagement of families and carers in collaboration with RACF staff to enable good person-centred and relationship-centred care should continue long after transition into residential care.

# RECOMMENDATIONS

## Australian Government:

1. Funds a network of key workers to support the carer and person with dementia, which would include the period of moving into residential care.
2. Increases funding to the National Dementia Helpline to provide counselling to people experiencing the emotional impact of moving into residential care.
3. Develops standardised application and information forms which are accepted by all agencies.
4. Develops alternative models of housing which improve the experience of settling in to a new environment, particularly for people with younger onset dementia, Aboriginal people, Culturally and Linguistically Diverse (CALD) communities, and those with mental health conditions.
5. Develops the Aged Care Gateway to ensure:
  - it supports access to information for consumers to make choices about alternative housing options, including Aboriginal and CALD communities
  - it directs and refers people to the National Dementia Helpline
  - the My Aged Care website and associated call centre provides information about RACFs with dementia specific services and up to date information on vacancies
6. Instructs the Aged Care Standards and Accreditation Agency to monitor dementia design with performance reported on the My Aged Care website.
7. Focus its Living Longer Living Better workforce initiatives on leadership and management in aged care to promote quality dementia care.
8. Consults with people with dementia

and carers when developing the trial of consumer directed care in RAC.

9. Amends its policy on respite in RACFs to expand its potential use to include a staged approach to 'sharing the care'.

10. Funds further research that examines the subjective experience of people with dementia about this significant transition period in their lives.

## NSW Government:

11. Amends its policy on discharge planning from hospital for a person with dementia to provide two days' notice as a minimum to the person with dementia, their family and to RACF staff to provide better quality of support in the transition into residential care.

12. Instructs Local Health Districts to develop service pathways for the person with dementia and their carer to plan for a future that may include residential care.

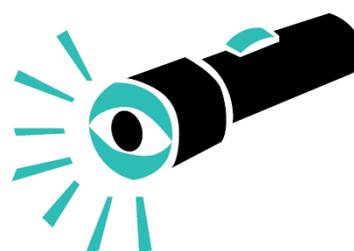
## Service Providers:

13. Providers of residential aged care:

- Develop guidelines for good communication standards that acknowledge the value of all stakeholders and enhance relationship-centred care during and after the transition into residential care.
- Acknowledge the emotional impact of the transition into a RACF on the carer and the person with dementia by using a person-centred approach to care.
- Provide education about dementia to carers of residents with dementia as well as all staff working in high care and low care facilities.
- Instigate consumer groups within each facility to hear the voice of the carers and/or support carers to join dementia carer support groups in the community.

- Enable staff to work within a person-centred approach that involves the person with dementia and their carer in their care planning, decision making and service delivery.
- Develop innovative accommodation models to address the needs identified in this research.

14. Dementia service providers develop and promote education for carers about the transition into residential care, before placement occurs.



## ENDNOTES

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## OTHER PUBLICATIONS

Social Research Publications by  
Alzheimer's Australia NSW

[Building Dementia and Age-Friendly  
Neighbourhoods - Discussion Paper 3 July  
2011\(PDF\)](#)

### **What prevents people with dementia making plans for their future? - Discussion Paper 4 Mar 2012**

Planning ahead is important for the whole population. We all need to make sure if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes. People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

[http://www.fightdementia.org.au/common/  
files/NSW/20120328-REP-DiscussionPaper4.  
pdf](http://www.fightdementia.org.au/common/files/NSW/20120328-REP-DiscussionPaper4.pdf)

### **Building Dementia and Age- Friendly Neighbourhoods - Discussion Paper 3 July 2011**

The needs of people with dementia and other types of cognitive impairment have helped shape the design of residential facilities, but the issue of accessibility to public places and spaces for people with dementia and their carers has been almost completely neglected. In a series of focus group consultations we asked members of the eight Alzheimer's Australia NSW regional consumer committees to describe how they experienced their surrounding neighbourhoods once they stepped outside the safety and familiarity of their front gate and made their way to the local shopping centre, park, doctor's surgery or club.

### **Addressing the stigma associated with dementia - Discussion Paper 2 Sep 2010**

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

[Addressing the Stigma associated with  
Dementia Discussion Paper 2 \(PDF\)](#)

Dementia is a condition that carries a heavy burden of stigma. People's attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

[Alzheimer's Australia NSW – Addressing the  
Stigma associated with Dementia - Executive  
Summary \(PDF\)](#)

### **Driving and dementia in New South Wales - Discussion Paper 1 Apr 2010**

A new discussion paper, Driving and Dementia in NSW, indicates there is little clear, accessible information about the rights and responsibilities of a driver after a diagnosis of dementia.

[Driving and Dementia in New South Wales  
Discussion Paper 1 \(PDF\)](#)

Issues raised include:

- Driver testing for people with dementia must be improved

- Legal obligations for a driver with dementia are unclear
- Call for improved transport alternatives for a person with dementia
- Need for better support for transition from driver to non-driver in NSW

[NSW Discussion Paper Key Recommendations \(PDF\)](#)

## Quality Support Groups Research Project

There is little knowledge of the way support groups in New South Wales are currently functioning, or how effectively they are providing support to their participants. The purpose of the Quality Support Groups Research Project is to understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

Quality Support Groups Research Project - Phase 3 The purpose of Phase 3 is to analyse findings from Phase 1 and Phase 2 of the Project. The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service to carers of people with dementia. This research upholds the mission of Alzheimer's Australia NSW to minimise the impact of dementia through leadership, innovation and partnerships. This is the third and final report into a research project that spanned 5 years and looked at what comprises a quality support group. This is the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia. Over the five years of the project more than 350 people took part, including leaders of the groups and carers who had at some time attended a support group.

Significant findings of the report are:

- Huge benefits of supports groups for people who attend on a regular basis

- The uncelebrated capacity of mutual aid amongst group members to assist each other
- The unexpected finding of the profound impact of grief and loss on the health and well-being of a carer of a person with dementia
- Some carers reported the grief and loss felt at the time of diagnosis was equal to or even greater than the grief felt when the person with dementia dies

[Quality Support Groups Research Project - Phase 3 Executive Summary \(pdf 45 KB\)](#)

The full Phase 3 report is available to purchase from Alzheimer's Australia Online Bookshop.

[Quality Support Groups Research Project - Phase 2 \(pdf 1.92 MB\)](#)

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

[Quality Support Groups Research Project - Phase 1 \(pdf 764\)](#)

The focus of phase one of the Quality Support Groups Research Project is a literature review of research conducted into dementia support groups and a survey of existing support groups in New South Wales to investigate the views of support group leaders.

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